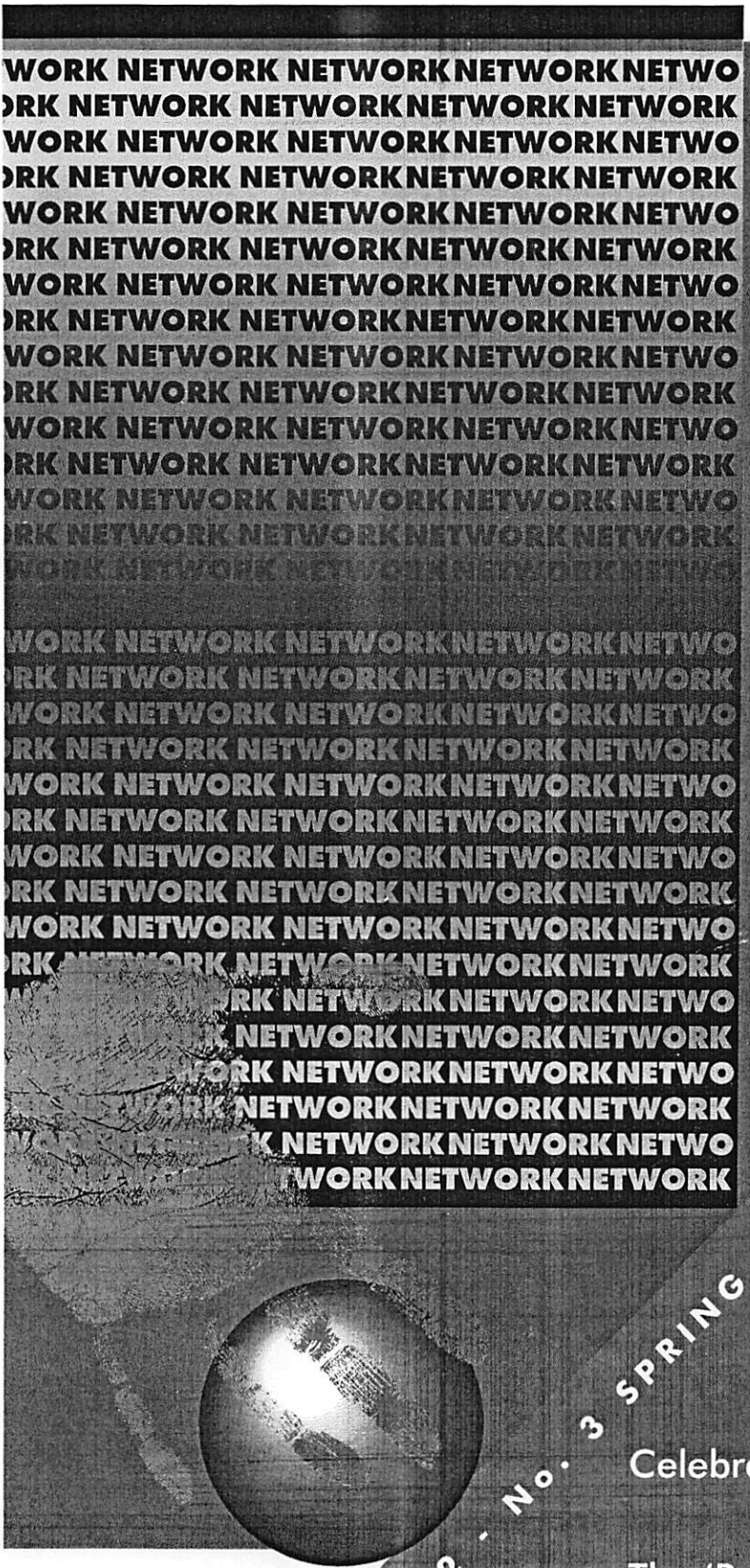
NETWORK



VOL 2 · No. 3 SPRING 1992

Celebrating Inclusionary Practices

The 'Butwhatabout' Kids

Lifestyle Improved by Surgery

The "BUTWHATABOUT" Kids

What about 'those' kids? Our answer is that 'those' kids are the very ones who need us the most. And in a delightful twist of logic, the education system NEEDS those children the most. 'Those' kids are the very people who may restore spirit and meaning to our communities, nurture our sanity, and salvage our survival as a race of caring human beings.

