

A First Nations Woman with Disabilities: “Listen to what I am saying!”

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Abstract

This article tells the story of a courageous First Nations woman living with severe disabilities in an urban prairie city. Her story is a story of resistance and resiliency and of continued healing. This exploratory and qualitative study applies culturally sensitive research methods and attempts to capture the rich voice of Hope as she tells her-story. Personal names such as Hope's have been changed in order to preserve confidentiality. Themes identified and described include grief, racism and verbal abuse, sexual abuse, health care concerns, resisting child welfare, isolation, poverty, relationships, and sexuality. Hope resisted, and through resilience, overcame much of the trauma but the scars are deep. Hope's healing is found in finding meaning in her life through raising her daughter, caring for others, and advocating for herself and other Aboriginal persons with disabilities. Poverty and vulnerability, however, continue to plague her life. All she asks is to be heard: “Listen to what I am saying!” Her message is one that every health and social service provider should hear.

Introduction

Like when you hear people say, “you walk the walk”, I always say, “I wheel the wheel”, you know. I wheeled and I wheeled and I wheeled and I’m wheeling away from poverty, hopefully from poverty. I hope from neglect. I hope from abuse. I’m trying to get away from those and hopefully my life will be better where somebody will care, where somebody will love me for who I am. Don’t look at my disability. Use your ears; don’t use your eyes. Listen to what I’m saying! (Hope, 47 years old)

Ethnic minority women with disabilities are disadvantaged as a result of their ethnicity, class and gender, as well as on the basis of their disability - a fact that has been recognized by a numerous researchers (Fine and Asch, 1988, 1992; Lisi, 1993; Quinn, 1994). First Nations women are even further marginalized and oppressed (Demas, 1993; Durst and Bluechardt, 2001; RCAP, 1996). They remain hidden in our communities, and health and social providers, including social workers, often overlook their needs.

Hope is a First Nations woman whose life story is a tale of resistance and resiliency against multiple forms of oppression (all names have been changed to preserve confidentiality). Her accident occurred in her early adolescence, resulting in spinal cord damage that left her a quadriplegic. She has no use of her legs and limited use of her arms and hands. This exploratory and qualitative study attempts to capture her-story from her perspective and offer insights into the ways in which she survives and recovers. Hope is a woman of remarkable courage and tenacity. She has experienced tragedy and loss of almost unimaginable proportions. She champions the cause of First Nations people with disabilities, especially the most marginalized, the poorest of the poor. At the time of the study, she was 47 years old, single, and the parent of a 17-year-old daughter. Hope and her daughter, Star, live in a small, cramped, one-bedroom apartment in a prairie urban community and for them, it has become “home.” She has lived on disability benefits under the social assistance program for all her adult life.

This article begins with a brief introduction explaining the research strategy employed to collect Hope's story. The article summarizes her story in a manner which is reflective of her experiences. From her story, a number of themes emerge including grief, racism and verbal abuse, sexual abuse, health care concerns, resisting child welfare, isolation, poverty, and relationships and sexuality. Hope's healing is found in finding meaning in her life through raising her daughter, caring for others and advocating for herself and other Aboriginal persons with disabilities. The paper concludes with a brief summary. Hope's language and personal words are woven throughout the article and every effort has been made to share the reality of her life as it really is. The article is meant to be enlightening and not meant to be prescriptive.

Methodology

In an effort to capture Hope's perspective, this research is exploratory and qualitative in nature. An oral history approach or narrative style was used in data collection and grounded theory was applied during the analysis. Women's oral history is a feminist approach “because it creates new material about women, validates women's experience, enhances communication among women, discovers women's roots, and develops a previously denied sense of continuity” (Reinharz, 1992, p.126). Since this study focuses on an individual and follows a life story, it is biographical in style. The oral history is also consistent with First Nations culture and tradition. According to Monture-Angus (1995),

A fundamental difference between Aboriginal and non-Aboriginal societies (is) the way in which truth is located. Truth in non-Aboriginal terms is located outside of the self. It is absolute and may be discovered only through years of study in institutions, which are sanctioned as sources of learning. In the Aboriginal way, truth is internal to the self (Monture-Angus, 1995, p. 217).

The research methods used in this study are of relevance to social workers and particularly First Nations/Aboriginal social workers. The researchers believe that oral history is a research method requiring many of the same skills as direct social work practice, including trust development, listening without judgment, comparing new information to information already obtained, and changing interpretation based upon new information.

