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Hope for the Mentally Retarded

CHILDREN who are handicapped mentally may be born into any family whether it be high or low on the social scale, rich or poor on the economic scale. Mental retardation plays no favourites. Anyone, and anyone's neighbour, can have this problem in his family. There is no sin, shame or blame attached to it.

Pearl Buck, author of *The Good Earth* and a dozen other novels, who won the Nobel Prize for her rich and truly epic descriptions of peasant life in China and for her biographical masterpieces, revealed to the world through her book *The Child Who Never Grew* that she was the mother of a retarded child. With this frank and moving story she raised hope in the hearts of legions of mothers and fathers of retarded children the world over.

To bear a child who is retarded mentally is not, she pointed out, an occasion for guilt feelings. Stripped of its technical terms, retardation is simply this: As a result of a combination of hundreds of medical, psychological and social factors, many of which are quite obscure, the child's mental growth is limited and will not progress to equal the "normal" stature of persons at the same age level. The retarded child learns more slowly than others and is limited in what he can learn. Simply stated, that is all.

This is not to say that retardation is not a serious affliction, but to deny that it is punishment for transgression against divine law and therefore something to be borne resignedly. It is, on the contrary, a challenge to parents and to society to help the afflicted child to make the most of his life.

The Irish, in their soft-spoken perceptive way, refer to the retarded child as "a person requiring special care."

Retarded children were once discarded children. They were treated with fear and rejection. Then, under the influence of education and science, the emphasis progressed through pity to acceptance and understanding.

We know today that the vast majority of the retarded can be successfully integrated into the mainstream of Canadian life. A great number can in fact progress to

the point of total self-care; many can become semi-dependent, and a substantial number become self-supporting.

Canadians are concerned

That Canadians are deeply concerned about the problem, and are putting forth great efforts to solve it, does not mean that Canada is unique in the number of retarded citizens. It does mean that mental retardation is a permanent condition and as such often shows up in an advanced and technical society.

Our society spotlights those who cannot keep up with the mass, but it also offers hope to them. We believe that every child in Canada, no matter what his limitations may be, is entitled as of right to a chance to develop in accordance with his capacity. We must give him — if we are to live up to our principles — what is needed to enable him to realize his potential whatever it may be.

The past twenty years have seen our awakening to realization of our obligations. There has been a dramatic increase in research directed toward prevention, treatment and care. Parents have banded together in nearly every city and village to provide facilities for application of what is learned. Governments have interested themselves, recognizing that the mentally handicapped children are entitled, according to their capabilities and needs, to the same privileges, opportunities and protection as other citizens.

At the Federal-Provincial Conference in 1964 a speaker spelled out society's responsibility to provide the mentally retarded with: (1) The opportunity for self-fulfilment; (2) The preservation of personal dignity and the protection of rights; (3) The opportunity to participate and contribute; (4) The opportunity to attain happiness.

This is a high ideal, but no higher than the situation warrants. Mental retardation is Canada's severestcrippler, disabling ten times as many persons as diabetes, twenty times as many as tuberculosis, and ten times as many as polio affected even during the peak of the scourge. We have an estimated 600,000

mentally retarded children and adults, and two million persons in their families are affected. There are nearly a dozen institutions each caring for more than a thousand mentally retarded, and scores of smaller institutions.

Who are the retarded?

Retardation has been measured in terms of intelligence-quotient, commonly referred to as "I.Q.". In these terms the mildly retarded child is generally defined within the I.Q. range of 50 to 70; the moderately retarded, 35 to 50; the severely retarded, 20 to 35, and the profoundly retarded, below 20. An intelligence-quotient of 90 to 110 is the range of ordinary or "average" minds.

Less than a generation ago many of the experts held that intelligence was fixed at birth. The stimulation animating workers in the field today springs from living proof that mental ability can grow when nourished with human warmth and encouragement.

There is abundant evidence that intelligence is strongly affected by environment. It is this new knowledge, giving expectancy of success in salvaging children's lives, that sparks the present effort all across Canada. Parents, schools, churches, professional people, and governments on all levels, are acknowledging their obligation to provide the environment in which retarded children can blossom into participating members of society.

Vital in this effort is the early detection of retardation. This involves first of all the parents and the family physician, and the primary responsibility in the child's early years rests upon the parents. Between the ages at which a child finishes his inoculations, around eighteen months or two years, and when he goes to school, there is a gap in medical supervision. The figures in any handicapped registry show that the number of children that are first diagnosed as being retarded at six or seven years of age is high.

If a child seems to be lagging in self-help, locomotion, eating, or in communication skills, its parents should seek the physician's opinion at once.

The physician's role at this moment is crucial. He has the professional training and skills to medically evaluate the child. His alertness may permit identification of retardation many years before a diagnosis might otherwise be made, thus making possible the beginning of helpful therapy that would modify or reverse the course of the disorder.

Professional help

The critical feature in detecting retardation is deviation from the usual development expected of normal children. The physician, the public health nurse, the social worker and the teacher are familiar with the developmental milestones. They will detect something possibly wrong if a child does not, at appropriate ages, sit up or grasp with the hands; walk

and talk; show interest in the immediate surroundings, or follow simple directions.