Text: Marsha Forest and Jack Pearpoint

WE WOKE UP early to drive to the Madawaska Kanu Centre about a half hour from our summer retreat in Ontario. We had signed up for the one week white water kayak course and had the usual apprehension one feels the first day of school. It's always humbling to be a student again.

We arrived. Our instructors were a healthy looking lot, brimming over with enthusiasm. After a hearty welcome, we were taken to a nearby lake to begin. The first thing we noticed was the mixed-bag of students in our group. They ranged from fourteen to 55. Women and men, all sizes and shapes. An interesting lot.

After warm up exercises and the accompanying moans and groans, we were wedged in kayaks. The first thing we would practice was getting out safely. We had naively assumed the name of the game was to stay in the boat - not to fall out. Wrong. Fall out we did - over and over again. That was our first learning of the week: Never assume you are going to learn what you think you are going to learn. BE OPEN.

The next exercise was the beginning of the Eskimo roll. We thought this would come in year two. Morning one we were instructed to *"tilt your body into the water, and from an upside down position, flip the boat up using only your hips and knees and very little hand pressure."* The Kanu Centre booklet says and we quote, *"It should feel very easy."* HA!

It wasn't. Marsha remembered sitting upside down in the water with her 49-year-old life scanning her eyes. She decided to get out of the kayak the first way we were taught. *"Pull the little tab on the kayak skirt and slip out gracefully"*. Graceful she wasn't, but slip out she did. She could see the rest of the class smiling and laughing. Jack was having a ball and at that moment, Marsha hated all of humankind, especially kayakers. But she persisted.

The next lesson was called the 'Bow Roll.' Here's how it's described in the Manual. (remember you are upside down in the water):

1. Slap the bottom of your kayak - to get attention.
2. Then wave your hands back and forth along-side of the boat.
3. The rescuer paddles quickly up to your boat and touches your waving hands with his bow.
4. Roll-up using his bow.

Marsha decided to try one more time. Bravely (or stupidly), she was under the water again, only this time she was certain she was drowning. Headlines flashed by. *'Noted Canadian educator lost under kayak on summer vacation.'* Once again, Marsha decided to get out the only way she could. She banged her knee and emerged gasping and spluttering. As everyone else played and paddled, she headed for the beach where she breathed, recovered, and sulked hoping nobody would notice.

Tears welled in her eyes. The internal argument raged. *"I'm having fun, right? I'm paying good money for this. I'm on vacation. Why am I doing this to myself??"*

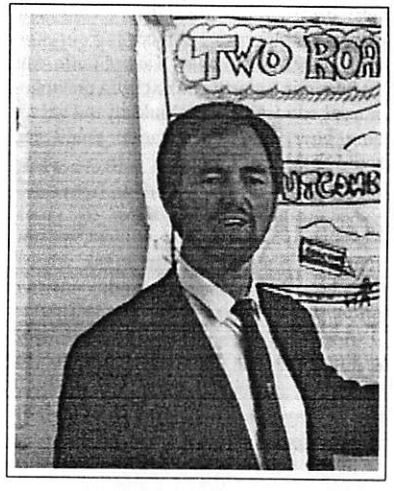
Marsha made an important decision - quickly. She took several deep breaths and headed for the lead teacher, a gracefully skilled kayaker. As calmly as she could, she said, *"Diane, this isn't for me. I'm not getting back in that little boat. I feel awful. I'm so embarrassed."* Mercifully, Diane smiled and explained this was not unusual.

"Some people find the kayak experience claustrophobic."

"Yes, yes, that's me. Claustrophobic. Do I have to go to Kayak special education?"

Diane did not give a lecture on the virtues of kayaking or 'sticking to it'. She didn't deliver the *"if at first you don't succeed try, again"* talk. Instead, she suggested we go right back to the office and arrange a transfer to the white water canoe class.

