

*Return to Jerry A*

## INTRODUCTION

May I begin by thanking you for inviting me to speak to you about the mentally retarded and the work that MARC is doing in this field.

Our mission is to make things easier for the parents and relatives of the retarded, and to do all we can to make life better for the retarded themselves.

To accomplish our mission, we have to bring to bear on the problem the forces of truth, religion, and friendship.

We want to know the truth about mental retardation. There is nothing about the subject that one needs to feel ashamed of. We are asking the scientists to study the subject and tell us all they can about it.

Religion has a vital role to play. When things seem darkest for the parents, it is only a religious faith that can point out the silver lining in the seemingly endless clouds of despair.

And last, but not least, is the force of friendship. The alternate name for our group is The Friends of the Mentally Retarded. We welcome the chance to tell our story so we can ask people like yourselves to be our friends - to be Friends of the Mentally Retarded.

## WHAT IT MEANS TO HAVE A RETARDED CHILD

To tell our story, let us sketch the picture of a retarded child and his family as their drama unfolds. As we do so we may note that the picture may be much worse in some families, a little better in others. And we must also reflect on the thought that many of these conditions could be improved immeasurably through an intelligent, widespread education of the general public.

This is one of the things MARC is attempting to do. That is why I am before you today.

Almost all retarded children are not so recognized at birth. The parents usually see the newborn as the lovable, sweet, cute little babies that they are. The parents usually also think that they see a normal intellect in the making. But in this, they are foredoomed to disappointment. As they look at their baby, they may project him ahead 20 years to see him entering college or getting ready to fit into the family business. If it's a she, they see her having a beautiful wedding and getting ready to raise her own happy family. But all this is not in the cards.

The realization of having a retarded child frequently comes slowly, painfully, first arising from doubts about tardiness in laughing, slow reactions to gentle stimulations, lateness in sitting up, crawling, standing, walking, uttering sounds, later words. The doubts grow, perplexities increase, because occasionally the child may do something that is "bright". The mother harbors the doubts and fears silently, while the father does the same, each dreading to mention the private, unarticulated secret, the gnawing dread that something is wrong with the child. Their predicament is made worse because nowhere in their schooling or training have they ever been told about

retarded children. The terms Mental Retardation or Mental Deficiency have never been part of their vocabulary.

But sooner or later, the day of climax is reached. It is the day of their greatest climax, of their greatest sorrow. Perhaps the school principal calls in the parents and has to tell them "Your child cannot keep up with the others. Your child is retarded." Perhaps it is their doctor. Or it may be a social worker or a clergyman.

To add to the crisis, the bearer of the bad news may feel so compassionate that the parents are given overtones of excessive hopes, or else a more pessimistic picture than is warranted. Frequently too, the news is not given in a manner best suited to the temperament of the parents. But who can blame the newsbearer for mishandling the situation since, in most cases, he or she has been untrained for the role, or if modern scientific knowledge is so backward in its understanding of mental retardation and its social effects?

And who can blame the parents if, in their emotionally charged state of thinking, they hardly understand the true verdict and all of its implication.

With the verdict now exposed, the parents undergo the first stage of this unhappy experience, - the shock stage! If they respond to help, they will eventually pass thru two other stages - the next one wherein they make a decision as to what to do with their child, and the final one, wherein they begin to think beyond their own problem and want to help others with their's. If they progress to this third stage, their adjustment to their misfortune will be quite complete.

### The Shock Stage

The first reaction generally felt by parents during this shock stage is that of being utterly alone. The tragedy is so deeply personal that the parent can now only see himself and the child. What goes on in the outside world is incidental. One mother, writing in the September 1954 issue of Adult Leadership, states - "I was sitting, vegetable-like in a chair, staring at the pattern of the rug, mired in self pity. Helplessly, hopelessly, trying to escape our problem." Another, writing in Sign Magazine states - "My husband has built a wall around himself to keep the pain out, but all he's doing is keeping help out and the pain in." Regardless as to whether or not these statements are typical, there is no denying the intense psychological shock that takes place, with the accompanying feelings of loneliness, desperateness, and helplessness.

Recognizing this, a booklet was prepared in 1954 by the State of Minnesota's Division of Public Welfare, with members of MARC and other parent's groups collaborating. Its title -

YOU ARE NOT ALONE!

And, appropriately enough, the first chapter is titled -

### It Happens to You.

Dr. Salvatore diMichael, a Ph.D. Psychologist, and executive secretary of the National Association for Retarded Children feels that this shock reaction is destructive only if excessive, or if counselling is not available for the parents.

