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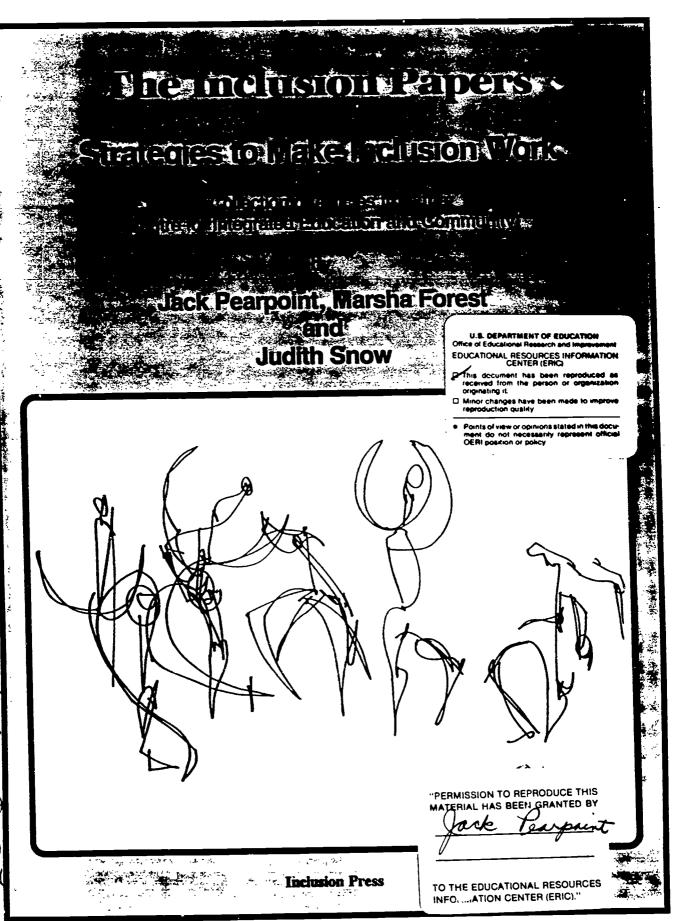
ABSTRACT

This collection of over 30 papers presents the view that all persons should be equally valued, provided equal opportunities, viewed as unique individuals, and be exposed to and learn from and about people with diverse characteristics. The papers offer insight into the process of moving forward to achieve both equity and excellence for all Canadian people, labeled "disabled" or not, in educational and other community settings. The articles call for advocacy, attitude change, and expanded availability of appropriate supports and services within schools and communities to allow everyone to participate and contribute in a meaningful way. Titles of sample papers include: "Two Roads: Inclusion or Exclusion"; "The 'Butwhatabout' Kids"; "Annie's Gift"; "Common Sense Tools: MAPS and CIRCLES"; "MAPS: Action Planning"; "Dreaming, Speaking and Creating"; "Kick 'em Out or Keep 'em In"; "Vive la Difference"; and "Natural Support Systems." (JDD)



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SATOK is BACK!

After a drought of 12 years, a world renowned artist, Ron Satok had his first showing at the Randolph Dance Studio in Toronto in March. Many artists have dry spells. Ron's is unique. Twelve years ago, he lost all sight from glaucoma. This past year, he began drawing again. His first showing was virtually sold out and bodes well for the art world and Ron. He and his wife, Susan, insist that the best paintings were the ones he drew with no ink in his pens. Ron laughs, "The pens smelled full. Susan just forgot to fill them."

Ron's topics are wide ranging, but the unique Satok composition — lines based on the curvature of his childhood violin — have tremendous movement and power. The location for the showing was perfect. The movement in Ron's works was mirrored in the studio, and surrounded by dancers. "It took me a long time to realize that my art was in my head. I saw objects for 48 years. I never drew objects. I drew what was in my mind." Different than Ron's sighted works, these new pieces have a kind simplicity and power that captivates enormous movement. Watch for Ron's next showing.

Ron's 12 year story is a saga of painful determination. After a traumatic period, he began again — the Satok School of the Arts was born. Dizzy Gillespie, a good friend, hosted a benefit for the launch in 1982. Ron has been teaching children and adults with special needs ever since — to give a sense of self-worth. He has also been doing "performance art" — painting huge wall size canvas murals to music while dancing. One of his most recent shows was the centerpiece of the 25th Anniversary of the Ontario College of Art. (An enormously powerful home video is available). On June 3, 1992, another Gala Benefit for the School will feature the Randolph Dance Theatre, Norman Amadio Jazz Quintet, Chinese Drummers and the Satok School of the Arts — at the Winter Garden Theatre in Toronto.

Ron's teaching and painting is unique, powerful and liberating. Ron and Susan live like the artists they are — happy, committed and poor. They will not give up their art, but a little less poverty would be acceptable.

If you are planning a major conference or event and want to set a unique tone, contact Ron and Susan. It is guaranteed to be an opening event that no one will ever forget. Contact: the **Satok School of the Arts**, 446 Ontario St., Toronto, Ont. M5A 2W1 Tel.: 416-967-0780.

Cover Design thanks to Ron Satok

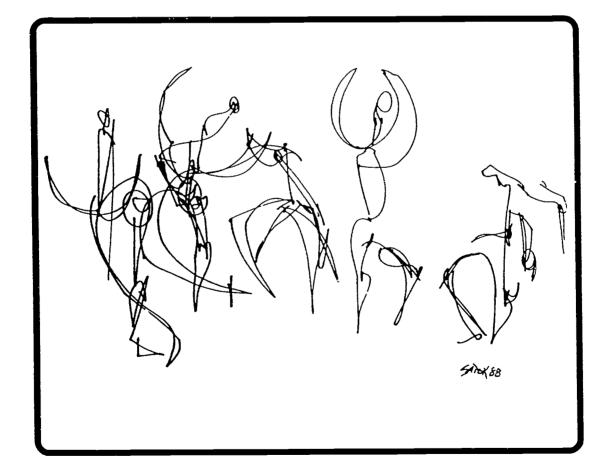


The Inclusion Papers Strategies to Make Inclusion Work

A Collection of Articles from the Centre

by

Jack Pearpoint, Marsha Forest and Judith Snow



Inclusion Press



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Multiculturalism & Citizenship Canada
Imperial Oil Limited



Dedication

A Maori Proverb

He aha te mea nui i tenei ao maku e ki atu He tangata! He tangata! He tangata!

Ask me what is most important in the world Let me tell you. It is people! It is people!

We dedicate this collection of work with thanks to our international Circle of Friends who have walked with us on our journey.



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Introduction

This is another in a series of books from Inclusion Press that is insightful, practical and highly useful to those of us on the road to inclusion. Many of the ideas and strategies the authors have developed (e.g. MAPS and Circles of Friends) have become recognized and used in schools and communities throughout the world.

The basic premise of the book is that there is a growing recognition of and respect for social justice, equal rights, acceptance, belonging and inclusion. This movement accepts that all persons should be equally valued, provided equal opportunities, viewed as unique individuals, and be exposed to and learn from and about people with diverse characteristics. These principles are becoming the guiding forces for integration in schools and society. Such a view of integration goes well beyond physical proximity to the need to develop and maintain inclusive schools and communities in which every person is welcomed, valued and expected to contribute as well as to be supported by his or her fellow members.

This growing movement has far-reaching implications and can provide insights in how to accept and approach people in society who have been labeled. Generally, people with disabilities have not had the principles of acceptance, social justice, equality, belonging and inclusion applied to them. For far too long they have been "devalued" citizens considered "better off" separated from their community peers.

However, through parent involvement, self-advocacy and the activity of other civil and human rights advocates, such views are beginning to change. The basic rights of people with disabilities to equal access and opportunities in the mainstream of educational and community life are being recognized and accepted. Attitudes, laws, and practices are beginning to change to reflect this forward movement.

While equality in terms of human rights has been the driving force behind many of the integration advances, increasing momentum is also being gained as a result of the positive impact that integration and inclusion has brought about. The benefits to all persons when previously excluded people are included are being recognized. Persons labeled disabled are beginning to be recognized as the unique, valuable individuals that they are with a wealth of gifts and talents to contribute to their educational and social communities. They are being recognized as sources of support rather than only as recipients of support. People previously denied participation in the mainstream are an important and valuable part of the community and an untapped resource that society no longer can afford to exclude or neglect.

However, to achieve totally inclusive schools and communities in which everyone is welcome, valued, and supported, and to which everyone contributes, much still needs to be done. Advocacy, attitude change, and expanded availability of appropriate supports and services within schools and communities that allow everyone to participate and contribute in a meaningful way are still needed. This book provides generous insight into the process of moving forward to achieve both equity and excellence for all people, labeled "disabled" or not, in educational and other community settings.

Susan & William Stainback, Ed.D.

Professors of Education University of Northern Iowa April 21, 1992



Inclusion! The Bigger Picture

by

Marsha Forest & Jack Pearpoint

Our key question as we initiate a new millennium is "How do we live with one another?" Inclusion is about learning to live WITH one another. Inclusion means "being with".

Inclusion means inclusion! It means affiliation, combination, comprisal, enclosure, involvement, surrounding. It means WITH... Inclusion means BEING WITH one another and caring for one another. It means inviting parents, students and community members to be part of a new culture, a new reality. Inclusion means joining with new and exciting educational concepts (cooperative education, adult education, whole language, computer technology, critical thinking). Inclusion means inviting those who have been left out (in any way) to come in, and asking them to help design new systems that encourage every person to participate to the fullness of their capacity - as partners and as members.

Inclusion means Welcome!

"I want to be included!" This simple statement is being spoken, signed, facilitated, key-boarded, whispered and shouted by people of all ages, shapes, sizes, colors and cultures. Many are making the request for themselves while others are asking for their friends or aging relatives. It is a simple request and the answer is equally easy. "Welcome! We want to include you. Come

and be a part of us and our community."

Why does this humble proposal evoke such strong reaction? Why is welcoming people labelled "disabled" seen as an activity of the "radical fringe"? Hospitality is not radical. Caring for our families and friends is not radical. In fact, hospitality and caring are foundations of our culture. So why the intense reaction about inclusion?

We believe that the Inclusion issue cuts directly to the core of our values and beliefs. Inclusion seems so simple, so full of common sense, and yet it is complex. Inclusion sets off fire works in the souls of those involved. Inclusion challenges our beliefs about humanity and cuts deep into the recesses of our hearts.

Inclusion is NOT about placing a child with a disability in a classroom or a school. That is only a tiny piece of the puzzle. Rather, inclusion is about how we deal with diversity, how we deal with difference, how we deal (or avoid dealing) with our mortality.

How else can we explain the emotions unleashed by the presence of a tiny child in a wheelchair or the presence of a teenager with down syndrome in a local school in Canada, the United States or Britain. Why do so many apparently "normal" adults lose their composure with a mere mention of including an excluded child. We conclude that the arrival of this person signals major change, and for many, change is something to fear - something fraught with danger.

However, in danger there is also opportunity for growth. Thus, schools and communities, teachers and citizens, who face their own fears and mortality by welcoming ALL children instantly create the climate for a new kind of growth. Inclusion becomes an oppor-



tunity and a catalyst to build a better, more humane and democratic system.

Inclusion does not mean we are all the same. Inclusion does not mean we all agree. Rather, inclusion celebrates our diversity and differences with respect and gratitude. The greater our diversity, the richer our capacity to create new visions. Inclusion is an antidote to racism and sexism because it welcomes these differences, and celebrates them as capacities rather than deficiencies. Inclusion is a farce when it only means "white, bright and middle class". Inclusion means all - together - supporting one another.

A child or adult with a disability is a symbolic personal crucible where we face our feelings about differences head on. Inclusion is about how we tolerate people who look, act or think differently than so-called "ordinary" people. Inclusion can be deeply disturbing for it challenges our unexamined notions of what "ordinary" and "normal" really mean. Our hidden values are paraded before us in action and reaction. Some of what we see is discomforting. The questions become very personal. How would I feel if I were unable to walk, talk or move? How would I feel if I had a child who was labelled? How do I feel about myself? How would I feet if I were disabled by an accident? And ultimately, the one common issue we all face (or deny): How do I feel about growing older? Where will I live? With whom will I associate? Will people (my family and my friends) care for me when I need help, or will they cast me aside? Will I live an endless death waiting hopelessly, helplessly, uselessly in a nursing home ward? What will become of me when I am old?

Inclusion instigates this kind of reflection. No wonder people react! Reflection is vital to everyone. Life must be examined to be lived fully. It may be painful, but the inquiry can be the beginning of building new personal futures. We owe a debt of gratitude to people who present us with this magnitude of challenge. Thus, welcoming people with challenging differences into our schools and communities is not simply for their benefit, it is for OUR health and survival.

The Need to Belong

Inclusion isn't a new program or something one "does" to or for someone else. It is a deeply rooted spiritual concept that one lives. It is not a trendy product or fad to be discarded. It is not a new label - "the inclusion kids". It is not a bandwagon. People are either included or excluded. One cannot be a little bit pregnant or a little bit included (like the myth of "inclusive" recess or lunch). One is either "in" or "out". One either belongs or doesn't belong. If we exclude people, we are programing them for the fight of their lives - to get in and to belong.

Most excluded people perceive that they have nothing to lose, and everything to gain in the battle to belong. Many youth consider it a matter of life and death. Teenagers join gangs because they are desperate to belong - to have meaning. Even when the gangs kill, youth join. The gangs meet their needs. Gangs are a logical response to society's failure to make teenagers feel belonging. When our youth literally die to belong, it is a searing warning for us to look hard at the system in which we live.

Many suggest that with our society in crisis, we need to mount the barricades and defend our turf. Typical responses include: hire more police, build more jails, create more special education, administer more electroshock, issue more behaviour modifying drugs. Control, control, control. There is another possibility. We could strive to welcome and include everyone, to build a society with more acceptance, more love, more care, more compassion.

Our world has serious challenges. We must face them honesty, analyze, learn from the past, then move forward. The need for change is not negotiable. The only question is whether we run with it, or be dragged kicking and screaming into the year 2000. Dealing with change is like running white water rapids. It is dangerous - but if you train and plan, it is the thrill of a life time. Change is here. Our societies are white water chutes. There is no portage. Our choices are limited: will we shriek with joy as we run the rapids, or will we just shriek?

Our world is rife with conflict. We must not deny it. Instead, we must strengthen our capacity and learn to live with differences and conflict while avoiding the tendency to slide into violence as a solution. Conflict is legitimate. We can agree to disagree. Resorting to violence is no longer viable. It will be our destruction.

With the advent of new technology, the critical issues of this new revolution of compassion will be to learn how to live with one another. If we are to survive, we will enter an era of "high touch" and genuine personal communication. Who better to instruct us in this new venture than those who have been excluded and rejected in the past.

Teenage suicide, random violence, drive-by shootings and gangs are simply signals of a deep social malaise that won't be cured by microwave thinking or slick packaged answers. We must think deeply. We must make tough decisions

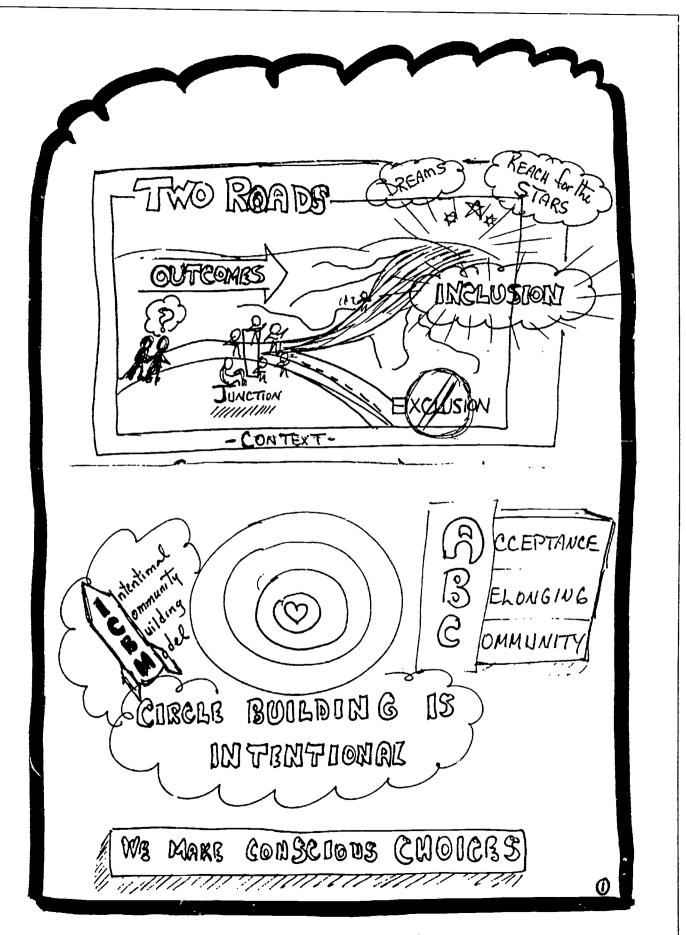
and be willing to work hard. Inclusion makes us think deeply about what we want our world to be. Who do we want as neighbors? What do we want our communities, churches, synagogues, mosques and schools to look like?

We believe communities of diversity are richer, better and more productive places in which to live and to learn. We believe that inclusive communities have the capacity to create the future. We want a better life for everyone. We want inclusion!

If we can pinpoint bomb cities half way around the globe, and send men and women into space, surely we can figure out how to live together with "liberty and justice for all". Inclusion is truly and simply a matter of will.

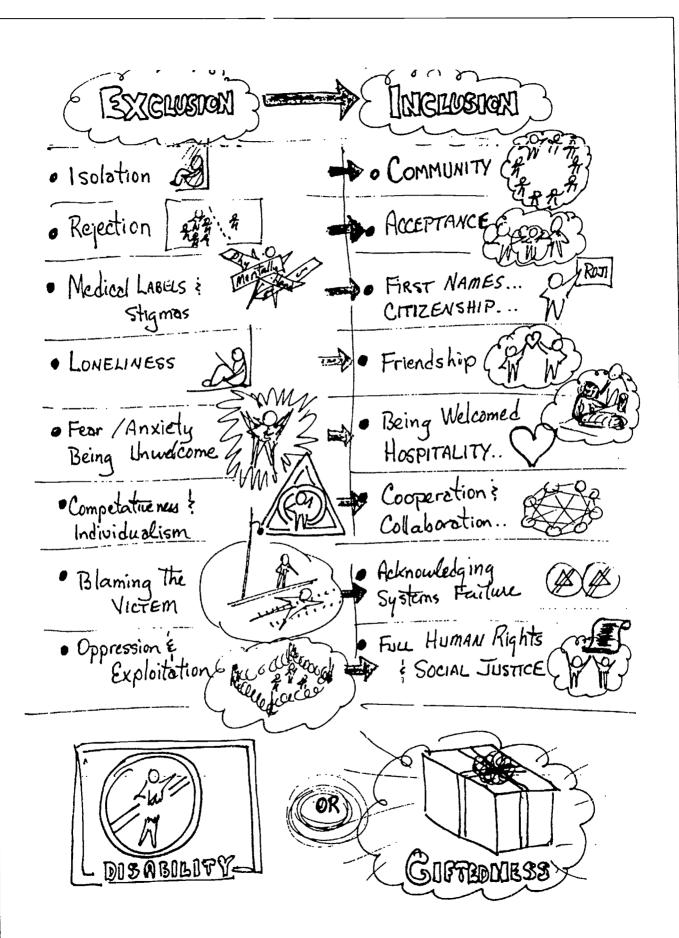
Our Centre is committed to work with people anywhere and everywhere to make this value a reality. Communities which reject the richness of diversity continue to put us all at risk - personally and internationally. Our future depends on our capacity to learn to live together without war - creating societies that build capacity with compassion for one and for all. Inclusion is about rebuilding our hearts and giving us the tools for the human race to survive as a global family.



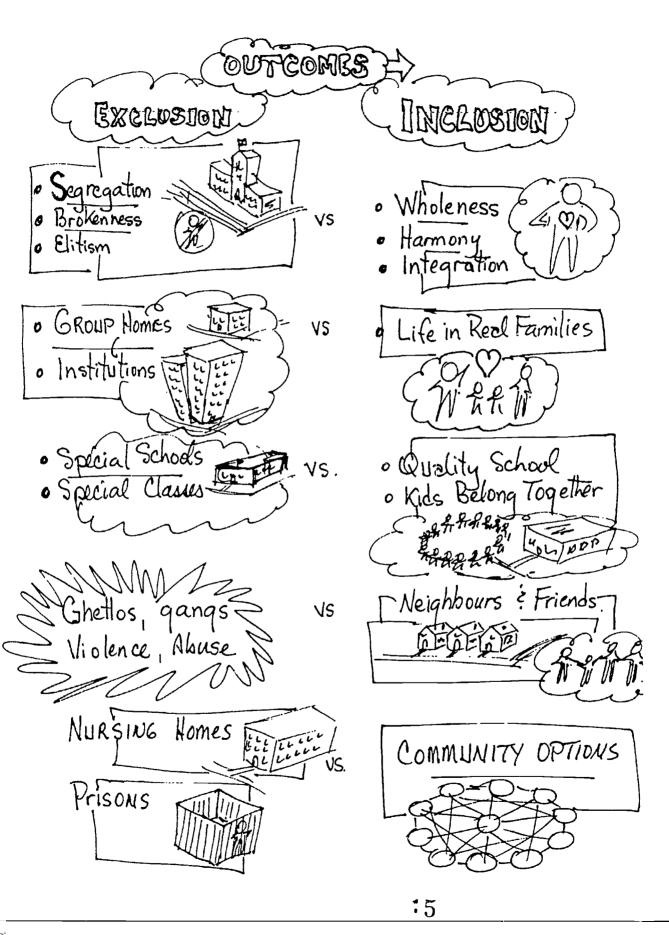


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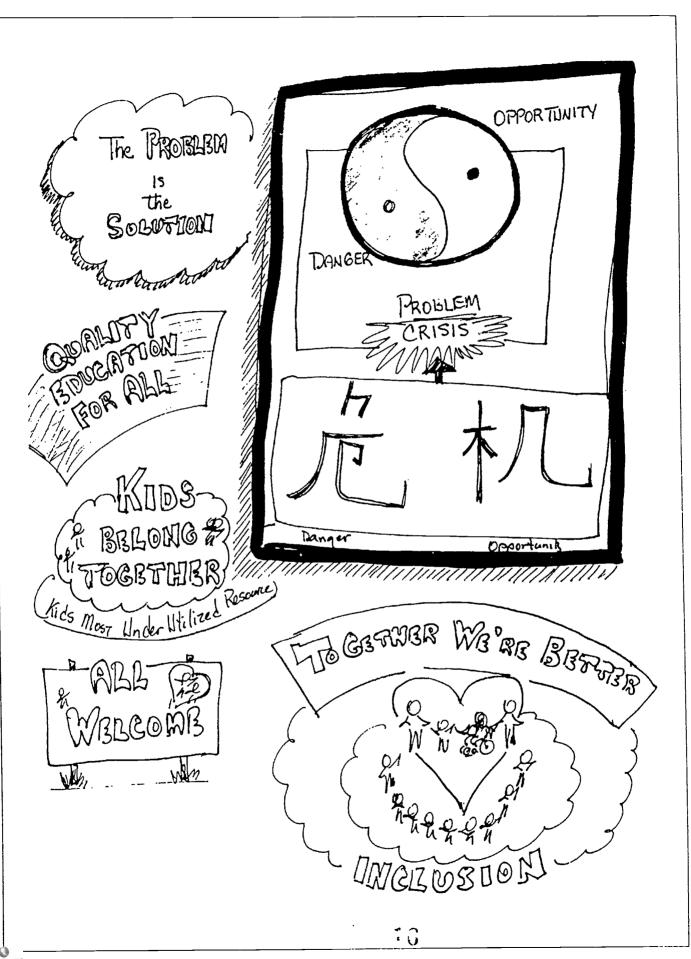


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Two Roads: Inclusion vs Exclusion



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TWO ROADS:

INCLUSION OR EXCLUSION?

Marsha Forest and Jack Pearpoint Centre for Integrated Education and Community

The key educational question for the year 2000 will NOT be "What is inclusion, integration, or mainstreaming?" The key question will be: What kind of schools and communities do we want for ourselves and our families? Will we take the road that says "educate the best and manage the rest", or will we take the road towards a peaceful and truly democratic society that will adequately meet the needs of all its citizens—rich and poor, black, white, red & yellow, male and female, old and young.

There is no doubt that we have the skill, technology and knowledge to build any kind of society and school system we want. If we can pinpoint bomb cities, send teams into space, build robots and mini computers, surely we have the ability to serve all our children in quality schools. The question is do we have the values and the political will to make the choice that will serve the many rather than the few.

We must decide. We must choose to travel one of two roads. We can't be in the middle. We have called these choices the EXCLUSION road or the INCLUSION road. The roads lead to radically different outcomes. Society is at a choice point — the road we choose has little to do with finances or law; it has everything to do with values and leadership.

The Centre for Integrated Education and Community has chosen the road less travelled — the road of inclusive schooling and community. This road welcomes everyone on the journey. As we travel together, we figure out what to do about the daily challenges presented to us. There is no blueprint or map. This is the road of the pioneer, the innovator, the creator. People choosing this road believe that "together we are better," and that "cooperation and collabo-

ration are the keys" to solving problems. Most positive solutions are found not by "experts", but by people themselves, as they get involved in their own interests, in their own neighbourhoods, churches, schools.

The Inclusion Road thrives on diversity and celebrates differences. It is the road which welcomes back those we have left out, kicked out or pushed out of systems, either through benign neglect or systemic and institutional abuse.

We must each choose consciously which road to travel. The road to inclusion is one of building **intentional educational community** in our schools. It demands hard work and commitment to the new ABC's. These ABC's are:

ACCEPTANCE BELONGING COMMUNITY

We know that when children feel these ABC's they will add a new "R" to the famous educational three R's:

READING RITING RITHMATIC RELATIONSHIPS

The Problem is the Solution

The secret of making this all happen is to turn the problem on its head and make the problem into the solution. Those we have seen and labelled as 'the problems' can be our greatest advocates and allies. It is often the "drop-outs", the "street kids", the people with disabilities, who have the most creative answers. They have the most to win or lose; and they have the most intimate knowledge of their own problems. Given an invitation to partner with skilled professional educators, this new team can truly resolve problems and change the system.

Each of Us Must Choose: Inclusion or Exclusion

Exclusion

Both roads are open. Each of us has to make a conscious choice about



the path we travel. Leaders on the exclusion path "blame the victim" for his/her own problems. The exclusion road creates new labels as old ones die. "Learning disability" and "attention deficit disorder" are the current labels of choice. Exclusionists hold fast to the "medical model" and still believe that IQ tests, diagnostic assessment and packaged programs will save the day. They buy and sell solutions, and promote "magic bullets" and "medications" that will solve all our ills. This road has architects who build more prisons, institutions and sanitized homes for the aged. As Dr. Norman Bethune, the noted Canadian hero and physician once wrote so poignantly, "These men make the wounds.

The meaning of a policy of exclusion is revealed by a "reliable" senior government official's retort when asked "What should we do about those who aren't in the 'main' stream?" He responded partly in jest, partly in frustration: "We train the best, and shoot the rest." The comment was off-hand but identifies the dilemma. The unstated under-lying assumptions of exclusion are, among others, that:

* We are not all equal in capacity or value.

* It is not feasible to give equal opportunity.

* We must choose and thus train an elite who will take care of the 'rest'.

* 'They' will benefit through trickledown theory.

Inclusion

The road to inclusion is also a choice. People choosing inclusion look at whole systems and only label people by their names and their needs. Inclusion leaders foster cooperation and collaboration to solve problems while exclusion stresses competitiveness and individualism as the modis operendi.

Inclusive educators know through experience that they can solve virtually any student problem by putting people together and brainstorming on the problem. The people who gather know the person involved intimately, and they care. They are not psychologists and

doctors. Rather their first label is citizen, then neighbor, relative or friend (some of whom may coincidentally be psychologists and doctors.) Inclusion proponents believe in technology and science which serves people and is not used to make profit or war at the expense of human beings.

Inclusion is the opposite of exclusion and works from opposite assumptions:

- * We are unique in value; however, each has unique capacity.
- * All people can learn.
- * All people have contributions to make.
- * We have a responsibility and an opportunity to give every person the chance to make a contribution.

The criterion for inclusion is breathing, not IQ, income, colour, race, sex or language.

Critics of inclusion say:

- * It's too expensive.
- * "They" can't learn.
- * "They" don't know what's best for "them".
- * It can't be done.

As critics of exclusion, we say:

- * It's too expensive.
- * "They" can learn.
- * "They" people know a tremendous amount if asked.
- * It can be done.

OUTCOMES

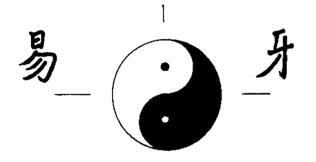
Exclusion	vs	Inclusion
Segregation, brokenness, elitism	vs	wholeness harmony Integration
group homes/ institutions	vs	real families
special schools special classes	vs	quality school where kids belong together
ghettos/gangs/ violence	vs	neighbors & friends
nursing homes, prisons	/ vs	community options



:6

The Inclusion Road is a Paradigm Movement from:

DISABILTY Paradigm	to	GIFTEDNESS Paradigm
isolation	to	community
rejection	to	acceptance
medical labels & & stigmas	to	first names & citizenship
loneliness	to	friendship
being unwelcome	to	being welcome
competitiveness individualism	to	cooperation & & collaboration
blaming the victim	to	acknowledging systems failure
oppression & exploitation	to	full human rights & social justice



Problem or Opportunity

The Chinese character for the word crisis is an amalgam of two pictographs - problem and opportunity. Few would deny that education is in crisis. This crisis presents an enormous opportunity to build something new. The issue is not to change the old, not to "move chairs on the Titanic", but to build a new ship with new seating.

The OUTCOMES of the old ways are clear. Today's education system serves one-third of its students well. But two-chirds are either hanging on or dropping out. For students with disabilities, the post secondary school graduation picture is bleak.

The state of Colorado asked parents

where their children (with disabilities) were five years after graduation. The findings were dismal and depressing. The majority of "graduates" were at home watching T.V. "What did we miss?" the Colorado educators asked. Families answered: "You missed my child's social needs...My child has no friends....Nobody calls....My son/daughter has no where to go and nobody to go with."

Colorado is moving to change this outcome. In the past five years they have moved 4000 students into regular schools from segregated institutional models. They are moving to a total inclusion model for ALL students and paying special attention to all "at risk" students by providing alternative choices at the high school level and full inclusion at the elementary grades.

Dr. Brian McNulty, State Director of Special Education for Colorado, learned that inclusion was not a money issue as their transition took place in the worst economic downturn in the state's history. Money had to be transformed in its flow. The real challenge was how to use the existing budget differently.

Else here in the USA and Canada, the same challenge is being met, and experience confirms that the barriers to "inclusion" are values, not budgets. Wherever change is occurring, two factors are common. Firstly, there is visionary leadership from senior management. Secondly, there is a grassroots parent or consumer movement that demands ALL children be served by our education system.

What We Have Learned

After 10 years of experience, we have learned that school children and particularly high school students are far more accepting than we ever thought they would be. When Tony came to the grade 8 class everyone was terrified. Tony used a wheel chair and didn't speak. We all met the first Monster - Fear. How would he learn, fit in, be part of anything the rest of the class was doing?

The fear dissolved as Tony wheeled in the door and a class meeting ensued where the students were actively encouraged



The THREE MONSTERS

There are three monsters out there that prevent this from happening.

The first monster is FEAR.

It is critical to name the fears and deal with them. All of us are afraid of the unknown, but instead of telling the fear like it is, we hide and blame others or say that something is impossible to do. But now we know that integration is possible. The data is in. The children will do just fine if we don't let our adult fears get in the way of progress.

The second monster is CONTROL.

As professionals we have to give up control and share power with those who have been in trouble. The first step is to invite those who have been left out to join us at the table. By asking the problems " to be part of the solution, we are entering into powerful partnerships for change. We empower both ourselves and our new partners. Everyone wins in this scenario.

The third monster is CHANGE.

Change, though inevitable, scares us all. We fear it. We are always more comfortable with the status quo. We must make the change we want explicit, face the fear, then give up the old controls that stop us from from moving ahead.

In-service education and staff development must deal with the three monsters before building models of curriculum. Creative curriculum will flow when teachers leap over the three monsters and know that their jobs and futures are secure. Teachers need to fully understand WHY change is being made. IFTHEY UNDERSTAND, most will buy into the process with enthusiasm.

Once the three monsters are out in the open field, we can laugh and cry together over our fears. Then and only then, can we start to deal with teaching all kids to read, write and be literate citizens in todays quickly changing and complex world.

to ask him or his family any questions on their minds. "How does he go to the bathroom?" was the natural first question. After much laughter more questions poured out, "How does he communicate; does he have friends; would he like to go to the dance next week?"

By the end of the hour, the class had Tony in the middle of their room and were planning how to get him to the Halloween dance. Did Tony understand the grade 8 history class? We don't know. We also don't know how many of the others kids really grasp the history lesson. However, we do know for a fact that Tony smiled more that week than he had in ten years. We know he received his first phone call, and he did attend the Halloween dance. To Tony, his parents and to us, that spells success! We also know that two potential drop outs stayed in school because of the presence of Tony. Weeks later they told the assistant principal that they were "staying in school cuz Tony needs us." That statement tickled the Second Monster - Control. Who's in charge here anyway?

We were also recently in an elementary school where 12 teachers sat in two rows waiting for us, "the experts", to tell them what to do about Rosa, a child having major behaviour problems at school. First, we broke the group out of the rows and created a circle. We explained our role was to be facilitators and catalysts, not "experts". We said we could help them figure out how to solve the problem. We suggested that first we needed to find out who Rosa was as a person, and who were the important people in her life.

Looking at Rosa's CIRCLE OF FRIENDS, it was immediately apparent that this little 10 year old was devastatingly alone. Her mother and a cat were her only companions. No wonder she was "acting out". She was sending a clear message. "Help me. I am alone. I am afraid.

The classroom teacher was empowered by this revelation. She went back to her class and opened a discussion about Rosa with the children. She asked for volunteers to get involved with Rosa. Fifteen children volunteered and have stayed together over a year forming



an active **Support Circle for Rosa and her mother**. Rosa has not been "cured or fixed", but her behavior has improved dramatically. The road is being paved for a different and better life for all sixteen children in the Circle. They have all benefited from their participation in the weekly circle meetings. No course '... "civics" could teach the democratic process, or the fragility and beauty of life, as well as these gatherings. It may well be that these lessons in living are more important to the education of these students than mastering a specific science experiment or equation.

The Myth of Special Education

The "magic bullet", the fairy dust of special education, is simply another case of the emperor wearing no clothes. A medical cure doesn't exist for children born with down syndrome, autism, spina bifida or cerebral palsy. There is no curative pill for the child born into abject poverty, the child trapped in the ghettos of Yellowknife or the Bronx.

Special education isn't a cure either. In the Winter 1990 issue of Counterpoint, published by the National Association of State Directors of Special Education, Shirley Thornton, Deputy Superintendent of Instruction in the California Education Agency, doubts special education helps children when she looks at outcome and drop-out data. Her summary is blunt: "Regular education can fail them a whole lot cheaper."

In education, the CURE is hard work, team work and intense struggle to figure out solutions to todays complex social and educational problems. The answers are going to be found simply by people making time to work together. There are no "micro-wave" answers. It takes time, energy and commit-

ment. It is hard work!

Giftedness vs "Un"Giftedness

We urge readers to join us on the Road to Inclusion by shifting from the disability myth to the giftedness paradigm. This is the heart of the road of INCLUSION. On the Inclusion journey, all children, and indeed all people, are gifted — all are unique and all have treasures to offer. If we fail to find the gift in a child, that child will likely end up rejected, illiterate and institutionalized - possibly in a jail. If we continue to label and test, we will see more gangs, more violence,

more despair. An Inclusive School labels all children "gifted and talented", and works toward an outcome that deals with the full human potential in each of us.

The Giftedness model is exciting, challenging and dynamic. It is the antithesis of labels and IQ scores. You can tell a "giftedness" school instantly. You feel the magic and energy. The halls are full of art, music and kids. The principal and staff are excited. No one is burned out and the parents and children are involved.

The "Giftedness" School is noisy, messy, and full of books, creative art work, music and people. Older citizens can be seen in the halls reading to younger children. High school students do their cooperative job placements helping in the younger grades. There is cross-age and same age peer tutoring and field trips happen all the time. The principal is hardly ever in her office.

The student population reflects the diversity of the society. Hair and clothing styles vary and some kids run around while others zoom by in their motorized wheelchairs. A sign language class is given at lunch so all the student body can communicate with Michael who is hearing impaired.

The fully inclusive quality school is still school of the future (and in some cases it is the school of the present.) Unfortunately, this school is not the norm. Our hope is that by 2000, the Inclusive school will be the norm in education, and that the road to exclusion will be an historical anomaly.

It is unethical, politically unacceptable and repugnant to write off marginalized people in our society. The cost of welfare maintenance is unbearable, either socially or economically. In short, exclusion does not work.

People who say it won't work are right if our thinking and answers are limited to the solutions we already have in place. We want to think about a new system, one that replaces the old, not just reforms it. Our vision of the new system is based on the value that 'everyone belongs' - ' all welcome'.

We all have the power to listen to 'voices' that are seldom heard. If we choose to make the time, to learn to listen, and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy, and find hope in our future. There is power in the powerless. We can be catalysts, or encrusted residue. The choice is ours.



GIFTEDNESS vs DISABILITY:

A Reflection

by Judith Snow

I am somewhat reflective these days, as I've discovered it doesn't help to run after answers. It's better to ask good questions. If we can frame a few good questions, we can spend our lives trying out answers.

One such question for me is: "How is it that I am not perceived to be a member of the public - a citizen? What can my friends do to change that perception?"

When I was born, I was a member of the general public. People were willing to support me because they expected something of me. There were systems to support me: education, transportation,

family, etc.

When I was 7 months old, I was labeled "disabled", and that label changed my life. People no longer expected my family to be there for me - or supported my family to be with me. The Educational system was no longer there for me. My family had to fight so I could go to school. The transportation system was no longer there for me - and still isn't. No one expected me to "be there" or to make a contribution.

Luckily for me, my family was different. They expected me to make a contribution. That fact made a tremen-

dous difference in my life.

The fact that I was not considered to be a member of the general public totally changed my life. Today, my life is built around the constant battle for me to simply be a member of the public.

Giftedness - What is it? Who has it?