Marsha said good-bye to her fellow kayakers sheepishly. Jack was supportive, but she was still embarrassed. She felt like a drop out, a failure. In spite of recalling all the fancy leadership and management theory about 'fast-failure', at that moment, she felt awful. *"My 'self-esteem' was at an all time low. My pride was hurt. I felt like a total loser."*



Jack Pearpoint is the Executive Director of the Centre for Integrated Education and Community in Ontario, Canada.

Back at the Centre the owners and managers heard about Marsha's plight. Before she could dry out, she was transferred and delivered personally to the beginner white water canoe group.

Her initial tandem canoe partner was a very tall thin Italian named 'Moss' who was a policeman in Rome. She loved him, the canoe, and her new 21-year-old instructor Sean McSweeney. *"I could see the water and the sky. When I fell into the rapids, which I did frequently that whole week, I was IN not UNDER the water. After a few forward strokes, cross draws, high and low braces, I was a new woman. Restored was my pride, my self esteem and my summer vacation."*

Why can't schools be run like the Madawaska Kanu Centre? Why can't students having trouble move around and find a comfortable place to learn? Why do we make students fail rather than giving them options and alternative choices?

Our experience at the Kanu Centre was fast becoming a new and exciting metaphor for us as educators. Our thinking and values about how we feel education could and should be was reaffirmed.

Marsha symbolised the student we too often lose. She didn't fit in kayak school. The school then offered her another positive option with another teacher and in another location. They did not insist she continue to be miserable and fail (and thus quit dejected, hurt and angry). Instead they offered another way to learn the same basic skills - in a two person canoe - not alone - and above the water. It worked. Marsha had a ball and learned to love white water canoeing.

When children 'fail', our systems too often simply label and 'blame the victims' who are tested and placed in special education despite the massive data which shows this approach doesn't work. To us special education is neither special nor educational. Special education is an expensive and poor excuse for not finding creative and unique options to keep ALL children in the 'main stream' of life.

ALL MEANS ALL

Our belief is: ALL MEANS ALL!, no 'buts' about it. Still we hear a litany of 'buts' which are international in nature.

- But, we're too small.
- But, we're too big.
- But, we don't have the budget.
- But, we don't have the community support.
- But, we don't have the training.

'But' really means *"I don't want to do it,"* or *"I'm not willing to figure out a way to do it!"* If your husband or wife starts a discussion saying, *"Darling I love you, BUT ..."* - you know you're in big trouble. The 'But' in this case really means:

- I'm leaving.
- I don't love you anymore.
- Get lost!

'But' is an excuse word. There are no excuses for losing the numbers of students who are presently being kicked out, pushed out or 'dropped out' of our schools. In his excellent new book The Classroom Crucible, Edward Pauly states:

" ... American Education is failing, and the reforms and rhetoric aimed at salvaging it are based on ineffective, misdirected views of how schools work." (Basic Books, 1991. pg 1.)

" ... American education is already in deep trouble, and it is quite possible that it will deteriorate even further. The education policy debate and most of the education reform movements are engaged in a fruitless search for magic-bullet solutions to education's problems, even when all the evidence shows that no magic bullets exist. While the debate continues, the nation's students are caught in an education system that is sliding from mediocrity to outright failure. (Basic Books, 1991. pg 197).

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The system needs to show students with deeds not simply words that it really cares. Words like love, compassion, caring, helping are coming back to the forefront, hopefully replacing words like control, testing, behaviour management, technique, programs.

What better way for any system to start than to welcome ALL students into its schools and classrooms and stop sorting kids into little boxes. Today, more and more labels abound. As we get rid of one, another pops up. We seem to be investing energy in searching for more labels and tests rather than finding new solutions to complex social issues.