It has been found that an effective type of counselling results when parents who have been through the mill talk it over with parents who have just found out their child is retarded. The help and comfort resulting is analogous to the help given to an alcoholic when he contacts Alcoholics Anonymous.

Here is where MARC plays one of its most important roles. A parent referred to MARC finds that he IS NOT ALONE. He finds out that he is indeed one of many. He is referred to other parents who have had the same experience he is now undergoing.

Knowing that there is someone to fall back on, the shock seems to serve a constructive psychological purpose. The person must now examine himself, his marriage partner, his child, and his relations to people that count. This new, stark reality of life must be integrated into his personal set of values. If his personal values are solid and stable, then the adjustment will be less painful, more rapid. If one's inner resources are weak, uncertain, and based on false social values, then the shock will be very disturbing. In any event, the shock serves the purpose of withdrawing the "ego", collecting the psychological energies upon an important function, namely, to re-examine the basic foundations for the meaning of life and to give the person a chance to refine or realign himself with the realities of living with himself, his family, his friends, and neighbors.

In this process, the parent often asks the question "Why did it happen to me?" One is struck by the frequent repetition of this very phrase as one reads the story of parents, hears their accounts, or reflects on what physicians, social workers and psychologists tell of their experiences in counselling parents.

You may be struck by the similarity of this reaction to that you yourself or a close friend of yours experienced as the immediate reaction to the great grief resulting from the loss of a loved one. Clare Booth Luce, for example, as reported in Newsweek this spring, uttered this question when in the depths of self despair following the death of her only daughter.

In other words, we see how the parent or the individual must find meaning for such deeply stirring events. He must try and relate it to his pattern of life values. He must somehow make it make sense.

### Gaining Perspective

With competent counselling behind him, the parent emerges from the shock stage with a grim determination to do all he can about the problem.

With this in mind, the second chapter of "YOU ARE NOT ALONE" is appropriately titled -

**"You See Things in Perspective"**

And again, MARC is ready to help the parent see things in perspective.

First of all we deal with the parents' feeling of guilt. Apparently there is a widespread feeling that the birth of a handicapped child is God's way of punishing the parents for past sins.

A short time ago I was shocked to have a young girl stenographer tell me that the clergyman in her small town had given a sermon stating this very thing. Mr. Schoenbaum, the executive director of the Minnesota Crippled Children's society has told us the results of a study made by a graduate student at the University of Iowa. This student reported that he had interviewed 150 parents of retarded children and found that 80% of them believed that their child was the result of God's punishment.

Apparently little has been done to dispel this idea since the time of Christ. Even in those ancient days people had this idea about the handicapped. Thus, in the New Testament, as recorded by St. John, Chapter 9, we read the following:

"And as He was passing by, He saw a man, blind from birth. And His disciples asked him, "Rabbi, who has sinned, this man or his parents that he should be born blind?"

JESUS answered, "Neither has this man sinned, NOR HIS PARENTS, but the works of GOD were to be made manifest in him."

With this perfect advice from Jesus to sustain and comfort us, we next proceed to explain to the parents "How the Works of God are Manifest in the Handicapped."

By his reply, Jesus invited his followers to look about them to observe their fellow men, to get a composite picture of what God had actually done when he made Man, the Animals and the growing things.

This invitation of Christ went unheeded for many centuries until a genius by the name of Francis Galton came into being in the 19th century. Galton was a cousin of Darwin and had an insatiable curiosity about people. Both Galton and Darwin were extremely brilliant men and whereas Darwin began to wonder about the origin and development of man and life, Galton began to wonder why people were so different. "Why", he asked himself, "were he and his cousin so brilliant? Why were so many other people so much less talented?" Galton, with the instinct of the great scientist he turned out to be, set about answering his questions by observing people and cataloging them as regards their ability. During the years from 1850 to 1890, Galton literally measured and classified everything he set his eyes upon. And while he was far from anti-social, he unnerved more than he hostess by using parties as a glorious opportunity for classifying the other guests according to their table manners, their nervous mannerisms, their conversations, and countless other subjects.

To handle his data, Galton created a branch of science known as "Statistics". This science, as Galton conceived it, was also found to apply to the results obtained in games of chance. Needless to say, this discovery created quite a stir. Obviously, it represented a more practical application of statistics than trying to explain away the vagaries of the human race. Mathematicians too were quite taken up with the mathematical and philosophical implications of statistics. Research on Statistics and the development of the mathematics of statistics has continued at a feverish pace ever since. Today we are using Galton's brain child in the form of the opinion polls that tell us more about ourselves than we ourselves really know. It is Statistics that is behind the electronic computers and the electronic brains. Statistical Quality Control is now the science that serves as the yardstick for controlling production in our modern factories and makes it possible to switch factories over to "automation."

