

MAKING A DIFFERENCE:

**What communities can do to prevent
mental handicap and promote lives of quality**

**Volume III: Helping children live,
learn and grow in their communities**



MAKING A DIFFERENCE

Helping children live, learn and grow in their communities

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Financial assistance provided by:

Health Promotion Contributions Program,

Health Promotion Directorate,

Health and Welfare Canada

International Association for the Scientific

Study of Mental Deficiency

Canadian Association for Community Living

ISBN 0-920121-16-0

Canadian Cataloguing in Publication Data

Main entry under title:

Helping children live, learn and grow in their communities

(Making a difference ; v. 3)

Bibliography: p.

ISBN 0-920121-16-0

1. Mentally handicapped children - Care and treatment. 2. Developmentally disabled children - Care and treatment. I. National Institute on Mental Retardation. II. Series.

HV891.H44 1986

362.3'8

C86-093553-1

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National Institute on Mental Retardation
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CANADA

need of treatment. (John did go to the hospital when he had pneumonia, because that is where anyone would go in the case of physical illness.)

- *Integrated educational and recreational experiences are quite simply non-negotiable. John will never attend a segregated school.*
- *The whole family adapts or finds ways which enable John to go swimming for fun, as opposed to "therapy."*

In the short term, Warren and Dawn have two goals for John: to get him into an electric wheelchair so he can have independent movement and get around on his own; and to enhance his means of expressive communication so he can communicate with others outside his close family circle.

Warren, Dawn and their two sons are not saints, martyrs, or perfect human beings. They are not wealthy, nor do they have access to unlimited

resources. What they do have is a healthy attitude towards life and living. They are realists and yet they have aspirations.

It is true that John still has very demanding needs. Yet the key to prevention in his life has been that his family has been willing to work harder than most to meet the challenges he faces.

They are willing because they have dreams for their sons. In Warren's words, "We want both boys to be happy, to have a great life with lots of good friends around. We want both boys to be confident that they can tackle anything, and although they may not succeed, they can give everything a good, solid try."

"We don't make assumptions about what John or Jamie can or cannot do. We'll wait and see, and give them the supports, so that they can both do more than they think they can do, and more than we think they can do."

► ELEMENTS OF PREVENTION

■ Recognizing the child for who he or she is

Until a family comes to terms with their child as he or she really is – not the "perfect" child they wished for – they will not get what they want and need from the human services system.

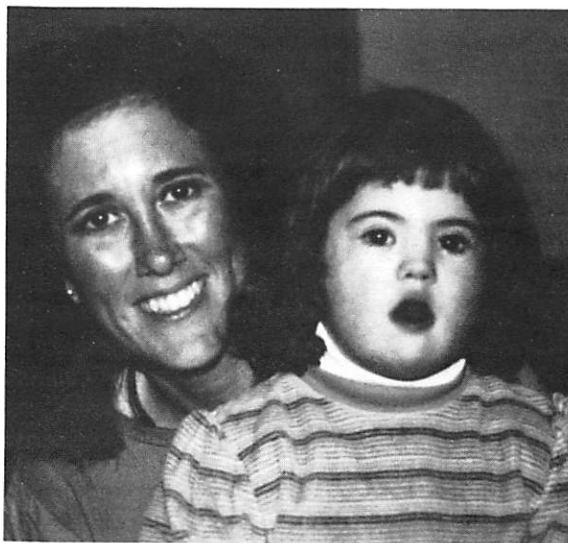
Every family hopes for a son or daughter who will be healthy, happy, bright, successful, loving, athletic, musical and just all-around wonderful.

When the child comes into the world and does not fit their "perfect" picture, trouble can arise. The family, though, must accept that this is *their child*, and belongs to them. They must be encouraged to do everything in their power to meet the child's needs, and enable the child to reach his or her potential.

The stories in this volume are about families who truly and whole-heartedly accept and love their children as they are. These are not people seeking "magic cures," or "instant fix-its" for their sons and daughters. These are families who make demands on the existing systems: the health system, the school system or the social service

system. These are families who insist that their sons and daughters receive the time and effort they deserve.

■ Love is not enough



local associations, but also as front line fighters for their sons and daughters. Fathers of children with handicaps are coming out of the closet.

Warren and his wife Dawn represent an ever-growing group of parents who are choosing to invite children with handicaps into their homes and families.

Warren and Dawn adopted twin boys, six years old, who had spent all of their young lives in foster homes. Each boy carried stigmatizing labels. Jamie was described as having "developmental lags," and being a "slow learner." John was assessed as being "a profoundly retarded male with severe cerebral palsy." The report condemned him to "never functioning at a level above 12 months," and stated that, "he cannot sit up independently and most likely never will, and has no prognosis of an independent means of communication." It was recommended that John attend a segregated school program and not take part in leisure activities because of his severe asthma.

Yet after only one year with this family to love them and push them as they would any children, one has to wonder about the competence of the medical, psychological and educational reports.

Jamie is a typical eight-year old, reading at his grade level and functioning like any other ram-bunctious boy. Aside from visits to the optometrist for the occasional pair of new glasses, he need only visit a pediatrician at the usual intervals. He is seen both by his doctor and by his new teachers as "an average to above-average eight-year-old in all dimensions."

John is another story. He is a child who should alert every parent, every teacher, every social worker and every physician to the key to prevention.

Warren, when asked to describe John, said the following:

"John is my son. He's eight years old and has a twin brother named Jamie. John is an extremely bright, alert child who has a tremendous capacity to draw people to him. He is unbelievably determined and strong-willed. He learns exceedingly quickly, and has taught all of us in the family how to communicate with him.

"John is so smart that he intuitively seems to know who sees him as a person, and who sees him as handicapped. He refuses the time of day to

anyone who treats him like a baby or a sick person.

"My son is in a wheelchair, going to an integrated alternative school with his brother. He goes to sleepovers with his friends, and to birthday parties, just like everyone else. He rides a pony and goes hiking and camping with the family during the summer. He loves music.

"My son is not sick, and he is not going to be fixed or cured because he does not need to be fixed or cured. He does need special equipment and certain kinds of assistance. For example, it would be easier to take him to a movie if the theatre is accessible to wheelchairs. But if it's not, we all go anyway. He doesn't sit in the wheelchair section because he is not a wheelchair - he sits with us.

"John fights with Jamie occasionally and sometimes gets very frustrated and angry with his limited communication. A friend of his at school discovered he knew all his letters and numbers. He is learning to read and with his new vocabulary, he can put together a story when someone writes individual words on bristol board for him.

"These days he doesn't need arm rests or chest straps to hold him in his wheelchair, and he doesn't need as much seizure medication.

"He came to us eating puréed food, and now he's a pizza fan and is especially fond of Big Macs. When he came to us he hadn't been toilet trained. Now he knows the sign for 'bathroom', and is able to tell us when he wants to go."

What made the difference for John?

- John moved from a group home to a real family.
- This family has the attitude of "loving John for who he is," not for what he is labelled as being. They have selected schools, doctors and teachers who have positive attitudes and values. Even babysitters are screened, and selected only if they have no preconceived notions about John's abilities.
- The family simply does not associate with people who see John as being sick or handicapped.
- The family legitimizes John's anger and frustration. Because he cannot speak yet, they perceive what he is saying and feeling through his eyes and body.
- The family will not readily go into hospital settings, because they recognize that John is not in



segregationists. In time, they will see that you are right. Set an example for them.