There are people in every generation who can run really well and do amazing physical feats. People like Ben Johnson, and Olympic divers and skaters. We say they are gifted. It is interesting that there are as many people like Ben Johnson as there are like me. But there is one profound difference. People really enjoy and value the fact that Ben can run, or that my classmate Beverly could dive. I don't understand what intrinsic

use it is to be an Olympic class diver or

For Bev to become an Olympic class diver, our society created thousands of gifts. We created opportunities for pool builders, coaches, pool cleaners, advertisers, swim suit manufacturers, etc. People got up at four o'clock every morning, traveled thousands of miles, raised tens of thousands of dollars. Thousands of people were involved in making this possible.

A person who is labeled disabled needs exactly the same support. I need people to be friends, to tutor, to raise money, to set up special places, to do governmental negotiations -exactly the same things that Beverly needed to become an Olympic class diver.

What is the difference? What prevents society from seeing me as impor-

tant and exciting as Bev?

There was a serious mistake. Someone jumped the gun and labeled me a problem. Instead of seeing me as a gift and an opportunity, I was called a problem and became a project. I was not supported by "the community". I was serviced by staff. People's livelihood was determined by their fixation on fixing me. But this is crazy because we are not fixable. We never stop to think about that. Our society has created a billion-dollar industry to fix people who are not fixable. It is destined to failure. It doesn't work, and there are tremendous costs both to society and to the people who cannot be fixed.

People's lives are wasted. The "helpers" get trained to do something that is useless and doesn't work. Not surprisingly, there is an incredible burn out rate. When things don't work, people get angry and that breeds violence. It is no wonder that so many special educators and human service workers spend the vast majority of their time doing paper work. It is a logical response when their job (to fix people) doesn't work and only generates frustration and anger.

There is another cost. The Community is denied the talents, gifts, contributions and opportunities of all the people

who are excluded.

The answer is simple - see me as gifted not as disabled. Throw away the concept of disability. Welcome the concept of *Giftedness*.



Full Inclusion is Possible

By Marsha Forest

I am privileged to act as an education advisor to two unique school systems in southern Ontario, Canada: The Hamilton-Wentworth Separate School Board and the Waterloo Region Separate School Board. The stated goal and philosophy of both these systems is that each belongs, meaning that all children go to their neighborhood schools and attend age appropriate regular classes. (The criteria for full inclusion is "breathing" i.e., life itself.) Supports and services go to the child when needed. Other systems and places in Canada are also moving in this direction, but I would say these two school boards give us an especially clear image of what is possible and how simple it is to include everyone once we decide to do just that.

For too long, integration, or mainstreaming, has been thought to mean placement of a child with a handicap in a school or classroom. Integration truly has a much deeper meaning that's expressed in the terms "inclusion" and "belonging". Unless this deep meaning is addressed, the movement to integrate children with disabilities will be a placement issue rather than a philosophical debate.

What we are really doing is asking a new set of questions: What kind of school communities do we want? Who do we want our children to grow up with? What values will we model for our children? What do we want the future to look like? These are the questions that must be asked, rather than, "How do we do it?" I believe that if we truly understand the why of integration, the how will follow quite easily. If we really want someone to be part of our lives, we

will do what it takes to welcome that person and accommodate his or her needs.

Imagine for a moment that you have a child who today is happy, healthy, attending his or her local school, and progressing normally. Reflect for a moment on where you would want the child to go to school should he or she be in a car accident and become unable to walk without assistance and unable to learn as quickly. Whenever I ask this question of educators who are also parents, I always receive the same answer: the parent would want the child to stay with the family, as well as be with friends at the regular school in the regular classroom with all the necessary supports.

It's obvious that we've created a system of segregation and isolation that at best doesn't make sense, and at worst is cruel and mean. We must change this not simply for the sake of the person with the disability, but for all of us. And we must act quickly before a new generation repeats our mistakes.

Leadership is One Key

Courageous and dynamic leadership that has a clear vision of where the system is heading is a common element between the Hamilton and Waterloo systems, as well as in other places where quality education exists. Jim Hansen, now retired, was for over twenty years, the guiding force in the Hamilton system, which was integrating children when no one was even talking about the issue. Jim was the gutsy, tough talking, no nonsense Superintendent of Operations who believed without a doubt that all children can learn together and that segregating students is poor educational practice. His system has welcomed all children since 1969.

George Flynn arrived in Waterloo Region as the Director of Education in 1985 and has moved it toward full inclu-



sion since his arrival. In a recent brief to the Select Committee on Education of the Legislative Assembly of Ontario (Sept. 12, 1988) he wrote:

"The function of the education process is to liberate the mind, strengthen its critical powers, inform it with knowledge, engage its human sympathies and illuminate its moral and practical choices. It has never been the intended purpose of education to resist or reject people; on the contrary, it is the goal of education to deliver us from the captivity of unexamined life. The human values of liberty, dignity, privacy and responsibility, which education supports, apply equally to all people...People matter most."

These two individuals have provided the leadership needed to inspire their school systems to fully include and welcome all children.

Flight or Change

We can fight and debate and go to court. We can have due process hearings (in the U.S.) and Tribunals (in Canada). We can hire lawyers who can argue anything. Or, we can stop and look at what we are doing to one another and to our society.

Our schools are simply a reflection of who we are as a culture. According to all the major studies in both our countries, we are not doing too well. Illiteracy is rampant, dropouts fill our streets, our prisons are bulging at the seams. According to some, the school system is only adequately serving 20% of our population. The rest are not getting a fair deal.

I used to wonder why many special education people got so incredibly uptight when the subject of integration was raised. Now I understand. Adults often feel threatened when they know they will need to change and that's what this issue is all about — it has little or nothing to do with some little kid with cerebral palsy, or downs syndrome. It has everything to do with change, with our values, and with our very philosophy of

education and life itself. Change can be threatening or challenging.

The Living Proof

The Hamilon and Waterloo Systems have given us a glimpse, a living laboratory in which to watch education for the year 2000 in practice. I have seen that full integration can be, and indeed is, a reality. We have the "living proof" right in our own backyard.

There are no neat formulas or magic recipes that either school board would give you. They are not perfect. They are however, incredibly child-centered systems with leadership that believes in team building, cooperation, collaboration and learning. They are also systems that dare talk about love and social justice.

To me, the key to all of the above is that a new generation is being born - a generation who tolerates difference and change far better than I do, who are less afraid, and who are more loving to people with differences.

The integration of children with disabilities is not an issue of "mainstreaming"; it is an issue of inclusion. It is very simple. If we want it to happen it will. It takes time and hard work; the re-education of the adults in any system is a big job. The children are easier for they are less afraid of the unknown. Full inclusion can work. If we involve the children and ask them to help us, it will work beyond our wildest dreams. If we listen to the children and follow their lead, we will see a new system emerge in which all learn and each belongs.

The inclusion of those we have labelled and excluded will liberate our hearts and souls. We will all not only read and write better, but we will be part of creating a more loving and caring world.



Inclusion vs. Exclusion Society is at a Turning Point

by Jack Pearpoint

"Those who are members of society, and those who are marginalized from society, have a great need for each other's gifts.

"The sand of ordinary life is lived in community where people spend their days doing very ordinary things. They write, talk on telephones, teach children, play with babies, wash dishes, go for walks, read books, and cry on each other's shoulders. All of this happens in ordinary places on commonplace streets, all the time, everywhere. This very commonness is a real gift, a real benefit not to be ignored.

"The gift of surviving and growing through change belongs to the outcast.

"Living on the margin either bums you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; someone who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions."

Judith Snow at Frontier College, 89th Annual Meeting, Oct. 1988

Our society has reached a turning point where we must make decisions about values, direction and budgets. We no longer have the luxury of 'buying' a piece of all the solutions — and thus never having to answer hard questions. The hard questions are about values — what do we believe in? What kind of future do we want for our children? How do we get there?

My analysis identifies two opposing trends, two waging factions: inclusion versus exclusion. This dilemma is broader than "schooling" and education. Most post- industrialized societies have begun to come to terms with the fact of limited resources. The debate is between people who believe in exclusivity and those who believe in inclusion (egalitarian opportunity as the predominant value).

I believe that 'inclusive' options (all welcome) will utilize the talents of people who would be discarded and written off in the 'exclusive' model. The 'outsiders' will bring new perspectives and new talents to 'policy conundrums' where we are in a rut and need 'fresh ideas.'

The meaning of a policy of exclusion is revealed by a 'reliable' senior government official's retort when asked "What should we do about those who aren't in the 'main' stream?" He responded partly in jest, partly in frustration: "We train the best, and shoot the rest." The comment was off-hand but identifies the dilemma. The unstated underlying assumptions of exclusion are, among others, that:

- We are not all equal in capacity or value.
- It is not feasible to give equal opportunity.
- •We must choose and thus train an elite who will take care of the 'rest.'
- They' w'll benefit through the trickle-down theory.

Inclusion is the opposite and works from opposite assumptions:

- We are unique in value; however, each has unique capacity.
- All people can learn.
- All people have contributions to make.

We have a responsibility and an opportunity to give every person the



chance to make a contribution.

The criterion for inclusion is breathing, not IQ, income, colour, race, sex or language. Critics of inclusion say:

- It's too expensive.
- 'They' can't learn.
- 'They' don't know what's best for 'them.'
 - It can't be done.

As a critic of exclusion, I say:

- It's too expensive.
- 'They' can learn.
- 'They' —people know a tremendous amount if asked.
 - It can be done.

It is unethical, politically unacceptable and repugnant to 'write off marginalized people in our society. The cost of 'welfare maintenance' is unbearable, either socially or economically. In short, exclusion does not work.

The critics are right if our thinking and answers are limited to the solutions we already have in place. I want to think about a new system, one that replaces the old, not just reforms it. My vision of the new system is based on the value that 'everyone belongs' — 'all welcome.'

We all have the power to listen to 'voices' that are seldom heard. If we choose to make the time, to learn to listen, and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy, and find hope in our future. There is power in the powerless. We can be catalysts, or encrusted residue. The choice is ours.

Language of Us/Them

We like things
They fixate on objects
We try to make friends
They display attention
seeking behaviour
We take breaks

They display off task behavior We stand up for ourselves

They are non-compliant

We have hobbies
They self-stim

We choose our friends wisely

They display poor peer socialization

We persevere

They perseverate

We love people

They have dependencies on people

We go for a walk

They run away

We insist

They tantrum

We change our minds

They are disoriented and have short attention spans

We have talents

They have splinter skills

We are human

They are ...?

Meyer Shevin



The "Butwhatabout" Kids!

Marsha Forest and Jack Pearpoint Centre for Integrated Education and Community

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 whitewater kayak course and had the usual apprehension one feels the first day of school. It's always humbling to be a student again.

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 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.

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 on page 41 of the Kayak and Open Canoe Technique 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 whitewater 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. Inspite 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."

Back at the Centre, Claudia Kerckhoff-Van Wijk and Dirk Van Wijk, the husband and wife owners and managers (and former whitewater champions) heard Marsha's plight. Before she could dry out, she was transfered and delivered personally to the beginner whitewater 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 symbolized 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 whitewater 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 "mainstream" 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 <u>The Classroom Crucible</u>, 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. " (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).

The system needs to show students with doeds, 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, behavior 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 called B.D., E.D., S.E.D., A.D.D. 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 kids with challenging behaviours. Also common sense. "Butwhatabout" the kid who screams. bites, hits, rocks, does abusive things to his/her own body, doesn't use a regular bathroom, etc. 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.

Two Stories

The two stories following (one from Canada and one from the United States) symbolize 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 homerooms - 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, "If 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 realized 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 mouth was, i.e. put up or shut up. 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.

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 offense. It is not life-threatening like a gun or knife.

This "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 unraveling 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 favorite stories. It was reading and language time. It seemed to me everyone was



The inclusion papers

benefiting. Why do we make something 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 Laurence'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.

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 21 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 (guiet 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 whitewater 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 foliow 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 my 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 Kitchener. Ontario

Brian Cullen is the energetic principal of St. Francis, an elementary School of over 350 students in Kitchener, Ont. Brian decided in 1987 to close his special education segregated classes and move 17 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 feces around the room. Kerry Gorman, a great teacher, called me on the intercom 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 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 8th 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 acting the way he was.

"The children felt Sam needed to be involved in everything "normal" at the school. He went to soccer games, dances, etc. 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 grade eight 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."

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 "antisocial, aggressive behaviour". Reports said: "Len is too behaviour disordered for the trainable retarded class and too retarded for the behavior 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 six class, along with the other eleven year olds.

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

"Out of 17 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 f___ 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 proaram."

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 TO-GETHER.

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 say "Yes-But" or "Butwhatabout".

For more information about strategies specifically designed to integrate all "at-risk" children and adults (MAPS and CIRCLES OF FRIENDS) write Marsha Forest and Jack Pearpoint:

The Centre for Integrated Education and Community

24 Thome Crescent Toronto, Ontario Canada. M6H 2S5. Phone/fax (416-658-5363).

We welcome comments.

For more information on whitewater kayaking, write:

Madawaska Kanu Camp

Box 635
Barry's Bay, Ontario KOJ 1BO (613-756-3620).

Also, thanks for the Graphic (p. 67) of the Kayak and Open Canoe Technque booklet by Claudia Kerckhoff-Van Vijk & Dirk Van Wijk, Illustrated by Angela Scherer.



 $\hat{\sigma}$

DICK and JANE

They've shared the same mat since they were children, lately though the staff has been setting them down so that they're facing in opposite directions of one another, probably to avoid any funny stuff.

It doesn't matter that much though; they'll nestle together no matter what, knowing that they're all they have, they learn to make do.

Her body is that of a child though her face is taking on the features of a beautiful young woman; looking into her hazel eyes, I'm almost mesmerized by their sparkle, it took me a while to figure out the score.

Finding pleasure in giving her lover a back rub
with spasmodic strokes of her arm, she massages the small of his back;
smiling, he responds in kind by running his whiskers through her toes,
she gives out a slight laugh;
they move an inch or two closer to each other
hoping that the staff doesn't pick up on the subtleties of the moment;
they don't of course.

Bob Williams



THE MARATHON MAN

Johnny ran. that was his problem, he was what the staff called a runner logical since he ran whenever he could—

one minute
they thought they had him
three ways to sunday
tied to the bedpost
with someone else's soiled sheets;

then they'd no sooner turn around and he'd be up to his harry houdini routine all over again.

even the aides admitted he was pretty smart for being a retard; all the rest of them would sit and rock.

but not Johnny he'd jump up dart this way and that.

then the next thing you know he'd find an open door or leap through a window

and he'd be clocking the mile on the institution's main drag at three-point-ninety-two like the long distant runner he longed to be.

they tried vinegar spray, four-point restraints, even leaden shoes.

nothing slowed his free stride until they placed electrodes on his hide and shocked him.

shocked him silly.

now he's on the back ward rocking to and fro to and fro to and fro. . . .

Bob Williams



ANNIE'S GIFT

Marsha Forest & Jack Pearpoint with Ellen Laurence & Bill Gillenwater

Juliana Laurence, known to those who love her as "Annie" is a beautiful child who lives in Greeley, Colorado with a loving family— her mother, Ellen; her Dad, Norm; her brother, Chris and sister Becca. Annie has a file inches thick describing her with medical labels and long words that mask the reality of who she truly is. The file and the jargon scare people away from getting to know this 9 year old child and her family.

Annie has had an ever changing series of labels from her earliest months on earth. She was first diagnosed as having cerebral palsy. Her mother Ellen suspected the big "A" - autism. Finally, the experts came to an agreement. "Annie is a person with cerebral palsy,

but without any autism."

The second diagn sis given to the Laurences said "severe mental retardation with the possibility of autism". Finally Retts Syndrome was the agreed upon diagnosis, but in Feb. 1990, that particular label was removed as Annie was "not degenerating fast enough for a typical Retts child." Her mother now says "Annie's back to being called just plain AUTISTIC and frankly by this point we don't care — she is just simply ANNIE."

For the first years of her life, Annie attended segregated schools for severely handicapped youngsters. She was definitely one of "those" kids who everyone said was impossible to integrate into a real school, let alone a regular class. Her behaviour was too inappropriate, too terrible, too challenging for the real

world - so said the schools.

However, while not in school, Annie lived with her family who had no training in behaviour management, autism, or mental retardation. They coped. Often they were tired, and needed a night away from all three kids, but they coped. They were a family.

The Laurences lived in an ordinary house, shopped at the neighbourhood grocery stores, ate at regular restaurants, attended the local Methodist church, and managed to keep Annie

with them throughout. But for her school hours, there were different rules. Annie had to "be with her own kind".

"Butwhatabout" Annie?

Whenever we meet one of the children people have described as "impossible to integrate" or "really challenging", we are always shocked! We have just recently coined a new all-purpose label for "difficult" children. We call it the "butwhatabout" kids. This label is applied by frustrated people who are resistant to integration. When parents like the Laurences want their child to attend a regular school, these people say: "Butwhatabout????" Annie was labeled a "Butwhatabout" child.

When we finally met Annie in person, we expected to see a raving out-of-control human being. Instead, we met a frail, thin, wiry young girl - a fragile child. She reached out to touch our hands. She presented herself as a portrait not unlike the child character Fantine in the play "Les Miserable." (Perhaps there is a creative job opportunity for Annie as one of the waifs in Les Miz.)

Annie was no monster, just a small child. To those who knew and loved her dearly, she was indeed a puzzle, a mystery, a tangle of unknown knots to be untied. She was fortunate to have a family who would literally do anything to help their daughter reach her full potential, whatever that might be.

In 1988, for job related reasons, Ellen and Norm decided to move to Greeley from the Boulder area. This was difficult, as it uprooted the entire family from a familiar and friendly neighbourhood. But like many North

American families, they were forced to move. It had nothing to do with Annie.

Ellen started exploring schools for

Annie and found four that were a possibility. School #1 presented its strong points as having a "life skills program" complete with dishwasher so the students never even had to appear in the regular cafeteria for lunch. Scratch #1.

School #2 had 18 "high needs" youngsters of all ages in one wing of a building. The kids were labelled SLIC (severely limited intellectual capacity).



The inclusion papers

Scratch #2.

School #3 had a principal who asked Ellen how fast Annie's condition would degenerate as he "could not justify investing a lot of time or money on a kid who was degenerating". Scratch #3.

And then like in the story of the 3 Bears, Ellen found the school that was,

and still is, JUST RIGHT!

Bill Gillenwater

Through luck, often the right people are at the right place at the right time. Bill Gillenwater arrived at Scott Elementary School in 1988. Bill is a true educator, a marvelous and humanistic school principal. He believes in the value and worth of every child.

Ellen Laurence met Bill Gillenwater. Bill decided to drive to Boulder to meet Annie as he doesn't like to talk about a child without meeting him/her in person. He met and was captivated by Annie. The rest is Colorado history.

Ellen was already in a state of advanced shock after schools #1,#2, and #3. She couldn't believe it when Bill casually said, "Of course she's welcome at Scott Elementary School. What do we need to do to make her and you happy here?" When Ellen regained consciousness, she and Norm celebrated their good fortune.

In Feb. 1990, Bill had decided to make some drastic changes in the delivery of special education services at Scott Elementary. He had kids labelled as being in need of something called "special education." He did not believe the traditional self-contained special education rooms were working for them.

From his diary, Bill 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 could not wait and study this for an additional 20 years to correct it."

Bill soon met Dr.Jeff Strully, the Executive Director of the Association for Community Living in Colorado, who became the first real professional ally in Bill's life who helped him get the sup-

ports, expertise and help he needed to make his school fully inclusive.

Bill remembers. "Fear was everywhere that spring. The talk in the staff room and in the halls revolved around the concept of including all kids. This issue polarized my staff.

"It was a small child named Annie who constantly brought the issue to a head. She made the word "inclusion" real. She challenged all of us to "put our money where our mouth was, i.e. put up

or shut-up."

Bill felt both cursed and blessed with this child and her extreme needs and behaviors. She was always walking over the edge of control and was constantly visible to the students, the parents and teachers. Her very presence in the halls challenged everyone to make their values clearly known. Annie's gift was to force an entire staff of adults to face themselves with an honesty that was rare to come by and often painful to face.

Bill wondered what he would have done as Annie's parent? He asked himself how he would have felt having a child like Annie at home day and night? Would he have the guts and courage to stand up for Annie if his job was put on the line? These and other questions gnawed at Bill and challenged him to be the educational leader all his friends and supporters knew he could be.

Excerpts from Bill's education log

tell the story in the raw:

"I told Ellen Laurence my feelings and fears for I truly believed and meant it when I said that ANNIE was the gift that would make our school a welcome place for everyone. Annie's strength and fragility touched my core. To me she was a beautiful, mystical puzzle. Annie Laurence was the very embodiment of what "inclusion for all" really meant at Scott School.

"On August 20, 1990, new and historic class lists were posted on the windows. There were no more self-contained classrooms at Scott Elementary. Special services and individualized attention would, of course, be given when needed, but not in segregated rooms.

"Marsha Forest and Annmarie



Ruttiman of the Centre for Integrated Education and Community in Toronto, Ontario, did a series of inservice programs for the Scott staff on the real meaning of inclusion and on the concept of building Circles of Friends. For many, the Kleenex on the table was necessary and welcome. For others, still faces of stone. For some, the assistance of Marsha and Annmarie was a dream and a hope; for others, they were a nightmare adding more fuel to the fire of inclusive education.

"For me, Marsha became another important friend and ally in our move to become an inclusive school.

"Sept. 4, 1990 — All kids came to the first day of school as Scott kids with names, individual needs, different learning styles, varied clothes—no "labelling blues" this year. There were 15 kids in regular settings who last year had been

in self-contained programs.

You can feel the drama in Bill's entries those first days. "The troops are holding, the kids are all included. Robert doesn't want to be Robert anymore, he wants to be Bob. Angela looks marvelous as a first grader, she sits straighter already. Ashley is the love of our life. As a kindergartner she will only know inclusion and never experience segregation, at least not at this school. We have to make this work for all the Ashley's of the world.

"Wesley is exhausted and says now he can't be a clown in first grade, he has to be a regular boy. Shaun is struggling. Steven can't do the regular work but is participating. In music, he was pointed to as a model of perfect behaviour. Our Steven?!"

Inclusion had become the hot topic of news in the whole community. Most of the conversations revolved around fear. Bill heard two nasty comments made directly outside his office from parents - "What a shame to have 10% of the kids dumped on the school while taking up 80% of everyone's time."—
"There are places for kids like these—its not in regular classes and it's not in our Scott School." Bill also received a small pile of unsigned, nasty, pointed and near-threatening letters from a parent

population of over 620.

The focus of the ferment always centered on Annie Laurence. A small group of vocal parents wanted Annie out of the school. Bill remembers, "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 must not be intimidated by this vocal minority!"

Annie Comes to School

"Annie finally arrived. She is a challenge we haven't been able to get through to yet. Her most challenging behaviour for all of us is that she pulls the hair of the other children in the school. This hair pulling is my biggest nightmare and will be the death of me yet. I spent half an hour with an irate parent on the phone tonight who did not want his daughter "attacked" ever again. The "attack", as I calmly tried to point out, was a hair pull by a ten year old child trying to communicate the best she can.

"I could live a life-time without ever hearing the word "attacked" again and it

wouldn't be long enough.

"The hair pulling is the single biggest deterrent to Annie's acceptance. Somewhere there has to be an answer. All the behaviour experts come and go with their fancy theories, but nothing works.

"Al! hell broke lose today. The parents of the "attacked" child came and demanded that their child be moved. They arrived at my office filled with all of the loaded emotional words they could think of. As the conversation unfolded, I found the mother herself had been abused as a child and had never dealt with it. Annie's hair tug was a symbol of her own trauma and nothing like that would touch her perfect daughter.

"I agreed to move the child to another class but insisted the the family go down the hall to actually see the monster they described. We saw the monster sitting and working on a computer and their daughter doing her work nearby and also sticking out her tongue at another girl in the class. Prejudice is prejudice no matter how you slice it.



"Later that week, we had our first parent group meeting. Three parents of formerly-labelled children attended. One of the families was a deaf couple who had never come near the parent association. In the past they never came at all for fear they would "hear" comments they could not face.

"The meeting went well and the group decided to include Integration as a topic at a future meeting. The best part of the evening was that I received no nasty phone messages at home that night. The ugly calls always come after 8 PM. Celebrate!!

The weeks are going by. Teachers are coming to me with success stories. We seem to have created a new and vast amount of collegiality, communication and teacher-to-teacher contact because of inclusion. We are problem-solving together over all the kids at our school. We've come a long way in a short time. Marsha told me to stick to my guns and ride out the storm and not let a vocal and nasty minority win over the majority of good will in the school and community. If I had capitulated to those strong negative people on the staff or in the parent group, everything I stood for would have gone down the drain. I must tell Marsha that she is confirmed!

"Annie still presents a challenge to the school, but she is accepted in the school community where she belongs. She has a class, but is not forced to attend her particular room. Our educational assistants take turns walking with her and observing where she goes, what she likes to do and who she likes best in the school. Everyone is learning to take the lead from Annie and we see ourselves as explorers on a new path. We talk openly to the other children about Annie. To them, she is no big deal.

"The Laurences have had to endure some nastiness in the community, but they are strong and have much support. If we can just ride this out, Marsha keeps telling me that Scott is influencing the country. I have trouble believing that, but I hope it's true. If we can do this at Scott, anyone can do it anywhere. Watching Annie and the other children in their new regular classes makes all the aggra-

vation worthwhile."

Ellen commented, "There were so many key players in this on-going drama - Julie, Kim, June and others. But I know in my heart, that Bill and his sometimes unpopular stands is the reason it is working. Thank god we found a man who loves a challenge!...

"We've been invited to participate as a sponsor in the next Colorado full inclusion conference as a district. Tim Waters, our Superintendent is taking a strong stand. I think we can truly influence the state and maybe even the country."

Ellen Laurence

Ellen Laurence also remembers those early days and hopes she doesn't have to relive the pain. She wanted everything to be so perfect for Norm and her other two children in their new community.. When she got the first two anonymous phone calls, she didn't want to tell anyone. When she got the third call, she broke down and told Julie and Bill what was going on. "In my masguided attempt to insulate and protect "the family", I didn't tell Norm and the kids initially. I got my support from Julie and Bill." In total there were 6 calls, which at the time seemed like 60. The tone of the calls were all the same:

"When are you going to get off this integration bandwagon and get your daughter out of OUR school."

"We don't want our son, who is our most important commodity, exposed to your daughter or anything on the seedier side of life."

"Get off of it. Drop it. Go where your

kid belongs — with her own kind."

The family received most of their support at this time from the staff at school. They were new in the community and didn't know many people. Bill, and the majority of the school staff, were infuriated by the attacks and the anonymity of the threats.

There are many important lessons to be learned from these "attack" inci-

dents:

1. Often people will say. "I got millions of calls and letters saying Annie shouldn't be here." The response has to be —"Tell me exactly how many letters.



calls, etc." One must be rational in the face of the negative impact of these horrible calls and letters. They repre-

sent a vocal minority.

2. The family and school must remain steadfast through the attack period and have a wide network of supporters from the community and outside to get them through. Ellen and Bill knew they had advocates in Greeley, in the State, and indeed across the U.S.A. and Canada.

The family has to say as the Laurence's did, "We are here to stay!". They were visible at work, in their church, and Chris and Becca took Annie everywhere. They could be seen bikeriding, hangin' out, at church. They were proud that Annie was their sister—a full and total part of their family.

* Most of all it was critical to remember that Scott had over 620 students and families. The Laurence's and Bill Gillenwater decided to go after the 600 good guys/gals and ignore the 6 bigots who wrote the nasty letters!!

* If families hang in, in most cases, they will ride out the storm and the bigots will either move, or as in this case, accept change. Bullies back off

when confronted.

* Negative feedback is very provocative and hurtful. Often we forget how small and puny the voice of the bully and bigot is. As the saying goes, "All that it takes for evil to triumph is for good people to remain silent." One must invite the voices of the good forces to sound out loud and clear, and steel oneself against the railings of prejudice.

ANNIE'S CIRCLE

The real heroes of this drama are Annie Laurence and her friends. They didn't know about all the adult guilt, pain and fear that Annie was creating. To the children, Annie was simply a kid in their class who acted a bit strange, but so what. So she pulled hair. So others carried bits of blanket or dolls.

The Integration facilitators Kim Wass and Julie Claeys helped the teachers build circles in every class and led many of the classroom meetings to discuss how to support Annie and any atrisk student. Sarah (one of Annie's friends) told us that she and Annie are going to be room-mates when they "grow-up" because Annie is going to need to live with someone who loves her. It is clear Sarah already loves Annie!

Julie and Marsha had the privilege and honour of talking with Annie's class on Feb.12, 1990. In that short time, Annie has become a comfortable member of June Griswold's third grade class. She has an educational assistant when needed, but is encircled constantly by a group of accepting and loving children.

Annie still pulls hair, but the kids have figured out how to deal with it. When we were in the room Annie went for the beautiful blond locks of one of her friends. Another little girl gently said "no", and took Annie's hand off the blond locks. The little blond girl then moved away while three other students took Annie and began reading to her. Surely a good behaviour management team would weep at this sight. A good cooperative consultant would cheer. Every caring educator would wonder at the beauty and ingenuity of children. Marsha had to grab the nearest Kleenex as she was so touched witnessing the care and gentleness shown by the children. You can imagine how Ellen Laurence felt when she heard the story.

The children, their teacher, Julie and Marsha all got together in one big circle to talk. Annie was there resting comfortably with her three best girl friends. She was quiet and acted perfectly for the 45 minute discussion. She never moved from the side of her friends. She did lay her hand on one of their laps. They stroked her head and hands constantly. Perhaps this scene is the answer we adults are seeking. Not gimmicks, gadgets, M&M candy or aversive shock, but good old-fashioned tender loving care, dished out in big spoonfuls from people your own size. It was, as the kids would say, "AWESOME!"

Julie and Marsha initiated a conversation with the children and their answers tell the whole story. Annie Laurence will have a different life because her family happened to live in the right place at the right time. They were lucky to live in a State where there were



The inclusion papers

people like: Bill Gillenwater, principal at their local school; Jeff Strully, Executive Director of ACL Colorado; the Peak Parent Centre; Brian McNulty, State Director of Special Education; and Tim Waters, Superintendent of the Greeley District.

Other Annies all over the world deserve the same treatment as this Annie. Inclusion should not be dependent on the good will of educators. It must be as Bill Gillenwater so eloquently said, a CIVIL RIGHT. It is Annie's right to get the ABC's — ACCEPTANCE, BELONGING AND COMMUNITY. It is also the right of all the other children in Bill's school to be exposed to life at it exists with all its beauty, pain, diversity and challenge.

The children are the fountain of opportunity we so often miss in our schools. At Scott, the adults allowed and even asked the children to be involved. The children are, and always will be, the secret weapon to solve any problems. If only we would ask them! The children at Scott are no different than the children in any state of the USA or any province in Canada.

Annie now has a firm foundation upon which to build. Scott Elementary and Bill Gillenwater have given her that chance. Some would cast the Annies aside. But we believe that "an injury to one is an injury to all". If we leave out Annie, so do we do injury to every child. As we accept ANNIE, violence and hate decrease. As we welcome ANNIE, all children feel better about themselves and learn more. As we welcome ANNIE, literacy increases and honesty abounds.

Annie came to Ellen and Norm Laurence with no packaged instructions. She came as she was and they had to figure out how to love her and keep her in their family, just as they figured it out for their other two children.

Annie is simply another child in the garden of children. She deserves to be nurtured and enjoyed with all the rest. She has found her place at Scott and truly BELONGS.

As we travel across the USA, Canada and Europe we get the same responses from children and teenagers. They are there to help us, to be involved.

They are waiting for an invitation. We must reach out to the most readily accessible resource in our communities and schools. We must give up our desire to find pat and simple solutions to complex problems. Annie will not and cannot be fixed or cured. She simply needs and wants to be fully welcomed. When this happens we can stand back and watch as she and all the others develop into whatever they can and will become.

The building of Annie's CIRCLE of FRIENDS can be seen or called a form of cooperative and collaborative education around the issue of acceptance and diversity. Whatever we want to call it we know it serves as a powerful tool. It needs as much time in teacher/staff development as building any aspect of the curriculum.

Talking to children openly and honestly is an art and needs to be discussed and practised. It is not always an easy task, especially if we, as adults, are uncomfortable with the topic. Any inservice training on CIRCLE BUILDING must deal with the fears and attitudes we all hold in our hearts around children who are poor, disabled, vulnerable, different and at risk. Teachers will (except in rare cases) rise to this challenge and be reminded of why they went into teaching in the first place.

That is the true gift of ANNIE. She has reminded us all of why we exist as human beings, as teachers, as parents, as friends.

The children of Greeley, Colorado are the magic and the greatest resource for our future.

In April, 1991, Annie, this severely/profoundly retarded child, said her first sentence - with witnesses:

"Judy my friend!" That says it all...

Ellen Laurence gave another reflection of Inclusion: "Annie has a 2 pm intravenous antibiotic. It's done in a classroom on a beanbag, with her friends lying around her - reading, watching movies, etc. It's absolutely no Big Deal! It would make an amazing picture."



What is Success?

Ellen Laurence has hung in through endless meetings and conferences about her daughter. She has tried hard to keep her whole family together, supported, and uplifted through a difficult move. She always has a smile on her face and although she does cry (at night and alone) over the rejection of her daughter in the past, today she celebrates the good fortune of being in a welcoming school and community.

Ellen remembers clearly when she first got hooked on a full welcome for her daughter. She attended a parent meeting in Boulder, Colorado in 1986 where Marsha Forest showed slides and spoke of the integrated settings in Hamilton and Kitchener, Ontario. Ellen loved Marsha and her stories but felt integration certainly wouldn't work for her daughter. It was marvelous for all her friends' kids — kids with cerebral palsy or Down Syndrome, etc., but Annie was far too "handicapped." Ellen shudders as she remembers how she felt."This is all pie in the sky," she thought. But the images did remain in her mind and for some reason she kept bumping into Marsha everywhere she went in Colorado and at other national conferences.

One day it all just snapped into place. Since Annie was a full member of the family, why, in heavens name, should she attend a segregated school? "These days I'm embarrassed to say that Annie attended a segregated preschool. It is so totally polar to everything I now believe. I did what I thought was best and what everyone was telling me was best. I felt Annie needed kids who would not tease her and that she needed speech therapy and occupational therapy. I thought maybe all the therapies could "fix her". Now I wouldn't have anything but full inclusion and neither would Norm.

"Norm's been the quiet supportive one. We both realized a few years ago that we (or our insurance) could purchase anything Annie needs except the one thing money could never buy and insurance can't provide — that is real friends."

It has all been worth it because of what's happened this year. Four parents who may have been among the

negative ones have openly apologized to the Laurences, and have asked that their daughters be in the same class as Annie next year. One parent told Ellen: "Whatever class Annie is in, that's where I want my daughter. My child is a nicer person because of Annie."

It is difficult, if not impossible, to mend the brokenness, isolation and stripping of dignity for a person who has experienced segregation all their lives. Why not start with the little children and build something new. Being together with real kids in regular schools and classrooms are the first and foremost criteria for anything that follows. All else is simply worthless and built on a foundation of sand if the social relationships are not intact.

When the foundation is built, when the welcome is made, when the child is circled then, and only then, can reading, writing, arithmetic, history, etc., be taught with meaning and dignity.

For Annie communication is starting, behaviour is changing and it is because of the successful welcome of her original second grade teacher Chris Neilsen whose attitude we would like to clone. Chris said, "I don't have a clue what to do. I never took a course in special education but I'd like to have Annie as part of my class and together we can figure it out."

Outcome: Success!

On January 26, 1991 the Laurence's decided to have a party for Annie. It was to be an ice skating and pizza party. They invited the whole class of 26 children. Ellen and Norm thought if 6-8 kids attended, they would call it a success. To their shock, surprise and delight, 35 people showed up. ALL but two kids (one was sick the other out of town) plus brothers and sisters, parents and teachers. Norm happily had to run to the local pizza shop to purchase more food as he only ordered enough for the 6 guests he expected. "Never in our wildest dreams did we think so many people would come to the party."

On Feb. 22-23, 1991 at the <u>Second Annual Conference on Inclusive Education</u> in Denver, Co, (sponsored by the



Colorado Association for Community Living, the Peak Parent Centre, and District 6 - Greeley) over 1100 people registered and 100 were turned away, (up from 400 attendees the year before). Bill Gillenwater and Ellen Laurence (plus several teachers from Bill's staff) told their story. They have moved from simply supporting Annie to assisting in developing State and national policy.

The Last Words

The last words go to the people on the front line. We can only surmise, but I think Annie's words have already been chosen - her first spoken sentence:

"Judy my friend!"

Annie's teacher, June Griswold wrote a letter to Ellen and Norm. It is entitled:

Annie's Gift to us!

Annie's gift to the students in her third grade class is, very simply, LOVE. She has taught everyone to love in a manner that some have never experienced — UNCONDITION-ALLY!

The students love her without reservation, because that is the way that she loves them. Daily the students celebrate her very presence in the classroom. Those little caterpillars that started the school year in Room 16 spent a minimal time in their cocoons. They then emerged as butterflies, free to flit through life's garden, sipping nectar from the flowers of all their experiences, including those new and different experiences with Annie. Each taste of that sweet juice has allowed them to reach greater heights academically and socially. And the little bug who has allowed them to feel so free around anyone, regardless of aptitude or ability, is Annie. What greater gift can anyone receive?

Annie's teacher wants everyone, but especially educators to recognize the fact that she is an ordinary person.

There was no "special training" to

get ready for Annie in the classroom. Annie's inclusion in the classroom was not a monumental effort nor did it occur after many hours of intense preparation. Annie was accepted just as all students in the class were accepted. Yes, there were adjustments to make. Yes, things are different than they would have been without Annie. But what educator can honestly say that she has been "specially trained" to meet the needs of every single student and situation in her classroom? While Annie was teaching her friends to love her unconditionally, she was teaching her teacher to do the same. And, when her teacher is being perfectly honest, she does admit that she doesn't feel as ordinary as she did at the beginning of the school year. She feels enriched and fortunate, because she is also the recipient of Annie's unique gift.

Last but not least, a letter from Ellen...

Dear Marsha & Jack,

Just Some Thoughts
Annie is back on round-the-clock
intravenous antibiotics, so maybe
my fatigue makes me a little bit
more introspective.

One of the biggest blessings for me in the last year and a half - due to Bill and his troops - is the measure of tranquility that I'm feeling for the first time in 9 years.

I know that Annie now has adults AND KIDS in her life who truly love her and will keep her safe (besides her family).

