Volume I

A Philosophy

of Progress

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A COMPREHENSIVE PLAN TO COMBAT MENTAL RETARDATION IN THE STATE OF MINNESOTA

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Report to the Governor

2 A COMPREHENSIVE PLAN TO COMBAT MENTAL RETARDATION IN THE STATE OF MINNESOTA

VOLUME I.

A PHILOSOPHY OF PROGRESS

Prepared by the 1 Minnesota Mental Retardation Planning Council

3 April, 1966
2 vols.
Centennial Office Building
St. Paul, Minnesota 55101

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STATE OF MINNESOTA
MENTAL RETARDATION PLANNING COUNCIL
CENTENNIAL BUILDING
ST. PAUL, MINNESOTA 55101

March 1, 1966

Honorable Karl F. Rolvaag
Governor of Minnesota
Room 130 - State Capitol
St. Paul, Minnesota

Dear Governor Rolvaag:

It is with great pride that we present to you the report of the Mental Retardation Planning Council. The recommendations contained herein are the product of extensive investigation and deliberation. They reflect the work not only of the Planning Council, but also of the Task Forces and Regional Committees whose membership includes hundreds of professional and lay persons from all over the State.

The work of the Planning Council has been financed by Public Law 88-156, which provided for the preparation of a comprehensive State plan to combat mental retardation. Volume I of the plan consists of reports of the nine Task Forces, with many significant recommendations relating to needed improvements in Minnesota's array of services for the mentally retarded. Volume II comprises the Planning Council's recommendations concerning regional deployment of services and the facilities needed to house them. The latter volume also serves as the statewide construction plan, required under the provisions of Public Law 88-164 in order to qualify for Federal matching funds for construction of needed mental retardation facilities.

The neglect of mentally retarded children and adults in our population has moved the members of the Planning Council deeply. These are indeed "children in need". We thank you for the opportunity you have given us to serve them. We beg our fellow citizens to join with you and with us in a great campaign to serve them better.

Children must no longer lie alone on the cold terrazzo floor of an unattended ward, or sit idly in the back room of their home or of a foster home, without schooling or social opportunity or recognition or acceptance. Retardation can be prevented. It can be ameliorated. The retarded can be helped. This comprehensive plan will guide our efforts—though it is offered with full recognition of the constantly changing pattern of our knowledge, goals and attitudes, and of our abilities and our limitations.

Honorable Karl F. Rolvaag March 1, 1966

All of us join in enthusiastic endorsement of the contents of these two volumes and look with relish on our new responsibility to implement the recommendations, to translate the dreams of the planners into real-life help and service.

The implementation process will go forward with a two-year Federally supported grant. While the Planning Council is to carry the major responsibility, we will depend heavily on your continuing leadership and will seek the support and understanding of the State legislature, the various State departments of government, the voluntary agencies, and the citizenry at large.

Respectfully submitted,

Sally Luther

(Mrs.) Sally Luther, Chairman
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I. INTRODUCTION

Because mental retardation is not a static disease entity, but a changing symptom of a complex interaction of many factors which are not yet completely understood, it is difficult to find a thoroughly satisfactory definition. Three are in common use:

> The mentally retarded are children and adults who, as a result of inadequately developed intelligence, are significantly impaired in their ability to learn and to adapt to the demands of society.
> (President's Panel, 1962)

> The mentally retarded person is one who, from childhood, experiences unusual difficulty in learning and is relatively ineffective in applying whatever he has learned to the problems of ordinary living; he needs special training and guidance to make the most of his capacities, whatever they may be. (National Association for Retarded Children)

> Mental Retardation refers to sub-average general intellectual functioning which manifests itself during the developmental period and is associated with impairment in adaptive behavior. (American Association of Mental Deficiency)

The last of these seems to embody best the limitation in functional characteristics which always attends the symptom called "mental retardation", regardless of how or when it occurs in the life of a given individual. "Sub-average" refers to performance which is greater than one standard deviation* below the population mean of the age group being assessed. Level of "general intellectural functioning" may be evaluated by performance on one or more of the individual objective tests devised for that purpose. The upper age limit of the "developmental period" may be regarded, for practical purposes, as approximately sixteen years. "Adaptive behavior" incorporates maturation, learning, and social adjustment. It is "impairment" in one or more of these aspects of adaptation which determines the need for special or professional services and sometimes for protective legal action.[1]

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* A statistical unit expressing difference from the mean of a range of measurements in a sample.

1. Heber, Rick. "Definition of Mental Retardation". In Mental Retardation, Readings and Resources, Ed. Jerome H. Rothstein. Holt, Rinehart & Winston, New York, 1961. p.9-10.

The term "mental retardation", as used in this report, incorporates all of the meanings which have been ascribed historically to such concepts as amentia, feeblemindedness, mental deficiency, mental subnormality, idiocy, imbecility, moronity, and oligophrenia. "Mental retardation" was chosen because it seems at present to be the preferred and most easily understood term among persons of all diciplines.

It cannot be overemphasized that mental retardation is not a tidy, clearly defined, unchanging entity, but is a function of the way in which society defines, perceives, reacts to, and attempts to cope with the problem. In the words of Sarason and Gladwin

> Real understanding...can only be approached by paying more than lip service to the fact that this is a social and cultural as well as a biological and psychological problem. In our society the problem looms large—statistically, financially, and emotionally; in most non-European societies it is inconsequential, confined to cases of severe pathological defect who are cared for, as long as they live, with a minimum of distress or dislocation. The difference lies in culturally determined attitudes, behaviors, and criteria of social acceptability... Even a child with a severe defect must be viewed as deficient <u>relative to</u> cultural standards of acceptability; the cause of his deficiency may be organic, but its magnitude is dependent upon social criteria.[2]

<u>Prevalence</u>

Despite the importance of mental retardation as a major health, social, and economic problems, exact figures as to numbers of retarded persons are not available. The <u>Manual on Program Development in Mental Retardation</u>, published by the American Association on Mental Deficiency in 1962, states that there are "presently no...data which permit a precise statement of the prevalence of mental retardation."[3] Although incidence surveys have been conducted in various states, notably New York, Michigan, and Illinois, it is generally agreed in the literature that no comprehen-

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2. Masland, Richard L., Sarason, Seymour B., and Gladwin, Thomas. <u>Mental Subnormality.</u> Basic Books, New York, 1958. p. 145.

3. Gardner, William F. and Nisonger, Herschel W. <u>A Manual on Program Development in Mental Retardation</u>. Monograph Supplement to the <u>American Journal of Mental Deficiency</u>, January, 1962. p. 18.

sive survey of the number of mentally retarded in a given community has been carried out using satisfactory techniques of identification.

It is often estimated that three per cent of the population, or about five and one-half million individuals*, are mentally retarded. If a conservative population projection of 230 million Americans by 1980 is realized, as many as 6,900,000 persons may by then be considered retarded. Based on this customary three per cent figure, a breakdown frequently presented in terms of 126,000 annual live births is as follows:

> Approximately 4,200, or 0.1% of all births, or one child out of every 1,000 born, is severely or profoundly retarded, needing constant care or supervision throughout his life;
>
> approximately 12,600, or 0.3% of all births, or three children per 1,000 born, are moderately retarded, capable of developing self-protection skills and limited skills for semi-productive effort and partial self support in a protected environment;
>
> approximately 110,000, or 2.6% of all births, or about 26 children per 1,000 born are mildly retarded, capable of adjustment from a marginal role in society to complete assimilation.

Using the same percentages, it is also estimated that 60,000 to 90,000 individuals are at present severely retarded, 300,000 to 350,000 are moderately retarded, 5,000,000 mildly retarded. Three per cent of the estimated total 5 or 6 million retarded are said to be severely retarded, 13 per cent moderately retarded, 83 per cent mildly retarded.

It is important to realize that, in actual practice, the national incidence estimate of three per cent has never been reached for an unselected segment of the population in any study where rigorous criteria of mental retardation are employed. Recent investigators favor using a one per cent incidence figure

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* Based on an estimated 180,000,000 population.

based on agency case loads at any given time, and generally broken down as follows: mildly retarded, 75 per cent; moderately retarded, 20 per cent; severely retarded, five per cent.

However, since mental retardation is not always a *life-long* unalterable condition, but is instead a complex set of manifestations of an individual's relationship with his immediate environment, an overall incidence figure has little meaning. It may not be translated into an equivalent figure on prevalence because

> incidence and prevalence rates would be equal only if mental retardation were always identifiable at the same age, for instance at birth, if the condition remained unchanged through life, and if the mortality of the retarded was the same as that of the average population. Facts do not conform to these requirements.[4]

What the three per cent figure really seems to mean is "three per cent of the school population," for when the mentally retarded are not lumped together but are identified by age groups, prevalence estimates range from 0.3% at pre-school age to 3% at school age to 1% post school.[5]

Apparently the "visibility" of the retarded is different at different age levels, one reason being that techniques for discovering these individuals, based primarily on academic standards which prevail only during the school years, are most frequently utilized and are most effective during those years. Further, the schools have access by virtue of mandatory attendance laws to a "captive audience", consisting of almost all persons of school age, whereas it is harder to locate individuals in other age groups. In the past only a small number of pre-schoolers have been identified, most of them with gross physical defects—partly because physical and environmental factors have not yet had a chance to affect the child, partly because instruments for detection are not yet well developed for this age level, and partly because our standards of evaluation are less

4. Mental Retardation, A Handbook for the Primary Physician. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 124.
5. The President's Panel on Mental Retardation. Report of the Task Force on Education and Rehabilitation. Washington, D.C. August, 1962.

stringent. From ages 10 to 14, when the most rigid standards of school achievement are imposed, as many as eight to ten per cent of the school population have been labeled mentally retarded.[6] Dybwad suggests caution in the use of such figures, since

> in many cases the basis for these classifications remains in practice the intelligence quotient (IQ) arrived at on the basis of one or more standard tests, with different ceilings prevailing from state to state. In view of the fact that the numbers sharply increase the higher the ceiling is pushed, those using an IQ of 75 would include a far larger group among the mentally retarded than those using the lower figure of 70. Furthermore, we are not dealing with static groups. Studies both here and abroad have shown that an individual can move from one group into another as a result of improved performance.[7]

Thus many of these individuals "disappear" after about age 14 to 16, when they are reabsorbed into the body of the community, presumably to function at least marginally. The difference in prevalence may be attributed to the fact that society's standards of competency and expectations vary for each of its members at various ages. Such a difference does not necessarily reflect a change in functioning level of the individual. Mortality rates of the retarded, in spite of advances in lifesaving methods, exceed those of the general population, thus helping to account for some of the drop in adult prevalence. Dr. George Tarjan, Superintendent and Medical Director of Pacific State Hospital, Pomona, California, provides an excellent summary of the situation:

> Evidence therefore strongly suggests that the prevalence of diagnosed or "visible" mental retardation in the general population is not 3% but is at a significantly lower figure, closer to 1%; that prevalence varies with age; and that within the retarded population the distribution of IQ differs among the various chronological age groups.
>
> What are the implications of this difference between the assumed prevalence rate of 3% and the probable case-finding rate of 1%?

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6. The President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p.6

7. Dybwad, Gunnar. "Mental Retardation." In Mental Retardation, Readings and Resources, Ed. Jerome H. Rothstein. Holt, Rinehart and Winston, New York, 1961. p.7.

Let us use a hypothetical community of 100,000 as an example. Under the first assumption we would expect to find a total of 3,000 mentally retarded individuals in the community. Of these, approximately 360 should be under the age of 6 years, twice that number of school age, a similar number between 18 and 24, and over 1,500 above that age. If the degree of retardation did not affect mortality, 100 of the 3,000 mentally retarded individuals would be expected to have IQs below 20, 400 between 20 and 49, and 2,500 between 50 and 70.

In practice we are more likely to find that the total number of visible retardates is around 1,000 rather than 3,000. Particularly striking differences would be noted in certain age and IQ categories Instead of identifying the 300 mildly retarded children under the age of 6, we would find 15; and in lieu of 1,400 mildly retarded adults over 24, we would identify only some 65. Higher than average death rates decrease the total number of persons with IQ's less than 20 from 100 to below 50; and the complement of those with IQ's between 20 and 50 from 400 to 150. Diminished case finding of mild retardation during the preschool years, and the reabsorption of this group into the general population during adulthood would decrease the total number of mildly retarded individuals of all ages from 2,500 to 700. The 3% prevalence rate would probably be verified only in one group, i.e., the mildly retarded of school age.[8]

Gardner and Nisonger suggest that at best "it would be safe to say that at some time in their lives about three per cent of the population could be classified as mentally retarded."[9] Even more conservatively, it has been observed that "the best statement regarding prevalence that can be made at this time is that it may be sufficiently greater than the approximate one per cent now known to all agencies to suggest that the continued demand and need for service will exceed availability of such services for many years to come."[10]

Even such well qualified, careful statements have little meaning unless we are in possession of far more particularized information. We have already mentioned age and degree of retardation in relation to shifting criteria and

8. Mental Retardation, A Handbook for the Primary Physician. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 125-6.

9. Gardner, William I. and Nisonger, Herschel W. A Manual on Program Development in Mental Retardation. Monograph Supplement to the American Journal of Mental Deficiency, January, 1962. p. 18.

10. Special Problems in Vocational Rehabilitation of the Mentally Retarded. Conference proceedings, U.S. Dept. of Health, Education, & Welfare. Vocational Rehabilitation Administration, November, 1963. p. 15

unacceptability of techniques and instruments for identification. It is becoming axiomatic as studies proliferate that the majority of the mentally retarded are to be found in the disadvantaged strata of society. For example, Project 681,[11] a study of the "school-rehabilitation" needs of retarded youth, reveals that 49 per cent of secondary special class pupils in Minneapolis from September, 1957, to June, 1960 lived in areas of the city which had "high rates of delinquency and social disadvantagement." According to the same study, 65 per cent of ninth grade special class students sampled lived in the "sociologically deteriorated central area of the city" where only 27 per cent of the city's juvenile population lived. These data are in agreement with the results of a well-known survey made in Chicago in 1952, which showed that 65 per cent of pupils in special classess for the retarded came from eleven slum areas (out of seventy-five urban areas), in which ten to 30 per cent of all school-age children were referred for psychological evaluations.[12] To quote the President's Panel:

> Extraordinarily heavy prevalence in certain deprived population groups suggests a major causative role...for adverse social, economic, and cultural factors...Whether the causes of retardation in a specific individual may turn out to be biomedical or environmental in nature, there is highly suggestive evidence that the root causes of a great part of the problem of mental retardation are to found in bad social and economic conditions...and that correction of these fundamental conditions is necessary to prevent mental retardation successfully on a truly significant scale.[13]

Accordingly the Departmental Advisory Group on Cultural Deprivation has been appointed nationally with representation from all agencies of the Department of Health, Education, and Welfare, in order to assemble pertinent facts and develop programs for preventive action on Federal and State levels. Since at present only a small proportion of mental retardation can be prevented through biomedical

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11. Retarded Youth: Their School Rehabilitation Needs. Research and Demonstration Project 681 sponsored by the Minneapolis Public Schools. Federal Vocational Rehabilitation Administration, March, 1965. pp. 44, 72.

12. The President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p.4

13. Ibid., p. 8-9

means, current programs stress the need to attack the bulk of cases through improving environmental factors in culturally deprived groups. A growing body of research evidence appears to support the wisdom of this trend; however, careful studies are needed to illustrate precisely how sociocultural factors operate to interfere with and retard human development.

Geographical, ethnic, racial, and demographic variations in prevalence of mental retardation must also be taken into account. Although four per cent (716,000) of the draftees examined during World War II were rejected on the basis of "mental deficiency," the percentage varied regionally from one per cent in the Far West to nearly ten per cent in the Southeast; taken by state, rates range from one-half to one per cent in some states, to almost 14 per cent in others. Selective Service statistics indicate that draft rejection rates were six times as high for non-whites, suggesting the effects of lack of opportunity, educational deficits, and other negative environmental factors.

It must also be recognized that individuals are evaluated primarily on the basis of standard intelligence tests, in the school years as well as in the mass Army screenings, and that standard intelligence tests "contain a large element of social class or cultural bias (because of which) the intellectual potential of the so-called retarded persons, as well as his level of functioning outside the test situation, cannot be assumed to have been adequately assessed".[14] Later on, when socially adaptive rather than academic performance is the criterion, many of these individuals no longer appear to be retarded. As Heber puts it:

> Mental retardation is a term descriptive of the <u>current</u> status of the individual with respect to intellectual functioning and adaptive behavior. Consequently, an individual may meet the criteria of mental retardation at one time and not at another. A person may change status as a result of changes in social standards or conditions, or as a result of changes in efficiency of intellectual

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14. Masland, Richard L., Sarason, Seymour B., and Gladwin, Thomas. <u>Mental Subnormality</u>. Basic Books, New York, 1958. p. 194.

> functioning, with level of efficiency always being determined in relation to the behavioral standards and norms for the individual's chronological age group.[15]

In educating the public to the magnitude of the problem it is indeed dramatic to say, for example, that "mental retardation afflicts twice as many individuals as blindness, polio, cerebral palsy, and rheumatic heart disease, combined." Our concern in this report is the preparation of a comprehensive plan for day-to-day use in Minnesota—a plan which will encompass all of the programs and services needed to effectively combat mental retardation. To accomplish this purpose we need to research our figures carefully and to analyze them with respect to rates and degree of occurrence within various sub-groups of the population in Minnesota. Again quoting Dr. Tarjan:

> There is need for intensive research in epidemiology to establish actual prevalence and to reappraise the findings intermittently, because changes in case-finding techniques, in life expectancy, in treatment, and in employment standards modify prevalence. Planning of services, however, cannot await the collection of final data. Adequate information on prevalence and on the age and IQ distribution of the afflicted is desirable, but the retarded children and adults of today urgently require care. It is imperative that our best epidemiologic knowledge, though limited, be put to use to avoid planning for inadequate or excessive service.[16]

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15. The President's Panel on Mental Retardation. Report of the Task Force on Education and Rehabilitation. August, 1962. p. 11

16. Mental Retardation, A Handbook for the Primary Physician. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 126.

II. PREVENTION, DIAGNOSIS AND TREATMENT

Prevention

The ultimate goal in working with mental retardation is prevention. Were all mental retardation prevented, the concomitant problems would no longer exist. Obviously this is a goal not easily realized, since the causes of mental retardation are so varied and, for the great bulk of cases, still unknown. Nevertheless, any reduction in incidence, however small, is significant. The present testing of newborns for the metabolic disorder called phenylketonuria (PKU) is an example of how research can reduce incidence. Statistically, PKU occurs only once in about 10,000 births, but the prevention of its effects will save many children from a lifetime of retardation.

The President's Panel states that "full application and utilization of existing knowlege...would eliminate perhaps half or more of all new cases of mental retardation."[17] Dr. George Gardner, Director of the Judge Baker Guidance Clinic in Boston, has written: "Of course we do not have all the answers to the manifold problems of diagnosis, prevention, treatment, and care of these conditions that concern us. But...no one can cite another childhood disability of this size, or any disease condition for that matter, where the gap or lag between what we do know and its effective application in significantly large and crucial areas is so great or has been allowed to exist for so long."[18] It is apparent that economic as well as human value dictate a maximum effort for prevention.

Preventive intervention is usually described as primary, that is prevention of conditions which result in mental retardation; and secondary, that is, efforts

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17. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 147.

18. Mental Retardation, A Handbook for the Primary Physician. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 116.

which serve to lessen the consequences of retardation once it has occurred. In other words, action on the primary level may "prevent the occurrence of retardation," while action on the secondary level "through early diagnosis and treatment...may modify or reverse the course of the disease."[19]

Primary Prevention. Over 200 causes of retardation have been identified, yet in the majority of cases the physician diagnoses he is unable to specify etiology. He can, however, take effective preventive action in those cases where

> organic pathology as a result of disease or injuries is...demonstrable, most readily in instances where the degree of retardation is severe and there has been gross brain damage. There are a great many diseases and conditions which affect the brain and result in retardation, including infections or poisons in the mother's system during prgnancy, infection of the central nervous system during infancy, injuries to the brain at birth, head injuries in childhood, metabolic disorders determined by heredity, and abnormal brain growth.[20]

Table 1 outlines some of the biomedical causes of mental retardation with appropriate preventive measures. It must be realized that the number of cases which are thus accounted for is small.

In the largest percentage of cases of mental retardation, consisting primarily of mildly retarded persons without gross abnormality of the brain, specific causes cannot yet be identified. Yet, even here, research is casting light on a complex interaction of factors:

> It seems reasonable to believe that some members of this group are affected by operation of genetic and hereditary factors which are not yet clearly identifiable or understood. Similarly, a significant role for biomedical causes is suggested by data which show clearly that children born of mothers without prenatal care have an incidence of retardation many times higher than children born with proper maternal care. For example, a variety of unfavorable health factors, including lack of prenatal care, poor nutrition, deficient postnatal care, and similar unfavorable factors,

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19. Mental Retardation, A Handbook for the Primary Physician. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 17.

20. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 6, 7.

LEGISLATIVE REFERENCE
STATE OF

TABLE 1

BIOMEDICAL CAUSES OF MENTAL RETARDATION
WITH APPROPRIATE PREVENTIVE MEASURES

Cause of Retardation	Preventive Measure
PRENATAL	
Maternal disease	
Acute bacterial infection	Early treatment
Sub-clinical urinary tract infection	Routine detection procedures
Viral infections, such as German measles (rubella)	Early treatment
Syphilis	Prenatal blood tests and treatment
Thyroid disease, diabetes	Better medical management and anticipation of possible problems in new-born
Teratogenic agents	
Drugs (administered to mother)	Minimum medication during first trimester of pregnancy
Excessive radiation, either during pre-marital or pre-conception period or during pregnancy	Strict enforcement of standards in use of x-ray and other equipment producing ionizing radiation.
Chromosomal disorders and other genetic factors	Genetic counseling, laboratory (chromosomal) studies; earlier pregnancy in some instances; voluntary sterilization
NATAL	
Factors involving maternal health and fetal abnormality, such as	
Bleeding and toxemia, often associated with premature birth; mechanical injuries; anoxia	Improved obstetrical practice; increased alertness of physicians to "high risk" situations
Prematurity	Adequate pre-natal care; professional and public education
Pharmacologic problems	
Metabolic, hematological, hormonal, or neurological disturbances in newborn, usually caused by maternal overdosage of Vitamin K, sulfa compounds, tranquilizers, etc.	Conservative use of medications; Apgar tests; Careful assessment and follow-up on developmental status of "high risk" infants
Blood incompatibilities between mother and infant	Routine pre-natal blood tests; prompt exchange transfusions

Continued on next page.

TABLE 1 (Cont'd)

BIOMEDICAL CAUSES OF MENTAL RETARDATION
WITH APPROPRIATE PREVENTIVE MEASURES

Cause of Retardation	Preventive Measure
POSTNATAL	
Congenital Anomalies	Early detection; routine recording of head measurements during first year
Inborn Metabolic Errors	
Phenylketonuria	Simple screening of newborn, laboratory tests on suspected cases, dietary change
Galactosemia	Identification of carrier state in parents, early treatment with galactose-free diet pre- and post-natal
Cretinism	Early and aggressive therapy based on continuous follow-up with determination of bone-age, growth, etc.
Encephalopathies which may follow	
Measles (roseola)	Widespread use of measles vaccine
Tuberculosis	Case-finding by routine tuberculin tests (especially among "high risk" groups)
Bacterial meningitides	Early recognition and prompt treatment
Accidents and Poisons	
Head trauma	Use of automobile seat belts; provision of day-care centers and proper play areas
Lead poisoning	Public education and control
"Battered-child syndrome"	Statutes requiring medical reporting of physical abuse in children
Miscellaneous	
Febrile seizures with or without asphyxia	Consideration of anti-convulsant medication for 2 to 4 year period
Treatment of infantile diarrheal disease	Use of half-strengh skim milk or half-strength electrolyte solution in treatment
Inadequate nutrition	Public health efforts

> may produce damage to the brain or to the body which cannot be generally measured with present techniques but which will constitute a drag on physical and neurological development. Clearly, however, the incidence of mental retardation is heavily correlated with a lack of proper maternal and perinatal health care, which in turn is closely associated with unfavorable socioeconomic status of families or whole neighborhoods or groups in the population.
>
> The majority of the mentally retarded are the children of the more disadvantaged classes of our society. This extraordinarily heavy prevalence in certain deprived population groups suggests a major causative role...for adverse social, economic, and cultural factors.[21]

Thus, primary prevention of mental retardation in all of its complexity requires simultaneous action on all fronts--biological, psychological, and sociocultural.

Secondary Prevention. The Joint Expert Committee of the World Health Organization has said:

> Although some forms of mental subnormality, usually those of severe grade, are recognizable at birth, the majority of cases look much like normal children and are first distinguished by slowness of development. During the period of infancy, only cases of fairly gross handicap are likely to be diagnosed. In the preschool years, however, it becomes possible to discover a good deal of moderate subnormality and some mild cases.[22]

In speaking about early detection and diagnosis, we are really talking about secondary prevention, because in an increasing number of instances, detection and diagnosis of an underlying biological abnormality can lead to the prevention of brain disease and consequent retardation.

Early casefinding can minimize developmental problems associated with hearing impairment, speech disorders, stimulus deprivation, epilepsy, and other handicaps, as well as to reverse the effects of both phenylketonuria and galactosemia. Casefinding efforts must be continuous because many detectable symptoms of mental retardation are not apparent at earliest stages of development. Each newborn infant is entitled to and must have ongoing health supervision by a private physi-

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21. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 7-8.

22. World Health Organization, The Mentally Subnormal Child. Technical Report Series 75, 1954.

cian, pediatrician, or well-child clinic. Biological, neurological and psychological screening tests should be performed as a part of pre-natal care and at periodic intervals during the child's development. Systematic examination of preschool children in the community would help to identify handicaps early and would thus be a boon to schools and parents in planning for each child's optimum development. In the words of Anthony J. Celebrezze, former Secretary of Health, Education, and Welfare, "Crucially important is early identification of the retarded. The earlier their condition is discovered, the greater the likelihood of success in reducing or completely reversing the damage that has already been done, whether due to cultural or other factors."[23]

Diagnosis

Continuous casefinding must be complemented by complete diagnostic workup, including consultation with medical specialists and psychological evaluation, whenever mental retardation is suspected. It would seem most expedient and economical to utilize existing community services whenever possible since many parents cannot afford extensive diagnostic services. In addition there is the difficulty of

> deciding who is a subnormal child and who is not. Since the casefinding and diagnostic problems range over the whole field of physical health, mental health, and educational guidance, and since the retarded child is not only retarded but also has the health, social, and educational needs common to all children... previous tendencies toward isolation of these children and segregation of services available to them should be terminated.[24]

Comprehensive evaluation requires a multidisciplinary team approach. Often the family finds it difficult to secure an adequate diagnosis because of limitations of present knowledge, limitations of diagnostic instruments, and scarcity

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23. World Health Organization, The Mentally Subnormal Child. Technical Report Series 75, 1954.

