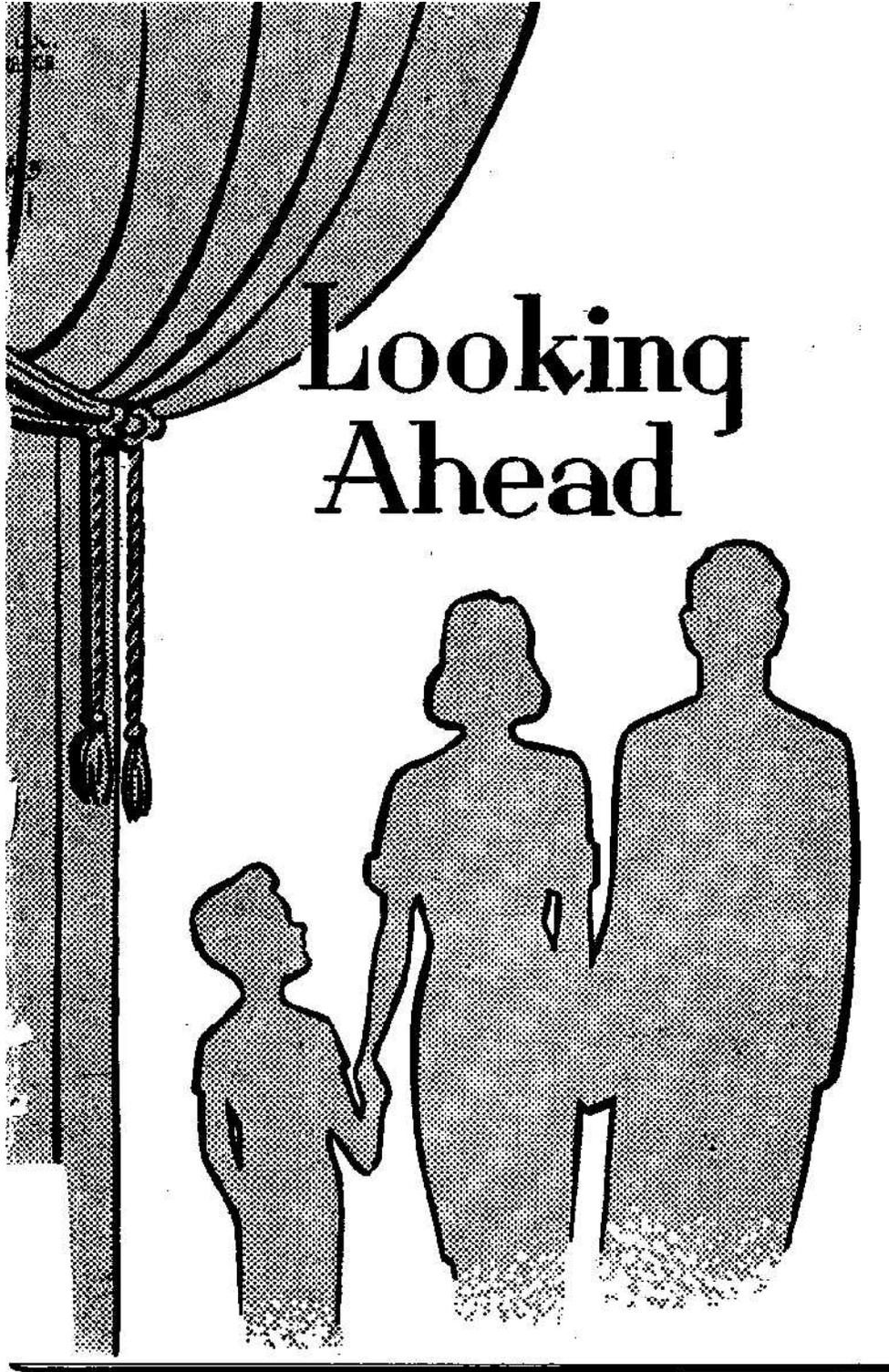


Looking Ahead



Looking Ahead

Suggestions For Parents
of
Mentally Retarded Children



State of Minnesota
DEPARTMENT OF PUBLIC WELFARE
117 University Avenue
ST. PAUL, MINNESOTA
1956

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Cover and Drawings by Mr. E. F. Matthes, Minneapolis, Minn.