I know I have always tried to do my best, and more for her. I can look back without a whole lot of regrets.

I'm fighting "the good fight" with a lot of help from my friends!

Why is it Working?

1. Mutual Respect/Friendship
I'm not dealt with as some
unpleasant by-product of Annie.
I'm a respected member of the



TEAM.

- 2. It isn't ASSUMED that because I'm a parent, my emotions will get in the way of my judgement.
- 3. Like me, the staff wants the very best that life has to offer for Annie. We tend to be "partners in dreaming", so I'm never LABELED: "Rejecting of her Limitations".
- 4. We're all acutely aware of her vulnerability, so I'm not LABELED OVER PROTECTIVE or POSSESSIVE when I ask for a measure of safety.
- 5. Because of the above, I'm not set up to fail, or then posture myself as "one of those aggressive mothers".

Marsha & Jack - I cried when I read the draft of this article. It is wonderful! And as a parent who's kid is always receiving something, it's really healing to think of "her giftedness" as Judith Snow would say.

Love Ellen.



QUESTIONS AND ANSWERS FROM ANNIE'S CLASSMATES

HOW HAS ANNIE BEING HERE HELPED YOU?

- * Annie makes us all feel happy. Without her we wouldn't be the best class.
- * I feel good playing with Annie.
- * Knowing Annie has helped me learn to control my little sisters at home.
- * If I ever decide to work with people like Annie when I get older, I'll know what to do to help.
- * I got a new friend.
- * Having Annie here made me feel different inside, like positive.
- * It's fun having Annie here with us.

HOW DO YOU THINK IT HAS HELPED ANNIE TO BE HERE IN THIS CLASS?

- * She talks a lot more here with us.
- * She says a lot more words.
- * She has more friends here.
- * She learns a lot from us.
- * She doesn't pull hair as much anymore.
- * She's in a good mood more with us.

WHAT ADVICE WOULD YOU GIVE OTHERS ABOUT HAVING ALL STUDENTS IN REGULAR CLASSES?

- * Put only one kid with a special need in each classroom.
- * Tell the teachers that kids will be and act more normal if they are in regular classes.
- * Treat all kids like regular kids.

WHY DO YOU THINK ANNIE PULLS PEOPLE'S HAIR?

- * She likes blond hair.
- * She pulls hair when she's in a bad mood.
- * She is trying to say "hi".

- * She is trying to get your attention in the best way she can.
- * She pulls hair when her ears hurt.
- * She is trying to pull us close to her. Trying to pull us back to her.

WHAT IF SOMEONE CAME TO YOUR SCHOOL AND TOLD YOU THAT ANNIE HAD TO GO TO A SPECIAL SCHOOL OR SEPARATE CLASS.

- (There was a loud chorus of NO's)
- * She is learning so much here with us than she's ever learned before. Why would she go away?
- * No way! She really likes us and is attached to us.
- * No! She's a regular person here just like we all are.
- * She learns more here and she's happier here than anywhere else.
- * No! She has her friends here.

BEFORE I GO, CAN YOU TELL ME WHAT YOU THINK MAKES A GOOD TEACHER SO I CAN TELL ALL THE TEACHERS I WORK WITH WHAT YOU THINK.

- * A really good teacher gives you love but doesn't baby you.
- * Someone who is nice to you.
- * A good teacher has a good sense of humour.
- * A good teacher teaches you lots of new things every day.
- * Someone who knows when you feel bad and takes the time to talk to you.
- * A good teacher is 'cool' and 'awesome'.
- * A good teacher is never too busy to stop and give you a hug.
- * They joke around with you.
- * They accept everyone as they are.

There is great wisdom in this childhood common sense. We too could relearn what we have forgotten — if we would listen.



Common Sense Tools: MAPS and CIRCLES:

for Inclusive Education

Marsha Forest & Jack Pearpoint Centre for Integrated Education and Community

Annie, Tommy, Jay, Andreas, Katherine, Becky, Erica, Mark, Greg, Miller, Katherine, Peter... the list is too long and too painful to produce. These are the names of children who have been rejected by the public schools of Canada and the USA. They are black and white, girls and boys, youth and teenagers. In common is their parent's simple dream of having their children accepted and educated in one quality school alongside their neighbors. In common is their rejection from the schools of our nations. In common is the label "disabled" pinned on them, like the yellow star pinned on people labeled Jewish, and the pink triangle pinned on people labelled homosexual, during that terrible period called World War II.

The Nurenberg Trials confirmed to the world that pinning yellow stars and pink triangles on people was unacceptable. It was ruled a crime against "humanity". But today, no Nurenberg trials have ruled that IQ scores and disability labels are often death sentences to the children we "place" into "disability" boxes. Special education is one such disability box which we know now is neither special nor indeed educational in any sense of the word. This is no longer hot "news". The data has been in for several years. The outcome for people labeled "disabled" is a life of loneliness, poverty, and joblessness - not an outcome any family would choose for their

sons or daughters. Despite this data, segregation still thrives and is considered an "acceptable" educational placement and practice. It is still OK to talk of "them" and "us".

Segregation is NOT acceptable. It is bad pedagogy (for ALL children), it is uneconomic, immoral and unethical. In short, segregation must stop. This article is about how to integrate children, end segregation, and improve educational outcomes for all.

No matter where we go, people are talking about the "Butwhatabout" Kids. Some of the presently popular euphemisms include hard-to-serve, at-risk, etc. Why don't we just admit it outright. These are children and teenagers who scare us to death, who threaten our mortality and who make us vulnerable and nervous. That is natural, normal and human. What is unnatural, abnormal, unacceptable and inhuman is our systematic "boxing" and subsequent rejection of the people - or the illusions about people that we fear. We encourage people to square off with the fear - conquer it, and welcome all people back to our communities - complete with their mortality, vulnerability and incredible capacities to teach us about what is important in life.

THE MONSTER WE CALL FEAR

The first task is to face this monster called fear. Mythology tells us that most "fear" monsters are slain merely by facing them. We don't tell teachers to give up their fears. Rather, we suggest they face them - head on; take up a mighty sword and slay them, one by one.

FEAR is the most frequent word we hear as we talk with educators. "Don't be afraid," many people say. But not us. We encourage teachers to, "Be afraid! Talk about the fear. Name it! Get it on



the table!" When the fear monster is out in the open, you can kill it, go around it, or learn to ignore it. You can manage it. But as long as the fear is unnamed, the fantasy will frighten us more than any reality. Fear of the unknown, fear of failure, fear of not knowing what to do, fear of mortality. These are real fears. Once faced, fears can be overcome.

When we meet fearful teachers, we offer a little "monster powder". We propose an alternative to these fearful human mortals who are just like us. Our "monster powders" are state of the art strategies that build confidence and a better future for all our children. MAPS and CIRCLES of FRIENDS are tools which take the responsibility off one person and puts planning in the hands of a team comprised of school personnel, family and the children themselves.

MAPS and CIRCLES are based on common sense and don't cost a great deal of money.

But Beware. These strategies require three important pre-conditions:

- l. The desire to slay the monster of fear.
- 2. The desire and ability to learn and change.
- 3. The desire and ability to work as a member of a team.

We feel if teachers cannot meet these criteria, they should consider another career!

Strong words you say. You bet.
These times call for strong words and bold deeds. The crimes of illiteracy, miseducation, and rejection can no longer be tolerated. We know too much. Systems like Johnson City in New York and Waterloo Region in Ontario, Canada prove what can be done. These beacons in a still-too-bleak educational land-scape have no more money and no more brain power than any other system.

What distinguishes them is leadership with guts, clear values, and the vision of an outcome that spells success for all children entering the doors of our schools today.

We no longer have to prove that quality education can work. It can. It is now up to others to justify why they cannot deliver quality education to all their children as they do with daily success in Johnson City or Kitchener.

Reversing Reject.on - Full Inclusion for All

The Centre for Integrated Education and Community is devoted to reversing the rejection of the Beckys, Katherines, Judiths, Suneels, Sunitas, etc. We are developing state of the art strategies and training workshops to help systems and individuals reverse the terrible tide of segregation and engage the challenge and thrill of full inclusion for all. Because we are white water canoe and kayak enthusiasts, we see the path like a white water rapid - full of rocks and churning water - but a great challenge and lots of fun!

No Magic Bullets; No Micro Wave Solutions; Just Hard Work

We make no claim that a MAP or a CIRCLE as described in this article is a magic bullet or microwave solution. These strategies, developed and practiced for a decade with live children in real school systems in Canada and the USA, are simply tools in the arsenal for quality education for all - a dream we believe to be viable and necessary.

MAKING A MAP

This strategy has been pioneered and used by many teachers and families in the past ten years. The laboratory has been two school boards in Canada.



(The Hamilton-Wentworth Separate School Board under the leadership of Jim Hansen and the Waterloo Region Separate School Board under the Directorship of George Flynn.) First and foremost, these two boards (approximately 20,000 students each) believe wholeheartedly that:

- * all students belong in regular classrooms no ifs, ands or buts
- * ordinary teachers can teach all children
- * necessary supports will be provided when necessary
- * quality education is a right not a privilege
- * outcomes must be success, literacy and graduation for all
- * creative alternatives will be available for populations not succeeding in the ordinary fashion (i.e. they developed store-front schools, cross age tutoring, alternative high school programming as required).

A Cookbook Lesson

We love to eat and cook. A quote from the back cover of the original 1973 version of Tassajara Cooking sums up our feelings about the strategies we have developed:

"This is a book to help you actually cook - a cooking book. The recipes are not for you to follow, they are for you to create, invent, test. It explains things you need to know, and things to watch out for. There are plenty of things left for you to discover, learn, stumble upon. Blessings. You're on your own. Together with everything."

We invite you to treat MAPS and CIRCLES as recipes from the "Tassajara Inclusion Cookbook". MAPS & CIRCLES are designed to help you do it...not to do it for you. You must "create, invent, test. They explain things you need to know, and things to watch out for. There are

plenty of things left for you to discover, learn, stumble upon. Blessings. You're on your own. Together with everything." Read on in the Tassajara spirit.

We recently received a phone call that illustrates the dangers of seeing strategies as "magic bullets." The organizer of an upcoming workshop called and asked, "Will the participants at your workshop really leave knowing how to include all kids in regular classes?"

Marsha took a deep breath and answered in a friendly but firm tone. "No. In two days you don't learn brain surgery and in two days no one person can learn "IT" i.e. how to integrate all children magically into school. We hope the participants will get a tasty appetizer which will give them the inspiration and confidence to begin, and to continue to get more in-depth knowledge, training and experience of the issue." The caller reframed the concern, and inquired if a reasonable revised objective might be that everyone leave the workshop feeling confident that this was the right direction for their school system. We said that too was our hope, and that most people would be ready to dive right in and try it out!

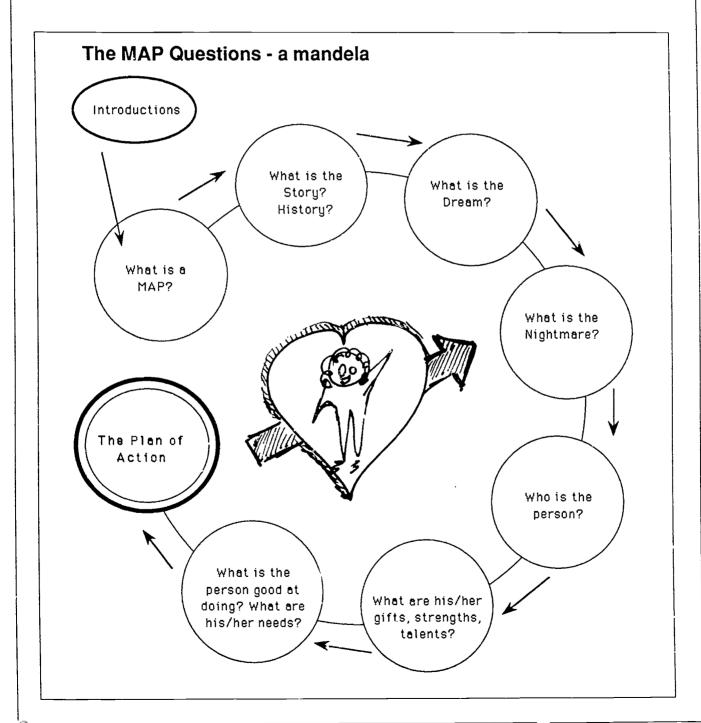
It is glib to think that anyone will learn all they need to know about dealing with children with complex needs in two days. But, with consistent use of MAPS and Circles strategies, as well as other exciting state-of-the-art approaches, within a year, we have found great success in being able to include almost all children.

What we've learned in ten years is that we can welcome ALL students into our nation's schools and classrooms - if we want to. This is regardless of the complexity of children's needs - be they physical, mental or emotional. After all, "untrained" parents have been doing it for years. As one of our friends said

after the birth of her daughter - "Jane didn't come with a set of directions. If we figured it out, so can a school. After all, teachers are paid for it, we're not. And they are trained educators, and we're not!! It should be easier for them. Basically, it is very simple. If they want Jane, they'll figure it out just like we did. All it takes is time and love."

MAPS

MAPS is a collaborative action planning process that brings the key actors in a child's life together. In the spirit of cooperation, this team creates a plan of action to be implemented in a regular classroom setting. It is NOT a case conference or an Individual Education





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Plan (IEP), (but the results can certainly be used on any IEP form).

MAPS is facilitated by two people - practicing what it preaches - "together we're better". One person acts as the MAPS RECORDER, making a public record (preferably using graphics) on large chart paper. This is an essential element of a MAP. The other person is the HOST who welcomes the group, explains the process and facilitates the MAP.

Essential elements of a MAP:

- l. co-facilitation (Host and Recorder) (can be interchanged)
- 2. graphic recording with colorful markers on chart paper
- 3. hospitality a personal and informal atmosphere (snacks, beverages, tokens of thanks)
- 4. all key actors in child's life present and participating
- 5. focus person and their siblings and friends present and participating
- 6. key issues addressed: WHAT DOES the CHILD and/or FAMILY WANT?
- 7. decision to meet again (with a date)
- 8. concrete plan of action (actual things to do right away)

Without these essential elements, the plan is not a MAP. It may be something similar but a MAP must have the above eight elements (or have a good reason to leave an element out.)

A MAP is made up of Questions that can be conceptualized as a circle. Each key must be used but there is no particular order. The facilitators decide on their direction depending on the needs of the group.

Setting the tone and introductions:

Before the MAP, the facilitators set

up the room in an informal semi-circle with comfortable chairs. Chart paper and clean markers should be ready. Snacks are available for people before the session begins. Colorful name tags are ready. The facilitators invite the group to be seated, introduce themselves, then ask everyone:

Facilitator:

"Please tell us who you are and explain your relationship to Mark (the focus person)."

Question #1—What is a MAP?

The facilitator asks the participants to think of a MAP and asks, "What is a MAP?" Here's how one recent group answered:

Participants:

"A MAP shows direction.

It tells you how to get from one place to another.

It shows you how to find stuff. A MAP tell s you where to go."

Facilitator:

"That's exactly what we're here to do. To show direction for Mark's life, to help him and his family get from one place (the segregated class) to another place (the regular class).

The MAP will also help us figure out how to find the "stuff" that Mark needs. If we all work together, we can decide where to go next. Together we can create a plan of action that we can put into practice for Mark starting right away."

Question #2 - (which can also merge with the dream Question #3) What is the Story?

Facilitator:

"Please tell us your story. What are the most important things that have happened since Mark was born? I know



you can go on and on with this, so I'll limit you to 5-7 minutes. Tell us what you feel is really important for all of us to hear ana to know about Mark's story."

The facilitator must be careful not to make this a case history. She/he must listen with all heart, soul and body. The recorder writes the story - words, pictures and images. The facilitator also asks the participants to listen with their hearts.

"Don't listen just with your ears. Listen with your whole body. Don't be judgmental. This is not a trial. Try to feel, hear what the person is telling you from inside - as if it were your own story". We often ask this question before the dream. It depends on the tone and mood of the group. The recorder summarizes the story after the family or person has completed their thoughts being sure that the facts are correct and the essential elements of the story are there. The recorder should request the assistance of the MAPS team to correct spelling, facts, etc. Making simple errors (especially with people's names) can be very upsetting to some people, so legitimize corrections. Request assistance. This increases group participation and ownership.

Question #3 - What is Your Dream?

This is really the heart and soul of the MAP. The facilitator must build an atmosphere so that the family feels comfortable to say what their dreams, hopes and wants really are.

Facilitator:

"If you could dream the dream you really want, if you could have anything with no holds barred, what do you really truly want for yourselves and for Mark? Money is no object. Don't hold back. Let yourselves be free to really say what you

want. Don't ask for what you think you can get. This is different. This is what you really want and dream about or pray for."

There is often a deathly silence at this moment. It is essential. Do not interrupt. Wait. Allow the family time to build up their courage to get out their real feelings and hopes. If this is rushed, the whole MAP may be futile.

When a facilitator asks the question about people's dreams with a full heart, so that people gain the confidence to risk stating their buried dreams, profound things often happen. A pattern has emerged after years of asking this question. Parents all over the continent have told us that the MAP empowered them to dream again. As one Colorado parent stated, "A map is a way of restoring the dream to a family". With older teenagers or adults, the person states their own dream. The MAP restores a dream to the individual.

BUTWHATABOUT

"BUT", someone out there is thinking. "Butwhatabout" the person who can't speak? We have done many MAPS with children labelled "non-verbal". Although these children don't speak, they certainly communicate. And if the group knows the child well, someone will be able to articulate their own dreams for the child, and also the dreams they think the child might have.

Facilitator:

"If Mark could speak, what do you think his dream would be?"

Families often weep openly as they tell us, "My dream is that my child be happy, be included in school, walk or ride to school with his sister, be invited to

birthday parties, have a hamburger with a friend, and have the phone ring just for him."

One 12 year old girl told us "I want a trip to Hawaii and a job with computers. Also a pet dog." She was clear as a bell!

One parent of a medically fragile child told us, "I want my child to have one real friend before she dies. My nightmare is that my child will never know friendship." (This little girl did die soon after, but because she had moved into a district that welcomed her, the mother did get her wish. The entire 3rd grade class attended her daughter's funeral. The family knew that their daughter had made real friends in her all-too-short life.

Question #4 - What is my/our Nightmare?

Many people consider the Nightmare question the hardest to ask. We believe it is one of the most important because the MAP must identify the nightmare in order to avoid it. Unless the MAP prevents the nightmare, it is a waste. Unless the OUTCOME of the plan of action is to prevent the worst from happening, all we are doing is simply busy-work.

In ten years of doing MAPS, these are the most consistent responses to this question.

"My nightmare is that my child will end up in an institution with no one to love him/her."

"We will die and my child will be alone and put in a group home."

"My child will never have a friend."

No one has ever said.

"I'm afraid my child will not get an A in math or learn phonics."

No one has ever said.

"I'm afraid there won't be a proper functional curriculum."

This question often breaks the ice between warring factions. When school staff see that the parents want what every parent wants for their children, barriers break down. We have seen wars melt into peace treaties. A Kentucky woman broke down describing how her eighteen year old son was currently living out his nightmare, institutionalized, after having blinded himself.

"Our family is in the nightmare," she wept. "All we wanted, all we want now is some shred of human kindness and friendship to our son.."

We had to stop for coffee as all participants, both factions, were in tears. For the first time, they were meeting as human beings rather than as warriors on opposing sides of a placement review table.

Facilitators do not have to be familiar with the person or the family, butmust know the MAPS process inside/out. The facilitators must first and foremost believe 150% in the fact that full inclusion is possible for all! The facilitators must be good listeners - able to hear great pain without providing immediate advice and solutions.

The teachers and school personnel are a part of the group. The facilitators can be school personnel or an external team. The facilitation role is to pull information from the group and move it along into an action plan. The recorder creates a photograph of what the group says with color, graphics, and also summarizes what has been said before going to the next step.

Questions #1-4 are Part I of a MAP. It is often necessary to take a break at this point. The second part will be lighter, faster paced and move toward the action plan.



MAPS — Part II

Question #5 - Who is Mark?

We like to draw an outline of a person on the chart paper and hand out post-it notes to change the mood and motion of the MAP. This is a brainstorm session. Each person writes a word or phrase (one per post-it note) and posts it on the outline. This gives us a snap shot of the person. A recent MAP of a 12 year old boy had these words:

curious, handsome, determined, likes good snacks, always hungry, potential, my son, dimples, pretty ordinary, my brother, very active, pest, a little brat, somebody's great friend someday, an interesting boy, lively, likes to play with drums, great family.

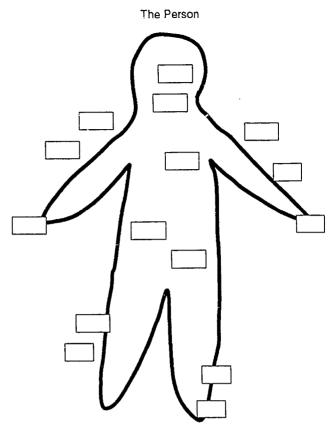
The recorder attempts to group the words to get a picture of Mark. We sometimes ask, "What have other people said about Mark in the past? What words have been used before in other meetings?" In this case, these were the words previously used to describe Mark:

retarded, developmental delayed, autistic, severely autistic.

These should be posted separately, but the recorder may want to highlight the dramatic differences between the two portraits of the same person.

Question #6 - What are Mark's strengths and unique gifts?

Another list was generated:
happy, beautiful boy, loving,
friendly, he can look you in the
eye and smile, gives a lot, he



Place "Post-its" all over an outline of the person

has a 'look', helps to put things in perspective, makes you feel good.

Question #7 - What does Mark like to do? What is Mark good at? What are his needs?

This brainstormed list is important as it gives us many ideas for the curriculum and daily program:

Mark likes to throw balls, play with ropes and strings, climbing in parks, eating, relax, swim laps in the pool, play in water puddles, go skating, play in clothes closets, be with people.

By this point, we have generated an enormous volume of information on Mark. We ask,

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"First and foremost, what do we all need to make this (the DREAM?) happen? What does Mark need? What does Martha (the teacher) need? What does the family need?"

At this MAP, the only people present were Mark's mom, dad, teenage sister, and a dedicated teacher/friend. When it came to Mark's needs, there was a real consensus that Mark "needs to be involved, and to meet people his own age." The family needed him to meet other children so his mother could begin to build a life of her own. The family agreed that a "worker" (to help build community integration) would be a godsend. They wanted that person to take Mark to local places where he could "get involved" with other kids. The job description for that person was developed from what was said at the MAP:

- * find places where he can meet kids
- * find kids to spend time with him
- * go to the youth centre
- * get involved in trips, swimming and activities
- * develop more communication skills

Question #8: The Plan of Action:

When you frame the needs question carefully, it flows directly into a plan of action. In some circumstances, ie., planning a curriculum, we might draw the timetable, and have the other students brainstorm all the activities that Mark likes and could do. Then, we explore the logistics. If Mark is going to get from History to gym, and be dressed in 10 minutes, he will need help - a guide. Who would be willing to help? We link specific people to specific times, places, classes, activities.

In this instance, the family enthusiastically agreed to plan a pizza party at their home and invite some neighbor-

hood kids - that weekend. Together with Greg, the teacher/friend, they started to look for a community integration facilitator. Greg agreed to facilitate another MAP with a wider group in one month. A date was set.

Concluding a MAP

A Map must be concluded. The recorder walks/talks the group through a summary of the charts and presents the charts to the family as a gift - along with other gifts i.e. a plant, a cake, something sweet, something that grows.

Before it ends, the host/facilitator asks each participant one more process question.

Facilitator:

"Will you give me one word, or a phrase to sum up your experience of this MAP. Off the top of your head...the first word that springs to mind..."

Here's what this group said:

Mom: I'm relieved. Great session.

Dad: Very positive. Thanks.

Sister: Awesome

Mark: (gives us all a really big

smile.)

Greg: Fabulous and positive.

THE KALEIDOSCOPE

The metaphor for the MAP is a kaleidoscope. The kaleidoscope is a magical toy, a mysterious and beautiful tool that changes constantly. Through the eyepiece we see little bits of beautiful color turning together into an ever-changing luminous melody of color and light.

We see the *kaleidoscope* as the outcome of each MAP. It is a medley of people working together to make something unique and better happens. It is more than anyone can do alone. It proves what we strongly believe - *TO-GETHER WE'RE BETTER!*

CIRCLES OF FRIENDS

Stop. Take thirty seconds. Try to imagine a world in which you did not have a single person who truly loved you. Imagine having no family and no friends. Imagine that only paid personnel see you in the morning and at bedtime. Imagine a world where none of your peers spoke or walked. Take a moment to remember how it feels to be that lonely and isolated.

Recently, we met a young woman who literally had no one in her life. She had been abandoned by her parents at the age of four and placed in a group home for children with "severe to profound mental retardation". As we did her MAP, she sat with us and listened intensely to the conversation. We were told that she banged her head and screamed constantly. The person we observed sat still for two hours and listened intently. What did she hear? What did she understand? It is our belief that she heard and felt our concern, that through her blind eyes she saw love and people who were afraid for her life. We believe she responded to that caring by sitting with us for two hours. She is sixteen years old and knows no one her own age.

It was clear that an intentional circle needed to be built immediately. Diane had been physically present in a regular high school but spent her days in a segregated class. She was present - but invisible. No one really knew her.

The school called together a group of teenagers and teachers who expressed an interest in helping Diane.

"How would you feel if your life looked like Diane's?" we asked.

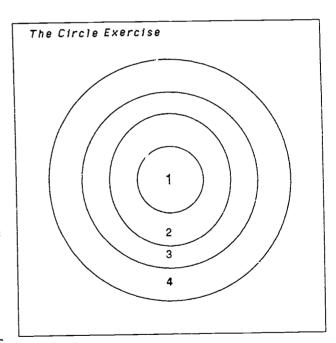
One young woman said quietly but without hesitation,

"I'd commit suicide."
Others said,

"I'd sleep all the time. I'd take drugs. I'd drink.

I'd kill someone."

They saw immediately that what Diane needed most was to be with them - to get out of the segregated room. They brainstormed places they could go with Diane. There was a rock concert coming up. One student volunteered to take Diane with her and her other friends. Another decided to visit Diane and have dinner with her at the group home. The students thought Diane would like the music and cooking classes which were noisy and the teachers were "pretty cool". The ideas flew. Diane sat through the meeting with a smile as she gently rocked back and forth, back and forth.



Several teachers decided to get involved. Rather than blaming themselves for what they had not done in the past, they switched their energy into actions they could deliver in the future.

The result: six months later, Diane has regular visitors to her group home; she has gone out more in six months



than in the past ten years; and one teacher and student seem to have formed a special bond with her. They have invited Diane to their homes for dinners and Sunday outings. It's a good start. Best of all, Diane is out of the segregated room and goes to music, cooking and other regular classes. She hangs out in the lunch room, and has stopped poking the corners of her eyes and screaming as much as before. Is Diane "cured"? No! Does she now have people to talk to, things to do, a life to look forward too? Yes! Equally important, Diane's classmates are learning and gaining even more than Diane. They are getting "experience" (hands on training has always been the best) in problem solving (number one issue in the curriculum, with a REAL and relevant problem. They have to create curriculum, timetables and trouble shoot with Diane. They are learning to manage teachers, manage behaviour and confront values issues. Their acquaintance/friendship with Diane may be one of the most important learning activities of their lives. There is still a long way to go, but the circle has started. Diane has a dream, and her new friends are part of it.

A CIRCLE AT CAMP

Norman wanted to go to camp, but everywhere he and his family went they were told that Norman's needs were too great. One young counsellor who had completed one of our workshops decided to put the learning into action. He wrote us this letter which illustrates the simplicity and complexity of the idea of a CIRCLE.

"We decided Norman could attend our camp. That was a big step in the right direction. I had all the kids together in the recreation hall and I gave my little speech. 'A

circle of friends is a support group that helps any camper having problems feel more welcome and included.' I was received with blank stares. Oops, I thought, I better look at my course notes again. I blew it that time.'

"After bombing with this great opening statement, I simply asked the kids to talk about Norman, who they had met that morning. 'What do you think Norman can do all day at camp?' Boom! Everyone was talking at once. That was a question ten year olds could relate to - it wasn't a lecture on circles.

"The meeting lasted about twenty minutes, ending with suggestions about how they could do things together with Norman. I asked for a smaller group of volunteers to help me plan Norman's day. EVERYONE VOLUNTEERED.

"Norman's biggest challenge and the reason he had been rejected by every other camp in the universe was "weak bladder control." Several people (adults) had suggested that Norman should sleep in a separate building to "hide" the problem.

"I decided (with Norman's permission of course) to put the issue out in the open. The children suggested (quite matter-of-factly) that they take turns waking Norman up in the night to go to the bathroom. It never occurred to them (and they rejected outright) the suggestion that he sleep in another building! The counsellors volunteered to take turns helping when needed.

"Many baseball games, slumber parties, cance and splashing trips later, Norman no longer requires a "one-to-one" worker. His bladder problems are getting better (only twice a week instead of every night). Norman's circle of supporters (now a smaller group of real

potential friends) meets for an hour every four days. The children and counsellors really look forward to it. So does Norman. Norman's circle has become a place for all involved to get support. Last week Norman wasn't even the issue. The topic of the day was Tanya's bad temper.

"Finally I should tell you that the social worker called me in shock regarding the progress Norman had made. She asked if we could work on building a circle in his school and in his group home community this Fall. I told her I would love to come and help one of the school people become a facilitator. I guess I really learned a lot in the workshop on MAPS and CIRCLES. Norman was my chance to try it out myself. It was the best experience of my career. I'm launched.

Thanks and Love." (Dan)

To us MAPS and CIRCLES are like building a good foundation for a house. What good is a castle if it is made on sand? What good are communication skills if you have no one to talk to? What good is physical mobility if you have no where to go? What good is life itself if you have no one to share it with?

The Centre for Integrated Education and Community (CIEC) is busy refining its training institutes and workshops so that we can spread the word about the beauty that lies in the heart of inclusion. We have no pretences that we have THE answer. We do however have years of experience, and hundreds of success stories that tell us full integration and quality education are indeed possible.

We have no illusion that in a short article we can do more than whet your appetite to learn more. Please write us with your questions and concerns. We see ourselves as problem-solvers and facilitators, not answer givers. We enjoy working with people who see problems as challenges to be solved. This final story illustrates our point.

We had just finished a week-long white-water canoe/kayak course. We thought that our friend Judith Snow might really enjoy a raft trip down the incredible river we had run in our smaller craft.

We approached the staff at the Madawaska Kanu Centre. We told them that Judith travelled around in a wheel-chair which she drove with her thumb. We explained she only had use of her mouth and thumb for mobility.

Before we got the words out, these energetic rafters were planning where Judith would sit, how many extra people they'd need to carry her into the raft, and how she could enjoy actually going in the water to body surf.

They were beyond us. We only had her in the boat. They had her in the water too. What a difference! Most people look at Judith and only see PROBLEMS. To the rafters, this would be fun, a challenge. If she wanted to go, they would take her. There was no question. End of story

How refresh: 1g! If we can create the opportunity for Judith to go rafting and surfing in the Madawaska river, surely we can create the opportunity for all the children in Canada and the U.S.A. to attend school alongside their neighbours and friends. There are simply no more excuses! Judith hasn't decided if she really wants to go rafting, but the vast majority of families have decided that they want to be welcomed in their neighborhood schools. Attitudes are the major barrier and are no longer an adequate excuse. We must welcome all children now. It is their right. Our future depends on it. There is simply a need for action - NOW.



MAPS:

ACTION PLANNING

to welcome people
of all ages
into full life
at home, school,
work and play.

Marsha Forest & Jack Pearpoint

"What's a Map?"

It is always the first question. It was so common, we incorporated it as the very first question in a series of "8 KEY MAPS QUESTIONS".

In workshops to implement the MAPS process, we begin by asking the participants: "WHAT IS A MAP?". A recent group answered as follows:

-something that gives direction -a thing that helps you get som >where

-routes to different places

-opens new ways to get anywhere

-to help you find your place

-a way to find a new way

-stops you from getting lost

A Short History:

MAPS was originally designed by a team of educators who were searching for ways to help welcome children with disabilities back into regular schools and classrooms.

The concept of MAPS has now expanded. We see MAPS as a tool to help both organizations and individuals who are at risk of being isolated, institutionalized, left out, kicked out or locked out of the mainstream of life. This includes populations of people such as our older citizens, people with behavioral challenges, people in trouble with the law, people on the streets, people with mental health problems, and organizations who help these varied populations.

A MAP IS NOT and A MAP IS...

It is important at the outset to state clearly what a MAP is and what a MAP is NOT:

1. A MAP is NOT a trick, gimmick, quick fix, or a micro-wave solution to complex human problems. It is NOT a one shot session that will provide the magic bullet to blast a vulnerable person into the life of the community.

A MAP is a problem-solving approach to the complex human issues of life. It can and must be done as often as needed. At its core, it is PERSONAL, COMMON SENSE and FROM THE HEART. A MAP must ask over and over again - DOES WHAT WE ARE DOING MAKE SENSE FOR THIS PERSON OR ORGANIZATION?

- 2. A MAP is not a replacement for an Individual Education Plan (IEP). A MAP session may help provide information for an IEP or some other needed legal documentation, but it is not a substitute and must not be treated as such. In a MAP, the people giving input are personally and/or professionally involved in the person's life. MAPS participants and contributors must be people who know the person or organization intimately, not simply people who have tested or given intermittent therapy to a person.
- **3. A MAP is not controlled by experts** in order to design a neat program package.

The outcome of a MAP must be a **PERSONALIZED PLAN OF ACTION** that

has three criteria:

a. The plan is personalized i.e. tailor made for the person or organization. It is a one-of-a-kind MAP.

b. The person is at the heart of the MAP.

- c. The plan assists in bringing the person or organization closer and closer into the daily life of the school or community.
- 4. A MAP is not a tool to make any segregated setting better. MAPS was designed to liberate people from



institutional care. It is only for people and organizations trying to figure out together how to get a person fully included in life.

- **5.** A MAP is not an academic exercise. It is a genuine personal approach to problem-solving. A MAP is for people who are vulnerable and outcome decisions have life and death implications for how the person will live his or her life. It is not a professional controlled/expert model/top-down management tool. It is a group, problem-solving, cooperative, collaborative team approach to planning.
- 6. A MAP is not a Neutral Tool. The MAP facilitator must be skilled in group process, have leadership ability, have a problem-solving orientation, and most of all, have values that are clearly in favour of fully inclusive education and living. MAPS makes the value-judgement that it is better for all of us to figure out how to live together than to put people in little (or big) segregated boxes. MAPS facilitators must have a clear vision and share beliefs favouring the road of inclusion in all aspects of life.
- 7. MAPS is not talk. It is talk and Action. A MAP gives clear direction and takes action steps to move in the direction of inclusion. Most of all, MAPS is ongoing. It is a life long process of figuring out how to prevent the nightmare of segregation and how to enter into relationships that will lead to physical, mental and spiritual well-being.
- 8. The metaphor for the MAP is a KALEIDOSCOPE. The KALEIDOSCOPE is a magical toy, a mysterious and beautiful tool that changes constantly. Through the eyepiece we see little bits of colour turning together into an ever changing luminous melody of colour and light.

We see the KALEIDOSCOPE as the outcome of each MAP. It is a medley of people working together to make something unique and better happen. It is more than they can do alone.

A MAP is a tool for creating a struggling community where all feel empowered to belong, to be needed, to be in control of their own lives. Most of all, people should feel loved for exactly who and what they are.

The Assumptions of the MAP Process:

- 1. All people are valuable and can contribute to life on this globe.
- 2. All people have abilities, talents and gifts.
 - 3. All people can learn!
- 4. **Disability is a social construct.** People are not disabled. Systems disable people.
- 5. There is no need for special education or special educators. There is a real need for support, services, and educators who will reach out and nurture the potential of every child.
- 6. The only label we recommend is a person's name. Labels hide the fact that we really don't know what to do. After that, we suggest adopting a problem-solving mode that creatively figures out what to do for each unique individual.
- 7. Common sense is most important and least common sense.

What We are Not Saying:

1. We are not saying that money isn't necessary. We want all the money currently spent on testing, bussing and special education to be spent on inclusion: i.e. teacher assistants, child support workers, technical assistance, appropriate technology, etc. Money is definitely needed to provide the necessary support. However, "accessibility" is also a state of mind - and budgets must not be used as excuses not to include people.



- 2. We are not saying that anyone should be "dumped" without support and sit all day, unsupported in a regular class. We are saying that a team can figure out alternatives to segregated settings and find new, unique and better alternatives.
- 3. We are not saying that special educators are bad. We are saying that they have a major role to play in shifting the paradigm into "giftedness" rather than "disability". Not only is there greater job security, it is a more rewarding and exciting educational environment to live and work in.

We see all people as "gifted."

We believe all people are special, unique and different. Because of this, some people fall through the cracks, get missed by the system or scare us half to death. We need to admit that we have missed a lot of people. We need to welcome everyone back into the mud, blood, gore and glory of life. Together, we need to figure out how to right past wrongs.

MAPS is just one small way that helps people come together to solve complex problems. MAPS is only necessary when you bump into a problem that seems difficult. It is one of many tools. Try it, use it, write to us about your experiences. We find MAP MAK-ERS a pretty exciting bunch of people who like the personal and common sense team approach to creating a lifelong, caring and common sense curricula.

Who Goes to a MAP? - Friends!

The size of the group that gathers for a MAP session can vary from 2 to two dozen. The key ingredients for participants are Intimate and Personal Contact with the individual being mapped. A grandmother or neighbor, a friend - all are on equal footing with doctors, lawyers and teachers. Parents and family usually have the most to offer - if asked. Their perspectives are all welcome in a MAP. Professionals are welcome too -

but as individuals - not as "therapists".

As groups grow, the age spectrum tends to become more comprehensive. For example, for a MAP on a 10 year old, there would be several peers, perhaps some teenagers, parents, relatives, and some individuals with "elder" sta-

Peer participation is critical. In a school situation, class/age/mates have enormous untapped energy and creative capacity. They often empower the teachers with new ideas, person power and just "straight talk". The usual constraint is from us - adults. We often restrain or downgrade the participation of peers. They are critical and equal partners in the process.

There is a delicate question about whether the individual being "mapped" should be present. It is a judgement call. It works both ways. We hedge toward full participation. People understand an enormous amount - more than we think. A MAP is an upper for people who have been excluded. Why not give them a boost. It also saves time in try-

ing to explain it all later.