Many writers have observed that research has traditionally been done from the perspective of the dominant culture, and has, therefore, come from an ethnocentric perspective, leaving disadvantaged people on the margins (Anderson, Armitage, Jack, and Wittmer 1990; Kirby and McKenna, 1989; Reinhartz, 1992) and specifically Aboriginal people (Gilchrist, 1997; Smith, 2001). Oral history has the potential to overcome this shortcoming and has always been an important part of research with people who are marginalized (Anderson et al., 1990; Reinhartz, 1992). It can provide the opportunity to give “voice” to the marginalized and excluded members of society.

Progressive researchers argue that social research is dependent upon context (Kirby and McKenna, 1989). They challenge the traditional assumption that research is carried out in an objective, non-involved manner and is therefore capable of representing everyone equally (Durst, 2004; Kirby and McKenna, 1989; Smith, 2001). Kirby and McKenna (1989) state that knowledge is developed and research is produced in a manner: “which represents the political and social interests of a particular group” (p. 16). They point out that: “research has often been a tool of domination and oppression, which has helped perpetuate and maintain current power relations of inequality [and that] too often researchers have been well trained in patterns of thinking which not only conflict with their understanding, but explain and justify a world many are actually interested in changing” (p.16-17). Social research is political (Durst, 2004).

Hope’s Story

Prior to examining the themes, the authors would like to briefly introduce Hope to the reader by telling the story of her childhood accident that left her quadriplegic and her struggle to survive and thrive as a First Nations woman with a severe disability.

Hope spent her early years in a remote First Nations community in northern Saskatchewan. She recalled the day of her accident in vivid detail. Hope was 13 years old and visiting her neighbour’s home when she entered a bedroom where she heard children playing. She thought that she would play with them for a while before she went home to finish her chores. And that is when everything went wrong.

From the side of my eye, I seen one of the younger girls – she was maybe 12, 13 and she picked up the gun. One of the kids knocked it down earlier on I guess. She picked it up and it went off. It was the strangest feeling. Everything just went black, and I guess when it hit the nerve right away it felt like I was shrinking. I was already losing - I lost my sensation but when you get shot, it feels like you're shrinking. And it just felt like I was shrinking and the first thing I knew I'd opened my eyes, I was laying there. I was trying to get up and I couldn't get up. I just heard kids crying all over the place.

After a rough and painful 400 kilometre road trip, Hope arrived at a large urban hospital where she found, “nurses and nurses and nurses and doctors and doctors!” “It was loneliness, and I think it was cultural shock” coming from a small isolated First Nations community to the sterile medical environment of an urban hospital. As she started to heal, she states, “You start realizing, am I ever going to get better? And then weeks turn into months and months and into years. It was thirteen and a half months straight I didn't hear from my mom. I didn't hear from my brothers and my sisters. I didn't hear from my dad. No phone calls, no letters.” She felt abandoned by her own family. It is not clear why her family did not try harder to reach her and support her. The travelling distance was a barrier and even telephone calls were expensive. Also, the family had its own social and emotional problems. Once Hope left the community, her family seemed to forget about her. Hope's feelings of family abandonment have never completely healed. After a lengthy rehabilitation, she returned to her community for a short time and never felt like she belonged. She wanted to return to the city to access personal care and health services.

Themes from Hope's Life

Through careful data analysis, the following themes emerged; each is vividly illustrated with Hope's voice. The multiple themes represent cumulative “trauma” that are inter-related and build on each other. The first theme is “Grief.”

Grief

The theme of grief includes grieving the loss of mobility and abilities, as well as the loss of family and community. In addition, there are ongoing losses from a diminishing mobility associated with aging.

Hope lost the use of her legs and much of the use of one hand. She had to relearn skills like writing, dressing herself, and going to the bathroom. She had to learn new skills that she did not want to learn such as using a wheelchair, writing with her left hand, feeding herself, and asking for help to do things she used to do on her own without assistance.