However well-informed parents may be they cannot rely upon their own knowledge in deciding whether a child is retarded or not. A hasty judgment may harm the child. He may be suffering from defective hearing or vision, cerebral palsy, communication disorder, emotional disorder, or some chronic illness.

Some children are slow starters, and may catch up on the second lap. You cannot jump to the conclusion that because a child is performing at half his chronological age today his I.Q. will be fifty in later years. Only combinations of medical, psychological, educational and social work personnel should make appraisal as to the presence of retardation.

Early detection enables parents, with the guidance of professional people, to help the child to have at least an equal chance in life with normal children.

The cause of retardation is difficult to determine. About 200 factors have been identified after wide research, including genetic accidents, infectious diseases, toxic agents, birth injuries, glandular disorders, premature birth, and cultural deprivation.

Dr. Mathilde Krim, a member of the United States President's Committee on Mental Retardation, said in an article this year: "Over fifty per cent of the existing cases of mental retardation could be prevented if all segments of our population were reached by basic health services and would know how to apply those relatively simple and well-established preventive measures that have become part of the life of the more aware and affluent among us."

A course to follow

Every person should learn before marriage the facts about genetic upsets. The genetic material that determines our inherited physical and mental characteristics is located in 46 small bodies present in the nucleus of every living cell. These are called chromosomes. Sometimes something goes wrong in our germ cells or during the first cell division, and abnormalities arise. Science has not yet found a way to prevent these occurrences. The thing to do is to recognize that they can happen, so as not to be caught unprepared and unqualified to deal with them.

The discovery of retardation in a child is a crisis situation in even the best-informed family. Usually there are three major problem areas: the parents' struggle to accept and value this special child; the effect on other members of the family; and the continuous care of the child and later as an adult.

Feelings of shame or guilt are enemies alike of the parents and the child. These may drive the parents into either rejection or over-protectiveness, and both can often be more emotionally damaging to the child than retardation properly dealt with.

Parents can make not only mature acceptance but a courageous and intelligent response to the challenge.

They should look for the best available counsel from professional people who are engaged in research and treatment. They should adopt a constructive attitude, and learn to live with the situation without undue stress. They will develop ingenuity and resourcefulness in dealing with strange and difficult situations. In this way, with warm love and affectionate care, they help the retarded child to develop positively and lead a useful, happy life.

When it is learned that a child is retarded, a well-rounded plan must be made to insure continuous care so that he may achieve his maximum potential. This starts with cuddling and caressing so that the child has from the beginning a feeling of belonging, and the plan progresses through many stages to final provision for guardianship upon the death of the parents.

Teaching the mentally retarded person to become self-supporting is not enough. It is also vital to help him to become fully integrated into the mainstream of society. Herein the role of the clergy is most important.

Some churches have special classes that include retarded children so that they may learn to participate in worship with their families. In some places, committees on religion for the retarded provide materials and resources that will strengthen religious leaders and congregations in their task of ministering to the retarded children and their families.

What is being done

There is new hope abroad in Canada. Just a generation ago the retarded were considered to be "hopeless cases", doomed to live out their lives in institutions or at home, in the shadows, with no hope for the future. Until a few years ago there was no public recognition of the problem; there were no special courses in universities; there was very little interest by the official health, welfare and educational organizations; the interest of the governments was limited to operation of custodial institutions. This in spite of the fact that as long ago as 1871 the Inspector of Asylums and Prisons for Ontario, J. W. Langmuir, recommended that separate training schools be established for retarded children.

Today, governments are contributing millions of dollars, though this supports only part of the cost of the still very limited services which are being provided. Some of the money needed is raised by the 325 local branches of the Canadian Association for the Mentally Retarded through the annual "Flowers of Hope" campaign. About four million dollars was contributed by the public in the C.A.M.R. "National Crusade for the Mentally Retarded" in 1966. This was to help the Association to launch a nation-wide series of demonstrations and research projects.

The chairman was Donald S. Anderson, Vice-President of the Royal Bank. Deeply impressed by what he learned during the campaign, Mr. Anderson summed up his experience in this way: "In many

respects the National Crusade and the development of research and demonstration projects were the most meaningful of all the special events created for Canada's one hundredth anniversary. The Crusade represents an investment in developing a major national human resource previously untapped — half a million young Canadians who could become productive, useful citizens if they were given the benefit of modern science and skills. It was the first truly nation-wide attempt to go beyond providing merely food, shelter and routine maintenance for the retarded. It led us to acknowledge in a tangible way the right to equal opportunity for this population of disadvantaged citizens."

The Canadian Association for the Mentally Retarded, formerly called the Canadian Association for Retarded Children, is behind the effort to cope with what is at the same time a national and a sadly personal problem.

Incorporated in 1958 as a non-profit, non-sectarian and non-political organization, the C.A.M.R. is a national voluntary association which has developed its activity from a scattering of improvised class-rooms in church basements and town halls into a national network of training facilities and services involving more than 325 local associations and ten provincial divisions. It guides the work of some 20,000 active members and more than 150,000 volunteers. It is an associate member of the Canadian Medical Association, which has urged its affiliated associations to engage in total planning for the mentally retarded.