'YES-BUT' KIDS

We must get rid of the notion of 'Yes-But Kids.' There are no 'Yes-Buts.' There are only children. Recently, we spoke at an educational conference entitled *"All Kids Belong Together."* Good title, but that's all it was - a title. Speaker after speaker talked about quality education for 'all BUT'. By the time the BUTS were finished, we concluded no one would be left in 'regular' education. And when the BUTS stopped, the 'Butwhatabouts' began. The logical outcome of that conference was an education system that *"educates the best and simply manages and labels the rest."*

It's easy to teach kids who are easy to teach. This is a truism. It is, however a challenge to teach children with challenging behaviours. Also common sense. 'Butwhatabout' the kid who screams, bites, hits, rocks, does abusive things to his/her own body, or doesn't use a regular bathroom. What about 'those' kids? Our answer is that 'those kids' are the very ones who need us the most. And in a delightful twist of logic, the education system NEEDS those children the most. 'Those kids' are the very people who may restore spirit and meaning to our communities, nurture our sanity, and salvage our survival as a race of caring human beings.

What we do and how we treat the people we call 'Yes-Buts' and "Butwhatabouts" tell us about who we are as people, as professionals and as a nation. Our values come clean in our reaction to these very students. They are the barometer of our values and our vision.

STORIES

The two stories following (one from Canada and one from the United States) symbolise what is great and new in education. These principals and teachers represent the many wonderful educators who truly care about ALL kids. They too had fears, but they persisted and triumphed. They show what is possible. Neither of these schools have extraordinary funding or staff. They are ordinary schools doing extraordinary education for all children. They have principals who are leaders with a vision and mission to educate ALL children. They are still the exception, but with such leadership, this could one day be the norm.

The principals of both St. Francis School in Kitchener, Ontario and Scott Elementary School in Greeley, Colorado have the simple-minded philosophy that their job is to serve the needs of all the families in their community - no buts about it. They have a clear vision and a clear value base. If these schools can do it, so can everybody. It is simply a matter of will.

Scott Elementary School, Greeley, Colorado.

Bill Gillenwater is the principal of Scott Elementary School in Greeley. He decided in February, 1990, to close his special education rooms and move all the children into their age appropriate home rooms - with the necessary supports going to the classroom teacher. To some this was heresy and lunacy; to most it was simply an idea whose time had come.

From Bill's diary he recalls, *"I believed that moving to a fully inclusive school was really a civil rights issue. I didn't feel we could make the needed change by putting this up to a staff vote. In my mind, the rights of children were clearly being violated at the school in which I was principal. We couldn't wait an additional twenty years to correct this."*

On August 20, 1990, new and historic class lists went up at Scott elementary. There were no more self-contained special education classrooms. Bill had several 'Yes-But' Kids but one really stood out.

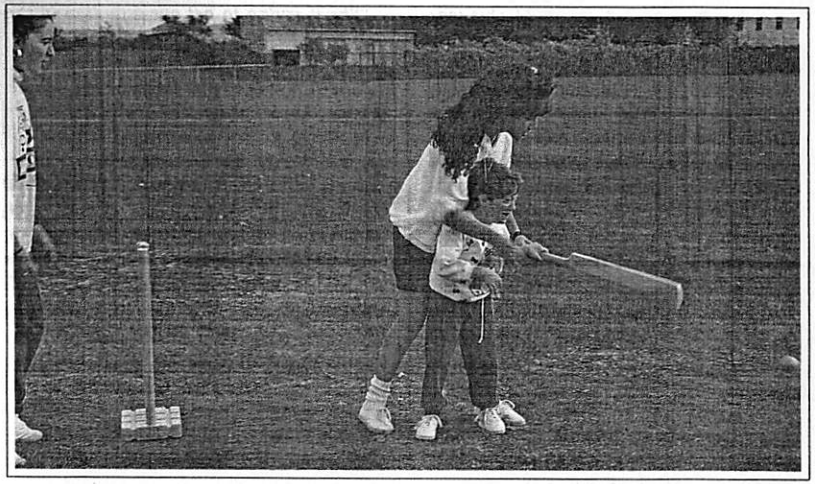
Juliana Laurence, known to those who love her as Annie, was a small, frail and beautiful child. Daughter of Norm and Ellen Laurence. Annie and her family had for years been shuffled from program to program in search of the magic-bullet. None had yet been found. Ellen simply wanted her daughter to go to school with her brother and sister. She wanted Annie to have friends, to have a chance to be a little girl.

After doing the rounds again, and being rejected by two schools, Ellen met Bill. He said, *"Of course Annie is welcome at Scott. What do we need to do to make her happy and learning?"* Ellen was in shock!