24. President's Panel on Mental Retardation. Report of the Task Force on Prevention, Clinical Services, and Residential Care. August, 1962. p. 21.

of well trained professionals in this field. In making a diagnostic evaluation the various specialties might interact as follows: the medical disciplines would determine whether the patient is physically able to attend school and whether there are remedial physical defects; the psychologist would decide whether the patient is mentally able to profit from schooling, and whether his capacity for understanding language is such that he can profit from schooling; the social worker or public health nurse would provide information on availability of schools and data on the family; and the educator would select the appropriate educational placement. The careful explanation of all findings to the patient's family is a major task in itself. Such is the team approach to evaluation.

At present retarded children in Minnesota are served diagnostically by Community Mental Health Centers, Child Development Centers, schools, outpatient hospital clinics, State institutions, and the University of Minnesota clinics. However, the services provided are uneven in quality and, in many areas of the State, inadequate. School health programs in particular have a vast potential, largely undeveloped, for identification and evaluation of mental retardation and other handicaps.

The roles of the family physician and the pediatrician in the diagnostic process merit special attention. The family physician or the pediatrician is often the first to see the mentally retarded infant after discharge from the hospital, or to make the initial diagnosis at a later developmental stage. He is in a position to study the suspected retarded child longitudinally, to contribute valuable observations about growth and development, to initiate comprehensive evaluation when needed. He can interpret diagnostic implications to the parents over the years. He can help to increase the child's total capacity by diagnosing other defects, such as dental or orthopedic problems. He is in a sensitive position for noting and interpreting as they occur any improvements or changes in the dynamic syndrome which is mental retardation.

Treatment - Total Care

Medical supervision of the whole child should be the physician's responsibility to the retarded, as to the normal, individual. He is probably the only professional who will maintain a continuous working relationship with the child and family during the individual's total life span. Ideally, the physician should provide a liaison between the family and the many specialists and clinics involved in total evaluation. He should be active in long-range planning for the child and should follow through on aspects of care which fall within his province of knowledge and involvement. He should treat associated physical handicaps to maximize the child's functioning level. As in the management of any chronic illness, he should take the initiative in making periodic checks. He can counsel the parents most effectively, if he is sufficiently informed about retardation and community resources for coping with the problem. The size of that if, which is the condition for all effective treatment by the individual physician, is described below:

> Unfortunately, at the present time, physicians are not well educated as to the general problems of the retarded...Until the proficiency of the general physician, pediatrician or internist in the field of mental retardation is improved by futher training...the director of a diagnostic and evaluation center will need to substitute for the individual physician. The physician who is familiar with the life of the family and community should be the ideal focus. However, at present his knowledge of community resources, especially educational and vocational opportunities for the retarded, is woefully inadequate and requires concentrated upgrading.[25]

Futhermore, the physician is not always in a position to play this central role, even if he were able and willing. Many families neither have nor want a family physician. Many parents can scarcely be motivated to take their children to a clinic for needed services, let alone to become involved in long term office management. In these cases, where a child is not under a doctor's care,

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25. The President's Panel on Mental Retardation. Report of the Task Force on Prevention, Clinical Services, and Residential Care. August, 1962. p. 34

clinics and agencies must develop long-range treatment plans and must try to motivate and educate apathetic parents to utilize available help and services.

Parent Counseling

> The matter of providing sympathetic and intelligent professional counseling to the families of the mentally retarded has been repeatedly cited as an urgent need. The anxiety and emotional tension put upon these families can hardly be comprehended by those who have not experienced this tragedy, and the parents particularly are concerned that few of them have skilled help at a time when they so critically need it. Over and over again strained relationships between husband and wife, or between family and neighbors are recounted—strains that ultimately result in separation or divorce, or physical, emotional, or social breakdowns within the family group. The still-prevalent stigma associated with mental retardation, as well as the heavy physical burdens of caring for a handicapped person, are experiences that undoubtedly take a heavy toll from the most competent and secure person. It is the opinion of parents and others that family counseling, both on a group and on an individual basis, if of first importance.[26]

Dr. Martha M. Elliott, Chief of the Children's Bureau, recently said: "'When officials of public agencies ask what kinds of services should be provided for retarded children, my advice is, ask the parents. They are often best qualified to say what help they need, where professional persons have to provide the how's. Thus, we laymen and professionals are indispensable to one another in our efforts to make up for past neglect of this serious medical, emotional, social and educational problem.'"[27]

In an article in Children (January-February, 1956),[28] Letha Patterson, parent of a retarded child and member of the National Association for Retarded Children, brings together written and spoken insights which have come her way from both professional workers and parents. Mrs. Patterson urges:

(1) Tell us the nature of the problem as soon as possible.
(2) Always see both parents. Both parents should be present whenever possible, and at least on first consultation regarding a child's

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26. Begab, Michael J. The Mentally Retarded Child: A Guide to Services of Social Agencies. Children's Bureau. 1963.

27. Elliott, Martha M. In Children, Jan.-Feb., 1956.

28. Patterson, Letha L. "Some Pointers for Professionals." In Children, Jan.-Feb., 1956.

handicap. It is difficult for a mother to go home and re-state, interpret, and answer questions about a problem she does not clearly understand herself. Often the problem with its fears has brought about a lack of communication between the mother and father; establishing adequate communication is difficult in any marriage.

(3) Watch your language. Parents need to understand the implications of their problem but too often we are given professional gobbledygook, or at the other extreme plain talk of an obnoxious variety.

(4) Help us to see that this is our problem. Too many well-meaning professional people in the past have thought they knew what was good for us and have recommended, even insisted, on institutionalization. Only as we parents are helped to work through our problems, can we find any peace of mind. If we have not planned for our child ourselves, if someone else has made the decision, we have not really made up our own minds and so must keep going over the ground again and again.

(5) Help us to understand our problem. Parents differ in quantity and quality of information they can absorb during different phases of this problem.

(6) Know your resources.

(7) Never put us on the defensive.

(8) Remember that parents who have retarded children are just people.

(9) Remember that we are parents and that you are professionals.

(10) Remember the importance of your attitude toward us. Sometimes I think your colleagues place too much emphasis on "objectivity" and not enough on "loving kindness".

Dr. Harriet Blodgett, Chairman of the Governor's Advisory Board on Handicapped, Gifted and Exceptional Children, presents a professional's point of view.

I suggest that one of the factors which interferes with clear thinking on the part of society's professional representatives in this area is misguided sympathy with the misfortune of the parents of retarded children, which feeds into circular mismanagement of the total problem through "weaseling" methods of coming to grips with its interpretation and with action. Granted that to have a mentally retarded child is an unfortunate event, it is not the only unfortunate event that can and does happen to people, and action stemming from sympathy <u>only</u> is likely to be limited in value and not necessarily wise in judgement. I submit that parents need, first of all, information. They need this to be presented sypathetically but factually and honestly. They need it to be personalized for their own child and their own situation, but in the framework of broad professional knowledge and experience with the total problem of retardation. They need practical kinds of help with behavior management, understanding, acceptance, fostering growth in independence and self-sufficiency, avoidance of secondary emotion and dependency problems of the retarded child, avoidance of intra-family problems related to unequal distribution of parental attention and reward. They need informational steering toward sources of help—not only counseling and supportive kinds of help, but planning help, knowledge of resources, and help in selecting those resources appropriate to their needs and situation. I submit that we have often short-changed parents through trying to counsel them in accordance with what we think they want to hear,

rather than what we know to be true. We have been fearful of putting our professional knowledge to the test of individual application.[29]

On the subject of home training, Arthur J. Lesser states:

> What is proving most meaningful to the parents is the help they receive in home training and every day living with their retarded child. At an evaluation conference short-term goals may be set, such as learning self feeding or toilet training. As one goal is reached the next is planned. The processes involved in guiding many children to achieve degrees of self help are basically the same as in normal children. With an understanding of the child's potentiality for achievement and of the specific goals to be reached, the public health nurse is in a key position to assist the family in helping the child in reaching his goals. She is, however, dependent upon the mental retardation clinic for the evaluation of the child and his family. She needs to maintain a continuing relationship with the clinic staff in working with mentally retarded children in their homes in order to give understanding support to their parents and to participate in the training programs that are directed to the total plan of care for each child.[30]

The purpose of counseling is to enable the family of a retarded person to understand, accept, and cope with the problems of mental retardation. Counseling can be conveniently divided into four types:

1. Pre-marriage, genetic, pre-natal. This type of counseling is especially important where there is a family history of retardation.
2. When retardation is first suspected or apparent.
3. After a diagnostic evaluation has been completed.
4. When the focus of effort is "life planning."

Each of these approaches differs as it pertains to the extremes of: early recognition of forms of severe retardation such as mongolism; later recognition, usually during the beginning school years, of moderate retardation.

In each instance the counselor, whether doctor, clergyman, social worker, psychologist, nurse, or other professional, should be able to speak with the

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29. Blodgett, Harriet. Personal communication. 1965.

30. Lesser, Arthur J. "New Programs for Mentally Retarded Children." Paper read at a meeting of the American Public Health Association. Cleveland, 1954.

authority which comes from a thorough knowledge of mental retardation and of available resources, as well as from the establishment of a good rapport with the family. When severe retardation is suspected, the person who is most frequently involved in initial counseling, who discusses with parents the presence or possibility of retardation, is the family physician—general practitioner, pediatrician, or obstetrician. When there is a probable diagnosis of retardation, the parents must be informed and provision must be made for comprehensive evaluation. When there is uncertainty, the physician should point out the possibility of retardation and should arrange for appropriate diagnostic studies. The physician may wish to observe the child over a considerable period of time before taking more definitive steps. If, as is often the case, the family physician feels inadequate to counsel the family because of limited training and exposure to the problems of retardation, he should at least be aware of diagnostic and other services to which he can refer them.

Mild or moderate retardation is frequently discovered when the child begins to attend school. A classroom teacher, counselor or principal, may suspect retardation. Since these individuals cannot make definitive diagnoses, referral must be made for further evaluation. Counseling in these situations may consist largely of presenting the problem to the parents so that they will cooperate with appropriate action.

When a child who has been referred to a diagnostic service has been thoroughly evaluated, a conference should be arranged between the family and that member of the diagnostic team who is able to discuss problems and answer questions most authoritatively. Following the conference a report in lay language should be sent to the parents and to the family physician; the latter should also receive any additional professional information which might be of value. Such direct communication may minimize confusion which often arises from relayed information.

So far as is possible, treatment programs should be worked out with the

family doctor. Treatment possibilities should be presented to the family in the initial counseling session. Although there is a severe shortage of personnel trained to provide the many necessary facets of treatment, there is often dormant in the community professional or lay talent which with additional training could be utilized.

Recommendations Concerning Prevention, Diagnosis and Treatment:

Primary Prevention

1. The task of primary prevention is the foremost concern in our comprehensive plan to combat mental retardation; therefore, research into the etiology of retardation should be given priority and support by all involved agencies, services, and individuals.

2. Present medical knowledge, which has already identified numerous precise causes of mental retardation, should be vigorously disseminated and utilized as a basis for preventive action.

3. Genetic counseling services, such as those offered by the Genetic Counseling Unit of the State Department of Health, should be expanded and utilized more widely, particularly in dealing with "high risk" populations. Professional and lay publics must be educated to the value of genetic counseling as a preventive measure and a research tool.

4. Adequate pre-natal, perinatal, and post-natal care should be made available to every expectant mother regardless of ability to pay; the public as well as the professional must be educated to the indispensability of this care.

5. Emphasis should be given to programs which show promise of improving individual functioning through attacking the medical, social and cultural "tap roots of dysfunction" characteristic of the lower socio-economic strata of our society, thereby helping to prevent mental retardation. Such programs should ideally encompass (a) education of disadvantaged adults to the importance of such preventive necessities as pre-natal, perinatal and post-natal care, adequate nutrition, and post-natal stimulation of the infant; and (b) early educational enrichment of disadvantaged children in the hope of offsetting some of the drastic effects of deprivation on their motivations and abilities.

   Accordingly, Project Head Start, which took place throughout Minnesota in the summer of 1965, should be carefully appraised as a pilot demonstration

of the effect of various techniques of medical and psychological evaluation, cultural enrichment, and parental education, on a group of disadvantaged pre-school children. Areas of the State which have large numbers of low-income families should be encouraged to participate in such programs, with appropriate implementation on the State and Federal level.

Secondary Prevention and Case-Finding

6. Our mandate to "find" the retarded, and thereby to engage in secondary preventive activity, begins at birth; therefore, physicians, nurses, and other personnel in clinics and hospitals must be trained to be alert to all handicaps and signs of mental retardation from birth. All handicapped or mentally retarded should be identified on hospital or clinic records so that systematized, coordinated follow-through can be effected. "High risk"* groups should receive special attention, by means of careful records kept of such possible predisposing factors as genetic disease in relatives or siblings and history of the developmental period.

7. Since we cannot expect follow-through to be undertaken by already overburdened workers, an administrative structure which cuts across the Departments of Health, Education, and Welfare should be designated and staffed to coordinate community efforts in case-finding and integrate them into the total community program. This consolidation might best be accomplished on a regional basis. Whatever agency assumes this function must be adequately staffed with trained personnel.

8. It is recognized, and strongly underlined, that early case-finding must be followed by evaluation and planning by pertinent disciplines, with provision of needed services for those cases identified.

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* "High risk" embodies such factors as abnormal pregnancy, maternal infection, birth injury, genetic disease history, present or potential exposure to emotional or socio-cultural deprivation. For a more complete disucssion of high risk factors, we refer the reader to p. 32 of the American Medical Association Handbook on Mental Retardation.

9. All available techniques which may help to identify the handicapped child at an earlier age should be utilized. The choice of technique will depend upon the particular milieu in which case-finding is being attempted.

a. In rural areas, it would be feasible to send one or two well trained school census enumerators into the homes of pre-school children to inquire into and observe possible handicapping conditions including retardation; on the other hand, such a technique might be inappropriate in an urban setting where apparently many handicapped children are already being identified by the school prior to enrollment.

b. The instrumental potential of the schools for finding the obviously handicapped child via such techniques as the kindergarten roundup and improved school census should be extended downward to age two or three, with arrangements made with the family physician, the pediatrician, and with community agencies and resources for appropriate medical, psychological and paramedical follow-up. This broadening of the schools' catalytic role in case-finding would also help their own planning for the handicapped child, particularly in providing enrichment and special training at a pre-kindergarten level.

c. New or experimental instruments such as the Doll Developmental Scale, the Illinois Test of Psycholinguistic Abilities, or the so-called "culture free" tests, should be used in programs where they may contribute to improved knowledge of how to locate and assess the mentally retarded in the pre-school age group. Better evaluative instruments for this age group must be developed through research and deomonstration.

10. To make the school census more useful in locating children who may be in need of evaluation and service, the following improvements are recommended:

Institute training sessions for enumators, possibly under University or State college auspices, in which they learn <u>how</u> to ask questions as well as how to observe in the home. A portion of the ten dollar State "census" aid

presently paid to the schools per reported child might be used to cover the expense of training these enumerators, whose findings could serve as a resource for all community agencies.

Further revise the school census form in the direction of more specific questions regarding the child's motor and sensory capabilities, as well as selected aspects of his growth and development.

11. A centralized reporting system of all school age children (under 16) excused or excluded from school should be established on a statewide basis, with a designated agent, as the State Department of Education, to receive this information and to ensure follow-up in provision of services or other disposition. These cases are already known to the school excusal agent, so that the mechanism of setting up such a reporting system would not be difficult. (A pilot project to develop a workable system is underway in the Minneapolis schools.)

12. Intelligence tests should be used as only one part of a total study of the developmental potential of the child and should be administered by competent psychologists who are trained in working with children. Intelligence tests should always be carefully interpreted, but particularly when administered to pre-school children, since research evidence indicates that the majority of retarded cannot be reliably identified through existing intelligence tests during the first six years of life; special care should be taken in interpretation of results when testing the culturally deprived or handicapped.

Diagnosis

13. Child Development Centers should be established throughout the State to provide multidisciplinary evaluation services to all handicapped children. Whenever possible, existing facilities, such as Community Mental Health Centers, existing Child Development Centers at Fergus Falls and Owatonna, community hospitals, State institutions, crippled children's services, and private

facilities should be utilized for this purpose. Establishment of one or more clinics on an interstate basis should also be explored.

14. The staff of the Child Development Centers may find it necessary to travel to more remote areas of the State to provide needed evaluative services in instances where patient travel is impracticable; these "traveling teams" should be carefully matched with local professionals so that effective treatment and planning can be carried out on the local level after the team has departed.

15. At least one highly specialized diagnostic center should be located at University Hospitals, or at a State hospital or institution, or in a private medical facility, to accommodate selected referrals.

16. Well-baby clinics should be utilized as diagnostic resources and referral channels for those retarded children who turn up in the normal case load. These clinics should maintain adequate pre-natal and post-natal follow-through on suspect "high risk" families, most of whom derive from the lower socio-economic strata which comprise the clinic patient group, so as to institute measures preventive of retardation as soon as possible; day care centers and sheltered workshops might also be utilized in this manner.

17. Research and teaching concerning all aspects of retardation should be an integral component of all diagnostic centers, not only because scientific investigation is inseparable from a dynamic diagnostic process, but also because a "climate of research" must exist if the participation of high-level professional personnel in diagnostic teams is to be secured. This dual aim would probably be best realized through the establishment of University sponsored fellowship and training programs in conjunction with the various diagnostic centers.

18. A comprehensive diagnostic evaluation may best be carried out by a team of medical and paramedical specialists, i.e., pediatrician, neurologist,

psychiatrist, public health nurse, psychologist, social worker, speech pathologist, genetic counselor, dentist. Not all will see every child, but will be available as their contributions are needed.

19. An adequate diagnostic evaluation should be prerequisite to all placements in State residential facilities and, whenever, possible, should be prerequisite to <u>any</u> placement, planning, or provision of service for a retarded person.

20. The family physician or pediatrician, who often is the first to suspect retardation and to refer the patient for diagnostic services, should be included as an active and integral participant in diagnostic staffing and formulation of treatment plans.

21. Diagnosis and evaluation must be an ongoing process throughout the life of the retarded person, a process which identifies changing needs as they evolve and suggests alternative plans of service as new needs and combinations of needs arise.

22. Health insurance plans should be encouraged to provide coverage for complete diagnostic evaluation of handicapped persons.

23. Professional training programs in mental retardation must begin at the undergraduate level, in medicine as well as in other professional disciplines, if we are to adequately staff diagnostic and treatment facilities. Programs should be structured along biochemical, genetic, or other specific lines of inquiry, in order to attract the best scientific minds to careers in mental retardation.

23. The University of Minnesota is a major resource in the undergraduate, graduate, and postgraduate education of professional personnel in the area of mental retardation; an on-going program of postgraduate education in mental retardation for professional personnel should be established in order that effective measures in prevention, diagnosis, and treatment of mental retardation may be perpetuated on the community level.

Parent Counseling

25. Every professional person involved in counseling should possess a thorough knowledge of retardation as it relates to his particular field of specialization and should be familiar with all available community resources for diagnosis and treatment.

26. Child Development Centers should serve in a consultative, educational, and informational capacity; Community Mental Health Centers, professional societies, and lay associations should also serve in this capacity, particularly in communities where Child Development Centers have not been established.

27. The education of physicians, teachers, clergymen, psychologists, nurses, social workers and the many other persons who come in contact with retarded persons should include exposure to the subject matter of mental retardation, counseling techniques, and the emotional problems of children and of the handicapped. These areas should also be a part of in-service training institutes, seminars, workshops, refresher courses, and programs of professional associations and societies.

28. Social agencies should work in a team relationship with the staff of the Child Development Centers in order to coordinate family counseling efforts.

29. When a team approach is used, the person counseling and interpreting to the family should be a member of the team for whom the family has high regard. In many cases this will be the physician, in others the public health nurse, the social worker, or psychologist.

30. Parents should be fully informed (keeping in mind their ability to use information), by whatever professional person is doing the counseling.

31. Parents should be responsible for maintaining their involvement in the on-going counseling process. Professionals should be responsible for making sure that counseling is available as needed.

32. Ideally, every child who is performing unsatisfactorily in school should be

evaluated medically and psychologically before planning for his educational needs.

33. Appropriate information about a child should be available to professionals who are working with him. (a) Where confidential information is involved, a release form should be signed by the parent before any information is communicated. (b) An agency may often find it advisable to include with pertinent information a cover letter interpreting salient or ambiguous data to the recipient, since inter-professional communication is often hampered by inadequate background in the other's field.

34. Because of the therapeutic value to parents of non-professional support, parents should be encouraged to participate in citizen groups such as the Association for Retarded Children.

35. Local Associations for Retarded Children, whose membership until now has consisted primarily of parents of severely or moderately retarded children, should expand activities which are likely to attract parents of the minimally retarded.

36. Parents should receive guidance in asking meaningful questions of the professional persons with whom they will come in contact as they obtain evaluation, treatment, and counseling services. Professionals should likewise be alerted to the kinds of things parents will want to know, as well as to the availability of a variety of community resources.

III. RESIDENTIAL CARE

Residential care refers to placing a patient in any facility outside his own home which provides care on a 24 hour a day basis. The views of the President's Panel regarding residential care, as presented below, coincide with those of the Task Force and its several sub-committees.

> Residential care has an important place among the various services required for the retarded and, for many years, it was practically the only service of any importance in this country. The view that a large institution is one of several rather than the main resource in the care of the retarded is not yet established in the United States as it is in the Scandinavian countries and in England, Holland, and other parts of Europe where significant community services are a part of their program. In this country, institutions represent the greatest investment of manpower, buildings, and funds, and thus are highly visible. This is a consequence of the historical pattern of our concern for the retarded, and a coincidence of the physical nature of residential facilities, which are very large in many cases and frequently at some distance from centers of population.
>
> The challenge to State institutions is how to accelerate the change from large, isolated facilities to smaller units close to the homes of the patients and to the health, education, and social resources of the community; and the challenge to both State and private residential facilities is how to replace the old concept of custodial care wherever it still exists with modern programs of therapy, education, and research.
>
> <u>Institutional care should be restricted to those whose specific needs can be met best by this type of service.</u>
>
> Institutions are one facet in the continuum of care. The decision to place a retarded person in residential care must be made on the basis of careful review of the diagnosis and symptoms of the individual, the needs of his family, and other resources available in the community. Professional judgement and recommendations are indispensable, but the decision-making process must also include members of the family if they are at all competent to participate.
>
> Because of the tremendous variations in the problem presented, it is unwise to generalize with respect to the desirability of keeping retarded children in their own homes. The attitude of parents on this matter ranges all the way from determination to retain the child whether or not it is wise for them to do so, to the despair that results from carrying an intolerable burden. The financial capabilities of families covers an equally wide range; thus what is "best" for the retarded child, his family, and the community can properly be determined only by adequate professional evaluations, skillful counseling, and an objective point of view

on the part of local and State authorities.

There will always be some retarded individuals for whom a residential setting for a short or long period will be the treatment choice. In making this decision, the emotional stability of the family and the degree of dependence of the retarded person involved are key factors. If the total well-being of the retarded person depends on the care of trained personnel, and if his presence in the home conflicts with the fulfillment of the needs of other members of the family, he probably should not remain at home. If a retarded person is to live at home, it is important to determine whether the community has the supplementary facilities he needs.

Age is an important and sometimes controlling factor. Studies have shown consistently that infants and even young children up to 6 and 7 years of age are usually better served in their own or in an adequate foster home or in boarding home group care. The need for schooling alone rarely calls for admission to an institution today except in rural areas where facilities are scarce. Most often, admission is necessitated by unmet medical, nursing, or behavioral needs, by death of parents, or by lack of stability in the family.

Many retarded people have a critical need not being met in the community; the need may be a foster home, an educational opportunity, or only routine medical and dental care. Every effort should be made to satisfy needs such as these through available or new resources rather than resorting in a routine fashion to institutional care.

The following objectives for residential care should be considered by boards of private institutions, appropriate authorities of the States, and the Council of State Governments.

(1) Every such institution including those that care for the seriously retarded should be basically therapeutic in character and emphasis and closely linked to appropriate medical, education, and welfare programs in the community.

(2) Every institution has some unique quality or potential that can be developed for the benefit of the entire field. No institution should be regarded as merely "custodial"; those caring for the profoundly retarded offer unusual opportunities for the application of new methods of treatment and care and for research.

(3) Diagnosis and evaluation should take place before admission and be followed promptly by treatment when the patient is received.

(4) The institution should extend its services beyond the traditional boundaries of its own campus and reach out to assist the patient and his family before his actual admission; this facilitates visits by parents and friends after admission and is an important factor in early adjustment.

(5) Flexible admission and release policies and outpatient programs similar to those of hospital or school are essential in meeting the needs of the retarded and their families.

(6) The goal of every residential program should be the elimination or amelioration of as many symptoms as possible and the achievement of independent, semi-dependent, or even a sheltered extramural life for every person under care in accordance with his potential. This can be accomplished only by a devoted staff with a variety of professional skills and a competent administration.

Indoor and outdoor recreation; social activities; programs of physical fitness; opportunities for self-expression through music, painting, worship; and other creative outlets are essential aspects of sound institutional programs.

(7) No child or adult shall remain in residential care any longer than necessary. Regular and frequent reevaluations must be scheduled to reveal any possibilities that may have been developed in his community and to determine whether the individual himself has reached the point where he may profit by some other form of care.

(8) If and when the child or adult is ready for return to the community, adequate resources and services for support should be made available. It may not be wise or possible for some to return to their own families, hence the importance of developing foster or boarding home placements or homes for small groups similar to those in several European countries.

(9) Responsibility for the care of persons returned to the community should not relinquished by the institution until assistance is assured from some other source; efforts should be made to see that community services are made available to him before he leaves.

(10) Many residential populations lend themselves to certain unique research undertakings, particularly of a clinical nature. Continued clinical evaluation of the institution program itself requires personnel with a research point of view.

(11) The future of residential care must be viewed in the context of State and regional needs and resources; i.e., more than one State should be included in planning in many instances, as the geographical characteristics and resources of some States are such that they cannot meet the needs alone. Joint planning and development of interstate facilities is particularly important in providing facilities for such combinations of handicap as the blind and the deaf mentally retarded.

As the states and the boards of public and private institutions plan for the future, problems of the size of institutions, program, and personnel are paramount. Bringing the provision of services as close as possible to the local community is a basic tenet on which the Panel's recommendations rest. This would be consistent with the general movement of health and mental health services in this direction, in itself an important key movement in developing new services of the retarded.[31]

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31. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 134-138, 141.