MAPS Facilitation:

"Mapping" is a collaborative process. It is virtually impossible to "do it alone". One individual focuses on the questions - facilitating the group. The other is the Recorder. They may interchange from time to time. The role of the facilitator is relatively straight forward - even though it requires practice, intuition and skill. Making it look easy comes from years of practice.

Public recording is also a critical part of the process. There are several reasons for the graphic recording.

> 1. Public recording acknowledges everyone's participation each person gets their mark on

the paper.

2. It creates "images" that speed up the process. People are able to visualize the elements in the questions - and see both their dreams and their nightmares.

3. It creates a history. The records from each MAP are kept and are often used to recall the



past. Remarkably, many people cannot believe the changes in their own perceptions and reality until they see the actual records of

an earlier MAP.

4. It maintains interest - and assists recall. It helps to keep it

moving.

5. It makes people feel good. They feel special. All this for "me". All these people. All this - and all these wonderful words - that are recorded for posterity (and for ACTION planning).

The "recorder" need not be an artist. That is not the point. However, it is vital that the individual print/write clearly and use "people's own words" and images. You can supplement - but be sure

everyone is included.

The Recorder and Facilitator are a TEAM. They must work well together. Alternating roles can keep the MAP process moving. But as usual, a solid value base and "practice" are the secrets of the trade. If you are committed to the process, try it. The way to learn is to do it.

MAPS: EIGHT KEY QUESTIONS

- 1. What is a MAP? Ask the participants.
- 2. What is the Story/History of the person, family? Ask those most intimate with the person to relate the highlights (and low points) of the individuals history (short - 10-15 minutes).
- 3. What is the dream? What do you really hope for, pray for, wish for? Do not be limited by money or reality. What would you dare to dream if you could have anything you wanted? Remind people not to ask for what they don't want. They just might get it.
- 4. What is the nightmare? What is your greatest fear? For us, this question is the hardest to ask and the most important to get on the table. We must understand the nightmare in order to prevent it. Preventing the nightmare is

the measure of success. The MAPS outcome must reflect an understanding of the nightmare. All actions are targeted to prevent the nightmare from happening. For families of children with disabilities, the nightmares are consis-

> "My nightmare is that I will die and no one will be there to love and care for my child."

> "My child will end up in an institution - alone and without friends."

> "My child will die without ever knowing real life and experiencing friends.

No parent has ever said: "My nightmare is that my child won't attend university, won't get an A on the next test, or won't learn how to spell."

- **5. Who is the Person?** This question shifts the MAP into a brainstorm mode. Everyone present is asked to give words or phrases that describe the person in question. Here's an example from a recent MAP:
 - "Who is Margot?"
 - *15 years old
 - * lots of fun
 - * active like crazy
 - * radical
 - * very radical
 - * bad (really means good)

To some, Margot is a "severely handicapped, autistic, mentally retarded teenager." To the members of the MAPS group (three of whom were teenagers), Margot was mostly "BAD!" (which they translated to us as meaning good).

- 6. What are Margot's strengths, abilities, gifts, talents? What does she do well? What does she like to do? This is also a brainstorm. It should not take long. Generate a list.
- 7. What are Margot's real current **NEEDS?** Much like the strengths, this is a brainstorm. Don't let people stop each other. Just record people's words and perceptions. Keep it short. Don't get bogged down.



In this MAP, there was uniform agreement that what Margot needed most of all was:

* FRIENDS

* PLACES TO GO

- * TO BE IN A REAL, REGULAR HIGH SCHOOL.
- **8. What is the Plan of ACTION** for Margot and for the MAPS team? All ideas were listed to start the process of getting Margot into her local High School.

A MAP is a catalyst to begin a process of change. A date was set for the next MAP. A commitment was made on the part of several key professionals and two energetic and "bad/cool" teenagers to meet as a smaller group. The MAP is on the drawing board. Over the next months & years, it will take on more detail and undergo constant revision. MAPS is a process. It is not a one shot cure. But it certainly is a beginning to plan and implement a better life.

For information on MAPS process, write:

The Centre for Integrated Education and Community,

24 Thome Crescent, Toronto, Ontario, Canada M6H 2S5.

Books:

ACTION FOR INCLUSION Strategies for making Inclusion happen by O'Brien & Fores. 8,000 copies in print!

Refections on Inclusive Education: Short reflections by the late Patrick Mackan, C.R.- perfect for schools, churches. Profound words from the heart of "Father Pat".

FROM BEHIND THE PIANO, the Building of Judith Snow's Unique Circle of Friends by Jack Pearpoint. A story of courage, defeat and victory - more fascinating than fiction.

(\$10 plus \$3 shipping and handling from the Centre - address above.)

CIRCLE OF FRIENDS by Bob and Martha Perske is a book of the stories (and faces) of inclusion. It is a must and can be ordered through Abingdon Press in Nashville or Welch Publishing Co. in Burlington, Ont. (416-681-2760)

Videos:

Miller's MAP: A brand new 40 minute video. How to make Inclusion happen involving a team of children, parents, neighbors and professionals in a creative team. Co-facilitation. Colorful graphics.

Available through the Centre. (\$55 includes shipping and handling). U.S. distributor "Expectations Unlimited" P.O. Box 655, Niwot, Colorado, 80544

With A Little Help From My Friends: A 60 minute video featuring students involved in the MAPS process. (available as above.)

Kids Belong Together: A 24 minute video - the story of teachers and children living and learning together. MAPS in action featuring Patrick Mackan. (\$55 from the Centre)



50 Years of No Special Reason

The day and hour had finally arrived.

This was to be the day the consulting speech pathologist was going to let us know when Vi was finally going to get her augmentative communication syst?m.

Anticipation loomed like the hot sticky July air, which pervaded her unit cubicle, where we all had gathered to hear the news.

Five minutes into his polite but rambling recitation, though, it became apparent that the only news he had for us that day was no news at all:

A glich had developed here or there, a microswitch had failed, a proverbial monkey wrench had been thrown into the works again.

Nothing new Proverbial monkey wrenches always had a strange magnetic attraction to Vi.

They seek her out and then boomerang in God only knows how many directions.

So, it must have come as quite a surprise to him when I asked how much longer it'd take to get back on track this time.

"Why," he quizzically replied, "is there any special reason all the rush???"

"No, no special reason," I said, in a mute sigh only Vi could understand.

"no, no special reason at all. . ."

"Except that she has been 50 years of no special reasons."

Bob Williams



The Dynamics of Support Circles

Patrick Mackan and Roslyn Cormier

Friendship is what carries us over the waters of life. Everyone needs friends. Human life and growth is meaningless without them. A group of grade 4 children in Stratford, Ontario, described the importance of friends in this simple way:

"Friends play with us, share with us, help us, cheer us up, care for us, go out of their way to help us, talk to us, make us feel special, stick up for us, and listen to us."

As more Canadian schools are registering students with disabilities in regular classrooms, the needs and dreams of these students call for support from fellow students. Classmates are invited into the life of the student with disabilities in order to meet the need for acceptance and belonging. The role of a support friend is to enhance that possibility. Support circles increase the enrichment of classroom life and provide opportunities for friendship and community involvement. Support circles are appearing across the entire K to 12 spectrum. In the early grades they are less structured. Everybody seems to be part of the class and young children just naturally accept one another. As children get older, the support circle of friends becomes more structured.

Although each situation and child is unique, beginning at about grade 4, the support circle has to be intentionally designed.

The establishment of support circles is simply a specific invitation for students to come into the life of another person who needs their love and concern in order to grow and develop. Any student can respond to the invitation to be involved. Support circles seem

to attract people who like people. Very often the most unlikely students consent. It has surprised many teachers as to who volunteers. In Ottawa, a school troublemaker became the most committed advocate to the support circle concept. In general, there will be as many reasons a student answers an invitation to come into a support circle as there are students who respond. It may be a value system, a personal experience, a perception of justice, a sense of compassion, or a feeling for what it must mean to be isolated. Some may come forward out of their own need to love or to be loved. Some students seem to have an intuition that sees the person rather than the disability. Some may see the disability first and only later see through it to the person. But whatever the reason, we can never predetermine the quality of the response. The best bet is to just take the responders as they are. It will be this cake mix of motives that will produce beautiful fruit in the growth of the support circle. It will be all these different reasons underlying the response that will energize the circle itself.

To get the right mix of students we must take care not to define the purpose of the circle too specifically. It is best seen as a call into another person's life.

The creation of the support circle begins with listening to the story of the person with special needs. Someone who is familiar with the story, relates it to a class or group of students. The story highlights the isolation and segregation that has been in the life of the person. Here is truly someone who needs friendship. In essence, fellow students are invited to be a part of this student's life. This is not a call for volunteers to help, but a cry to love another person by coming into that person's life. This is an invitation to a relationship.

Our experience in schools across Canada suggests that the story, once heard, elicits in the listener some expression from his or her own life experience. Students who join support circles often know themselves what it is

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like not to be loved, to be alone, to feel rejected. Paul, a student who acted out in bizarre ways to gain attention resisted all protestations that he was loved until he experienced the presence in the school of Samuel, another student with very profound disabilities. When Samuel was seen to be really accepted and loved, Paul realized he, too was loved. Paul's bizarre behaviour came to a dramatic end. Again and again there is evidence that responding to the invitation to enter into a meaningful personal relationship with another human being comes from a deep need within the self for personal growth and meaning. The support circle provides a unique environment for learning about self and others that no other school program can match. The wisdom of bringing all children together for their schooling is providing a quality education for all students in many dramatic ways.

In most cases, more students respond to the invitation to join a support circle than are going to be required. In one high school in Mississauga 70 came forward (while only 40 were deemed necessary for the forming of five circles). Techniques and methods in forming circles have been developed and address such an issue as this. In this article, the dynamics of circles are being highlighted rather than technique.

The whole process of establishing support circles requires a facilitator if the circle is to achieve its maximum benefit. Usually, the facilitator is a staff member of the school community. This could be a teacher assistant, a regular teacher, a special education person, a chaplain or one of the school administrators. In each case, the facilitator volunteers for the task. The person involved in facilitation must not only see the enormous benefit of the support circle but must also be committed to making it work. A good facilitator will act as yeast which allows all the ingredients of the group to come to fruition. A poor facilitator can be an oven door slamming, causing the mix to fall and be ineffec-

tive. The good facilitator allows the group to empower itself and to take control and responsibility for their role as a support vehicle. The support members are encouraged to use their own insights with the guidance of the facilitator.

Once formed, the support circle needs to meet regularly. They constantly need to work out the dynamics of the circle. At the group meeting, members discuss how they can include their friend in upcoming school events and social get-togethers. They seek ways to broaden the possibilities for friendship. The facilitator, as a representative of the school, assists in making these things happen. Often, there are initial problems and these need to be discussed and solutions sought. In Ottawa, a student previously labelled "trainable mentally retarded" and segregated for ten of his school years, had difficulty behaving properly in the school cafeteria. The large group of students at lunch fascinated him. He would roam all over the cafeteria helping himself to french fries. The support circle discussed the situation and found a simple solution. They paired him with a friend he greatly admired. No more french fry stealing. In North York, another support circle discussed the screaming and hollering of their friend in the school library. Their simple solution was to take her to a rock concert where screaming and hollering was appropriate behaviour. She no longer screams in the library, but she sure bellows at rock concerts. In Brantford, a support group found the drooling of their friend was a hindrance to his making friends. They decided, with the support of their facilitator, to stroke his arm every time he drooled. The drooling lessened.

There is no end to situations a support circle can deal with in order for the person with disabilities to enter into a full relationship with the community. It is not the student with the disability that is the focus of the support group,



but the relationship of that person to others. It is the relational aspect of the student's life that is the proper domain of the support circle.

A whole set of dynamics in the lives of the members of the circle emerges. There evolves a sense of respect and trust. As circle members come to know each other, the possibility of intimacy happens, and trusted friendship comes about. The circle members become friends and some become close friends.

Comments from teenagers involved in support circles:

"Our modelling is so important. What we do, Tom does. Often, when he is bad, we have to accept some responsibility for that. He began being very hyper — just being here. But being around us has settled him right down and he doesn't needs pills anymore."

"From the beginning, I didn't think that the support circle was anything for me. I was opinionated, quick tempered, and argumentative in class. So how could I teach Jane to be cool and patient and so on? Now, as a result of being in the support circle I have had to review my morals, my life, my priorities, my choices. I love her. I wish I wasn't graduating. Jane has taught me a lot. I realize how much I will miss her."

"I saw Jeff as just different. But now I see him as just like everyone else. I get mad at him like anybody else."

"I am a lot like Jennifer. She has taught me a lot. I have learned patience. I have become attached. I will miss her."

"When I was first accepted into another high school, it was no big deal leaving here, but now I know how much I am going to miss you guys. We should put a person like Tom in every high school. The circle is what I will miss most about this school."

"Will I ever miss Tony. He has become a real part of me." "Jim's early behaviour was hyped. Now he has had time to relax and has really settled."

"As to proper bellaviour with women, the girls are handling it beautifully. You are not supposed to do that', they tell Jim and he stops."

"Jim's coordination has really improved. In soccer, he used to look at the ball and kick and miss. Now he just kicks. He even passes the ball and has picked up sharing and teamwork. We'll try to get him on the badminton and basketball teams next season."

"I see Jim in each of us. We feel the same things. My `make my day' reaction to my sister is the same as his reaction to some people who annoy him."

"I never thought about such people before. I felt sorry but never cared. Now I see Jim as a special person — what a difference. I look more at his personality, not the physical him."

"I had known Jim a little — have seen him around. I was afraid of him as he was unpredictable and I was scared. When I heard about the support circle I didn't think about getting involved. Now I understand it more. One thing — I don't take my everyday life for granted. I think of my abilities and reflect on having them and using them."

These students in the support circle come to see each other in a new and exciting way. They not only gain insights about their own selves, but have the privilege of sharing these "revelations" with others. This is a dynamic that seems to happen nowhere else in the school experience. It is this relational component that gives the members of the circle a heightened sense of dignity, value and self-worth. It frees them to be better students and citizens. The mutual relationships that develop offer unique opportunities for personal growth. Being



with others in a circle of friends builds a trust of others because everyone in the group is concerned about one another. There is an evident lack of selfishness which leads to a trusting relationships that are not judgmental, suspicious, jealous or doubting. It is precisely here that friendship has the possibility of becoming mutual love. This in turn leads to an enormous increase in self-confidence.

In order for a support circle to function well, the members must grow together. Otherwise, the circle could disintegrate into a group of individuals who give of themselves but do not receive anything of value from each other. The personal growth of each person in the circle spins off to other networks in life. Parents have remarked how the attitudes of their son or daughter has changed since their involvement in a circle.

Support circles can be too big and likewise too small. Our experience tells us that the optimum size is somewhere between six and ten persons. This is the number that seems to promote dialogue and personal relationships. To determine the size of membership in the circle or who of the many responders should be selected, we suggest an event such as a pizza party or recreation activity that allows people to get to know each other informally. As a follow-up to such an event, the responders could be asked to express, through a poem or other artistic expression, just why the circle appeals to them.

It is essential that the person with disabilities be seen as a member of the circle and not its focus. The person with challenging needs is not the centre of the circle but very properly part of its circumference. He or she is a full member who has many gifts to bring. It is important to recall what was said previ-

ously — it is the relationships in the person's life that the circle supports. Where better to begin than in the circle itself? It is the formation of friendship with the person in the circle itself that takes priority over involvement in activities just for the sake of involvement. The developing of friendship takes time, attention and togetherness. The circle members have to determine how to work all this out.

There is something dramatic happening in schools where integration is taking place under the banner "Kids Belong Together". It is obvious that the philosophy of full integration is providing quality education and life for all students. The recognition of the "giftedness" of every child creates a non-threatening and enriching atmosphere in the entire school community. The focus on individuals rather than labels or problems sets all kids free. This gives a sense of joy and a sense of self-worth. There is an aura of love and kids are free to learn. "Happy kids learn!" The excitement of the discovery of self leads children to want to learn more. Complete integration where "Kids Belong Together" and are supported in circles of friendship is creating a new and different school.

Dr. Patrick Mackan was co-director with Marsha Forest and Jack Pearpoint of the Centre for Integrated Education and Community in Toronto until his untimely death on Nov. 23, 1990.

{Patrick Mackan can be seen in the half hour video "Kids Belong Together", which focuses on building Circles of Support in schools. The Centre has also published a book entitled <u>Reflections on Inclusive Education</u> written by Pat just before he died. An order form is at the end of this book.}

Rosyln Cormier is an associate of the Centre for Integrated Education and Community and the founder of the Centre for Inclusive Education in Kitchener-Waterloo, Ontario.



"be nice"

by Marsha Forest, 1992

beware the person who says
"be nice"
for "be nice" advice turns
warm hearts
to ice...

"be nice" is advice for those
who would beat
those with hot passion into refreat
it is always said in an
arrogant voice
masked by the rhetoric of their
favorite word "choice"...

"be nice" means smile, it means
fit in

"do it the way it's always been"—
don't show anger
don't show pain

"be nice" is the phrase of the
arrogant and vain...

ghetto residents are told to
"be nice"
for that they pay a terrible price
but the nice folks are being
exposed as they lie
as the bombs they drop
pollute air, sea and sky...

this is no time for niceness
my friends
this is the time for passion and fire
time to expose the mask
of the liar...

the polite ones come in all shapes and sizes men and women black and white their common voice says, "give up your fight!" the forests are cut the air is in pain and acid stings our gentle rain and acid stings our gentle rain...

"be nice
they said as warsaw burned
as the ovens turned
the bones became ashes
and teeth became dust
but "be polite" for
in god we trust...

none of my heroes were ever called "nice"
their souls are filled with passion and spice and inclusion won't happen because we are NICE... it means breaking down walls made of centuries of ice and ice will only melt with heat with the motion of wheels, with the rhythm of feet...

the lines in the world are
being redrawn
and we are getting together
and strong
with poetry and song
and all we want is that
each belong...

the forests are cut the air is in pain and acid stings our gentle rain and acid stings our gentle rain.

Carla's in High School

Marsha Forest, Rosemary Deeley & Jack Pearpoint

Carla's in high school.

That may not seem like news to you, but it is. Let us tell you why...

The first striking thing you notice about Carla is her size. She is <u>very</u> small. Her records tell you that she is also an exceptional pupil -- multiple exceptionalities the reports go on to say. Trainable retarded. She is described as having severe physical and academic limitations, Turner's Syndrome, scoliosis, speech delay, gross motor delay and at the end of grade eight is described as being at the preschool level.

Carla just turned 15 and began her second year in high school this past September, 1989. She has earned many new labels at the high school she attends -- cute, sociable, fun, cool, trendy, helpful and capable..

When she first entered the doors of Cardinal Newman East high school in Hamilton, Ontario in Sept. 1988, everyone was concerned and a little scared, particularly for Carla's physical safety. The school campus has about 800 large-sized high school students. The building has two floors and there were genuine concerns over Carla being accidently knocked down, trampled or falling down the stairs.

If you have spent any time in a high school recently, you will realize these concerns were justified.

What really happened however, was that everyone, especially the other students, learned to be aware of Carla's presence in the school. They knew when they were rushing down halls that she

might suddenly appear. They were always prepared to stop in midflight. We have seen students joking, pushing, or shoving one another in the halls only to stop suddenly and make a space like the parting of the red sea while Carla strolls safely past and the activity then resumes at full blast.

In two years Carla has not been knocked over, trampled upon, pushed or fallen down the stairs.

The school year in this Canadian High School is divided into 2 semesters. A student usually takes 4 courses. The standard day is four 76 minute periods with one lunch break.

In her first semester, Carla was enrolled in two classes -- typing and science. She began by attending each class for 30 minutes and gradually worked into the full 76 minutes. The aim for these classes for Carla was to learn to:

- * Sit quietly and attentively in a class,
- * Develop good social relations with her peers,
- * Be with her friends in a normal classroom environment,
 - $\ ^*$ Follow regular classroom instruction.

The aim of all these activities is to have Carla ready to get a real job in the summer, and in the future, a real job with real people in real places. High School settings are perfect places to practice to make this happen.

As well, there were specific academic goals for each subject.

Typing: Carla learned to recognize and use several keys including the space bar. She also mastered feeding the paper into the machine. Science: Carla participated in simple experiments and learned a wide range of new vocabulary.

Because Carla tires easily, she



rested in the resource room area for approximately two periods. While there, she had tutorials on her computer, sight vocabulary reading and time to socialize with her high school buddies.

In semester II, Carla was ready for more classes -- Vocal Music, Art and Food and Nutrition (Cooking). She attended two of these classes for the full 76 minutes and one for 45 minutes. In addition, she traveled to her cooking class via the shuttle bus to the other campus with her friends. With some simple modifications she thrived in all three classes.

Carla received three Basic Modified credits last year and all her courses this year are for credit. It should also be noted that all Carla's classes include students from Basic, General and Advanced levels.

<u>CARLA'S TIMETABLE NOW</u>: Carla is now able to handle a full schedule of 4 classes. She participates for the full 76 minutes. Her schedule is as follows:

Period 1 -- Sewing (NFM2G1)

Period 2 -- History (HCT2A7)

Period 3 -- Lunch

Period 4 -- English (ENG1G1)

Period 5 -- Physical Educ (PHF1G1)

<u>Sewing class</u>: Carla is learning the symbols found on clothing and what they mean, as well as the recognition of the "tools" of sewing.

Their first project involved decorating a T-shirt or sneakers using stencils and paint. Carla chose to "do" her white tennis shoes.

Their second project involves the making of a sweatshirt. Her teacher has an open mind and says: "Where there is a will there's a way for Carla to sew. We just have to find the way." She decided to put the sewing foot pedal on the table.

Carla uses her hand to push the pedal.

At present. Carla is practicing along with the other students on paper and without thread -- following the marked lines. She is doing remarkably well.

The other students really enjoy Carla's participation in the class and are learning valuable lessons through the attitude of their creative teacher.

History class: Carla is working on a modified unit on Canada. This involves such things as recognizing a map of Canada, locating the province of Ontario, recognizing the birds and animals of Canada, and narrowing down to her city and community. There is an assistant in the room for half this period. The rest of the time Carla works alone or with another student.

LUNCH: Carla is a social butterfly and like most high school students, lunch is her favorite period of the day. She eats in the noisy cafeteria with her friends. After lunch she can be found chatting with the other kids out in the halls or in front of the lockers.

ENGLISH: Carla stays just over half time in this class as she is getting very tired by this time of day. While there, she works on increasing her sight vocabulary, writing her name and listening to stories told by the class and teacher.

PHYSICAL EDUCATION: The teacher considers Carla a real asset particularly during warm up exercises which is her favorite part. The rest of the girls hate the warm ups. Carla shames them into hard work. In phys. ed., Carla is becoming more comfortable walking on uneven surfaces. She is learning to kick a soccer ball, play baseball and cricket, run, and change quickly for classes.

Carla's physical stamina has increased incredibly this past year. Considering her size, her physical condition, the length of the halls she travels and



the stairs she climbs, her progress is really astounding.

FRIENDS & STUFF: Carla usually attends all school dances and has become quite comfortable in that atmosphere. She also attends school football games. She has established a couple of good firm friendships. These friends phone her regularly and insist that she phone back. Her mother reports that she now races for the phone along with her brothers. These girl friends visit one another and go to the mall and bowling.

SUPPORT: A special education resource teacher in augmentative communication comes to work with Carla once every two weeks to add new symbols to her communications book. Carla uses both the book and some speech.

THE REPORT CARD:

Comments quoted from Carla's report card:

Subject: Clothing - very good

- I am pleased with Carla's progress. The sweatshirt will prove a challenge to all of us. I know Carla will be successful.

Subject: History - satisfactory

-- Some days Caria's progress is great -- some days it's not. Subject: Physical Educ - very good

-- Carla especially enjoys the warm up exercises. She gets involved in all the activities she can.

Final comments:

Now let's put all the above in perspective.

If Carla was in most neighbouring Canadian cities, she would attend a segregated high school for the "retarded" and be treated as a medically fragile, severely handicapped student. She is lucky to be living in Hamilton and attending the Separate School Board there. They believe

that ALL CHILDREN BELONG:

- * in their neighbourhood schools,
- * with an age appropriate program plan.

Their goal is full participation in the community as an adult..

Carla is also lucky to have a creative and imaginative high school special education teacher, Rosemary Deeley, who believes that Carla has the right to be in high school and the right to an excellent school day.

Carla is also lucky to have supportive and nurturing parents who are willing to take risks.

Be assured that Carla is indeed a student with many, many challenging needs. Everyone said she could not be integrated, it wouldn't work. But in the Hamilton Separate School Board, anything can be done because they believe it can be done.

This kind of high school program can be achieved for ANY student if the school is ready, willing and able to say "we'll do it!". It doesn't take incredible skills. But it does take a new and different value system which assumes that:

- * Carla can and will take her rightful place along with her typical peers in her neighbourhood high school.
- * This indeed is the best place for Carla to be.

To see Carla in High School gives us hope and great joy.

To see other children not have this chance gives us cause for much sorrow and anguish.

We hope this article will inspire others to dare to do what the staff and students have done at Cardinal Newman High School.

GO FOR IT!



Hamilton, Ontario Cardinal Newman East High School Carla Barbadoro Update - Feb. 7, 1992

Here we are back at Cardinal Newman. Carla is now 17 years old. It seems amazing that we met Carla when she was 12 and now she's a teen. She is back in school after a serious illness which kept her in the hospital for several weeks. She is very susceptible to infections so all are also concerned re: her health. Everyone is delighted she's back.

Carla has a full and exciting weekly program at high school.

Period 1—Grade 11 Math. (She has an individualized program which she implements with the assistance of a teaching assistant and peer tutors.)

Period 2 — Gym — she's just one of the gang. We visited Carla in the gym class. Here's Carla, just out of the hospital, shaky on her feet, half the size of everyone in the room and bouncing away to the loud aerobic music with the rest of the boys and girls. A friend stays with her the whole time helping when necessary. Jack shot "medically fragile" Carla thriving on "warm-ups" - her favourite part of gym class. She is recovering her health and bouncing away.

Period 3 — Lunch and lunch preparation (just one of the kids).

Period 4 —Cooking. Carla's program is a modification of the regular cooking curriculum. The teacher built a small platform so Carla could reach the stove.

Period 5 — Instrumental music. Carla participates along with the rest of the class. All the students are getting exposure to a range of instruments. Carla too.

Every Wednesday Carla has a "real" job placement at the Pine Villa Nursing Home. This placement was chosen after doing a MAP of Carla's strengths and desires. She loves older people and all agreed it would be both a safe and

stimulating environment in which Carla could learn and work. Now many of the residents "live for" Wednesday mornings with Carla. Her mom describes Carla as the Pine Villa social director. The residents and staff won't let Carla take another job placement as they all adore her and she them. She is seen as a contributing, valuable motivator.

Carla does a variety of jobs at Pine Villa - chats with residents, takes juice around, works in hair-dressing, hands out notices, takes materials around for the craft program and helps set up for special events.

A final thought as we left the school: As we were leaving, we quietly moved to a corner to watch a scene unfold that really says it all.

Picture this. Fifteen large teenagers with assorted hair styles standing and sitting around a picnic-type table near the entrance to the school. Suddenly we catch a glimpse of a small person in the midst of this teenage throng. It's Carla. She is conversing with two long-haired blond boys. She is laughing as they sign to her. One young man is signing her favorite song. Everyone is noisy and laughing.

Carla is really just one of the kids.
Why can't this happen everywhere?
Why do so many people still make
something so human, so simple, so
wonderful to see — so complex?

Suddenly it seems clear — it's not about Carla at all. It is about you and me, about our aging parents, about the stranger that moves into town. It is about racism and sexism. It is about dealing with our mortality and vulnerability as human beings. It is about life and most of all it's about love.

ROSEMARY DEELEY is a high school special education teacher at Cardinal Newman High School East in Hamilton, Ontario.



The inclusion papers

DREAMING, SPEAKING AND CREATING

WHAT I KNOW ABOUT COMMUNITY

by

Judith A. Snow

First, A Story

For many years I have known and learned from a young man named Peter. He is now in his early twenties and when I first met him he was 12 or 13 years old. I like to tell people about Peter because in reflecting on the events of his life I have been introduced to many realities about how people can achieve positive community together.

Peter is a person who doesn't speak. He uses no verbal language and he employs only 3 signs. The sign he uses most reliably is the one for "more", usually to indicate that he would like to continue to eat. Peter does walk and with a great deal of assistance and guidance he looks after his own personal needs. He enjoys participating in a variety of simple daily tasks such as setting table for a meal, serving food, and the like. He often enjoys swimming or listening to music, but otherwise is not particularly athletic or recreationally minded. He is usually comfortable just hanging around with a "gang" of familiar friends. Many people would label Peter severely mentally retarded.

When I first met Peter he had just finished elementary school. For two years he had been part of a regular class of students at a private school which was consciously trying to provide the best educational opportunities to a diverse group of children whose families

could afford to send them to that school. His participation with the other students and in the curriculum was supported by a young woman whose role was to do what was necessary to maintain the students' and teacher's connection to Peter. The family had borne the cost of Cammie's presence in the school.

When Peter's days at elementary school were finished his parents had few options for further schooling for him. There were no junior high schools where Peter would be welcome to participate with "regular" teenagers. Among segregated schools and classes Peter was offered only a place where he would share his days with a small number of students, all of whom had significant difficulties in learning and speech, often coupled with physical limitations. Peter's parents struggled with the school system to gain, at a minimum, Peter's participation with children who spoke. But they were refused even this source of stimulation and challenge for him.

Let me say at this point that Peter's family recognized that he had very important gifts; in particular the gift of trust. Peter is unable to predict a great deal about the world around him. When he enters places he has never been before, for example when he climbs a flight of stairs that he has never been up before, he cannot know that there will be a room at the top of those stairs, complete with a floor, ceiling, perhaps chairs to sit on, perhaps food to eat. This uncertainty disappears after a first experience with a new place, but it also can be very difficult for Peter to know where he is going at any given time. He simply doesn't have the language to have a conversation with people about where he is going with them and what they will be doing there. In spite of this Peter likes to go places with people and will often go happily where he has never been before.



expressing complete confidence in his guides.

At the special school, when Peter was about 14, his family and friends began to notice a real change in him. Inside the classroom he spent more and more time sitting quietly by himself flipping the end of his sock back and forth. In this state, called "disappearing" by his mother, he became increasingly less interested in doing even the few things that went on in the classroom that he enjoyed, things like getting out lunch bags and arranging the room for the noon meal. When Peter was doing something he did enjoy like swinging in the schoolyard it became difficult to coax him to move on to a new activity. He began to resist other's guidance frequently. What was happening to Peter's great gift of trust? If he learned to resist other's guidance how could he live anything but a very restricted life? His parents and friends were deeply worried.

After trying unsuccessfully to get Peter's school principal to move him to a more stimulating class, his parents decided to hire someone to go to school with him. With their own money they recruited a young man, David: an artist who had extensive experience with the sort of life situations that often confront people labelled handicapped. David's fundamental job description was to find interesting things for Peter to do at school, helping him to keep connected with his world.

Within three weeks David was saying that either Peter and he had to get out of that school or he would have to resign. The basic problem was that there was nothing of genuine interest or importance happening at that school and so there was nothing to connect Peter to. David was going crazy there, much less Peter!

Peter's parents were faced with a real crisis. They feared that if they withdrew Peter from the "special" school system and if things did not work, their relationship with the segregated school board could be difficult to establish again. However they knew that David wasn't exaggerating and that Peter was losing ground. They decided with great trepidation to permit David to withdraw Peter from school.

And so David and Peter began to wander the city of Toronto. There was some direction to their travels but not much. They created a list of friends' homes to visit on a frequent basis. They tended to follow the subway line because David doesn't drive. They often dropped in on coffee or doughnut shops or grocery stores because there their presence wouldn't be remarkable and because Peter likes food. Here and there they found jobs that they could do for neighbours like sorting stuff or stowing boxes. Often they seemed to be just wandering.

In a short period of time David contacted a number of alternative high schools run by the public school board. At one in particular he found a friendly welcome. The administrator took the opportunity to get to know David and Peter better. After continued exploration it seemed that the students also were interested in Peter and had some ideas about how he could participate with them. The structure of the school allowed the students some real say in the way their curriculum was developed. It became clear that at this school there would again be a genuine opportunity for Peter to be involved with his peers in interesting ways. David and Peter were once again going to school.

Peter soon had several regular activities. His day would often include setting up the cafeteria for lunch and

tidying up after. Food preparation for himself and others, and eating, were regular events along with frequent trips at recess and breaks to the local coffee shop with other students. Students worked with Peter on different ways that he could enjoy using the class computer. David and Peter often handled the mail for their school plus another high school near by.

But perhaps the most unpredictable activity that Peter got involved with was a sound poetry class. It seems that there is a form of poetry based on inarticulate sounds, building words and phrases around the impressions that these sounds evoke in the artist. The students were fascinated by the sounds that Peter makes and, at one of the planning sessions that were held to design Peter's participation at school. the idea was born to have a sound poetry class. The class was coordinated by a friend of David's who is a poet, and the students, including Peter, worked on a variety of compositions based on his and other people's sounds. At the end of the year the class put on a performance at a small club in downtown Toronto, with Peter taking part in the show.

After approximately two years at this school it seemed time to move on. Peter was now 17, an age when many teenagers are thinking of leaving school. David and Peter hit the bricks again. But this time there was a great deal more focus in their travels about town.

David lived in the west end of Toronto, occupying a former warehouse where he had plenty of room to construct large sculptures. His neighbourhood was culturally and functionally diverse with a rich variety of people and activities in all sorts of small interesting places. Peter lived in a much more subdued part of town. David decided to bring him daily to be part of the general

hubbub of the west end. Once again in a remarkably short period of time a pattern began to emerge.

Daily the pair would travel throughout the neighbourhood and along the east-west subway line. Frequent stops included coffee and cheese shops, small stores, and local churches. They had time and inclination to stop and chat. have a snack, do a chore or run an errand. David soon discovered that there were small organizations in the area, working on a shoestring to achieve a more peaceful world, a cleaner environment, or other similar projects. Peter and David began to help run off brochures, get mailings out, deliver packages in the area, etc. In a short time they were just part of the regular scene, fulfilling their very-much-appreciated function. Peter was chosen as Volunteer of the Year one Christmas and was written up in the local newspaper.

Other neighbours took notice of the presence and activities of Peter and David. People on the regular route would talk about this pair to each other, and if David happened to be seen without Peter people would enquire about Peter's health and whereabouts. A local United Church minister opened his church hall for meetings of people interested in responding better to the lives of vulnerable people among us. Neighbours began to talk about the west end as a community. Peter's parents moved in to the area to foster and be part of this new life.

One of the frequent stops became the residence of some Anglican monks. Quite possibly the initial attraction was that these men liked to put on some of the best lunches in town. But one of the monks was the priest at the nearby Anglican church and he invited Peter and David to participate in the Sunday service with him. Soon after that he



invited Peter to serve the altar during the Eucharist. Peter continues in this role more than two years later. The priest says that this is one of the best things that has ever happened to him and the parish.

You see, one of Peter's greatest gifts is that he likes food, and the communion service is all about sharing a deeply significant meal as a community, rich and poor, young and old, stable and vulnerable together in the presence of a God who is Himself our food and nurturer. In his deep, respectful and radiant understanding that a meal is being prepared and served, Peter recalls the priest and the congregation to a renewed appreciation of their shared ritual.

In a short time the brothers began to invite families with "different" children and other vulnerable members of the parish to take a more active role in the community life. Some began to be altar servers as well and others began to be involved in other ways. All expressed that they felt welcome in a way which was virtually unique in their lives. The congregation came to life with a renewed interest. Meetings were held to decide how the congregation could respond more effectively to their vulnerable members. They looked for a way to help these people find the supports they require so that they would not be forced to move out of the neighbourhood into group homes and nursing homes.

The congregation decided to set up a trust fund to help raise funds and channel government dollars for hands-cn support to these vulnerable members. In addition a group formed a planning and action body to help each of the effected families and individuals clarify their needs, prepare proposals and find the necessary resources and personal support.

All this is the result in good part of the presence and participation of Peter, a young man who has never spoken and who is labelled by health professionals as severely mentally retarded. Yet within the space of less than 6 years and while still in his teens Peter's impact on his community rivals that of most mature, active, capable and ablebodied adult citizens. Peter has been a poet, food handler, odd-job man, messenger, neighbourhood organizer, peace activist, community builder and evangelist. He has never acted alone but few successful people do. David and others have been key to every development, but the impetus has come from Peter.

Reflecting on these facts has caused me to notice and learn much about what it means to be a fulfilled human being. Peter's contribution has also caused me to think about what it could mean to be a person who doesn't speak. Finally Peter's life, as well my own physical disability and my reflections on the lives of others who have been labelled handicapped, have caused me to ponder many issues around disability itself. I am writing this to bring you Peter's story and some of my ponderings as well.

Gifts

Once my father told me that in ancient China the very rich or powerful families would bind the feet of young girls. As these girls grew up they became unable to walk more than a few hobbled steps. If a woman were truly rich and powerful she would give up walking altogether and she would also grow her finger nails until her hands were heavy and functionless. She would be carried about all day by slaves who bore her chair and her cushions to support her hands. They would feed her and look after her every need.

Now what is interesting to me about



this story, and the reason my father told it to me, is that my body works as if I were one of those ancient Chinese ladies. I get around in a fancy motorized wheelchair and a van adapted with a wheelchair lift. I type on a computer with a breath control that reads my puffs and sips as Morse Code and translates the code into letters and computer controls. Otherwise my every physical need from eating to driving the van must be met by a team of attendants. These attendants cover a 24 hour shift and their wages are funded with government dollars.

One critical difference between my life and that of an ancient Chinese lady is that she was considered to be of value in her society just because she was there. Her mere presence as a symbol was of more value than any other potential contribution she could make and she was supported and shaped through great suffering to become that symbol.

In my world, people are valued according to their conspicuous function and activity. Few things are viewed more negatively than disability in my society. People with apparent disabilities are usually subjected to endless efforts to "cure" them or, like Peter, educate them out of their differences. All the time this is going on they are also being segregated out of everyday life and being denied ordinary, obviously desirable experiences such as work, play, income, friends and intimacy. In a great many parts of our society people with disabilities are also being selected for death. Today doctors regularly use amniocentesis to discover Down Syndrome, (which Peter has), or Muscular Dystrophy, (which I have), or Spinal Bifida, and then recommend abortion for this reason only. Others are denied ordinary health care or important services, leading to death from treatable

infections, starvation, etc.