And if all this were not enough, we must add that it was Galton who proposed identifying people by fingerprints. The Frenchman, Bertillon made his mark in history by doing it.

Presently I will explain a little of Galton's theories. Suffice it to say for now that Galton's findings went unheeded until early in the Twentieth Century. Galton's observations about the intelligence of people were subjective - were based on how intelligent he thought people were. It remained for a Frenchman by the name of Alfred Binet to devise a test for measuring the intelligence of people. Binet's methods were applied and improved upon in America by Professor Terman of Stanford University. The fact that this is a rather recent science is illustrated by the fact that Professor Terman is still alive today and is as preoccupied as Galton was in unraveling the whys and wherefores of the distribution of intelligence amongst the human race.

Applying the findings of Galton, Binet, Terman and many others, we find that the works of God manifest themselves as follows:

About 59% of the people are said to have normal intelligence. It is for them that the curriculum of our public schools is geared. Off to one side of the normal people we find a group of 14% who are less intelligent, said to be "Low Normal". Off in the other direction we find another group of 14% who are regarded as "bright" - as more intelligent than normal. The "Low Normals" have trouble getting through school, although they generally make it. The bright people can breeze through school without studying, and with studying, generally get wonderful grades. Off on the low side we have another group of people, numbering around 4% who are said to be dull normal. These people cannot keep up with a regular classroom situation and need special help. Off on the other end we have another group of people, numbering around 4% who are said to be very bright. These are the people who generally end up in the more exacting professions. Finally, we find ourselves dealing with the least capable 3% of the population, the mentally retarded. To compensate for them, we also have a small group of superior people, numbering 2%. These are the people who are our natural leaders. These are the people that blaze the paths of progress that the rest of us follow along in.

(Joke: These are the people that belong to the \_\_\_\_\_ club.)

Just why the intelligence of people is distributed in this fashion is not known. The geneticists say that this is the result of the chance distribution of multiple genes at conception. In other words, when chance is operating, this is what happens. The mere fact, however, that chance operates in such an orderly and predictable fashion, makes one conclude that here indeed is the way of GOD.

There is even more that makes one feel this way. Both Galton and Terman have also found that there are almost irreversible forces at work to maintain this distribution of intelligence. Very bright people, for example, generally have children less intelligent than they. Thus an Einstein seldom begets an Einstein. The children of the bright, tend towards the normal. You all remember the old slogan "From riches to rags in three generations". If all this is surprising, consider an even more surprising fact. The children of dull parents, and indeed, even of retarded parents, tend towards the normal by being more intelligent than their parents. For example, studies at the Dight Institute at the University of Minnesota disclosed that a group of mentally retarded women committed to the State School for retarded at Faribault had an average IQ of 52. These women were pregnant when committed. Their babies had an average IQ of 72, with one of the babies having an IQ of a little over 100, which is normal, and another of the babies having an IQ of 120, which is "bright".

Thus we say to the parents:

The birth of retarded children is inevitable.  
It is a normal population characteristic.  
It is no more shameful or freakish to have a retarded child than to have a very bright or superior child.

Any couple has about 2-3 chances in a hundred of having a retarded child.

You just happened to catch the wrong odds/

Before we leave this subject, we wish to clear up one other point, and, at the same time to add a word of caution. About twenty-five years ago scientists were sidetracked by not knowing the above facts and by misapplying the important findings of the French Monk - Mendel, the so-called father of the science of Genetics. These scientists falsely concluded that almost all mental retardation was inherited, in the sense of its being a "family tree" sort of condition. Moreover, they believed the condition was found almost entirely in marginal, depraved families. The story of the Kallikaks and the Jukes was taught to our college and graduate students without a true analysis of the serious limitations and the false conclusions of these genealogical studies. It is interesting to note that the general textbooks on psychology no longer mention these studies. We like to point out that amongst MARC members are several large company vice presidents, a board of directors member of two large firms, at least 10 lawyers, no less than 10 engineers, chemists, physicists, and so on. We know almost everyone in town who has retarded children. They range from millionaires (both those who made their dough the hard way and those who were born with the silver spoon in their mouth) to those who are indeed about as unrefined as

the Kallikaks. In short, the city of Minneapolis itself offers proof that the retarded can be and are born to people in all walks of life.

Now for the word of caution. We tell our parents that a small number of retarded children do result from a "family tree" sort of a situation; from what the geneticists describe as the combination of dominant or recessive genes. Thus we strongly urge parents who have had a retarded child and wish to have other children, to consult first with doctors and especially geneticists.

Dr. Reed, of the Dight Institute says, "Lightning can strike in the same place more than once". In some specific cases the chances for having retarded children are higher than the 2-3% chance cited as the general rule.

