

Foreword

Who Am I?

Basil H. Johnston

When asked "What did you learn from your language studies?" a grade 12 student from the Sarnia Indian Reserve begged for time to consider the question. Later that day she gave her reply. "I expected to learn about my heritage and so discover who I am." Then after a moment added, "I learned nothing about our people. I don't know who I am."

Another student from Cape Crocker, when asked the same question, answered, "To learn about our heritage."

In taking a five-week in-depth unit on North American Indians, a grade 5 boy attending the Churchill Avenue Public School in North York hoped that he could fulfill his ambition to be an Indian. But the course failed this boy. He had expected much from the unit of study but it gave him less, far less, than he had expected.

After studying social structure, hunting and fishing, cooking, dress, dwellings and how Indians go about from one place to another, that student felt let down, bored to exasperation. He asked me, a visitor to his school, "Is that all there is to Indians, Sir?"

That student, and thousands of other students like him, native and non-native, wanted to know how to get into the mind, spirit, and heart of the Indian, and so regard the world and life as an Indian. What would he have to know to be an Indian? What would he have to do? How would he have to feel?

From their replies, students seem to have a clearer idea of what they want from their language studies than do the mandarins at the Ministry of Education who designed the curriculae for the study of native languages.

But our native language studies are hollow and shallow. They teach little or nothing that would instill a sense of "this is what I am, this is what I want to be."

As long ago as 1968, longer, students taking courses on natives began learning about themselves, or about Indians, saw and sensed the inadequacy of their studies.

To want to know who one is goes beyond knowing one's cultural, ethnic heritage. When a child or an adult sets out to find who he or she is, such a person is seeking to learn what kind of person he or she is, what kind of person he or she ought to be. And that is what a person must do to give meaning to his life and actions.

Long ago, but not too long ago, a learned man went to an old Indian man to learn his ancestral language and his traditions.

As they passed through the woods the first morning, the old man said not a word. Around midday they came to a spring at the foot of a hill. At the spring's edge the old man knelt down and looked into the bottom of the spring. The learned young man too looked into the spring to see what the old man was looking at but he saw nothing save some leaves, twigs, pebbles and sand at the bottom. After some time, the old man rose to his feet and both he and his learned companion continued on their way.

By the fifth day the learned man, weary of hearing no word from the old man and tired in mind of doing the same thing day after day, ask the old man why he looked into the spring each time they came by it.

"To look at myself," the old man replied and then added his own questions, "Why? Don't you look at yourself now and again?"

The learned man was piqued by the question. It was uncalled for. He had come to learn his ancestral language and heritage, not play head games. In five days he had yet to learn something.

It was as if the old man had read the learned man's thoughts; he told the young man that he would teach him some medicine the very next day. The day following, the old man took his learned friend to a pond deep in the woods. On the water's surface were hundreds of water lilies.

"Get me the flower in the middle of the pond," the old man said. "I'll tell you which one when you get there."

When the learned man got to the water lilies farthest from the shore, the old man directed him to one particular flower by saying, "Yes, that's the one."

The learned man slipped one hand under the head of the flower as if to break it from its stalk. Before he did so, the old man cried out, "No! The entire flower, stalk and roots."

Only by going down beneath the surface of the water, time after time, was the learned man able to lift the water lily from its bed. Without waiting for the water lily to dry and to be turned into medicine, the learned man returned to the city.

Some years later the learned man, looking out his window to watch the falling snow, saw the old man's face outside. The old man said, "You wanted to learn. You wanted someone to tell you. I took you to the forest, to the trees, the wind, the birds, the animals, the insects, the sun, the clouds to tell you better than I could about life. But you didn't listen. You thought that all you needed to do to make medicine was to pick a plant."

Only then did the learned man understand what the old man was trying to teach him. But the learned man did not go back.

Youths and adults want to know who they are. They want to be able to say, "I am... This is what my people have done. This is what I can do." To know one's heritage and its achievements lends pride and purpose to one's course in life.

For many people, not knowing their national heritage or not knowing enough has instilled shame and even bewildered them in choosing which path of life to take.

Basil H. Johnston

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A Personal Response to Basil Johnston's Narrative on First Nations People and Disability

I feel honoured that Basil Johnston gave up some of his time from his busy schedule to submit a narrative for this special issue on First Nations people and Developmental Disability. Traditional Ojibway teachings inform us to seek the advice of our Elders in whatever new objectives and/or goals we are anticipating to achieve.

From a First Nations perspective, there exists an expectation that our heritage and culture should be taught and reinforced through academia and the education system, but it seems that our world-views are often missing or devalued in society. It is often the case that others (particularly non First Nations people) think they know what is best for us. Our knowledge is meaningful to us, while the knowledge others provide is often hollow and is, typically, not appropriate. Basil Johnston's narrative reminds us that the issues facing people with developmental disability within the First Nation population are not clearly understood by mainstream society and, as a result, are often overlooked. With this in mind, this special issue on First Nations people and Developmental Disability provides to opportunity to begin to elucidate current research projects and understandings in this field.