PREFACE

Parents of the mentally retarded will welcome this booklet as the third link in a chain being forged by the Department of Public Welfare to give them strength, confidence and knowledge in facing up to the task ahead. TEACH ME and You ARE NOT ALONE are the first two links in this chain.

LOOKING AHEAD, like its predecessor, You ARE NOT ALONE, is unique in that it represents, in its pages, the combined efforts of professional staff members and parents of the retarded. Here the technical knowledge of the professional worker is blended with the warmth and understanding of parents who possess a knowledge gained only through *feeling* and *doing*.

The result is a warm, friendly and informative little booklet designed to make the road ahead shorter and smoother for other parents of the mentally retarded.

On behalf of those whom it may help, may I express my sincere gratitude to the Conference Committee on Mental Deficiency — parents of retarded children, county welfare workers and state agency staff members in the central office and state institutions — who gave unselfishly of their time to carry out this project.

It is my hope that to those parents who are now "looking ahead" to plans for the future, this booklet may prove of real service in giving understanding of what can be done and how professional persons may serve them in making plans for the present and the future.

**MORRIS HURSH, Commissioner
Department of Public Welfare**

INTRODUCTION

This is the third in a series of booklets published by the Minnesota Department of Public Welfare for parents who have a mentally retarded child, possibly an adult in years but a child in mental growth. The first booklet, *TEACH ME*, offers practical and specific suggestions for training the very slow child. The second, *You ARE NOT ALONE*, helps bridge the gap between the first shock and confusion upon learning your child is retarded and your decision to seek guidance in planning for him. Both *You ARE NOT ALONE* and this booklet are the result of group discussion by the Conference Committee on Mental Deficiency, a committee composed of parents of retarded children, county welfare workers, and state agency staff members from both the central office and state institutions.

In *You ARE NOT ALONE* we speak to parents experiencing the most trying of all times: after they have learned that their child is mentally retarded and have discussed it briefly with their physician or a social worker with the welfare board. We tell a little about the causes and meaning of "mental retardation," and assure you who are parents that "You Are Not Alone" in your problem. We attempt to help you see things in perspective and get your bearings. We answer some of your questions concerning practical problems and point out where you can go for help.

The present booklet, *LOOKING AHEAD*, was written for parents who are now ready to talk of plans for their child's future security and happiness. It describes in some detail the services your county welfare board can offer so you can consider what is best. It explains guardianship, and offers information on facilities to help in caring for your child at home, in a foster home, or in an institution. It suggests other individuals and groups who can help you understand your child, and plan for his future.



YOU WILL NEED TO PLAN, IF . . .

Your child, like Jane, is an infant and your family doctor diagnosed her at birth, or soon after birth, as mentally deficient and advised you to make plans for her care.

JANE IS THE DAUGHTER of Mr. and Mrs. K. They had looked forward with a great deal of anticipation and excitement, but with some anxiety too, to the day when their first child would be born. A girl was born without any apparent complications.

However, a day or two passed and neither Mrs. K. nor her husband had been permitted to see their new baby. The nurses were evasive to the K's questions. The family doctor said, merely, that because of a complication baby Jane should be kept in the hospital nursery for a few days longer. He assured them that Jane was in good health, but that he wanted to study her for a short time.

Finally, Jane was brought in to Mrs. K. Both Mr. K. and the doctor were present. The parents were immediately aware that something was wrong. The infant was quite small, and her skin seemed more wrinkled than that of other babies they had seen. Her head was almost as broad as it was long, and she had slanting eyes. Jane lay passively and did not move, although her eyes were open. They were both stunned when the doctor gently told them that their baby was a mongoloid type and could never

develop either physically or mentally like other children. He explained to them some of the implications.

Your child, like Billy, is older but helpless and your doctor has advised you to consider plans for his care outside the home.