Now on to another point. You will recall that as we discussed the various groupings of people according to their intelligence, we found the grouping symmetrical around the central class of normal people. At the tail ends we ended up with the least capable 3%, the mentally retarded; and the most capable 2%, the superior.

The difference of 1% is symbolical since our percentage estimates of the various groupings are certainly not accurate within 1%. Hence, our percentage figures are, to a certain extent, arbitrary. This discrepancy between the number of retarded and superior is accounted for by the fact that something like  $1/3$  to  $1/6$  of the retarded are caused by so-called "environmental factors". This term distinguishes these types from the so-called genetical types we have been discussing up to now. The genetical types are those whose condition is determined at the instant of conception.

The environmental types result largely from malformations in the development of the fetus during the pregnancy period. As a baby develops within his mother's womb, he follows a very rigid timetable during the first three months. Every day, literally something new is added. Anything that interferes with the normal pattern of development is almost certain to harm the unborn baby and cause him to emerge into the world less than perfect. Thus we have children born handicapped in many ways, both physically and mentally. Such retarded children are generally the least capable of all. Worse yet, about 50% of them are physically handicapped as well, so much so that to see them for the first time is a shocking experience.

Brain damaged children also belong to this class. The birth process itself is said to subject a person to the worst physical beating most people ever experience. Thus, birth injuries do occur, and when the brain is thusly injured, a rather unique type of retardation results.

Then too, illness or injury after birth can cause mental retardation, and again we classify such cases as environmental.

As we approach the conclusion of today's discussion, we can now become a little more specific about the retarded. We say that they are the least capable 3% of our population. In Minnesota this represents a rather staggering number - 90,000 people.



We say that 0.1% of our population is so severely retarded as to be completely dependent. Most of these are the environmental types. They will not attain a mental age greater than three years, no matter how old they become. Some cannot walk. Some cannot talk. Some don't even know enough to feed themselves. Most have physical handicaps as well. They must have constant supervision whether at home or in institutions. 0.10% is a small number, but in Minnesota this adds up to 3,000 people.

We say that 0.4% of our population is so retarded as to be semi-dependent. We used to call such people imbeciles. They have a mental age from three to seven years as fully grown adults. These people can be trained to learn self care, acceptable social behavior, and even useful work under environmental types. In Minnesota we have 12,000 such people.

Finally we say that 2.5% of our population is just retarded enough to be classified as "marginally independent". These are the people we used to call morons and dullards. Fortunately most of these will be able to support themselves in adulthood, provided they receive training geared to their abilities, provided they have the stability and love springing from a good family environment, and provided they receive occasional counselling and assistance in adulthood as various crises develop in their lives. We estimate the number of such people in Minnesota to be 75,000.

Drawing from all three of these groups, experience has shown that 1% of our population is sufficiently retarded to remain a continuing concern of society. This 1% will always need constant supervision of one sort or another. Thus, in Minnesota we have a total of 30,000 such people out of the total of 90,000 mentally retarded people.

When these facts and statistics are translated into human feelings and everyday emotions we begin to assess the true meaning of mental retardation. 30,000 families in Minnesota must accept the cross of having a member who must always be attended to. 60,000 other families must accept and live with a member who must always be watched, checked up on, and helped through problems which to others seem quite simple.

Of all the problems facing the community, only those dealing with the mentally ill surpass in sheer numbers the problems presented by the retarded.

I am happy to say that we in Minnesota are at the forefront in doing something about the problem. But it is a rather empty joy because we are only beginning to do things which should have been done many years ago. And, unfortunately, we aren't doing nearly enough right now.

In our counselling work at MARC we do O.K. covering the ground I have described thus far. But as we enter with the parents into the second phase of their problem - helping them to decide what to do about their child - we frequently have to admit that right now there is nothing to offer. Several weeks ago I received a call from a lady. Her boy is twenty years old and has a paper route which occupies him only a few hours a day. There is nothing for him to do the rest of



the time. The woman has taken a night job, working from 11:00 P.M. to 7:00 A.M. so that she can be at home during the day to keep track of him. "Please," she asked, "isn't there something else we can find for the boy to do?" "The hours and the worry are wearing me down". I could offer her nothing but sympathy. And as I hung up the phone I burned with a frustrated resentment, and could only resolve, as I so often do, to keep working, to keep hacking away at the problem, so that maybe someday I can call her back and offer her the help she needs.

So you see, we do need help. We do need more Friends of the Mentally Retarded. And if you want me back again, I'll tell you what facilities there are for the retarded, what we are doing to try and bring more into being, and what plans and projects we have for the immediate future.

*John L. Holahan*