

You are not alone



You Are Not Alone

Information Helpful to Parents of
Retarded Children



State of Minnesota
DEPARTMENT OF PUBLIC WELFARE
117 University Avenue ST.
PAUL, MINNESOTA
1954

CONTENTS

	Page
Preface	4
Foreword	5
Chapter I, It Happens to You	7
Chapter II, You See Things in Perspective.	9
Chapter III, You Begin To Question and To Plan	11
Chapter IV, You Consult Your County Welfare Board...	13
Chapter V, How Your County Welfare Board Can Help..	15
Chapter VI, You Seek Other Parents	18
Chapter VII, In Summary	20
Chapter VIII, References You May Find Helpful	21

Cover and Drawings by Don Ritchison, Faribault



PREFACE

"You Are Not Alone" is not only the title of this booklet but a statement of fact for parents of retarded children. In Minnesota last year over 800 mentally retarded babies were born. And approximately one per cent of all babies born in this state each year are mentally retarded. This is a big problem, both to the agencies responsible for helping them, and, more particularly, to the parents who discover they have a mentally retarded child.

It is our hope that "You Are Not Alone" will lead to earlier understanding of available resources to lessen the parents' shock and confusion following a diagnosis of mental deficiency in their child. Earlier understanding, in turn, will eventually mean greater happiness for each child and his family.

The booklet is the result of group discussion by the Conference Committee on Mental Deficiency, composed of parents of retarded children, county welfare workers and staff members of the Department of Public Welfare. Miss Phyllis Mickelson, a Department social worker, has done the actual writing, but the finished text stems from group discussion and criticism. The parent members of the Committee were the ones the group most relied upon to determine the best way of presenting facts in order that they would be meaningful to other parents.

As a publication of the Department of Public Welfare, this booklet emphasizes the help which the County Welfare Board can give, because one of its legal functions is to plan for retarded children. Parent organizations are equally emphasized, however, because no one can do for a parent facing this problem what can be done by another parent who has gone through the same shock and grief.

Physicians, psychologists and other professional persons each make their own contribution to the mentally retarded child. The Committee realizes that the role of the physician is of basic importance and therefore sought and secured their cooperation and approval, as evidenced by the Foreword of the Minnesota State Medical Association which follows.

JARLE LEIRFALLOM, Commissioner
Department of Public Welfare

FOREWORD

It is difficult for both parents and physicians to face the problem of a child who is mentally retarded. In most instances, the physician who first recognizes the condition and must discuss the situation with the parents is either the family physician or the family pediatrician. In either instance, the physician usually has known the infant from the time of birth and often the family for years before that. He also lives in the same community with them, and may have almost daily contact with the parents.

There is scarcely any community into which one or more mentally retarded children have not been born, although there are seldom many such children in any one small community. Institutional care, although often wise and sometimes necessary, is not the only or most advantageous solution to every problem of mental retardation. Each situation must be worked out individually.

This booklet has been prepared by experienced social workers and psychologists with the assistance of parents of retarded children and that of physicians. It should be of help to both parent and physician at that most trying of all times: just after the initial recognition of and first discussion of mental retardation.

GEORGE B. LOGAN, M. D., Chairman,
Child Health Committee,
Minnesota State Medical Association



I. IT HAPPENS TO YOU

Perhaps your doctor has just told you that your baby has been born different, and that so far as medical science now knows, he can never be a normal child. Perhaps your Mary has been slow to walk and talk, and you realize that she is not developing like your other children. Perhaps your Johnny has been sent home from school because he can't keep up. Perhaps, in short, you have discovered that you are the one couple in approximately every 100 who must plan for a "mentally retarded" child.

If you are like most mothers and fathers, you probably have no way of knowing, at first, that this experience has come to many other parents. As far as you know, you are the only parents in the world with this particular trouble, and this can make you feel needlessly hurt, helpless and alone.

Before this happened to you, you probably hadn't realized that mental deficiency can — and does — happen to anyone. That it occurs in every race and religion, to the rich and to the poor, to the most highly educated and the most successful as well as to the "underprivileged" and to people who are "just average."