Private Institutions

Unique opportunities are open to the private institutions in the country. There are many ways in which they can serve as important links in a continuum of community services and cogent reasons why they should become increasingly strong factors in programs for the retarded; first is the fact that our society believes in and profits by a fruitful partnership of public and private services in every area of endeavor; second and more explicit, it is the opportunity that the high quality institution offers to the States by way of a spearhead or vehicle for demonstration and experimentation in residential care. A great deal of value could accrue to both voluntary and public programs for the retarded if more states would apply in carefully selected instances the "purchase of care" plan whereby a private institution for the retarded is conducting, or can conduct for the State institution or other State programs, a unique service of special value. It is suggested that this possibility be thoroughly explored by those States which have not yet considered or used this resource. It is important that in any such plan the purchase of care should be made on a cost accounting rather than a flat basis and that the amount paid by the State in any year should not exceed the total amount of the budget of the institution for that year. Otherwise, the institution would in a sense lose its private status and be subject to State control.

States have the responsibility to maintain effective licensing and inspection of all private facilities offering residential care for the retarded. Private institutions of appropriate standards and level of patient care that meets State requirements should be eligible for all support and subsidies outlined in these recommendations, among others, which are germane to the future of residential care in the United States.

(1) Impetus should be given in the United States to the development of a wider range of diversified residential arrangements for those retarded persons who, for whatever reason, cannot live with their own or foster families; that is, small units designed in program and structure meet different needs.

(2) Emphasis should be directed to the development of group homes in urban and suburban areas for small homogenous groups of retarded persons who can use the various community opportunities for work, recreation, and education, and to the design, construction, staffing, and use of living units for six to ten children within larger institutions.

One of the best hopes for the improvement of both public and private institutions in the States may come from interdepartmental committees and equally strong citizens' committees, both appointed by the Governors and responsible to them.

If the membership of a citizens' committee includes knowledgeable and militant people who will acquaint themselves with the problems of the retarded in the State and help to determine what is needed to improve and develop the program, there will be substantial

progress; in fact, it is doubtful whether fundamental improvement in residential care where it is needed the most can take place without an organized and sustained citizen effort.[32]

Multi-Purpose State Institutions

The bulk of Minnesota's retarded persons who require residential care are located in the large institutions at Faribault, Cambridge, and Brainerd. These total 5,845 persons. In addition there is a waiting list of 754 persons.[33] Faribault is 23 per cent overcrowded, Cambridge 14 per cent, while Brainerd is operating at 86 per cent of capacity. These figures are based on State Department of Health licensing regulations, which require sixty square feet of floor space for each bed.[34]

Over the years, large facilities have served as "catch alls" for retarded persons whose ages and degree of retardation vary widely. Severe staff shortages have made it impossible to serve adequately either patients or community.

Minnesota's historical responsibility, as a State, for the welfare of the mentally retarded is clear. The residential institutions are a part of this responsibility. Conditions at State institutions are grossly unsatisfactory and fail, in many instances, to meet the standards of the Department of Welfare. Those who participated in the recent series of institutional bus tours led by Governor Rolvaag, or in the series of tours sponsored last year by the Minnesota Association for Retarded Children, have been shocked and saddened by the conditions in which many human beings must live.

The most serious deficiency in the State schools and hospitals is the shortage of staff, especially of psychiatric aides and other patient care workers.

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32. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 145-146.

33. Statistical Summary of Mentally Deficient and Epileptic Patients Under Supervison. Department of Public Welfare. Fiscal year ending June 30, 1964. Table A-3.

34. Minnesota State Plan for Hospitals, Public Health Centers, and Related Medical Facilities. Sixteenth Annual Revision. Minnesota Department of Health, 1964-65.

TABLE 2

PATIENTS RESIDING IN FARIBAULT, CAMBRIDGE AND BRAINERD STATE SCHOOLS AND HOSPITALS FOR THE RETARDED AND LAKE OWASSO CHILDREN'S HOME AS OF JUNE, 1965 GROUPED ACCORDING TO PROGRAM*, SEX, AND COUNTY OF RESIDENCE

COUNTY	PATIENTS IN COUNTY			PROGRAM NUMBERS 1		2		3		4		5		6	
		M	F	M	F	M	F	M	F	M	F	M	F	M	F
Aitkin	49	24	25	1	0	3	1	0	1	1	4	6	11	13	8
Anoka	78	46	32	4	5	14	5	0	5	4	2	13	5	11	10
Becker	49	30	19	3	0	0	1	0	0	1	4	5	5	21	9
Beltrami	66	33	33	4	1	2	1	1	0	1	5	11	15	14	11
Benton	57	30	27	4	0	2	0	1	0	2	7	9	11	12	9
Big Stone	23	11	12	0	0	2	2	0	0	0	1	6	6	3	3
Blue Earth	88	51	37	4	2	5	0	2	3	4	5	18	15	18	12
Brown	61	20	41	1	3	1	1	2	5	3	6	5	18	8	8
Carlton	44	23	21	3	1	4	0	1	1	1	4	7	8	7	7
Carver	38	22	16	0	0	1	0	3	0	3	3	10	9	5	4
Cass	65	41	24	4	1	6	1	0	1	2	4	12	1	17	16
Chippewa	38	19	19	0	2	2	0	1	1	1	2	6	12	9	2
Chisago	28	10	18	2	3	1	0	0	2	1	1	4	3	2	9
Clay	53	28	25	3	3	4	3	0	0	4	3	5	6	12	10
Clearwater	13	8	5	0	0	0	0	0	0	1	1	5	3	2	1
Cook	8	6	2	0	1	0	0	0	0	0	0	2	2	0	3
Cottonwood	34	17	17	2	1	2	0	2	2	4	4	2	4	5	6
Crow Wing	85	41	44	0	2	5	1	0	1	6	5	9	12	21	23
Dakota	107	56	51	4	6	10	4	4	5	0	8	19	16	19	12
Dodge	36	16	20	3	3	2	0	0	1	0	3	4	7	7	6
Douglas	38	22	16	0	0	3	0	1	1	4	1	7	7	7	7
Faribault	45	24	21	1	1	0	0	3	0	3	2	10	13	7	5
Fillmore	32	23	9	1	0	1	0	1	0	4	1	10	5	6	3
Freeborn	57	31	26	3	0	2	1	3	2	2	3	12	13	9	7
Goodhue	72	38	34	2	2	3	0	3	4	2	6	14	14	14	8
Grant	20	8	12	0	0	0	0	0	2	1	1	5	5	2	4
Hennepin	1209	647	562	40	45	75	32	77	38	57	66	209	227	189	154

(Cont'd. on next page)

* For description of Programs, see page 42-44.

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TABLE 2 (Cont'd.)

PATIENTS RESIDING IN FARIBAULT, CAMBRIDGE AND BRAINERD STATE SCHOOLS AND HOSPITALS FOR THE RETARDED AND LAKE OWASSO CHILDREN'S HOME AS OF JUNE, 1965 GROUPED ACCORDING TO PROGRAM*, SEX, AND COUNTY OF RESIDENCE

COUNTY	PATIENTS IN COUNTY			PROGRAM NUMBERS 1		2		3		4		5		6	
		M	F	M	F	M	F	M	F	M	F	M	F	M	F
Houston	20	14	6	0	1	3	0	0	1	2	2	4	1	5	1
Hubbard	31	12	19	1	2	0	0	0	0	0	3	6	7	5	7
Isanti	25	13	12	0	0	2	1	1	0	0	4	3	2	7	5
Itasca	61	29	32	5	1	4	1	1	2	2	2	8	13	9	13
Jackson	23	12	11	0	0	1	0	2	0	2	0	4	7	3	4
Kanabec	20	16	4	0	0	1	0	2	0	1	0	5	2	7	2
Kandiyohi	46	29	17	2	0	0	1	0	1	3	5	9	5	15	5
Kittson	28	16	12	3	1	2	0	0	0	0	2	6	5	5	4
Koochiching	49	25	24	1	3	2	0	1	0	2	2	8	3	11	16
Lac qui Parle	20	7	13	0	0	0	0	0	0	0	3	5	6	2	4
Lake	16	8	8	0	0	1	1	1	0	1	1	3	3	2	3
Lake of the Woods	7	2	5	0	0	1	0	0	0	0	0	0	3	1	2
Le Sueur	32	13	19	0	1	0	1	1	3	2	3	5	6	5	5
Lincoln	23	9	14	0	2	1	0	1	0	3	2	2	6	2	4
Lyon	30	16	14	0	0	1	0	0	0	1	2	7	9	7	3
Mc Leod	45	27	18	0	2	3	0	1	0	4	2	7	13	12	1
Mahnoman	23	11	12	1	0	1	1	0	1	0	1	0	3	9	6
Marshall	28	13	15	0	1	1	1	0	0	3	1	6	6	3	6
Martin	40	22	18	4	1	1	0	1	2	1	4	3	6	12	5
Meeker	28	17	11	1	1	2	0	0	0	2	2	8	6	4	2
Mille Lacs	24	12	12	0	3	0	0	0	0	1	0	4	6	7	3
Morrison	77	41	36	4	0	2	3	3	1	2	3	11	15	19	14
Mower	75	51	24	3	1	5	0	7	3	9	3	11	10	16	7
Murray	23	12	11	1	0	0	1	0	0	4	2	1	2	6	6
Nicollet	22	14	8	3	0	0	0	1	1	0	1	3	4	7	2
Nobles	39	22	17	0	2	0	0	1	1	2	1	9	7	10	6

(Cont'd. on next page)

* For description of Programs, see page 42-44.

TABLE 2 (Cont'd.)

PATIENTS RESIDING IN FARIBAULT, CAMBRIDGE AND BRAINERD STATE SCHOOLS AND HOSPITALS FOR THE RETARDED AND LAKE OWASSO CHILDREN'S HOME AS OF JUNE, 1965 GROUPED ACCORDING TO PROGRAM*, SEX, AND COUNTY OF RESIDENCE

COUNTY	PATIENTS IN COUNTY			PROGRAM NUMBERS											
				1		2		3		4		5		6	
		M	F	M	F	M	F	M	F	M	F	M	F	M	F
Norman	31	13	18	0	1	2	2	0	1	1	0	4	6	6	8
Olmsted	96	48	48	6	2	4	2	4	2	5	5	13	21	16	16
Ottertail	91	50	41	2	4	4	2	2	3	4	2	14	21	24	9
Pennington	19	10	9	0	0	1	0	0	1	1	1	4	1	4	6
Pine	45	24	21	1	2	1	0	1	0	0	3	10	12	11	4
Pipestone	26	15	11	0	0	1	0	0	0	0	1	7	6	7	4
Polk	69	40	29	1	0	6	3	1	2	5	4	13	11	14	9
Pope	26	15	11	0	1	3	0	3	1	0	0	6	7	3	2
Ramsey	734	385	349	39	36	75	36	11	10	56	47	114	133	90	87
Red Lake	24	13	11	1	0	1	0	0	0	1	1	3	7	7	3
Redwood	42	22	20	0	2	1	0	0	0	1	3	11	8	9	7
Renville	60	30	30	1	1	1	0	5	1	2	2	8	18	13	8
Rice	85	51	34	4	4	2	1	8	2	3	5	9	8	25	14
Rock	19	12	7	0	0	1	0	1	0	1	1	4	1	5	5
Roseau	34	20	14	2	1	4	0	1	0	0	2	9	7	4	4
St. Louis	396	195	201	13	13	30	7	4	10	19	23	59	71	70	77
Scott	39	25	14	3	1	4	0	2	0	2	0	7	12	7	1
Sherburne	27	16	11	2	2	1	1	2	0	1	0	2	5	8	3
Sibley	22	10	12	1	1	1	0	0	1	3	0	3	6	2	4
Stearns	158	86	72	9	4	7	6	0	1	8	9	36	26	26	26
Steele	32	14	18	0	0	0	0	2	2	4	3	6	9	2	4
Stevens	15	7	8	1	0	0	0	0	0	1	1	3	4	2	3
Swift	34	17	17	1	2	3	0	0	1	1	3	8	4	4	7
Todd	57	29	28	2	0	6	0	0	0	2	4	9	15	10	9
Traverse	21	11	10	0	0	0	1	1	1	2	1	7	6	1	1

(Cont'd. on next page)

* For description of Programs, see page 42-44.

TABLE 2 (Cont'd.)

PATIENTS RESIDING IN FARIBAULT, CAMBRIDGE AND BRAINERD STATE SCHOOLS AND HOSPITALS FOR THE RETARDED AND LAKE OWASSO CHILDREN'S HOME AS OF JUNE, 1965 GROUPED ACCORDING TO PROGRAM*, SEX, AND COUNTY OF RESIDENCE

COUNTY	PATIENTS IN COUNTY			PROGRAM NUMBERS 1		2		3		4		5		6	
		M	F	M	F	M	F	M	F	M	F	M	F	M	F
Wabasha	33	14	19	0	0	1	2	1	2	0	2	9	8	3	5
Wadena	21	15	6	1	0	2	0	1	0	3	0	4	5	4	1
Waseca	31	15	16	0	0	0	0	0	1	4	4	5	6	6	5
Washington	73	42	31	5	2	12	4	1	1	2	2	12	12	10	10
Watonwan	33	18	15	1	0	2	1	1	0	2	2	4	6	8	6
Wilkin	26	12	14	0	2	2	1	0	0	1	1	4	3	5	7
Winona	64	32	32	1	0	1	0	0	2	5	3	9	9	16	18
Wright	44	24	20	1	2	3	1	0	2	0	1	7	6	13	8
Yellow Medicine	38	19	19	0	0	2	0	3	1	1	1	8	8	5	9
SUB-TOTALS				216	187	368	134	184	139	300	340	994	1097	1071	883
TOTALS	5913	3133	2780	403		502		323		640		2091		1954	

* For description of Programs, see page 42-44.

The 1962 Governor's Advisory Committee wrote:

> (1) Many children spend all day in bed, often with soiled diapers, because no staff member is available to care for them out of their cribs or to change their diapers — except by schedule;
> (2) Some children cry, but do so alone because no one is available to comfort them;
> (3) Children look out of windows at playgrounds, but are confined indoors because of lack of recreational workers;
> (4) Patients, hundreds of them, have nothing to do but to sit, walk aimlessly, sleep excessively, or watch television;
> (5) Meals are gulped and spilled by patients who should have help in eating; helpless patients are fed in rushed fashion by other patients;
> (6) Patients, in large numbers, come up to visitors, obviously craving a touch, a word, or some other form of attention.[35]

The situation had not changed appreciably up to the 1965 legislative session. At that time 421 new positions were allocated and are being phased in at the rate of 105 every six months during the 1965-67 biennium. While this represents a great forward stride, it falls far short of the 833 positions recommended by the Minnesota Association for Retarded Children and the Department of Public Welfare, or the 578 recommended by Governor Rolvaag in his budget message.

Additional staff alone is not the solution to the manifold problems which exist in State residential facilities for the retarded. The large multi-purpose institution must be integrated into a continuum of services in which smaller community facilities play an important part. This will require a redefinition of the role and function of these facilities.

Institutions for the mentally retarded provide three basic services: custodial care, training, and medical services. Ideally an individual enters an institution because it best meets his needs, those of his family, and those of

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35. State of Minnesota. A Report of the Governor's Advisory Committee on Mental Retardation. October, 1962. See Chap. IV and Appendices D & F.

the community. However, too often an individual is placed in an institution because there is no other service or facility available to him.

The task force has defined the broad goals of residential facilities as:

1. Creation of an atmosphere in which every patient can develop to his full potential.

2. Establishment of a standard of physical, nursing, and medical care which, at the very minmum, is as good as that available to a non-retarded person in the community.

3. Development of sufficient flexibility in programming and administration to ensure successful coordination of these facilities into comprehensive Statewide planning of services for the mentally retarded.

In order to accomplish these goals, the kinds of services needed by specific groups of patients presently in State institutions must be carefully delineated. An excellent beginning in this direction has been made in the classification scheme presented on pages 42-44.

Small Residential Facilities

The advantages afforded by small residential facilities, whether State supported or private non-profit, were outlined by the task force as follows:

1. Facilities can be located so as to be easily accessible to community agencies responsible for placement. Thus a continuity of counseling and other services can be maintained.

2. Community support and sensitivity to the problems of the mentally retarded are stimulated. The facility can be integrated into an array of community services rather than being isolated. Volunteer and professional services are more readily available.

3. Facilities are more accessible to the families of residents. The task force felt that geographical proximity is a major factor in maintaining the interest of the family, which is indispensable to

CHARACTERISTICS OF PATIENTS IN EACH OF SIX PROGRAMS BEING ESTABLISHED IN STATE INSTITUTIONS FOR THE MENTALLY RETARDED

1. Child Activation Program. This program is for children from birth to puberty who are bedfast or non-ambulatory. These children have usually suffered major central nervous system damage; their physical helplessness is caused by their having severely damaged or under-developed brains. They do not, however, have such severe physical problems that they require complicated nursing care and special nursing equipment such as is found on a ward for seriously ill children. If these children are given large amounts of affectionate attention and are encouraged to see, hear, and move, a significant number may learn to sit in wheel chairs, crawl, walk with help, and to evidence in manner and appearance the development of the capacity to feel happiness and enthusiasm.

2. Child Development Program. This program is for children who can walk. Their ages may range from three or four up to eleven or twelve. Children within this group vary greatly: some may be constantly overactive, other quiet and withdrawn; some may be physically disfigured but fairly bright, others may be doll-like in appearance but not respond noticeably to people or to playthings. Epileptic seizures are fairly common. These children greatly need warm and affectionate mothering, appropriate disciplining, and special kinds of education and training programs. This program is called "Child Development" because all of these children are in a most important period of physical and personality growth. What happens to them at this time will have much to do with how capable and stable they will be when they become adults.

3. Teenage Program. This program is for ambulatory children who have passed the age of puberty, but are not yet old enough to participate in vocational training or other more adult activities. Some of the mildly retarded children in this group frequently have been sent to an institution because their

hostile, destructive behavior has excluded them from special education programs in their home communities. Others with mild degrees of retardation have been admitted to the institution because they have developed serious degrees of mental illness. This group also includes some mildly and moderately retarded children who cannot remain at home because their home communities do not provide classes for "educable" and "trainable" children. severely retarded children have come to this program from the Child Development Program and demonstrate behavior usually believed to be related to bodily and emotional changes which take place at puberty. Because of the cost of the services, such as psychiatry, psychology, occupational therapy, and special activities, which are required to program adequately for the complex needs of children in the Teenage Program, it is likely that this group will remain in residential care in State facilities.

4. Adult Activation Program. This program is for bedfast and non-ambulatory patients who are too old to be included in the Child Activation Program. These patients need close attention and constant watchfulness for indication for potential progress. Many of them, after years of bed care, have developed serious but correctable losses of use of arms or legs, or have become twisted and stiffened so that they cannot use wheel chairs or walk. The mental capacity of these patients may be very low, or it may merely appear to be low because they have suffered damage to those parts of the brain necessary for speech. This is essentially a hospital program for persons who require a great amount of care by physicians specializing in orthopedics, neurology, and neuropsychiatry and nurses and technicians specially trained to provide physiotherapy and other rehabilitative services.

5. Adult Motivation Program. This program is for ambulatory older adolescents and adults of all ages who have very limited intelligence and who frequently suffer from severe emotional disorganization. They may show very odd

behavior and often seem to have little meaningful or understandable contact with people and things around them. Some of these persons wander around actively but aimlessly, while others sit on the floor rocking or making strange noises. Some make great efforts to communicate with friends or strangers, others appear to be withdrawn and frightened. These patients, however, often show a surprising capacity for taking part in occupational therapy and recreational activities. It may be possible to discover many secrets of how the mind and emotions function through neurological and psychiatric research with these patients.

6. Adult Social Achievement Program. This program is for those late adolescent and adult patients who have no serious intellectual handicaps, no serious physical problems, and mo major degrees of mental illness. These patients find it difficult to adapt to the demands of society, generally because they have not had adequate vocational education and training and have spent so much time in institutions that they have never learned how to get along with non-retarded persons or how to use the work and recreation opportunities available in communities. Some persons in this program become panic-stricken at the thought of being independent, others have personality characteristics which cause others to dislike them. This program is call the Adult Social Achievement Program because it is designed to provide the educational, social, and psychological experiences which will enable these people to function successfully in the community-at-large.

patient well-being and morale.

4. Facilities could provide a variety of services, including long and short term foster care, diagnostic services, day care, sheltered workshops, and counseling.

5. Facilities can provide more personalized care than is possible in large institutions.

6. Decentralization of facilities could broaden the base for recruitment of staff and development of supportive services.

Table 3 lists sixteen licensed group facilities presently in operation in Minnesota. As of January, 1965, their enrollment was 885. These facilities are sponsored by church groups, private non-profit corporations, proprietary corporations, various foundations, and the State. Approximately 1,780 other retarded persons reside in nursing homes, boarding homes, and correctional institutions which also serve the "normal" population.[36]

Use of Hospitals for the Mentally Ill

Careful consideration should be given to the future role which hospitals for the mentally ill may play in providing residential care for the mentally retarded. Whereas the population of the State institutions for the mentally retarded has grown to 6,200, with an estimated 700 on the "waiting list", the total number of hospitalized mentally ill in Minnesota has declined from a high of 11,300 to about 6,400 at present. Problems which will require exploration are: dynamics of mixing in integrated programs; groups of retarded which can be best served by integration; staff training and attitudes; parent and community attitudes; will the mentally retarded become "second class" citizens?

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36. Figures obtained from Standards and Licensing Division, Department of Public Welfare.

TABLE 3

Licensed Group Facilities

Private Group Care		Jan, 1965 Enrollment	Licensed Capacity
Welcome Home, St. Paul		11	30
Rolling Acres Residential Care Center, Excelsior		14	13
Champion Children's Home, Duluth		39	39
Lake Park-Wild Rice Children's Home, Fergus Falls		25	25
Pettit Children's Home, Sauk Centre		20	20
Vasa Lutheran Home for Children, Red Wing		52	55
Lakeview Home, Sauk Centre		8	8
Richard Paul Foundation Home, St. Paul		12	12
Roseau Children's Home, Roseau		15	45
The Angels, Minnetonka		35	35
Julie Billiart Home, Jackson		30	30
Dorothe Lane Children's Home, Sauk Centre		10	11
	Sub-Total	271	323
Group Living Facilities for Adult Retarded			
Greenbriar Home, Inc., St. Paul		112	112
Ottertail Group Living Project, Fergus Falls		7	9
	Sub-Total	119	121
Private Residential Schools			
Hammer School, Inc., Wayzata		42	42
Laura Baker School, Northfield		54	55
	Sub-Total	96	97
State Institutions			
Shakopee Home for Children, Shakopee		30	30
Owatonna State School, Owatonna		201	211
Lake Owasso Children's Home, Lake Owasso		130	130
	Sub-Total	362	371
	TOTAL	848	912

Placement

The decision as to whether or not to place an individual in a residential facility should begin with a diagnostic evaluation of the needs of the retarded individual and his family as they relate to the larger community. On the basis of this evaluation, determination is made as to where and how the combination of individual, family, and community needs can best be met. Whatever course of action is chosen, those responsible must take into account the dynamic, changing nature of needs of the retardate, his family, and the community. Provision for regular reevaluation must be made.

An individual who has been placed in a residential facility should be transferred or released when he has received maximum benefit from the placement or when comparable benefits are available in the community. The facility must define treatment goals and must devise effective methods for achieving these goals. Discharge into the community will be more successful if a philosophy of acceptance has been gradually created. Follow-up counseling is essential. The decision to discharge a patient should be a joint one made by the institution, the county, parent or guardian. The decision to return a patient to an institution after release should also be the joint responsibility of parents, county, and institution.

Programs, Licensing, and Financial Considerations

Throughout our study and discussion two issues have emerged which require much further study as well as legislative and administrative action. Without their implementaton, no major improvements can be accomplished in residential care.

1. Enforceable Licensing Standards

   Adequate programming for various groups of retarded persons, whether they be in public or private facilities, must be guaranteed through practical and enforceable licensing standards. Concern has frequently been

expressed regarding quality of programs in both State operated and private facilities. In State facilities, control of standards rests with the legislature through its power to appropriate funds and deploy personnel. In non-State facilities, control is provided through State licensure. Means must be found to assure the maintenance of minimum standards in all facilities.

Present licensing procedures for community facilities are not formulated so as to ensure constructive treatment programs or adequate care. Program standards should be built into the licensing procedure.

2. Redistribution of Financial Responsibility

Under present law the county of residence pays only ten dollars a month for the residential care of any mentally retarded person placed in a State facility. The county may be partially reimbursed by parents (up to ten per cent), social security, aid to the disabled, or other source. The State pays the remainder. If the county places a retardate in a non-State facility, the county alone bears the full cost of care, again except for moneys which may be recovered from parents or other sources.

The results of this inequitable distribution of cost of residential care are threefold: (1) it is financially advantageous for counties to press for placement of patients in State institutions, rather than in smaller non-State facilities, irrespective of the patient's need; (2) non-State facilities are placed in the undesirable position vis-a-vis long-range development of programs and treatment for a given patient of merely being used temporarily to absorb persons on the "waiting list" for State institutions;* (3) the county often feels that it is "subsidizing" the State in those instances where it pays for non-State care of a retardate.

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* The Department of Public Welfare estimates that 300 to 400 persons on the "waiting list" are presently cared for in non-State residential facilities. For many of these patients, the present placement may be the most beneficial one.

Recommendations Concerning Residential Care

Placement

1. Placement in a residential facility should be based on comprehensive diagnostic evaluation. A plan for periodic review is essential and should be a legal requirement.
2. The willing consent of the parents should be secured before placement plans are worked out between the County Welfare Board or licensed private agency and the residential facility.
3. The placement agency is responsible for counseling parents in preparation for placement, and for explaining progress and alternatives during and after placement. This implies that the agency must have first hand knowledge of available facilities, programs, staffing, and limitations of service.
4. The placing agency and the institution must provide long-term family counseling. The institution should furnish periodic progress reports to the placing agency.

Programming

5. Residential programs should be continuously redefined by the responsible agency to ensure applications of current knowledge and research.
6. Professional organizations and administrative agencies, both national and State, should develop standards for the services which comprise a desirable treatment program.
7. Program content should include medical and custodial care, education, training, work, recreation, and religious services designed to enable the individual to develop to his fullest potential. The American Association on Mental Deficiency Standards for State Residential Institutions for the Mentally Retarded, January, 1964, should serve as guidelines.
   a. In order to accomplish program goals, facilities must be adequately and appropriately staffed.

b. The State Departments of Public Welfare, Education, and Health must provide supervisory staff sufficient to inspect, support, and enforce standards.