The most heart-breaking loss was the loss of her will to live. Hope reported that for ten years after her accident she wanted to commit suicide and actually slept with a knife beside her bed. Over the years, Hope has known many people with disabilities who have killed themselves - more men than women. Even now she says,

Something in you right away says, I'm useless, I'm no good anymore. You could be disabled today and when you get up in the hospital, the first thing you'll think of, I'm no good any more. I can't do anything anymore. I'm just a nuisance and I want to die. All those are steps, you know... the first ten years of my life after my accident I wanted to commit suicide. I didn't want to live. I didn't want nothing.

Hope still grieves but fights back with resiliency and determination. Now she asks herself,

Why are you still crying? Why are you still - I don't know what it is, but it's still - you want your tear glands to quit working. Like, quit working already, you know! It's over! They still keep coming, you know what I mean. I don't want any more. I want it to stop, but the more I start talking about it, it's just tearing you apart [she is crying].

Racism and Verbal Abuse

Hope experienced incidents of racism and verbal abuse. During her adolescent years, she was moved to four different foster homes and in one home she reports,

[The children of her foster parents would say], “Oh, you Indians are so lazy. And all you Indians drink, too.” And what not. Or he’d say, “Oh, you stink,” or ‘You know,’ or something like that. And the parents would laugh.

In another home, Hope was harassed and abused over petty issues such as consuming too much electricity or toilet paper. She was not made to feel welcome or a part of the family as is the intent of foster care. She also talked about the humiliation and degradation she suffered from so-called “friends.” On one occasion, she asked a friend to push her wheelchair along the street. They met an acquaintance who assumed that Hope was a “date” for the evening, and ignoring Hope, he commented to her friend, “I didn’t think you’d go that low [to date a person with a disability].” She stills feels the pain and reacts angrily to this humiliation and abuse.

Sexual Abuse

The trauma of repeated sexual abuse is another theme that weaves through Hope’s life story. In her first foster home, a son of the foster parents sexually abused her. “And that boy would come in there all alone and feel you up and kiss you all over and you couldn’t fight back because you ... you couldn’t fight back.” She complained and was moved to her next foster home where the foster dad made sexual comments to her. During rehabilitation, she experienced sexual abuse from a health care worker.

[An orderly] took me to physiotherapy and he started molesting me and I said, ‘don’t.’ And after that, he knew, I guess, I could talk. I didn’t say too much, I just said ‘don’t.’ But he was probably scared maybe I would tell. But I never did tell. I just want to get out of here.

Later at university, she encountered inappropriate sexual comments from a faculty member. She came to believe that: "No matter where you go, you're always sexually abused... If some guy can take advantage of you, if you're disabled, he will." She has learned to live with this vulnerability to sexual abuse and does her best to protect herself and her daughter.

Health Care Concerns

The theme of health care concerns includes being treated without dignity by health care professionals and bladder infections. It also includes having little input into health related decisions. This section highlights Hope's resiliency in her struggle to maintain, as best as she can, her independence and control over her life.

She talked about the lack of dignity with which she was treated in hospital. For example, as a young, modest adolescent, she was sometimes left uncovered and she was unable to reach for the blanket to cover herself. Hospital visitors casually walked by and saw her naked, and she was devastated.

Painful bladder infections are a recurring health problem for people who are paraplegics and quadriplegics; regular urination helps prevent these infections. According to Hope, many people in wheelchairs deliberately do not drink sufficient water to prevent these infections. She explains that it is physically awkward and complicated to use the washroom and so they avoid public toilets whenever possible. Besides the physical hassle, it can be difficult to find wheelchair accessible washrooms that can adequately accommodate motorized chairs.

For the first ten months I just wanted to be a wallflower. I just wanted to be home bound. I didn't want to go anywhere because if I went anywhere I had trouble with going to the bathroom or not making it in time, wetting myself and then being really miserable. [So], I don't drink because I don't want to go to the bathroom because it's too difficult to go. So I'm plagued with bladder infection(s) constantly. And you take antibiotics - it's like a vicious cycle all the time. It's bladder infection - it's yeast infection - it's bladder infection - it's yeast infection.

These are some of the examples that demonstrate her continued frustration over her lack of control over her physical body and the health consequences with which she routinely lives. The lack of fully accessible washrooms and the personal care supports she needs illustrate systemic discrimination against all independent persons using wheelchairs for mobility.