BILLY HAD SEEMED normal and healthy at birth, and Mr. and Mrs. B. had been proud and happy when they brought him home from the hospital and showed him to their three older children. But as Billy grew they began to be worried. He showed no signs of recognizing either his mother or father for many months, was unresponsive to the people and things about him. He did not begin teething until a number of months beyond the normal time; didn't notice bright objects or grasp for them; and was unable to hold up his head until a year and a half old.

Because Billy was healthy, the B's had had little occasion, except during the first month or so after his birth, to take him to the doctor. Finally, however, he was given a thorough examination and their worries were confirmed: their youngest child was mentally retarded and would always have to have everything done for him.

They decided to care for him at home and did so for several years. But as Billy became older the burden of his care increased. Problems also developed with the older children. While young they had adjusted well enough to their retarded brother, but now the older children, in their teens, were starting to complain. They felt embarrassed about Billy's presence in the home. The oldest girl stated flatly that she would not bring her friends into the house, with the result that she was out frequently, and sometimes late, with boys and girls her parents had not even met.

The B's again consulted their family doctor and he repeated advice he had given previously — that they should not continue to care for their retarded son in the home.

Your child, like Paul, is older but not yet of school age, and you have noticed that he can't seem to keep up with his playmates and is destructive in the home. You wonder what is wrong.

PAUL, MR. AND MRS. Y'S four year old boy, in some ways looks and acts like the other neighborhood children of his age. He was a happy and responsive baby and developed like most of the other children but was slow in

learning to feed himself. He still cannot help with dressing himself, and does not make his toilet needs known.

Recently, Mrs. Y. has been concerned because Paul is not playing well with his playmates. Because he demands their constant attention, Paul's playmates quickly tire of him; they leave him alone, often in a temper tantrum.

When in the house he also demands attention constantly. The boy is unruly, disobedient and has taken to destroying things. Punishment does not help, but makes matters worse.

Mr. and Mrs. Y are beginning to fear something must be wrong with Paul and wonder if they should have him examined.

Your child, like Sam, has not been doing well in school. A study by the school psychologist revealed him to be mentally retarded.

SAM, MR. AND MRS. W'S third child, entered the first grade last fall from kindergarten, where he had had some difficulty in adjusting to the class routine and other children. Progress was slow, but there seemed no really big problem.

In first grade, however, reports from the school became progressively worse. Frequent discussions with Mr. and Mrs. W., and their efforts to help, failed to improve the situation.

Sam began arriving later and later at school, often as late as two hours. When he entered the classroom, he would stand at his desk when the other children were seated. He played constantly, and in general, refused to abide by schoolroom regulations. He paid attention only when holding the center of the stage; at other times his interest wandered. He was not popular with the other children.

About a month before the end of the school year, Sam's teacher called on Mrs. W. and told her that her youngest son's work had been so poor that he would be unable to go on to the second grade. She suggested an examination by the psychologist, who soon would visit the W's school.

The psychological study confirmed the teacher's opinion that Sam was mentally retarded and would never be able to compete with normal children.

Your "child", like David, is an adult in years and still a child mentally. You have kept him at home but must now find care for him outside the home.

DAVID, THE D'S SON, is a fully-grown 28 year old man, but with the mentality of a six year old child.

He is helpful about the house, does simple jobs, such as cutting the grass and sweeping the floor, and is clean and neat about his person. He has a happy disposition, is eager to please, and seldom gets angry. When something does displease him, David goes to his room and sulks but never becomes so angry that he breaks things.

Recently, however, the neighbors have been talking. Some of them feel uncomfortable to have a strapping, six-foot young man wandering around the neighborhood all day playing like a child, Parents of the nearby grade school children also are complaining. Although the D's try to keep David from playing with the children, he has been doing so more and more, to the displeasure of the neighboring parents and their children. The most serious complaint has come from two older men who live down the block. David recently has taken a fancy to these men, and each evening, as they pass his house on the way home from work, he runs across the yard to greet them, waving his arms and shouting. Not understanding this as a friendly expression of a six year old, they have become angry and embarrassed, and have threatened to go to the police.