8. Periodic professional and administrative review must guide creation of treatment programs so that when a resident patient has received the maximum benefit from a given facility transfer or discharge can be effected.

9. A statement from the residential facility describing provisions which have been made for adequate and appropriate treatment programs for individuals in residence should be mandatory in applications for licensing, grants-in-aid, governmental payment of fees, contractual agreements, or any combination thereof.

10. Regulations enforcing health, fire, and program standards must apply to public as well as to private facilities.

11. To ensure orderly development of programs and services for the retarded in the local community, a Statewide and regional facilities construction plan is essential. (See Vol. II)

Facilities

12. The patient populations of the State institutions at Cambridge, Brainerd, and Faribault should be periodically evaluated so that programs which meet the changing needs of individuals can be provided.

13. Clear guidelines as to patient groups whose needs can probably be met best in State insitutions should be developed in order to assist agencies in making appropriate placements.

14. Future construction of facilities should be decentralized and planned to meet specialized needs of segments of the retarded population, as opposed to serving the entire range of retardation disabilities. Facilities may be owned and operated on a single or multi-county basis by the State, by private non-profit foundations and corporations, or by any combination thereof. Faci-

lities may be subsidized or may contract for services. Legal barriers to such arrangements should be removed.

a. The State facilities construction plan should emphasize smaller comprehensive residential facilities located near population centers where auxiliary services are available--general hospital, special education, etc.

b. The State construction plan should also consider locating facilities near the borders of neighboring States to enable interstate use of services.

15. State institutions at Faribault, Cambridge, and Brainerd should be structured to provide comprehensive services to their regions, i.e., diagnostic evaluations, outpatient and inpatient sheltered workshops, work-training stations, day care, day-night centers, long and short term residential care, consultative services to community agencies, field placements for pre-professional students, and research and training in cooperation with universities and colleges.

Finances

16. a. Costs of residential care should be shared by parent, county, State, school, or agency according to legally defined responsibilities; The division of responsibility should be such that financial considerations do not determine treatment services. Further legislation or modification of administrative rules should be effected as required.

b. It is recommended that, irrespective of whether placement is made in a State or non-State facility, (1) the county of residence pay ten dollars per month toward the residential care of any retarded person requiring such care, (2) parents pay up to ten per cent, based on cost of care in a State facility, and (3) the State pay the remainder.

17. A cost accounting system for residential care programs should be devised.

This system would form a basis for a realistic financial approach to both private and public care at all levels of government.

18. Both State and county must be alerted to the availability of increasing Federal support for the retarded, as various programs under Medicare, Economic Opportunity Act, Manpower Training Act, and other new legislation, emerge.

Research and Demonstration

19. The place of mental hospitals in serving the retarded must be re-examined. Several alternatives present themselves:

    a. Integration of selected mentally retarded persons in mental hospital programs.

    b. Separate programs and living quarters for retarded on the same grounds as mental hospitals.

    c. Conversion of one or more of the State's seven mental hospitals to facilities serving the retarded.

20. A study might be made of the effect on previously institutionalized retardates of placement in community facilities.

IV. EDUCATION AND HABILITATION

Most citizens of Minnesota receive and benefit from a broad range of public services—including many relating to education and habilitation. Public school programs are provided for most children. Many attend State operated colleges, graduate schools, and professional schools. Habilitation services—such as pre-vocational training and counseling, sheltered workshops for the handicapped, and working training—are provided to others.

Unfortunately these basic services are not available to all citizens. All too frequently, those who are overlooked include the mentally retarded. Some retarded children are excused from school because no special classes are available, while others enjoy school services of only limited kinds. Older retarded persons are frequently excluded from vocational training situations.

Progress has been made in overcoming these inequities, especially in the past decade. The number of school programs provided for the retarded has grown from 212 in 1957, at which time the State legislature made special classes for educable retarded children mandatory, to 651 as of November, 1964. (Table 4). Nevertheless, less than half the mentally retarded children in Minnesota who could benefit from special education are receiving it. It is assumed—conservatively—that two per cent of all school age children need special education programs for reason of mental retardation. Minnesota has approximately 900,000 school age children; two per cent of this number is 18,000. Yet only 8,000 children were served during the 1964-65 school year. Deficiencies relating to the retarded are most striking in rural areas. More programs for severely retarded children and for older school-age retardates are needed throughout the State.

The picture regarding habilitation of the retarded is a similar mixture of problems and progress. Development of habilitation services required by the the retarded has only begun and vast efforts will be needed to afford even a modicum of service to all retarded persons of employable age. A special concern is

TABLE 4

GROWTH OF SPECIAL EDUCATION PROGRAMS
FOR THE MENTALLY RETARDATION IN MINNESOTA [1]

SCHOOL YEAR	Educable Classes	Pupils in Classes	Trainable Classes	Pupils in Classes	Total Classes	Total Pupils in Classes	Cost of Special Services (State Aids)
1960-61	403	5229	42	368	445	5597	$ 1,430,129
1961-62	473	5839	58	427	531	6266	$ 1,668,407
1962-63	477	6341	51	435	528	6776	$ 1,837,879
1963-64	495	6803	55	483	550	7286	$ 2,045,719
1964-65	561	7423	71	585	632	8008	$ 2,549,981

1 - Minnesota Department of Education Annual Reports.

the need to develop sheltered work stations for an estimated three to four thousand retarded adults in Minnesota who will need such accommodations if they are to make an economic contribution to their communities.

Minnesota as a State has a clear mandate to provide suitable education for all children. The Minnesota constitution refers to education directly in Article VIII, Section I, as follows:

> "Uniform System of Public Schools. The stability of a republic form of government depending mainly upon the intelligence of the people, it shall be the duty of the legislature to establish a general and uniform system of public schools."

The difficulty in implementing the constitutional provision as stated above can be traced to an inadequate organizational structure. State responsibility for education has been, by statute, fragmented and diffused among numerous boards and systems. At present four major State agencies have responsibility in education: the State Board of Education (supervising 578 twelve-year high school districts, 22 area-vocational-technical schools, and 900 common school districts); the Board of Regents of the University of Minnesota (governing the university on four different campuses); the State College Board (governing six State colleges) and the Junior College Board (governing 17 junior colleges). A fifth agency, the Higher Education Liaison and Facilities Commission, composed of members of the other four boards and ten members appointed by the Governor, was established by the 1965 Legislature. Recommendations dealing with mental retardation must likewise be submitted to many separate and independent governing units. Administrative and organizational principles indicate that the absence of coordination and articulation makes it difficult if not impossible to achieve full implementation of recommended program changes and new programs. Responsibility for revision of the organizational structure for public education is a legislative one. The achievement of improved programs in special education is dependent upon action in this area.

Although most of this report centers on community developments needed to

provide suitable education and habilitation programs, there is urgent need to develop similar programs in State institutions for the retarded at Brainerd, Cambridge, Faribault, and Owatonna.

Education

It is often useful to divide the school age mentally retarded population (ages 5-21) into two main groups, the educable retarded and the trainable retarded.

> The educable retarded are those individuals who, because of impaired mental development, are unable to benefit adequately from regular school classes. Given specially trained teachers, added attention, and a level and type of curriculum adjusted to their abilities and future needs, the majority can become economically and socially independent. Generally, persons in this group achieve scores on standard intelligence tests ranging from about 50 to 80. It must be stressed that the group is by no means homogeneous. Within the 'educable' group, wide variations in characteristics within and between individuals exist.
>
> The trainable retarded are those individuals whose severe degree of mental handicap precludes successful participation in programs of instruction for the educable retarded. In classes of instruction geared to their level, however, they can learn self-care, social adjustment, and practical skills which will allow them to become semi-independent in a sheltered environment. Intelligence test scores for this group range from about 30 to 50 or 55. Again, it must be understood that classification of individual children as "trainable" os an oversimplification; great individual differences exist within the group.

Present law in Minnesota is mandatory with respect to school attendance of the educable retarded and thus implies strong obligation on the part of local school districts to provide suitable programs for the educable retarded. This obligation remains unfulfilled in many communities. It is estimated that ten to twenty school age retarded children per 1,000 are "educable" and are available for special classes. Based on this estimate, potential population for educable classes in Minnesota would be about 18,000. The number in classes 1964-65 was 7,423.

Public school programs for the trainable retarded are not mandatory. Although the number of classes for trainable children has grown from 21 in 1957

to 70 in 1964, (Table 4), only about one-third of the trainable retarded children needing special education are now receiving it. It is estimated that between two and four school age children per thousand are "trainable" and are available for community classes. Based on this estimate, potential population for trainable classes in Minnesota would range from 2,000 to 4,000 pupils. The number in classes in 1964-65 was 585.

Educational programs for the mentally retarded should provide a continuum of instruction adapted to the specific needs of each child, progressing through the stage where he is prepared to function at his highest potential level. For the educable retarded child this preparation should extend beyond elementary school to include secondary special classes and work-training programs. The trainable retarded child must be provided with programs which will develop self-help, socialization, and economically useful skills. Many retarded persons, when past school years, will require a sheltered environment if they are to perform useful work. A major effort is needed to establish a sufficient number of sheltered work stations.

The costs of educational programs for the retarded should be borne by the school district and the State just as in the case of other children. Parents of retarded children should not have to pay for the special education programs their children need. State offices should be watchful to see that no economic test of families is ever made in deciding upon an educational program.

Personnel Problems. Perhaps the single most frustrating circumstance relating to education of the mentally retarded is the continuing shortage of well-trained teachers and other personnel necessary to conduct school programs. Many school districts now operating programs for mentally retarded children are forced to hire teachers with inadequate training. One approach to the solution of this problem is the establishment of an additional specialized teacher training center. Minnesota now has four such centers, at Moorhead, St. Cloud, and Mankato State

Colleges, and at the University of Minnesota (Minneapolis Campus). Each center has demonstrated that, if special training is available, potential teachers of the retarded can be recruited from the immediate student body and from nearby communities.

Programs in specialized teacher preparation have been initiated at Bemidji and Winona State Colleges and at the University of Minnesota at Duluth. At present the greatest deficiency seems to exist in the northeastern portion of the State. The task force, therefore, recommends that the University of Minnesota-Duluth be encouraged to extend its present summer program into a more comprehensive form of specialized teacher preparation. It may be desirable to explore development of an interstate plan between the University of Minnesota-Duluth and Wisconsin State University at Superior, which also has a teacher education program. Federal support of teacher education should facilitate launching of needed programs.

Most of the development of special education programs for the mentally retarded in the past dozen years in Minnesota has been at the elementary school level. More recently there have been signs of burgeoning secondary school programs for the retarded, but teacher preparation for work at that level is lagging. The recruitment of secondary teachers for work with the retarded presents a major challenge. In the past the recruitment pool has been mainly teachers and teacher-trainees at the elementary school level. While these persons may continue to serve as one source of secondary special teachers, new sources must be found. Preparation programs for secondary teachers should be designed to meet the unique needs of retarded students of high school age, with emphasis on such topics as: occupational and vocational information, evaluation of work skills, developmental reading for the retarded, social living skills. Secondary teachers of vocational skills must also be trained to know and understand the abilities and limitations of the retarded adolescent.

Another problem concerns preparation of teachers of the trainable retarded. There has been little in training and certification programs to differentiate teachers of eudcable children from teachers of trainable children. A recent

committee project sponsored by the State Department of Education has resulted in a clearer differentiation of the needs of teachers of the two groups. Staff representatives of the State Colleges and University of Minnesota have met to devise a concerted approach to the problem of training and certification of special teachers. New, somewhat less stringent certification requirements have been designed for teachers of the trainable and will shortly be reviewed by the State Board of Education. Similar coordination of resources and plans will be necessary as consideration is given to the many children who have multiple handicaps—including mental retardation.

Great care must be taken in the recruitment of potential teachers and other professional personnel for special education programs. Despite the efforts of some individuals, there are undoubtedly young people who go through teacher education programs in Minnesota without ever being confronted with the possibilities of a career in special education. For others this confrontation comes at a time when it is too late to redirect their programs. At the high school level also there are many opportunities to inform and motivate potential special teachers, psychologists, and others. Active early recruiting will ensure that all potential teachers are aware of the field of special education and have been given all pertinent information, interpretation, and assistance.

Resources which may be used in carrying out a broadened recruiting programs are many and varied. Information can be distributed through high school counselors. Liaison can be established through the Future Teachers of America with prospective teachers, in order to inform them about special education programs. The Minnesota Council for Exceptional Children and the Association for Retarded Children could be utilized more fully than they are now for the dissemination of information regarding special education. Films, special "career days," and classroom visitations can be used in a total recruitment program.

College instructors, local teachers, parents, and many others have roles to

play in recruitment, but responsibility for initiating and coordinating recruitment programs should be focused in one agency in order to achieve maximum results throughout the State. This leadership could best be assumed by the Special Education Division of the State Department of Education, which would have the responsibility for the development of materials and for the overall coordination of Statewide recruiting.

Related to the shortage of professional personnel is the fact that often highly trained staff members spend too much time in performing routine functions. A substantial increase in available personnel and a freeing of some professional individuals to assume supervisory roles could probably be accomplished through wider use of semi-professional personnel who have had some specialized training in mental retardation. The paramedical specialties have demonstrated the value of semi-professional trained technical personnel, e.g., practical nurses, nurses' aides, and medical laboratory assistants. Analogous semi-professional positions should be developed in fields of service to the mentally retarded. Such trained personnel would function, under professional supervision, as assistants in special classes, and in recreational, daytime activity, work training, and sheltered work programs.

One Minnesota junior college, St. Mary's, is planning to start a training program of this type in the fall of 1967. Encouragement and assistance should be given to the development and growth of such programs in Junior Colleges and Vocational Schools.

Quality of School Programs. Educators who are involved in programs for the mentally retarded are becoming increasingly concerned about the qualitative improvement of such programs. One aspect of this concern is the lack of continuity which frequently exists among the various levels of school programs and during the transitional stage between secondary school and employment or general community life. Unless curricula are carefully planned and coordinated, children may

experience great difficulty in moving from one special education program to another. Other specific problems areas are: curriculm development, psychological services, parent consultation, supervision, and in-service education. These are important general problems which are not the responsibility of any one teacher. They can be solved only through employment by the State Department of Education of additional highly trained supervisors and field consultants, and by enforcement of standards regarding special education supervisory personnel in the local school systems.

It is recognized, however, that many small school districts do not employ enough teachers of the retarded to justify the employment of specialized supervisors within individual districts. Frequently a program for the retarded offered at the elementary level in one school district "feeds" to a program at the junior high level in another district and to a senior high program in still another district. In other cases, a school district offers a complete program within its own boundaries but is not large enough to provide supervisory personnel. In such instances it is strongly recommended that supervisory personnel be hired jointly by the cooperating school systems.

Closely related is the severe problem of inadequate State supervision of school programs for the retarded. At present only one mental retardation consultant is authorized in the regular complement of the State Department of Education. This consultant is expected to supervise more than 625 special classes, to help organize new programs, to advise regarding innumerable special problems, and to interact with various State and local agencies. He is patently unable to do so many things over so broad a geographic area as Minnesota. If appropriate attention is to be given to the quality of special programs, more State level personnel are needed.

Further study should be given to the possibility of decentralizing special education consultant offices of the State Department of Education so that greater proximity and regional specialization may be achieved. Consultants might live in

various regions of the State and commute as necessary to St. Paul rather than vice versa.

The task force is aware of plans for studies of the organization of the State Department of Education and recognizes a need for realignment of present arrangements to bring about better communications within the department. It is urged that, as projected studies go forward, attention be given to the special education and rehabilitation administrative units.

Children Excluded from School

Commitment to a principle of education for all children obviously does not permit exclusion of any child from school, except under extraordinary circumstances. Incumbent upon the schools is the responsibility to tailor programs to fit pupil needs, not to select and reject students to fit rigidly defined programs. Health and welfare agencies are obliged to work with the schools to meet chidren's needs when these go beyond what the schools can reasonably be expected to meet on their own. A searching and continuing review should be made of all procedures used by schools in excluding or excusing children from school attendance. It is believed that such a review would reveal many cases of mental retardation, as well as an unknown number of other kinds of problems.

A pilot study was carried out in the Minneapolis Public Schools in the summer of 1965 to find out how data on children excused from school attendance might be structured to yield meaningful statistics for the purpose of State-wide interagency planning of services for the handicapped. Results indicated that 33 per cent of 358 children (ages 6-20) excused from school between September, 1964 and June, 1965 were mentally retarded.[37]

Closely related is the need for local schools to follow the progress of all

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37. Acker, Doris & Warfield, Grace. Report of a Study of Minneapolis School Pupils Who Were Legally Excused from School Attendance During the Year 1964-65. Summer, 1965.

resident pupils who are sent out of their district for any educational purpose. School districts should be required to undertake annual reviews of educational programs of all children of school age who are legal residents of the district but who are served in school programs of State schools or in public schools outside the home district.

Standards and Costs. Cost to the local school district should not determine educational plans for children who require special programs. If the cost to the district of education were to be uniform, whether a child be enrolled in a local community program, in a State institution, or in a program in another district, choice of placement would be based on meeting the needs of the child, rather than on financial considerations. The implications for residential care in Minnesota are obvious. It may certainly be that many children are being placed in institutions who could remain at home if the dollars and cents differential were removed. Districts would also be motivated to start their own special programs to accommodate children who are presently being served in other districts.

This equalization of costs might be accomplished by the institution's billing local school districts for the education of children in institutional programs. Or an adjustment in State aids paid to each district might be made, taking into account the number of children served in programs outside the district.

The plan should be organized so that there is neither penalty nor profit to a district whether the child is served in the district or in an out-of-district program. If a specific plan following this principle is applied to the mentally retarded it should be made equally and exactly applicable to other areas of special education, such as hearing or vision handicaps.

It should be pointed out that school programs offered within institutions such as Owatonna State School or at any of the three State schools and hospitals for the retarded do not always meet standards which the State holds for other agencies. For example, special teachers are sometimes employed in the institutions

who do not meet specialized certification standards required by the State in local schools. Also, standards regarding length of school day or size of classes in local schools are often not satisfied in institutions for the retarded.

Legislative Problems. Justification for State and Federal support of special education programs is clear. Because of low incidence and factors which distort chance distribution, handicapped children are not randomly distributed among local school districts. Planning and financial support must stem from a base larger than the local school district can provide. When special education and habilitation services are offered at the local level, the need for expensive residential care is often reduced and the child can develop techniques for living in the community.

State aids are provided to partially offset the additional cost incurred by the public schools in serving handicapped children. Aids are presently granted to meet two-thirds of the salaries of "essential" personnel — school psychologists, social workers, supervisors, vocational rehabilitation counselors, speech therapists, and classroom teachers — up to $4,000. With the exception of classroom teachers, these essential personnel provide services which are not usually afforded non-handicapped children. At present State aids cover approximately 54 per cent of salaries of all essential personnel. However, only 35 per cent of the salaries of such personnel as school psychologists or social workers can be met by current State aid allotments; thus, the sponsoring district assumes 65 per cent of the extra cost of employing these persons. State aids for special education should be adjusted so that local school districts are not faced with an additional financial burden when they provide special programs for the handicapped. Complete removal of the limit would not be costly and would encourage school districts to employ badly needed supervisory and professional personnel.

Special education programs are often relegated to whatever facilities may be left over after regular school programs have been accommodated. Often these

are the older or less desirable classrooms, ill-suited to the kind of educational program which would be most beneficial for retarded children. It is well known to special education administrators that good facilities and good programs draw families which have handicapped children. Thus concentrations of handicapped children and burdens for special school construction tend to develop in a limited number of school districts which make special efforts to provide adequate programs.

Although Public Law 88-164, which appropriated funds for construction of mental retardation facilities, appears to exclude classroom construction in public schools, Public Law 89-10, Title I, offers exciting possibilities whereby local school districts may initiate special education programs, including construction of facilities. Federal guidelines state that the approaches which can be used are almost without limit. Programs focused upon the educationally deprived might include the services of counselors, psychologists, psychometrists, doctors, nurses, social workers, and speech and hearing specialists. The aim in applying for funds is "to design a project which will give reasonable promise of substantial progress toward meeting the special education needs of educationally deprived children in school attendance areas having high concentrations of children from low income families." It is the responsibility of local school districts to design and prepare projects. Local groups have been urged to cooperate with their school districts in developing projects suitable for serving handicapped children, including the mentally retarded.

Pre-School Programs and Day Activity Centers. Two programs closely related to traditional education are developing rapidly. The first has to do with pre-school children who may be retarded or at "high risk" with respect to potential retardation. No clear and comprehensive responsibility for developing and regulating standards for such pre-school programs has been achieved in Minnesota. The second program is that of the daytime activity centers, which are reimbursed up to fifty per cent of operating cost by the State; at present 40 daytime activity

centers receive State support.

A more comprehensive set of standards for both pre-schools and daytime activity centers should be developed and fully regulated as a condition of State support and licensing. (See Chapter V , Community-Based Services.) It is apparent that responsibility for initiating and enforcing such standards is vested in several department of State government; thus needed action should involve interdepartmental participation and support. Representatives of Welfare, Education, and Health departments should formulate a plan under which such programs will be carried out. Each of these departments has a major and distinct interest in programs for pre-school children. Similarly, there are interests and talents in several departments which should be coordinated in behalf of daytime activity centers. Programs developed through interagency planning and cooperation will have the greatest chance of providing maximum benefit to pre-school children.

Intermediate Unit of School Administration. One of the major continuing problems in Minnesota is the persistence of many small school districts and the lack of an effective intermediate unit of school administration, thus making it impossible to develop programs to meet "low incidence" problems. The State now has 976 common school districts (elementary) and 453 independent school districts (1-12 or K-12). Of these 1,429 districts, approximately 90 per cent have nine (9) or fewer teachers.

Many states are organizing school administrative units which serve an area larger than the single local district, and provide specialized services to be shared among the several local districts. It appears to be distinctly advantageous to have a Statewide plan (see recent developments in Wisconsin, for example) for organization of such intermediate units. Studies and planning in this regard are long overdue for the State of Minnesota. Efforts to achieve further consolidation of school districts should be pressed forward vigorously, but an intermediate unit plan also should be developed without further delay.

Since specialized services for the retarded necessarily involve more than education, it is important that maximum coordination be achieved among health, welfare and education services. The task force commends to the Planning Council for consideration the so-called "90 minute" or "zone center" plan of Illinois as an indication of what should be attempted in Minnesota. "Zone-centered" means services which are district or community-centered, not primarily serving a single city or county, but located at or near the center of a zone's population. No person in the zone should have to travel more than an hour and a half (90 minutes) by automobile to reach a service.

Habilitation

The term "habilitation" refers to the last phases of formal education and to post-school experience in which the major focus is preparation for and induction into employment. In planning a comprehensive program of service for the mentally retarded, considerable emphasis must be placed upon developing the capacity of each individual for useful work. While it is unrealistic to expect every mentally retarded person to become self-supporting through gainful work activities, a series of research and demonstration projects by the U.S. Vocational Rehabilitation Administration indicates that about 85 per cent of the mentally retarded are capable of independent, self-supporting living in communities, with adequate social and occupational adjustments.

The number of mentally retarded persons rehabilitated--placed in remunerative employment after a period of special educational and rehabilitative service--each year in Minnesota is mounting steadily. However, the number is still disproportionately low in relation to the total mentally retarded population. Undoubtedly, there would be a considerable increase if all mentally retarded persons were provided with adequate services directed toward developing their work potential. Those who are unable to work in competitive employment can work productively in sheltered workshops or in homebound activities. Even severely retarded persons

can be taught to perform simple household tasks or self-care activities.

To ensure that the greatest possible number of the mentally retarded are rehabilitated into remunerative employment, a comprehensive program of services should be developed, incorporating the following concepts:

1. Services which contribute or will ultimately contribute to the vocational effectiveness of the individual should be begun early and sustained as long as necessary.
2. There should be a closely coordinated system of educational, vocational, rehabilitation, and placement services designed to equip and train the mentally retarded and to assist them in finding suitable employment.
3. Continuing social and auxiliary services should be provided as necessary to enable the mentally retarded to maintain employment and community adjustment.
4. Research and demonstration projects in the area of occupational preparation should be developed as a means of improving and extending services.
5. There should be a continuous program of public information, designed to enlist the support of employers and the public at large in occupational preparation and placement of the mentally retarded.

A truly successful program of occupational preparation and placement of the mentally retarded requires coordination and cooperation of both public and private agencies throughout the State. At present there is no adequate mechanism for securing this approach on a statewide basis. It is necessary to strengthen cooperative planning and joint efforts among rehabilitation, education, welfare and other agencies concerned with the mentally retarded.

An effective program for the occupational preparation of the mentally retarded should contain the following services:

1. Vocational evaluation, counseling, and job placement.
2. Training courses in appropriate vocational areas.

3. Joint school-work-experience programs, operated cooperatively by the school district and the Division of Vocational Rehabilitation.

4. Clearly defined and adequately supervised programs for on-the-job training of retarded workers.

5. Employment training facilities for those who require further vocational preparation after completion of the public school program.

6. Sheltered workshops for retarded workers capable of productive work in a supervised sheltered setting.

7. Vocational rehabilitation services in conjunction with residential institutions.

8. Counseling services to parents to provide them with an adequate understanding of the employment potentials of their children and to offer guidance which will enable them to participate more fully in the rehabilitation process.

9. Supportive services and facilities, such as supervised residential facilities, long term counseling services, legal services and special recreational activities.

10. Cooperative programs involving vocational schools and vocational rehabilitation services which maximize use of all vocational training resources of the State.

Level of Financial Support and Staff. The clearest conclusion drawn by the task force from its study of the present habilitation program for the mentally retarded and from consideration of the broad and exceedingly important work to be done in this sphere is simply that the State has not adequately supported the needed programs. Minnesota has regularly been losing more than a half million dollars a year in Federal funds available to match State funds for rehabilitation programs. It is urgent that the State legislature take action to liberalize both funds and personnel complements to qualify Minnesota for its rightful share of

of Federal support, and to expand vocational rehabilitation programs serving the retarded.

The Division of Vocational Rehabilitation, State Department of Education, must have enough counselors in all districts of the State so that evaluation, counseling, training, placement and other habilitative services can be readily provided to all mentally retarded persons who are in need of them. Even at past referral rates, Division of Vocational Rehabilitation counselors have been expected to provide a broad range of individualized services while having 100 or more clients in their caseloads at one time. Counselors are also badly needed at Cambridge, Brainerd, Faribault, and Owatonna if mentally retarded persons capable of vocational independence are to be returned to jobs in the community.

Personnel Problems. Staff turnover among the key personnel in State vocational rehabilitation programs has been high, and it is apparent that salary limitations have been critical. In a study conducted by State Civil Service Department covering a two and one-half year period ending in March , 1965, it was shown that twenty-six counselors had resigned. At the time the study was completed forty-seven counselors were employed. Thus turnover rate appears to be in excess of twenty per cent per year.