Many years ago I started to ponder how one society could value one physical and mental state so highly that people would put their children through torture to ensure they attained it while another would value the same state so negatively that it would kill any children if possible if they happened to develop it. Even more important to me, I began to try to figure out how people could be persuaded that disability is not a threat. Although disability may be viewed as negative itself, that does not mean that the people who are disabled could not be seen as also embodying other possibilities. On the other hand, is disability so negative as to have no redeeming qualities to celebrate?

Here is an important clue I had. People who know a person with a handicap very well, someone such as a parent, sibling or a family friend, will often say about that individual that they are a wonderful person and that this was not apparent to them at first. For example, a young man I know is a person who doesn't speak. He is attending a neighbourhood high school. His support circle publishes a newsletter for family and friends to tell of his goingson. In a recent edition of his newsletter the support worker made a point of saying how unexpectedly enjoyable her time with him has been.

My point is both that people virtually always discover something that brings them pleasure when they get to know someone who is labelled handicapped and that this pleasurable discovery virtually always comes as a genuine surprise. But when we meet new people, in general, we usually do discover something about them that we like. Hardly ever do we hate everything about someone both on first meeting and after getting to know them better. So why are



people so surprised by this discovery when confronted by a person who is called handicapped?

By following this question I came to this realization. Everyone is gifted.

This realization is partly masked from us because we usually think of gifts as being extraordinary qualities. We think that only a few people have them. But giftedness is actually a common human trait, one that is a fundamental to our capacity and need to be creatures of community.

Gifts are our capacities to create opportunities for ourselves and others to interact and do things together, things that have mutual meaning. So, for example, if you are interested in an evening of softball and you have six people on your team, you have an opportunity to offer gifts to several people, including some innocent bystanders who might just end up watching. You can't play softball without at least seven people per team. So when the seventh person comes along, willing to play, that person's presence is a gift to many other people, even if she or he doesn't play very well.

Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions, of everything that is meaningful.

In addition to our presence each of us has a grab bag of other ordinary gifts that allow for us to create and participate in daily opportunities. From getting up, making breakfast, washing dishes or loading a dishwasher, talking on a telephone, writing on a piece of paper, listening to another person, getting from one place to another, enjoying some music, expressing an opinion, going to a meeting, playing with a baby or having tun with a friend, a variety of simple activities taking place in ordinary

places on ordinary streets make up the fabric of the vast majority of our work, family life, private life and public contribution.

Beyond ordinary giftedness there is extraordinary giftedness, the kind that extends opportunity for interaction and meaning to a larger number and variety of people. One person is not just nice to be with but is a truly funny comedian; another doesn't just get around but dances on skates beautifully; another not only shows up for the PTA regularly but has ideas that are engaging and changing the face of the local school board.

Each person has a variety of ordinary and extraordinary gifts. The people whom we call handicapped are people who are missing some typical ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.

Seeing disability somehow prevents us from seeing the gifts in a person, at least at first. And so we are surprised when we find ourselves experiencing pleasure, meaning, and opportunity in the presence of a disabled person.

Furthermore giftedness grows from different roots making it possible to speak of three different sorts of gifts. First, some gifts seem to arise simply because of the unique makeup of the individual. One person picks up whistling at age 5, another has always enjoyed listening to other's stories. Secondly, some gifts are tied to a general characteristic. Only women bear babies. Lastly, many gifts arise from the efforts that an individual makes to deal with her or his experience. After a long fight with cancer a person may develop a high tolerance for pain, an appreciation for beautiful sunrises and the desire, time and capacity to visit severely ill people.

I began to play with this analysis while considering Peter's life. Clearly some of the events around him arise because of the uniqueness of Peter himself. For example Peter's love of food and his great gift of trust have shone through virtually every aspect of his participation during these many years. Some of his gifts have emerged primarily because of the interaction of the world on Peter and him on the world. His participation as a sound poet falls into this category. But other gifts are grounded in Peter's disability itself.

People around Peter often report that they feel more in touch with, more grounded in time and space. One of Peter's contributions has been to give many people a sense of neighbourhood in west end Toronto. A common aspect of disability is a relative slowness or awkwardness of movement. Peter walks in a slow, deliberate manner, often slowing the pace of his more typical peers. He also relates very much in terms of the familiarity of the space he is in. When you walk with Peter you have a beautiful opportunity to relate to the unique character of the time and space you are in right now. For a few moments space is more than distance to cover and time is richer than a measure of how long it takes to get from here to there. Thus being with Peter can be a spiritually grounding experience for a modern citizen who is frequently dislocated from time, space and neighbourhood. This gift of Peter's arises directly from his Down Syndrome.

People with mental and physical disabilities have a common experience in today's world which makes them bearers of some gifts that are typical for them but not for ordinary citizens. For example services that are directed toward people with disability are usually driven by motives that are based in charity,

therapy or protection. In almost all cases these services are directed by professionals who view themselves as experts on what the client needs because of being disabled.

In contrast ordinary citizens receive services which are driven by the understanding that the citizen desires to be and must become an active participant in society, playing some roles in keeping regular daily life going. Thus ordinary services attempt to maintain the participation of people, keeping the roads open, fuel in cars and buses, food in stores, information universally available, water on tap, sewers flushing and children being introduced to the meaningful symbols of the culture. Although not everything runs smoothly all the time and one can always criticize and imagine a better way in which these things and others could be done it is clear that the basic purpose of ordinary services is to nurture the capacity of the ordinary citizen to do whatever that citizen decides she or he wants to do.

When I was in high school one of the students was an Olympic diver, a veteran with many medals. My community seemed to know just what she needed to continue to be both a gifted diver and one of our classmates. We knew that she needed access to the swimming pool at 5:30 a.m. every morning, she needed tutoring to keep up when she travelled, she needed friends, recognition and to graduate along with us. She needed a volunteer sports club locally and various national and international organizations to maintain her opportunities to dive.

Now a student with disabilities needs exactly the same sort of opportunity and structure to participate along with fellow students. But in our world it is fun and exciting to support an Olympic diver and a burden to support a child with disabilities. The way we view



giftedness makes all the difference.

My point is that disabled people live in a world which fails to foster participation for them. Also the existence of this "special" set of services often blocks people from access to regular services. The most blatant example of this is special education. As more and more special classes and schools were established in the 50's and 60's, more and more children were segregated from the regular classroom. But special education leads more than 90% of the time to sheltered workshops and institutionalized poverty. Thus children who might have coped on the margins of society have been systematically cut off from true participation in the name of therapeutic education.

In what way is this tragic situation a gift? Many people labelled disabled have discovered that they can find no automatic place for themselves in society. Instead they have found the capacity in themselves to dream for and build something new. Just as Peter created a poetry class where there was none, a neighbourhood out of a collection of lower middle-class stores, houses and churches, and a community out of a bored congregation, so do many other people pushed beyond the margins find they must create the very opportunities they require out of the scraps of the world.

As it happens this society functions less and less well for ordinary ciuzens, with increasing breakdown everywhere in our time. In this context the creative capacity of people with disability has become a gift of great importance. This gift is bound up with the ability to dream, an ability which I will describe here.

Dreaming

How did David know what to explore

to find a way to support Peter's accomplishments? Is there a way that Peter and others like him can let us know about themselves and their needs and desires other than simply going passively along when things are going well and resisting when things are not to their liking? I thought about this for a long time and then another experience gave me a clue.

In the mid 80's I was giving a workshop on Building Supportive Relationships to a small group who included many parents, some of children with handicappist labels. I remember one woman in particular who was in her mid-to-late 50's. I was exploring stories of how people solve problems and develop their life path. I was doing this as much for my own edification as for theirs.

This woman told me that when she had been a teenager she had wanted to be a missionary. As time passed for her, however, she had gotten married in her early 20's and had 3 children. To her it seemed as if she had had to put aside the dream of being a missionary and carry ou e life script of being a homemaker. But all the while she kept up an interest in theology and religion, taking a Bible study here and there, reading theological works or joining a prayer group. When her own kids were teenagers her marriage seemed rocky and she began to attend some of the newlyformed Marriage Encounter groups. She found these very fulfilling and soon persuaded her husband to join with her in these groups. Together they became very active in Marriage Encounter and at the time of my workshop they were leaders in the movement.

One day she had realized that, for her, Marriage Encounter had become the concrete fulfillment of her much remembered dream to be a missionary. I have asked many people about dreams. For me dreaming is like a delightful mystery constantly teaching me something and always eluding me just a little. But this is what I have come to understand about dreaming so far.

Dreams are threads of meaning and insight that run throughout the daily life and fabric of everyone's individual life. In fact dreams in some way seem to be part of the very structure of our life, being part of the very impulse that gives purpose, meaning and shape to living. But dreams are not confined only to the individual's experience. They are part of the glue that brings us together as social beings. Dreams form a basis of the impulses that cause and allow us to find purpose and fulfillment in relating to each other. When we dream we are dreaming about something essential to ourselves and also significant to others in our lives, others that may not actually come into our lives for days or years to come. So dreams are not a phenomenon of the moment but communicate, preserve and carry a form of living energy across people and time.

As mystical as all this sounds the actual working of dreams is basically quite simple. Imagine for example two six year old children. You ask each one of them what they dream of being when they become adults and they each tell you that they want to become firefighters. But a person who knows them both well would know, or could ask to discover, some things quite different in the dreams of these two children. One is expressing her interest in being of service to other people and being a firefighter is the most challenging and scrvice-oriented adult experience she has yet encountered. For the other, lots of colour, light, noise and excitement are important. Being a firefighter seems for now his best opportunity to star in a

splashy, dramatic life. Twelve years later we may find a young woman studying at a community college to become an ambulance paramedic and a young man apprenticing in summer stock Shakespearean theatre. They would laugh if you reminded them about being firefighters but the thread is there, alive and strong enough to guide these young people.

Dreams have a great deal of power in themselves but they do not act in a vacuum untouched by other factors. In fact there is a constant dynamic process going on between the dreaming of people and the real opportunities that a community offers to its citizens. Dreaming shapes reality and reality shapes the conscious face of dreaming. Thus there is a political dimension to dreaming.

The story of my missionary friend illustrates this. When she was a teenager there was no Marriage Encounter. She couldn't have said at six years of age, "I want to be a Marriage Encounter leader." Those around her during those young years probably were at least tempted to say to her, "You can't become a missionary. There is a war going on. Find a nice young man after this is over and concentrate on raising your kids, rebuilding your country's economy and supporting the returning men to start life over again."

But by putting even a little energy into discovering and fulfilling the meaning of the dream, the conscious expression of it changed in fantasy for her and different opportunities emerged at the same time. Even reading and Bible study gave her more understanding of her own impulse. They also led her to new people, new prayer and other groups, ultimately to discover that other people shared some of the same problems and aspirations that she experienced. Eventually dream and reality

interconnected for her and many others in a new opportunity, never before available in that form in the human community.

Experience shapes the neverstopped energy of a dream like banks guide the waters of a river. And the dream creates a new dimension of reality like a river wears a rocky cliff into a sandy beach. Thus dreaming is actually one of the powers that shapes the human community.

It is important to recognize that in this way dreaming is like speaking. Both dreaming and speaking seem to be driven by our conscious will and often seem to be going on completely within ourselves. They seem to be taking place as fantasy and as talking to ourselves. But they are also and most importantly a public phenomenon in that both exist to shape our relationships and opportunities. Like speaking, dreaming has the power to create. Dreaming and speaking create each other like white allows us to see black and black allows us to see white. Together dreaming and speaking are the stuff of communication.

Ancient philosophies acknowledged that "the word" was a creative power. Dreaming is a deep form of communication and is as much a part of "the word" as speaking is. Just as speech flows from person to person and through communication media, dreams are also communicated. Dreaming must be taken seriously as a powerful force shaping our lives.

Gifted Dreaming

It became clear to me from Peter and David that dreaming and listening are human capacities that also are subject to giftedness. In other words nearly everyone dreams and nearly everyone listens to the dreams of others but some

people can take these capacities to extraordinary powerfulness. And like all giftedness this extraordinary power to dream or to listen to dreams may be spurred from an individual innate capacity, from membership within a particular class of people and/or from interaction with personal circumstances.

Let me focus on Peter for a moment. Peter doesn't speak. He is also perceived as being profoundly handicapped. In my opinion these two forces have shaped Peter's being so that he has become an extraordinarily gifted dreamer.

On the one hand not speaking has left wide open Peter's opportunity to communicate through dreaming. In fact it could be that in not speaking Peter is not expressing a disability at all but in some way choosing to not speak in order to become a better dreamer.

On the other hand Peter has experienced the greatly reduced opportunity to participate in society that all people with disability experience at this time. This prejudice and lack of support and opportunity mean that people with disability have a very narrowed choice of ways to fulfill their dreams.

Several consequences result. One is that the individual's dreams fail to be shaped by an on going interaction with reality and may thus seem to others to remain fantastic, childlike or unreal and unrealistic. Another consequence is that the individual squarely faces a choice. She or he may give up and become a puppet in life, controlled by everyone else's vision of how this life should unfold. Not giving up means searching and fighting for even scraps of opportunity to bring dreams to life.

Another critical consequence of being pushed to the margins of society is that the individual has a particularly clear view of just how the opportunities



of society itself can be becoming more and more inadequate. Thus for example a young woman from North Toronto may have several options to fulfill her dreams but all of them leave some of her self unfulfilled. As she moves through her lifetime she may feel many years of dissatisfaction, but never be able to definitely decide what is missing or discover that her ennui is shared by nearly all her typical neighbours. The woman on the margins is much better situated to see that not only is the margin no place to get genuine fulfillment but that in fact North Toronto leaves much to be desired as well. With less to give up she is free to dream of a completely new society with newly created opportunities. Her dreams may remain naive in detail but they can become powerful in their vision of the possibility of something fresh and creative.

The person who doesn't speak and who is labelled handicapped has an exquisite possibility of 'becoming a powerful, highly gifted dreamer. If such a person is offered the power to interact with daily reality he or she may become the cornerstone to some intense and beneficial changes. The realization of this wonderful gift depends on at least two factors. One is that the individual does not give up and give in to the handicapped role assigned to him or her. The other is that the person must be empowered to begin and carry out the necessary interactions with reality.

Through his parents, Cammie, David and later through many others, Peter had just this sort of opportunity. It is a blessing that Peter did not give up as a child.

Gifted Listening and Waiting

The last subject I would like to explore is a process that I call listening or, sometimes, listening and waiting.

Dreamers are empowered to bring their dreams to life by a combination of factors. The principal characteristic of this empowering force is that it is willingly offered to the dreamer by other members of the community. David provides a good model of the empowerment that dreamers require.

David could have joined the numbers of people who were, and are, convinced that they knew what Peter was all about. Many are the individuals who are certified in the ways and means of deciding what Peter and his "kind" need and how they should spend their days and lives. David definitely could have furthered his career by using his time with Peter to get on the professional ladder toward such certaication.

Instead David put himself in the position of trying to "listen" for Peter's uniqueness, his dream. He experimented with a method of trying to observe and sense the activities and environments, the encounters and relationships that would provide Peter with opportunities to rub his dreams against reality. He kept the process going for years, not moving too far ahead of Peter, but also not stopping at some point of either frustration or success.

This listening involves a complex process of putting the other person first. It involves repeated trials and many experiments. Listening is often done best by a person who is more familiar with the "territory" than the dreamer, as this person knows at least some of the "doors" that can be opened, though perhaps in a new way. The listener must be prepared to act in a trustworthy way while freely giving trust to the dreamer even when that person is floundering.

The listener must encourage and challenge the dreamer or else he or she may never really interact with daily life

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as it is. This forcefulness must be kept in balance with "waiting", or moving forward only when the dreamer is truly ready to move. Otherwise the dreamer loses control of the process, becoming subject to the will of the other who would again define the uniqueness out of the dreamer's vision.

The listener may set aside some of her or his own dreaming for awhile in order to truly empower the dreamer. In a listening relationship like David's and Peter's, however, it becomes clear that it can go on for many years because it is part of the listener's dream and gift to be a good listener. The listening relationship thus has the potential to be a mutually fulfilling one.

In small ways we have all listened and waited for one another at some time. But like all gifts, the humility and willingness that characterize true listening have been honed to a fine edge by only a few.

Listening and Dreaming a New Community

In the past and at this point in history we offer the greatest gift and power of listening to another's dreams mainly to a few powerful members of our world. We freely give the power and resources to bring dreams true mainly to a few individuals favoured by relationship, wealth and other lucky breaks. Other more typical citizens depend on the community as it was presented to them and other strokes of fate to be able to live out their dreams and enrich the world with their presence.

Still others, like the majority of people labelled handicapped, have been denied the empowerment of being included in the listening circle. People, influenced by prejudice and structures that declare that the people who are disabled are not truly human and have

no meaning in their lives, have cut off this listening relationship. This has also closed the opportunity that our communities would be strengthened and enriched by the vision and efforts of people with disabilities.

Tragically these exiles are sometimes the very gifted dreamers that the world could rely on the most to engender creative, renewing change.

These thoughts are offered in the very personal hope that they may prepare you for an opportunity to enter into relationship with someone who has been exiled. Act on the faith that this person has dreams and hopes much like your own and that this person has meaning in her or his life that can be conveyed to you and that has the power to enrich your life and the lives of others.

Suppose for a time that this person may be the bearer of a deep and creative dream. Bend your will and your inner and outer ear to listen to this dream. Walk into the daily activities and environments of life with this person as dream and reality react in a creative dance of meaning.

Try this and may you rejoice in all that you create together.

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Gallant and Gaunt Their Beauty

Look deep, deep into the eyes of my people:

Caged eyes,

Peering out through the bars of their sanitized, steel-white cribs.

Do not try to evade their entrancing gaze for it will not release you.

Look deep, deep into the eyes of my People.

Look deep, deep into the faces of my people:

Ageless but worn faces, scarred beyond the years,

Tenuously connected to bodies, twisted and bent by gravity's pull and years of lying supine.

Do not abandon those others coldly ignore:

Look deep, deep into the eyes of my people.

Look deep, Deep into the hearts of my people: Witness their horror, Witness their pain.

Horror and pain your spoken words alone will never soothe.

Do not try to explain it away, they will never believe you.

Look deep, deep into the eyes of my people.

Look deep, deep into the souls of my people:

Feel their soft, entrancing spirit.

A spirit, which time alone will never dim.

Look deep. Deep into the eyes of my people

Gallant and gaunt, their beauty.

Beauty, your spoken words can never capture.

Bob Williams

Kick 'Em Out or Keep 'Em In Exclusion or Inclusion

Jack Pearpoint & Marsha Forest

We are always asked about students whose behaviours constitute a formidable challenge to educators. In regard to students who exhibit such behaviours, there are two competing themes in the educational literature: "kick 'em out or keep 'em in".

On the "kick 'em out" side, in Connecticut for example, a 6.9 million dollar institution is planned for children who are so 'severely behaviourally disordered' that they need rooms with video surveillance. When asked who actually would be served by this building, no clear answer was given.

However, on the "keep 'em in" side, with the recognition and utilization of innovative support options, inclusion is not only possible but highly desirable. In addition, by using millions of dollars to support educational reform rather than build institutions, we believe we can come up with worthwhile alternatives to the "kick 'em out" model.

The process toward inclusive education is indeed a process - a journey to create an education system where excellence and equity walk hand in hand and where the highest values of our nations are respected, honoured and achieved. The purpose of this article is to help make inclusive education a viable option for students who have or could potentially exhibit severe aggressive behaviours. We will do this by presenting possible solutions that have been successfully used in keeping or returning such students to the educational and community mainstream.

THE PROBLEM

In a perfect world, all children would grow up in a nurturing environment, in strong families (which could be variable in design), and thus feel secure, loved, and confident about their future. They would have hope, dignity, self esteem. They would have friends. They would interact with and for people because it was right - not out of greed or selfishness. They would have learned how to learn, to accept challenges, and to push themselves to their own limits — whatever they might be.

However, the future is not so rosy for an enormous number of children — many children are experiencing little other than frustration and failure within our educational and social system, others have already fallen through the cracks. Many have already learned to be "incorrigible".

Increases in teenage suicide are a barometer of how many youth view the future — they don't see one. They are imploding with despair at the very time when they should be vibrant about their lives.

In a society rampant with cynicism and defeatism, it is hard to face reality optimistically. But that is exactly what we must do. We must immerse ourselves in life — with real people. It is hard, but it is healthier than the latest food/clothing or technology fad. It is real. And it is economically sound. There are massive numbers of students having school problems, who are screaming at us with their behaviours. They are telling us that school is irrelevant, boring, dull, not meeting their needs, and driving them crazy. These students drop out, or get kicked out, form gangs, and get in trouble and we continue to blame the victims rather than looking deep at ourselves and our school system for creative answers and alternatives.

STUDENTS AS SOLUTIONS

The following two case studies illustrate how students can serve as both valuable and effective resources in helping classmates who exhibit challenging aggressive behaviour.

Jane's Story

Jane, a generally well behaved 12-year-old started doing strange things at school. The principal, teacher and resource person agreed to call in the "behaviour" specialists to design a "compliance training" program.

For a short while Jane stopped being a nuisance and life went on until she suddenly attacked a schoolmate on the school yard, knocked the girl to the ground touching her breasts and genital area. She had to be physically pulled away.

The "attack" frightened the other child involved but did not seriously injure her.

The principal immediately phoned both sets of parents and, to his surprise, the mother of the "attacked" student did not get hysterical as soon as she realized her daughter was not hurt.

Jane's entire family was called in for a serious talk with the principal. Jane was suspended.

Enlist Student Help:

The following is the process used to involve Jane's classmates in helping her to be more accepted and welcomed by her school peers and concurrently eliminate her undesirable aggressive behaviours.

Rule #1 Go to the students. Be honest with them.

"Hi, I'm Marsha and I just heard about what happened in the yard between Jane and Melissa. I think it's important that we talk about this frankly and confidentially." I asked them what confidentiality meant. They understood. A pin could have dropped in the room.

Rule #2 Talk to students as if you were talking to your own friends. Don't lecture. Make the discussion a conversation.

Teachers know how to teach, but many have forgotten how to talk to children or young adults as people. Children hate it when you water-down important issues or skirt around the truth. Be direct.

Rule #3 Ask questions. Ask opinions. such as WHAT DO YOU THINK?

Simply ask, "What do you think is happening to Jane? What's your view of the incident? Tell us your opinion."

A torrent of pent up thoughts gushed forth and the adults later said that they were amazed at the seriousness, thoughtfulness, sincerity and depth of the children's answers.

The students basically felt Jane was totally isolated at school, had no friends and was miserable and unhappy. Jane's parents, they added, treated her like a baby and wouldn't let her go out much. They said, "She's a real pest at school, bothers everyone and is getting more and more out of hand." The following is an actual list of what the students in Grade 8 said when asked to give words to describe Jane:

- * lonely
- * depressed
- * empty
- * like an outcast
- * bored
- * horrible
- * upset
- * like in jail
- * like committing suicide
- * dead



Rule #4 Ask students to help. Value their opinions. Make them part of a team with the teachers to solve real problems.

We've always been suspect of simulations. There are enough real-life issues and problems to deal with. We don't need to role-play and make up games. This was real. The children were involved and captured by the reality of helping a flesh-and-blood person solve a genuinely serious problem.

Rule #5 Stop talking about the "problem" person and turn the conversation around to each students' own life.

When the conversation about Jane got quite heated, Marsha asked everyone to forget Jane for a moment, and think of their own lives. She did this by having each student construct their own illustration of their circles of friends. Marsha gave each student a sheet of paper and asked them to draw four concentric circles from a small one in the centre of the page with each of the others progressively larger around the smaller ones. She told them that the four circles should be large enough to cover the entire page. She then said:

A. In circle #1, the smallest and closest to the centre, put the names of people who are the closest to you in your own life - the people you love most.

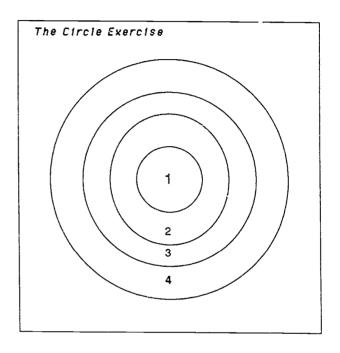
(When everyone was finished Marsha asked for responses. 'Why did you put those people in circle one? What do you do with the people in circle one? How do you feel about the people in circle one? How do those people feel about you?')

- B. Circle #2 is exactly the same except the people aren't quite as close as circle #1. Follow the same procedure.
- C. Circle #3 are groups of people in your life or individuals sports groups,

teams, Boy/Girl Scouts, church groups, etc.

D. Circle #4 are people paid to be in your life i.e. teachers, doctors, hairdressers, and the like

(Throughout the procedures students were requested to share and discuss their insights).



- E. The students were then asked to switch gears for a moment and think about how they would feel if they had just a few or no people in their circles. (A circle illustration of a person whose life included a few friends was shown to the students.)
- F. How would you feel if your life looked like this?
- G. How do you think you'd ACT if your life looked like this drawing? Here is a list of actual student responses:
 - * I'd act silly
 - * I'd die
 - * I'd act mean
 - * I'd do bad things
 - * I'd act stupid
 - * I'd commit suicide
 - * I'd be scared to death



- * I'd think I had to go to an institution
- * I'd annoy people
- * I'd hurt people

When we have done this with children and adults, without exception they connect the "behaviours" to a person's attempt to send messages. In this case, everyone realized that Jane was behaving a certain way because she was sending a message to us. It's our job to figure out the message, respond positively, and thus change the destructive behaviour.

The circle process can't be done by lecturing. People have to experientially relate Jane's suffering to their own lives and see that how people behave has something to do with their environment. We can't simply "fix" people without looking at their whole life.

The Grade 8 students immediately saw that Jane was acting in almost the same ways they described in their lists. What particularly scared them was the part about suicide. The final question involves ACTION...

- H. What can WE do to get Jane back on track? Again, a flood of response:
- * tell her right away that we're her friends
 - * tell her we like her
 - * invite her to our parties
 - * go shopping with her
 - * phone her
 - * visit her at home
 - * make sure she's not alone

An interesting event happened during this discussion. The principal of the school got so excited about the process that he went to his office and cancelled recess that morning so the discussion could continue and he could participate.

To make a long story short, the students did what they said they'd do, and Jane's behaviour has changed remarkably.

Rule #6 There has to be a strong adult in the environment to facilitate and assist the circle to grow and stay together.

Jane must also be present at all (or most) meetings. The group should name itself, but not use the name of the person.

The special education teacher took on the task of nurturing what Marsha had started. A group of 17 students from the class decided to name themselves the S.W.A.T. Team (Students Who Are Together).

Follow Up

Marsha returned to the class two months later to follow up the situation and find out in their words what was happening. The following is a summary of the discussion:

"Our S.W.A.T. team has a weekly meeting with Mrs. G (the resource teacher). Jane comes to every meeting. At the first meeting we told Jane we wanted to help and be her friends. We told her that no matter what she did. we'd be there for her. We apologized for not being around enough before. Sarah invited her to a party and Sue went to visit her at home. Danny, Rose and Linda call her a lot. Jane's happy now cause she's got the S.W.A.T. team and because she has friends. We're all making new friends. Jane's whole attitude has changed and she hasn't hit or attacked anyone since we talked to her."

Educator Response

The <u>teachers</u> reported that they are amazed at the change in Jane and that she is:

- * more included in everything the other kids do
 - * knows everyone in the class now
 - * is generally happier



- * is much friendlier and
- * hasn't been in the principals office in two months

Students' Response

I asked the S.W.A.T. team to write a few notes about their experience with Jane. Here's what they had to say:

A Poem About Jane

Jane came three years ago
No one did she really know
We tried to teach her wrong from right
Tried to make her days sunny and bright
Still she walked around so sad
And we knew that we had
To make her feel like one of us
And over her we'd all fuss
Now Jane has many good friends
And I hop "our" friendship never ends.
(T. W.)

"Jane has changed since her first meeting with the S.W.A.T. team. These past couple of weeks she's really opened up. She now feels she belongs, and she knows we are her friends. She hasn't been acting up or annoying us like she used to. Instead she's been very friendly. She used to ignore us, now she's cheery and always talks to us.

"She was just recently invited to her first party with boys. She really enjoyed it. I think Jane has really changed. She used to be so quiet and always kept to herself. Now she is more outgoing and talkative. Like any teenager Jane needs friends and a social life."(M. M.)

"Before S.W.A.T. I found Jane moody, babyish, she swore, she spat and once in awhile she would pee in her pants. When S.W.A.T. started helping, Jane was overjoyed.

"Jane would always say she didn't care about anyone or about school. About 4 days after saying how she didn't care

about school she got suspended because she touched a kid in the private spot.

"Because of S.W.A.T. she is really changing now. I called her at home and she talked to me for ten minutes on the phone. Jane is trying to act like us! She's becoming LIKE us!" (K. B.)

"When Jane first came to this school I could tell she was nervous so I became her friend. As time went on, Jane started following me everywhere I went and she wouldn't even let me talk to my friends in private.

"Finally a group in my class formed the S.W.A.T. team. Jane began to change. She stopped swearing and doesn't follow me everywhere I go. She's more open to everyone. I think the S.W.A.T. team really has improved Jane's behaviour and attitude toward other people." (N. S.)

Jeff's Story

Jeff is another student at Jane's school. He too was described as a major behaviour problem. His teacher was concerned he would be in big trouble in high school.

After hearing what had happened with Jane, Jeff's teacher wanted to give it a try for Jeff. But everyone was concerned that the Grade 7's were not as good a group as the Grade 8's and wondered if they would respond in a similar fashion. (Jeff's story, while described more concisely here, operated on the same rules described in Jane's story.)

If anything, the Grade 7's surpassed their classmates in Grade 8 and surprised everyone by their sensitivity to Jeff. The following is the student oriented intervention sequence that occurred for Jeff.

A. "What are some words to describe Jeff?" They said:

* he fights all the time



- * pushes
- * acts rough
- * picks on the little kids
- * hides
- * swears a lot
- * doesn't talk
- * bothers the girls
- * is lonely
- * makes rude noises when he eats
- * takes things and doesn't give them back

B. "Can you think of anything good about Jeff?" They said:

- * he says hello to some people,
- * finishes his work,
- * offers to help some people,
- * listens.
- * participates well in gym
- * tries hard.

C. "How would you feel if you had no one or few people in your life?" They said:

- * suicidal
- * depressed
- * lonely
- * sad
- * I wouldn't care about anything or anyone
- * down in the dumps
- * weird
- * nobody loves me

D. "What would you do and how would you act if your life had no or few friends?" They said:

- * quiet
- * aggressive
- * rude
- * meun
- * disruptive
- * lost
- * unable to concentrate
- * fail
- * immature
- * centred out

- * try to get attention
- * lying
- * making up stories
- * steal
- * bored
- * crying for help
- * lonely
- * want attention
- * want to be alone
- * need someone to talk to

With the help of the teachers, the class drew a picture of what Jeff's life actually looks like:

Circle #1: Jeff is very close to his older brother.

Circle #2: Jeff likes Mrs. G and another teacher.

Circle #3: He's not involved, in any after-school activities.

Circle #4: Teachers, doctors
The students were shocked and
surprised at the drawings of Jeff's life. It
had few, if any, friends.

E. "How do you think Jeff feels about his life?" They answered:

- * depressed
- * lonely
- * sad
- * angry
- * upset
- * down in the dumps
- * weird

They all agreed Jeff needed friends who could understand his isolation and anger. Almost the whole class volunteered to get involved.

Conclusions: Student Solutions

Jane and Jeff aren't real names, but they are real children. These stories can be replicated for any child at risk of being left out or kicked out at any age. There are no children anywhere, be it in Toronto, Los Angeles, or a small rural town in Iowa, who do not respond to



honesty, openness and truth.

Children, and especially teenagers, know the pressures of life these days. They relate to suicide, death, war, disease. They don't want to run a vay from these problems. They want and need to face them head on. They need teachers to help them face life, not run from it.

It is often the adults who are frightened to confront the pain of growing up and growing older. We are creating new labels to mask our ignorance and our fear. Diseases are born: L.D. (learning disabilities), B.D. (behaviour disorders), A.D.D. (attention deficit disorders), M.B.D. (minimal brain damage). Living, however, is not a disease to be cured by the medical profession.

What we suggest costs little and is based on common sense and human kindness.

Let's talk to our children and to each other. Let's listen to the joy, sorrow and pain of our neighbours. Let's not pretend we live in a Pollyanna world. Let's find solutions together!

Jane and Jeff could have ended up in jail, group homes or on the street. Instead they are going to parties, going to the mall, and heading for a decent future.

The above is practical. It is not magic. It is not an answer. It is a process, a journey.

What do we need to make more Jane and Jeff stories:

timetime to listen
time to dream
time to hear
time to cry and laugh
time to work
time to act and
time to listen again and again

COMMUNITY MEMBERS AS SOLUTIONS

The following is one case study of how a community member who experienced exclusion for his undesirable behaviour used his experiences to assist youth considered to have severe behaviour problems to learn to function and succeed in the educational and community mainstream. There are a number of such cases that can be cited but only one is included here to illustrate that community members, including those many people considered to be a problem, can provide solutions if given the opportunity and support.

Charlie's Story

Some years ago, Frontier College in Toronto, began a small program — originally to respond to our expectations about the "literacy" needs of prisoners in Canadian jails. We learned a great deal by listening. First, we had to learn how to listen, not just to the words, but to the meaning. And when we listened we discovered that "reading & writing" wasn't uppermost in prisoners' minds. They wanted to get out of jail. They wanted jobs. We adapted and decided to help people get jobs when they were released.

We knew most inmates didn't have enormous "job skills", that tests wouldn't tell us much about what people could or would do, and that we would simply lose credibility by resorting to them. We devised a very simple test. Over coffee, we asked people, "What do you like? What do you want to do?"

We made all kinds of excellent guesses about what people wanted and needed. Usually we were wrong. But we listened, and because we actually tried to find jobs that people said they wanted, our small program worked remarkably well.

Then along came Charlie.

Charlie Tann had been in prison for 27 years. He was "released" to see us largely because he was dying of cirrhosis. He had been given three months to live, and it was going to be more convenient to have him die "on the outside". We were a bit traumatized by Charlie, but didn't know what else to do, so we asked, "What would you like to do?"

Charlie replied, "I'd like to work with kids."

When we regained consciousness, Charlie made his case. He had been in front of juries before and we were just another jury. He argued that he had completely wasted his life, had been addicted to every drug, messed up in every conceivable way, and that was exactly what he had to offer. He argued that none of us could really communicate with kids who were already on the skids, but he could. He could tell them he was just like them and if they weren't smarter, they would end up just like him - dying - after having spent most of his life in jail, for nothing. Charlie argued he could do something we couldn't, and he deserved the chance. He said he wanted to do something decent in his life, and he didn't have long to do it.

Charlie was convincing. He sold us. Then the nightmare began. We talked to school board people. That was a bust. No responsible official would be caught dead allowing a life-long criminal like Charlie near children. We retreated to the prison system. There was a "lockup" where young offenders were stored after everyone had given up. We talked to them and reluctantly they agreed. They had young offenders who had frustrated their best efforts again and again. Fundamentally it was a waiting game — waiting for death by suicide. overdose or murder. Those were the choices. No one had anything to lose.

Charlie got access to some kids.

Charlie's "technique" was extraordinary. He went into the lockup, picked the toughest kid, and appointed himself his/her friend for life. It was remarkable. He would walk in, sit down and say, "Angie, I'm your friend". That was it. That was Charlie's technique. He would tell them, "I am self-appointed. I have decided I am your friend. There is nothing you can do about it. There is nothing you can do to offend me, because I have done worse. And I will find you — and I will be your friend. You're stuck with me."

This message of unconditional love coming from a hardened life-long criminal was staggering to kids. They didn't know how to deal with it. Each, in their own way, tested Charlie. They ran, did drugs, stole his money and clothes. Charlie always found them and offered more. Mostly he gave the only real thing he had to give — himself — a commodity that was in very short supply.

Not all of Charlie's kids survived, but Angie and Kelly made it.

I found out about Angie by accident. I was at a meeting when a young woman came up to me and asked, "Remember me?"

I drew a blank. She said, "I'm Angie....Charlie's Angie. I'm a mom now and going to school part time."

But at that moment my world closed in. You see, Charlie had died — four years after all the doctors said he couldn't live another day. Charlie drove himself beyond bodily limits - because he had to live to save more kids. And he did. Angie was the first of Charlie's kids. She was one of the toughest women offenders in Canadian prison history and today she is Angie...

And there isn't just one Angie. There are hundreds. Charlie even married one of his "stray kids". I got a call from her



recently. She just graduated from University at the top of her class. Her professor called as well. He had never had a student like Kelly. He didn't know why. I did. Kelly was one of Charlie's successes.

Charlie, the problem, a rejected community member, became Charlie, part of the solution. A number of "incorrigible" teens, through his help and others like him, were able to turn students from undesirable behaviours toward more acceptable positive behaviours through acceptance, friendship, inclusion, and success in the mainstream of educational and community life.

Charlie couldn't have used a wasted life to salvage doomed youth if some "straight" people hadn't been willing to trust and work with him. This isn't a traditional partnership. It isn't based on a negotiated contract. But if anything, the bonds are more powerful and the implications more dramatic.

Conclusion: Community Members

It is easy to think that Charlie was wonderful, but what does Charlie have to do with oil spills, war in the Gulf, the school crisis, etc.

Our point is that there are Charlie's everywhere. Hopefully most won't have to waste 27 years in jail before someone connects with them. But in your family, your classrooms, across your fence or street, at work, school and in your church or synagogue, there are people with whom you can partner.

As long as we push people out — reject them — devastation and despair will continue. People will grow more angry, more frustrated. Violence will erupt — anarchy will reign.

We don't have to let this happen. We can begin now — at home, with our families, our friends, our classrooms,

our communities.

The accumulated anger and frustration of decades of systematic failure and rejection will not disappear overnight. There are no "microwave" solutions to long term problems.

Charlie Tann couldn't possibly have helped kids. Think about it. He was an uneducated life-long criminal.

But Charlie did save lives. He and others like him are among our best teachers.

SUMMARY

Students who display severe behaviour difficulties, like all children, can and should be included in our schools and communities. The key to making this possible is relationships. It should be no great mystery that if we can't lean over the back fence and talk to our neighbours as people, similar trends ooze into boardrooms, international negotiations and prison ranges. There is a common factor — people relating.

A fundamental element of relationships is that everyone has a role to play. Not everyone can or should be the same. A person with degrees in theoretical physics may not be a master of human relations or be able to repair the lawn mower. An "untrained" farm hand may organize a complex baseball tournament and be "Mr. Fix-it". The point is, we all have strengths and gifts. Too often, the people we identify as "the problem" are a key to the solution. We need to invite them into problem-solving partnerships.