- Surround yourself with positive energy, not negativity.
- Realize that the fight is forever...and if you want a change, you have to struggle for it.

The role of professionals

How can professionals help parents advocate more effectively for their children's rights and be less fearful of making demands on the school and health system?

- The professional educator, social worker, doctor, etc., can help a parent see that he or she does not have to, and in fact cannot, do it all alone. The professional must first and foremost help the parent build a support group comprising

friends, relatives and other professionals.

- The professional can help the parent to be a good enough parent, not a saint or a martyr. The parent must learn to accept that he or she is human and fallible and can make mistakes.
- The professional can admit that he or she doesn't have all the answers and doesn't know it all. One parent broke down and cried in gratitude and relief when she finally met a doctor who admitted he did not know, without further tests, why the child was not learning.
- Professionals can laugh, cry and get involved. Too many faculties of education and schools of social work advise objectivity and distance. We strongly disagree. By getting involved, the professional can give advice based on close observation, not speculation.
- Professionals should recognize that not all parents want what we're advocating. Just as there are parents of typical children who want different things, so there are parents of handicapped children who have different views. We must overcome the fictitious mystique of the parent of the handicapped child. All parents are not what we want them to be.

The answer lies in the partnership of like-minded individuals and organizations who are calling for change. It is not parents vs. teachers or parents vs. doctors – it is some parents and teachers versus the status quo.

Both parents and professionals who want change, particularly in the school system, should understand the nature of schools and the difficulty in changing them. They should also believe that they have nothing to lose and everything to gain.

▶ MAKING A DIFFERENCE

For years, people seemed to think that children with handicaps only had mothers. These mothers were seen as either a curse or a cure, and as women who dropped their lives, their jobs, their aspirations, and devoted every minute to their son or daughter. It appeared that there was only one choice to be made: the child's life, or the mother's.

This is neither fair nor just. Women today have choices which enable them to have their own lives,

and raise a family. Those options are just as viable for a mother with a child with a mental handicap, as for any mother of a typical child.

One way in which the options of mothers are being facilitated is through greater involvement by fathers who are coming to the forefront of their children's lives. This is as true with fathers of handicapped children, as with other fathers. We are watching them not only as board members of



This opened Suni's eyes to the fact that there was still a world beyond her own tiny three-room apartment. It was a role model for her: someone changing the system and herself, too. The two of them began to meet. Because Suni had been told countless times that Tom had no future, she had become passive. Her only outlet was complaining about the situation to Brenda.

One day, Brenda got fed up. She told Suni in no uncertain terms that with such a defeatist attitude, she would never obtain anything in life for Tom, or for herself. She told her friend what no one else had pointed out before: that Suni was holding Tom back with her attitude problem.

Suni realized that Brenda was right, but she needed a plan of action. The two women recruited some other friends, and formed a support circle for both Tom and Suni. Soon Suni felt less alone, less frightened, less deserted. She assessed what she could and could not do, then she "got her act together."

Today, Tom is in a kindergarten in a school near his home. He is talking, walking and learning – all things his mother was told he would never do. This growing child sings the words to new pop songs, and best of all: he has a new circle of friends.

Although, the preceding story focuses on the role that parents can play in integration, it is essential to see that *everyone* has a part to play. You don't have to be a parent to be involved in change. In fact, the more people from a variety of backgrounds who become involved, the more accessible and permanent change will be.

As a parent, teacher, social worker, school administrator, businessperson, politician, or just an interested member of the community, you can join with us in playing a vital role.

Suni is a single mother who lives in a large metropolitan centre in western Canada. Her son, Tom, has been given every possible label, including "severe to profound mental retardation," "autism," "behaviour disorders," and so on.

His mother, however, could not accept that he was different, or "as bad as everyone kept telling me he was."

Suni began a persistent search for someone to tell her Tom had a future. She ran into brick walls until she too was labelled as "emotionally disturbed," and "depressive."

Suddenly we had two labels in a two-person family. Apparently there were no people left.

Then Suni met a woman in her community; Brenda, who was herself a mother and fighting for a good education for her two typical children. This woman was also involved in the native community, and in the peace movement.

This story makes valuable points about what parents, teachers, administrators and friends can do to facilitate change:

- Don't always listen to the experts; they can be wrong. Better yet, select your own experts.
- Be positive about the child. Focus on his or her strengths and abilities, not weaknesses and disabilities. Ask yourself, "What can he do? What does he need to do it?"
- Shoot for the moon. Don't associate with pessimists who harp on the fact that the child can't be an astronaut. Stay with your fellow dreamers and optimists.
- Focus on what "typical" children of that age do. Avoid segregation.
- Don't condemn yourself for being wrong once in a while. No one is perfect and you will learn from your mistakes.
- Talk to people who are more advanced than you are. Seek out the visionaries, and meet children living in the real world, not the segregated one.
- Don't waste your time in futile arguments with

that freedom to choose, including when to get up, where to go, what to eat, and even the freedom to make mistakes, is life.

Professionals must work together to give people this right. They must stop telling families who have a handicapped child where to send the child, what doctors to see, and basically how to control his or her future. Children must be given the options which would be a matter of course for a child without a handicap.

The need for fun

Children with a mental handicap are traditionally offered "play therapy," or teaching.

Why not offer them just plain fun? If we can't enjoy our children, we have a problem. Fortunately, a new breed of parents is discovering that laughter and good times are for all families, not just for those who do not have a handicapped member.

► EVERYONE HAS A ROLE TO PLAY

In 1981, Anna Lovich gave birth to a baby girl with Down syndrome at a large urban hospital. She decided, against doctors' advice, to keep her child, Sally, at home.

Anna went to the best children's centre and was encouraged to stimulate and educate her daughter. She was told that Sally was to attend the local segregated preschool, then the local segregated elementary and middle school, then the local segregated workshop.

The people at the centre thought this was marvellous, because only a decade ago, Sally would have been sent hundreds of miles away, banished to a huge institution.

Anna, however, was uncomfortable. It all seemed too easy. By "local," the professionals referred to places that were over 45 minutes away from Sally's home. Anna's first thought was that "local" referred to her neighbourhood school. She also wondered why everyone was so worried about what Sally would do when she was 21, when she was only four years old.

Anna started meeting with other mothers who were also unprepared to accept this blueprint for their sons and daughters. They heard another side to the story from people who had also been labelled but who had been successful in breaking out of the predicted pattern and becoming participating members of society. Inspired by them, the group started to have a new vision.

This vision was simple. Indeed, it was the same vision all parents have for any children. Why, Anna and her group wondered, should their vision be any different than any other parent's? Aren't all children children, and don't they have

the same needs? Why should there be a double standard?

Anna met the Woronkos, and the Woronkos brought the Goldsteins, and the Goldsteins introduced the Laubachs, and the Laubachs told the Perrons... These parents began their own group, the Integration Action Group, with their own convictions and values.

These families connected with others all over Canada and charted the following statement of principles:

- all children can learn and develop;
- all children have the right to live at home in a family;
- all children have the right to share educational experiences with others their own age;
- all children have the right to neighbourhood friends and relationships;
- all children have the right to supports and services as needed, and these should be available in the neighbourhood school, in a regular classroom setting;
- all children have the right to an education that will prepare them to live and work in the real world;
- all children have the right to acquire the daily social and coping skills that develop through life in the community;
- all children have the right to be "just one of the kids";
- successful integration of a child with extra needs benefits not only the child, but also his or her friends and peers, the school system, and society as a whole.