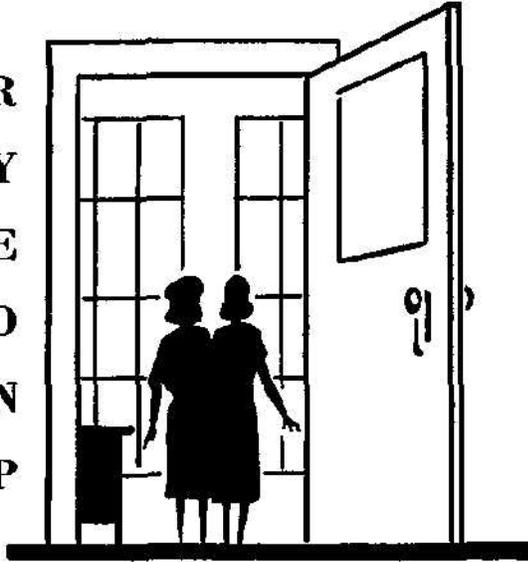
The D's, who passed middle age some time ago, are wondering what will happen to their boy when they can no longer care for him. They are thinking that they should plan for his care among others like himself, and for his life-long security.

THESE ARE ONLY A FEW of the most common problems encountered by parents of retarded children. Other examples are the multiple handicapped children who are mentally retarded as well as blind, deaf, or crippled. *Your* particular problem may not be described, because we cannot show *all* the individual problems, but only some that are most common. There also are those children who now present no serious problems in or outside the home, whose condition is accepted by parents and family, but who eventually may need the help of the welfare board for

long range planning. Also, there are the older boys and girls who are unable to secure jobs because of their limited ability.

If your problem is like any of these you will need to do something about it. First you will want to visit your county welfare board, where you can learn some of the things that might be done for your child. In the next chapter we will tell more about the county welfare board and its services.

**YOUR
COUNTY
WELFARE
BOARD
CAN
HELP**



HOW CAN YOUR COUNTY WELFARE BOARD HELP YOU?

THE SOCIAL WORKERS of the county welfare board in your community will be able to tell you of the help available for the retarded. On request, they will assist you in securing a diagnostic study and in following the recommendations made. Also, they will help you decide which of the various plans is best for your child and indicate available facilities for care and training. They will then help you secure the facilities desired — or substitutes, if there is to be a delay in some desired plans.

What Is It?

Most county welfare boards consist of the elected county commissioners and lay persona appointed by the Commissioner of Public Welfare. They work in cooperation with the State Department of Public Welfare. Each board employs a staff of social workers, persons who are skilled in assisting individuals with personal or family problems. It is the responsibility of each county welfare department to give service to the community as specified by law.

Where Is It Located?

Each of Minnesota's counties has a county welfare board usually located in the county court house. The exceptions to this are listed in the enclosed directory.

YOU, AS PARENTS OF A RETARDED CHILD, ARE URGED TO CONTACT YOUR LOCAL COUNTY WELFARE BOARD FOR THE ASSISTANCE IT CAN OFFER.

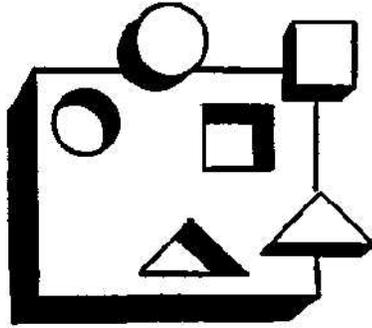
START OFF ON THE



UNLESS YOU HAVE ALREADY received advice based on a careful diagnostic study, you should obtain such a study before making any definite plan for your child. Your county welfare board will assist you in arranging for examinations which will reveal the degree and kind of retardation affecting your child. Such studies have two values: they form a firm foundation for sound planning by showing what your child may require in the way of care and training; they also may show his possibilities for future development.

Where can you go for such studies? There are a number of persons and facilities in Minnesota offering diagnostic services for your child. Which you choose may depend on how much you can afford to pay and where they are located. Mental health clinics and guidance centers are maintained under both public and private auspices in the state. Some of the larger county welfare boards have their own psychologists.