If rehabilitative services are to develop adequately, it is essential that the Division of Vocational Rehabilitation be enabled to employ a corps of fully trained professional counselors and other specialists. Turnover rate must be held at very low levels, for otherwise service is quickly reduced to routine and impersonal procedures which simply are not effective.

School-Rehabilitation Cooperative Program. The Division of Vocational Rehabilitation has established a basic plan of cooperation with the Division of Special Education and the various school districts throughout the State. The purpose of this plan is to utilize more fully available Federal vocational rehabilitation funds by assigning these funds to local school districts which can then hire

additional personnel to help the retardate bridge the gap between the school and the world of work. As of Fall, 1965, the cooperative arrangement was in operation in the Minneapolis, St. Paul, and Rochester school systems; plans exist for its development in Duluth and St. Cloud, as well as in other school districts in the State, including Cokato, Pipestone and Windom.

The Divisions of Vocational Rehabilitation and Special Education and the cooperating school districts deserve high commendation for the progress made in developing and implementing cooperative plans. It is important that the plan be extended to all parts of the State as soon as such action is feasible. Cooperative programs should be expanded further to assign more vocational rehabilitation counselors to the public schools.

Artificial distinctions have sometimes been allowed to enter decisions about which agencies shall be designated and supported by State and Federal funds for vocational rehabilitation purposes. Care must be taken so that schools which develop rehabilitation resources are not excluded from supports.

Habilitation Programs in State Institutions. The task force has not undertaken a detailed study of habilitative programs in the State institutions at Brainerd, Cambridge, Faribault and Owatonna. A major concern in each of these institutions involves preparation of patients for work performance. Indeed, the institutions are dependent upon patient work for basic maintenance and operations--perhaps to the point where greater remuneration should be offered to some patients.

Potentialities for coordination of the institutional programs with services offered by the State Division of Vocational Rehabilitation have been recognized but little developed. Presently, cooperative rehabilitation services are being provided on a part-time basis at all of the mentioned facilities; however, this provision should be increased to include a rehabilitation counselor in each of the institutions, in order to faciliate return to the community of as many retardates as are potentially capable of making a community adjustment. To extend and improve

such services will require an expanded staff for the Division of Vocational Rehabilitation as well as a substantial increase in the funding of the program, so that adequate post-institutional vocational services may be furnished to retardates.

Access to Training Centers

It is exceedingly important that a study be made of vocational schools, trade schools, and privately operated schools to determine ways by which retarded persons may gain ready access to these resources. Highly specialized training facilities of all types needed by retarded youth and adults cannot be created in separate, categorical form. Modification, flexibility, and adaptation of general facilities must be sought in order to meet the needs of the retarded. It is important that the needs of mentally retarded persons be more fully represented in all plans and operations of vocational schools and related facilities.

Recommendations Concerning Education and Habilitation

Education

1. Complete educational programs for educable and trainable children, including elementary, secondary, and work-training programs, should be made available to every eligible person by local school districts. Where it is not practical to conduct a complete program in any district, cooperative arrangements should be made with other districts to provide such services. The cost of such services should be covered entirely by public revenues.
2. Legislation should be enacted whereby provision of special education services to trainable mentally retarded children becomes mandatory in the State of Minnesota.
3. Additional college programs for training special education teachers should be initiated in the State, following carefully coordinated planning with existing programs and appropriate interstate deliberations.
4. Colleges and universities which offer training for teachers of the mentally retarded are urged to give major attention to the development and improvement of programs for secondary teachers.
5. Colleges and universities which offer training for teachers of the retarded are urged to develop necessary specialized resources to prepare teachers of trainable retarded and multiply handicapped children and to coordinate their efforts in doing so.
6. The State Department of Education should be given specific responsibility for leadership in a broadly conceived and implemented program to recruit prospective teachers of the mentally retarded.
7. Institutions and agencies serving the mentally retarded are encouraged to experiment in the broader use of program aides who may help to alleviate the severe professional personnel shortage. Junior colleges and vocational schools are encouraged to undertake experimental programs for the specialized

training of semi-professional personnel in close cooperation with schools and other agencies serving the retarded.

8. Present State Department of Education regulations pertaining to supervision of programs for the retarded should be enforced and strengthened. The Special Education Section should play a leadership role in developing patterns of supervision in local school districts required by regulation to provide such supervision and should encourage smaller school districts to cooperate in providing necessary supervision. In addition, the Special Education Section should require an annual progress report from all school districts which presently have pupils on waiting lists for admission to special classes for the retarded.

9. The State Department of Education should be authorized and funded to employ a minimum of four consultants in the field of mental retardation, and to establish regional offices. Administrative alignment of the Division of Special Education and Rehabilitation within the State Department of Education should be given careful consideration in current studies of departmental organization. Significance of the relation of special education administration to the total education administration must be given due regard at all service levels. The administrative position of the vocational rehabilitation division is similarly influential in service outcomes for the retarded and should be carefully evaluated.

10. Statutory and regulatory provision must be made to assure that school districts maintain active educational concern for every child of school age (or until the child completes high school) who is legally a resident of the district. Children excluded or excused from school for a period more than two weeks (and others not in school for whatever reason) should be reported to the State Department of Education. The State Department of Education should prepare, at regular intervals, a summary report on children not attending

school, including reasons for non-attendance, and should recommend development of services needed by children not receiving services. Such reports should be a part of the Department's annual report to the State Board of Education, the Governor, and the legislature, so that implications which go beyond the purview of a single department may be known and followed for appropriate action.

11. School districts should be required to undertake annual reviews of educational programs of all children of school age who are legal residents of the district but who are served in school programs of State schools or in public schools outside the home district.

12. State institutions which provide education programs for children should be authorized to charge back to the school district of residence of such children an amount equal to the average per pupil expenditure for education in the child's resident district, except that the proportion of such expenditures covered by State allocations should not be included.

13. Minimum standards for educational programs at State institutions for the mentally retarded, with regard to teacher qualifications, class size, and other relevant items, should be essentially the same as those applicable to special classes in the public schools.

14. State special aids to school districts should be such that the cost to the districts for each retarded child in school is essentially the same as for a normal child in school. An adjustment in State aids by the 1967 legislature is recommended to achieve this goal. Study of needed adjustments should be undertaken as soon as possible.

15. Local groups are urged to work through their school districts in developing projects for specialized educational facilities for handicapped children which will qualify them for Federal assistance under Public Law 89-10.

16. An inter-departmental study should be made with a view toward clarification

and coordination of responsibilities for leadership in prescribing and regulating standards regarding pre-school programs and daytime activity centers for retarded and culturally disadvantaged children.

17. The Governor and the Legislature should initiate a planning activity directed toward formulation of a Statewide plan for "intermediate units" for administration of specialized, shared, school services.

18. In planning intermediate local or regional services, efforts should be made to achieve coterminous regions for various kinds of State services and to develop comprehensive zone or regional centers which offer comprehensive diagnostic, treatment, educational and consultation services.

Habilitation

19. Legislative appropriations and staff complement authorization for the State Vocational Rehabilitation Program must be, at a minimum, sufficient to match all Federal vocational rehabilitation funds for which Minnesota is eligible.

20. The complement of counselors in the Division of Vocational Rehabilitation should be substantially increased. A study of current work loads and future demands should be undertaken to establish the number of counselors needed to provide adequate services to all mentally retarded persons who can profit from the State program. The study should also concern itself with the need for more supervisory, administrative, and consultant staff members to effectively carry out the services of the Division of Vocational Rehabilitation and to coordinate their services with those of other public and private agencies.

21. A special study should be made by the State Civil Service Department or an outside agency to determine reasons for the high staff turnover in the State Division of Vocational Rehabilitation and to recommend necessary actions to achieve a solution to present staffing problems in the Division.

22. Staff positions should be established in the Vocational Rehabilitation Division, on State and district office levels, to provide leadership and

coordination of the cooperative programs in the schools.

23. The State Division of Vocation Rehabilitation should set standards and criteria which recognize that rehabilitation, evaluation, and training programs may develop in schools as well as in rehabilitation centers. Distinction between an acceptable or non-acceptable service should be based upon such standards, not on the location of the program. Schools should be encouraged to develop programs with the understanding and assurance of financial support.

24. Rehabilitation Service Units should be established in each of the institutions for the retarded through cooperative agreements similar to those which have provided impetus to school rehabilitation programs.

25. The State Board of Education should encourage Area Vocational Schools to develop programs geared to the specialized training needs of the mentally retarded. Lines of communication should be developed with those agencies and with governing boards concerned with all public and private trade schools, in order to insure consideration of the needs of the retarded in program planning and program modification in such schools.

V. COMMUNITY BASED SERVICES

An individual in our society is expected to acquire and maintain throughout his lifetime a complex array of knowledge and skills which will enable him to adjust to the multiple personal, social, civic, economic, vocational, and educational demands which that society makes upon him. For the mentally retarded, about 95 per cent of whom live in their home communities, these adjustments are particularly difficult. However, when the community makes available appropriate special services, retarded persons can develop to the maximum of their potential and can become responsible contributing members of society. These services must not be left to chance but must be carefully planned and coordinated. Because retarded persons vary in their capabilities and needs, not all parts of a comprehensive program will apply to each of them. Some will require total care throughout their lifespan; others will need only intermittent services such as special education or work-training.

The State provides services for retarded persons either directly or through financial and consultative assistance to local communities. Local governmental or private agencies provide services independently or with State and Federal financial assistance. Within this framework responsibility should be clarified and efforts should be directed toward initiating, funding, and guiding a variety of community services. For example, consultant services offered by the State should be available on a regional basis rather than in the central offices of the various State departments. At present, responsibility for development of community programs in Minnesota is divided and indefinite, leading to overlap in some areas and serious deficiencies in others.

There is a direct relationship between the quantity and quality of services offered by the community and the effective functioning of the State residential institutions. As community services proliferate, State institutions need no longer

try to be all things to all patients. Local, regional, and State committees must continuously evaluate community services which exist and must spark development of those which do not.

In promoting community services, it is desirable to achieve maximum flexibility in funding the services, and to secure a high degree of inter-agency cooperation. For example, a daytime activity center and classes for trainable children could be conducted in the same building. This particular combination would require that State funds be provided by the Department of Public Welfare and Education, matched by local county or private funds for the daytime activity center, and by local school district funds for the special classes. Complicated though it may seem, such an arrangement would be highly desirable since it would facilitate coordination of services and movement of retarded persons from one service to another in accordance with their needs.

Community responsibility and intervention begin upon referral by parents, physicians, social agencies, schools, or police. A diagnostic evaluation should be the first step in determining future planning. Appropriate services should then be made available to individuals, to families, and to agencies. Factors such as lack of commitment to guardianship or inability to pay should not preclude provision of needed services.

The Community Based Services task force identified the following essential community services, not all of which will be used by every retarded person.

1. Prenatal and postnatal care.
2. Diagnosis and evaluation; medical, psychological, psychiatric and social services; continuing re-evaluation as needed; and referral to appropriate treatment resources.
3. Counseling and parent education.
4. Homemaker services.
5. Nursery and nursery school programs.

6. Day-care or night-care services.
7. Daytime activity programs.
8. Special education at elementary and secondary levels for both trainable and educable retardates.
9. Work training, pre-vocational training, vocational habilitation or rehabilitation, and job placement.
10. Sheltered workshops.
11. Boarding homes, both temporary and permanent; part time boarding for weekends or short stays.
12. Sheltered living for adults.
13. Religious education classes.
14. Recreation services and camping.
15. Social activities for adults.
16. Half-way houses.
17. Special treatment services, e.g., speech and hearing therapy, vision screening, dental care, physical therapy.
18. Nursing homes.

Because many community services have been studied by the other task forces, this report concerns itself primarily with home training, nursery schools, daytime activity programs, religious classes, recreational services (including character building organizations and camping) and social activities.

Home Training

Most parents of retarded children who live at home are confronted with baffling problems in the seemingly impossible task of daily care and management. The traditional counselors, i.e., physicians, clergymen, psychologists, and social workers, are at odds among themselves about whether retarded children should be kept at home or placed in residential facilities. For example, many physicians still believe that a mongoloid child who remains at home will cause

psychic damage to normal siblings, that he will grow to be a physical menace to the neighborhood, that he will develop serious sexual problems. On the other hand, experienced social workers generally maintain that the mongoloid child needs the warmth of his own family in the early years of his life as does any other child.

Unfortunately, the array of community services which would help families of the retarded to cope with these day-to-day problems has been slow in developing. Hopefully, these services will multiply within the next few years.

Helping parents to understand the special needs of their child and guiding them in daily management may make the difference between a constructive life and a dismal one for the entire family. Public health nurses and County Welfare Board home health care personnel should receive special instruction in handling retarded children; staffs should be enlarged so that home visits can be made on a regular basis. Short term home health care is desirable and should be available as a structured, supervised service by well trained persons. It cannot be confined, as in the past, to attempts by already overburdened public health nurses and county welfare workers.

Urban communities might present a course, on television or in adult education programs, in home management of the retarded child, with a variety of specialists participating: a public health nurse could demonstrate actual feeding techniques; a child psychologist could discuss the management of aggressive, hyperactive, or withdrawn behavior; a daytime activity center staff could demonstrate training activities which help prepare a child for school. Another alternative might be the preparation of a film or series of films for use with community groups throughout the State. In non-urban communities, the public health nurse or the county welfare board could conduct a class for parents. State and junior colleges might also sponsor classes.

Nursery School Programs

Nursery school programs are of benefit to the pre-school age retarded child, who is frequently ostracized by his peers and has little opportunity to develop social skills. Nursery schools provide invaluable experience in adjusting to other children and help to prepare the child for admission to school by developing physical coordination, motor skills, ability to distinguish colors, rhythm, and the like. Whenever possible, educable retarded children should be integrated into normal nursery school situations. In urban centers particularly, nurseries which provide service for normal children should be encouraged to create special classes for retarded. Daytime activity centers should care for all pre-school retarded children who cannot be served in nursery programs.

Daytime Activity Centers

The retarded child who is either too young, too old, or too severely handicaped to attend special classes for trainable or educable children places a great strain on the personal and financial resources of his family. Daytime activity centers can help to ease this strain. While some private centers have existed for many years, Minnesota's major advances have occurred since 1961. At that time the State legislature appropriated funds to subsidize centers on a matching basis and assigned administrative responsibility to the Department of Public Welfare, which already had the authority to license and to set standards for centers. The 1965 legislature appropriated $425,000 dollars and authorized cities, towns, and counties to levy taxes for matching purposes. This support must be increased so that local costs can be met. At the same time, State matching appropriations must grow in order to finance new centers and improve existing ones. As of February 1, 1966, forty State-supported centers were functioning, seven were operating without State support, and interest in establishing centers in twenty-three other areas by September, 1966 had been indicated to State officials. A Daytime Activity Center Advisory Committee has been appointed, with lay and professional membership broadly representative of agencies throughout the State.

Daytime activity centers are designed to serve retardates who are not eligible for trainable or educable classes as well as pre-school and post-school retardates of any level or age. A primary contribution of the centers should be the preparation of children to attend trainable classes in the public schools. Children who cannot qualify for public school admission because of multiple handicaps should also be included.

Daytime activity center participation offers a basis for comparing a retarded persons with his peers and for evaluating his progress over a long period of time. Adolescent and adult programs should build on existing social and self-help skills with pre-vocational and social training as a goal. For certain severely retarded adults the daytime activity center is the only community service available. As more sheltered workshops and recreation programs are established, many retarded adults may divide their time among these resources and thus lead more constructive and satisfying lives.

Daytime activity centers should also offer a program adapted to the ability level of the profoundly retarded—available for a few hours a day, or possibly on a less-than-daily basis. This would allow mothers physical and psychological relief from the unremitting care which is often necessary for this group

The primary purposes of a daytime activity center, as defined by the task force, are:

1. To offer a program which is suited to the capabilities and limitations of each individual and is structured by his own needs and ability to progress.
2. To provide constructive, meaningful use of time.
3. To help the retardate to adjust within the family and community.
4. To offer parent counseling.
5. To facilitate casefinding, with emphasis on discovery and management of remedial conditions.

6. To free parents from constant care of the retarded, so that they may allot more time to other essential family needs.

7. To integrate agency services for the retarded so that a continuum of appropriate services is available to the retarded at all stages of his life.

8. To provide a setting for long-range diagnostic studies of the individual.

Before a daytime activity center can be established, a sufficient number of retarded persons who will use the service must be identified by Associations for Retarded Children, schools, County Welfare Boards, churches, public health nurses, or other social agencies. A local governing board must be established, giving attention to interagency representation. Help in organizing, financing, staffing, and programming centers is available from the Department of Public Welfare, and from State and local Associations for Retarded Children. The Department of Public Welfare has been hampered in its efforts to provide guidance because the position of State consultant to the centers has remained vacant. Planning and programming should be flexible and dynamic, since new centers will probably expand rapidly. It is not unusual for families of hitherto unknown retardates to seek services once a center opens.

It is difficult to project future needs or locations at this time. Incidence studies such as that made by Dr. Elizabeth Slocombe in Lyon County (1964) should be undertaken on a regional basis throughout Minnesota. State Departments, hospitals, physicians, and private institutions should cooperate in furnishing data. Such studies will provide objective bases for estimating the future need for daytime activity centers and other services. In the meantime, the desirability of providing services within an hour's drive of the client's home suggests a minimum of one daytime activity center per county. Long distances between communities may in some cases necessitate boarding daytime activity center clients during the school week, in order to insure a sufficient number of participants.

Daytime activity centers offer a rich field for volunteers. Experience has shown that parent volunteers work better with groups which do not include their own children. Opportunities for recruiting prospective workers into this field from among volunteers should be exploited.

Daytime activity centers should not operate in a vacuum. Working arrangements should be made with social service facilities in the community. Opportunities for utilization of physical, occupational, and speech therapies should be developed. Diagnostic evaluations by physicians and psychologists should be required. County welfare departments should make readily available the services of trained social workers to help in long-range planning for each center enrollee.

Transportation costs should be included in arriving at total cost of daytime activity center services per pupil. State and local matching grants should be sufficient to permit this inclusion. The Ramsey County Welfare Board has recently ruled that a mentally retarded person or his parents or guardian may apply to the Board for financial assistance to cover not only tuition, but also transportation and other program costs incurred in attending a center. Other counties should be encouraged to make similar arrangements. Transportation should be contracted for with an outside agent such as school bus, tax-cab service, or community-owned station wagon, or parents. In the latter case, adequate insurance must be arranged.

Recreation

Recreation is a long neglected area of service for the mentally retarded, one which requires definition and clarification.

Many mildly retarded children and adults are prevented by their lack of normal neighborhood and school experiences from participating successfully in recreational programs planned for normal populations. They need special services to prepare them for assimilation into these programs. Group work services aimed at helping the mildly retarded person learn how to behave in a socially acceptable

manner, how to relate to peers, and how to develop recreational skills (e.g., dancing, games, and sports) can make the difference between success and failure in many of life's situations. Moderately, severely, and profoundly retarded persons will also need specialized recreational services. Such programs, which demand an interdisciplinary approach, should begin in the pre-school years and continue through old age regardless of whether the individual is in a residential facility, a public or private school, a rehabilitation center, hospital, or at home.

Parent groups should work with churches and local service organizations to obtain the special recreational services which are needed and to encourage the integration of more able retarded children and adults into scouting activities, municipal and school recreation groups, and church groups. Both public and private agencies which provide recreational programs and services must be encouraged to include the mentally retarded whenever possible.

The limited amount of published material concerning recreation for the mentally retarded is primarily descriptive and is not based on research or program evaluation. It deals almost exclusively with children's activities or group experiences. The public must be made aware of the retardate's need for constructive leisure time activity as well as of his ability to profit immeasurably from recreational pursuits. Federal, State, and local responsibility for recreational programs must be clarified in order to achieve the goal of adequate recreation programs for the retarded.

Camping

Camping programs for the retarded are also limited. The Minnesota Association for Retarded Children operates a residential camp at Annandale, the only major residential camping facility used exclusively by the retarded. Rolling Acres has for many years operated a residential camp which includes retarded children and adults living at home or in institutions. State residential institutions,

as well as many smaller facilities, have worked out camping programs for their residents. Various day camps also serve the retarded. But the great majority of retarded persons who live at home are not included in any camping program except as they can adjust to a "normal" situation. Day camping, overnight camping, and weekly camping programs should be provided by church groups, character building organizations (such as Campfire Girls, Boy Scouts, Girl Scouts, 4-H, Y.M.C.A., Y.W.C.A.) private agencies, daytime activity centers, and community recreation programs.

Counseling Services for Adult Retardates

As more mentally retarded adults are integrated into the life of the community, the need for a continuing source of guidance and counseling will become more pressing. Counseling centers can orient retarded adults to the community and can direct them to appropriate facilities for needed services. Counseling services should be an integral function of County Welfare Boards, Division of Vocational Rehabilitation, Community Mental Health Centers, public health nursing service, Daytime Activity Centers, State school and hospitals, diagnostic facilities, and private social agencies. Legal aid may often be required in order to clarify the legal status of retardates. Services of the Bar Association and Legal Aid Society should be available and utilized as needed.

Religious Training

Provision of religious training to the mentally retarded through denominational instruction, released time programs, and week-end classes, is a matter of serious and practical moment. Religious training can be of great spiritual benefit to the retarded, who are able to derive from it internal strength and security, as well as a greater measure of self-control. The Councils of Churches, the Confraternity of Christian Doctrine, and the Rabbinical Associations should be involved in the planning of religious education programs for the mentally retarded. Inter-denominational programs would make it possible to divide groups according to age

and ability, and thus to facilitate teaching.

The Summer School of Christian Education, sponsored by the Minnesota Council of Churches, offers an excellent training program for teachers of special religious education classes for the retarded. The confraternity of Christian Doctrine has in the past offered a two-day training institute for released time class teachers of the mentally retarded. Such training can raise the quality of religious education.

* * *

Little has been programmed in Minnesota in the way of camping and recreational activities, religious training, and social activities for adults. Detailed information on kinds of activities which are available—their organization, frequency, leadership, and degree of public acceptance—is needed in order to develop a body of useful materials. Some of these data are emerging:

The Missouri Synod of the Lutheran Church sponsors a religious instruction program and makes available suggested special materials and techniques. Literature has also been published by other denominations.

The St. Paul Association for Retarded Children has developed a book of recreational activities for retarded persons.

A manual for program development in daytime activity centers will soon be available from the Mental Retardation Section of the Department of Public Welfare.

The National Association for Retarded Children is a resource for publications, both its own and those of other agencies.

The American Association for Mental Deficiency has published an excellent monograph entitled A Manual on Program Development in Mental Retardation.[38]

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38. Gardner, William I. and Nisonger, Herschel W. A Manual on Program Development in Mental Retardation. Monograph Supplement to the American Journal of Mental Deficiency, Volume 66, No. 4, January, 1962.

The Minnesota Association for Retarded Children, through experience gained at Camp Friendship at Annandale, can contribute much to our knowledge of how to structure camping experiences for the retarded.

Recommendations Concerning Community-Based Services

1. Community-based services should be made available to all retarded persons according to need, irrespective of such factors as commitment to guardianship or ability to pay.

2. The Minnesota Association for Retarded Children should continue to compile the best available information on programming for a wide variety of community services and to disseminate this information to all local chapters.

3. Local Associations for Retarded Children and other agencies including churches, schools, and private agencies, must assume primary responsibility for stimulating the development of recreation and camping programs, religious education classes, nursery schools and other services in the community. These groups must seek to create acceptance of the mentally retarded through public education and action aimed at helping public officials and policy-makers initiate or improve services.

4. Needed community services are sometimes available but not utilized because the parents, retardate, or counselor (e.g., physician, county welfare case-worker, special education teacher, etc.) are unaware of all local resources. Ideally all professionals dealing with the retarded should be familiar with the entire spectrum of community facilities. County Welfare Departments, Community Mental Health Centers, and local Associations for Retarded Children should serve as information sources and should promote closer liaison between agencies

5. Home health care and homemaker services should be developed by County Welfare Departments or County Public Nursing Boards and by private social agencies.

6. Urban communities with adult education programs should offer courses in home management of the retarded child, with a variety of specialists participating: a public health nurse could demonstrate actual feeding techniques; a child psychologist could discuss the management of aggressive, hyperactive, or

withdrawn behavior; a daytime activity center staff could demonstrate training activities which help prepare a child for school. Such a program could be presented on television, or as an evening adult education course. A film based on this same material could be widely disseminated to Associations for Retarded Children, public health nurses, and Daytime Activity Centers.

7. State departments must provide more consultant services.

   a. The Department of Public Welfare should employ a minimum of one program consultant for each of the six mental retardation facilities construction regions.

   b. Special education consultants, vocational rehabilitation counselors, and community service consultants are all needed and should be requested by the appropriate departments. Their services should be available on a regional basis rather than in the central offices of the various State departments.

8. Counties, municipalities and school districts must provide additional public health nurses, county welfare case workers, psychologists, school counselors, special education teachers, and other appropriate professional personnel in sufficient quantity to meet the direct service needs of retarded.

9. County Welfare Board case workers, social agency personnel, and public health nurses should be informed on the subject of mental retardation and be available to help parents in managing their retarded children at home.

10. a. Daytime activity centers should be developed wherever need can be demonstrated, with a goal of at least one center in every county.

    b. Consideration should be given to making the Daytime Activity Center Advisory Committee a statutory body with fixed terms of office. The Advisory Committee is to be commended for making provision for broad interagency representation on local governing boards.

    c. Local public tax support should be increased in order to meet local costs.

Greater State matching appropriations must also be increased to finance additional centers and to upgrade and expand existing centers.

d. The twenty-five cent per capita State support limitation for daytime activity centers should be removed.

e. Rent should be allowed as a local matching sum.

f. Transportation costs should be included in arriving at total cost of daytime activity center services per pupil. State and local matching grants should be sufficient to permit this inclusion.

g. Daytime activity centers should utilize volunteer services on a wide scale.

11. Daytime activity centers, schools, State institutions and other agencies should explore joint use of facilities and combinations of financing which could broaden the range of services provided by all of them. For example, the Daytime Activity Center at Rochester State Hospital is housed on the same campus with a Community Mental Health Center.