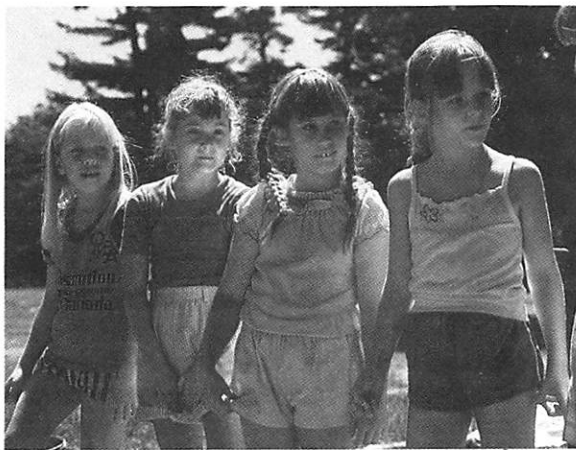
► THE NEEDS OF ALL CHILDREN

Dr. William Glasser is well-known for his books on mental health and education, particularly **Schools Without Failure** and **Reality Therapy**.

In his most recent book, **Take Effective Control of Your Life**, this noted psychiatrist states that all human beings have four basic psychological needs:

The need to belong – to love, share and cooperate

Every one of us needs friends, family and love. The people we write about in this volume are no exception. These are parents who saw that their children were lonely and unhappy, and wanted to help them make friends. It is a sad fact that adults with a mental handicap have few, if any, unpaid people in their lives. This is through no fault of their own. Our society has taken them away from neighbourhood schools and segregated them for learning as well as for leisure. It is no wonder they never learned how to behave as accepted, fellow social beings. We taught them all the skills but the most important one: that of interacting with friends.



In an interview, the noted performance artist Ronald Satok stressed again and again that what he needed most when he lost his sight was friends. They get to the core of us and affirm us as entire human beings.

“I didn’t need or want people feeling sorry for me,” Mr. Satok explained. “I shunned them like the plague. I was still an artist because I paint what I know, not what I see. I work with many parents of children with challenging needs, and I advise these parents to make sure their children are surrounded by people who will be their friends – not therapists or counsellors, but real friends. Without this, what’s life?”

The need for power

Each of us strives for power and recognition, be it negative or positive. In this instance, think of power as turning on a light, so that the surge of electricity lights up a dark house.

Most people with handicapping labels have little or no power...people have power over them. They are told where to go to school, and where to live. Ironically, our society has forced them into segregated and isolated environments. Yet when given a choice, they would elect the least restricting option, just as anyone else would.

All oppressed groups seek power, because without it, no changes would be made. For example, it was the power of the consumer movement which changed the name of the Canadian Association for the Mentally Retarded (CAMR) to the Canadian Association for Community Living (CACL).

True professionals will *share* power with the people they serve, resulting in benefits for everyone involved. A major problem with school systems is that they get in a power struggle with parents, oblivious to the fact that partnership is the only answer, not a win/lose situation.

The need for freedom

Tony McGilvary has spent most of his adult life in prison. He began as a child with the label “slow, and a behaviour problem.” By 12, he was in and out of group homes and juvenile detention centres.

Now, after spending 26 years behind bars, he is free and dedicating his life to keeping other children from living life under a label. He knows



doesn't feel that she has to do everything alone. She has friends who will stay with Cathy when she and Stan take a holiday, and she has hope. Stan has become a leader in the movement for integration, and speaks about what can be achieved to teachers and parents all over Canada.

Cathy's story is a true illustration of how further handicap can be prevented and a life of quality can be promoted:

- Cathy Woronko has been prevented from living out her life as the victim of institutionalization;
- Cathy has been prevented from heading for a sheltered work environment, because she will

learn more skills at a regular school and ultimately be more employable;

- another generation has been prevented from living *down* to the false limitations of their *labels*, because Cathy's abilities, not disabilities, are being addressed and promoted;
- the Woronko family has been prevented from breaking down, because support systems, including in-home respite care, are being provided to them.

Living, learning and growing in the community

As we mentioned in Volumes I and II of **Making a Difference**, helping children remain with their own or alternative families is essential in preventing further handicap and promoting lives of quality. As children grow, the issue of prevention goes even further beyond health care than we had discussed originally.

Of course, we are still concerned that children be immunized appropriately and that potential health hazards be eliminated from their environment, but there are also additional concerns which take on growing importance, especially for children who already have a handicap.

In this volume, we look at how living within a natural or alternative family, learning in an integrated environment with non-handicapped peers, and growing up in one's own community, can and does prevent handicapping circumstances and conditions and promotes lives of quality.

► INTRODUCTION



Cathy Woronko awoke one morning recently to find her new school uniform on her bed. Her Mom came into her room to help her dress for her first day at high school. An air of excitement filled the house. Mr. Woronko and Cathy's brother, both with rolls of film in their cameras, anxiously waited for her to descend the stairs.

Finally she appeared, in the plaid skirt, starched white blouse and navy tie that all the girls wore to St. Joan's High School.

Hundreds of scenes like this were being played simultaneously all over this Canadian community. Expectant teenagers were starting high school while their excited parents captured a special moment: their child taking another step in growing up.

But for the Woronko family, there was a big difference. Cathy had been labelled as "severely to profoundly mentally handicapped," and had been in segregated services since the age of one. Although her parents were never entirely comfortable with this arrangement, they saw no other alternative.

However, in 1984 the Woronkos attended their first seminar at the National Institute on Mental Retardation. The options covered during the course of the discussions on educational integra-

tion led Mr. Woronko to declare, "I felt as if I had been mugged."

At the seminar, the Woronkos and twenty other families explored different alternatives and dreamed different dreams for their sons and daughters. The Woronkos decided that they had had enough of segregation.

And so began a process that led their daughter Cathy from a segregated school to the regular high school which her brother will also attend. She now has her own program, developed by a team of professionals in conjunction with family members.

Despite tremendous resistance, pressure on the family and time constraints, the Woronkos had gone to court and won the right for Cathy to attend a regular high school. They won because they were not alone. They had a support network ready to lift their spirits whenever they were down...not just because flowers and balloons were sent to their home during their days in court, but because they had a new vision, and most of all because they finally saw Cathy as an evolving person, not a "mentally retarded client."

The theme of this volume of **Making a Difference** can be summed up by the Woronkos' story. Their story is the future. By helping Cathy become a real member of her family and her community, we have prevented circumstances that would have caused her to become socially disadvantaged and acquire further handicaps. We have also given her the chance to ameliorate her handicap by learning new skills which will enable her to function better in the community.

The Woronkos are not special or unusual, or rich or famous. They represent thousands of families all over our country who are uniting, combining their resources to create social change. They have become a moving force behind improvements in the lives of their sons and daughters.

If you visit the Woronkos today, you'll see that they are all different. Stephane, Cathy's younger brother, was ready to organize his friends to demand that his sister be allowed to attend a regular school. Marthe, Cathy's mom, looks ten years younger and for the first time in seventeen years,

PREFACE

In May, 1983, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded) convened a group of approximately twenty people from across Canada in order to review developments in the field of prevention, to discuss the role of CACL and its member provincial and local associations in the field of prevention, to gain a better understanding of the role of the federal government in the field of prevention, and to develop a feasible action plan for future CACL involvement in this area. This symposium, made possible largely through a grant from the Health Promotion Directorate of Health and Welfare Canada, was the culmination of several years' work on the part of CACL. Since 1976, CACL had had a committee responsible for the area of prevention, and in 1979, when the CACL's Board of Directors conducted a major self-evaluation of the association's goals and structure, prevention was identified as one of the major directions to be undertaken by CACL.