The Department of Public Welfare offers the facility of the Bureau of Psychological Services, whose psychologists travel throughout the state conducting tests and studies. This service is secured through county welfare boards. Some public schools employ either full or part-time psychologists to do this work. Many of these low- or no-cost services are listed in the enclosed directory.



AN INDIVIDUAL PLAN FOR YOUR CHILD

BROADLY SPEAKING, there are three possible plans open to parents of retarded children, any one of which may be the most practical at a given time. You can continue to care for your child at home, receiving family counseling: from the welfare agency if you wish it You may decide that he should be cared for in a private institution or boarding home, in which case the welfare agency may assist in making the necessary arrangements. Under some circumstances, in order to arrange boarding care the welfare board may provide financial assistance as needed.

Parents may feel that placement in a state institution is the best solution, at least for the present. If this is their decision, the county agency worker will guide the parents through the necessary legal procedure, and will continue to be interested and give needed service after the child is in the institution.

Keeping Your Child At Home

When parents decide to keep their child at home, there may be available in their own locality one or more community services for temporary care — day-care centers, public school classes, and church school classes.

Private Day-care Centers

Day-care centers exist in some counties to give care and training to retarded children who can be out of their homes during the day, and for whom there may be no public school facilities. The programs of such centers vary from primary habit-training to limited teaching of reading and writing. Day-care centers are sometimes sponsored and supported in part by parent organizations, other community organizations, or from welfare funds such as Community Chest. Frequently, a fee is charged, based on the parents' ability to pay. Also, there are some centers operated by private individuals,

Public Schools

Some public schools have classes for retarded children who may eventually become self-supporting. These classes are conducted much the same as those for normal children. They are, however, designed to meet the special needs of retarded children by placing more emphasis on teaching practical subjects. Several public schools also have classes for some of the more severely retarded children. They emphasize socialization, self-care and muscular coordination, and may offer some word recognition and simple number work.

Religious Instruction

In some communities various faiths offer religious training for children too retarded to attend regular services. This may consist of teaching the children Bible stories or simplified catechism. Music and visual aids may be used.

Placing Your Child in a Boarding Home Boarding Homes

Parents may decide that the best plan for their child is care outside the home. If so, they will find there are private or public facilities which offer full-time care. Private facilities include family boarding homes, and residential homes which care for a larger number of children.

Family boarding homes are those in which children are accepted to live as members of the family. Licensed by the state as meeting certain standards, these are given continuing supervision by the county welfare boards or private agencies. These boarding homes may or may not be in the parents' own community, but the majority of the children placed in them are from the same county in which the home is located. Minnesota has several thousand family boarding homes, most of which are for normal children. However, some are licensed to care for retarded children. Arrangements for placement in these homes are made through the county welfare board.

Residential homes are licensed and supervised directly by the state. Although caring for a larger number of children, they offer much the same advantages as the boarding home: the child lives in a home-like atmosphere and receives individual attention. These facilities are available for children from all over the state. Ordinarily, the welfare board of the county where the parent lives cooperates in making placement plans — sometimes including financial arrangements. The welfare board in the county where the residential home is located may participate in making plans and giving personal supervision. In some instances, parents may make arrangements directly with the home.

Nursing Homes

Nursing homes exist primarily to care for aged people but occasionally will also accept the mentally deficient adult. Those admitted to nursing homes are mostly the older retarded persons for whom no other plans are possible. Usually they have been living at home but must now receive care outside the home.

Placing Your Child in a State Institution

Most mentally deficient children not living at home are residents of one of the state institutions for mentally deficient and epileptic children and adults.

All arrangements for meeting the requirements for placement in one of the state institutions are made with the local county welfare board. It should be pointed out that due to the

lack of institutional space, there is a "waiting list." Your welfare board will have detailed information concerning this.

Before being admitted to a state institution, a child must be placed by court action under guardianship of the state. Because guardianship is somewhat complicated, and yet extremely important to you as parents, it will be discussed in the next chapter.