12. Provision should be made at the State level for effective coordination of all community services and facilities.

VI. EMPLOYMENT

An excellent statement regarding employment of the mentally retarded appears in the President's Panel:

> Help for mentally retarded persons in gaining employment is one of the most important services that can be rendered to the nation and to those who are handicapped. Employment has both social and economic benefits and few aspects of life in our society are more important to the individual.
>
> Suitability for employment has its origins in health, family life, and relationships outside the family such as religion and education. When more significant progress has been made by the mentally retarded in these other areas, the problem of gaining and holding a job more frequently can be surmounted successfully.
>
> In our complex industrial economy where technological progress and automation are eliminating more than one million unskilled jobs a year, the problem of employment for the retarded is accentuated. Automation is tending to throw the mentally retarded into competition with more capable persons who are displaced from ordinary jobs. It is fortunate that there is substantial expansion in some sections of the economy (for example, the service industries) which can employ individuals with lesser skills.[39]

The mentally retarded have a hard time finding and holding jobs—even ordinary jobs—for many reasons. While the skills required for many jobs are comparatively simple, necessary basic training is often not readily available. Area vocational schools can play an important part in providing this training to the mentally retarded. The "non-skill" requirements of many jobs, such as consistent application of effort, ability to travel to work place and arrive at a particular time, and accommodation to the demands of others, are difficult for the retarded to meet. Sometimes architectural barriers prevent the retardate who is also physically handicapped from working.

Often neither the mentally retarded person nor his parents and friends know where to find a job that he can perform; they generally are not aware of

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39. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. pp. 128-129

specific training which might be needed, the kinds of jobs the retarded can do, and non-skill requirements before and during employment. In short, the mentally retarded individual needs more highly structured resources for living, training, and working than does the normal person. At present these resources are severely limited.

Employers generally possess scant information concerning retarded persons and are inexperienced in supervising them in such a way as to bring out their full potential. Both employers and "normal" employees need education in dealing with retardates on the job. Many are still prejudiced to the effect that retarded persons are less than full service employees, are prone to accidents, and are an economic liability. Aggressive placement personnel must counsel more frequently with employers and must follow up on placements so as to enable the employer to understand the particular needs of the retardate who is working for him.

Automation may complicate the problem of employment of the retarded. However there is an as yet unproven contention that, as a result of automation, there will be available a greater number of simple jobs which the retarded can perform.

Project 681, a pilot work-study program conducted in the Minneapolis public school system, has developed a wealth of information applicable throughout the State. The project report defines the productivity continuum as follows:

> Productivity might be called the worker's contribution to our economy through his work efforts. In our society, this is an important concept. Normally, and in the competitive labor market, the worker trades his productivity for a wage, and normal productivity tends to define the normal wage. Of course, wage is related to other things, such as overhead. Most people are able to compete in this competitive situation which trades productivity for wage. They are in <u>competitive employment</u>.
>
> In rehabilitation, these ideas have to be modified because quite a few clients are not able to compete successfully in the productivity-wage trade. These clients are not competitive, and they get "traded out of the market." In general, these are people whose productivity is low, or who create an unusually high overhead in terms of supervision or in terms of their work requirements. To meet the needs of these noncompetitive people, rehabilitation has worked out the technologies of <u>sheltered employment</u> and <u>day activity</u>.[40]

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40. Krantz, Gordon. <u>The Productivity Continuum</u>, Research Project 681, Minneapolis Public Schools, December 3, 1964.

Employment assistance for the mentally retarded seeks to meet the problems of employment through private and public arrangements that:

1. Relate the education and training of the mentally retarded to employment requirements, especially through expert evaluation and counseling.

2. Advise the mentally retarded and their employers about the kinds of jobs they can perform and how jobs can be redesigned so that the mentally retarded can perform them.

3. Refer the mentally retarded to jobs they can perform or to training opportunities.

4. Advise the mentally retarded and their fellow workers and employers about the best ways for working together.

5. Expose the mentally retarded to work in competitive situations and initiate them into the needs of competitive work situations.

6. Provide the mentally retarded employment in non-competitive situations if competitive employment is not possible.[41]

Job Placements

The placement problems of the mentally retarded are similar to those of any handicapped individual. The important factors seem to be: accurate assessment of actual job requirements; accurate and meaningful job surveys; accurate diagnosis of the individual's capacities and abilities; and the combining of these factors in the selective placement process.

Selective placement demands a detailed analysis of job requirements as well as of the abilities of the individual. Over-dependence on intellectual capacity as a major criterion for job selection tends in many instances to discourage placement personnel and employers from examining other important abilities which an individual may possess.

Persons involved in job placement of the mentally retarded must be aware of and concerned with the entire range of abilities and limitation of the individual rather than concentrating solely on his intellectual functioning. When planning a

41. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. pp. 128-129.

program for placement, it is necessary to think about the individual rather than of broad categories such as "the mentally retarded" or "the mentally handicapped."

The placement counselor must not only be aware of these requirements himself but must convey this understanding to prospective employers. Focusing on job specifications and on the abilities of the individual is quite different from setting an arbitrary "floor" of, for example, a high school education, and selecting employees on this basis alone. The latter system tends to screen out retardates and often places over-qualified people in menial jobs.

The following description of possibilities for employment of retarded persons should be useful for the guidance of employers, agencies, and individuals seeking employment opportunities.

Unskilled Workers

The non-skilled work in manual occupations which generally require no special training. Frequently, jobs involve handling and moving objects or materials, for example, loading or unloading, digging, shoveling, hauling, hoisting, wrapping and mixing. Some of these jobs require heavy physical labor. Unskilled manual laborers are employed mainly in manufacturing plants, construction work, wholesale and retail trades, and transportation jobs. Employment of unskilled laborers has dropped over the past few decades but has remained relatively stable in recent years. In 1963 employment of unskilled laborers was approximately 3.7 million, representing only about five per cent of the nation's work force. The long-run decline in the employment of unskilled workers has occurred largely because mechanized handling equipment such as fork lift trucks, derricks, cranes, hoists and conveyer belts has greatly increased in factories, freight terminals, warehouses and construction operations.

The substitution of mechanical equipment for unskilled labor in industry is expected to continue in the '60's. However total employment in this occupational group probably will show little change mainly because demand for unskilled laborers in expanding industries is expected to offset the drop resulting from continuing mechanization. Deaths and retirements should result in 70,000 job openings each year.

Semi-Skilled

Semi-skilled workers make up the largest occupational group in the nations labor force. About 12 million persons, were employed in semi-skilled jobs in 1963. About 7 million of these semi-skilled workers were employed in manufacturing industries (for example, men's and women's clothing, auto, auto parts, food, cotton and wool textiles and machinery and electric and electronic equipment). Nearly one-third of all semi-skilled

workers are women. The largest number of women employed in manufacturing industries held jobs as sewing machine operators and assemblers.

Truck drivers are the largest single group of semi-skilled workers. Millions of other semi-skilled workers operate power driven machines in factories. Semi-skilled assemblers fit together parts such as tubes, sockets, wires in electric products. In general, semi-skilled operatives work with their hands. They have only brief on-the-job training. Usually they are told exactly what to do and how to do it and their work is supervised closely. They often repeat the same motions or the same jobs throughout the working day. Semi-skilled workers do not need to invest many years in learning a trade. The simplest repetitive and routine semi-skilled jobs can be learned in a day and mastered in a few weeks.
Adaptability, the ability to learn new jobs and the operation of new machines quickly, is an important qualification for semi-skilled workers. A semi-skilled worker must be dependable, come to work regularly, pay attention and follow instructions carefully. Frequently good eyesight and good coordination are required. Growth in semi-skilled jobs has been greatest in manufacturing industries (such as apparel and auto manufacturing) where production processes are divided and sub-divided into step-by-step sequences of relatively simple operations. During the 1960's the number of semi-skilled workers is expected to remain about the same or to decline somewhat because of automation, which has permitted great gains in production, with little or no increase in employment of semi-skilled machine operators. On the other hand, the creation of new jobs which is frequently a result of continuing technical advances in processing and products will favorably affect employment of semi-skilled workers. In addition, semi-skilled workers will have many job opportunities in plants which remain relatively unmechanized. Semi-skilled workers are more likely to lose their jobs during a business recession and to remain unemployed for longer periods of time than skilled or white collar workers.

About 35,000 semi-skilled workers will be needed each year to replace those who die or retire. Transfer rates for semi-skilled workers are high because a fairly large proportion of this group are young workers who tend to change jobs frequently and women workers who leave jobs to marry, raise families or move to other areas when husbands change jobs.

Other areas for possible employment of the mentally retarded are:

Food Service
Public Housekeeping
Assembler- semi-skilled and physically able and some aptitude for mechanical work. Look for a person who can do routine work at a steady pace.
Janitor - dependable, physically able, and thorough.
Messenger -dependable, able to work at a steady pace.
Apparel Industry - There are small plants in the Minneapolis area using less than 100 employees, making dresses, shirts, suits, caps, coats, etc. There is a need for power machine operators, assemblers or bundlers, hand sewing and steam pressing. There is a need for good eyesight, ability to work at a steady pace and have good finger dexterity.
Candy Makers - mixing machine operators, packaging and wrapping.
Printing - Paper bailers, stampers, stockers, bundlers, and tyers.
Laundry - sorters, markers, small sewing repairs, pressers.

Baking - mixing machine operators, bakers' helpers, slicers, wrapping machine operators. Bakers' helpers grease pans, remove pans from ovens, and wash pans.

Construction - laborers and hod-carriers. No formal training needed but need good physical condition and coordination. Roofers, cement workers and floor-coverers usually require 3 years apprenticeship.

Pulp and Paper products - Box manufacturing, assemblers, packers, watchmen and janitors.

Railroad Workers - Clerks, messengers, baggage handlers, trackmen, maintenance helpers.

Petroleum Products - Loading and unloading of supplies, packagers, shippers, watchmen, janitors and custodial workers. Service station attendants - pump gas and check oil and tires.

Farm Work -Machine operators - driving truck and tractor, plowing, cultivating, feed grinding, mixing, packing, grading, and processing farm products.

Dairy Farm - miling, cleaning, and feeding.

Poultry - feeding, and cleaning.

General - grain growing, picking, and storing.

Truck Farming - planting, cultivating, harvesting, packaging, crating, wrapping, and hauling to market.

Nursery - digging sod, loading and hauling, sodding, bathing trees, seeding and law maintenance.

Table 5 shows the kinds of jobs in which the mentally retarded were placed by the State Department of Vocation Rehabilitation from 1961 to 1964. The Minnesota Employment Service and other agencies throughout the State place handicapped persons regularly in a variety of jobs. However, much more needs to be done.

In 1965 the National Rehabilitation Association published a report based on national studies in which the entire staffs of all 90 State vocational rehabilitation agencies were involved. The report disclosed that, during a three month study period, only 5,993 "mentally retarded or deficient" referrals were processed for service by the 90 State agencies. To quote the National Rehabilitation Association report:

> By definition, approximately 2.2% of the total population are mentally or deficient and would score 69 or below on the Wechsler Adult Intelligence Scale. That would be over 4,000,000 people. Where are they?
>
> Administrators felt that many of these people were adjusted within the community, even though marginally, and not recognized as people with

TABLE 5

DIVISON OF VOCATIONAL REHABILITATION CLOSURE OCCUPATIONS
FOR MENTALLY RETARDED, 1961 - 1964

1963-64	1962-63	1961-62
165 TOTAL	150 TOTAL	141 TOTAL
24 Sheltered Workshop	27 Kitchen Workers	15 Farm Labor
22 Kitchen Workers	19 Sheltered Workshop	14 Sheltered Workshop
21 Miscellaneous	8 Miscellaneous	10 Dishwasher
13 Custodial	6 Hospital Attendants	10 Laborer
8 Housekeepers	6 Waiters and Waitresses	8 Babysitter
8 Hospital Attendants	5 Office Clerks	8 U. S. Navy-Army
6 Waitresses	5 Packers	7 Custodial
6 Armed Services	4 Elec.Mach.Assemblers	5 Kitchen Help
4 Transp.Equip.Laborers	4 Unpaid family worker	4 Bus Boy
3 Office Clerks	4 Gen. Farm Hands	4 Homemaker
2 Sales Clerks	3 Housekeeper	4 Nurses Aide
2 Handymen,private homes	3 Laundry Workers	3 Indeterminate
2 Maids	3 Homemakers	3 Housemaid
2 Nursemaids	3 Janitor and Sextons	3 Power Machine Operator
2 Barbers	3 Mechanics-Repairmen,Auto	3 Miscellaneous
2 Practical Nurses	3 Armed Forces	2 Cook
3 Farm Hands, general	3 Maids and Housemen	2 Dock Worker
2 Fruit Packers	2 Chauffeurs	2 File Clerk
2 Molders, Metal	2 Stock Clerks	2 General Clerk
2 Meatcutter	2 Nursemaids	2 Handyman
2 Textile Worker,SemiSkilled	2 Printing-Publish.Occup.	2 Presser
2 Seamstress	2 Construction	2 Waitress
1 Musician	2 Machine Shop	2 Car Washer
1 Commercial Artist	2 Cooks	1 Auto Body Repair
1 Bookkeeper	2 Stenos-Typists	1 Baker
1 Office Boy	2 Furniture Mfg.	1 Bell Boy
1 Typist	2 Dressmaking	1 Belt Worker
1 Stock Clerk	2 Trades-Service Occup.	1 Chicken Plucker
1 Canvasser	1 Machinist	1 Clothes Checker
1 Salesman	1 Gardner-Groundskeeper	1 Delivery
1 Maid, Hotel	1 Washers-Greasers	1 Electrician(apprentice)
1 Porter	1 Nursery-LandscapeLaborers	1 Garbage Collector
1 Hatchery Man	1 Hotel Clerk	1 Gas Station Attendant
1 Candy Shop Clerk	1 Office Machine Operator	1 Handbill Presser
1 Food Processor,Laborer	1 Dairy Farm Hand	1 Handicraftsman
1 Furrier's Helper	1 FillingSta.Attendant	1 Laundry Worker
1 Chauffeur	1 PhotographicProcess.Occup.	1 Leathercraft
1 Mechanic	1 Usher	1 Materials Handler
1 Dock Worker	1 Electroplating-Galvanizing	1 Meatcutter
1 Woodworking	1 Foundry Worker	1 Order Filler
1 Shoemaker	1 Upholsterer	1 Packer
1 Machine Shop Helper	1 Fab.PlasticProd.Mfg.	1 Painter's Assistant
1 Paperhanger	1 Fly Tying	1 Paper Route
1 Roofer	1 FoodProductsProduction	1 Parking Lot Attendant
1 Construction Worker	1 Consumers Salesman	1 Pin Setter
1 Laundry Worker	1 Extract,Mineral Occup.	1 Rag Baler & Sorter
1 Parking Lot Attendant	1 Warehouse &Related Occup.	1 Seamstress

IQ's or 69 or below. Some of these people may have other disabilities. Some may be identified with negative behavior--such as criminal, neurotic, or alcoholism--rather than low intelligence. Some may not be eligible or feasible for rehabilitation services. Some are served by other agencies.

Yet, despite these many explanations, there is still a significantly vast difference between 4,000,000 people and the number referred to State vocational rehabilitation agencies.

The needs of mentally retarded people should be studied more closely at the community level. Only a tiny fraction of mentally retarded come to vocational rehabilitation agencies.[42]

Sheltered Employment

Work training programs and sheltered employment are different concepts although they may be accomplished in the same work situation. Both are discussed more completely in Chapter IV, Education and Habilitation.

The President's Panel reflects the views of this task force when it states:

It is to the credit of the selection process that it results in an efficient placement of the vast majority of workers in the national labor force. Nevertheless, it also results ultimately in the rejection of a sizeable group of person from any type of employment. Because of physical, mental or social handicaps, these persons are unemployable by the standards of competitive enterprise. Yet frequently, they are persons who want to work and who possess considerable productive capacity. Many mentally retarded persons will be found in this group. If their productive capacity is not to be wasted and if they are not to be denied benefits enjoyed by their fellow citizens, it is essential that means be devised for providing employment opportunities which are in keeping with democratic principles and the national economy.

To provide opportunity for those persons who cannot be absorbed in existing work situations, there should be developed a system of sheltered work activities. This system should include (1) sheltered workshops and (2) sheltered work projects. These activities should be developed by both public and private agencies at all levels.

A predominant objective of each workshop or work project should be to rehabilitate the individual to the highest level of productivity of which is is capable. In many instances, the goal would be rehabilitation into competitive enterprise. In the operation of each activity, there should be a plan for providing or securing whatever rehabilitation services might be indicated including medical, psychological, social and vocational services. Pay rates should be kept below prevailing

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42. Dishart, Martin. Vital Issues and Recommendations from the 1965 National Institutes for Rehabilitation Research. National Rehabilitation Association, Washington, D. C., October, 1965. p. 25

industrial wage rates in order to provide monetary incentive for rehabilitation into competitive enterprise.

The term "sheltered work project" may require explanation. Traditionally, the workshop has been the medium for providing sheltered employment. However, many opportunities for purposeful, productive work are to be found outside the workshop. A sheltered work project is a sheltered work activity which is carried on in a setting other than that of a workshop. Activities which lend themselves to the development of sheltered work projects include conservation, maintenance of parks, recreational areas, and grounds of public institutions; domestic service occupations; certain types of health service occupations; and agricultural occupations. Sheltered work projects may also be operated in selected departments of industrial plants. Sheltered work projects should be under the guidance and control of workshops, rehabilitation centers, and other professional rehabilitation agents. Sheltered work projects should serve the relatively large numbers of disabled persons and undertake a great variety of activities useful to the community. At the same time, they require smaller capital investment in buildings and equipment than do other types of employment, including those of the workshop.[43]

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43. President's Panel on Mental Retardation. Report of the Task Force on Education and Rehabilitation. August, 1962.

Recommendations Concerning Employment:

1. Public and private groups should cooperate in educating employers and the public to the desirability of employing mentally retarded individuals in jobs which they can adequately perform, as well as in jobs for which they are, perhaps, better qualified than a "normal" individual.
2. Industrial designers and architects should design public and private buildings which eliminate architectural barriers to the handicapped.
3. Employers should realistically appraise the current trend toward requiring a high school education or advanced training for jobs whose practical demands do not warrant such qualifications. Similarly, performance on intelligence tests should not be the major hiring criterion for these jobs. Instead, the probationary period should be extended to provide greater opportunity for on-the-job evaluation of ability.
4. Labor unions should work out plans whereby qualified retarded persons can work in special situations, with adaptations of rules regarding less-than-minmum wage, seniority, and promotion.
5. Vocational schools and apprenticeship programs should open their doors to the retarded as they have to other handicapped persons. They should develop less rigorous entrance standards and training programs which will encourage training of the retarded.
6. Local service groups should assist the Division of Vocational Rehabilitation in exploring job opportunities for the retarded.

Government

7. State and local civil service should identify and make available positions which mentally retarded and other handicapped people can perform.*

* Since adoption of this report Minnesota's State Civil Service Commission has established a special job classification, Service Worker, for mentally retarded persons. Persons applying for this position will be screened by an evaluation board, rather than being asked to pass the usual paper and pencil tests.

a. Institutions present unique opportunities for work training and sheltered employment with living arrangements, as well as for regular employment. Institution staff should utilize these opportunities with imagination and foresight.

b. State and county highway departments should employ retardates to perform much of their seasonal work, such as landscaping and road repair.

c. State departments should explore employment of retardates in routine clerical jobs, many of which are well adapted to the capabilities and temperament of the retarded.

8. Federal, State, and local governmental civil service systems should re-evaluate testing and work performance techniques so as to avoid screening out persons who can adequately fill available positions and, at the same time, to prevent over-qualified individuals from filling positions which persons of lesser ability can handle. Interviewing and the demonstration type of test should be more widely utilized. Often only those who pass written tests are at present eligible for interview.

9. Institutions should give greater emphasis to realistic assesment of and training in skill and non-skill requirements of jobs. More intensive training should be given in personal hygiene, dress, and effective social interaction.

10. Specialists must be added to the staffs of the Division of Vocational Rehabilitation, Department of Education, Employment Security Department, and other agencies, to seek out employers, to place individuals, and to follow through after placement. Coordination among these various departments must be effected to avoid duplication of effort.

11. Placement specialists must follow through with counseling and supervision after a retarded person has been accepted for employment.

12. One counselor should be assigned by the Division of Vocational Rehabilitation to staff each of the institutions for the mentally retarded.

13. There should be much closer communication between State persons who determine eligibility for release from institutions and local persons who must assume responsibility for placing those who are released.

14. Whenever possible the United States Employment Service, County Welfare Department, Division of Vocational Rehabilitation, and other agencies should include retarded persons in Economic Opportunity and Manpower Training programs.

Sheltered Workshops

15. Sheltered workshop and work training opportunities should be expanded. All handicapped persons should be accommodated in such an expansion.

16. The Division of Vocational Rehabilitation should provide for a sound and orderly development of sheltered workshops with the help of subsidization by State government. Long term workshop employees must be supported through adequate appropriations by the State legislature.

17. Coordination among sheltered workshops must be sought on all levels of activity. Workshops should plan cooperatively in order to complement each other rather than compete.

    a. A central clearing house for contracts could be organized.

    b. Workshops might hire one or more competent "contract seekers," who, knowing the abilities and limitations of each workshop, could negotiate on behalf of each of them. Contracts beyond the capabilities of one workshop could be divided between two or more.

    c. Brochures outlining characteristics of various sheltered workshops should be prepared and made available to prospective customers.

18. Provision of half-way houses and sheltered living arrangements for people needing non-working hours supervision has been neglected. Residential arrangements should be worked out with workshops, county welfare departments, and placing agencies.

19. Government contractors should be encouraged to permit bidding by sheltered

workshops as well as by other sub-contractors.

20. Exploration should be made of the possibility of affording private employers who are willing to serve as work training or sheltered work stations the same subsidies, waivers of minimum wage, or waivers of union regulations presently granted to sheltered workshops.

Research and Demonstration

21. Application should be made for a grant to study employer attitudes toward hiring the mentally retarded. The study should be constructed so as to discover also how successfully retarded persons have been employed in industry and in which jobs they have attained great success.

VII. STAFFING, TRAINING, AND RECRUITING

Staffing

Only when sufficient numbers of well-trained professional and semi-professional personnel are deployed throughout the State will the mentally retarded in Minnesota receive the care they deserve. In order to reach this goal, we must determine accurately the numbers of personnel needed, and develop the most effective ways of recruiting and training them.

State Civil Service job descriptions identify eight-two position classes which serve the retarded, either exclusively or in part. Civil Service listings do not include: special teachers; workers in County Welfare Departments; the variety of staff needed for sheltered workshops, daytime activity centers, and similar facilities; and physicians, clergymen and other professional persons who come in contact with the mentally retarded in the course of their daily work.

The 1965 legislature authorized 421 new positions for the State institutions. These are being phased in at the rate of about 105 every six months. Additional appropriations were made to stimulate the growth of day care centers, special education classes, sheltered workshops, and community mental health centers. These new facilities, together with others to be constructed under various Federal, State, and local programs, will all require staffing. A great many supervisors, inspectors, community organizers, and other such personnel will be needed. It requires little imagination to realize that there will be no limit to the demand for well-trained staff.

The task force has listed the staff persons who are needed today in Minnesota in the three fields most closely associated with care of the mentally retarded:

1. Education and Habilitation

Supervisors
Teachers of the retarded
Teachers' aides
Guidance personnel
Rehabilitation center personnel
Sheltered workshop personnel
Day activity center personnel
Counselors trained in mental retardation

2. Medicine and Nursing *

Pediatricians
Psychiatrists - child psychiatrists
Researchers
Orthopedists
Neurologists
Rehabilitation therapists
Recreation therapists
Psychiatric technicians
Dentists
Public health nurses
Pediatric nurses
Psychiatric nurses
School health personnel
Genetic counselors
Physiotherapists
Occupational therapists
Opthalmologists

3. Psychology and Social Work

Clinical psychologists
Social workers
School psychologists

The Mental Health Planning Council has surveyed the manpower situation in the State with regard to psychologists, physicians, social workers, and nurses. Their observations are summarized below:

A. Psychologists. There are about 400 psychologists in Minnesota who hold the M.A. or Ph.D. degrees, exclusive of students still in training. About one-third of these are clinical psychologists, while the proportions of school and counseling psychologists are somewhat smaller.

The American Psychological Association does not recognize a Bachelor of Arts degree in psychology as sufficient professional training to allow an individual to render psychological services. The Association acknowledges that some functions may be well performed by persons specially trained at the Master's degree level in clinical, counseling, school, or educational psychology. Under State statute, status as a Certified Psychologist requires a Master's degree, one year of satisfactory employment as a psychologist, and successful completion of a written and oral examination conducted by the State Board of Examiners of Psychologists.

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* The Hill Family Foundation is supporting a study of doctors, dentists, and nurses in Minnesota. Publication is anticipated in Spring, 1966.

Certification as a School Psychologist requires the status of Certified Psychologist plus academic training beyond the Master's level to the equivalent of the University of Minnesota's diploma program as Specialist in School Psychological Services. A higher level of certification, Certified Consulting Psychologist, is provided for persons who possess the Ph.D. degree plus three years of experience and have been passed by the State Board of Examiners.

The University of Minnesota is the only educational insitution in the State which grants the Doctor of Philosophy degree in psychology. The approximate number of graduate students currently enrolled is 250.

B. Physicians. The Minnesota State Medical Association lists a membership of approximately 4,050 physicians and surgeons. The greatest number of these are engaged in the private practice of general medicine, i.e., they are "family doctors". Many others are members of specialty groups, and some of more than one specialty group. Most specialists are located in the large cities, at the University of Minnesota, and at the Mayo Clinic in Rochester.

The following numbers of Minnesta physicians have been certified by their respective specialty boards in fields related to mental retardation: Neurology and Psychiatry, 130; Obstetrics and Gynecology, 118; Opthalmology, 87; Orthopedics, 66; Pediatrics, 127.

At present the College of Medical Sciences at the University of Minnesota is the only medical school in the State. It graduates about 150 students per year. The Mayo Clinic maintains a graduate teaching program as an affiliate of the University Medical School. Efforts are under way on the part of Northern Association for Medical Education, a group of physicians and surgeons and lay persons, to build, staff and maintain a medical school in St. Paul.

The University of Minnesota Medical School is currently sponsoring post-graduate training in psychiatry for twenty-seven psychiatric resident physicians; of this group six are being trained at the Veteran's Hospital at Fort Snelling,

three at Hennepin County General Hospital, and three in the State hospital system. In addition, twenty-two psychiatric residents are being trained at Mayo Clinic. Since 1961 the Department of Public Welfare, University of Minnesota Medical School, Minnesota State Medical Association, and Minnesota Chapter of the Academy of General Practice have jointly offered a post-graduate short course in psychiatry for non-psychiatric physicians in various areas of the State supported by a National Institute of Mental Health training grant. From Fall of 1961 through June 30, 1964, a total of 119 physicians participated; from July 1, 1963 to June 30, 1964 forty physicians took part.

C. Social Workers. County Welfare Departments employed 1,089 social workers on all levels as of June 30, 1964. Eighty per cent of these workers held a Bachelor's degree; only ten per cent had had one or more years of graduate education in a school of social work. Seventy-five case aides were also employed.