The national symposium concluded an extensive two-and-a-half year consultation process with all regions of Canada through which a nationwide consensus had developed regarding the need for CACL to serve as a national coordinator and clearing house for information as well as a lobbyist at the federal level and provider of technical support. CACL would be supported in this role by its National Institute on Mental Retardation.

A significant contribution to the conceptualization of the problem was made at the symposium by Ron Draper of Health and Welfare Canada. Mr. Draper outlined a prevention strategy model developed by the World Health Organization (WHO) which he applied and adapted in his Directorate. Indeed, it was the presentation of this model which enabled the symposium to integrate CACL's interest in prevention within the context of the organization's overall concerns.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

Impairment refers to a physiological or psychological loss or abnormality which would

impair physical or mental function. Disability is a consequence of an impairment or a circumstance which prevents individuals from performing their social roles. Handicap refers to a disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of social roles. The concept of feedback refers to situations where further impairments and disabilities are acquired as a result of handicapping circumstances.

This approach fit in very well with CACL's concerns which focus primarily on individuals living with a mental handicap. Consequently, the notion of working not only to prevent impairment from occurring but also to minimize existing impairment and promote lives of quality for individuals provided the impetus for **Making a Difference**.

Although in **Making a Difference** we do not use the WHO terminology in such a specific way as described above, the WHO model provides the framework for these publications.

Making a Difference is a series of five monographs which address how communities can reduce the incidence of impairments which cause mental retardation and also how they can reduce those disabilities and handicaps which are environmentally caused – often by where people live or work or go to school.

A heartfelt thank you is extended to the Prevention Project Resource Team who developed the framework and content of this series, and to the staff of the National Institute on Mental Retardation for producing the final documents.

Sincere appreciation is offered to Dr. Maureen Law, Associate Deputy Minister, Health and Welfare Canada and to Mr. Ron Draper, Director General, Health Promotion Directorate, Health and Welfare Canada, for their support and direction in the process which we hope will "make a difference" for thousands of Canadians.

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Photographs

The photographs in Making a Difference are meant to illustrate certain situations and do not necessarily represent specific individuals or events.

Photographs of specific persons, however, are acknowledged.

Credits - Volume II

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Marilyn Dolmage (right), courtesy
Marsha Forest

page 11 - Rose and Maria Galati,
courtesy Rose Galati

page 12 - a Galati family wedding,
courtesy Rose Galati

page 23 - the Dolmage family,
courtesy Jim and Marilyn Dolmage

Dedication

Making a Difference is dedicated to Dr. Ronald J. Christie who spearheaded the involvement of the National Institute on Mental Retardation in the field of prevention. His death, in 1985, was a blow to the movement for persons with mental handicaps. Among his other accomplishments, Dr. Christie had also been an NIMR Associate, a former Vice-President of the Canadian Association for Community Living, a past President of the Metropolitan Toronto Association for the Mentally Retarded and a member of the American Association on Mental Deficiency.

Dr. Christie was a general practitioner in London, Ontario and a member of the Faculty of Medicine at the University of Western Ontario.

We believe that **Making a Difference** is a manifestation of Dr. Christie's hope that NIMR would take a leading role in not only helping to prevent mental handicaps, but also in promoting lives of quality for persons with mental handicaps.

NOTE

The examples and stories in **Making a Difference** are about real people and real situations. In some cases the names of individuals have been changed to avoid unwanted attention to families and children. We do encourage you, however, to contact us at NIMR if you would like to receive more information on a specific example or story.

MAKING A DIFFERENCE:

**What communities can do
to prevent mental handicap
and promote lives of quality**

**Volume III: Helping children live, learn
and grow in their communities**

National Institute on Mental Retardation

Everyone says they love their children. Who would say otherwise? But "love" means letting someone grow and develop in freedom. Love means loving individuals for who they really are, not for the persons you wish there were.

No one is saying this is easy. There are thousands of rejected children all over our country, isolated and segregated because of our limited view of love.

■ Environments are key

Children change dramatically, depending on their environment. Indeed all people do. Studies in psychology show that perfectly healthy people, when placed in mental hospitals and labelled "psychotic" are perceived as sick.

In order to prevent further handicap, we must prevent environments that cause handicaps. No one would willingly place a typical child in most environments in which we place children labelled as having a mental handicap. No matter how loving or caring the teacher, these environments are, on an educational scale, impoverished spaces for learning.

Children placed in caring family environments such as real homes have undergone dramatic improvements in their physical health, their intellectual growth and their personality. Children taken out of institutional settings look different six months later. Children who go from segregated schools into regular classes also look and behave more typically. This comes as no surprise.

The Galatis are a large, noisy clan. They have not one but two children labelled by the system as "severely-profoundly" handicapped.

When the first Galati daughter was born, the family decided she would live and be cared for at home. Both parents were teachers, so they could make sure their child learned as much as possible. They therefore rejected the professionals' recommendation to institutionalize Felicia.

When their second daughter was born, they found out she too had a "severe-profound" handicap. It was too much to handle. On the advice of family, friends and professionals, little Maria was placed in a "family style" group home



that looked beautiful and was in a community setting.

Rose Galati remembers a constant urge to look around the house for her "lost" baby. But top experts had told Rose and her husband Dominic that Maria couldn't even recognize human emotion.

Rose listened to the experts. Felicia went to a developmental centre where she passed the days among five other children who didn't speak or move. Maria remained in the group home and began to attend the local school near the group home. That is where changes began.

Rose was asked for permission to place Maria in an experimental project that would put one child with challenging needs in an age-appropriate regular classroom setting with supports. Having nothing to lose, Rose and Dominic agreed.

Maria attended kindergarten along with 20 other typical five-year olds. According to a social worker who knew Maria quite well, "Maria suddenly came alive. She had something to live for."

The other five-year olds, never having had a course in "mental retardation" or "normalization" treated Maria as "just one of the kids." One little boy decided he was going to help Maria learn to walk. Another little girl was convinced she'd help Maria talk. No one here treated Maria as anything other than the child she was.

The teachers were anxious at first, but with support they too joined in the spirit of the experiment and treated Maria as one of the kids. The little girl thrived. Her parents couldn't believe that this was happening, and started taking Maria home more often and buying her new school clothes.

They also met a group of "experts," who told them a new and different story. Their advice was to take Maria home and to demand integration at their local neighbourhood school. A social worker introduced them to the real life their daughter was living. Maria, although in a beautiful and clean environment, had different "staff" waking her up and putting her to bed daily. She had a series of houseparents who came and went and were paid to take care of her.

Dominic and Rose started to think about their daughter's life. Another friend of theirs, also a professional educator, challenged their passivity and disputed their belief in the labels placed on the two Galati daughters.

"But, what if I died? What if we were in a car accident and became disabled ourselves? What if... What if..."

Their friend replied, "Everyone fears that their children might be abandoned if they died... but

they also have friends and relatives who would be more than glad to take them if something ever did happen. Why don't you have people around you who would love and care for your children as you would?"

Dominic and Rose phoned her the next day. They had been up all night thinking about her question. None of their friends had ever taken care of the girls only because they had never asked them for help.