Bill observed Annie in her other school and realised Annie would be his challenge. He recalled with us, *"Annie constantly brought the issue to a head. She made the word inclusion real. She challenged all of us to put our money where our mouths are. But I knew that Annie was the 'gift' that would make our school a welcome place for ALL kids. I wondered if I'd have the guts and courage to stand up for Annie if my job were on the line."*

In this school of 620 pupils, there was a small, but vocal minority of parents and teachers who didn't want Annie around. *"There are special places for kids like her,"* said one parent.

"Children labelled autistic and profoundly retarded don't belong with or near my son," wrote another.



What better way for any system to start than to welcome ALL students into its schools and classrooms and stop sorting kids into little boxes.

Bill's diary recorded: *"I felt that I must be truly hearing what school principals in Mississippi heard in the 1960's. We've come so far and yet not moved an inch as a progressive and democratic society. I won't be intimidated by this vocal minority!"*

Bill and the Laurence family rode out this negative wave. They had a great deal of support from friends all over Colorado and indeed from all over North America. They needed it.

Annie's most challenging behaviour was 'hair pulling'. This was described by the anti-Annie forces as 'attacks'. It is reasonable and necessary to be concerned about safety in a school. But 'context' is critical. Hair-pulling is annoying, even painful, but it is not a capital offence. It is not life-threatening like a gun or knife.

The 'Yes-But' child's most serious offence was pulling other little girls' hair. The girls survived these attacks quite calmly. They were in fact the ones who eventually solved the problem. The children decided to firmly tell Annie, *"No! Don't do that!"* They simply learned to take her hands off the pulled hair.

The autism and mental retardation experts were committed to more complex strategies that had never worked. They never dreamed of involving the other children. This fancy and expensive technology - asking other children to get involved - is the magic needed to begin unravelling the mystery of the 'Yes-But' students.

Annie was fully welcomed by two regular education teachers. Marsha remembers the day she observed Annie and her grade two class at Scott. *"Annie was sitting in a small circle of little girls. She was resting on one child's lap as the others took turns reading her their favourite stories. It was reading and language time. It seemed to me everyone was benefitting. Why do we make some-*

thing so simple so complicated? This was simply good common sense high quality education."

Annie continues to live and learn at Scott. The storm has ended and Annie has new friends. The big success story came on January 26, 1991. The Lawrence's decided to have a pizza party for Annie. They invited all 26 children in Annie's class. They thought maybe six would show up. To their shock and delight, 35 people showed up - children, families, friends. Norm was happy to run for more pizza. *"Never in our wildest dreams did we think so many people would come,"* said Norm and Ellen.

When interviewed, the students in Annie's class told us that Annie is 'just-another-kid' in their class. Marsha asked the children why they thought Annie pulled hair. Their answers reveal a profound and common-sense wisdom that we as adults would be wise to hear.

"She likes hair. It feels good to her."

"She is trying to get our attention in the only way she knows."

"She is trying to say 'hi' to us."

"She is trying to pull us close to her. She is trying to pull us back to her."

To the children, Annie is not a child with challenging behaviour, a case of mental retardation or autism. To these children, Annie is just another kid, just a friend.

Annie is definitely one of the 'Yes-But' children. She is lucky to live in Greeley, Colorado with Bill Gillenwater as her school principal. However, she is no different than thousands of other Annies still locked up in psychiatric wards, Annies who get 'time-out' and 'behaviour' programs - who get squirted, shocked with cattle prods and put in restraints. What is different is that the people around Annie decided first and foremost that she needed a welcome, a place to belong. They decided to work together as a team to figure out what to do hour by hour and day by day. They decided to welcome Annie.

What we do and how we treat the people we call 'Yes-Buts' and "Butwhat abouts" tell us about who we are as people, as professionals and as a nation.