ABOUT 1917, THE PEOPLE of Minnesota agreed that mentally retarded persons needed more protection and services than were given to the average citizen. Therefore, laws were passed and a program set up so that the mentally retarded children and adults could be placed under the guardianship of the state. After this procedure, the Commissioner of Public Welfare is the guardian and is represented in each county by the welfare board. This guardianship is not automatic, but is secured by court action on the petition of the parents or other interested persons. It is for life, unless ended by court action.

Authority When Needed

Before telling you of the advantages of guardianship it should be understood that in addition to responsibility for the welfare of wards, guardianship carries authority to be used by the Commissioner when necessary. There *are* cases where mentally deficient or emotionally unstable parents are unable to plan and care for a retarded child. There are cases where apparently competent parents neglect or mistreat a child because of lack of understanding but refuse to ask for help. And there *are* mentally deficient persons — usually in their teens or older — who commit acts which make them a danger to themselves and others.

In such cases, the Commissioner really needs and has the authority to protect the retarded person by removing him to a secure situation. The removal may be needed also to protect others in the community. The law also recognizes that the mentally retarded cannot assume full adult responsibility and therefore says that they shall not marry.

Basis for Planning

There are many advantages in having your child placed under state guardianship. For instance, you will want to make sure he has good care all his life, particularly if he needs as much care as little Jane or Billy described in the first two examples given in chapter I,

Your child may be similar to Paul or Sam in the examples, and might benefit from special training. In this case you may be thinking of some day placing him in one of the state institutions, where he may have such training.

Your child may be a retarded person over 21 years of age. When a child becomes 21, a parent's legal authority over him ceases, although moral responsibility and natural parental interest in his protection continues. If he is severely retarded, the authority of his parents probably is not questioned. This would be true with David, or others somewhat like him. But children like Sam and Paul, described earlier, may not be so easily recognized as mentally retarded, when adult. A Sam or a Paul whose appearance does not indicate that there is retardation may choose associates that lead him into wrong acts, or he may be taken advantage of by persona for whom he might work. However, if the court finds Sam, Paul, or others like them mentally deficient, it provides guardianship in the person of the Commissioner of Public Welfare. The Commissioner can then exercise authority just as parents did in childhood.

Placement in a state institution is just one of the available plans which you may wish to make for your child, but it is one that frequently needs to be considered. To arrange for placement in a state institution he must first be placed under state guardianship. However, committing your child to state guardianship *does not mean that you must place him in an institution.*

Regardless of what plan you wish to make for him, you may welcome the fact that, if your child is committed to state guardianship, there is someone responsible for helping you to plan and to make certain that he receives the best available care and training.

Some Long Time Advantages

If your child is under guardianship, the Commissioner will continue to see that he is protected and cared for when you are no longer able to do so. In the event of the parents' sudden death, the county welfare board will see that the child is given immediate and continuing care. If money has been left in trust for him the welfare board will cooperate in planning with those responsible for its expenditure. Your local welfare board also has responsibility, wherever money is involved, to secure protection for a child under guardianship, to prevent others from taking advantage of his ignorance in such matters.

Meaning of Guardianship

Commitment to state guardianship does not mean that you give up parental rights and responsibility for your child. It does mean that the state will be legally responsible and have legal authority to see that he is protected and cared for all his life. In carrying out this responsibility you will continue planning for him with the help of your social worker and your wishes will be respected.

IN SUMMARY, state guardianship carries with it an assurance of lifetime service to you and your child. It is a requirement for placement in a state institution, and it gives authority to the state to protect your child in any way necessary. Some parents think of guardianship as insurance and rest content when it has been provided, knowing that, no matter what happens, their retarded children will receive care and protection.

HOW GUARDIANSHIP IS SECURED

A Petition is Filed in Court

As stated previously, securing state guardianship for your child involves court action. First, it will be necessary that a petition be signed requesting a hearing by your local Probate Court. Your county social worker can help you in arranging this. The social worker will talk with you either before or after the petition is filed, and, from the information you give, prepare a full "history" on your child. This history should include a description of the child's birth, his health, habits, and abilities, as well as some information on other members of the family. It will be used by the social worker, now and later, as a basis for planning: with you for your child, and also, by the court in deciding whether or not he should be placed under guardianship.