Several months later, Maria came home. Once Dominic and Rose looked around and asked for help, it was forthcoming. They are no longer afraid of dying. They are too busy living in a loving family environment and building support systems for both their daughters.

When Dominic and Rose were asked to describe their children now, they answered,

"We have two absolutely beautiful daughters. They have gorgeous eyes and are learning more each day. They have many friends in the neighbourhood. Maria is in first grade and Felicia in 6th grade. They go to school with their friends."



Maria and Felicia do have demanding mental and physical needs that go beyond what most families have to deal with. But they are both living proof that there is a better and more successful approach to helping children and families grow together.

We are used to seeing intellectually talented children and wealthy children get what they want from school systems. We applaud this. We want to encourage parents and educators of children not currently valued by the system to make the same demand for quality and excellence.

► THE CRISIS IN EDUCATION

Just in case anyone hasn't heard the news, the school systems all over North America are in bad shape. There are one million illiterate adults in Canada, and over four million functionally illiterate citizens. This does not even include anyone in correctional institutions or institutions for people with mental handicaps.

The key word in educational reports and studies is mediocrity. We in the field of mental handicap tend to think that we are the only ones hurt by the educational system. We are not. If we could join in with the millions of parents who also want a better education for their sons and daughters, imagine how powerful we could be.

In the most recent document studying schooling in the U.S., **A Place Called School: Prospects for the Future**, author John Goodland says that "...schools are in trouble... It is possible that our entire public education system is nearing collapse." This document, funded by 14 major foundations including Ford, Rockefeller and the U.S. Office of Education, presents all of us with an important and sobering consideration. It also makes those of us involved in the field of mental handicap realize that it is not only our children who are suffering from a poor education.

A frequent criticism of integration is that the education of the "typical" child will suffer if we place a child with challenging needs in a classroom. The fact is that the failure of our schools to educate is not the fault of one child in a wheelchair in a regular classroom.

Critiques of the educational system abound, yet little seems to change. Why? Because citizens have left education to the educators and have not dared challenge the system. Furthermore, many highly educated and insightful people have opted out of public education altogether. In the city of Toronto, for example, the public school system is losing population by at least 1 percent a year while Catholic and private systems are overflowing. Surely this is a trend that warrants our concern.

Some educational myths

Let's look at some current misconceptions and beliefs hampering progress for children with challenging needs.

Dr. Arthur Coombs, one of the leading educators in North America concludes that, "The myths we firmly believe in are the current greatest source of failure in our public schools. Myths are false or inaccurate beliefs that are generally held to be true... In education they exist by the dozen. If today's schools are to meet the challenges of our changing society, we must break loose from the myths that bind us."

The following summarizes the major myths that hinder students with challenging needs, as documented in his book **Myths in Education**.

The credentials myth

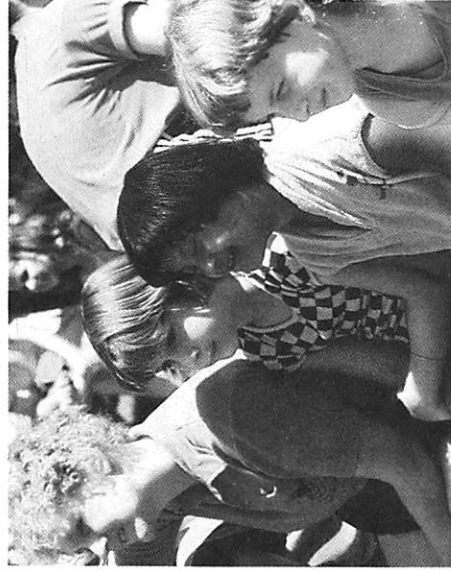
The credentials myth maintains that holding special education credentials grants the possessor greater wisdom or dependability. This is also known as the "expert" or "specialist" syndrome. Too often, we assume that specialists know everything and that the opinions of lay persons are not as viable. Yet in many instances, their opinions or observations have proven more valid than those of the experts. A good and effective education system will use the resources and talents of all kinds of people.

The myth of fixed intelligence

This myth has received its stamp of approval from a number of psychologists who make a very good living by testing and labelling people.

In many cities across Canada, a child's whole future is determined by whether he or she gets an I.Q. score of over 50. If it's over, the child may enter a regular school, but never a regular classroom. If it's below 50, the child is condemned to "retarded schools" and "developmental centres" for life.

This myth even has categories. Children are classified as gifted, average, developmental, slow, dull, educable, etc. They are then grouped accordingly. Many contemporary psychologists point out that intelligence is *not* fixed, and that the possibilities, not the limitations, are what really count.



The father of intelligence testing, Alfred Binet, had this to say:

Some recent philosophers appear to have given their support to the deplorable verdict that the intelligence of an individual is a fixed quantity which cannot be augmented. We must protest and act against the brutal pessimism...

A child's mind is like a field in which an expert farmer has advised a change in the method of cultivation with the result that in place of desert land we now have a harvest. It is in this particular sense, the only one which is significant that we say that the intelligence of children may be increased. One increases that which constitutes the intelligence of a school child, namely, the capacity to learn, to improve with instruction (Wolf, 1973).

Major thinkers such as Dr. Leon Kamin of Princeton University have challenged the validity and reliability of our use of I.Q. and other forms of testing. In his book **The Science and Politics of I.Q.**, Kamin attacks the notion of intelligence as largely inherited, and contends that testing has served as an instrument of oppression against the poor and those whom our society does not value.

Dr. Harry Silverman of the Ontario Institute for Studies in Education speaks of the misuse of tests. He recounts the story of a little boy who today would be in special education classes due to his problems in learning and his aberrant behaviour. This child, he then tells us, was Beethoven.

The Association for People with Severe Handicaps (TASH), an American group, passed the following resolution in regard to I.Q. tests:

BE IT RESOLVED that TASH supports the decision rendered by the Federal District Court in California in the case of Larry P. V. Riles, that standardized I.Q. tests cannot be used as determinants of placement or labelling of individuals with handicaps. FURTHERMORE, the Association opposes the utilization of standardized I.Q. tests for the identification, evaluation, and/or placement labelling of persons with severely handicapping conditions. (October 1979).

They myth of the value of grouping

In reality, the way in which students are traditionally grouped has little or nothing to do with efficiency or learning. How students are grouped is not a dynamic of learning. It is usually designed to help teachers and administrators carry out their tasks.

Methods of grouping that isolate students from their peers, no matter how kind the intention, do more harm than good when seen in a broader perspective.

Progressive communities are attempting to break the grouping myth through the use of family groupings. Exciting results can be found in alternative public and private schools across Canada. They not only fully integrate children with differing talents and abilities, but use cross age and cross grade level groupings. Research on alternative programs shows they do as well as or better than most traditionally placed students, even on standardized achievement tests. Students in these alternative programs also feel better about themselves and have a positive attitude toward school and learning.

All children deserve terrific teachers, great classrooms and beautiful surroundings and outstanding service. They deserve the most up-to-date techniques and technology.

So, instead of labelling children we suggest a more functional and common sense approach.

► A PROPOSAL FOR THE SCHOOL SYSTEM: LIVING AND LEARNING WITH COMMON SENSE

The following is a description of an educational model which we believe to be effective in meeting the educational needs of children. This Education for Community Living (ECL) model challenges traditional approaches to educating children with handicaps.