The C.A.M.R. has played an important role in helping with the establishment of clinics, diagnostic centres and treatment facilities throughout the country. Its branches operate or were instrumental in the establishment of more than 700 special classes and schools; they direct more than a hundred sheltered workshops; they set up and administer community based residences, summer camps, recreation programmes, pre-school and Sunday school classes, parent guidance and consultant services, seminars and conferences.

Emphasis on action

The C.A.M.R. has organized itself so as to emphasize progressing with every new discovery. Eighty per cent of its funds goes into development rather than into theoretical research. It has a programme of demonstration projects covering every province. So effective has been its leadership in pioneering work and in service to the retarded that the C.A.M.R. was awarded the international Raphael Award by the Joseph P. Kennedy Jr. Foundation.

The focal point of the demonstration projects is the Kinsmen National Institute on Mental Retardation. The four hundred Associations of Kinsmen across Canada have adopted the Institute as their national project, and have contributed \$350,000 to it.

Operating under its own board of directors re-

sponsible to the Canadian Association for the Mentally Retarded, and the guidance of a cross section of professional advisers, the Institute will be a clearing house for all research findings in Canada and abroad. It will study, collate and disseminate meaningful information so that the retarded in all parts of Canada may benefit immediately.

The C.A.M.R. has from its beginning resisted the tendency revealed in many research efforts: the proneness to have reports end up in filing cabinets. If scientific knowledge is the vehicle by which the retarded children may be helped, then effective communication must be thought of as the road upon which the vehicle moves.

The National Institute will seek to blend the highly theoretical scientific and professional elements with the very practical services such as those performed by the local associations and other community agencies. Once the value of a new technique or theory is demonstrated, the Institute will make it available across Canada as fast as news travels.

Evidence of the Association's determination to carry the message of hope, and to give information to both lay and professional readers about developments that support that hope, is found in its journal, *Mental Retardation* (the French-language edition is called *Déficience Mentale*), the circulation of which has grown from a few dozen copies to 13,000. Provincial and local "newsletters" reach another 50,000.

Community effort

Following the Second World War a parents' or "grass-roots" movement began to take form in several parts of Canada. Local citizens' groups were determined to do something in this neglected field. They worked with such fervour and effect that they stimulated the interest of public bodies and aroused the public conscience. They believed that if citizens joined forces with those already engaged in helping the mentally retarded all of the retarded could lead fuller, more productive and happier lives. The Canadian Association for the Mentally Retarded is the official organ of these lay groups.

The local associations work at community level. They arrange for the operation of special classes in or associated with the schools; they meet to share their experiences and to exchange ideas; they operate day nurseries and pre-school programmes, co-operative baby-sitting, home visiting, information centres, sheltered workshops and small residences. They have succeeded in gaining increased acceptance of the retarded in their communities, they have provided volunteers for many activities, and they have carried out fund raising drives.

These associations do not put themselves forward as experts, but they do bring together parents and those who can help in a professional way.

Suspected or feared mental retardation in a child is not a subject for amateur diagnosis or treatment. The

brain is a too-sensitive instrument to be fiddled with by anyone who does not know his way around amid the infinite aspects of human behaviour.

The prevention and treatment of mental retardation requires as much human study and effort as did the achievement of a landing on the moon. All the disciplines are involved: medical, nursing, psychology, social work, education, and speech, occupational and physical therapy. The C.A.M.R., the Institute, and the provincial and local associations are co-operating to bring together the thousands of professional workers and those who need their services.

The child's viewpoint

Everyone who hopes to contribute toward increasing the life happiness of retarded children must occasionally get down on his knees and regard the world from the child's viewpoint.

The view from down there is full of frustration and anxiety. The child is very sensitive to his backwardness and unable to understand his inability to keep up with others. He is subject to taunting by his companions, and suffers through the misunderstanding of parents and teachers. Sometimes the eagerness of adults to see him make progress pushes him beyond his utmost ability, and he takes refuge in sullenness.

What he craves is understanding and patient love and support. These will encourage him to strike out, to try, and to try again.

On our adult level we need to provide for those who find things not so easy, to discover their resources and develop them. We have no magic formula which will increase intelligence; all we can do is show the retarded child how to make maximum use of his existing capacity.

Our task is to concentrate on the improvement of those circumstances affecting health, personality, manual skills, living conditions, education, and the other things which may assure the retarded child a hopeful opportunity in the rough and tumble of life.

There is a high ground-swell of interest and excitement surging all about those who are giving their effort and support to this work.

These workers base their effort on these beliefs: the retarded are human beings; they need and respond to love and affection; they can truly learn; they need the opportunity to express themselves and to be creative; they desperately need companionship.

No one summed up the nation's obligation and opportunity better than did the late Georges P. Vanier, then Governor General of Canada, in 1965, in his plea for a rightful place in our society for the mentally retarded. Here is what he said:

"I throw out this challenge to all those who believe in the value of the human being. There are hundreds of thousands of inadequately cared-for persons who need your scientific knowledge, who have need for your heart, your affection and your love. They have already been waiting too long."