And until it happened to your child, you probably knew very little about the causes of this particular condition. Perhaps you thought — mistakenly — that it was due entirely to heredity, or to "bad blood" in the family. You probably hadn't heard about children whose brains simply failed to develop normally or were damaged before or after birth by some accident or illness; about children called "Mongoloids," the cause of whose difficulty doctors still can't explain; about these, and all the many other kinds — and the many different causes — of mental deficiency that there actually are.

If you are like most mothers and fathers, probably all you know, to begin with, is that it has happened to your child, and that it's pretty hard to take.

At first, you are probably not particularly aware of the great differences in ability covered by the term "mentally deficient" either, or of how this affects the plans that must be made for care and training. For example, some children are so severely retarded that they will always require complete physical care. Other children are less retarded. They will always need someone to look after them, but can learn to walk and talk, to care for their own personal needs, to follow simple directions, and to read and write their own names. Still others may be able to go as far as the 5th and 6th grade with special help, and may be able eventually to earn their own living at simple, unskilled work. Again, some may look perfectly normal physically, while others may be "obviously" retarded, or have other noticeable handicaps. Yet all are called "mentally deficient" or "mentally retarded."

Perhaps by the time you read this, your doctor will already have fully discussed all of the details of your child's condition with you, as planning for all such children is based first upon sound medical diagnosis. If so, you may then be faced primarily with the problem of making the very best plan for your child's future that you can.

No matter how upset you may feel at this point, it is important for you to know as quickly as you can that there is help readily available to you in this type of planning. Not help in the form of a miracle that will make your child normal. But help from your county social worker who can give you the information and counsel that you may need in planning for your child's future care and training; and help and encouragement from other parents like yourself, who know and understand how you feel because they have been through this same experience themselves. In fact, that is what this booklet is about: to tell you what this help is and where you can get it, if you decide that it can be of use to you.

**For Just as You Are Not Alone in Your Problem, You
Need Not Work Alone in Its Solution!**



II. YOU SEE THINGS IN PERSPECTIVE

Because it is a hard thing for any parent to come to accept the fact that his child is "mentally retarded," perhaps you would like a little time to get your bearings and to sort out your own feelings first. Knowing how other parents have felt and what they have done when faced with a problem like yours may help to give you added perspective too. And so, what is it like, and how does it feel to be the parent of a mentally retarded child? And what are some of the special problems that you may have to solve?

If you are like most parents, you cannot help being numb from shock at first. And as in any state of shock, you are apt to feel quite helpless and overwhelmed. You don't know what to do, how to act, what to say or where to turn. You can't believe it's really true.

And so, to begin with, you probably ask: "How could this happen to us? Surely, it can't be true. We can't — we won't — believe it. The doctor or the psychologist must be wrong. Perhaps if we tried another doctor or another psychologist, he would be able to tell us something different. It must be some sort of a mistake."

In some ways the shock may be more sudden if your doctor is able to tell you right after your baby is born than if the diagnosis cannot be made until some months or years later. By then it may be only a confirmation of what you already know or suspect, although by then, you may have built up more defenses against facing the truth. Either way, however, it is not easy to accept, and you cannot be expected to do it overnight. If you are like most parents, you will need some time to get used to the idea, to absorb the facts slowly and to turn them over and over again in your mind, alternately accepting and rejecting them before you are finally ready and able to accept the fact that your child really is different. Only then,

however, are you ready to plan for your child on a realistic basis. And only then will you be able to admit and to talk about the things your child can not do, as well as those things he can do.

Even with the passage of time, however, and even though the specialists you consult agree, your hopes for a miracle may not completely disappear. Each time you read in the newspapers or magazines about a new "cure," your hopes may be revived, and in spite of what the experts say, it may be a long time before you stop hoping secretly that your child can be made normal. That is perfectly natural and human, provided that while you hope, you also begin to study and plan for your child as he now is. As you do this, you may find, as other parents before you have found, that more can be done for your child than you had thought at first — even though you now accept that he will never be a "normal" child.

If you are like most parents, underneath your shock and bewilderment, you cannot help feeling heartache, disappointment and grief — mixed, at times, perhaps, with some resentment too. Heartache and grief that you have not had a normal child, and that you will not have the pride and joy of watching him grow up like other children, of watching him compete with them on equal terms, or even perhaps excelling them. Heartache and grief that the dreams you dreamed before his birth cannot now be realized, and that your child may never reach a full mental maturity — may never really grow up completely and be independent of you.