Resisting Child Welfare

Hope returned to the hospital and the health care system for the birth of her daughter who was delivered by Caesarean. This delayed her hospital discharge for a month and she describes her experiences in the following story:

And [after the Caesarean] I started getting stronger and that's where they [health and social service workers] came in - a whole bunch of them came in... and, said "Well, I guess we'll have to let you go." They kept coughing and saying, "How are you?" and cough and "What are you gonna do when you go home?" and then finally he said, "You know, you haven't proved to us that you could look after the baby when you leave here." And I didn't know I had to prove to them that I could look after her. And besides when they took my wheelchair out they put it out in the hallway and when I rang the bell nobody would come when she started crying because she was at the foot of the bed in her little basket there. So then I freaked out on them and I told them, "I'm taking her home and it'll be over my dead body if anybody's gonna take her away from me! I can look after her! I am a quadriplegic; I am disabled and I look after myself! Sure, I could look after a baby!" I just kept going on and on and, "Okay, fine! You can go home and you can take the baby."

Although customs may vary, in all cultures the birth of a child is a cause for celebration with showers and gifts. Bringing a baby home from the hospital is usually an exciting experience shared by family and perhaps friends. With no interested friends or family and the father of the baby long gone, Hope and Star took a taxi home alone. The hospital and public health professionals never expected her to mother her child and did not prepare her for motherhood. Furthermore, she had no role model or her

own mother present to teach and help. Alone, she fought to keep her child and alone she set out to raise her.

And now I'm sitting here, and "Oh Gosh. Now I have a baby at home and I have to learn how to look after her." At the time I went for an appointment, the doctor said a month later, "She's doing well." A few years later, she's still living. And we were still doing fine [She is now 17 years old].

Hope is not alone in resisting the oppressive policies of the child welfare system. First Nations mothers have had a long history of resisting the removal of their children, often unsuccessfully. First, the residential schools, then the apprehensions of the 60s scoop devastated First Nations children, families and communities (Durst, 1999). Even with the development of First Nations Child and Family agencies, the rates of First Nations children in-care are consistently higher than the national average (Durst, 1999). The historical impacts are overwhelming and long lasting: the need for healing has only recently been recognized. Hope's resistance is even more admirable in light of the history of First Nations concerns about their children being "in care" and under the authority of the child welfare system.

Isolation

This trauma includes the deep isolation and loneliness that come from living away from family and community and the loneliness that comes with living with a disability and "not fitting in." Hope's story is full of accounts of the isolation in which she and other Aboriginal people with disabilities live.

She talks about the chronic loneliness that persons with physical disabilities experience. She has learned to count on herself more, and on others less. "I think it's worse than the Black Plague sometimes. I think, loneliness is so awful. I think sometimes as we get older, because we've been lonely for so long - I think sometimes, most of the time, we die of loneliness. We're the great pretenders," she says, pretending everything is fine, but feeling very lost and alone.

Living in the urban community and dealing with health and social service agencies, Hope has adapted and developed skills in what she calls the “white man’s world.” Although these survival skills are helpful, they also personally conflicting.

But yet you’re already, I always say, white man oriented. You’re a native, but you’re white man oriented so you don’t really fit - you’re in your own world. You don’t fit in the white society and you don’t fit in the native society so you’re in-between the cracks and you’re mixed up.

Hope mixes in philosophical beliefs with stark realism when she says, “We’re the only ones that can make us happy. If we’re living in a lonely world, let’s find something to keep us happy even if [it is] saying, ‘I’m living one more day.’”

She believes the most important thing is human connection - just somebody being there, regardless of whether they are Aboriginal or not. When she gets so lonely she cannot stand it any more, she goes out in the street. As soon as she gets out there, she meets someone she knows, and they will go for coffee, to bingo, or window-shopping.

People always say, “Why do you go to the bingo all the time?” Bingo is happiness for me. As soon as I get there, I’m a totally different person. I don’t know if you noticed, but my eyes sparkle, my smile is there and I’m just shining because I’m at the bingo. And I’m just happy all over ... I can go there and play with just 50 cents as long as I’m sitting there playing bingo.

She talked about the differences that keep people with disabilities and able-bodied people apart:

But the able-bodied world and the disabled world, we are really in two different worlds. We’re trying to make the able-bodied people understand what our situation is. The able-bodied people don’t want to understand what our situation is. They’d rather keep away from us. They’re uncomfortable when they’re near us.