Meanwhile, back at the Kanu Centre

Marsha was quavering at the top of Chalet and Staircase rapids. *"My heart pounded. My canoe partner was a slight, thin, twenty-one year old woman from New Hampshire. She was at the stern of the canoe, I was in the bow. The water looked to me like Niagara Falls. Our twenty-one year old instructor helped us plan a course of action. We took off. Down the rapids we flew. We literally bounced off one rock and sped backward into the next set of rapids. This wasn't the way we planned it as we careened through the churning Madawaska. We got the canoe facing downstream again, took another set of rapids and spun into an eddy (quiet water) where we had been heading. I was screaming for joy. "But, we didn't do it the way we said we would," said my perfectionist partner.*

I was in another space, "We made it! We didn't lose the boat, the paddles or end up in the water," (like we did the next time around).

Annie is a lot like those turbulent waters. Beautiful and yet unpredictable. We can't always see what is underneath the surface. We can do the best we can, chart a course of action, but we must always have the flexibility and courage to change course, even in midstream, in order to reach our destination.

It was actually challenging and fun getting through the white water of the Madawaska. It should be an exciting venture figuring out how to get through to Annie. She is a person who challenges us to be creative in figuring out the puzzle named Annie and the route to follow so we enjoy life - including the rapids together.

The instructors at the Kanu Centre saw every problem as a challenge not as an impossible demand. We told the raft team about our friend Judith Snow, a person who uses a wheel-chair and is described by many as *"one of the most physically disabled people in Canada."* We asked if the rafters would take Judith down the rapids. Their response was universally a resounding, *"YES! Great! When? What does she need? How many extra people? What equipment?"* This refreshing response is unfortunately not common in our schools when we ask if a student with extra needs can come in the door.

We'd like to trade Sean, Diane, Claudia and Dirk for many of the education administrators now running schools - schools that still reject the Judiths and Annies of the world. We would like to see the philosophy and practice of the Madawaska Kanu Centre permeate our school systems. This way, more kids would stay in the boat rather than falling out into the prison stream, the institution stream, and too often, tragically drowning and wearing out those who try to do the rescue.

The last words in this story go to Annie's wonderful teacher, June Griswold and her third grade class at Scott Elementary School. They were asked, *"What advice would you give others who are thinking about inviting students similar to Annie to their schools?"*

"Tell the teachers that all kids act more normal if they are with their friends."

"Tell everyone to treat all kids like regular kids 'cuz like all kids are like regular kids."

"Having Annie here has made me feel better about myself."

"It's fun having Annie here."

"Annie makes us all feel happy. Without her we wouldn't be the best class that we

are with her here with us."

"Having Annie here has made me feel different inside, like positive."

"I learn more when Annie's around. She makes me feel like I belong, too."

St. Francis Elementary School

Brian Cullen is the energetic principal of St. Francis, an elementary School of over 350 students in Kitchener, Ontario. Brian decided in 1987 to close his special education segregated classes and move seventeen students from self-contained classes into the regular education stream.

His philosophy is straightforward.

"Nothing is impossible if you have the commitment to educate all kids. You just have to work harder, problem solve and find the right combination of supports so that kids can learn in natural settings.

Some principals still think it's OK to reject and separate kids. I just don't hold that philosophy. It is not OK to reject anyone. Another school would have recommended a psychiatric residential treatment facility for the two boys I'm talking about. But we decided they belonged at our school and we'd do everything possible to make them welcome."

Sam was described as a developmentally handicapped child who was non-verbal and whose behaviours made it difficult for him to learn or get along with others. He came to St. Francis from a distant hospital, a residential treatment centre for people with psychiatric problems. Sam had lived there for four years. Initially he went for 'an assessment'. Like the character in One Flew Over the Cuckoo's Nest, Sam got lost in the bureaucracy. He ended up living there. After two years, his family totally abandoned him. It took another two years to find a place for Sam to live. He is now in a group home in Waterloo and goes to a regular High School.

"When he came to our school we knew very little about him. He simply showed up. Our first step was to get to know him. On his second day at school he defecated and started throwing the faeces around the room. Kerry Gorman, a great teacher, called me on my beeper for the first time in four years. Together, we cleaned the kid up, put him back together, and continued the rest of day. That afternoon we had a major planning meeting."