The ECL model is based on the concept that "special" education is obsolete, leaving only one system of education for *all* children, with

modifications and adaptations made when necessary. Two streams are not needed, because there is only one type of student: a child. Children are more like one another than they are different from each other. We need therefore to focus on their similarities, not their differences; on their strengths and needs, not only their weaknesses or disabilities.

The following chart shows the differences in the ECL model as opposed to traditional educational approaches.

TRADITIONAL APPROACH

Educational programs are created, directed and measured by "experts."

Program content is determined by "experts."

Educational resources are usually only in the classroom and are often scarce.

Children are taught only by certified teachers with the content prescribed by specialists. Primary responsibility is with the professionals.

The same educational strategies are used for everyone.

Expectations for students with mental handicaps are not very high.

ECL APPROACH

Programs are a result of functional planning by a team of professionals and people intimately involved in the child's life.

Program content is based on the child's total life environment and determined by a team.

Resources in the community are often used and are generally plentiful.

Children are taught by professionals and non-certified personnel with the content prescribed by specialists in consultation with the team, including the family. Primary responsibility lies with the team.

Different strategies are used with different students.

Expectations are much higher with the long-term goals being that individuals will ultimately live and participate in the community.

In the ECL approach, children have more options. They can learn in the community; community members are welcome to enter the school to meet the students; there is a circle of support around each child for education and planning; and as children mature, their options increase.

The ECL model studies and uses the most

current educational research and theories on how all people learn. The model understands that learning is not linear, but built from many experiences.

We know today that learning does not occur in a neat, straightforward or orderly fashion. It occurs in spurts and leaps, with the major direction being forward. Everyone wants to learn,



and everyone can learn. It is up to us to devise creative solutions and methods for teaching and getting information across.

But school imparts much more than information, reading, writing and arithmetic. School teaches first and foremost a set of social relations. How to act. How to dress. How to talk and with whom. School is a powerful political tool that teaches workers to work, and rulers to rule.

Some schools teach some children how to be handicapped. Integration can and must reverse this process.

Things that stop students from learning

Grouping children who have the same or similar characteristics will stop them from learning. For example, if there are five children in one room who do not walk, talk or eat by themselves, how can we expect them to learn? Why does this still happen when we know the effect of modelling on the process of learning? Children must have appropriate role models, because they copy what they see.

Would anyone put a talking seven year old in a room with six children who do not speak? Of course not. Then why would anyone accept it for the child who is not yet talking? A child needs the

models of other noisy seven year olds even more than he or she needs the teacher.

Some argue that handicapped children will feel out of place and would prefer to learn "with their own kind." Nonsense! Handicapped children do need to be among their own kind...other *children*.

Children need to make mistakes and discover their own ways of doing things. Teachers and parents must stop constantly criticizing, correcting and teaching. Instead, we need to stop and observe, listen and learn, as long as the child's safety is not in question.

The absolute absurdity of the education system is the classroom with two or more children who do not speak. Observers have commented on pupil responses to teachers' and aides' talk in these settings. The results are predictable. Teachers and aides participate and respond while the children sit passively and wait. This is at best absurd, and at worst cruel. Once a teacher observed a segregated classroom and compared the experience to a situation in "One Flew Over the Cuckoo's Nest." The aides sat in a circle with their students and excitedly sang the "Peanut Butter and Jelly" song, while the students sat, drooled, and stimulated themselves. Who could blame the students? They were bored beyond caring.

► An Individual Education Plan (IEP)

Bernadette is one example of a student with an Individual Education Plan (IEP) in action. After spending her life in segregated schools, she was moved into regular high school classrooms for integration. This is an advantage for her, for she will develop relevant skills, and more importantly, make friends. However, it is also a benefit to her fellow students. They will have an opportunity to assist, interact and teach a person with special needs. All will develop a more realistic and balanced view of humanity.

A comprehensive schedule is drawn up, and implemented gradually because some of the underlying concepts may be new to the teachers and students. Meetings are held between faculty members to explain the rationale and let them know what to expect.

The goals and objectives are specific, and can be broken down in examples like these from Bernadette's individual plan of action.

GOALS AND OBJECTIVES

DOMESTIC SKILLS:

To learn to dress and undress appropriately when arriving at the school, going on outings, going to the gym, going swimming (in natural contexts that arise in the course of daily routines at school)

To develop the following domestic skills: learn simple food preparation; spreading cream cheese

To learn how to set the table for one or more people at snack time and meal time; and to clean up afterwards

To learn to use the cafeteria

To learn grooming and hygiene skills in natural contexts as the need arises; e.g., washing hands before having a meal or before preparing foods, brushing teeth after a meal, washing hands and face after a meal, brushing hair when appropriate

More detailed breakdowns and goals are also supplied for short-term goals and in order that the teacher and Bernadette's classmates will know specifically what is to be achieved:

To learn to dress and undress appropriately when arriving at the school, going on outings, going to the gym and going swimming (in natural contexts that arise in the course of daily routines at school).

Bernadette will perform the necessary dressing skills when she arrives at the school, and at other appropriate times such as before and after gym class and swimming. This activity will be carried out in the same room as for Bernadette's peers. Example: when changing clothes for gym, Bernadette will remove her shoes, skirt, and blouse, and will put on her sweatshirt, pants and running shoes.

Short-term objectives:

Bernadette will learn to carry out the following tasks independently: removing her skirt and removing her blouse (with hand over hand assistance for unbuttoning).

To develop the following domestic skills: simple food preparation such as making toast, mixing

RATIONALE

Increase her ability to function in home, school and community settings; will promote independence

Participate in functional mealtime activities; opportunities for social interaction

Routine functional activity

Use an important school facility that provides many opportunities for social interaction

Clean and neat appearance facilitates social interaction; hygiene skills are important and useful for life

juice, spreading cream cheese. Bernadette will prepare food items in the Home Economics room:

Fast and easy items:

- cream cheese on a bagel
- peanut butter sandwich
- juice from frozen concentrate
- raw vegetables (wash and break to size, e.g., cauliflower, mushrooms; no cutting required)

Items requiring the use of appliances:

- milkshake in a blender
- popcorn in an electric popcorn maker
- toast in a toaster

Short-term objectives:

Bernadette will learn to carry out the following tasks independently: pouring a liquid from one container to another and pressing a button to activate an appliance.

After one year in an integrated classroom setting, Bernadette will have made dramatic progress. She will be able to function better in the community, with new friends. It is important to remember that they, too, will have become better people...through knowing Bernadette.

What to look for in your community schools

We recommend that you check the following things at your child's school, to ensure that it is a healthy, productive, stimulating environment.

- What kind of sign is on the door of your child's school? "Welcome to our school. We are pleased that you could visit. Please come to our office, where a student will be assigned to make your stay with us pleasant. We then invite you to have a cup of tea or coffee. The principal would be pleased to talk to you after your visit. Have fun!" Or are you greeted by something like this? "All visitors will report to the principal's office immediately upon entering the grounds of this school. Trespassers will be removed and prosecuted."
- Next, look at the walls and hallways. What do you see? If there is nothing but grey or green paint, tread warily. You should see colour and excitement and children's art. You should also hear music and happy voices and smell paint and good food.

If you see and feel nothing, what do you think your children are learning? If there is not child art, or child-made materials clearly in view throughout the classrooms and corridors of the school, something is wrong.

Extensive research on teaching and education shows us that there are answers to the question, "What makes a good classroom and what makes a good teacher?" Dr. S. Allan Cohen, professor and director of the Reading and Language Arts Center of the graduate school at Yeshiva University in New York states confidently that in a good classroom, teachers individualize learning for all students, spend a great deal of time on reading and language activities and place emphasis on active participation.