Hope has noticed that when she introduces someone with a disability to an able-bodied person, often the able-bodied person will talk to her rather than to the person sitting beside her, asking things like, "What happened to him?" or "Does he want a coffee?" She does not understand why they do not ask directly. She summed up the situation:

They don't care about disabled people because we live in a Western culture where everybody's supposed to be normal. They're supposed to be perfect and they're supposed to be beautiful. I'm disabled. I'm a nice person, I'm beautiful inside, but able-bodied people can't see that.

Hope illustrates more than the mainstream's ideas of normalcy and beauty but as well, she shows the general discomfort with persons who appear or act differently than themselves. The inappropriate and exclusionary behaviour towards people with disabilities is common and hurtful and further isolates all persons with disabilities.

Poverty

Poverty permeates every area of Hope's life. Hope lives on meagre social assistance that does not include attendant services. An adequate income would make her life vastly different. She could possibly own a vehicle, and could hire home care and other support services which would improve her lifestyle and even her physical health. Hope has never been employed for wages. Even though she successfully completed a Bachelor of Education degree, she was never hired as a teacher. She was told that her disability would prevent her from teaching children. Education and training have often been purported to be a panacea for persons with disabilities (BC Society, 1993, Alberta, 1993, Canada, 1987, Canada, 1998). Even with education, numerous barriers inhibit successful employment and these include transportation, special health needs, workplace accommodation, and sufficient remuneration to cover extra costs that the persons with disabilities incur (SPCW, 1996). The barriers to employment for many persons with disabilities, and particularly urban Aboriginal persons, remain insurmountable (Durst and Bluechardt, 2001).

This trap of poverty strikes from a number of levels. She is a First Nations person, a woman, a person with disabilities, and a single parent on social assistance. Persons from each of these groups have statistically higher levels of unemployment, under-employment and poverty. It is a poverty trap and there is little optimism that her situation will improve. As she ages, perhaps, it will be worse, until she is no longer able to care for herself and requires some form of institutional care.

Relationships and Sexuality

Hope did not date until her late twenties because she was concentrating on her education and on coping with daily living. When she started dating, the relationships never lasted. She said men told her they would call and did not. They said the wheelchair would not get in the way of their relationship, but she believes it did. And she knows that she also let the wheelchair come between her and the men she dated, primarily because of the fatalistic attitude she had towards the relationships. She would say to herself, “I’m in a wheelchair and I know it’s not gonna last anyways, but ... I’ll have fun while it lasts.” “Every time a guy would say, ‘I don’t care if you’re in a wheelchair. It doesn’t bother me,’ she would bitterly say to herself, “Only time will tell.” Then she would not hear from the man again. Hope said that, as long as she and her guy were in the bedroom, everything was fine, but when they went out in public, she often felt like her partner was ashamed of her. She was often introduced as “a friend” rather than a girlfriend, which hurt.

Meeting people, she finds that many able-bodied people are curious about the sexual behaviour of people with disabilities.

For me, I used to find able-bodied men would ask me, “Well, what do you do about sex?” When you start going out with somebody, you start getting to know them... Things just come - just like able-bodied women, I guess. It’s just that sometimes they feel uncomfortable and you feel uncomfortable because you can’t hold your legs, eh? So you say, “Hold my legs still, or hold them up like this, or keep them bent” or whatever. In sexuality you find your own ways of doing things that work, I guess.

Hope accepts her limitations and finds creative ways to minimize the disability and maximize the pleasure. This curiosity from others also includes women, especially women who have recently acquired a disability. She has been repeatedly asked by these women whether or not they can enjoy sex and become pregnant. She reassures them that her child was born after her disability and that, although the women and their partners will have to make some adjustments, they will still be able to enjoy sexual intimacy.

It's funny when you're having sex, you know, because my legs - when you're spastic too your legs will move on you and it was so funny. And sometimes too ... you'd have bladder problems. So when you're having sex, make sure you go to the bathroom before you start having sex because of the pressure on the bladder and because your bladder's weak. Just little things like that. It just comes with the territory. It was okay. Too bad I had to cut it off when I was younger. Sometimes you miss it, but sometimes, if you can do without it, there's other ways you can enjoy life, I guess... Sex isn't everything.