Since you cannot help grieving, it will be much better for you to express your feelings than to try to bottle them up inside. Particularly at first, tears and lamentations may help you to feel better and to relieve your tension, for they are a natural expression of your sorrow. However, just as soon as you feel equal to it, you should begin to reach out for help in planning for your child. It will help you personally to have something to plan for — and it will help your child.



III. YOU BEGIN TO QUESTION AND TO PLAN

As the parent of a retarded child, you will have many practical problems to solve too. These are bound to come up no matter how well you understand and accept your child's condition, for a handicapped child, by his very nature and by the nature of the world we live in, is more difficult to care for and plan for than an average child. The average schedule just will not fit him, and his presence in the home, the school and community does create special problems. And so, if you are like most parents, questions and problems like these may be bothering you:

How can we explain our child's condition to our other children — to our relatives, friends and neighbors?

Are we apt to have another retarded child ?

Will our child "grow out of it"?

How can we do what is best for our child without sacrificing our other children and our own welfare and happiness ?

Should we place our child in an institution especially planned for him, or would he be better off at home?

What should we do if there is disagreement in the family about future planning ?

How can we train our child at home ?

How much will he be able to learn?

Where can we get information about schools to meet his needs ?

What will our child be like when he is grown ? Will he be able to earn his own living and to marry ? Or will he always need to be looked after like a child ?

Who will look after our child when we no longer can ?

Your doctor may already have answered certain of these questions for you. However, to many of these questions — particularly those involving future planning — there is no one right answer that is the same for every parent and every child. Instead, the answer will depend not only upon the child's condition, but upon home conditions too, upon what the parents would like to see done, and upon what special resources are available for the particular child. All of these factors must be studied and discussed on an individual basis, for they can vary greatly.

And so, that is why this booklet was written. Not to give you a ready-made solution for your own problem, for that would be impossible without knowing all of your circumstances. It would also violate your right to make up your own mind. But to tell you how you can get in touch with people in this state who are prepared to help you find the answers to the questions that are troubling you, and to work out the plans for your child that will suit him best.

Fortunately, you live in a state that has long recognized that the parents of a mentally retarded child need, and are entitled to, special help in planning for their child. Wherever you may live in Minnesota, there are two sources of help ready and waiting for your use: help from your County Welfare Board — a public agency which is responsible by law for providing special services for the mentally retarded — and help from the Minnesota Society for the Mentally Retarded — a voluntary state-wide organization of parents like yourself. These two agencies stand ready — not to take over completely for you — but to give you the information and special services that you may need in planning for your child.

Perhaps the doctor or other person who gave you this booklet has already told you something about these agencies. Perhaps, however, you would like to know more about them in order to decide if they can be of use to you.



IV. YOU CONSULT YOUR COUNTY WELFARE BOARD

In whatever Minnesota county you may live, you have an agency right on the local level to which you may quickly and easily turn for information and help in planning for your mentally retarded child or relative. This agency is your local County Welfare Board.

Since it is part of the job of each welfare board to act as a sort of clearing house of information on resources for the care and training of the mentally retarded, early contact with their office may save you needless time, effort and money. Yet it need not place you under any obligation whatsoever, for any parent who needs or wants these services is entitled to them.

Unfortunately, many parents hesitate to contact their local welfare board because they have the mistaken idea that it only gives relief to the poor. Actually, each county welfare board is primarily a service agency. In addition to providing various types of financial aid, the Legislature has made it responsible for a wide variety of welfare services. An important part of these is service to children and adults who are mentally retarded. Most parents feel more comfortable about making application when they understand that they have a legal right to these services and that other equally capable parents are using them too.

Other parents, however, may hesitate to consult their local welfare board for fear that the social worker may try to force their child into an institution or to impose some other plan upon them. Again, however, the social worker does not

suggest the same ready-made plan to every parent who comes to her. Instead, her job is to help each father and mother find out about all of the possible resources and plans that might fit their child. In this way, parents can often have a wider range of choices — and a better understanding of these choices — than might otherwise be true. Furthermore, since social workers specialize in this type of counseling and are not personally involved in the problem, they can often help parents in ways that friends or relatives cannot.