Together, in these new and genuine partnerships, the impossible can become the possible. If we invite the people who are our charges and/or are "labeled as problems" to join with us, the talent, commitment, creativity and resources are there.

It is a matter of will.

DIAMOND in the ROUGH

Pockets of Excellence

by

Jack Pearpoint & Marsha Forest

Kanienkeha:ka/Gayok'ohno Immersion Schools on the Six Nations Reserve

They are everywhere - in the most unlikely places - pockets of excellence.

We were hesitant to write about the First Language Association on the Six Nations Reserve near Brantford, Ontario - because sometimes, notoriety can spoil the beautiful simplicity and clarity of a program like we were privileged to see recently.

We spent a day with several parents - visiting the community and classrooms. There are 156 students participating in full time language immersion in the Mohawk and Cayuga languages. The classes began five years ago when several families on the Six Nations reserve grew frustrated with the high incidence of failure for Aboriginal students - on their reserve and across Canada. They wanted to do something.

They met and talked, and cried and talked and talked. They wanted a future for their children. In the conversations, they realized that the elders of the community were the only people still speaking their own aboriginal languages. They realized that only 250 of the 16,000 people on the reserve spoke Mohawk or Cavuga. That was when they realized that their children's future depended on giving them an understanding of who they were and where they came from. They decided to create a school that would be rooted in the history and tradition of the culture of the Six Nations Confederacy. The key was to preserve the soul of their culture - their languages. So they started.

Five years later, we visited one of two locations on the reserve where a collection of "portables" corners a rural junction. There was no hint of excellence as we drove up. Portables look fairly boring in all school settings.

But then we walked in. It was small. cramped - a grade four class with a marvellous teacher who was squeezed on a tiny chair in one of five foursomes. Each grouping was totally immersed in stripping small piles of local roots (a traditional wild horse radish) which they had just picked. We were told they would be canning them the following day. There was no discipline problem. The teacher, a venerable Mother Earth, led a choral practice of a traditional Mohawk lullaby in Mohawk as they stripped the roots. A woman from the reserve had moved to British Columbia. They were making a tape to send to her new baby - a new member of the Six Nations.

We had a one word synopsis of what we saw and loved. The children exuded PRIDE! They were Mohawk Indians from the Six Nations Reserve. They were all getting jackets with their names, and the name of the school - IN MOHAWK. That is a red badge of courage that these children will wear lifelong because of the remarkable educational foundation being built in this little school.

There were several teaching aides - some of whom were also learning Mohawk. They never had the opportunity before. Many of them will spend their lives learning to overcome the cultural genocide that was imposed on so many for so long in the Residential Schools. They were beaten when they spoke "Indian", and gradually came to believe they were inferior. It takes hard work to unlearn lies that have been beaten into little children. That is why this school is so different - so important. These children have a different foundation. They are proud of their heritage and secure in their foundations.

One of the symptoms of health was that elders are regular visitors. We were told they



glowed when the children could understand the language of their forefathers. Now the stories can be told the way they were meant to be told - not translated and watered down. The children chatter in English and Mohawk. They are quite delighted that we can't understand and they can teach us. Mother Earth tells us that the children she has nurtured for five years are beginning to have the confidence to speak outside the school. She hears them on the playground. Next, she wants to build the confidence so they will speak Mohawk in the Mall. That will be the real test...We are sure they will pass.

Later, we visited the Grade One group. Pride beamed from tiny faces. An equally radiant elder teacher drilled the class through a Mohawk lesson that Paul O'Friere would have been proud of. The teacher later explained hesitatingly that she didn't have much formal education. We affirmed her wonderfully common sense approach. She simply listened to the children talking and taught them Mohawk for their issues of the day. Naturally, the children learned.

That night the parents met in the fire hall. We were invited to the meeting. They have been meeting Monday nights for five years. They care about their children. They are committed to building a future for them. We didn't know the agenda - or how long the meeting would last. No one explained. The meeting just began. Fifteen parents - all ages. The first issue was a presentation on a proposed structure for a new school board. It was complex and full of legal frameworks because it had to fit into the regulatory system of the Department of Indian Affairs. People were patient, but incisive and articulate. The proposal was that the First Language Association would operate as a committee (with full curriculum control) within the overall Board for the Reserve. A mother was quick to point out that there would only be one "pot of gold", thus the Board would actually control their immersion school. Gentle discussion followed - with a kind of

underlying clarity. Their immersion program was not widely supported and they had fought hard to maintain its independence within the system. They would not give up the key to their children's future lightly. They invited the "English" school people to come and talk to them, and they said they would talk more.

There was a kind of inner clarity to the evening which we could only observe. We weren't sure what we were to do - if anything. Then we were on the agenda. Mike asked us to talk about what we had seen.

It was a magical moment - sitting in the Ohswekan fire hall around a rickety table on blue plastic chairs. There were no videos, no overheads - just parents who were fighting to create a future for their children. Marsha spoke from her heart. She told parents she had seen a little school that was a gem - that filled students, teachers and parents with pride about being Mohawk Indians. She told them they were right to fight for their culture and they should not stop because the children in those classes would not be filled with despair. They would not commit suicide. The little fire hall was awash in tears. This tiny group of parents, struggling in isolation to create a future for their children, desperately needed to hear that they were on the right track. They understood fighting. They could stand up to government bureaucracies. But for a moment, they let their pain bleed through. They were so terrified they might not be right. They feared for the survival of their children. And they were bruised by the internal attacks. Their little school experiment was so threatening to "the system" that many neighbours and friends challenged their choice. They were not accepted within their own community. It was painful - when the essence of their little school was to build a stronger community for the future. But, it is terrifying for individuals to admit how much of their culture they have forgotten after centuries of colonial domination. The little school that is building a future based on their



own heritage dredges up that recognition that pain. It is very threatening.

So parents needed to be told that they were doing the right thing. When Marsha finished, I told them what they already knew that North American school systems were failing all minority groups miserably. I told them that their language was the key - and that they were building a future for their children. They should let nothing and no one stand in their path.

There were more tears and a long silence. Parents began to speak. They talked of the pain of being challenged by their own people. They shed tears as they talked of their own insecurity. A mother told a story. The whole school had a rally in the arena. There were teams. The parents from the Immersion school were recruited to help out. The question was what would the children from the Immersion school shout -- Go Reds Go - or "? ". The real issue was that the parents who were asked to lead were being asked to stand up in front of others - their families and friends and speak Mohawk and Cayuga. They were ashamed and frightened. It took enormous courage to cheerlead for six-year olds in Mohawk. The children didn't have any trouble. They just liked shouting -Mohawk or English - it didn't' matter. But the parents and teachers had to overcome their inhibitions to speak out - to speak up in Mohawk in their own community. The insecurity runs very deep.

And from a classroom, a parent teacher's aid grasped for the tools to help her children. She said she was taking a "unqualified" teacher training program, but it wasn't giving answers to the real problems of her children. Through tears she told us she was trying behaviour management, but that was when the kids began to act up. Then she would fall back to being mother, and everything seemed to work better. She told us that one of her students was acting out. As a mother, she asked the other students to help her. Together, as they talked, the child wept, "No

more hydro..." Like children all over the world, she acted up when her family was in crisis. She didn't know how to tell her friends and teacher that their power had been cut off. She was too embarrassed and too proud to announce that, so she messed up her school work. She wanted to stay at school. It was safe and there was hydro.

We told a weeping mother/teacher's aide that she should never lose her maternal instinct - regardless of what teacher education classes might direct. That little girl still doesn't have hydro, but at least she knows she is loved, and won't be rejected because of poverty. And the hydro will come back in time - but self confidence, once destroyed is very hard to rebuild. In the First Language Association schools on the Six Nations Reserve, self-confidence and pride is still secure. And thus, we believe, the future has a solid foundation.

It was a privilege to be invited to a small community and find an educational diamond in the rough. It would be a privilege to assist that community to polish their diamond - but not too much. The children in the Immersion School can already see the star within the diamond. It doesn't need to go on public display to convince them of its value. Better to be closer to the rock, and the earth and the water - where Aboriginal values are rooted. That is their future.

We had just returned from seeing some wonderful schools in Sweden and Denmark. And within days, within hours of our home, we were immersed in a culture as distant as Sweden - with the seeds of excellence just as bright.

Inclusion and Integration took on new and deeper meaning in Ohsweken.



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What If???

What if autism is a mistake?

Someone else's mistake?

Ours; not theirs.

What if autism really is...

Flawed communication?

More ours than theirs.

What If the Truth

Suddenly all came gushing out

Like vinegar spray or electric shock from a Sibis?

What if they started handing out Nobels

For humanity's inhumanity?

Who do you think would win more?

Us or them?

What if autism is a mistake?

Someone else's mistake.

Bob Williams

Bob Williams is a poet, writer & activist in Washington, D.C. We include this and other poems by Bob with gratitude.



Vive la Difference

A Medical School Course With a Difference

> J. Pearpoint M. Forest Y. Talbot

ABSTRACT

Physicians meet clier to with special challenges and life styles in their daily practice. Vive la Difference, a selective program offered at the University of Toronto to First year medical students, aims at increasing student awareness of their own attitudes toward their inner city clients. The paper outlines the content and process of this teaching experience.

Vive la Difference

The streets are exploding. People are getting hurt. There is poverty, racism, violence. Single parents, kids, gangs, drugs, booze - families - all are part of the explosion of life on the street - life in urban war zones.

Modern medicine - like most other institutions - is ill equipped to deal with this new reality. But it is here. There is no choice. Next week it will be more intense. Crack babies and multiple addictions will haunt all our corridors.

"Vive la Difference" is an optional course for a select group of 1st year medical students at the University of Toronto to explore the implications of these issues. It was developed by Dr. Yves Talbot, (Head of Family Medicine at Mount Sinai Hospital in Toronto), Jack Pearpoint (then President of Frontier College) and Dr. Marsha Forest, Founding Director of the Centre for Integrated Education.

It began late one night in 1985. The three met to discuss how medical stu-

dents could become more familiar with the reality that they would be facing in cities - a reality that was untouched by the vast majority of their course work. Five years later, Vive la Difference recruitment is by word of mouth - from previous students. The limit of 12 has always been exceeded by students' demands. A healthy sign.

Objectives:

The original course objectives:

To increase awareness of one's own values and attitudes toward people with disabilities and to confront issues such as illiteracy and different lifestyles.

The description explained:

Family physicians working in the community deal with patients with various ailments and lifestyles. Because of this, the physicians' values are constantly challenged. Being aware of one's own biases and understanding the patients' needs are essential to the delivery of care.

We specified that, Students participating in this course should be prepared to come away with attitudes that will never be the same.

Our original focus was on issues affecting people labelled mentally retarded. However, in discussing how to sensitize and expose students to these issues, we confronted our own biases. Similar issues were faced by many socalled "deviant" populations. We decided to expose the students to the broadest possible spectrum of life that they would encounter in an inner city practice.

The time available was 10 two-hour blocks in the spring. We decided that following the first meeting at the University, all other "encounters" should be closer to the "home turf" of some of the people we wanted students to meet.

Our focus was to "introduce" the

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students to people - to sub-cultures who will require medical care, and who are at risk of being gravely misunderstood and thus mistreated.

The list of "labels/issues" we tried to expose people to included:

- * Mentally Handicapped
- * Physically Handicapped
- * Street People
- * Aging People
- * Chronically mentally ill
- * Gay, Lesbian and Aids
- * Addiction Problems drugs and alcohol
- * Prisons
- * Prostitution
- * Illiteracy

Many of the people overlapped several categories - but the pattern is clear.

Process:

The Structure was experiential. We wanted to affect attitude - and our assumption was that to cut through to raw attitude, the approach had to be experential. But experiences in isolation have minimal impact. Thus, we designed each unit to include time for:

- 1. a presentation
- 2. processing

The presentation was "real life", by real people on their own turf, about issues those people considered important in their experiences with the medical system. We encouraged question and answer time - pushing people to ask the questions they were afraid/embarrassed to ask.

We followed this with our "processing" time. We withdrew as a group to discuss the presentation without the guests present. This processing tended to have two components. Firstly, the students talked to each other about their reactions - their values - their beliefs. Again and again, the students reflected that this was the only opportu-

nity they had to actually get to "know" their fellow students. They worked long hours together, but seldom did they ever actually get to "know" how another student thought. Informally, the faculty would join in and guide the discussion to a second stage. Invariably, students would make remarks like. "It would never happen like that...", at which point, it was absolutely essential for the physician (Yves) to report that these things happen - in the emergency ward, etc - and thus introduce "reality". Similarly, Marsha and Jack added lateral examples, so that it did not become simply a "show", but rather a sampling of broader, more complex, societal is-

A Sample Course:

An afternoon with Judith Snow - in her apartment. Judith became part of our core faculty. Judith is an amazing woman, and one of the leading authorities on the continent on deinstitutionalization and building support systems for people. But on first encounter, the students only saw a "quad four" - not a person - but a diagnosis of profound disability. In fact, Judith has no controlled movement except in her face and 1/4 inch in her right thumb - which is how she drives her wheelchair. She types 35 words a minute on her computer using a "sip and puff" attachment. She travels the world lecturing. But like almost all of us. on first encounter, the students could only see a wheelchair - and disability.

A student's written journal recorded the following:

"The first thing I noticed about Judith was her wheelchair. My feelings were mixed. I felt sorry for her. I felt curious about her and I couldn't understand how she could possibly live outside an institution.



"After the session, and after leaving Judith's apartment, I felt mad both at the community at large, and at myself for knowing so little and having such preconceived notions. I started questioning everything as I never had before. What was my role as a doctor anyway?"

The whole situation was traumatic for these young medical students. Judith is one of the most physically disabled persons in Canada - and she lives independently - in her own apartment - with her own attendant care system. She works - full time - and travels internationally. All our predispositions suggest that Judith should be dead - and if living - on a nursing ward. And then she lectures. She tells her own story of medical experimentation that lost the use of her arms; of being malnourished almost to death in a geriatric hospital, the only place for her after finishing her Masters Degree in Counselling. We always arrange the room so that people naturally have to help Judith with snacks, and help her drink her tea. No one ever thinks about "the handicapped" quite the same after spending an afternoon with Judith. Part of the power of time with Judith is her amazing capacity to include people. She is not alone.

This gives the flavour of the course. Week after week, punctuated with regular "rest stops" for reflection and always - treats from a bakery, we led each new group forward.

Selection of Co-faculty:

The range of communities we introduced people to varied - slightly. The list of topics was easy to generate. The presenters were a more delicate selection. Some have become "regulars". Others we dropped after a try-out. The selection criteria to be co-faculty were:

* a personal interaction with the

medical system in the past.

- * being in control of the frustration/ anger from that experience
- * an acceptance that the "students" had done nothing to them..
- * a willingness to contribute to medical training
- * a willingness to tell their own story publicly
- * a capacity to articulate their experience to a group without being intimidated.

We learned a great deal in selecting co-faculty. Initially, we were worried that we would have trouble finding individuals and/or groups to teach about their various communities. We were wrong. We are lobbied constantly by various people to add them/their issue into the course. A more delicate problem was the issue of hostility to the medical profession which is substantial in many communities on the street. It was healthy for the students to see "hostility" - but not too much. The individuals had to be controlled enough to "explain" their feelings - not just explode at "doctors".

The Streets and Illiteracy:

As the weeks passed, different street communities told their story. Each year, we toured Beat the Street - and went on a guided "street walk" led by young people - who live on the street - or in nightly hostels. Our guides were young kids - troubled, articulate, yearning for a future. They were also pimps and prostitutes and addicts. To survive, many were involved in crime. Aids was part of their reality. Violence was everywhere. But at Beat the Street, these kids were students and tutors - teaching each other to read and write. Almost all had been scathed by school, but their formal skills were limited. As the constantly changing cast on the street told their



stories, our students heard about abuse, neglect, rape, abandonment. They heard kids tell how their "community" on the street was their "family" - they had friends. None glorified the street, but few were ready to "go home". That was even more dangerous. Most wanted a way out - but they didn't know where to begin.

"I definitely live in a sheltered world. Today we met the people at Beat the Street. It was the first time I had ever seen a hooker or met a street person. I found out "they" were people - not stereotypes. I'll be a more sensitive doctor as I'm starting to question my own narrow world and open it up."

- a student

These two sessions - at the beginning of the course usually took a whole day to "process". The experience was so staggering to most that it challenged their values - their beliefs - assumptions they had made about systems, people, and medicine. Invariably, "horror stories" of neglect and mistreatment arose. These were hard for students to hear. It was a painful listening, and they needed to talk out their feelings and the information.

Institutions:

And so the course continued. Another "constant" was a presentation from "People First" - an association of people labelled mentally handicapped. Peter Park and Pat Worth, Presidents of associations in Ontario always left people in stunned silence. Peter spent 17 years locked up on a back ward. He is now married and working full time. Pat spent almost as many years in institutions after being abandoned by his family. He jumped through a window to escape - and now heads the provincial association. Their stories shatter stu-

dent confidence in "institutional support". People cannot believe that they were "labelled" mentally retarded. One student commented that Pat's lecture was perhaps the most brilliant he had ever heard - and he specifically compared Pat to his university lecturers.

This is where the role of the faculty becomes critical. Independent of what has actually been said, some students begin to get very defensive. They rally to protect "medicine" and social values. They don't want to believe what they are hearing, but they have no alternative. Debates ensue. They want to rationalize that every guest is a "special case". They want us to tell them that what they have heard about is not real - that it is an aberration - a quirky exception. The role of the physician here is vital. Someone in authority has to say to the students, "They are telling the truth. ... This happens all the time. ... I have made decisions that were mistakes - like what happened to these people." And in the same breath, it is essential not to idolize the presenters. Street people can and will also be miserable, abusive, violent, etc. The picture is far from all "sweetness and light". But, on Saturday night when a beaten up, single mum arrives in emergency smelling of booze and filth, it is absolutely essential to remember that she is a person and deserves to be treated like a decent human being. It will be hard, but if you remember that every person has another side. The patient is BOTH a loving mother, and a woman who has hit hard times and the bottle to deal with her agony. It will be easier to listen for relevant symptoms which may well be more complicated than a hangover, if students remember...

One of the messages that came from almost every community was their shared terror of the medical system.



They begged, without exception, to be treated like people - and to be preserved from arbitrary abuse and mechanical treatment. They wanted to be well, to see doctors, but preferably on their own turf.

Different Sexual Preferences:

Our afternoon with gay and lesbian families was shattering without exception. Most of the students "knew about gays" from television or a walk on Yonge street on Saturday night. They had no knowledge of "families" - but most important - they thought they did. Our meeting was at a very middle class apartment. Four co-faculty talked. Two men and two women - both of whom are raising families. Preliminary discomfort dissipated quickly as the students discovered that Neil and Dale were extraordinarily competent and caring professionals - who loved each other very much. They were a stable couple - in a society with very little family stability. They had teenage sons who were "straight" but comfortable with their "parents". The details varied from year to year, but the session was about shattering myths. No one denied that there were flamboyant gays - much like there are super macho men. But we all learned that one must not operate on grossly inadequate stereotypes. And the pain of rejection by many doctors - when people are genuinely ill - was a story that the students did not want to hear, but they listened.

People in Prisons:

All of us have strong opinions about the people we label criminals. But, most of us will only see these people through the glare of television. We seldom encounter the real people. Doctors are more likely to meet all types. The urban street scene includes extensive crime -

gangs, violence. One of our sessions on alternate years was to spend a block of time with individuals who had spent their lives - largely in jail. These sessions were fascinating in that they forced the students to think about - and articulate another packet of largely unexamined beliefs. Spending a block of time with a man who has been convicted of murder - and is unrepentant - is sobering. But it was particularly disturbing because most of the people we met were charming. They were "sales people" and could sell you a bill of goods - any bill of goods. And as gentle and pleasant as they were with our students, clearly there was another side - of danger, violence and the excitement of all that. Fortunately, by choosing carefully, our co-faculty didn't spend all their time telling entertaining stories. A lifer left the students with a homework assignment. "If you want to know what its like in prison, go home, take the door off your bathroom, move the television in if you want, but stay there - just for a long weekend. And remember, no door, no leaving." We never checked to see if any of the students actually locked themselves in, but the example conveyed meaning. Gradually, the students came to understand the meaning of "institutionalization" and the profound impact it has on people.

Dinner with Felicia & Maria

The closing session of the course was always very special. Our food theme moved into high gear as we had a dinner with a family - like the Galatis - in their home. Rose and Dom Galati are teachers. Their two beautiful teenage daughters, Felicia & Maria are both medically fragile and labelled profoundly mentally and physically handicapped. They live at home with their parents and go to regular schools. That is what is



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special. The historical pattern would have been (and was for Maria) "life" in a series of care giving institutions. But Rose and Dom loved their children and wanted them to experience all of life they could. They fought and worked and have integrated their children back into their community - their church, their neighborhood. The children have friends. This seems so simple, but it has been a massive battle. It involved changing the basic belief systems of school boards, and others - to see that Felicia and Maria are human beings. They too have contributions to make, and the right to be full citizens.

As people sat over dinner, feeding Felicia and Maria, and feeling the warmth of a healthy Italian family, the discussion about the power of physicians to sign children into institutions for life took on a crystal clarity. The impact deepened as each person gradually realized that all of us age and become "imperfect" and thus could become victims of a medical sentence to "institutionalization". Rose talked about the pain of the well-intended remarks of physicians as they informed her that her second newborn would also be a "vegetable". Good intentions don't make up for the months of grief that ensue from that kind of remark. The discussion always returns to people - recalling individuals they have met - people new to their consciousness.

The students recall Norman Kunc, born with cerebral palsy. Doctor's told Norman's mother to let him die - or to put him away. Today, Norman still has cerebral palsy. Medicine cannot fix that. But he was a gold medal winner at York University. He is a practising family counsellor, and of all things, an internationally renowned speaker. People with cerebral palsy aren't supposed to be "speakers". Organizations pay to have

Norman speak. He is also an expert sailor (solo racing) and a master chess player. It would have been so much better if the physicians had been brutally frank with Norman's mother and said, "We think your child has cerebral palsy. We simply do not know what that means in terms of his potential, but take your child home and love him." Our concept of "normality" needs to be broadened - and more inclusive.

Rose and Dom give the same message over dinner. It is hard to eat at someone's table and not remember that they are people first - not just "cases".

Delicate Issues:

There are many hard discussions in Vive la Difference. Two of the issues that are constant are "deinstitutionalization" and "power". A sub-theme for almost all the co-faculty - regardless of their community is the destructive power of institutional containment - and the counterveiling need to be recognized as a person - a whole person. It remains a delicate balance to understand and remember that when you are medically sick, a hospital (institution) is a very helpful and important asset. But, the profound impact of the institutional reality can be so intimidating and upsetting to many people - and almost all of the people we encounter, that to have a positive net impact. those institutional encounters must be minimized.

The second issue that is a struggle for student doctors was a surprise to us. The issue is power. On average, the students did not want to accept the reality that they would be very powerful people. They wanted to be thought of as "nice and caring". They wanted to avoid the fact that doctors are powerful in our society. A doctor's signature can commit a person to treatment - to surgery - to procedures that can save a life. But

the fact is that a doctor has power of life and death over many patients - at the very time when we are most vulnerable. Coming to terms with that power and influence, and still remaining sensitive and caring was an issue that students struggled with.

Evaluation:

The evaluations on this course are fascinating. The most negative comment is actually a positive. Students complain that this is not available to all students. "It should be compulsory". On their own initiative, classes have written to the Dean and proposed it. Students write about the fact that they have been forced to think about issues they never thought about - and to come to terms with their own values. Almost to a person, they say they will never be the same. They rate it as one of their best classes ever.

The fact that the students from previous years recruit students from the new crop says a great deal. We have another informal measure. Our course has recently been on Tuesdays. On Wednesdays, there is a formal gathering of all the 1st year students. The Wednesday gossip has been, "What did Vive la Difference do yesterday?" The word is getting out. Some students even organized extra additional sessions with some of our speakers - for their fellow students - evenings. That is a very clear evaluation message.

We attribute our success to the excellence of our co-faculty - who have been hurt badly, but have turned the hurt into helping. They want to produce a generation of professionals who won't make the same mistakes that caused such agony in their lives. But, their energy was to build a partnership of trust - and to support the caring competence of these students - who desper-

ately want to be caring and competent.

Students are required to write a page after each session on the impact of the session on their own life. The authors are currently reviewing 5 years of this data through content analysis.

We hit a chord. We assume that these students want to be good doctors. We appeal to their best instincts. We give them an opportunity to examine their own values, and to meet co-faculty who can genuinely help them to be better professionals. To practice good medicine in the inner city of the 90's, you need to understand the enormous variety of communities that will cross thresholds. Vive la Difference gives students and introduction to those realities—and skills and knowledge that allows them to go further if and when they are ready.

The last words go to the students:

"This course has been a fantastic learning experience. It has taught me that although I thought I was openminded, I wasn't. This is the first course I've taken that encouraged me to participate and discuss my values. Everyone should have to take this course."

- a student

"Vive la Difference" certainly worked! You took a naive young group of medical students and actually made them think about themselves and issues they will be facing every day in the future."

- a student

"I have not had to think about my values, dreams, etc. I was too busy studying for medical school and getting A's." - a student

"I won't simply accept things now like the need to put people in institutions, segregated schools, etc. I want to learn more, think more and I know I'll be a better doctor because of this course."

- a student.





•"FROM BEHIND THE PIANO" • . a review. Linda Shaw London, England

Jack Pearpoint has written an honest and enthusiastic book which encourages us to build friendships that cross over the barriers which separate the family of man.

The main character in Jack's story is a person with a disability, yet this is not a story about disability.

Jack's book about his friendship with Judith Snow is important because it provides vital information for fellow travellers on the road to inclusion.

Jack freely shares what he and his friends have discovered so far on their journey. He spots landmarks, iliuminates potholes and identifies lessons which need to be known on the way. And his teaching helps us to proceed with our own steps towards building communities where all individuals belong and can become more truly themselves.

John O'Brien says in his afterward to Jack's trail-blazing account: "Judith's

concerns are human concerns".

And Judith says of herself (quoted by Jack): "It is more a matter of creating the world in which I can be myself with my friends. We have to create the language, the vision, the structures and the relationships. We create the meaning. All that so we can be ourselves".

What the book makes brilliantly clear is that Judith's experience of shaking off disability, "a version of myself which never was myself", ranks alongside many other heroic freedom struggles and is equally significant in its teaching potential.

What becomes highlighted (and once under the spotlight reminds us that we knew it already) is that the desire to emerge from exclusion, stigma, low expectation, and devaluation into full personhood vibrates across the diversity and scale of humanity - as does the desire to understand how to prevent these divisions in the first place.

Jack and Judith's twelve-year friendship began when home for Judith was a chronic care geriatric ward and her health was deteriorating because of the inability of medical and social services to meet her needs.

Judith tried to pursue life as a member of the staff at York University but her "placement" on a geriatric ward made that increasingly difficult. She frequently missed meals because the hospital refused to alter her "feeding" slot and she suffered from water retention from not being allowed to go to the bathroom regu-

larly.

Jack became the "administrative genius" (Judith's words) behind an evolving community support system which was jettisoned into action when Judith collapsed after escaping from hospital. She decided dying on the street was a better option than dying on a geriatric ward in an institution. Her friends and colleagues decided they wanted her to live.

Jack charts the fight for Judith's survival in intimate detail, mapping out a complex range of issues, topics, emotions, difficulties and achievements. As he says, "it's a biased account".

Judith's fear of abandonment, the dangers of dependency and creating expectations that cannot be fulfilled are key considerations. As friends, what level of commitment and support must Jack and his wife, Marsha Forest, show to Judith in order for her to trust them?

The hunt for money is a constant theme, as is the nature and status of Judith's attendants -paid or unpaid? And how do friends, parents, and Judith's husband fit in?

The morality of Judith being a "living pioneer" in a campaign for legislative change, the most constructive way to approach policy makers ("get to their hearts, not their policy manuals"), and the responsibility of keeping Judith safe during surgery are all covered in the telling of her survival strategy.

Also explored is the "dignity of risk" in the context of Judith's desire for physical

and emotional adventure, and the conviction that being supportive must mean supporting Judith's "right to decide" and her "right to make responsible mistakes".

Finally, there's the sobering fact that in Judith's life, her achievements are no protection against threats to her safety.

At the beginning of 1990 two important developments demonstrated both her strengths and her vulnerabilities. An announcement by the Ontario Ministry of Community and Social Services of a new programme of attendant care was a tribute to the 20 year campaigning efforts of Judith and her friends. The news that Judith's employers proposed abandoning their role in her funding network - a financial support system which had been painstakingly and precariously put together in the absence of adequate official arrangements - meant her life was in jeopardy.

In the end disaster was averted, but as Jack points out: "Judith was being discarded for obscure, unstated reasons of bureaucratic convenience. She was messy and hard to make neat and tidy. This is precisely the history of human services. No one meant to do harm. However, ignorance and lack of careful attention once again put Judith's life on the line. It was another terrifying symbol of how institutions and systems, no matter how caring, can hurt people".

But insensitive services and bureaucrats do not bear all the responsibility when people are pushed aside and economics and scheduling take over from dignity and morality.

Jack's story of Judith's emergence "from behind the piano" leaves us in no doubt that the task of building inclusive communities has to focus on both faces of exclusion: the process of perpetuating exclusion and the process of allowing exclusion to happen.

In Judith's story this was experienced as "being disabled" and "accepting it", acquiescing to the teacher who repositioned her behind the piano during a concert dress rehearsal. Judith allowed herself to be tucked away. She chose to keep quiet and accept what her teacher thought was good enough for her. As Jack points out, it's likely the teacher had no idea of the trauma he was inflicting.

Understanding the dynamics of exclusion and what we need to do to stop it, becomes more possible when we work in friendship, across the barriers with people at the sides, "the dreamers at the edge".

John O'Brien has comforting words about how to come to terms with the inadequacy of our human frailty in attempting to solve seemingly overwhelming problems.

In his "afterward" chapter, reflecting on the story of Judith and her companions, he reminds us that the root meaning of the word company is nourishment and mutual protection and that it was in company through shared meals and shared work - that Jack and Judith's friendship slowly grew.

According to John: "We don't have to

be friends all at once. We don't have to trip ourselves up trying to will something that only comes spontaneously. It's enough for us to choose to faithfully share daily work and daily bread".

Linda Shaw, Centre for Studies on Integration in Education (CSIE), London, England. July, 1991.

"From Behind the Piano" by Jack Pearpoint is published by the Inclusion Press, 24 Thome Crescent, Toronto, Ontario, Canada, M6H 2S5. Proceeds from sales will assist the Centre for Integrated Education and Community based at the same address.

When No One Answers

A child sees me. Naturally curious, he looks to his mother, "Why?" "Shhh!" is her answer. Time passes; we meet again, the child and I, I smile recalling his curiosity. This time he isn't curious though He picks up a stone, throwing it in my direction he yells, "Get ya mental" Where did he learn that? Surely not his mother, her only answer was "Shhh!"

Bob Williams



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THE EMPEROR IS NAKED

Marsha Forest & Jack Pearpoint

The Emperor (special education) is naked (not working). There is something better out there not only for all students, but for all of us and our families.

We need to shout this news from the rooftops - All children need to belong and feel wanted and loved... All children need to have fun and enjoy noise and laughter in their lives... All children need to take risks and fall and cry and get hurt... All children need to be in real families and real schools and real neighbourhoods. All children need friends.

Recently, we were at a meeting enthusiastically telling stories of children we know who are fully included in regular schools and classrooms. A young teacher interrupted:

"But what about getting Melanie to the bathroom?" she asked. "How can she go to the bathroom, she has no arms! It's just not practical."

We have always suspected that what drives most of special education is a preoccupation with bathrooms, toilet training and bowel movements. Now- we were sure this was true. "But what was really underlying this teacher's preoccupation with the bathroom?" <u>Our</u> answer: FEAR. Once she faced her fear, she could laugh at the utter foolishness of her initial response. She laughed and then changed!

The teacher was afraid of the unknown. She was afraid to admit her fear. She was afraid she might not know what to do with Melanie. She, as most of us, feared anything new and different. But instead of talking about FEAR she talked about the bathroom.

Let's look at some of the ridiculous things we do:

If a child needs more relationships - we give him less: we assign an educational assistant and build a one-to-one dependency.

If a child needs more time - we give her less hours at school and more hours riding around town to "segregation land" in a "special bus."

If a child needs normal behaviour models - we give him six other kids, who scream, as his "pals" and then we wonder why he doesn't improve and doesn't build relationships.

If a child needs more communication - we put her in a room with ten other kids who don't communicate well and again we wonder why she won't learn and won't behave i.e. comply.

The above is called crazy-making behaviour and it must stop - NOW!!

Children don't need segregated, community-based experiences in supermarkets. They need to go shopping with their classmates when the need arises. Children at age ten don't need jobs outside of the school, they need to do errands in the school that are typical for ten year-olds. High school kids don't need work experience that's different than their typical peers. They need to build relationships so that their friends and the mothers and fathers of their friends who own stores or work in factories will encourage their co-workers to hire their son's friend. Most people get jobs through personal networks, not simply job experience programs.

Surely if we can put men and women on the moon, we can figure out how to get a five year-old to the washroom and



The inclusion papers

how to get a 21 year old a job! It is all pure nonsense that we can't do it. It is a simply a matter of will.

GRADE 7/8 St. Francis School:

Integration is happening. Several school systems in Canada and the United States are proving that true inclusion can work. These school boards are good places for ALL children. They have policies of equality on issues involving racial minorities, women, etc. They believe that EACH BELONGS.

Once one system can do it, it forces everyone else to prove why they can't. It is no longer up to us to show why integration can work. We know it can. It is up to others to show why they can't do it.

We know the blocks aren't money or staff. We know it is strong leadership and clear values that make the difference. We need to applaud those who believe in love and inclusion and expose those who would create a new elite in our schools.

When the staff decided to welcome all children back into their regular classes at St. Francis Elementary School (Waterloo Region Separate School Board) we simply went to talk to the children and ask them what they thought about this issue.

Their questions and responses touched everyone involved. (The reader can watch and hear these children in the video *With A Little Help From My Friends.*) Some of their questions were:

"Why did we segregate people in the first place?"

"What was everyone learning in that "life-skills" room anyway - nothing ! think."

"How would you feel if you weren't with kids your own age and had to go on "special" trips to the circus, bowling and that stuff."

We had to answer these and other questions. Entering into honest dialogue with children wasn't always easy for the teachers. "I know how to teach these kids, but I've forgotten how to talk to them," one teacher admitted.

We asked the children how they would feel if they had no friends, if no one ever called them, and if they never could go to parties, sports events, etc. with their friends. We explained that most people with disabilities had few people in their lives other than those paid to be in their lives. How would that make you feel?

"I'd feel old."

"I'd want to die."

"I'd feel like I was in jail."

"I'd think only the teachers were my friends."

"I'd commit suicide."

And so all the children previously in segregated classes were "welcomed home."

Everyone was nervous, no one knew what individual programs would look like, but with teamwork and support everyone survived and indeed thrived. Today the Waterloo Region Catholic School Board is a model. People flock to Kitchener from all over the world to see inclusion in process.

If you visit you won't see the perfect school or system. It is far from perfect but it is on the road. It is, after all, just a school system and has the problems that beset most schools but there's a real difference.

IN THE WATERLOO REGION, IT'S NOT FOR THEM - IT'S FOR US!

Too often integration or mainstreaming has been seen as a placement issue. It is something we do *for* or *to* "them." But integration isn't another charity ball for the disabled. Integration in the true sense of the word meaning making whole is for US ALL. It truly takes the philosopher Martin Buber's concept of "I-Thou" and puts it into action.



1:4

All too often we see "I-It" relationships in schools between pupils or between pupil and teacher and too often between teacher and teacher.

Bringing back children who have been historically left out also brings back our humanity. You can't teach the value of love, diversity or tolerance by preaching or lecturing AT people - we all have to live these values and have real situations to test our morality and humanity.

"But, tell me how to do it," teachers ask in frustration. Those who truly understand the why seem to do the what quite easily. What to do comes out of a team problemsolving process of adults and children who together come up with creative solutions to unique challenges.

It is impossible to train people in the abstract to do this kind of work. There is no way to do in-service for this new way of thinking except to have the children present and discuss values and attitudes, cry and laugh together and work cooperatively as problems arise. It is no longer the lone ranger teacher having to come up with the answer. It is the whole school and community, parents, consultants, and most of all, the children who can help.

A TRUE STORY

About a year after May had been fully included in Grade 7/8, she and some of her friends went to a neighbouring school yard to play. Some Grade 8 boys from the other school started teasing a child in a wheelchair. The girls, smaller by far than these boys, hesitated for a moment before they took on these bullies.

Amy, the leader of the girls told the boys to stop. They didn't. She persisted. Amy was, by this time, furious. When they got back to school they stormed into the principal's office and wanted him to take immediate action against these bullies at School A.

We visited the class soon after the incident and asked everyone to tell us what had happened. Alively debate ensued about whether Amy and her friends should have gotten involved.

Some of the children felt Amy had been "foolish," "stupid," "naive," etc. to take on boys much bigger and stronger than herself. "She could have been hurt," some felt.

Amy was indignant. "You have to stand up for what's right," she argued. Her friends (including May) chimed in arguing for what was right and decent according to them.

We widened the conversation by asking what they thought the role of students in South Africa today is and indeed, what happened in Nazi Germany when non-Jewish children befriended Jewish children.

The room was in an uproar of incredible philosophical debate. The teacher was struck that the level of discussion was far more sophisticated than among several of her graduate seminars at university. The discussion was thoughtful, deep and passionate.

The issue in the Waterloo Region has gone far beyond "integration" and ranges into the real meaning of community, social justice and the integrity of each individual. We were impressed, moved and thrilled to see this group of children handling the "big" ideas that we so infrequently allow children to discuss.

MICROWAVE THINKING AND FEELING

Society today wants the quick fix, the quick high. Teachers seek out the "answer." Well, we mustn't give in. Good teachers know that real learning takes time and that education is a journey and a process.

Inclusion won't cook fast in the microwave. Inclusive education means commit-



ment and energy of a different kind. It needs teachers who can talk to children, touch them, teach them and laugh and cry with them.

The learning going on in the Waterloo Region under the gutsy and able leadership of George Flynn, the Director of Education, is like a jewel. It shines and it lasts. Amy and Becky and May and Susie and the crew don't know anything about special education. We hope they never will.

WHAT WE NEED TO MAKE THIS

HAPPEN: We need more leadership with the guts and courage displayed by Amy, May, Becky, and others. We need more educational leaders who take the time to read and think and who know the research on what makes an effective school. We need more leaders who still love and care about ALL kids. We need people who will dare to expose special education as an empty shell and who have the courage to move ahead into the year 2000.