For myself and other researchers working with First Nations people, most research papers addressing an issue regarding First Nations people, and written within a disability context, do not tell the whole story – there is much more to it than what can be read on the surface. Interpreting Basil's teaching suggests that one must look, not only at what the researchers have found, but also beyond one's cultural context, one's own heritage to understand the meaning of it all. First Nation researchers, in particular, have a special responsibility to always be aware of what they are doing and not to forget who they are, or where they have come from. We must seek our place by learning to understand what we are doing. Approaching research in this manner ensures that the knowledge base that we are providing to other interested people on First Nations and Developmental Disability will be meaningful and beneficial for all.

Miigwetch,

Rose Mandamin-Cameron

Editorial

Margo Greenwood and Sarah de Leeuw

Imagine for a moment the following scene. A family in an isolated northern community is gathered around a vehicle to watch their son, Ruben, leave for an urban centre. The son is leaving because he is unable to access services in his own community, services that are needed to make his life, and the disability with which he lives, more bearable. Although his family knows that leaving is the best option for Ruben, the knowledge does not lessen the sadness in their hearts. Nor does the knowledge lessen the family's fear of what Ruben will encounter during his journey to access better services because, in their hearts, they know too that Ruben faces significant risk of further hurt simply because he is a young Aboriginal youth with a developmental disability.

At the heart of this scene is a complex set of intersections between Aboriginality, disability, and marginalization. The intersection of these three realities is also at the heart of each of the papers that comprise this issue of the *Journal on Developmental Disabilities*. Considerations of Aboriginality, disability, and marginalization are complex and "messy" topics: each of the authors acknowledges the difficulties inherent both in conceptualizing the nuances of the individual realities under consideration and in working through the many implications of understanding how the three collude. Fudge Schormans and Mandamin-Cameron, for instance, argue that the marginalization of Aboriginal children with disabilities, particularly as that marginalization manifests within the Child Welfare System, is fundamentally linked to social and historical constructions that have resulted in social oppression and institutional discrimination against Aboriginal children with disabilities. In her paper, Carlson similarly explores the layered relationships between oppression, marginalization, and the social disadvantages of Aboriginal families and their developmentally disabled children. She imbeds her considerations within discussions of conflicting world views and values, particularly the tensions between Aboriginal and non-Aboriginal world views values. In their paper, Mushquash and Bova assert that assessment tools for determining cognitive ability do not adequately account for cultural specificity, particularly with regard to Aboriginal peoples. While acknowledging the conceptual complexity of 'culture,' Mushquash and Bova also argue that the results of assessment procedures, like the procedures themselves, do not appropriately account for cultural uniqueness and individuality. The findings of Roe, Dittberner and

Lesley suggest that Aboriginality is strongly associated with sustaining low trauma fractures within residential care environments. Finally, through an analysis of the 2001 Canadian Incidence Study of Reported Child Abuse and Neglect, the authors of "Aboriginal Children with and without Developmental Delay: Characteristics of Maltreatment" make two arguments. First, not only are Aboriginal families overrepresented within the Child Welfare System, but, second, Aboriginal children also comprise a significant percentage of those children with developmental delays who are entering the Child Welfare System.

Not unlike the multiple and complex emotions felt by Ruben's family upon witnessing his exit from their community, the papers in this issue point to the layered and imbricated nature of Aboriginality and disability. This complexity conspires to produce social fragility for Aboriginal children with disabilities, a reality that ultimately affects families, communities, and larger social structures within which all are contained and embedded. Ultimately, what Ruben's family knows, the authors of each of the paper also know: Aboriginal peoples (particularly children and youth) with developmental delays face the very real possibility of double marginalization and increased potential for social vulnerability. Importantly, then, while both culture and ability can be conceptualized as socially constructed phenomena, the vulnerability and marginalization that both combine to produce are very 'real' and materially experienced day to day realities for those who embody (who are, if you will) the social constructs.

Perhaps the most challenging reality of all is the reality that, although change is urgently needed, change comes slowly. Ruben and his family, like many Aboriginal families living with members whose reality includes a developmental disability, hope that change will come and that it will come sooner rather than later. Indeed, like the authors of this collection suggest, if change takes too long to occur, there exists very real consequences for Aboriginal peoples with developmental disabilities. In essence, then, what must be striven for is a change that results in a shift from the present landscape of social vulnerability to an environment of care and consideration that is culturally sensitive, mindful of nuance, and based on the best available research. Ultimately, this is the conclusion reached by the authors of the papers that follow.

The authors identify gaps in the research that point to the need for targeted, culturally appropriate, and sensitive research. They explore the nature of the nexus between Aboriginality and developmental disability and, though diverse in their areas of study and the experiences the authors bring to their

research, each of the papers underscores the need for research that will improve and enhance the lives of Aboriginal children with developmental disabilities and, associatively, the lives of their families and their communities as a whole. Certainly this is a laudable goal, one addressed passionately and thoughtfully within the pages of this collection. We must all hope, and work toward, turning these goals into realities. The lives of Ruben and his family wait in the balance.

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