There is no doubt Sam was one of the 'Yes-But' Kids. But for Brian, there was no doubt that Sam had to stay. It never entered his mind that Sam should go anywhere else. Brian's first concern was to pull together a team and develop contingency plans. Sam was defecating regularly. Brian remembers it this way:

"We figured this was a really neat challenge. We never had a kid like Sam before. We had to set up a system to get rid of this behaviour.

We were also worried about chunks of the day when Sam got involved in unsafe activities. He'd run into the street and lie in the middle of the road. He'd dive in puddles of mud. We were worried. One other annoying problem was that Sam would slap other kids. This ended immediately when we encouraged Sam's classmates to return the slap in kind.

It took a good three months before we noticed any real change, but by the end of the year the defecation problem had been eradicated. Sam didn't run in the street very often, and he didn't slap anyone - well hardly ever."

How did St. Francis manage to do what the psychiatric hospital and hundreds of specialists had failed to do in the past? The lesson is simple and profound. Brian, Kerry, and Jenn George (the special education resource teacher) didn't think they were doing anything unique.

Here's how Brian describes the first few weeks:

"There was no shower in the school so we used a pail and sponge. We had to dress for Sam's bad times, so we got big lab coats from the shop teacher and we wore boots. This was messy stuff. We think Sam really enjoyed people washing him so we switched to teaching him to clean himself which he did. This of course took longer. He would dump the pail of water so we got him a mop. We never resorted to punishment. We needed extra clothes and that's about it."

Brian was amazed at the reaction of Sam's 5th grade classmates. *"I can't believe how the other kids reacted. They were disgusted at first, but they were really sensitive. They were never mean, in fact, they were actually getting closer to him because they felt so badly for him.*

It was surprising but not one parent complained and believe me they all heard about Sam.

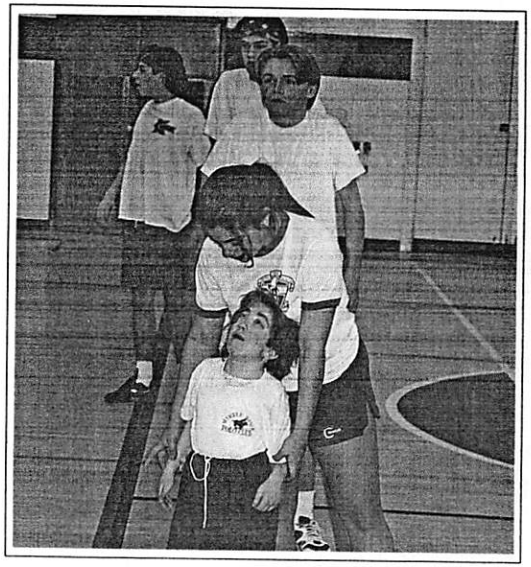
Much credit of course goes to Kerry Gorman and Sam's Circle of Friends. This circle was established and facilitated by Kerry beginning the first week of school! Ten kids have been faithfully involved and helped in trying to figure out why Sam was the way he was.

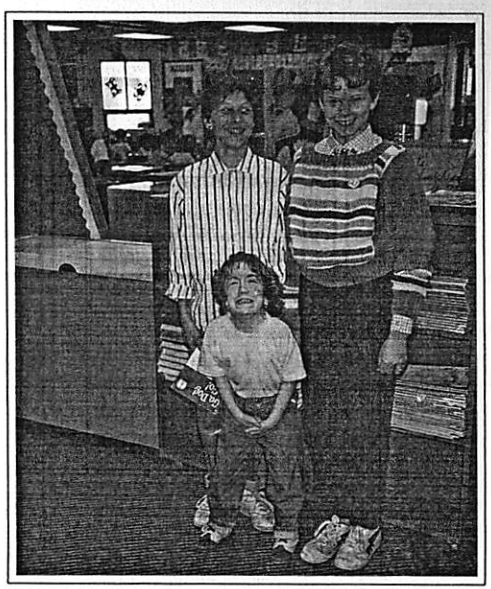
The children felt Sam needed to be involved in everything 'normal' at the school. He went to social and sporting events such as soccer games and dances. He went on a camping retreat. Because someone had taken him out of the real world for four important years of his life, the students felt the priority was to keep him in the world.

At the eighth grade graduation ceremony, Sam got his certificate and the biggest round of applause of any student.

