

promisingpractices

Deborah Nielsen

“A Gift to Our School”

Inclusion of the Medically Complex Student

Cheryl Skura and Michelle McGowan have a dream: they imagine a school that truly welcomes all children – a caring community that embraces all learners with their many needs and diversities. And they’ve gone the distance to make that dream come true. These two dynamic women are the driving force behind a team of teachers who are dedicated to providing all students with optimum opportunities for learning.



In November 2002, Cheryl (a resource teacher) and Michelle (a school counsellor) accepted an award on behalf of Charleswood Junior High School, which is located in Pembina Trails School Division in Winnipeg, Manitoba. The staff of their school was recognized by the National Association for Community Living for “Best Practice in Inclusive Education in Canada”.

Our son, Mark, was the focus of an innovative program that embodies the philosophy of the Pembina Trails School Division – that schools are for all children.

An Intensive Care Patient In A Classroom?

“Inclusion” was not an educational concept when I began my teaching career in the early seventies. When “integration” occurred in the classroom in that era, it typically referred to the

accommodation of a child who was wheel-chair bound or a child with mild learning difficulties. These students were generally capable of achieving academic success with input from the resource teacher. It was unheard of to have students with complex medical needs in the regular classroom. Children with chronic illnesses did not attend school.

Today, modern health care and life-saving technology have made it possible for children with all types of disabilities and complex health conditions to be successfully raised and educated in their own neighbourhoods. These advances have led to a new group of children in our schools. There are an estimated 200 Canadian children under the age of 18 who are considered “medically complex”. In the past, these children would have been cared for in a hospital. Now they attend their local schools and are instructed alongside their peers.

A medically complex diagnosis can include cerebral palsy, muscular dystrophy, spina bifida, cancer or, as in Mark's case, multiple conditions which threaten the child's ability to survive. These are the children who require the services of a doctor on a weekly basis and a registered nurse daily. Medical interventions can include respiratory life support, tube feeding, intravenous monitoring, chest physiotherapy, lung suctioning, administration of oxygen and the management of medications.

Life and Death

It was with some trepidation, therefore, that my husband and I sent our first child into the Manitoba school system in 1992. Mark was born in 1987 with an undiagnosed neurological disorder. It was two years before we were able to bring him home from the hospital, and even then he required 24-hour care. His condition required me to leave teaching indefinitely.

Mark experienced severe respiratory and feeding complications, as well as physical and mental disabilities. Care

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involved the monitoring of breathing, body temperature, tube feeding and other bodily functions. There were also untold mobility issues.

Many schools across Canada are now making good attempts at the inclusion of students with disabilities. It is widely accepted that there are mutual and reciprocal benefits for all in an inclusive school community. In an inclusive school, the students get to know each other on a close personal basis, and they learn about the uniqueness of each person. However, inclusion of a medically complex child raises an array of issues. The peer group is asked to accept and develop a relationship with a student who could, at any time, present them with a complicated situation – possibly involving life and death!

Although Mark's elementary years went very smoothly, we were not optimistic about his entrance into grade seven. As a teacher, I knew that it is often difficult for students in this age group to accept differences. Conformity is valued. My husband and I were worried that Mark would be ostracized or, at the very least, ignored.

Gentle Teaching

We enrolled Mark in our local junior high. This facility houses 600 grade seven to nine students. The philosophy of the school is based on the concept of "Gentle Teaching", a mandate that encourages the staff to honour each student, especially those most marginalized. The school's mission statement



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Il est déjà assez difficile pour de jeunes adolescents d'interagir, sans avoir en plus à composer avec un handicap et la technologie. Chaque jour, l'équipe formée d'enseignants, d'infirmières, d'aides-enseignants, d'orthopédagogues et de conseillers en orientation organisent des moments propices à l'enseignement alors que Mark interagit avec ses camarades de classe. La présence de Mark a eu une influence positive sur les autres élèves qui ont noté qu'il a besoin de faire partie du groupe. Les élèves du Charleswood Junior High School sont encouragés par le fait que si on peut avoir des plans, des espoirs et des rêves pour un enfant aussi vulnérable et handicapé que Mark, ils peuvent sûrement réaliser leurs propres rêves.

makes a commitment to “a safe, supportive environment where trust, mutual respect and an acceptance of differences are consistently practised.”