After Star was born, Hope felt pressure to find a man and create a "home" in the model of the nuclear family. She was seeking security and stability as well as companionship and support in the sharing of the responsibility of raising her young daughter. She has noticed that more men than women with disabilities seem to be in relationships, which is supported by the research by Fine and Ash (1992) who found that 60 percent of men are in relationships versus 49 percent of women. It seems as if men have a better chance of finding someone to provide care than women. Hope began noticing that Star was jealous of Hope's boyfriends, and the men did not always want Star around. This dynamic is not uncommon for other mother-led families. Hope would sometimes tell Star,

"Don't bother him. He doesn't like you around." And you know how guys are; they don't like other men's kids. And I finally realized, you know, why am I doing this? My daughter's number one in my life, no matter what. And that's it, I said, I can't do this. And I was just a young girl. I was 32 and from then on to now I am alone. You get used to it, and you say, life goes on.

It must be a difficult decision that almost all single mothers and many attached mothers make: the sacrifice of their own pleasure and emotional, social and physical needs to provide a safe, secure and loving environment for their children. Hope bravely made this decision and with acceptance, moved forward.

In spite of her celibacy, Hope still thinks about physical and emotional sexuality. She states that she longs to be held, have someone there to caress her hair, kiss her and make her feel loved and lovable.

Making Meaning

In the process of identifying themes in Hope's story, it quickly became apparent that the challenges and oppression do not tell the entire story. A significant theme that involves resiliency and healing is the way in which Hope has made meaning of her life. Finding or "making meaning" is the process whereby people make sense out of their life experiences. For example, a person who loses a spouse to cancer may choose to be involved in fund raising for cancer research. Much of the literature dealing with the search for meaning is found in the literature on grief (Rando, 1991; Kublier-Ross 1969). Hillyer (1993) has written on grief as it pertains to disability. With a permanent disability, the grief is not time limited and Hillyer describes it as "chronic sorrow" (1993, p. 72). Making meaning of Hope's life was an essential part of her healing and overcoming the sorrow and hopelessness that she first found surrounding herself. It has meant having a positive attitude, being a parent to her daughter, supporting others in similar situations to her own, and fighting for what she believes in by advocating for herself and other First Nations people with disabilities. Through this process, she overcomes barriers, heals her traumas and demonstrates her resiliency.

Making meaning through being a mother

Her pregnancy was a time of transition for Hope. She began to take better care of herself and got her own apartment. She was fulfilling one of her dreams - to be a mother. She was forced to be innovative and compensate for her limited mobility. For example, she used satin sheets on the bed, so she could use her "hook stick" to slide Star on the slippery sheets.

And I lost her one night! I was moving around trying to get myself ready and I turned around and no baby was on the bed! But my bed had a little groove in the corner so it wasn't quite pushed in the corner. And then I looked and here she is looking at me, smiling [she laughs].

As the years passed, mother and daughter developed a deep relationship and intimate rhythm to their lives. They could be frequently seen “buzzing” along the sidewalk in her motorized chair with Star perched on her lap. As Star matured, a role reversal began to occur, with Star providing care to her mother. “She’s the caregiver now. It’s not fair. It’s not fair to her and I’m struggling with that.” This change represents a challenge to the meaning found in parenting and has become a source of guilt. As many mothers experience, Hope wants her adult child to move on with her own life but needs to expand her sources of “meaning.” The fact that Star provides necessary personal care creates further sources of guilt for both women and generates a sense of entrapment. It also creates an uncertainty for the future that both prefer to avoid discussing.

Making meaning through caring for others

Visiting people with disabilities and peer counselling continues to fill much of Hope’s days and feeds her spirit. It did not take her long to discover a hidden population of isolated and lonely Aboriginal persons throughout the downtown core. She became active in listening to their stories, and in encouraging them to accept and adjust to their disabilities. She encourages them to get out of their apartments and interact with people. After Star was born, Hope began taking her along when she visited Aboriginal people with disabilities. Hope and Star washed and dried their dishes, took out their garbage, watched TV with them, cut their hair, or bought groceries for them. As she met new people with disabilities, she reached out to them, too. When Star was 12 years old, she thought she should get paid for the service she was helping her mom provide. Hope felt differently, and shared her beliefs with her daughter. She said, “Well, it’s not the money thing, my girl. It’s from the bottom of your heart, you’re trying to do something, and you’re trying to help somebody that’s less fortunate than you. You got two good legs and two good arms.”

This spirit of helping others and caring for others is an important source of meaning and gives Hope strength and optimism. It enables her to see and value her own abilities and contributions.