As of January 1, 1966, the Community Mental Health Centers in Minnesota had authorization to hire forty-seven social workers (some part-time); private mental health centers, sixteen (excluding Mayo Clinic); State Hospitals for the mentally ill, forty-nine full-time, five part-time; State schools and hospitals for the retarded, eighteen; University of Minnesota Hospitals, eight; private hospitals participating in community psychiatric care, two full-time, four part-time (excluding Mayo); Minnesota Residential Treatment Center, five.

Private agencies, child-caring institutions, and correctional facilities also employ a limited number of social workers.

The University of Minnesota is the only post-graduate social work training center in the State. A large number of private and State colleges offer courses on an undergraduate level which may lead either to employment in the field or to graduate work.

D. Nurses. As of January 31, 1963 there were 16,104 licensed registered nurses in Minnesota, of whom 12,897 were employed. As of the same date 3,547

licensed practical nurses were employed; 793 were licensed but not known to be employed. On the basis of the 1960 census and excluding school nurses, additional personnel needed to staff public health services in Minnesota are estimated as follows [44]: 300 additional public health nurses; 400 additional registered nurses; 200 additional licensed practical nurses. Yet the 1962 Annual Report of Local Service Statistics shows that the vacancy trend is increasing. As of January 1, 1960, there were 499 public health nurses employed in Minnesota. Fifteen counties make no provision for county public health nursing services.

The staffing problems in State institutions are well documented.[45,46] The Minnesota Association for Retarded Children prepared in December, 1964 a study of staffing in State institutions for the mentally retarded.[47] Staffing ratios for patient care workers, i.e., psychiatric technicians, technician trainees, registered nurses, and practical nurses, were compared with standards set by the American Association for Mental Deficiency, as shown below:

	A.M.	P.M.	Night	Total Personnel Needed *
Faribault	1:23.5	1:32.1	1:82.4	
A.A.M.D.	1:7.2	1:10	1:20.5	832
Cambridge	1:18.5	1:22.5	1:62.6	
A.A.M.D.	1:6.4	1:8.7	1:19.7	575
Brainerd	1:28.2	1:33.1	1:46.4	
A.A.M.D.	1:7.4	1:10	1:17.6	359

* Based on total patient populations in June, 1965.

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44. Telephone communication from Alberta Wilson, Chief, Section of Nursing, Dept. of Health, June 30, 1965.

45. A Report of the Governor's Advisory Committee on Mental Retardation. State of Minnesota. October, 1962.

46. A Study of Staffing in Minnesota Institutions for the Mentally Retarded. Minnesota Association for Retarded Children. December, 1964.

47. Ibid., p. 4-15.

As of October, 1965, there were 515 patient care workers at Faribault, 358 at Cambrige, 202 at Brainerd, categorized as follows:

	Psychiatric Technicians	R.N.	P.N.	Technician Trainees	TOTAL
Faribault	395	34	11	75	515
Cambridge	281	25	0	52	358
Brainerd	121	17	1	63	202
TOTAL	797	76	12	190	1075

Psychiatric technicians, who are responsible for daily care of patients, are paid 270 dollars a month as trainees, 281 dollars after six months, and 292 dollars after one year and successful completion of the State Civil Service Examination. The maximum salary which a Psychiatric Technician I can earn is 356 dollars per month.

Dr. Richard Bartman, Director, Children's Mental Health Services, Department of Public Welfare, has said:

> If an institution is established to care for persons with disabilities, the staffing pattern should be determined by the nature and extent of the disabilities of those persons admitted to the institution. This statement would appear to be a truism. It is, in fact, a truism if one looks at the staffing patterns of tuberculosis hospitals, general hospitals, private psychiatric hospitals, rehabilitation centers, and special schools. Curiously, however, this is far from the case when one compares the needs of persons in public institutions for the mentally retarded with the staffing patterns provided for them. The recent survey of the patient population in Minnesota's institutions for retarded has clearly shown the broad range of the disabilities that one finds in such facilities, and also demonstrates the remarkable discrepancy between the needs of these patients and the services that are provided for them through current budgetary allotments. This discrepancy is too great to be accounted for by variations in professional opinions. It appears to rest on lack of information on the part of those who have the final say in budgetary allotments which in turn may be related to reluctance to come to grips with such a massive, complex, and costly problem.[48]

We have been going 'round in a vicious circle, not programming adequately because of insufficient staff, and hence being unable to determine the quantity and

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48. A Report of the Governor's Advisory Committee on Mental Retardation. State of Minnesota. October, 1962. p. 79.

quality of staff which can successfully implement the many and varied programs we need. This circle must be broken if we are to keep pace with the many new concepts and developments in the field and allow the retarded to make the astonishing progress of which many are capable.

Training

Many persons who are at present working with the mentally retarded are doing so because of fortuitous opportunities which have arisen in the course of career development, rather than on the basis of decisions made in high school and college leading to a planned course of study and training. Discussions with physicians, psychologists, social workers, and other practitioners and perusal of professional journals reveals a lack of interest in retardation similar to the public apathy which is responsible for society's neglect of this segment of our population. The mentally retarded, because of their limited intellectual abilities, have been perceived as affording a practitioner much less challenge and opportunity to achieve successful treatment than have the mentally ill. Years of work by the Associations for Retarded Children and, in the past two or three years, stimulation of a general public awareness by the Kennedy family, are just beginning to reap results in professional quarters.

There are very few courses relating to mental retardation taught in any of Minnesota's colleges or professional schools. (Appendix C). Special education is the only professional discipline which even defines mental retardation as a field of study. At a recent Mental Retardation Planning Council Public Information Workshop with representatives of liberal arts colleges from all over the State, the shortage of persons qualified to teach such courses was identified as a major problem. Another reason cited for the dearth of course work offered was the low status of mental retardation in teaching priority.

Since fully trained professionals will be in very short supply for a long time to come, administrators of programs should spell out those functions which pro-

fessionals must perform and those which can be executed by semi-professionals of lesser education or training. In a study of post-high school vocational and technical education, the American Council on Education called for immediate steps to assure an adequate supply of manpower below the bachelor's level. Dr. Grant Venn, author of the study, said: "A major difficulty in achieving this goal is the prestige of the baccalaureate degree vis-a-vis vocational or technical competence...Two-year colleges must make vocational and technical education a major part of their mission."[49] The junior colleges in Minnesota have a significant role to play in the training of semi-professional personnel. Chapter 837, Section 29, of the 1963 Minnesota Sessions Laws, empowers the State Junior College Board to "prescribe courses of study, including...training in semi-professional and technical fields". St. Mary's Junior College in Minneapolis has recently applied for a Federal grant for a pilot project to train aides for special education classrooms and daytime activity centers. Such training will miss the mark unless agencies and, more important, professional organizations recognize the significant role which less highly trained people can play.

Within various agencies, in-service training programs for employees are continuous and diversified. Although the quality of these programs is uneven and very difficult to measure, this type of training does serve to improve the care of retarded persons.

State training programs have been detailed by the Minnesota Civil Service Department, as follows:

> 1. Institution Trainee. There are two types of institution trainees: (a) High School students are hired during the summer between their junior and senior years to work in institutions, with several of them splitting up a full time job. They are usually assigned to food service and ward work and are paid one dollar an hour. (b) College students are also hired during the summer and work mostly in the nursing, social service, and recreation programs. Here again their training is

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49. From "The Burgeoning Community College--Is It Really Higher Education?" by Bert Schwartz. Saturday Review, December 19, 1964.

mostly of the on-the-job variety. They are paid 200 dollars a month. About ten to twelve students per year participate in each program.

The objective of both programs is to familiarize students with the State hospitals and to interest them in making a career of institutional employment at either the semi-professional or professional level. A similar program is also in effect at Owatonna State School for the training of houseparents.

2. Psychiatric Technician. This is the basic program in the State hospitals for providing trained semi-professional nursing help on the wards. Prospective employees are screened by means of group intelligence test and an oral examination by a board consisting usually of the superintendent of nurses, the personnel officer, and the chief of the rehabilitative services. If an individual passes this screening, he is hired on a trainee basis for a period of one year, during which time he is given a minimum stated number of classroom hours of instruction as well as supervised work on the ward. At the end of this period, he is admitted to the Psychiatric Technician examination; if he completes the test successfully he is hired on a full time basis.

The State has also applied for funds under the Manpower Development and Training Act for a six month concentrated training program for Psychiatric Technicians. This program consists of 265 hours of class on the care of the mentally retarded and 535 hours of clinical supervised training on the wards. Clinical orientation includes two weeks at a State hospital for the mentally ill and two weeks in a nursing home, with visits to daytime activity centers, rehabilitation centers, and other community agencies. Applications have been approved for two of the hospitals, and the method of financing as well as a suitable curriculum are being worked out. If this type of program is successful, it well replace the present one year Psychiatric Technician training program.

3. Nurse Affiliate. All of the State Hospitals for the mentally ill sponsor a three-month psychiatric affiliation for student nurses in the three year and baccalaureate programs, which includes a one-day field trip to one of the institutions for the retarded for orientation to care and nursing of the mentally retarded. About 850 students per year participate in this program.

4. Other Programs. There are also under consideration a number of projects proposed to assess the value of various kinds of training in the Houseparent classes at Owatonna State School.

5. Stipends. The Department of Welfare has stipends available for registered nurses, licensed practical nurses, psychologists, occupational therapists, recreational therapists, and social workers.

In the registered nurse program, there are provisions for Baccalaureate degrees which provide stipends of 225 to 325 dollars per month, depending upon the marital status of the individual and the number of dependents. Out of this amount the student pays his own tuition and fees. Another program, leading to a diploma from a three year nursing school, offers scholarships of from 200 to 300 dollars a month, again depending on marital status and number of dependents and out of which the student

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pays tuition and fees. There is also a scholarship program for Licensed Practical Nurses which carried a stipend of up to 200 dollars a month. A committee determines the amount to be granted to each student on an individual basis.

In 1965-66 a total of 35,832 dollars in State Mental Health funds was awarded to fourteen students in this program. Twelve of these are in the Baccalaureate program (eight former students, four new); two are in the practical nurse program (one former, one new). Twelve applications were rejected because of insufficient funds.

The stipend arrangement is also available for psychologists who enter graduate work. It provides a monthly allotment of from 225 to 325 dollars, depending on marital status and number of dependents, and also includes the cost of tuition. In addition to the Master's degree scholarships, there are stipends available for psychologists pursuing a Doctor's degree. These individuals receive approximately seventy-five per cent of the salary they were earning at the time of approval of the scholarship. In addition they receive full tuition expenses. In 1965-66, a total of 17,360 dollars in State Mental Health Funds was awarded for four students in this program.

Persons who have completed the sophomore or junior year and show evidence of acceptance into a recognized school of occupational therapy may be granted scholarships at the rate of 225 to 325 dollars a month, again dependent upon marital status and number of dependents. They also receive the cost of tuition. Individuals who have graduated from an accredited university and are accepted into a school of therapeutic recreation may be granted scholarships of the same amount up to two years of graduate training. In 1965-66, a total of 13,199 dollars in State Mental Health funds was awarded for four students.

In the field of social work, individuals who have graduated from an accredited college or university and show evidence of acceptance into a graduate school of social work may receive a stipend of from 225 to 325 dollars a month, depending upon marital status and number of dependents, in addition to the cost of tuition. This scholarship continues through the two years of graduate study. In 1965-66, forty-two students received 132,493 dollars in Federal Child Welfare funds, while nine students received 25,469 dollars in State Mental Health funds.

6. Residency program for psychiatrists. A total of twenty-six physicians have participated in this program since it began in 1955. They have received a total of 431,814 dollars in State Mental Health funds. In 1965-66, the nine physicians who participated were paid a total of 58,125 dollars. This program extends over five years, three of which are spent at a hospital of the individual's own choosing, the other two at one of the State hospitals as "obligatory" service with compensation of $14,000 a year.

7. Department of Education Stipends. Under Public Law 88-164, Federal monies are available for the training of teachers and leadership personnel in the education of handicapped children.--Two type of grants are available as follows:

(a) Summer session traineeships for summer of 1966.
These traineeships are five weeks in duration—the length of a single session at the University of Minnesota and at the State colleges. However, the grant may be used at any teacher training institution in the United States which offers a full summer program in the disability area of study. Of the 51 traineeships available, 27 are awarded for work with the mentally retarded.

Each recipient will receive a 75 dollar a week stipend, and the college or university in which the recipient is enrolled will receive a support grant of 75 dollars a week to cover tuition. Applicants must hold or be eligible for a valid Minnesota teaching certificate, with preference given to persons already employed or certified in special education.

(b) Graduate fellowships for the 1966-67 school year. A total of six grants, two of which are for work with the mentally retarded, are available. Fellowships may be used at any teacher training institution in the United States which offers a full graduate program in the area of special education in which application is made. To be eligible, an individual must have an undergraduate degree, have or be eligible for a valid Minnesota teaching certificate, have had at least one year of successful teaching of handicapped children.

The tax-free stipend is paid directly to the student; $2,000 to first year graduate students, $2,400 to second year graduate students, $2,800 to third year graduate students. A $400 allowance is made for each dependent. Tuition fees are all included in the supporting $2,500 grant paid to the college or university in which recipient is enrolled.

It should be remembered that with the availability of funds under the Manpower Development and Training Act and the recently passed Economic Opportunity Act, as well as the possibility of financing from the National Institute of Mental Health, there are currently a number of applications for training programs which are in process and on which there is no information available at this time. While attempts are being made to provide enough highly skilled professional personnel, perhaps the major effort is being directed toward ward and cottage personnel. The goal is not only to offer specific training, but also to try to evaluate those characteristics which can be used for predicting success on the job as well as the results of various types of orientation and training procedures.

There are many other short term training programs, a few of which are listed here:

1. Owatonna State School training program for house parents, financed by the Department of Public Welfare.

2. Faribault State School and Hospital augmented training program for psychiatric technicians, financed by the Department of Public Welfare.
3. A series of in-service institutes for Daytime Activity Center workers, Public Health Nurses, sheltered workshop personnel, and others, sponsored by the University of Minnesota Continuation Center, or by the Department of Public Welfare,
4. Minnesota Association for Child Caring Institutions training program, geared for persons who are not college trained.

Recruiting

The awakening during the last several years to the needs of the mentally retarded has been dramatic, and the demand for personnel far exceeds supply. The number of professionals coming out of our colleges at present cannot match the demand for their services. Many fields which utilize the same kinds of personnel are rapidly advancing, which makes for a very competitive situation. All disciplines must work together to encourage more people to work in the area of mental retardation and to stimulate schools and colleges to institute programs which will train a wide variety of practitioners.

Mental retardation as a field of endeavor must be made attractive to young professionals. Orientation to career opportunities in working with the mentally retarded should begin in high school and continue through college. High school and college counselors should be educated to understand mental retardation as a phenomenom and to stimulate student awareness and interest in the field. High school and college students must be encouraged to participate in volunteer programs, camping, summer training sessions at State institutions, etc. (See Public Awareness report.)

The field of mental retardation could also emerge as a life work for social workers, psychologists, nurses, therapists, teachers, boarding parents, and community organizers who are already practicing their professions. Recognition

of this possibility by the public, by training facilities, and by agencies, could greatly influence recruiting and could stimulate the provision of promotional opportunities (now largely lacking) within the specialty of mental retardation, thus helping to keep valuable workers in the field.

The task force identified other obstacles which must be removed if enough people are to be recruited to work with the retarded. For example, many services to the retarded are performed under State or other public auspices. Although starting salaries and fringe benefits appear to be competitive with those in private agencies, legislative bodies have placed ceilings on salaries of administrators and professionals, thus "compacting" maximum salaries well below the limits of the private sector of our economy. This low ceiling has the effect of discouraging people from entering public service on a career basis and also results in rapid turnover after experience has been acquired. Raising the salary limits of a few top professionals would undoubtedly help to attract and retain a greater number of well qualified people in key positions. Reasonable comparability with similar university positions might be utilized as a benchmark. The employment of many truly able top level professionals would in turn attract other persons into public service.

Quality of working conditions, especially in institutions, is a major factor in recruitment. The present institutional situation, wherein large numbers of patients are cared for by a pitifully small staff, can scarcely be expected to attract additional staff members. Staffing patterns should be based on the clearly defined needs of large homogeneous groups of patients, with position responsibilities delegated accordingly. Professionals should be encouraged to engage in research activities and should be provided with time, facilities, and funds with which to carry out worthwhile projects. Opportunities should also be made available for activities which will contribute to general professional advancement.

Recruitment of professionals tends to be more difficult in areas removed from population centers. Cities harbor universities and colleges, communities of professionals, and other cultural advantages, all vitally important in attracting professional personnel. On the other hand, decentralization of services would broaden the base for recruitment of non-professional staff and volunteers, would make available a greater number of field placements, and would serve as an instrument for more widespread public awareness of the problems of retardation.

All possible sources of future personnel must be identified and made the target of specific recruitment programs. Services of volunteers, especially junior and senior high school students, should be used extensively in Daytime Activity Centers, institutions, camps, special classes, and recreational programs. Up-to-date information about mental retardation as a career field should be sent to counselors in high schools and colleges. Career days, facilities visits, and other forms of exposure to the field should be exploited as fully as possible.

There is a growing reservior of older people who are looking for meaningful activities. These persons may be past retirement age for full-time employment but could be hired on a consultant or contractual basis. Similarly, many housewives who have been trained as nurses, teachers, therapists, etc., could be recruited on a part-time basis. Part-time employees may present problems in scheduling and in providing coverage in times of sickness, but they can perform needed services at a time when trained persons are in short supply. Facilities, especially smaller ones, may be able to obtain professional services by contracting from or sharing time with schools, county welfare boards, and other agencies in the community.

Retraining programs for persons displaced from their jobs by automation should be considered as a means of bringing more people into the field.

The use of "indigenous personnel", as outlined below, should be fully explored.

> Neighborhood people functioning as non-professionals appear to be highly successful in developing rapport with low-income clients,

including the most deprived and disadvantaged individuals in the community. Their success seems to stem from the fact that they are similar to the clients in terms of background, style, language, ethnicity, and interests. For this reason, and also because they serve as excellent role models, we would recommend that a great many more non-professionals be employed as aides in hospitals and social agencies in various capacities.[50]

Finally, it is not inappropriate to look to the retarded themselves as an important source of manpower in caring for the handicapped.

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50. New Approaches to Mental Health Treatment for Labor and Low Income Groups. National Institute of Labor Education. Report #2. February, 1964.

Recommendations Concerning Staffing, Training, and Recruiting

Staffing

1. Competent professionals must create standards which specify the kinds and numbers of staff persons required to effect various programs in State and private institutions in Minnesota. Until such standards are devised, staffing patterns should comply with standards published by the American Association of Mental Deficiency.

2. All agencies must recognize the need for specialized training for personnel who work in the area of mental retardation. Personnel classification systems should designate appropriate promotional levels so that persons who have acquired special skills and knowledge relative to mental retardation can be promoted within their field of specialization.

3. Salaries and working conditions in the field of mental retardation must be in accord with the competitive market.

4. Salaries of top level administrators and professionals in public service should be commensurate with those of persons with equal responsibilities in the private sector of the economy.

5. The State should take the lead in setting realistic levels of qualification for State employment, so that (a) able personnel are not eliminated by too stringent formal requirements from jobs they might effectively perform, and (b) persons of high qualification are channeled into appropriate jobs, rather than being hired for jobs which can be carried out by those of lesser training.

6. There should be greater recognition by agencies and professionals that levels of training other than four years of college plus graduate school are appropriate for many levels of work with retarded persons.

7. Special consideration should be given wherever possible to the gainful employment of retarded persons in State and private agencies and facilities.

Training

8. Junior colleges, State colleges, and vocational schools should train persons to assume semi-professional positions in a variety of mental retardation facilities.

9. A course on the "exceptional child" should be included in all teacher training curricula. Curricula for school administrators should include a thorough orientation to the necessity for, and benefits of, special education.

10. More college courses pertaining to mental retardation should be offered in summer school, extension school, and in the regular curricula of professional and semi-professional training.

11. Whenever possible State institutions of higher learning should cooperate with State agencies and residential facilities serving the mentally retarded in developing specialized training programs and sharing field placements, designing and carrying out research activities, utilizing staff, and recruiting personnel.

12. More scholarships and fellowships should be made available to undergraduate students who are interested in working with the mentally retarded. Assistance should be given in guiding people into areas of greatest need.

13. Consultants within the various State departments should cooperate in planning for a continuity of interdepartmental short term courses on mental retardation, to be available to all health care professionals employed by the State.

14. Those working with the mentally retarded within the framework of State government should be exposed to intensive in-service education programs and should be encouraged to take advanced course work in Minnesota or elsewhere, without loss of salary.

15. Civil service departments and public administrative agencies should explore the retraining of workers displaced by automation as a potential source of manpower.

Recruiting

16. Orientation to career possibilities in working with the mentally retarded should begin in junior and senior high school and should continue through the college years.

17. Available personnel in a community should be recruited to work with the retarded. Housewives with career training, retired persons, and those trained persons who can work part-time are suggested as manpower resources.

18. Volunteer service should be utilized extensively as a recruiting device.

19. Service for the mentally retarded should, whenever possible, be located in various population centers around the State. A location in college communities should help in attracting professional staff. Decentralization would also broaden the base for recruitment of volunteers and sub-professional staff, and would make available more field placements. It would also increase public awareness, which is vital to continued progress.

20. Time and opportunity for research should be made available to all professionals, together with assistance in obtaining government and private support for worthwhile projects.

VIII. VOLUNTEER SERVICES

Volunteer service describes a gratuitous effort on the part of an individual who wishes to share the responsibilities of those democratic institutions concerned with the advancement of human welfare. The benefits of citizen participation are best realized when a coordinated volunteer service program is an integral part of the total organization of community services. A primary ingredient of a successful volunteer program is the existence of good rapport, built on mutual respect and responsibility, between volunteer and professional; each must have well-defined areas of competence, understood and appreciated by the other.

Basic principals fundamental to giving and receiving volunteer services are outlined below:

Volunteer Responsibility

Volunteers need not necessarily possess special educational qualifications, talents, or skills in order to be effective. The most important attributes of a good volunteer are genuine interest and the ability to give of himself to others. Volunteer service is a responsibility which also requires:

1. Conviction of purpose, exercise of intelligence and energy, and a conscientious approach to work assigned.

2. An orientation to the objectives, problems, needs, and resources of the program or agency with which the volunteer is identified.

3. A willingness to prepare adequately for work to be done, in accordance with recognized standards for training, conduct, and quality of service.

4. Ability to adapt special skills and experience to the structure of various required activities.

5. Flexibility enabling one to accept change of assignment when, after objective evaluation, it is deemed advisable.

Agency Responsibility

Working with volunteers is a fundamental part of a professional worker's responsibility. Professionals and volunteers, each performing widely separated

functions, can do more together than can either group alone. In putting this philosophy into practice, organizations and agencies using volunteers have these responsibilities:

1. Accepting the role of volunteers, recognizing their contribution, respecting their needs and abilities, and taking the time to do something positive about these factors as they relate to the program of the agency.

2. Analyzing the organization's work, defining specific jobs involved in the total plan, determining the division of work between professional and volunteer, deciding which skills, abilities, and qualifications are desirable for the best performance of the task.

3. Informing all agency staff of the philosophy behind a volunteer program and soliciting their suggestions as to how volunteer services might be most effectively used to benefit clients and to reach the agency's objectives.

4. Developing attitudes essential for effective supervision and establishment of a good working relationship within the volunteer group.

5. Making necessary arrangements for recruiting, screening, training, and placing of volunteers; developing methods of recognition and promotion; providing satisfactory working conditions; and furnishing all possible opportunities for enriching experiences consistent with sound policy.

6. Helping volunteers develop confidence and self-assurance in their own ability to contribute worthwhile service to the community.[51]

In addition to providing members of the community with the opportunity to perform useful work in the service of others, volunteer programs are a valuable resource for recruitment of future professional staff, stimulation of public awareness, and fostering of an informed citizenry.

Volunteer services are a relatively untouched source of help in serving the mentally retarded. Mental Retardation Planning Council regional appraisals

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51. Adapted from A Guide Book For Planning A Volunteer Program, Kansas Department of Social Welfare. p. 2,3.

(Volume II) underline the scarcity of volunteer services to the retarded in Minnesota, with the exception of the volunteer programs at the major State institutions.

Volunteer services coordinators, who would organize and administer volunteer activities, should be employed by State institutions, counties, groups of counties, and regions of the State. With the increasing integration of mental health and mental retardation programs, coordinators should probably administer volunteer services for both. A survey of volunteer services presently being performed at State institutions and in various facilities under the auspices of the Ramsey and St. Louis County Welfare Departments (Appendix D) suggests only a few of the innumerable services which volunteers might render to the mentally retarded. With the rapid growth of community-based services for the retarded, opportunities for volunteers are increasingly available to an expanding segment of the population. Agencies, volunteers, and organizations which sponsor volunteers should examine their communities for such opportunities.

Volunteer Service to the Retarded

Volunteers, in giving direct service to retarded persons, perform these major functions:

1. Engaging in useful work which will personalize treatment of the retardate, broaden his outlook, and help him to feel important and loved; thus, the "dehumanization" which often attends long-term institutionalization will be avoided.

2. Supplementing, not supplanting, professional services. Volunteers should not be assigned to jobs which are the responsibility of paid personnel. Exceptions might sometimes be made in essential jobs impossible to fill with paid personnel because of limited availability of manpower. Occasionally volunteers might also perform a particular service in order to demonstrate the value of funding such a service on an ongoing basis.

3. Filling gaps in the continuum of care where no professional service is available, such as religious education, camping, recreation, and leisure time programs. Many programs have been initiated by volunteers, and, after proving their value, have been accepted as public and private responsibilities.

The need for volunteers can be arrived at by determining the needs of the community, identifying the specific agency services which a volunteer might perform, and listing those groups and associations within the community which are potential sources of volunteer power. The latter might include service clubs, veterans' organizations, churches, and the many other groups which make up the community. This kind of survey is a good starting point for expansion of volunteer services.

Selection of volunteers is a two-way street. Agencies should outline jobs to be performed by volunteers and should actively recruit. Groups who sponsor volunteers should request their members to complete application blanks indicating interests, background, availability, and other pertinent data. Complete job descriptions should be written for every conceivable volunteer assignment.

Volunteers should be provided with training programs which will help to assess their abilities and sharpen their interest. This training should include orientation to mental retardation, and to specific agency programs, goals, philosophy, and procedures. Good materials are available through National, State and local Associations for Retarded Children, Mental Health Associations, the State Department of Public Welfare, and the Federal Department of Health, Education and Welfare. Periodic regional training programs might be a continuing program of the Associations for Retarded Children, using as faculty both professional staff and experienced volunteers.