One needs only to make a casual visit to the school to experience the effect of their philosophy. A positive, purposeful atmosphere pervades the building. Students are relaxed and engaged with each other as well as with staff. There is a strong sense of caring and camaraderie. Students with special

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needs are difficult to identify among the energetic groups of adolescents filling the hallways. The distinct hum of power wheelchairs is the only obvious sign that inclusion is a part of the school setting.

Cheryl Skura and Michelle McGowan realized that one of the main barriers to accommodating students with special needs is the self-consciousness of this age group. Certainly with Mark there was reason to be concerned. It is hard enough for young teenagers to approach each other without having to deal with disabilities and technology.

They made a plan to connect students with Mark in a natural way, emphasizing common interests and appealing to the students' sense of normalcy.

Within the classroom setting, Mark was initially presented as a student with an ordinary family and friends, who liked music and computers. The issues of his health and disabilities were not minimized in the explanation, but kept in a perspective of “who Mark is”. A large disciplinary team drew up his program with this normalizing connection in mind. A personal agenda of individual skill development was delineated in his Student Education Plan. This plan comprised Mark's main program, but he would also attend classes alongside his peers. The key to the success of this program was the registered nurse who accompanied Mark throughout the day. This position was shared by two nurses who were trained to carry out the objectives of the Student Education Plan in addition to monitoring and attending to Mark's medical needs. Each day, the team of teachers, nurse /teaching assistant, resource teacher and counsellor planned and watched for teachable moments as Mark interacted with his classmates.

There was no end to the creativity that ensued around these attempts. Mark's lessons evolved from whatever his friends were doing. If they were bowling in gym, Mark would join them

using a rainspout to transfer the ball from his hand to the alley. In a Musical Theatre production, Mark played his part as a soldier outside a castle. The Home Economics teacher ensured that interaction between the students and Mark occurred by putting him in charge of electrical power. Using a switch, Mark would start the current needed to run the appliances.

Mark's morning job was to collect the class attendance slips and deliver them to the office. With each personal interaction opportunity that presented



itself in these situations, Mark was taught how to greet people and how to engage in conversation. In summary, the approach consisted of supporting the belief that even with major obstacles, all students can achieve their potential in a normal educational environment.

The Gift of Professional Challenge

As Mark makes the transition into high school, he has achieved most of the goals that had been set out for him in grade seven. His communication and social skills have improved. He has perfected the complicated science of driving an electric wheelchair using head controls.

Assisted by adaptive computer technology, he has continually worked at mastering skills that will further aid him in his journey of connecting with others and becoming increasingly independent.

Mark's inclusion has enhanced professional teamwork at the school. He has helped focus groups of people on jointly developed objectives as they have addressed his learning needs. Primarily due to his health concerns and the sometimes over-whelming

intensity of his needs, a support network has developed among the staff. The group meets regularly to discuss Mark's program. Individuals, however, also find themselves exchanging ideas and sharing expertise at the informal level. My husband and I are also invited and consulted, and we are considered equal members of the team. Each person who works with Mark has learned to rely solidly on others for ideas and for reinforcement. This has helped build a collaborative framework that has assisted in the support of all students. Together with continuous problem solving and shared responsibility for the divisional philosophy, accountability for the diversity of all student needs has been fostered. The focus has shifted to the child, with curriculum and related tasks becoming secondary to relationships.

The classroom teachers report that Mark's presence in their classes has had a positive impact on student attitude. There is a greater acceptance of students who were formerly marginalized. Students can be observed reaching out to assist, interact and be touched by the unique situations involved in these relationships. The students have demonstrated an increased tolerance of differences in each other.