Making meaning through advocacy

Hope began advocating for herself at a young age. After the accident and the initial rehabilitation, she was discharged to the care of her family on the isolated reserve. She was not cared for properly and, as a result, she persistently wrote letters to the hospital social worker, insisting she needed to return to the city or risk not surviving. When she was living in the city, she insisted on moving from abusive foster homes. She eventually found modest and affordable housing. At university, she requested extensions for assignments due to health reasons. She stood her ground when health and social service staff questioned her ability to parent and were preparing to apprehend her newborn baby. Alone, she resisted and fought for herself and her child.

She not only advocates for herself. She has devoted much time to advocating for First Nations people with disabilities. She speaks to university classes, conference groups, and anyone else who wants to learn about the situation of First Nations people with disabilities. She lobbies First Nations governments to pay attention to the needs of their people who have disabilities. She challenges her Band Councillors to do more for members with disabilities. She gets frustrated and angry because it seems the voices of people with disabilities are not heard - even by her First Nations people. She is frustrated with the jurisdictional battles between the federal and provincial governments about the responsibility for urban First Nations people with disabilities.

During a television interview, she argued that First Nations people with disabilities have been “studied to death.” Hope illustrated her point by covering copies of the studies with talcum powder. She held the studies over her head and said, “They have good ideas in these books, if they would just follow them - all the recommendations native disabled have, but they’re only dust collectors.” Then she dropped the copies of the studies and the “dust” flew up and around her, poignantly making her point.

She says small gains are being made because more people are listening, but Aboriginal people with disabilities continue to be marginalized. Groups and associations are fragmented and many do not include Aboriginal people. Funding continues to exist on a project-by-project basis, and when the term funding is gone, so is the project.

Conclusion

Permeating this research, and emerging in all of the themes, were the issues of isolation, poverty, dependence, and a pervasive vulnerability. Hope's profound poverty affects all areas of her life. Because of her poverty and her vulnerability to abuse, she cannot obtain personal supports, which would enable her to be more independent and live in greater dignity. Her poverty, difficulty with mobility, the minimum amount of support, and her isolation have left her vulnerable to ill health and physical harm. She was vulnerable to, and experienced, sexual abuse in the hospital, in foster homes and even at university. The level of vulnerability she experienced during her pregnancy is beyond imagination. She lives in a dangerous part of the city where she could be robbed or attacked. She is vulnerable when she travels home alone at night. She struggles through snow and harsh weather; she has been stuck and trapped in severe cold temperatures. She spends long hours isolated in a cramped apartment where an accident or fire could end her life. As she ages, her limited abilities further deteriorate and she faces the prospect that her daughter will marry and leave to create her own independent life. Underneath the smiles, she worries about her future.

Despite the challenges she faces, Hope has found powerful ways to make meaning of her life. Her standpoint has certainly been informed by personal experience and many years of advocacy work. One of her goals is to continually find ways to have the stories of Aboriginal people with disabilities heard by a variety of audiences, so they become more visible to policy makers in both the Aboriginal/First Nations communities and in the dominant culture. She wants to reach health and social service professionals and the general public. Her concern is always for the improved well-being of Aboriginal people with disabilities. Her passion and her will to live are found in her advocacy work. One of her dreams is for people with disabilities to be a strong united group who can effectively advocate for themselves.

So, “***Listen to what I’m saying. If your eyes interfere with what I’m trying to tell you, close your eyes and just listen.***” Her-story is a life of resistance and resiliency and a powerful lesson for all social workers and health care professionals. Megwetch, Hope, megwetch. May all of your dreams come true.

Acknowledgements

The authors acknowledge the invaluable contribution of two amazing First Nations women: Georgina Morin and Melissa Rezansoff. This research was partially funded by the Social Sciences and Humanities Research Council (SSHRC).

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NATIVE SOCIAL WORK JOURNAL

***Resistance and Resiliency:
Addressing Historical Trauma of Aboriginal Peoples***

*The Native Social Work Journal is registered with the Canadian
Association of Learned Journals*

Volume 6, Number 1, March 2007

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Published by the Native Social Work Journal
Laurentian University
Sudbury, Ontario

Printed by the Laurentian University Press
Sudbury, Ontario

Cover Artwork by Leland Bell

ISSN 1206-5323
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