V. HOW YOUR COUNTY WELFARE BOARD CAN HELP

"But just how can the social worker in my local welfare board actually help me?" you ask. Here are some examples of the specific services that she is prepared to help you secure:

Diagnostic Study

All children who are considered to be mentally retarded should have a complete medical study. In addition to a complete examination by a physician, this should include testing by a certified psychologist. If your child has not had such study, the social worker can help you to arrange for this. In case the services of a psychologist are not available in your community, she can assist you or your physician to secure the services of a psychologist employed by the State Department of Public Welfare. The doctor, of course, will correct any remediable physical defects. The findings of the psychologist, in turn, can be especially helpful to you in understanding your child's actual abilities and what you can expect him to learn, both today and in the future.

Home Care

If you wish to keep your child at home, the social worker can help you to find out what special resources there are in the community that might aid you in this.

School Plans

If your child has been excluded or sent home from school, the social worker can help you to find out whether there are any special classes in your community or in nearby areas for which your child will qualify. If there are none, she may suggest other plans for you to consider.

Information on Private Schools

Your social worker can help you to find out about private boarding homes, schools and institutions in this and other states, which might suit your child — their location, approximate cost, type of care and how to apply. If she does not have this specific information right at hand, she will know where to get it for you.

Referral to a Parents' Group

Your social worker knows about the Minnesota Society for the Mentally Retarded and is often working in close cooperation with them. If you wish, she can help you to contact your nearest chapter. Or, lacking a group in your area, she may be able to put you in touch with other parents nearby with whom you can discuss your common problems.

Information on State Guardianship

Your social worker will also be glad to explain the program of state guardianship offered by your State Department of Public Welfare. Operating both for the child in an institution and for the child who remains at home, state guardianship can protect you and your child against unforeseen events by making sure that there will always be someone standing by to guard his welfare.

Information on State Institutions

Perhaps you and your doctor consider it wise to think of institutional care. If so, your local social worker is the logical person to talk with, for in each local community she serves as the authorized agent of the State Commissioner of Public Welfare in all matters relating to the mentally retarded. In this way the Department of Public Welfare makes sure that there is someone in each local community with whom families may easily talk.

As the authorized agent of the Commissioner of Public Welfare, your social worker can help you find out which one of the various state institutions for the mentally retarded will best fit your child. She can explain how admissions are arranged, whether there is a waiting list, describe the type of care and training that is provided, explain vacation and release procedures, or help you find the answer to any other question you may have in mind.

If you wish, she will be glad to arrange for you to visit the appropriate institution so that you may actually see the facilities for yourself and confer with the Superintendent and with members of his professional staff.

Should you decide upon an institutional plan, the social worker can explain and assist you with the required Court hearing. And if there will be a waiting period, she may be able to help you to work out some substitute plan for your child during that time.

Getting such information, of course, in no way obligates you to decide on an institutional plan. However, it may help you to make a better informed decision and one with which you will be better satisfied in the long run.

A Place to Talk Things Over

Finally, if there is disagreement in your family about what should be done, the social worker will be glad to talk things over with those who are concerned — not in order to take sides, but in an effort to help you reach a better understanding. This is one reason why she will always want to talk with both parents if possible, for she knows that both parents must take part in and be satisfied with the decision.

• * *

These, then, are some of the typical services that the social worker in your local welfare board can offer. If you would like to talk over plans in relation to your child, or if you are troubled in your own mind or confused by conflicting advice, you may write, phone, or call in person for an appointment. Your Welfare Board is usually located in your County Court House or in a nearby building.



VI. YOU SEEK OTHER PARENTS

Essential as professional advice may be, if you are like many parents, you may also wish to be in touch with other parents like yourself. More and more parents are finding that there is a freedom and a satisfaction in talking over their problems with other parents that they can find nowhere else. Who knows better than they what you are thinking and feeling? The questions, the conflicts, the worries that may be troubling you. The sense of loneliness and isolation that so often comes at first. One mother expressed it this way: "Finding a parents' group was like coming home at last. We'd never actually talked to another parent or seen another child like ours before. For the first time since our child was born, we did not have to try to hide our troubles. We felt accepted and comfortable at last."