A Hearing is Held

A hearing is then held in Probate Court. Your child must be present with you. The county attorney will represent the person filing the petition (usually the parents). Two doctors will be there to assure the judge that the diagnosis of mental deficiency is correct. Another person will be appointed to act as "guardian ad litem", or guardian just during the time of court, to be certain that the child's rights are respected. A social worker from the welfare board will usually be present to assist you in giving information to the judge. The court proceedings are kept as private as possible.

Legal Safeguards

You may wonder why so many persons need to be present at the hearing, when you feel certain that your child is retarded and that you are doing the right thing by placing him under guardianship. However, every effort must be made to be positive that your child is truly mentally retarded and that you understand *the meaning of guardianship*. This court procedure is a safeguard against the very rare parent who may have a question-

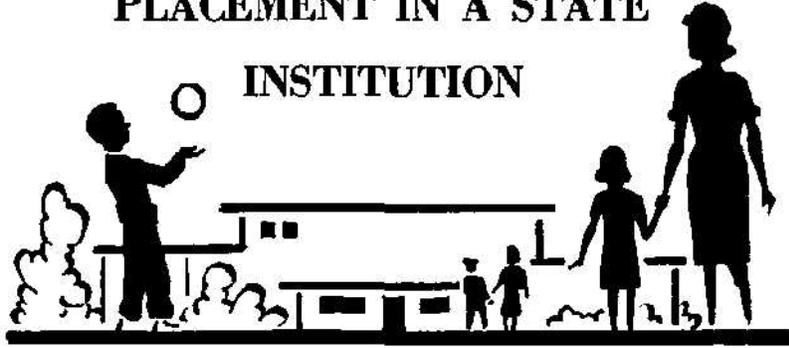
able motive in coming into court, perhaps wanting to shift responsibility for a child who is not mentally deficient. It is also an assurance that there has been adequate study as a basis for the decision that has been made.

Assistance in Preparing for Hearing

Your county welfare social worker will answer questions you may have concerning guardianship, and will explain and help you with the details of the court procedure. Whatever arrangements you are now making for your child, you should give serious consideration to the many advantages and safeguards offered by the state guardianship program.

PLACEMENT IN A STATE

INSTITUTION



TEMPORARY PLANS MAY BE NECESSARY

WHEN YOU PLACE your child under guardianship, your county welfare board has definite responsibility for aiding you in making plans in the community or elsewhere. Although you may have felt it urgent to have him cared for outside the home and were seeking placement in a state institution at the time you asked for guardianship, it is unlikely that there will be space immediately. Your welfare board will tell you of available boarding or residential homes. If such care is necessary, your social worker will discuss the cost with you. If you are unable to meet the total expense he can indicate the way in which the welfare board will be able to help. Minnesota realizes that many parents require help to meet this unusual expense; parents need not hesitate to discuss such matters with the social worker.

Perhaps you do not wish full time boarding care, but do want your child to be with others for a part of the day. Your welfare board will tell you what your community has to offer, and will help in making plans to the extent you wish help, and facilities are available.

When the Institution Can Accept Your Child

It may be many, many months or even several years after you request placement in a state institution before your child can be admitted. This is because there is a long "waiting list" for this type of care. When your child's name is reached, the social worker will tell you of it and *let you determine whether you wish*

to accept it. It is only in cases where parents are themselves incompetent or a child is extremely neglected or a menace to others that the welfare board insists upon acceptance of the space. However, if the county is paying for care in a boarding home it might consider this an expense no longer justified. When your child enters the institution, your social worker cannot promise you in what building he will be placed or what specific training will be given. The institution staff must study him and place him where it is felt his needs can best be met.

Preparing for Entrance

If you decide to accept the space offered, your social worker will help you make the necessary arrangements. A physical examination and certain immunizations must be given. Your social worker will supply the form to be completed by your doctor.