Schools and teachers who use tests and labels are creating useless and harmful information. Cohen states that, "Teachers who use labels on children are just hiding behind their ignorance of what to do."

Dr. Frank Smith, the noted Canadian scholar on education, particularly in the area of reading and writing, has a similar view on what makes a good education system.

Good teachers and systems are intelligently



eclectic; they use what works when they see it can work, even though they may not be sure why.

Smith goes on to say that there are two basic necessities for learning to read:

- the availability of interesting materials that make sense to the learner,
- an understanding adult as a guide (Smith, 1979).

Summary of key elements in a good teaching/learning situation

This is another checklist when you go into a school. These elements are current in any text on education. If this is not happening in your school, you must take action to make it happen.

Integration is a prerequisite to learning. Integration in itself does not guarantee education but it is a necessary precondition for learning.

- The teacher and students should both be active participants and partners in the process of learning.
- There should be no labels used except the child's name.
- The teacher should be able to give you the child's program based on strengths and needs, not test score results.
- The teacher should have high expectations and hopes for your child.

- There should be an abundance of student-made materials in the room.
- There should be an abundance of equipment appropriate to your child's age, such as computers, musical instruments, art supplies, books, games, etc.
- The program should be interdisciplinary in nature. This means that math is related to reading and art. Learning should not be sectioned.
- The teacher should look healthy and happy and have a pleasant tone of voice. Beware of the tired teacher who is irritable all day.
- Touching. Are children hugged appropriately and given feedback both verbally and through a pat on the shoulder or a hug?
- The teacher should challenge the children and not let them give up easily.
- The teacher should organize older children coming in to assist the younger ones and within the classroom children should help one another in different areas.

Here is an example:

Jane was integrated into an exciting grade one program. She seemingly did not have very much to teach the other children who were ahead of her in almost all areas. The educational team sat down to brainstorm what Jane could teach another child. AHA! Jane was a whiz at the alphabet. She knew the letters forwards and backwards. Jane became the alphabet tutor. Was she ever proud!

Every child can be a teacher to another child. Pride in helping someone else is a proven technique for confidence and skill building.

► **The Wellington County Separate School Board: how they did it**

As early as 1973, the Wellington County Separate School Board (WCSSB) in Guelph, Ontario, was examining its delivery of special education services to children in need of special programming. They were being served either in confined classrooms outside their home school community or by non-Catholic systems in segregated schools.

After intensive planning and substantial research, the board began working toward the following goal in September 1977.

"...to have every child's educational needs met in his/her home school in a regular classroom setting in accordance with their educational needs, be they of average ability, gifted or in need of remediation. Each child's social, emotional, intellectual and physical needs must be addressed."

The WCSSB program is based on children's needs. According to the board's own documents, a "needs-based program" is one which accepts:

- *that any particular child has needs that are relevant to particular situations and particular points in time;*
- *that learning is a key element in a child's educational development;*
- *that progressive development is applicable to the learning situation which in turn can be programmed and timed to suit a child's particular need;*
- *that "special education" is an integral part of each school and each classroom teacher's program;*
- *that each child is exceptional.*

The program attempts to respond to:

- *identified needs of any child;*
- *identified needs of any classroom teacher, in respect to a child's needs;*
- *a request for assistance from any child, teacher, principal, parent, etc.*

The program responds by:

- *developing an educational program;*
- *monitoring the program regularly and making necessary adjustments or modifications;*
- *following up after the intervention ends.*

Mrs. Pat Billings, a "methods and resource" specialist at St. Joseph School, speaks candidly about the system. "You can't beat it," she said. "I used to be a teacher in a self-contained special education class and now I'd never go back to that! The thing that makes this work is that it comes from the top. We get excellent professional development, courses in task analysis, communication skills, and so on."

Pat said, "Initially there was lots of resistance. Classroom teachers were apprehensive but the Superintendent of Programming got the teachers involved in the planning and gave them support in many ways, especially good in-service."

"People here work very hard," she went on. "Principals can't sit behind their desks any more because they, too, are part of the planning. One key to success is that the teachers see the principals as a supportive part of the team."

Believe it or not, there are no special education teachers in the Wellington County Separate School Board and there are no special education classes.

A visit to St. John Elementary school . . .

Ken McKenzie is bursting with enthusiasm about his school, his staff and his children. He's the principal and his office is symbolic of his attitude. It's a sitting room with a couch, chairs and interesting posters. There are 425 children at St. John. Ken explained that many of his pupils get extra help, but he has two students with particularly challenging needs. No labels for Ken McKenzie. "These two children would be in special schools in any other setting," he told me.

Anna, age 13, is currently in grade six and is going on to the junior high school in the fall. She comes to school in a wheelchair because she has cerebral palsy and was in a development centre until two years ago when her parents decided to send her to a local school. I observed Anna in her own study room having a private lesson with a teacher using a communication board.

Ken is also particularly proud of Maria, a beautiful young girl of 11, who lives near him. She had little speech when she first arrived. She used guttural sounds and was immature socially. Maria is now talking fluently, is starting to read and has good language and social skills. The other children tend to mother her a bit, but the school is working on this issue.

Both Maria and Anna are now well integrated into the whole life of the school and community. Ken had only one inquiry from a parent as to why Anna was attending St. John. His reply was quick and to the point: "Why is your child here? To get an education of course." End of discussion.

Dr. Joe Waters, the Superintendent of Programming, explains the success in meeting the needs of children in his school board stems from the school-based "prescriptive team." The main goal of a school-based prescriptive team is one of shared responsibility in providing programs to

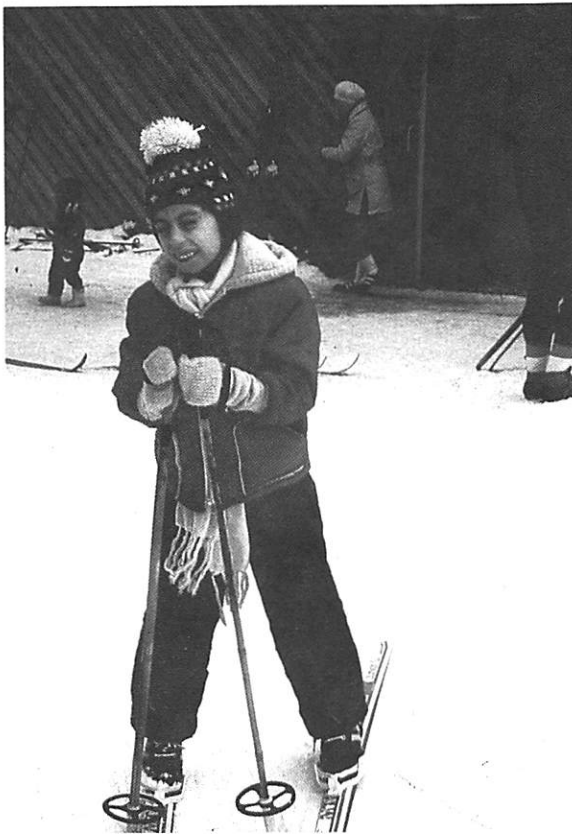
meet needs in order to maximize each child's potential.