Cheryl and Michelle speak of Mark as a gift to their school. He has provided them with new challenges and with new professional opportunities. They echo the feelings of some of Mark's classmates who have volunteered to be involved in his planning process. At one of the meetings, the students expressed their concerns. They observed that Mark needs to be "one of the gang." He needs the same chance to learn. The students said, "If we can, so can Mark." The students at Charleswood Junior High are inspired by the fact that if there are plans, hopes and dreams for one who is so vulnerable and compromised, then surely they can realize their own dreams. 🗨️

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Change is part of growth and development, and we can see that the education of Aboriginal students continues to transform, as the voices of the Aboriginal people get stronger in the process of formal education for their children. It is important that both the Aboriginal and Non-Aboriginal peoples recognize this strength when negotiating with the different governments for quality education for Aboriginal people.

The Aboriginal people have experienced many changes in their educational situation. They started with their traditional culture, language and traditional ways of being. The Euro-western school system negated the Aboriginal way of life. This left the Aboriginal people in a deficit position without a strong voice for many years. It is only recently that the Aboriginal people have taken it upon themselves to strength their voice in relation to education programs and curriculum for Aboriginal students. With the strength of voice and the growth and development in Aboriginal education, there is hope for Aboriginal people to continue to strive for cultural wholeness. This cultural wholeness can only come, as the Aboriginal children experience the changes to the educational system so they can carry on their nations with traditional knowledge and values. 🗨️

- 1 S. Watt-Cloutier, "Honouring Our past, Creating Our Future: Education In Northern and Remote Communities," in Marlene Brant Castellano, Lynne Davis, and Louise Lahache, eds., *Aboriginal Education*, 2000.
- 2 In this report, the term "Aboriginal" refers to First Nations, Inuit and Métis persons and collectivities. The terms "Indian," "Native," or "Indigenous" may also be used, depending on the context and the usage current in the regions, or work environments. Where experience in a particular territory is under discussion, the Nation name (e.g., Odawa, or Oneida) is usually preferred.
- 3 Unpublished Thesis *In Search of Voice: A Collaborative Investigation on Learning Experiences of all Onyota'a:ka*
- 4 A. Solomon, "Education" in Michael Posluns, ed., *Songs for the People: Teachings on the Natural Way* (Toronto: 1991), 79.
Author's note: I would like to take this opportunity to thank Sister Eva M. Solomon for permission to use her father's poem "Education". Contributions to assist Aboriginal students can be made to: The Eva and Art Solomon Bursary Fund, c/o Diane Beauparlant, Laurentian University, 935 Ramsey Lake Rd. Sudbury, ON P3E 2C6.
- 5 Marie Battiste, Introduction to Marie Battiste and Jean Barman, eds. *First Nations Education in Canada: The Circle Unfolds* (Vancouver: UBC Press, 1995) viii.
- 6 Literacy and Aboriginal Success (n.d.). The Movement for Canadian Literacy (MCL). [on-line] <http://www.literacy.ca/litand/13.htm>
- 7 E. Hampton, "Toward a Redefinition of Indian Education," in Marie Battiste and Jean Barman, eds., *First Nations Education in Canada: The Circle Unfolds* (Vancouver: UBC Press, 1995) 31.
- 8 Ibid.
- 9 G.M. Charlston, *Tradition and Education*. (Ottawa: Assembly of First Nations, 1988) 1.
- 10 J. Archibald, "Locally Developed Native Studies Curriculum: An Historical and Philosophical Rationale," in Marie Battiste and Jean Barman, eds. *First Nations Education in Canada: The Circle Unfolds* (Vancouver: UBC Press. 1995) 289.
- 11 Coalition for the Advancement of Aboriginal Studies, *Learning About Walking in Beauty: Placing Aboriginal Perspectives in Canadian Classrooms* (Toronto: Coalition for the Advancement of Aboriginal Studies, 2002) 58.
- 12 S. Willet and C. Willet, *An Aboriginal Landscape*, (Unpublished report. Ottawa: Canadian Teachers' Federation, 2002) 5.
- 13 Canadian Teachers' Federation, *Ad Hoc Committee on the Aboriginal Voice in CTF Report* (Ottawa, 2000) 17.

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