Special Education is an idea whose time is up. It is now time to build inclusive communities where together we can teach our children to love as well as to read and write. We need most of all to believe fully and finally that ALL truly means ALL.

We now need to put that ALL into practice and bring our children home to where they can all learn from one another. We need to do it now so we won't have to publish papers like this in 20 years!

We need to act now because as, Amy said, "It's not fair to treat some people like they don't belong."

CONCLUSION

Working with hurt and rejected people is not always easy. It takes time, energy and the power of love. There are no simple answers except that we must do it because

if we don't, the human cost to us and our children will be enormous.

The greatest diseases in North America today are loneliness and meaninglessness. Bringing back the least powerful into our schools is an incredible antidote to the consequence of these diseases — suicide. alcoholism and drugs. Helping one another is a beautiful thing, but it's not something you simply talk about - it is something you do.

INTERVIEW With MAY RUSSELL at RESURRECTION HIGH SCHOOL. Waterloo, Ontario. April 8, 1992

As many readers will remember, May Russell is featured in the video "With A Little Help From My Friends." May had just been fully integrated into the grade 7/8 class at St. Francis School. Many have asked how May and her friends are. Here's the answer.

Marsha: Many people ask me about you and how you're doing. How has life changed for you since we filmed the video four years ago?

May: Much. Like a lot!

Marsha: How? Tell me what's changed?

May: My attitude.

Marsha: What changed your attitude most?

May: I found out that women do got strength and the right to do whatever they want to do. Men cannot take that away.

Marsha: Who influenced you about the role of women.

May: The Minister on the Status of Women. I just got back from Ottawa. My mother and I met the minister. And my teachers influenced me, too.

Marsha: Do you still have some of the same friends that you had when we made the video'.



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May: Sometimes. Amy, Becky, Judy, Fatima. Some has changed. One has brown hair now. So that's that.

Marsha: How old are you now and what do you want to do when you finish high school.

May: I'm 17. I might go back to Ottawa, go to the University of Ottawa and then I'll stay there and start my own business and even do some business with the Prime Minister.

Marsha: I'm writing an article for our newspaper. What advice would you like me to give people involved in school inclusion.

May: I could say that women, all women, got the right to have a friend and to be a friend.

Marsha: May, do you remember the night we were all on TV, on the Shirley Show. Linda Till was trying to get her daughter Becky into a regular school. The interview wasn't very friendly.

May: I remember. I stood up and said I agree with Mrs. Till and I do also agree with Marsha Forest and what she says about Circle of Friends. At the end you started to cry.

Marsha: I cried because Linda and I were being attacked so unfairly and you had the courage to stand up publicly to defend and honor us.

May: And then I remember Marsha Forest say, "May, you made my day!"

Marsha: Do you know why I said that?

May: Because I protected you from those people who acted like a bunch of garbage. Marsha I want to add one more person to my circle. Anton, do you want to join us. If you do you may become a star, too.

If May lived in another community

one hour away from Waterloo, her chances in life would have been much different. She is one of the fortunate students who is reaching her potential as a human being because of an education system that believed that May had the RIGHT to a quality education not based on down syndrome, but based on the condition of being considered a full human being. May's language, interests and confidence stem from the opportunities she's been given by both a loving family and a loving school system. Congratulations to all involved.

GIFTEDNESS

by

Judith A. Snow Visiting Scholar Centre for Integrated Education and Community

There is in the world today a vibrant new culture. It is young and rough, but its birth has been true and with proper nurturance, its life and growth promise to be dramatic. It is the culture of inclusion.

The culture of inclusion begins in the affirmation that all human beings are gifted. This statement sounds strange to many ears because our traditional world reserves the adjective "gifted" for only a chosen few whose talents and abilities, usually in very circumscribed ways, impress, enlighten, entertain or serve the rest of us. The inclusion culture views giftedness much differently.

We affirm that giftedness is actually a common human trait, one that is fundamental to our capacity to be creatures of community. Gifts are whatever we are, whatever we do or whatever we have that allows us to create opportunities for ourselves and others to interact and do things together - interactions that are meaningful between at least two people. So, for example, if you are interested in an evening's fun of softball and you have six people on your team, you have an opportunity to offer to several people, including some bystanders who might just end up watching. But you can't play softball without at least seven people per team. So when the seventh person comes along, that person's pres-

ence is a gift to many other people, even if she or he doesn't play very well.

Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions - of everything that is meaningful in our lives.

Also fundamental to each person's presence is each person's difference. In fact presence is not possible without difference since even on a very simplistic level difference is essential to life. For example none of us would be here if the male and female difference did not exist. Meaning depends on difference as well since if we were all the same there would be nothing to share or contribute to one another. Therefore, not sameness, but presence and difference are fundamental to life and community.

In addition to our presence each of us has a grab bag of other ordinary gifts that allow for us to create and participate in daily opportunities. From getting up, making breakfast, washing dishes or loading a dishwasher, talking on a telephone, writing on a piece of paper, listening to another person, getting from one place to another, enjoying some music, expressing an opinion, going to a meeting, playing with a baby or having fun with a friend, a variety of simple activities taking place in ordinary places on ordinary streets make up the fabric of the vast majority of our work, family life, private life and public contribution.

Beyond ordinary giftedness there is extraordinary giftedness, the kind that extends opportunity for interaction and meaning to a larger number and variety of people. One person is not just nice to be with, but is a truly funny comedian; another doesn't just get around, but dances on skates beautifully; another not only shows up for the PTA regularly, but has ideas that are engaging and



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changing the face of the local school board.

Each person has a variety of ordinary and extraordinary gifts. The people who we call handicapped are people who are missing some typical ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.

In fact it is not just that walking is a gift and not walking is not a gift, or that knowing how to put your clothes on right is a gift and not knowing how is not a gift. Rather walking is a gift and not walking is also a gift; knowing how to dress is a gift and not knowing how to dress is also a gift. Each creates the possibility of meaningful interaction.

The affirmation of giftedness creates the need for us to organize our homes, schools, work places and other establishments differently and this is what has given birth to the inclusion culture. In the past we became efficient at separating people into classifications of supposed sameness. Now we are struggling to build our community life up from the foundation of our enriching differences.

In North America the Canada geese fly south every fall and north in the spring covering thousands of miles each way. The birds fly in a V-formation, with one bird in front followed by two diverging lines of flyers. The lead bird breaks the wind resistance for the two behind. who in turn are shields for the bird behind each of them, down to the end of the line. But in the course of each flight, the leader drops out of position to go to the end of the line and to be replaced by one of the following birds over and over again. In this way no one bird is ever leader so long as to be exhausted or to deny opportunity to another bird. In turn each bird is the guide. This a model of

organizing a community so that the gifts of all benefit everyone.

In the schools, we see classrooms of creative learning being founded on the support that children and teachers can offer to each other in the spirit of cooperation. In housing, we see people forming inclusive, intentionally mutually-supportive developments where vulnerable people anchor circles of caring. In decision-making bodies, we see people taking leadership in turns based on their energy, experience, desire and availability, being able to give way to one another at the right time.

Of course these efforts at inclusive community are isolated and foundationally weak. But the seed has been well sown. These efforts support each other and inspire others to change. The story of inclusion has a vigorous beginning and promises a very creative future.

THE NEED FOR REDEFINITION

Dr. Gary O. Bunch York University

Full inclusion of all students in regular classrooms is a concept which challenges many educators, many parents, and the community at large. The idea that some children should not be/cannot be accepted in regular classrooms has permeated our view of what the form of our educational system should be.

Over the past forty to fifty years we have convinced ourselves that some children are best assisted if we educate them in isolation from the general educational community. They are best assisted if they are tested, the degrees of their deficiencies measured and enumerated, and if they are categorized and educated by their disability label. They are best assisted if we surround them with others with similar challenges to their learning. They are best assisted if we provide them with teachers with special training for their measured, enumerated, and labeled needs. To do otherwise would be to do less than was needed and appropriate.

This view of the educational world has had a number of unfortunate results for teachers and children. Regular classroom teachers were made aware that they were incapable of dealing effectively with any but "regular" students. They were made aware that "special education" teachers were the ones with the ability, the patience, and the preparation to deal with the teaching challenges posed by "special" students.

Even when a regular classroom teacher accepted a student with special needs into the regular classroom, the child was not the responsibility of that regular classroom teacher. The responsibility belonged to a special education teacher who taught and/or otherwise supported the child. The child uid not have a fundamental right to be in the regular class. the parents had little choice in the educational placement of their child, and the regular classroom teacher was not responsible for programming, progress, and success.

Full inclusion challenges all of the above. It says that all children have the right to be together in the community of a regular classroom. It says that all children have the right to go to the school closest to their homes. It says that education should not be based on measurement of a condition of challenge, but on the needs of the individual child. It says that all teachers can teach, and that all teachers can teach all children effectively. It says that family, friends, peers, and the child have a role to play in educational decisions.

Full inclusion is perceived as radical in that it argues for major aspects of the educational system to be redefined. It calls for redefinition of what a teacher is. It calls for redefinition of who might be a student. It calls for redefinition of what an educational program might be.

Creation of a separate special education system has stripped teachers both of responsibility for students with special needs and of a significant part of their professional image. Under the dual system of regular and special education most teachers were considered able only to teach the average student. Teachers with special training dealt with those considered other than average. Regular classroom teachers had circumscribed



responsibility when the question of whom they could teach arose. They could teach some but not others. With circumscribed responsibility came an attenuated professional image. The abilities and preparation of teachers were open to question. Could teachers really be considered professionals, by others and by themselves, if all the challenging to teach students had to be removed from regular classrooms for an appropriate education by a separate group of specialist teachers? Inclusion of all students in regular classrooms would mean that the image of the regular classroom teacher, and that of special education teacher, would change in responsibility and image. All learners, no matter what strengths and challenges they have in learning, would be the responsibility of the regular teacher. It goes without saying that the teacher must be supported in classroom practice, in professional preparation, and in continued study to accept this altered role. The major part of this support would come from a close colleague with special preparation in the learning of children with special needs and acting in concert with the regular classroom teacher. It goes without saying, as well, that the teacher, regular classroom or support specialist, who accepts this responsibility will attain a new level of professionalism whether viewed by self or others.

Elaboration and proliferation of the special education structure has sundered the student body as effectively as a cleaver. The majority of students present no unusual challenge in their learning and are considered "regular" participants in the educational process. They attend school in their own neighbourhoods, commune with peers in the neighbourhood school and in the lc al community, and are expected to

progress well in both education and vocation. Some students are considered "special" and are not accepted participants in the regular educational process. They must be tested, measured, and categorized by disability. They must go to special classes or schools. They do not fit in with their neighbourhood peers in the school or in the community. Expectations for progress in school and in work are limited.

Full inclusion challenges these dynamics. The concept defines all learners as full participants in the educational process. No student is "special". though all have individual strengths and needs. All students participate in the educational life of the neighbourhood school where they meet peers and become an accepted part of the community. All have individualized expectations for progress in education and work. All are part of a society which recognizes that it is normal to be different, and that a society which attempts to hide its differences is unjust and incomplete.

Full inclusion challenges the belief and practice that a set curriculum rules the classroom. Under this traditional belief all learners are viewed as able to benefit from, and master within an acceptable range, a common curriculum. It is the teacher's responsibility to present and teach that curriculum. It is the student's responsibility to study and learn that curriculum. If a student is not at a level where the set curriculum can be studied and learned, that student must go elsewhere because an appropriate educational program cannot be designed and implemented in the regular classroom. Some flexibility in student response to the set curriculum may be acceptable, but only within narrow limits. It is the curriculum

which directs education for students. not the strengths and needs of the students, and not the interests and abilities of the teacher. If full inclusion were to be · implemented, the strengths and needs of the individual student would become more important than the curriculum. Instruction would address strengths and needs in the regular classroom picking up the curricular sequence at the juncture appropriate to the individual. Students would study in the same subject area with the majority at approximately the same juncture in the curriculum. and others, quite possibly, at different junctures. The student's needs and abilities and the teacher's professional responses to these would rule the classroom.

The development of a special, segregated form of education for some students forty and fifty years in our past reflected the understanding and laws of society at that time. It represented an attempt to bring into the educational system many children previously denied a place in that system. It represented an attempt to more effectively educate students whose learning puzzled and challenged teachers. It represented an educational adaptation of the medical model in which general practitioners deal with garden variety needs and specialists deal with those of a more serious health nature. Unfortunately. both in education and medicine, this model resulted in more warehousing of those with special needs than in amelioration of those needs. This point echoes other unfortunate results discussed earlier.

Society has moved on. Our laws are different now, as are our understandings of the needs and rights of children and families. All children share a fundamental right to an education.

Institutions which separate individuals from their families and friends in unnatural ways are far less acceptable than was previously the case. Research has proven that educating students with challenging needs at a remove from regular education with specialists is no more, or even less, productive than educating them in regular classrooms. We live in a time when any form of warehousing, whether it be in special education classrooms or in special schools and hospitals, for the sake of preserving a structure designed on outmoded concepts of educational effectiveness is vigorously questioned. It is time now to accept that past practice should not be present practice in responding to the needs of students with challenging needs. It is time to reunite the educational system. It is time to bring all students, whatever the level of educational need, and all teachers, regular classroom and specialist, back together in the neighbourhood school. We cannot permit the timid, the entrenched, the traditionalists, and those tied to structures of the past to deny educational choice to the populace. We must move to a stronger, more just, fully inclusive educational community.



Hardening of the Categories

by Jim Paladino, C.P.A.

Researchers have compiled results of exhaustive studies proving that there is an insidious killer of Community running rampant in society. It's spread remains unchecked to date, and the prognosis is always fatal if left untreated. In it's final, more lethal states it is also identified by names such as segregation, alienation and rejection. This debilitating disease can strike at all humans, regardless and because of race, creed, color, sex, nationality or political persuasion, among other issues.

The recent research seems to confirm that Hardening of the Categories particularly thrives around the lives of people with disabilities. (See other labels: infirmed, handicapped, invalids, retards, cripples). The hardening appears innocently enough at an early age, usually characterized by a lack of understanding or fear of the unfamiliar, reinforced by a world of adults doing their best to categorize, divide, label, fragment, or otherwise put into a box anything or anyone outside the accepted standards. Physical and mental strength and agility, as well as standards of "pretty" or "handsome" appearance are set for the child as ideals to be sought from even the earliest age. Everyone not meeting those standards is given a tag so as to set them apart as having failed to meet the standard qualifications for the Community.

This is definitely the best time to

engage in early intervention values therapy, preferably from the moment of awakening in the morning until sleep every night. Parents and relatives make the best therapists for this intensive patterning treatment, although acquaintances in the neighborhood Community may provide valuable volunteer support. This regimen should be continued until the patterning of the values of respect and human caring become second nature - or rather first nature - to the children. This early intervention alone may not be sufficient to prevent some hardening from occurring later in life. Continuous mainstream injections of the recognition of people's gifts and possibilities are needed. Some amount of relapse is present in nearly all cases.

Unfortunately, few cases of this malady are reported and receive treatment until the affliction is firmly entrenched deep in the body of the Community. Treatment is no longer directed at a cure for the missing values causing the affliction, but merely at easing the effect of the symptoms through the protection of rights. Many parent groups and advocacy organizations are available to administer this form of therapy. Some laws have been enacted to perform similar rights therapy, but often these may cause serious side effects, and in many cases increase the spread of categories to epidemic proportions.

Unfortunately, Hardening of the Categories is frequently discovered in conjunction with other Community threatening diseases. Some of these ailments and infirmities and their accompanying warning signs are as follows:

System Fibrosis: Unchecked, this early sign of hardening of the Categories

permeates throughout all known vital systems (school, medical, housing, etc.) entangling the structures of these programs in debilitating paperwork and rendering them uncontrollable and often useless.

Yearning Disability: Sets in when the Community loses the ability to understand that all people have hopes, dreams and desires.

Sharing Impairment: Occurs when one or more hardened categories determines that one or more other categories is not entitled to the same rights and privileges as they are.

Budget Deficit Attention Disorder:

Categorizes the most vulnerable, labelled populations together for purposes of receiving the first and deepest cuts in bad economic times. Same symptom appears at the school level as at the state and federal level. Listen carefully for the early warning sounds such as "We'd like to provide that service, but you know how tight the budget is."

Fragile Hex: The vexing hex of the "medically fragile" category. May also be known as Humpty Dumpty Syndrome. The well meaning Community wouldn't want the egg to crack so instead it protects through exclusion. Out of sight, out of mind.

Mythical Memberships: Perhaps the most frightening variation of Hardening of the Categories, most people assume this sickness can only strike in the form of political parties, nationalism, or professional educator organizations. However, many healthy-appearing parent and advocacy "groups" have underlying values and agendas which

can alienate the Community through the same type of fear and lack of understanding.

Values Dementia: As one gravitates toward a category, one may assume the beliefs of the grouping. This often interferes with memory of the earlier instilled values of respect and human caring. Slowly, all independently held values are forgotten and are replaced by those of the category. Some confusion may ensue when the victim attempts to apply their previous values to only the members of the current category. This particularly occurs after prolonged exposure to the Mythical Memberships mentioned above.

Of course, these are but a few of the Community killers loose in our society today. The only true cure is a steady diet high in the value of respect for ALL fellow community members. Recognition of the underlying value of all human beings and acceptance of them with open arms is assumed. It takes joy in the gifts of each individual, acknowledging that the gifts of individuals are what makes for a vibrant, stimulating and diverse community. Community does not divide, but by its very definition operates as a whole. A lack of ability by one or some of its members to perform a particular task is much easier to overcome when Community works together as a living, healthy, and functioning system. True Community heals itself.



NATURAL SUPPORT SYSTEMS

Families, Friends, and Circles

by

Marsha Forest, Jack Pearpoint and Judith Snow

WHAT HAVE WE LEARNED ABOUT NATURAL SUPPORT?

- 1. Natural Supports alone are not enough. They may be the first, but are never the only condition necessary to create the fullness of life. For the natural supports to be utilized, intentional interventions MUST be used in what some consider to be "unnatural" ways.
- 2. Natural Supports occur in natural environments. In order to find the Natural Supports surrounding any individual, a person must be in "natural" environments in his/her own home; in his/her own regular school environment; in her/his own community; in a real job in the real world.
- **3. Natural Supports require leadership.** Someone must take leadership to facilitate the Natural Supports.
- 4. The Ultimate Natural Support Resource People. The most underutilized resource in our communities, schools, work places, leisure places, is people. People are out there in droves, in all spaces and places. Natural Supports come in all shapes, sizes, colours and ages.
 - 5. Natural Support challenges the

medical model. A Natural Support approach challenges the traditional authoritarian/patriarchal/medical model. It assumes that ordinary people can do extraordinary things when valueladen leadership is in place. It assumes people care and will help when asked.

- 6. Natural Support needs an Invitation. Someone must ask those who are the Natural Supports to participate, to be involved, to be committed, to come to the meetings, to stay involved, to struggle and to have fun!
- 7. Natural Supports save lives.
 Natural Supports are the key to saving the lives of people in trouble. Without Natural Supports, Judith Snow would choose death; without Natural Supports, Ida Snyderman, Marsha's mother chose to stop talking; without Natural Supports, children die, adults die, we all die.
- 8. Natural Support is a lifelong survival issue. In her inimitable style, Judith commented that "Natural Supports" were beginning to sound like a technology that you could purchase and press the button. We are talking about the stuff of which people are made and effective support isn't a technology. It is based on values and people friends and circles.

IT'S ABOUT VALUES...

Judith told a story that is wonderfully clarifying about what we consider important, and how arbitrary that is...

"Once my father told me that in ancient China the very rich or powerful families would bind the feet of young girls. As these girls grew up they became increasingly unable to walk more than a few hobbled steps. But if a woman were



truly rich and powerful, she would give up walking altogether and she would also grow her finger nails until her hands were heavy and functionless. She would be carried about all day by slaves who bore her chair and cushions to support her hands. They would feed her and look after her every need.

"Now what is interesting to me about this fact, and probably why my father told me about it, is that my body works as if I were one of those ancient Chinese ladies. I get around in a fancy motorized wheelchair and a van adapted with a lift for a wheelchair. I type on a computer with a breath control that reads the puffs and sips on a straw as Morse Code and translates the code into letters and computer controls. Otherwise my every physical need including driving the van must be met by a team of attendants. These attendants cover a 24 hour shift and wages are funded with government dollars.

"One critical difference between my life and that of an ancient Chinese lady is that she was considered to be of value in her society just because she was there. Not only was her potential contribution of no concern to the world of her day, but she was actively discouraged from being a direct contributor. In my world, people are valued according to their conspicuous function and activity. Few things are viewed more negatively than disability in my society, where people with apparent disabilities are usually subjected to endless efforts to cure them, or to educate them out of their differences. ... Others are denied ordinary health care or important services, leading to death from treatable infections, starvation, etc."

"GIFTEDNESS" - A Different Value...

Judith Snow has spent most of her life thinking about what and who is

valued, and why. She has spent time reflecting on a question that justifies careful thought:

"How is it that I am NOT perceived to be a member of the public - a citizen? What can my friends do to change that perception?

"When I was born, I was a member of the general public. People were willing to support me because they expected something of me. There were systems to support me: education, transportation, family, etc.

"When I was 7 months old, I was labeled "disabled", and that label changed my life. People no longer expected my family to be there for me - or supported my family to be with me. The Educational system was no longer there for me. My family had to fight so I could go to school. The transportation system was no longer there for me - and still isn't. No one expected me to "be there" or to make a contribution.

"Luckily for me, my family was different. They expected me to make a contribution. That fact made a tremendous difference in my life.

"The fact that I was not considered to be a member of the general public totally changed my life. Today, my life is built around the constant battle for me to simply be a member of the public."

GIFTEDNESS - What is it? Who has it?

"There are people in every generation who can run really well and do amazing physical feats. People like Ben Johnson, and Olympic divers and skaters. We say they are gifted. It is interesting that there are as many people like Ben Johnson as there are like me. But there is one profound difference. People really enjoy and value the fact that Ben can run, or that my classmate Beverly could dive. I don't understand what intrinsic use it is to be

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an Olympic class diver or runner.

"For Bev to become an Olympic class diver, our society created thousands of gifts. We created opportunities for pool builders, coaches, pool cleaners, advertisers, swim suit manufacturers, etc. People got up at four o'clock every morning, traveled thousands of miles, raised tens of thousands of dollars. Thousands of people were involved in making this possible.

"A person who is labeled disabled needs exactly the same support. I need people to set up organizations, to be friends, to tutor, to raise money, to set up special places, to do governmental negotiations -exactly the same things that Beverly needed to become an Olympic class diver.

"What is the difference? What prevents society from seeing me as important and exciting as Bev.

"There was a serious mistake. Someone jumped the gun and labeled us [people with disabilities] a problem. Instead of seeing us a gift and an opportunity, we are called problems and projects. We are not supported by "the community". We are serviced by staff. People's livelihood is determined by their fixation on fixing us. But this is crazy because we are not fixable. We never stop to think about that. Our society has created a billion dollar industry to fix people who are not fixable. It is destined to failure. It doesn't work, and there are tremendous costs both to society and to the people who cannot be fixed.

"People's lives are wasted. Some of the people who are labeled helpers get trained to do something that is useless and doesn't work. Not surprisingly, there is an incredible burn out rate. When things don't work, people get angry and that breeds violence. It is no wonder that so many human service workers spend the vast majority of their time doing paper work. It is a logical response when their job (to fix people) doesn't work and only generates frustration and anger."

Often we fail to appreciate how threatening a concept like Natural Supports is to medical and service systems. We surmise they don't understand the anger and hostility in their own reactions. But it is logical. Put simply, if you had trained for several years, and then worked for another twenty doing the best you could, and then some "untrained community types" actually succeeded in doing what you had been attempting for years, it would be very threatening. First, there is simply the question of power. Who is in charge here anyway? If a Circle of Friends starts to play a role in a "client's" life, it is a challenge to the power structure. At another level, it suggests that perhaps professionals have been wrong, or that they have "wasted" their lives. Seldom do people actually say this, but many feel it. There is also the threat to job security. If "they" can do it, maybe I won't be needed any more. Within this complex web of emotion and fact, it is easy to understand that conflicts emerge. Partnership would be a better way. There are things that friends do best, roles that are professional and service, and joint areas of expertise, cooperation and collaboration. If we take time, we can develop win-win scenarios, but everyone has to invest the time to listen first.

There is another cost of exclusion. The Community is denied the talents, gifts, contributions and opportunities of all the people who are excluded. It is ironic that after years of experience developing "systems" of support with staff and structures, we are now discovering that there are key ingredients

lacking. This does not mean that paid staff are unnecessary. On the contrary, there are very clear tasks for "professionals", but in addition, there are critical functions which they cannot fulfil directly, and which they must "facilitate". They must "nurture" Natural Supports, so that communities develop the capacity to genuinely welcome all people. accepting their gifts, and making them full citize s. For a long time, we assumed that this just "happened". It doesn't. It takes effort, patience, commitment - but most of all, we must value every person's gift. Without that value. that belief in every single person's capacity, Natural Support is just another system. It will be neither natural nor support. All our gifts will be lost in the wind.

NATURAL SUPPORTS:

Are they Natural or Manufactured? Intentional or Spontaneous? Genetic or Contrived?

For the last two years, Marsha has been working with a High School in Canada. The special education teacher at this school is an energetic and enthusiastic supporter of inclusive education. Let's call him Carl.

Strangely, every time Marsha left this school, she felt worn out and defeated. Why were things moving so slowly? Why were the students still spending so much time in the resource room? Why was there still a resource room at all? Why weren't the kids really connecting with one another? Why did it seem the students with challenging needs were tolerated, yet ignored in this school?

Recently, Marsha got her answer. Carl asked her to come to a meeting at his High School. She told him, "I will come one last time. I don't think I can help any further. In fact, I feel we are at an impasse."

Carl's meeting included a roomful of interested teachers and to her surprise, the school's principal. At the meeting Carl made a very startling speech. It was "true confessions" time.

"I want to publicly admit to everyone, that for two years I've been listening to Marsha, and then sabotaging everything she's tried to do here. I really didn't agree with her approach. I thought friendships and relationships should be natural and spontaneous. I hated the idea of having to 'manipulate' kids into 'manufactured' friendships. I thought the idea of a facilitator and meetings was all wrong. I never told Marsha my real feelings. I agreed in words that these kids should have friends. Who could disagree with that? BUT, I hated the thought of making friendship so contrived.

"This summer I realized something was really wrong with what I'd been doing here. Two of our kids graduated. I went to visit them in August and I was devastated by what I saw. The two young men were both in fairly good group homes. But their life now consisted of sitting and staring at the T.V. all day and night. They had nowhere to go and nobody to go with. They were alone.

"I really loved these guys. I had to ask myself why I had closed my eyes to the reality that I knew existed for adults with disabilities in our community. I had done nothing to prevent this nightmare. We physically welcomed students with challenging needs into this school, but we didn't do the work to connect them to people in the school or the community. We never did the hard work necessary to



open the possibility of real relationships and real life after high school.

"We did the job experience stuff. We did the 'life in the community curriculum'. But we never focused on what really gets people jobs — the people connection. We did the curriculum and forgot what was really important."

The room was silent as Carl finished his revelation. This was a highly respected teacher baring his heart and soul. The principal said that he thought that "Circle of Friends" was happening for all Carl's students. He was surprised to hear this story. A serious discussion ensued.

BUILDING INTENTIONAL COMMUNITY... Magic & Manipulation OR Planned Spontaneity...

Marsha's point to Carl and the entire group was that she had been talking about Building Intentiona! Community, not contriving or manipulating friendships. She explained that the Circle of Friends was a process and had to be the outcome of years of hard work. How that happened was up to the individuals involved. Intentionality, not Manipulation, is the key. As a team, we decided to begin immediately, and not to dwell on the past.

A little humour seemed to lift everyone's spirits and lessen the tension. Marsha compared her 'romantic evening' analogy to the notion of building intentional community. "Think of a romantic evening. What do you do? When I want a romantic evening at home, I intentionally cook a gourmet meal, make a double chocolate dessert, put on soft jazz, light scented canales, and hope for the best. The intentionality of my romantic mood might not work, but at least I

give it a good try."

Everyone could relate to the example. Was Marsha being manipulative or smart? Was she contrived or creative? Was she unnatural or setting the stage for a healthy fulfilled relationship? As a dear Scottish friend, Ethel Grey, has taught us: "Planned spontaneity my dear, it makes life so much more exciting."

SHOULDS...Who Made Those Rules Anyway?

Our critics say, "But it SHOULD be natural. It SHOULD be spontaneous." Who made that rule, we wonder? When people say, "It should happen naturally," we start to worry. We don't believe anything in life just happens naturally. Nor do we believe we can make everything we want happen. Life just doesn't work that way.

We do believe we can set the stage, create conditions for good relationships, good health, for optimal learning. Then we can Hope and continually Work for the best possible outcome.

We believe life "happens" by working hard at making life happen. That is how we attempt to live our lives. That is the basis of our belief in how a circle of friends is built.

To get to the "natural" in life, one often (always?) has to work very hard. For example, consider the amazing trip we took to be able to trek in the Himalayas of Nepal. In order to view the most incredible mountain range on earth - this great natural wonder - we had to plan ahead. We had to think about the cost, the weather, the clothes we would wear, our health.

"The best things in life are free," say the songwriters. But they omit that it often costs a mint to get to where you experience these wonders. We know from the research and writing of scholars such as Abraham Maslow and Rollo May, that before a person or family can truly experience a good relationship, they must have proper shelter, a job, income security. It is simply not true that the poor are happy in their poverty. The poor would like to be more comfortable. The unemployed would like to have jobs. Single moms or dads would like to have the supports required to pursue a creative relationship with their children.

Let's not romanticize the notion of "natural supports." When we look at people who have actually managed to survive in this world and have a circle of support, we see they are few and far between. We also see that it was blood. sweat and tears that got them to that circle and not simply good luck. From Behind the Piano, Jack Pearpoint's book, is a description of building a circle around his friend Judith Snow. The story of Judith and the Joshua Committee is one of struggle, pain and tears. It is also a celebration of friendship and love that has been the outcome of many years of struggle. Joy and struggle cannot be separated!

A PERSONAL STORY ... From Marsha

Recently, I had a personal experience seeing a genuine support circle form around my mother. It didn't happen naturally. Three years ago, my 80 year old, ill and fragile mother came from Florida to live near Jack and I in Toronto. We explored living together, but we hadn't done that for 30 years. It didn't work then, and wouldn't work now. So, we found a lovely retirement apartment that also provided nursing care. That was what my mother wanted. The setting was non-medicalized, small, personal, run like a small hotel, 5 minutes from our home.

I tried, with all my experience, to build a circle of support around my mother. All my friends pitched in to form visiting teams, to take my mother out, to share a meal with her, etc. She single-handedly sent them all away. Quietly and sadly she said: "These are your friends, not mine. I want my family, my own friends."

Gradually my mother withdrew into her own cocoon of a comfortable and sad silence. She no longer wanted me to read her the cards and letters from the family, or to see photographs of new born cousins.

Jack and I were away from Toronto frequently and there were periods when my mother was alone for weeks on end. Although surrounded by lovely people, she remained a stranger in a strange land. Canada was far from all those she truly knew and loved.

I was heartbroken. Each time I visited, I left saddened by the loneliness in my mother's eyes. She was always glad to see me, but I alone could not fill the void in my mother. As an only child, there were no duplicates or surrogates. I simply did the best I could for three years.

Then the miracle occurred. My family began to see the depth of my mother's loneliness. They invited her to come "home" to live in New York City, where there were dozens of relatives.

HOME AT LAST...

I remember the day vividly. Jack drove me and my mother to the airport. Air Canada graciously moved us into first class for the trip to Manhattan. My mother was going home. Now in a wheelchair, a frail snow haired 83 year-old and I returned to the Bronx where my mother had been born, and would eventually die. She was returning to her



home - not mine. My home (anyone's home) is truly where the heart is. My heart and life is centered around Jack, Judith, our work and building our Centre. My natural supports are far from New York. My mother's natural support network is New York.

My cousins had arranged a placement for my mother at the Hebrew Home for the Aged in the Bronx. For many older Jewish citizens like my mother, this home was a form of nirvana. This was a Jewish dream come true. Although I hate institutions of any kind, I never enjoyed any of my mother's living arrangements, including her condo in Florida. And she never fully appreciated my taste in living arrangements. As adults, we could respect each other's choices without full approval.

All was progressing nicely. My mother seemed quite content to be back in N.Y. She talked more than she had in three years in Toronto. She was quite responsive and calm. And then, 10 days after her arrival, she had a nasty accident. She fell and broke her hip.

The fall set her back greatly and was a blow to the whole family. We had brought her to N.Y. where she would be safe, comfortable and surrounded by family. My mother had to be transferred to a huge NYC hospital where she was "just another broken hip". Too many changes and traumas set her back greatly. She stopped talking and had trouble eating. A low grade infection set in.

The family smashed into action. They set up a team to visit the hospital in shifts to ensure my mom's safety. They began to have brunch meetings and telephone meetings. Intentionality was entering the once natural style of the family.

I suggested that they invite one or two other cousins into the process.

Visiting the hospital and long travel distances were stressful on the six major players.

When I arrived in N.Y., my mother was back at the Hebrew Home. Jack and I attended the Ida Support Team meeting at a cousin's home. It was reminiscent of the early days of Judith's Joshua Committee. There was a lot of yelling and arguing over issues. At times no one listened as each tried to state his/her opinions.

There was an argument. Should Ida have therapy to walk, or be left alone to be comfortable and at peace? The "fix Ida" (therapy) team lost to the "make Ida as comfortable and as secure as possible" group. Consensus was reached over a delicious Chinese meal, a few dry New York City martinis and a lot more spirited debate.

One thing struck me. These people really cared about my mother. They loved her. I was affirmed in my decision to move my mother to New York, my mom's natural support group. They were banding together naturally.

In an earlier crisis in Florida, none of the natural supports formed a team. Both my mother and the whole Florida situation fell apart. In New York, key actors took leadership and facilitated action. This time, there were truly 8 members of the Ida Team, (six local plus Jack and I). We were simply two members with no veto.

WAS THIS NATURAL SUPPORT?

Was this "natural" support? Definitely Yes **and** definitely No. Yes, because this was the group that was naturally drawn to Marsha's mother all her life. No, in the sense that these meetings had to be organized, leadership had to be exerted, structure had to be imposed.

If natural supports, i.e., the people

The inclusion papers

most drawn to another person, are not organized systemically and intentionally, then we lose the momentum and potential for a circle. In Toronto, there were few natural supports to call upon. We called on our natural support system - the people who loved and were attracted to us. There was literally no one outside of us who counted to Ida. Even Jack was peripheral for "natural support". Ida's criteria were "Jewish" and "family". It was not right or wrong. It was simply a fact.

We are proud of the Ida Team and happy to be a part of it. Eight people have come together to figure out how to help Ida have a life of dignity and respect. We have learned important lessons from all this.

As so called "experts" on circles, even for Ida, we could not make a circle happen in a context where there were no people who Ida liked/loved. The fact that we liked the people was not the issue. Ida chose not to enter into a relationship with "strangers."

Once we hit my mother's "home turf", she reopened to relationships and showed an interest in letters, pictures, and visitors. That is why it is important not to take children out of their neighborhoods, not to break up families, and not to "buy" friends. It doesn't work.

At the TASH Convention in Chicago in December, 1990, in a brilliant short talk, Herb Lovett cut through all the verbiage. He said there was one KEY Question: "Who loves this person?" Circles and Natural Supports share that key ingredient - with all the wonderment, confusion and anguish that entails.

CIRCLES AS NATURAL SUPPORT SYSTEMS FOR FAMILIES...

Most of us have natural circles of friends that constantly change over the

course of our lifetimes. Our circles expand and contract at different periods of our lives. These circles are both an ongoing process and the outcome of the lives we lead, the jobs we hold, the connections we make.

Some people's circles consist mostly of biological family. Others, especially those who have moved far from their biological families, have circles bound by ties of friendship.

Most of us don't spend time consciously figuring out who is in our circles. We take our relationships for granted except in times of trouble and stress. In times of crisis, we need to know who is there, who will stand up and be counted with us.

We also make our circles explicit when we have a special event - a societal rite of passage, i.e., a wedding, barmitzvah or graduation. Then we make guest lists. These lists categorize who we want to invite, who we absolutely must invite, (even though we don't want to), and who we won't invite even though we should.

WE ASSUME FRIENDS "JUST HAPPEN"...

Most parents take it for granted that their children will have a circle of friends, go to school, and get an education in the process. Parents take small children to birthday and Halloween parties, sports events and family parties. As children grow older, parents pray that their teenagers will have safe parties and get home from proms and graduation events in one piece.

But some parents sit and wait for the phone to ring, hoping someone somewhere will invite their son or daughter to just one party. These are the parents of children with labels children who go to strange schools and classes in strange neighborhoods, far

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from where their brothers and sisters go to school. These are the children labelled disabled. In truth, they are not disabled by their bodies, but by the fact that they are lonely, rejected and unwelcome.

To reverse this sad state of affairs we must:

- 1. First and foremost, welcome all children back where they belong to the families, schools, churches and the communities where they originated. Children must live in biological or adoptive families not group homes or institutions of any kind where payment substitutes care-givers for parents. No matter how caring, a paid professional cannot substitute for a parent.
- 2. All children must go to their local community schools those attended by their brothers and sisters. Then and only then can the process of healing begin and can we begin to build the network of relationships that all of us need to grow into healthy and thriving adults.

OUR PHONE RINGS...

The phone at the Centre for Integrated Education and Community rings incessantly with calls from parents of teenagers with disabilities. "Can you make our telephone ring? My child never gets invited to parties and never gets a call from a friend."

These parents agonize over the loneliness and isolation they see in their children's faces. These same parents often threaten to cut the cord to stop the phone ringing for their typical l6 year old daughter, while they pray that just once the call would be for their 18 year old son, who is labeled and alone.

One parent phoned recently and said she would fly anywhere to see and meet a 20 year old person with Down

Syndrome who had real friends, people to go out with, and a social life. This was a tragic call from a deeply saddened mother. It was not an unusual call.

Building a circle is one way to structure a solution to this problem. Everyone in the circle can phone once a week. It isn't that difficult.

CIRCLES ARE A PROCESS & AN OUTCOME...