Each of the board's elementary, junior high and high schools has a school-based prescriptive team which accepts:

- *that the centre of the program is at the individual school level;*
- *that the principal is the administrative head of the team;*
- *that the administrative and coordinating functions occur at the individual school level;*
- *that each school has a team composed of regular teaching personnel with the key personnel, the principal and "methods and resource" specialists having training in a broad general area of special education and pupil personnel service;*
- *that support personnel and materials are available at the individual school level;*
- *that disability labelling will disappear and be replaced with descriptions or objectives of the educational process or programs required;*
- *that pupil failure will become program and instructional failure;*
- *that school support personnel and methods and resource specialists will act as part of the school's instructional team, will work together with the regular teaching personnel and will be available regularly according to the size of the school;*
- *that the methods and resource specialists will be responsible for coordinating all team activities and for overseeing the actual implementation of the recommendations of the team;*
- *that additional support personnel from the central office will be available to the school team.*

Imagine a school system where:

- *all members of the school community are responsible for teaching children with a full range of special needs;*
- *supply teachers are available so that teachers can pursue quality professional development;*
- *the methods and resources specialists are regular classroom teachers who have been selected on the basis of their teaching talent, their personal skills, their qualifications and experience to act as support staff to classroom teachers;*
- *no formal testing is done but where all assessments are done to define needs and then to develop appropriate programs.*



Taking action

- Integration can work. If the top level administrators in a school system have a philosophy that *each belongs* then parents are welcomed and children are educated. No one is saying these systems are perfect but perfection is not the issue. These school systems are child-centred and needs-based, as opposed to being adult-centred and label-based.
 - Integration can also work in school systems where the top leadership is neutral or at least open to change. For many school systems and indeed for many people, change arouses the fear of the unknown and results in undue anxiety. Systems and people are therefore often resistant to new ideas.
- Parents in partnership with their advocates can win integrated placements for their children. But the families must not be naive or unarmed. Parents will only win if they
- are absolutely determined

- have no doubts about integration as an ideal
- totally accept their child
- understand school politics and dynamics
- do not expect perfection right away
- are prepared to act as educators of teachers and school administrators
- are willing to let people change.

We have learned in the past five years that resistant school systems and schools can do a 180-degree turn once the children are actually there.

Parents of children with handicaps need training in how to deal with systems, and practice in dealing with real school systems. They must know that once they demand integration they give up the special privileges of segregation. They buy into the same mediocrity that everyone else is fighting. They join the mainstream.

Parents of children with handicaps have to give up seeing their children as "special" and start seeing them as "one of the gang." This means no different treatment, no coddling and no pity.

One parent recently phoned a teacher demanding that her child have a nurse to feed her lunch as they used to do in the developmental centre. The answer was 'no'. A nurse wasn't needed at all but a student from a nearby high school volunteered to assist with her lunch in the company of all the other children. The mother was shocked at how much she had "bought into" the medical model.



Gus Nicolaidis and his parents are a case in point. Gus, now thriving in the 6th grade and walking to school with his younger brother, was

ready for integration far sooner than his mother and father. They had been holding him back by their own fears.

DON'TS

- you won't win if you are alone;
- you won't win if you are a pessimist;
- you won't win if you are not a positive thinker;
- and you won't win if you cling to labels.

DO'S

- you will win if you have allies and advocates;
- you will win if you see a future and are an optimist;
- you will win if you have hopes and dreams and creativity and imagination;
- you will win if you speak from your heart and use common sense;
- you will win if you smile and look healthy;
- you will win if you understand you are part of a movement for social justice and freedom;
- and most of all you will win if you are stubborn and persistent and courageous and full of energy.

Over the years many teachers and administrators have altered their attitudes. The key to change was having *one* child in the neighbourhood school and creating a network of support for the teacher. This does not require huge expenditures of money nor massive retraining – it requires a desire to change, and new attitudes.

The technology is available. There are the materials and the people ready, willing and able to help school boards evolve. There are model projects and school boards that serve as harbingers of a new and better future for all children.

A final success story

Jim and Marilyn Dolmage lived in a small, conservative community. They built a dream house on the lake and planned to raise their three children in an atmosphere they valued.

However, Jim and Marilyn were forced to leave this community and their friends because of an intractable school system which insisted that Matthew Dolmage attend the local "special" school for mentally handicapped children. The school board fought this case hard and spent thousands of dollars to keep Matthew out of his neighbourhood school.

What had the Dolmages wanted for Matthew? At first they wanted a self-contained classroom setting with a competent teacher who was trained in the use of sign language. As time went on, however, they started to want what they wanted for their other children. They wanted Matthew to go to school with his sister and brother and have an appropriate program in a regular classroom setting.

After two years of appeals and litigation the Dolmages are settled into a new home in Orillia. All three Dolmage children go to school together and Matthew is in a special class in the regular neighbourhood school with lots of integration into the other activities of the school.

"It's not perfect yet, but we're all working on it," says Marilyn Dolmage.

The real success is that Matthew feels good about himself these days. The first week of school a school taxi came to pick up Matthew, but the family politely refused. Matthew was to travel to school with his brother and sister or go in his own unique scooter. In bad weather he'll need some help and the family plans to recruit one of the older kids at the school.

The lunch room group at the school, called the "Eat Club Kids" is taking classes in sign language

in order to communicate better with Matthew.

He attended an integrated day camp program with the same children he goes to school with. This made it easier when he started school, as he knew all of them.

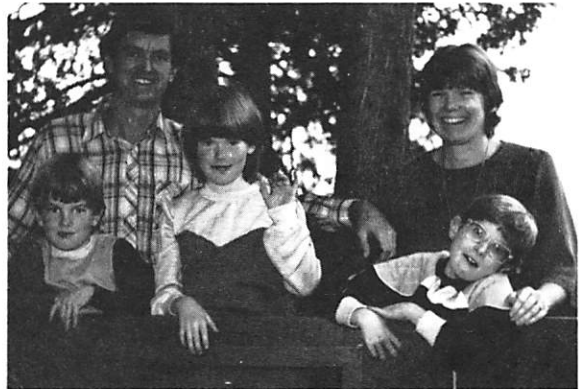
A nice spin-off of the Dolmage story is what happened to another group of parents in their new community. The school board was going to move a "developmental" class back to the special school. The parents, happy with the interaction their children had with their typical peers, simply asked if the class could remain. The board said 'yes'.

Marilyn was asked to summarize what she had learned from this whole episode in the life of her family:

- We all learned not to underestimate Matthew. The world is his if we prepare him and the world for each other.
- We used to accept labels and now we don't. They're stereotypical and useless. Matthew is much more like other kids than different from them.
- I regret now that I didn't simply register him in kindergarten in the neighbourhood school and fight the fight then. At that time when the school principal asked me about Matthew I told him all the problems and labels. I don't think I'd do that ever again. Now I see what he can do not what he can't.
- We thought we wanted a diagnosis, a cure, but we now know that we needed people who would tell us what to do; for example, how to get Mat-

thew from the floor to his knees; how to communicate with him.

- Some people really hate us. A lot of parents at the special school are secure and have their son's or daughter's future mapped out. They feel we've upset their apple cart. They feel we don't accept Matthew as "handicapped" and they are right. We know Matthew is unique and so are all our kids.
- We started with narrow self-interest – our son – and now we see this as an issue of human and civil rights.
- We're so lucky. We have a whole team of supportive people with us. We're all into computers now. We found a computer expert who is willing to work with us to help Matthew. We found professionals who said, "Let's try this or that and hope something exciting happens."
- All in all, it's been so worth it!



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