"This kid is still really a big challenge. We didn't cure him. We did what we could do."

"Tell the teachers that all kids act more normal if they are with their friends."
"Tell everyone to treat all kids like regular kids 'cus like all kids are like regular kids."





There are no 'Yes-Buts', no 'Butwhatabouts', No Buts about it. Just kids - KIDS who BELONG TOGETHER .

Brian credits what was done to an intuitive sense about what is right and just for all kids. He says, *"I don't even think about it anymore. You can take as many courses and workshops as you want but somewhere along the line it all comes down to a gut reaction about what to do that is respectful to the youngster in question and safe for everyone else. It's the right thing to do. That's it."*

Brian had one other student that was a 'Yes-But' student. Len came with several labels: multi-handicapped, communication disorder, trainable mentally retarded and severe behaviour disorder.

"Yes, I'd call Len one of the tough kids. He's right up there on top of my tough kid list, right beside Sam.

Len had been shunted from class to class. He had already been 'kicked out' of four or five other schools for his anti-social, aggressive behaviour. Reports said, 'Len is too behaviour disordered for the trainable retarded class and too retarded for the behaviour class.' This would have been funny if it weren't so tragic. He was also called a 'non-reader with no interest in academics'.

When he arrived at St. Francis, Len was eleven years old. He was placed in the regular grade five class along with the other eleven year olds.

Brian called Len 'V.P.' (for Vice-Principal) because he spent so much time in Brian's office refining his confrontational skills. Behaviour was the big issue.

"Out of seventeen kids, Len and Sam were our biggest concerns. Len was said to have 'aggressive behaviours' and we didn't know what he'd do. We found out quickly. He would use really foul language to the teachers. I got used to it. He would swear like crazy. Then a miracle occurred. For six weeks there was not one incident in the regular grade 6 class. Joan Marsh, another amazing teacher, showered him with love and gave him the impression she was crazy about him.

However, in the 7th week he freaked out! He was back in my office, but this time there was a real difference. I could talk to him this time around. He cooled down quicker, was more rational, and wanted to get back to classroom. I asked him, 'What's happening? What's the matter?' I told him I was disappointed and hurt. His answer floored me.

"I really like grade six, Mr. Cullen, but I can't #! read." He could have blown me over with a feather. I was so moved. He finally told us something he really wanted to do. None of us had ever thought of Len reading.*

"Well, you better get back and learn to read. We'll teach you right away!" The special education resource team figured out that Len loved GOBOTS (robot puzzles). They went shopping that evening and GOBOTS became the initial step in Len's reading and writing program.

Len is now in high school and is reading at the grade four level. He can read announcements on the Public Address system and is doing well. He isn't perfect and he isn't cured. He has good and bad days, but he's still at school and he has changed dramatically.

We asked Brian what he had learned through these experiences. *"No student will ever have the right to segregate themselves in my school. These kids have taught us how to be creative with resources, how to come up with solutions to problems that present themselves. Our school is better because of Len and Sam. We are all better as people and as a school system because of welcoming Len and Sam."*

These two stories speak volumes about the adults involved and about their values and beliefs. They had no more money and no more extra resources than any other school. The difference was their leadership and their teamwork. They had a commitment to meet the needs of all children and they did it.

There is no mystery or magic here. There is hard work - blood, sweat and tears at times. The only reward is a job well done and an entire community of adults and children who will never be the same because they welcomed two boys named Sam and Len.

There are no 'Yes-Buts', no 'Butwhatabouts', no Buts about it. Just kids - KIDS who BELONG TOGETHER. ❐

A Word About Language.
We have coined two new terms for use in this article:
'Yes-But' Kids (YBK'S)
'Butwhatabouts' (BWT'S).
These terms encompass all the students everyone thinks are impossible to integrate. These are also favourite expressions heard frequently at conferences on the issue of Full Inclusion. No sooner has the speaker concluded his/her remarks, than hands are flying to ask, 'Yes-But' or 'Butwhatabout'.

For more information about strategies which are specifically designed to integrate 'at-risk' children and adults (including MAPS and Circles of Friends) write to:

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