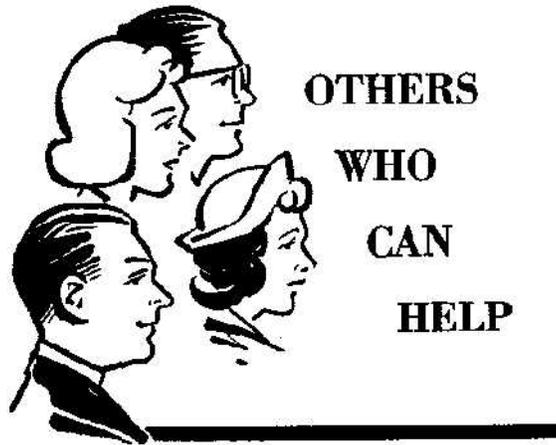
Then there is a question of clothes: you will be told by your welfare board what you should send with the child. Later you can discuss his needs with the staff at the institution.

There is also need for learning the policies and regulations of the institutions in relation to visiting, vacations, gifts, and other details associated with a happy adjustment. Then, too, the question of payment for his care must be discussed, and plans made for the trip to the institution. Your social worker will help you with all of these.

He is Still YOUR Child

When your child enters a state institution, a staff member will talk with you about him. While he remains there you can always discuss his problems personally or by letter to the superintendent. However, your county social worker is still interested and will be glad to talk with you about his future. If you want to bring your child home on a visit or vacation, or to live at home again, you *must* discuss plans with your county social worker.

Your role as parent is important when your child is in an institution. The responsibilities are different from those you had when he was in the home, but they do exist. By your continued interest and planning with the institution staff and the county social worker, your child's welfare will best be served.



PERSONS IN YOUR COMMUNITY

Your Family Physician

Before going to the welfare board, you probably talked many times with your family physician. Perhaps it was he who advised you to go to the welfare board. At any rate, he certainly will be the one who will help you to keep your child well. He also may give you guidance and help you to understand special problems which may exist.

Your Religious Leader

A talk with your religious leader may help you to understand and to overcome feelings of fear, discouragement, and even of rebellion that your child is different from the one about whom you dreamed before his birth.

Other Parents

Other parents of retarded children may be able to help you understand your child and your feelings about him. They perhaps can make helpful suggestions on how to train and teach your child. The social worker is ready, on request, to arrange for you to meet parents with a similar problem who can help you to know that you are not alone. This is true whether you live in a com-

munity where there is an organized group of parents, or far away from even a town. There are organized groups in a number of Minnesota communities. You will find encouragement if you become a part of such a group. Information regarding the location of these groups may be found in the directory enclosed with this booklet.

The County Nurse

In larger cities there may be public health clinics where you can get help from doctors and public health nurses in learning how to care for your child. If you live in a rural community or smaller city, there may be a county public health nurse who can give you this service. A nurse can understand the difficulties of feeding a child who is not taking his food as he should, of bathing and caring for an older child not able to sit up, or even roll over. She may have suggestions on how to do the tasks in the most simple way.

The Teacher

If your child is ready for school, the teacher may find the best way to help him to learn and to play with others. Talking with her may mean greater understanding,

Private Social Agencies

In some cities, there are private social agencies as well as county welfare boards. These help families meet many problems. Their services include giving counsel to members of a family to help them have a better understanding of one another, or help to straighten out a budget that would seem too great for the family income. Problems such as these arise frequently in a family where there is a retarded child. Sometimes these agencies are sponsored by a church or religious organization. Their social workers want to understand you and the problems in your family and to help so that these problems will be easier to bear.



HELP FOR THE ASKING . . .

THIS SMALL PAMPHLET cannot answer all the questions that you may want to ask. Many have to be answered in relation to your very special problems. Also, it cannot tell all the details of the law concerning guardianship or just exactly what you or the social worker will do under certain circumstances.

This is a booklet of general information to help you understand what Minnesota wants to do for you. It is hoped it will help you to ask questions for which *you* need an answer in order to plan for *your* child.

The list of organizations and agencies that is included may not be complete or absolutely correct for any date following that of its printing. However, again, if there is doubt, you should check with your welfare board. Remember the staff is there to work *with* you and *help* you.

NOTES

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