Other parents may have the answers to many of your questions too. Questions like "What can we tell our friends and neighbors?" "Which agencies in our community can be most helpful?" "How can we be sure that what we're doing is right?" They will be glad to share with you the answers that they have found. . . . Practical answers to practical questions, based on their own personal experiences.

Parents' groups have programs of education and social action too. They are usually working hard for such things as special classes in the public schools and for better institutional facilities. They are trying to get better services for all mentally retarded children, not just their own. Often too they have their own special projects like day care centers, private schools, Boy and Girl Scout troops, sheltered work-shops, or volunteer work in the state institutions. They are also doing more than anyone else to educate the general public on what mental deficiency is, why it happens, and the need to plan intelligently and adequately for all the mentally retarded. In this work they need and welcome the active help and support of every parent of such a child.

We are fortunate to have such a parents' group in this state. It is called the Minnesota Society for the Mentally Retarded. Mothers and fathers, relatives and friends of the mentally retarded from all over the state belong to it. It is an organization to which anyone may freely turn for advice and guidance.

When this booklet was written, the Minnesota Society had active chapters meeting regularly in Albert Lea, Austin, Duluth, Mankato, Minneapolis, Pipestone, Red Wing, Rice County, and St. Paul. Several other chapters were in the process of being formed. These local chapters form a state council which meets regularly, and all of the groups belong, in turn, to the National Association for Retarded Children.

If you are curious and would like to know more about this organization — and you do not know of a group in or near your community — write to the Minnesota Society for the Mentally Retarded, Powers Department Store, Minneapolis, Minnesota. Its officers will be glad to answer any of your questions and to send you a copy of their official pamphlet, "The Little Shoes." If you wish, they can put you in touch with your nearest chapter, or this failing, perhaps with other parents who may live near you.

In short, if you are the parents, the relative or friend of any mentally retarded person, the members of the Minnesota Society for the Mentally Retarded stand ready to help you in any way they can. You have only to reach out to them, and again, you will quickly find that You — and Your Child — are not alone!



VII. IN SUMMARY

These, then, are two major resources that you and your doctor may draw upon in planning for the welfare of your relative or child — your County Welfare Board, usually located in your County Court House, or in a nearby building — and the Minnesota Society for the Mentally Retarded, Powers Department Store, Minneapolis, Minnesota. Since these two agencies have a special interest in your problem, they can help you and your doctor bring together the special resources for care and training and the further understanding that you may want and need to help your child.

Being the mother or the father of a mentally retarded child may still be one of the most difficult and challenging experiences that you will ever face. Understanding and acceptance do not come without pain, and even with the advice of specialists, plans take time and are not always easy to work out. However, if you and your doctor can combine the assistance of these helping agencies, when appropriate and when needed, with your own interest and determination to help your child, you will eventually find:

For Your Child — the plan that will suit him best.

For Yourself — the peace of mind and satisfaction of knowing that you are doing all that you can.

For Your Community — the chance to work with other parents for the welfare of all mentally retarded children, not just your own.

And in the process you will constantly discover and rediscover that **YOU — AND YOUR CHILD — ARE NOT ALONE!**

VIII. REFERENCES YOU MAY FIND HELPFUL

Books

Buck, Pearl S. *The Child Who Never Grew*. New York: John Day Co., Inc. 1950. Also in *Ladies' Home Journal*, May, 1950, p. 34-35 ff. The story of Pearl Buck's own child.

Levinson, Abraham. *The Mentally Retarded Child. A Guide for Parents*. New York: John Day Co., 1952.

Pamphlets

The Little Shoes. Official pamphlet of the Minnesota Society for the Mentally Retarded. Free from the Society at Powers Department Store, Minneapolis, Minnesota.

Teach Me. A Guide for Parents and Others Who Have the Care of Subnormal Children. St. Paul, Minn.: Division of Public Institutions, 1945. Free to Minnesota parents through their local welfare board.

Articles

Spencer, Steven M. Retarded Children CAN Be Helped. *Saturday Evening Post*, October 11, 1952, p. 26-27 ff.

Newspapers

Children Limited. Published monthly by the National Association for Retarded Children, P. O. Box 85, Wall Street Station, New York 5, New York. \$1.00 for one year, \$1.50 for two years.