A Circle of Friends is both a Process and an Outcome. It is not a gimmick, a trick or a program. To build that process and to get that outcome takes energy, creativity and a deep belief that people of different abilities, colours, shapes, sizes etc., can be friends. Circle-building takes good planning, strategies, tactics, honest discussion, and many meetings. Support Circles do not and will not happen spontaneously. Nothing does.

THE CONCEPT OF THE DOUBLE CIRCLE...

For many years we have been focusing our work on building circles of friendship and support around children and teenagers. What we discovered in the process is that often the family i.e. the parent(s) is also isolated, lonely and rejected by his/her community. A story explains:

We were asked into a school to set the conditions to build support around Tanya, a 13 year old student with Down Syndrome. Tanya's mom was dissatisfied with the school's efforts. She complained constantly. The school was distressed. They were honestly trying their best. We were asked to visit the mom at home and to open blocked channels of communication between the home and the school.

At Tanya's home, we were greeted by an angry woman who complained bit-

terly that her daughter had no friends, the school wasn't trying, etc. Something felt deeply wrong. At a critical moment, one of us asked gently, "What does your own life look like, Mrs. James? Do you have any friends at work, at the church?" Mrs. James suddenly dropped her mask of anger and her tone of bitterness - tears of sorrow began to flow.

We all cried together. Through tears, Mrs. James told us how she had moved far from her family to where she felt her daughter would have a better chance. She had given up a job she liked in a community she knew, to come to a place where she was unemployed, her church community seemed cold and unfriendly, and where she had no friends.

We suggested that just for a short while, she stop worrying about her daughter and focus on herself. We suggested that someone from the school, who knew the church community, invite Mrs. James to the church. Another neighbor was recruited to help Mrs. James get to the local community college where a few courses might make her eligible for new job choices.

Six months later we bumped into Mrs. James at a meeting. We were stunned. She looked five years younger, had a job, and was the treasurer of the church women's group. Her daughter and her daughter's new best friend were with her. She told us the school was doing great. Tanya was on the baseball team and making real progress at school and in the community.

In this instance, the school had been sensitive and saw that the mother, not the child, was the prime candidate for a support circle. Once the mom felt less isolated, she relaxed and became more open and inviting to children in the community.

THE DOUBLE CIRCLE...

Experiences like this gave birth to our concept of the double circle. Parents, especially parents of teenagers, often need their own supports, which are different from the friends wanted or needed by their teenager. Families who are unstable and don't have support systems for themselves, cannot adequately build support around their children. A family needs to feel validated, valued, and supported in order to provide the necessary emotional, moral, spiritual and material support to children and teenagers at risk.

Katherine Woronko and her family, Stan, Marte and Stephan, are true pioneers in the field of building support circles, and double support circles. They are an example of a unit with a long lasting support system. We have learned several important lessons from this family.

When we met Stan and Marte Woronko, their daughter Katherine was in a group home for children with severe behaviour problems. The family was sad, isolated and lonely. Little did they know that they might long for some of that quiet five years later.

Over the years, they have opened their home, their hearts, their refrigerator, their vegetable garden. Most of all they have dared to open themselves and show their vulnerability to strangers who were willing to listen, dream, laugh and cry with them.

We have learned that to get support, one must show a need and invite others to enter your lives. In a society that values individualism, individual freedom and privacy, this is hard to do (especially for men).

Most of us will say the words, "We need one another". We know intellectually that we need to be open to one



another. But when push comes to shove, it is hard to reach out, even to our intimate marriage partners and say, "I hurt. I am in pain. Please hear me. Please help me."

It is important to turn words into deeds, and live these ideas. We have learned to live the circle in our daily lives. In periods of crisis, we have had to become vulnerable and ask for help. This is a rich and humbling experience. It is also human to ask for help. For centuries people in communities helped one another out of their various "holes". It is only recently, with the breakdown of the family, the dissolution of neighborhoods, and the diminished leadership of religions, that people have turned to professionals. Today, psychologists, psychiatrists, social workers, etc., provide the help once provided by family. neighbors, the local priest or rabbi. This does not deny the positive role professionals can and do play. Professionals are an important "add on", but never a substitute for friends and relatives who share a common history and a common struggle.

John McKnight tells wonderful stories to encourage us to rebuild our communities. He tells us that we already "know" how to build welcoming communities, and that we must "remember" and create welcoming environments where people eat, sing and celebrate together. This is a different reality from "professional-client" relationships. Circles are from the community moldmessy, creative, but with a capacity to both offer and receive the gift of hospitality.

WARNING - IT TAKES HARD WORK...

Beware of the school and family who think "friendships will happen naturally." This society spends billions of dollars to sell us products we don't need. There are products to deodorize every part of our bodies and products to make us smell like trees, flowers and drugs (the perfume opium). We sell deodorant to sanitize our homes, our workplaces, our cars and all parts of our bodies. We live in a society that sells pills to kill our pain. We buy medical and psychiatric cures before we look at our own lives. Seldom do we sit down and listen to one another, dream with one another, share our worst fears and nightmares or to celebrate our victories with one another.

In spite of this, we seem to believe that "love will bloom" and "friends will happen" spontaneously.

The tragic news is that for people with disabilities, for people with any "deviance", for people labelled elderly, life will be lonely and full of isolation and rejection if we just wait for it to happen "naturally".

Can you imagine what would happen if we took the billions we spend to advertise fast cars and alcohol, and instead advertised circle building and friendship? Can you imagine a campaign designed to make us all care about one another, rather than competing to look thinner and younger? Can you imagine if schools spent all their testing money on hiring "bridge-builders" and "community linkers" and "connectors" to actually help people find the natural supports in their home communities? Can you imagine building programs to train facilitators to build friendships rather than to build fleets of stealth hombers? It is ironic. There are always budgets to build new institutions, yet there is no money to hire an integration facilitator or to train people to bridge people back into true neighborhoods and communities.

It may be hard to imagine, but it is easy to start - in your own backyard - with your own mother, son, daughter, or friend who is vulnerable or at risk.

Most of all, the place to start is with yourself. How intentional are you in building your network of support? Do you make that phone call to say, "I Love You?" Do you remember to buy flowers for someone or write a thank you note to your son's teacher when she does something nice? Do you visit a sick friend in the hospital even though you are too busy? And do you make the time, to give yourself time, to just sit and reflect on life.

We are not sure of the answer. We do know that natural supports are the people who are drawn to one another naturally and organically. But this attraction is only the spark - only the INVITATION to begin a relationship. The natural must be nurtured and pruned to stay beautiful or it becomes an uncontrolled jungle.

To keep a garden beautiful, it must have a loving gardener. To keep an orchestra playing in harmony, it must have a conductor. To keep a relationship and friendship alive, it takes sustenance and time.

Friendship is like a garden and an orchestra. To keep the beauty and the melody, the friendship needs tender loving care and hard work. The result is as beautiful as a prize winning rose, as magnificent as a Beethoven symphony, and as precious as our view of the majestic peaks of the Himalayas.

ORIGINS OF THE JOSHUA COMMITTEE...

Judith Snow's Circle of Friends..

Jack recalls the formative time... I certainly don't know exactly how all this got started. Marsha was deeply involved,

and so was Judith. I was preoccupied with Frontier College. But somewhere along the line, Marsha and Judith began to talk about "circles". Since Judith had started dubbing herself a "portable visionary", I thought this was just another mirage. But over time, my hard nose became more pliable and I began to see that this was more than just words. I also began to understand that I was part of whatever it was.

The two of them. Marsha and Judith in full flight, was always a sight. They could generate enough energy to frighten fusion supporters. But gradually. I saw that this was more than just intense light. There really was content. The content was relationships. They both hammered away about the anguish of being a life-long loner. We all need friends and relationships. It took me a while to comprehend the step to "circles" - circles of friends. It was simple and profound. We all have layers of relationships - like concentric circles - with different levels of intensity in the relationships. What they discovered was that most people with labels had no people in their "inner" circles except perhaps immediate family. Then their lives were "blank" until you reached the "outer" circle with "paid people in your life". There, those with labels had long lists of "caring professionals" who often had to check the chart to get their name right.

Their vision was ridiculously simple. All one had to do to improve a person's life was to fill up the inner circles. It seemed like hocus pocus till you stopped and thought about putting a few friends in your life. Then it made sense - solid sense. So they began talking about circles - and how to build a circle of friends around a person who was lonely. And suddenly, in one of

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those blinding glimpses of the obvious, I realized that I had helped to build a circle of friends around Judith when she collapsed. We didn't use those words then, but the Joshua Committee was a circle of friends.

And now, even I talk about circles of friends. It's just good common sense. Judith and Marsha invented the term. But I feel rather good, because I was part of the experiment that moved that dream into reality. I always live events before I manage to put words around the reality of my life. That is why it is consistent that I am writing about the Joshua Committee and Circles now after living it for years. Ironically, now I understand that I was part of the Joshua Committee from the beginning. I was there - living it. I was slow to acknowledge that, but I was there all the time. Marsha knew it right away; Judith figured it out after a while; I eventually caught on. I was a lot slower. But now I am trying to recognize and live my reality more quickly. It's easier for me - and for everyone else. Less confusing. It's one of the little things that Judith has helped me to learn. Judith and I are very similar. It takes us both 10 years to recognize the obvious.

There were a thousand reasons that we shouldn't/couldn't trust each other, but we did anyway. Trust doesn't happen quickly. It takes time.

Judith also helped me to see that I am not an island. I too need a circle of friends. This is not something abstract. It is real. And you don't have to wait until everyone is dead or gone. You can do it now.

I have drawn my "circles" now. Fascinating what one sees. Almost all my friends have experience on the "margins" of life. I guess that says something about me.

THEN THE PERSKE'S WROTE "CIRCLES OF FRIENDS"...

I am definitely a slow learner in some areas. I had been living the reality of the Joshua Committee for years. We had weathered one crisis after another. We were very close friends. But still I didn't see anything extraordinary. It just seemed like common sense. It wasn't as if I didn't know differently. In just about every community I encountered through Frontier College, I saw people struggling in isolation, alone, unsupported. I saw a society with virtually no stable relationships - and few friends. I had no excuses for my oversight.

When Bob Perske, the American author who writes about friendship. came and spent time with us in the fall of 1987, he interviewed us all at length. I had a feeling he must be seeing something. He took photos, and his artistpartner and wife, Martha, drew a portrait of the Joshua Committee. It was stunning. I guess that was when I realized out loud that what we had been doing was something very special and unusual. I think now that my unconscious oversight was a way of avoiding the pain - the painful awareness of how impossible life must be for so many lonely people.

The Perske's book, **Circles of Friends**, was published in 1988. It was a runaway best seller in its category. Bob was asked to do the keynote address at the national TASH Conference (The Association for the Severely Handicapped) in Chicago that year. He read his story of the Joshua Committee. That was when I finally realized that our lives were not "normal", that the Joshua Committee was not regular, and that Judith was not just another friend. Both Marsha and Judith had known it

for years. I denied the obvious for good reasons. I believed then and still do today that anyone and everyone should have friends; that a Joshua Committee can be for anyone; and that it is entirely possible. I wanted to see it as so simple, that I denied its pioneering role and example. No more. I see it for what it is. But I still believe that it is very common sense stuff, and that anyone who wants a friend can do it.

If you choose to join a circle (where every person is an equal partner - by the very form of the circle), you create a capacity to revisit the past and to build the future. Some of the remembrances are painful, but within the pain, there are powerful lessons to be learned, like this story rediscovered from Judith's memories.

FROM BEHIND THE PLANO...

Very recently, Judith told several of us a very personal story - that she had partly buried, and partly denied. It was too painful to remember. But it is such an incredible allegory that it must be told.

The background includes some facts that Judith had told us long before. Her voice is very distinctive - husky - bass. She went from soprano to bass overnight when she was 10 years old. Doctors gave her steroids, experimentally, to see if it would increase muscle strength. One result was wrecked throat muscles and early puberty. Another was that Judith stopped singing and talking. She was embarrassed by the depth of her voice. At age 13, she had two radiation treatments, for the purpose of sterilization. They didn't work. They nearly killed her. There was no justification that makes any sense today. But it was the medical wisdom of the day that "people like that" should be sterilized.

They did it to Judith.

A second tragedy was that this trauma fundamentally undermined Judith's relationship with her family. "How could they do this to me? They wouldn't do it if they loved me..." It set a tone that took decades to overcome.

The story Judith just now recalled, happened in her graduating year in high school. She had regained some confidence and delighted in singing. It was one of the few activities she could participate in fully. When her voice had changed dramatically, children had made fun of her. It was hard for a child to be a bass. But Judith being Judith, she recovered her courage and sang in the school choir anyway. Although the high school welcomed her, Judith's memories are of loneliness. That is why it was so important when the music teacher seemed to like her, and welcomed her participation.

The Christmas concert was approaching. The choir was being featured. Dress rehearsal. Everyone was excited. But during the practice, Judith's favourite teacher "repositioned her" - behind the piano.

She went home and sat in stunned silence. She couldn't cry because it was not acceptable in her family. Her favourite teacher didn't want her either. She was distraught. She didn't know what to do. She desperately wanted to sing, to be part of the concert. She wanted to confront her teacher. But she was afraid that if she did, she would be rejected even more.

The following evening, Judith went to the concert. She placed herself BE-HIND THE PIANO and sang. But she stopped singing after that.

We have musical parties at our house. Judith always sits in front of the piano and sings her heart out. We

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didn't realize how important it was for Judith to sing or to sit in front of the piano. We didn't realize it until just now.

Judith now realizes what a profound experience that was. It was the beginning of Judith choosing to be "handicapped" and live with it. She could have driven in front of the piano, or beside the piano, but she acquiesced. She parked behind the piano of life. She accepted her "station". She chose not to confront her teacher. He likely had no idea about the trauma he was inflicting. But Judith chose to stay quiet. She was 18 years old.

Today of course, Judith has learned that if she stays behind the piano, she is dead. The piano was the nursing home and the geriatric centre. The piano is accepting what "others" decide is good enough for you. So today, Judith is struggling to overcome the traumas suffered by an impressionable teenager, being tucked behind the piano. It was her first concrete memory of being "disabled" and "accepting it". Accepting it was the devastating part.

Reflecting on those unhappy teen years, Judith now knows that was when she was learning "how to be handicapped". She was stubborn. She fought hard. But once learned, "unlearning handicapism" is a formidable challenge. Judith has done it. It is a remarkable feat of endurance and courage.

If Judith, a fighter for life, was trapped into acceptance for nearly 30 years, it is only reasonable to expect that all of us, with a fraction of Judith's determination, have equally accepted externally imposed limits - our own private "piano's" which we hide behind. Once again, her pioneering spirit offers all of us the opportunity to live and learn with her - about our capacity to be

free - our capacity to celebrate life - if we will only choose to live.

PLANNED SPONTANEITY From Here to 2009...

We celebrated Judith's 30th birth-day party in 1979 - on the day and year she was medically programmed to die. Now we are planning a real bash just before we ring in the millennium together. They said it couldn't be done. What did they know anyway? And besides, we learned, loved and lived a lot. We wouldn't trade a moment of it.

We are embarked on a journey together. This story is not done. We have just established the Centre for Integrated Education and Community. It will grow and present new challenges and opportunities. We are teaching together more. We are a good team - Marsha, Judith and I. And I am still learning from Judith. I am still listening to her talk about "giftedness" in my head. I am comfortable with the notion that we all have "gifts", but it is yet another leap to see "presence" as a gift. I am learning. Judith is teaching. We are doing it together.

And we all continue to explore new worlds. One of Judith's dreams was to be a "rock star" - in a rock video. We all knew it was ridiculous, but the impossible is only hard work for Judith. "Labelling Blues", a rock video by Greg Hoskins and the Stick People, with Judith in it, has just been released.

And the circles interlock again and again. Appropriately for renewed beginnings, Judith has just joined her Church choir. After 20 years of hiding behind the piano, she is coming out again.

As for us, we have realized at long last that Judith is part of our Circle of Friends. We have come full circle. We

circled around Judith in 1979, and now, she has circles around us. It is no longer us supporting her. Now we take turns as each of us needs support. It is an exchange among equals. Who could have foreseen?

We went canoeing again - in the brisk fall waters of the Madawaska River. Marsha was terrified that Judith would get hypothermia. I said "That's the wrong problem. If we flip, drowning will be the problem. Hypothermia comes later, if you survive." Marsha refocused her fear, turned it into an opportunity and recorded our adventure in slides. They are wonderful. So were the fall colours. We didn't run any rapids. We just went canoeing. If there was ever any doubt in my mind about the "dignity of risk", all I had to do was bask in the glow from Judith's face.

Later she said, "I was a little scared about drowning, but then I thought - what a way to go. It was so beautiful".

Marsha cooked a celebration dinner, and we toasted life as the coals glowed red in the wood stove.

And now we sit, looking forward to taking our "Institute" - the Centre - on the road - to England and New Zealand. We just ordered Judith's first passport. World here we come. And we are looking for a wheelchair-accessible motorcycle sidecar. Judith wants to do a bit of biking. And we have added gliding to the list.

Most important, we are relishing every moment of life as we reflect and dream with planned spontaneity for a celebration of our circle of friendship to ring in the year 2000 - together.

WHAT WORKS...

In all the "Circles" that seem to last and work, deep bonds have been built over the years. Themes leap out when one looks at successful circles like those of: Nicola and Katherine Shaffer; Katherine Woronko, the Woronko family and Arınmarie Ruttiman; Rose, Dom, Maria, Felicia Galati and their huge Italian family; Judith Snow, Marsha Forest, Jack Pearpoint and the Joshua Committee.

We're often asked, "What's all this circle stuff really about?" From successful surviving circles, some of the themes we have noticed include:

- . It's about Commitment: The process is long term and the struggle continuous. People must choose to get to know one another.
- . It's about complex human dilemmas: There are no micro-wave answers and quick fixes.
- . It's about successful Circles being built on hard work organizing, planning, blood, sweat, tears.
- . It's about a journey of continual problem solving. There are no simple answers.
- . It's about creative brainstorming and honesty. There are no tricks or gimmicks.
- . It's about being open to pain and suffering: Openness to the human condition is what it's all about. Once Fear and Pain are acknowledged, the door can be open to a spirit of adventure.
- . It's about nurturing a spirit of optimism in the knowledge that problems can be solved. Solutions can be found. The glass is half full, not half empty. Remember, if we only go to the glass to drink, it will empty. It needs to be replenished and filled. We need to



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build in supports that will fill our glasses.

- . It's about being open to non-traditional solutions to major life crises. We need to be ready to hear solutions from new sources i.e. younger people, non-professionals, wounded people themselves.
- . It's about learning from our history and building a better future. Master "Fast Failure". Failure (trying things out) is part of the process.
- . It's about big-heartedness and open-mindedness.
- . It's about Learning to "listen" to one another, and being open to hear and to act on new options.
- . It's about keeping the dream alive by continually reflecting, listening, dreaming, growing.
- . It's about celebrating successes even small ones.
- . It's about tolerating Rapid Change - What ever we think is complete will need fixing. Enjoy the journey - don't fight it.
- . And most of all, keep your eye on the prize. It's about friendship, love and community.

For Additional Reading on Circles and Support, we suggest:

- * Action for Inclusion: Forest & O'Brien, Inclusion Press
- * From Behind the Piano: Jack Pearpoint, Inclusion Press
- * It's About Relationships: Marsha Forest, Inclusion Press
- * Beyond Separate Education, Quality Education for All: Lipsky & Gartner, Paul Brookes Publishing
- * Educating All Students in the Mainstream of Regular Education: Stainback, Stainback & Forest, Paul Brookes Publishing.
- * Support Networks for Inclusive Schooling: Stainback & Stainback, Paul Brookes Publishing.
- * Circles of Friends: Perske & Perske, Abingdon Press, Nashville.
- * The Power of the Powerless: Christopher de Vinck, Doubleday
- * Cognitive Counseling & Persons with Special Needs: Herbert Lovett, Praeger.
- * Community Integration for People with Severe Disabilities: Taylor, Biklen, Knoll Editors, Teachers College Press

Video References:

- * With a Little Help From My Friends: Producer: Centre for Integrated Education, Directors: Marsha Forest & George Flynn
- * Kids Belong Together: Producer, People First of Lethbridge. Distributors: Inclusion Press
- * Miller's MAP: Producers Expectations Unlimited and Inclusion Press.

Reflections on Maori Education in Aotearoa

by

Marsha Forest & Jack Pearpoint

New Zealand, March, 1992

Six years ago we met Te Ripowai Higgins at an international education conference in Buenos Aires, Argentina. What drew us together was Te Ripowai's marvelous laughter and vitality, her enthusiasm for life and her passion for the education of the Maori children of Aotearoa (New Zealand). We spent hours eating, discussing and sharing ideas and stories.

Te Ripowai told us about growing up in the tribal lands of the proud Tuhoe people. We stayed up late into the night hearing stories about Auntie Uru, the uncles, all the cousins and the mokopuna (grandchildren) that formed life in that community. We shared our struggles as educators and as people.

Six years later we were to actually meet, greet and be warmly welcomed into Auntie Uru's home. Surrounded by a constantly changing delegation of her 32 mokopuna, she bathed us in a warmth we have experienced only in rare and treasured moments of life.

In our week with Te Ripowai's family, we strangers were fully, openly and warmly included - even consumed by the hospitality of this extended Maori family. Food was one symbol of welcome. We ate and ate, Tuhoe style described by cousin Eva as, "big breakfast, big lunch, big tea and big snacks!" The meals merged with Maori prayers, songs, humour and unforgettable "home cooking". The food

and company were superb.

We were taken to visit several Maori immersion Kohanga Reo (day care centres - called language nests) and primary schools. The children, teachers, parents and elders greeted us, prayed for us, sang to us, spoke to us and hugged us with a deep spiritual warmth that cannot be captured in mere words. The strength, the power, the harmony of chanting and singing voices ring in our ears and hearts.

We shared the struggle of Aboriginal Canadians and their parallel battle to preserve the essence of their culture their languages. We spoke of the controversy surrounding immersion education and of the preservation of language being the key to cultural survival as a people. We wholeheartedly supported the leadership we witnessed. We promised to write our impressions - about the pride and strength dawning in sparkling eves as Maori children renewed their cultural heritage - recalling the wisdom and strength that guided them across the Pacific to Aotearoa one thousand years ago. The schools were resplendent with vibrant colours, swirls of art, renewed pride, the dignity of wisdom, coherency of values and strength for the future. We saw, we felt, we drank in the enriched soul that is building the Maori future.

Hospitality is a rich word, but it does not convey the depth of spiritual and material welcome we were given by people who do not have great amounts of material wealth. People gave us their beds. They insisted. We were fed and fed and fed. Cousin Bernadine Takuta gave us an eagle bone carving done by her husband Newhai. He had started carving at the age of 39. She describes him as carving anything and everything in sight. We also received unique hand



woven flax baskets and a hand carved walking stick. The only acceptable response was to appreciate the richness of the giving from deep in our souls. We had a few small books, and gave our own writings, but our smiles and tears of appreciation were the only appropriate responses because they were from our hearts-like the gifts. What they most appreciated about us was our joy in eating. The Uncles reported that they truly enjoyed watching us enjoy their food. They told us that at first they were concerned that we might reject the fruits of their soil. There was much hearty laughter as we all together devoured the pork bones and watercress till it was gone. The potato bread, fried scones and honey also disappeared rapidly from the table much to the delight of all.

On March 26, 1992, we flew back to Auckland from Whakatane. We arrived at the airport with our rental car bloated with our new extended family, crushed in for the farewell. Te Ripowai led our troupe. With her, Uncle Joe and Uncle Whitu, Tuhoe elders who had told us stories, laughed, prayed and eaten with us as they guided us through their tribal homelands, and introduced us to Maori wisdom as we visited the local Marae (meeting houses), heard legends of the ages, and glimpsed the glory of sacred lands and burial places. We saw the historic cliffs and battle grounds at Lake Waikaremoaha (the sea of rippling waters). We saw and felt the spiritual oneness with the land in virgin tropical forest, misty mountain falls, and the timelessness of the giant tahe kaha trees standing proud with two millennia of momories to share. They were there. And Auntie Uru, composer, singer, dancer, mother of eleven, grandmother to 32 (and counting), lover of life - feed-

ing our bodies and our souls to the moment of takeoff. Noti, Te Ripowai's sister, making us promise to bring our "tramping" gear next time, and she will take us to the bush, and around their magical lake for five days of walking wonderment. We all shed tears as we bade farewell. We will return.

It was only one short week to be students of a culture that was nearly made extinct. Our work was reinforced and reaffirmed: Welcome, Hospitality, Heart, Belonging and Inclusion are at the soul of a decent and humane education system. Music, harmony, poetry, love must be at the helm for a society and for a school system in any culture to flourish.

We are not romanticizing Maori culture or claiming to be "experts" on Maori education. We did not see perfect people nor perfect families. We did see humility, hope, humour and healing. We saw no striving for material wealth or riches. We did see a deep striving for spiritual and cultural values - for a wealth of dignity and diversity - values we support in solidarity and unity.

A great honour was being present one evening at the rehearsal of the Te Herenga Waka (the gathering place of the many canoes - the university marae) Kapa Haka (Maori performing arts group), at the University of Victoria in Wellington. Invited by Professors Te Ripowai and Pou Temara, the traditional leader of the University of Wellington Marae, we watched (again with tears welling) young university students chanting and singing traditional Maori and modern songs. The intricately carved and painted roof and walls of the Marae glinted and swelled with surges of pride and militancy in soothing harmonies with fingers gently trembling like leaves in gentle breezes, then rafter

rattling terrifying & frightening "challenge" chants, clubs flashing in circular precision, as feet stomped and enemies cowered. In strong voices, reclaiming a once almost lost language, learning a new heritz Je, born of pride sweated from the dancers and lit the darkened Marae. We had the privilege of being in the present and seeing the future.

Just ten years ago, the Maori language was in danger of extinction. Today, the future is restored. A culture that was nearly confiscated like their stolen lands, is being restored. We are humbled and honoured to be able to bring this message of hope to the Aboriginal people of the America's, and people everywhere struggling for survival and dignity.

At Uncle Whitu's home, Maori proverbs hung on the wall. One said, "Wishing never filled a game bag." Wishing did not and is not creating the new generation of Maori youth who will change the face of Aotearoa - and indeed the world. It is hard work and courage, day after day, year after year to make the miracle happen.

We in education and human service work can find answers not only in books, but more fundamentally, in and from the people once robbed of their rightful place on the earth.

We will let our newly adoptive family have the final word in this article. Te Ripowai signed our beautiful Maori calendar with this proverb:

Hi mai ki ahau He aha te mea nui i tenei ao He tangata! He tangata! He tangata!

Translation:

Ask me

What is important in this world? It is People! It is People! It is People!

The Origin of the Tuhoe: The Mountain & the Mist Maiden Hine-pukohu-rangi came from the sky and she lured the mountain to earth with her. Their child was a mortal being, Tuhoe-potiki; his descendants are the Tuhoe people. Tuhoe are thus children of the supernatural, born of the remote mountain and the drifting mist.

The **Tuhoe** are truly *Tangatawhenua* - the people of the land. We are honoured to tell this story of our friendship with this tribe and their wonderful people.



Not Idolizing the Average

by
Judith Snow
Visiting Scholar
Centre for Integrated Education
and Community

Toronto April, 1992

Over many years, especially in the last fifteen years, more and more people are choosing to support and enjoy life with a person who is considered to be handicapped. This sharing of life together has many aspects of everyday relationships. Yet nearly always there are added dimensions of effort, struggle and risk. This difficult element exists partly because most people with handicaps require ongoing physical and emotional maintenance. But anxiety and effort are increased to numbing levels mostly by the endless, profound rejection and isolation that vulnerable people and therefore their friends and supporters experience in a culture devoted to idolizing the average.

Many people, even parents of a child newly in this position, establish their relationship with a person who is handicapped through a process of identifying with some unmet need the person is struggling with or through empathizing with an experience of injustice that the person is living. Taking on the role of therapist/advocate, one person stands by the other. Although there may be some or many successes in this battle, at some time the realization is heavily brought home that injustice and needi-

ness are permanent aspects of this person's life.

In fact, until this realization is accomplished, the interaction between the two people is often sustained mainly by the energy of the battle and by hopes for victory. While efforts are successful, this poses no great problem. But lack of progress either in therapeutic efforts or in efforts to get a better deal can lead to "burnout", and burnout to a diminishing or ending of the relationship.

Therapy calls for the person with a handicap to be seen as needing to be fixed in some way. Advocacy calls for the person with a handicap to be viewed as a victim of some outrageous misfortune or circumstance. Both these stances have value and can lead to good for the person and the community. But neither approach calls for a contribution from the person themselves in order to sustain the relationship or the work. And if success in therapy or advocacy is not quickly forthcoming, the relationship must suffer.

Sustained vibrant relationship demands that the person with a handicap be viewed with a different vision and listened to with a different ear. Foremost of the alternative possibilities is to see and hear the person as a welcome fellow traveler. The shared life journey is one of transforming human suffering by creating the supportive relationships we all need to sustain life.

As fellow participants in an imperfect community, many persons with disabilities have valuable gifts to offer. Some show a capacity to take a great deal of satisfaction from very simple everyday occurrences. The unusual behaviour of others can be a contribution to those who find society's restricted codes too tight for self-expression. The very presence of many people

with handicaps is a means out of the overwhelming individualism imposed by society's norms. Then there is an unlimited number of possible gifts that individually, each person with a handicap can hold, the nature of which can only be determined by those who stand close enough to watch, listen and share.

At its heart inclusion is a philosophy of creating community out of the presence and giftedness of everyone present. Given the world we now have, inclusion also necessarily involves welcoming into community those who have been excluded, and recreating the community so that these people's giftedness becomes part of the everyday life of all.

The good news of inclusion is that its success is not measured by the yard stick that advocates and therapists use. As soon as a person is recognized as being a member present in the community's body, and as soon as the process of recognizing that person's gifts has begun, and above all, as soon as that person's gifts are structured into the activities of everyday life, then inclusion is present. In this way alone can the person with a handicap genuinely be a community member working at making the community work for all, including themselves. Anything other than inclusion leaves the person waiting in their victim status - waiting for others to create a world where all their problems are solved and they can finally step on stage. This world hardly ever comes.

Inclusion is always available even when people still have skills to learn or health problems to overcome. Inclusion is always available even when services are inadequate or there is not enough money. Inclusion is always available when we haven't yet found the right person or worked out all the bugs in the plan. Inclusion is including the vulner-

able person in all the inadequacies, the "not yet's", the "can't get's". Inclusion is genuinely respecting and recognizing the person for who they are and what they are able to contribute, right now, in the life they are living right now - not the one they might have had, or maybe will have someday, when all the problems are solved. Inclusion recognizes neither handicapped nor normal, neither us nor them. All inclusion recognizes is that, if we work out today together - really together, today will be the best today we can have.

Inclusion demands t at everyone be supported to be a sustainer of relationship and a responsible contributor to community. As we work to build the vision of inclusion, we will find that there are not some working for others, but that we all can work for each other. The success we achieve will make the successes we don't achieve much more bearable.



DOING THE RIGHT THING ON 68th STREET IN NEW YORK CITY

this morning i woke up tired
wondering
why is it so hard to convince everyone
to welcome
abe, rachel, danny, maria?
why is something so simple
so complicated?
why are we invited all over the globe
to say that
*acceptance
*belonging

*community are the new abc's. why? why? why?

why can't abe and raphael be fully welcomed, accepted, included—loved! i know why.

abe challenges our valuesraphael faces us with our vulnerabilitymaria makes us question our soulrachel makes us define what we are and what we call—human.

we have a choice spend 865 million dollars on one stealth bomber

pinpoint bomb and make craters of once great ancient cities drop death and destruction of our brothers and sisters

or figure out solutions figure our how to live with one another and love with one another. its really just that simple and just that

complex... i get up and walk to 68th street exactly to the spot where i started teach-

ing
twenty eight years ago.
doing the right thing on 68th street i read
this reflection
and gently the audience bursts in warm
applause
i am back

Dear Teacher,

I am a survivor of a concentration camp. My eyes saw what no man should witness.

Gas chambers built by learned engineers.
Children poisoned by educated physicians.
Infants killed by trained nurses.
Women & babies shot & burned by high school & college graduates.

So, I am suspicious of education. My request is that teachers help students become human.

Your efforts must never produce learned monsters, skilled psychopaths, educated Eichmanns.

Reading, writing, arithmetic are important only if they serve to make our children more human..

from: Haim Ginott (1972) Teacher & Child



"First they came for the Jews and I did not speak out because I was not a Jew.

Then they came for the communists and I did not speak out - because I was not a communist.

Then they came for the trade unionists and I did not speak out because I was not a trade unionist.

Then they came for me and there was no one left to speak out for me."

Pastor Niemoeller (victim of the Nazis)

Language of Us/Them

We like things

They fixate on objects

We try to make friends

They display attention seeking behaviour

We take breaks

They display off task behavior

We stand up for ourselves

They are non-compliant

We have hobbies

They self-stim

We choose our friends wisely

They display poor peer socialization

We persevere

They perseverate

We love people

They have dependencies on people

We go for a walk

They run away

We insist

They tantrum

We change our minds

They are disoriented and have short attention spans

We have talents

They have splinter skills

We are human

They are ...?

Meyer Shevin



The New ABC's



Geebfgoog





COMMUNITY





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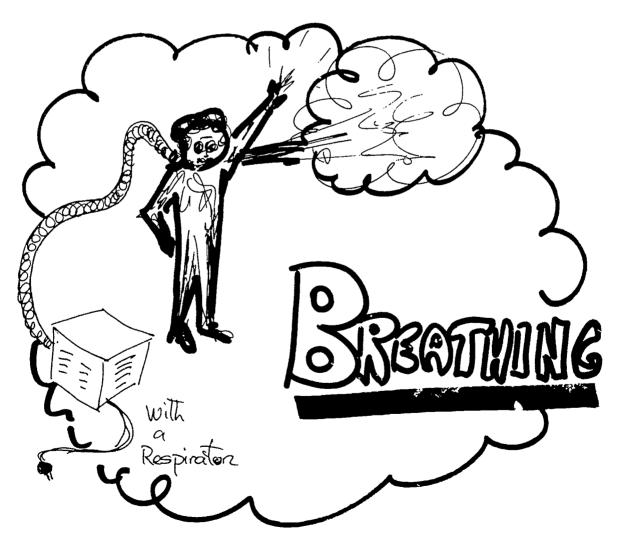




ERIC

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About the Authors

(order of appearance)

Jack Pearpoint

Jack is the founder and Executive Director of the Centre for Integrated Education & Community (CIEC) and the President of Inclusion Press. Jack has 25 years experience running innovative adult education and literacy organizations. He spent 5 years in Nigeria and Ghana with CUSO, then was President of Frontier College, Canada's oldest adult education institution, for over 15 years. Presently, Jack is an adjunct professor at McGill University, and spends his time advocating, writing and lecturing about a vision of a world where "Kids Belong Together". Jack is a member of Judith Snow's Joshua committee.

Marsha Forest

Marsha is the founder, and Director of Education of the Centre (CIEC) and Inclusion Press. Marsha has 25 years experience as a teacher and advocate for children and families. She has worked in special education and holds her doctorate in teacher education/leadership and administration. She is a well known and popular keynote speaker, workshop leader and video producer. Marsha is an Adjunct Professor at McGill University and Director of the McGill Summer Institute on Integrated Education and Community. Marsha is a member of Judith Snow's Joshua committee.

Judith Snow

Judith is the Visiting Scholar at the Centre (CEIC) in Toronto. Her life is a testimony to her courage and determination to live in the community on her own terms. Judith has challenged the system, thus graduated from York University with a Masters degree in counselling, and is now helping families, schools, and organizations to build circles of support and friendship around vulnerable and oppressed people. Judith is the founder/creator of the Joshua committee. Her work on Literacy and Inclusion is supported by a grant from the Secretary of State for Multicultu alism.

Bob Williams

Bob is a poet, writer & activist. He is a Policy Associate with the United Cerebral Palsy Associations in Washington, D.C. Bob was born with cerebral palsy. He seeks to live life to the fullest and to speak out for the rights of other labelled or oppressed individuals to do the same. Bob has played key roles in gaining passage of the Americans with Disabilities Act and other legislation.

Bob writes and speaks widely on such issues as the need for universal freedom of expression, choice and self-determination in the lives of all people. He has used a manual communication board for half his life and relies increasingly on the Touch Talker in his lobbying efforts and as a political organizing tool.



Patrick Mackan

Patrick Mackan C.R. was co-director of the Centre (CEIC) with Marsha and Jack until his untimely death on Nov. 23, 1990. Pat was a Resurrectionist priest, a teacher and a committed integration advocate. A native of Hamilton, Ont, he taught in many locations, was a school principal in North Bay and a parish priest and leader in the integration movement in Bermuda. He conducted institutes and workshops across Canada and United States. Pat had the respect and love of thousands of families and professionals who appreciated his leadership. He is missed but not forgotten.

Roslyn Cormier

Roslyn is an Associate of the Centre (CEIC) and the founder of the Centre for Inclusive Education in Kitchener-Waterloo, Ontario. Roslyn also worked extensively with Patrick Mackan and is continuing to run workshops and courses across Canada.

Yves Talbot

Dr. Yves Talbot is a family practitioner in Toronto. He was Head of Family Medicine at Mount Sinai Hospital. He is an innovator in medical education and is on the Faculty of the University of Toronto.

Ron Satok

Ron Satok is a Toronto artist and the founder and director of the Satok School of the Arts in Toronto (1981). See inside cover for more.

Mayer Shevin

Mayer is poet, teacher and advocate for choices and community connections for people with disabilities. He has worked in North Dakota, Ohio and New York State.

Linda Shaw

Linda is the co-director of the Centre for Studies in Integrated Education in London, England. She is a writer, adovate and publicist for inclusion in the United Kingdom.

Gary Bunch

Gary is a friend, a teacher and a professor of special education at York University in Toronto. He is chair of the Centre Board and has been a strong advocate for the rights of children for decades.

Jim Paladino

Jim is an amazing father of a clan of wonderful children in Greely, Colorado. He learned about inclusion at home and is now trying to teach school systems the same fundamental lessions.





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2nd Edition

•

by Jack Pearpoint, afterward by John O'Brien

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* The PATH Workbook

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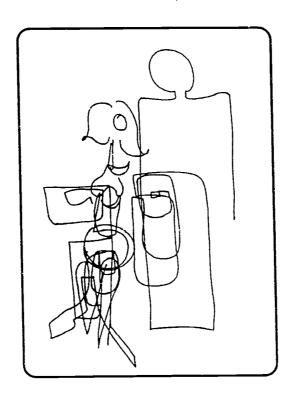
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