Supervision of volunteers demands several elements. Jobs should be specifically defined and should be useful and necessary. Jobs should give the volunteer a sense of responsibility and of recognition of the usefulness of his services. He should see where his effort fits into the accomplishment of total agency goals. He should report to one person in the agency, preferably the same individual who is responsible for his supervision and for making sure that the work is accomplished. This will not necessarily be the agency director or the volunteer services coordinator. Any agency which uses even one volunteer should have an individual

staff member in charge of the program. The sponsoring group from which he was recruited should also know who this person is.

The kinds of work volunteers perform at present and the extent and potential of volunteer services in the State are documented in the regional surveys. (Volume II). Where professionals and volunteers work together extensive and ongoing programs exist. Sometimes limited programs are developed through the special interest and enthusiasm of an individual in the community. Too often there are no programs at all.

Many people today have an abundance of leisure time and many others are retiring earlier than in the past. These and other factors contribute to the existence of a reservoir of capable citizens looking for useful activities. At the same time, many disabled or handicapped persons could benefit from the kinds of services and programs which are possible through the involvement of citizen groups. It is a test of our ingenuity and imagination to bring these two needs together for the mutual gain of all.

Recommendations Concerning Volunteer Services

1. More volunteer services coordinators should be employed by the State and by County Welfare Departments in order to serve adequately the ten State institutions, the eighty-seven counties, groups of counties, and regions of the State. Coordinators should organize and administer volunteer activities related to mental health as well as to mental retardation. Consideration should be given to the use of Federal funds to help set up a county volunteer coordinator system similar to the county extension agents.
2. Each agency or facility should designate one person to coordinate and supervise the volunteer program.
3. Increased coordination of all activities pertaining to mental retardation, including, but not limited to, volunteer services, should be effected at the State level by an administrative agency or structure shared by the Departments of Health, Education, and Welfare.
4. Although not all facilities which care for the retarded need volunteers, those in which volunteers would be useful should actively seek and receive their services.
5. Vigorous efforts should be made to identify and publicize unmet needs which can be remedied by volunteer services. At the same time, volunteers themselves should be encouraged to explore existing deficiencies in community programs for the retarded. Recreation, Sunday School classes, and social and club groups are examples of areas where individual imagination and interest have proved invaluable in initiating programs.
6. Local and State government agencies, school districts, and private non-profit organizations must be educated to the use of volunteers and brought to the realization that well-trained and well-oriented volunteers are in invaluable asset. They must recognize the many positive factors which accrue to both agency and client through citizen involvement. A volunteer

training and placement program which is effectively administered and coordnated is the best tool for achieving this education.

7. Persons of all ages, from 'teen to senior citizen, should be included in volunteer programs.

8. Training programs should be instituted for all volunteers. These programs should help to assess the abilities of volunteers, as well as sharpen their interest. Training should include orientation to mental retardation and to specific agency programs, goals, philosophy, and procedures. Orientation should occur before assignment of duties.

9. Transportation problems of volunteers should be met. Many groups such as teen-agers, older folks, and person having long distances to travel simply are not able to volunteer because transportation is not available. The sponsoring group or using agency should make appropriate provision for transportation.

10. Leading State and local officials should be regularly advised of the contributions of volunteers and should provide public commendation. Such recognition will help to stimulate growth of volunteer programs.

IX. RESEARCH

As prevention is the ultimate goal in combating mental retardation, so research is the means to that goal. Because of the polymorphous nature of mental retardation, it is becoming increasingly clear that research must be carried on by teams that span the disciplines of the medical and behavioral sciences. Although there have been sizeable achievements in mental retardation research in recent years, "areas of our current ignorance about the complex phenomena of retardation are still substantial." 52

In 1962 the Governor's Advisory Committee on Mental Retardation stated that

> Research is the key to the long-range solution of problems of mental retardation. The major orientation of research in this field should be toward the discovery of preventive measures to reduce the incidence of mental retardation. Secondly, research is necessary to evaluate and improve programs for the retarded.
>
> The State of Minnesota has invested very little in research in this field. Indeed, the lack of innovation and research is one of the most striking observations to be made in institutions and other programs. As a result, services are developed and plans are made with very few guide lines having been established through careful study. 53

Today, three years later, the picture in Minnesota is relatively unchanged. At the last legislative session, $280,000 was appropriated to the Department of Public Welfare for research during 1965 and 1966. Although this amount is not large, about $35,000 will be returned unused. The Department of Education received no State research funds for 1965-66. Further, the sum of $13,000 was allocated to Cambridge State School and Hospital for employment of a research director, but the position is still vacant. Thus the most immediate problem is not only one of insufficient funds, but also of finding capable research

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52. Tarjan, George, M.D. "Facilitation of Research Through Administration." In Role of the Residential Institution in Mental Retardation Research, Report of a Conference Sponsored by the National Association for Retarded Children, May 23-25, 1964. p. 30.

53. State of Minnesota. A Report of the Governor's Advisory Committee on Mental Retardation. October, 1962. p. 47

personnel to use effectively the funds which are available and by their efforts to call forth more sizeable appropriations. Such personnel are attracted to a milieu characterized by freedom and autonomy. Although State-supported research must rightfully give priority to projects which are directly related to State concerns, researchers must be given the freedom to formulate their own problems for study and must not be limited by administrative injunctions. The difficulty of securing good research people is complicated by the isolation of the State institutions from the rest of the scientific and cultural community, most of which centers around the University of Minnesota and the Twin Cities. Perhaps most significant, the various State departments do little to encourage research activities. They appear to share with State institutions the attitude that research is something of a luxury.

A survey of current research in Minnesota conducted by the Mental Retardation Planning Council Project Office in fall of 1964 and up-dated in March, 1965 unearthed forty-six ongoing projects and ten which had been completed, for a total of fifty-six. Although a preponderance of studies were associated with the University of Minnesota, affiliations of investigators also included institutions for the retarded, hospitals for the mentally ill, public school systems, Departments of Public Welfare, Health, and Vocational Rehabilitation, and the Mental Health Council, as well as State and private colleges. The greatest number of studies were being carried out in the biomedical and psychology-education fields. Sources of support were the Minnesota Association for Retarded Children, Minneapolis Association for Retarded Children, Department of Public Welfare, U. S. Public Health Service, National Institute of Neurological Diseases and Blindness, National Association for Mental Health, University of Minnesota, and Vocational Rehabilitation Administration, and unidentified fellowships, Federal funds, and private funds; nine investigators indicated that they were receiving no financial assistance.

It should be pointed out that many of the so-called "research" projects were actually service or demonstration projects which had little or nothing to do with research. In many cases, investigations were terminated not long after they were begun. Publication of results has not been common. Survey respondents indicated that they had encountered problems of insufficient time and inadequate staff, poor case records, difficulty in obtaining funds, prohibitive travel distances, lack of cooperation in the community or on the part of the institutional staff, unavailability of subjects, and unsuitable research facilities.

Three important research projects, two of them Federally funded, merit special mention. They are: Mental Retardation, a Family Study, a major investigation of the genetic aspects of mental retardation recently completed by Sheldon and Elizabeth Reed at Dight Institute[54]; Retarded Youth: Their School-Rehabilitation Needs, an excellent socio-cultural study of school and rehabilitation needs of educable retarded pupils in the Minneapolis schools[55]; and the Collaborative Perinatal Study, in progress at the University of Minnesota as part of a national research project to correlate a multiplicity of factors involved in pregnancy and child birth with subsequent child development.

At a State-wide Research Conference on Mental Retardation, sponsored by the Planning Council on May 7, 1965, it became apparent that wide-spread confusion exists concerning the practical difference between research and service. A large number of participants in the conference who designated their various activities as research are actually engaged in applying the results of research rather than

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54. Reed, Elizabeth W., and Reed, Sheldon C. Mental Retardation, A Family Study. W. B. Saunders Company, Philadelphia, 1965.

55. Retarded Youth: Their School-Rehabilitation Needs. Research and Demonstration Project 681. Minneapolis Public Schools. March, 1965.

in the search for basic answers which is research. The value of service programs is not being questioned, but a clarification of the distinction between research and service would have far-reaching implications for organizing and financing future projects.

Other deficiencies in the Minnesota research picture were enunciated by the task force as follows:

1. The status of mental retardation as a research area is low, making it difficult to interest able research personnel in working on problems related to retardation.
2. Existing facilities which might be utilized for research purposes are scattered among departments and disciplines and are not set up to aid and abet research endeavors.
3. Interdisciplinary communication and cooperation are lacking. The benefits of communication and direct observation in research cannot be overstated. Stimulation and support from other people play a large role in maintaining research interests and competency.
4. There is no centralized source of information on available research funds and how to obtain them.
5. Existing case material is hard to locate and not readily accessible. Often schools, hospitals, and institutions refuse to cooperate with researchers in making files and records available. In some instances, such as that of the Indian residing in Minnesota, there is legal prohibition against doing so. Research in mental retardation often depends upon these basic data, which should be available to researchers, with appropriate safeguards to ensure confidentiality.

The task force has based the general recommendations which follow on the results of the Project Office survey, extensive discussion at the Research Conference, and its own perception of needs.

Recommendations Concerning Research

1. A multidisciplinary Institute for Research in Mental Retardation and Human Development should be established in the State. The wealth of case material (including one of the highest percentages of institutionalized mentally retarded in the 50 states), the recognized medical and research competence, and the strong concern of an aroused public to "find the answers" to mental retardation are factors which support the wisdom and feasibility of such an institute.

Federal construction and operating grants are available. Public Law 88-164, in particular, authorizes appropriations in the amount of $6,000,000 for fiscal 1964, $8,000,000 for fiscal 1965, and $6,000,000 each for fiscal 1966 and fiscal 1967, for "project grants to assist in meeting the costs of construction of facilities for research, or research and related purposes, relating to human development, whether biological, medical, social, or behavioral, which may assist in finding the causes, and means of prevention, of mental retardation, or in finding means of ameliorating the effects of mental retardation."

Several possibilities present themselves: (a) The University of Minnesota with its land-grant tradition, and embracing as it does the many disciplines concerned with retardation, would be a most propitious site. (b) The proposed new Childrens Medical Center in Minneapolis, in affiliation with the University of Minnesota Medical School, might well undertake a key role in developing such a research center. (c) Rochester State Mental Hospital, with its close working relationship with the Mayo Medical complex, might also become a central research facility.

It is recommended that every effort be made to bring about the establishment of such a center. An ad hoc committee should be appointed by the governor to study carefully research centers which have been established in

other states under Public Law 88-164,* to unearth problems and procedures involved in setting up such an institute, particularly with regard to staffing, provision of tenure, and administrative and financial arrangements.

An effort should be made by the University of Minnesota or by the State to hire a key researcher who is dedicated to the cause of mental retardation and who is sufficiently distinguished to attract other researchers and funds in order to spark the development of a research center.

The research center should serve as: (a) A "base of operation" where, in addition to a permanent core staff, researchers who were pursuing for a time a problem related to mental retardation might come and go as dictated by the duration of their studies; (b) a central diagnostic facility, with a limited number of bed spaces; (c) an educational resource for the training of research and professional service personnel; (d) a focus for experimentation in the application of new findings and techniques; (e) an agent which would administer grant funds available for specific research projects and would obtain funds for necessary equipment and for payment of project personnel; (f) a locus for a central clearing-house.

2. A central clearing-house should be set up to accommodate all disciplines engaged in research. Failing the establishment of an institute as described above, the clearing-house function might be taken on by a designated State Department, a private agency such as the Minnesota Association for Retarded Children, the University of Minnesota, or a specially designated ongoing body such as the Mental Retardation Planning Council. The clearing-house would concern itself with all aspects of funding; coordination and communi-

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* Harvard Medical School is affiliated with two new centers--one at Walter E. Fernald State School at Waltham, Mass., the other at a Boston hospital. Other centers are being created at Children's Hospital, Cincinnati, Ohio; George Peabody College, Nashville, Tennessee; University of Washington, Seattle; Yeshiva University, New York City; Parsons State School, Parsons, Kansas together with the University of Kansas. A center is also proposed at University of Wisconsin.

cation among disciplines and with the lay public; securing of personnel and consultants for research projects; maintenance of a comprehensive library and index service, including a central registry of known cases; and other functions appropriate to the facilitation of research. A research coordinator should be appointed to ensure effective performance of the foregoing activities.

3. A permanent body is needed to coordinate future implementation of all mental retardation planning, including that related to research. This might be the Mental Retardation Planning Council. It might be an existing departmental structure which could be strengthened to assume this function. It might be a newly created structure which would be jointly administered by the Departments of Health, Education, and Welfare to parallel the Federal structure.

4. Regional evaluation centers, when established, should have a strong research orientation; these centers would also provide a nucleus of cases necessary to research activity. Federal funds are available for this purpose under Public Law 88-164.

5. A number of qualified persons must be recruited for research activities at institutions for the retarded (See Prevention, Diagnosis, and Treatment recommendations) and at other State facilities and agencies. Although it is recognized that elevation of standards of patient care in State institutions is uppermost and cannot be preempted by research activities, research should be a clearly designated function of State agencies and facilities, rather than a rarely realized luxury. High priority should be given to State institutions for requests for space and facilities for research projects.

6. Professional workers must be relieved as much as possible of administrative duties, so that they will have sufficient time and freedom to pursue research endeavors.

7. The State Department of Special Education should engage a full-time research coordinator to stimulate and further research activities and to disseminate

information concerning these activities.*

8. Funds should be provided by the State for "starter" grants to help initiate research projects and pilot studies by either beginning researchers or by experienced researchers whose direction is not yet completely clear. This kind of "seed money" is an excellent investment in promoting and encouraging research activity in the early, difficult phases.

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The four task force subcommittees have also set down a number of research questions which need to be explored in four major areas pertinent to understanding the mentally retarded—socio-cultural, psychological, educational, and bio-medical. Their ideas are by no means meant to be exhaustive, but rather suggestive of the kinds of problems which are as yet unexplored.

Socio-cultural Research

In the area of mental retardation, the urgency for socio-cultural research cannot be overemphasized. In an excellent report by the President's Panel Task Force on Behavioral and Social Research, the importance of research in the socio-cultural area is underscored:

> Our best estimate...is that of the five and one-half million retarded persons in the United States over four and one-half million have no known pathological anomalies. Since the great majority of mentally retarded persons present behavioral disabilities independent of demonstrable pathology of the central nervous system, behavior modification techniques are the only form of treatment or intervention available at this point in our knowledge. With this recognition, it becomes apparent that the behavioral and social sciences must become active

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* The Minnesota Department of Education made application in February, 1966 for Federal funds (P.L. 88-164) to support a pilot project establishing a research-demonstration unit in the Special Education Section. The project has been designed to (1) increase the level of understanding of research methods among special educators and the number and quality of research projects in public school settings, (2) integrate research findings and activities among various agencies and develop a system for disseminating these findings, and (3) help develop a pattern of interaction among local and State school personnel, university researchers, and personnel from other research-oriented agencies; and develop, where feasible, a format for use of highly trained researchers in local school systems.

participants and assume equal partnership with the biological sciences in research efforts which seek to discover more effective means of treatment, management, and, hopefully, of prevention.[56]

This is not, of course, to suggest that, of the roughly eighty per cent of the population labeled "retarded" with no known organic etiology, every member suffers exclusively from social or cultural disadvantage; but the probability seems extremely high that the great majority of that population has been deprived of the kinds of social stimulation and cultural experience that are necessary for rewarding participation in our society. (The question of why other similarly deprived persons are not labeled mentally retarded remains a fascinating and significant area for exploration.) Even in the case of those retarded whose difficulties may be traced to organic damage incurred in the peri-natal period or birth experience, considerable evidence is available[57] to demonstrate the greater frequency of such damage in low income groups and other disadvantaged segments of society.

The term "mental retardation" actually obscures much more than it reveals, for most of the unfortunates so labeled present a complex overlay of organic, psychiatric, and behavioral difficulties. Were we able to isolate the manifold sources of mental retardation, it is conceivable that we could distinguish two broad categories: (1) retardation presenting clear evidence of organic pathology—the "mentally defective"; and (2) retardation presenting no evidence of organic pathology, but strongly indicative of social or cultural disadvantage. Obviously, socio-cultural research focuses on the latter category.

If we express the extent of our research interests in the retarded child's social relations as a "circle of concern," we can see immediately that this circle

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56. President's Panel on Mental Retardation. Report of the Task Force on Behavioral and Social Research. March, 1964.

57. Masland, Richard L., Sarason, Seymour B., and Gladwin, Thomas. Mental Subnormality. Basic Books, New York, 1958.

enlarges in inverse proportion to the severity of retardation. When retardation is severe, the focus of the socio-cultural researcher is not so much the child, but others for whom the child presents a problem--the family, physicians, institutions, etc. When a child is "trainable," the circle expands to include research not only on the reception given to the retardate by his family, but also on his own relations with peers. With the "educable" child, we are very much concerned with his relation to the larger world including that whole network of social relations we call a community.

We present here only a few of the innumerable research problems in the socio-cultural area, in order to give a general impression of the kind of investigation which is sorely needed in an area that, until very recently, has been extremely neglected.

A. Prevalence and Incidence

We stand in great need of information about must how much "mental retardation" there is in Minnesota; where it is concentrated in the State, within regions of the State, and within metropolitan areas: in what social, economic, and cultural groupings it is over-represented. We need to know, especially, how the severity of retardation varies in such categories. After data on prevalence have been gathered and classified, we will be in a position to initiate studies to ascertain rates of retardation in, for example, different age groups of population.

B. Diagnosis

Urgent diagnostic problems confront every area of research on mental retardation. However, the role of socio-cultural research in diagnosis has been established only for a very short time. Specifically, social differences in modes of communication, as well as differential reception of "retardates" by people in different walks of life, are frequently interpreted as symptoms by professional people who have little or no knowledge

of socio-cultural variation in conduct. This is all the more the case, the less the severity of retardation. The pressing need for socio-cultural research on problems of diagnosis seems clear. An effort must be initiated immediately to separate from psychiatric and biochemical components those conventional experiential components of conduct that are ordinarily labeled "retarded."

C. Labeling

Although not all labeling is diagnosis, all diagnosis is labeling. We need to know how labeling a persons as "mentally retarded" (even silently, e.g., by singling him out for special attention in the school) influences his performance. Does labeling affect his abilities as a kind of "self-confirming prophecy"?

D. Imagery and Stereotyping

Probably one of the most important influences operating to impede socio-cultural research is the stereotype still maintained by many social and behavioral scientists that mental retardation is a wholly genetic phenomenon and, therefore, outside their fields of competence. Research must be undertaken precisely on the content of the imagery held by scientists, professionals, and laymen. Physicians, for example, are often traumatized at the delivery of a retarded infant and, with no assessment of the consequences, automatically recommend institutionalization. The sources and consequences of such imagery need extensive research.

E. Family

Far-reaching studies of family adaptation to retardation are called for. What are the consequences of retardation for family identity with relation to such concepts as the "bad seed" or the "wages of sin"? What, if anything, happens to the family's orientation to such cultural goals as success or mobility? Or, contrariwise, what happens to the retardate born into a

highly success-oriented family? Recent research[58] suggests that such children are institutionalized earlier and released later than children with similar degrees of retardation born into families with lower aspirations. We ought also to study families who have made successful adjustments to the presence of retarded children, emphasizing the positive aspects of coping with the problem.

F. Careers

The less severe the degree of retardation, the more fruitful it is to consider it as a process rather than a condition. Like any other social identity, "retardate" implies a career, or particular sequence of life-experiences.[59] There is an initiation, a maintenance phase, and a termination. Precisely under what circumstances is an individual initiated into his identify as "retardate"? How is he institutionalized? Here, there may well operate, as in the case of the mentally ill, a "betrayal funnel"[60] through which a person is channeled into an institution. Are the consequences for the progress of the person so committed greater, the older he is at commitment? What is the nature of the institutional discharge process? What are the norms by which the staff defines a resident as "good" or well-adjusted, therefore, ready for release? Do these parallel the norms which prevail in mental hospitals? Again, in the case of retardates who are not institutionalized, many "terminate their identities" (or at least lose them) after school age. What happens to such people? What new identities do

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58. Mercer, Jane R. "Social System Perspective and Clinical Perspective: Frames of Reference for Understanding Career Patterns of Persons Labeled as Mentally Retarded." Social Problems, XIII (Summer, 1965). p. 18-34.

59. Goffman, Erving. Asylums. Doubleday Anchor Books, Garden City, 1961.

60. Ibid., "The Moral Career of the Mental Patient."

they assume? How severely has the stigma of retardation affected their subsequent social participation and personal well-being?

G. Institutions

Is there a stratification of institutions in Minnesota in terms of desirability or reputation? If so, which institutions are considered more or less desirable? Why? By whom? What are the consequences for resident care and progress? There has been a long-standing awareness of the difficulty of recruiting quality personnel in State institutions generally. How does this affect institutions for the retarded? What are the primary incentives which do operate to recruit personnel? Do these affect the organization and administration of institutions?

Psychological Research

A psychological emphasis in research may be considered as one which aims at the identification and exploration of significant dimensions of individual function. Any of the traditional areas of psychological research--for example, studies of perception, memory, learning, childhood development--are appropriate to furthering our understanding of the phenomena of retardation and of the retarded individual. Psychological interest in the functioning individual, however, has increasingly widened to include the interplay of the individual with his milieu. As understanding of the complexity of interaction of individual and situational characteristics grows, traditional approaches to the problem at hand are often found wanting, and the need for research which can lead to new methods of dealing with this interaction is seen as urgent.

A. Psychological Evaluation

The familiar field of intelligence testing serves as an example of the major area of psychological assessment. Until recent years it was possible to think of intelligence as a property of the individual, roughly comparable with eye color. Psychologists (and others) might say "His I.Q. is 61," as if

"I.Q." were something present in the person, rather than a test score; and decisions about the person "having" this property could follow (as witness regulations enacted permitting commitment of people "having I.Q.'s" of 69 but not 71, or barring from special classes those "having I.Q.'s" above or below other such points).

Our present national concern with cultural deprivation as a limiting factor on individual development speaks clearly enough of our shift from the "individual property" concept of what are, indeed, individual characteristics to concern with the interaction of individual and situational characteristics. It is also evident that the changed concept requires more than a changed interpretation of old methods; it requires research to develop new methods and tools both in order that significant dimensions of function may be more clearly identified and described, and in order that greater confidence may be put in assessments of individuals and in the decisions based on them. In addition, the numerous psychological techniques for assessment (e.g., of correlates of brain disorder or damage) require further investigation to establish their contribution to diagnosis.

B. Treatment and Habilitation

In addition to assessment, a major concern of psychologists in regard to the retarded is that of "treatment," or attempts to maximize individual effectiveness, social acceptability, and personal experience of life. Here, as in the educational area, there has been recent impetus to analyze the tasks with which a person is confronted into their significant components and sequences, and to manipulate these in such a way as to enhance mastery. Treatment programs which attempt such application to some of the massive care problems of the institutionalized retarded are only in their initial exploratory stages. These early attempts offer hope that some of the sorest handicaps among the institutionalized retarded may be alleviated; such basic

functions as toileting and dressing and other self-care habits may be brought under the control of many who are otherwise chronically dependent on others for care in these regards. Extensive research support is not only needed if this promising area is to be pursued, but seems clearly warranted.

C. Prevention

Closely related to the area of treatment or behavior modification is research to elucidate what modifiable social situations or events damage the self-concept of the retarded individual and circumscribe his activity-sphere. The aim here would be prevention of disabilities and hardships which are often found in relation to retardation, but are not features of the initial handicap. Within the important area of community adjustment, numerous questions demand investigation: How freely does the retarded person move about in his community and make use of its resources? How does he come to know of those resources? And what obstacles does he meet in attempting to avail himself of its recreational, educational, religious and other facilities? What about these resources makes them either available to him, and rewarding, or inaccessible or thwarting? Here, the close relation of psychological research with other areas is evident: processes of "case-finding," paths to commitment or labeling need to be studied not only in their socio-cultural dimensions but in their impact on the experiencing individual; the biomedical areas of diagnosis and genetics counseling, similarly, hold many implications requiring elucidation.

D. Longitudinal Studies

Whatever the problem addressed in psychological research, a long-standing need has been for longitudinal studies, which have never been sufficient in number or variety. Many questions must remain inadequately answered until observations can be repeated over extended periods of time. Need for extended contact with the retarded by research personnel speaks partly of the

desirability of encouraging service organizations of all kinds (sheltered workshops, institutions, school systems) to support research as a basic part of their program. Through extended observation in these settings, the psychological researcher may be enabled to improve systems of selection for available programs, and to further analyze salient program dimensions in their significance for the retardates involved.

Educational Research*

The report of the task force on Behavioral and Social Research of the President's Panel describes succintly the state of affairs in educational research concerning mental retardation: "Research on educational practices has been sporadic, short-term in nature and inadequate in many other respects." [61] There is little sense in dwelling on the mistakes or shortcomings of the past. The best hope lies in trying to identify present and future needs and embarking on a program to fulfill them.

Since countless recommendations for educational research could be made, it makes the best sense to focus on several broad areas of research and within these areas to suggest some specific research problems.

A. Educational Procedures. At present, educational procedures, including educational placement, curriculum development, teaching methods, and skill development, are based mainly on subjective experience and untested assumptions rather than on research. That research which has been done has, to a great extent, been plagued by methodological problems which have often invalidated results.

1. Placement. The most that can be said for the few studies on placement

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* Our thanks to Dr. Charlotte Podolsky for her help in writing this section of the report.

61. President's Panel on Mental Retardation. Report of the Task Force on Behavioral and Social Research. March, 1964. p. 41

is that the results have been inconclusive. Not a single study has demonstrated that special class placement is more effective than regular class placement when the criterion of effectiveness is achievement. In fact, three of the four studies which used academic achievement as a criterion found regular class retardates to be superior. On the other hand, the results of teacher ratings and personality questionnaires seem to indicate that special class retardates had better social adjustment than retardates who remained in the regular class. However, it is important to point out that because of sampling problems (i.e., subjects in studies referred to above represent a very biased sample) and other methodological difficulities, special class placement has not received an adequate evaluation. Only well controlled studies of a longitudinal nature will give us the empirical evidence we need.

In addition to studying the effectiveness of special class placement, there is a need to identify variables which might interact with types of placement to result in a higher level of performance on the part of the child. Therefore, teacher and pupil characteristics should be studied systematically to determine whether certain kinds of teachers are more effective in special classes and whether special classes are more effective for some children than for others.

Related to these questions is one that asks how effective are pre-school programs for the educable mentally retarded. There is some evidence to indicate they are valuable. If so, we need additional studies to discover just which type of enriching pre-school experience pays off best.[62]

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62. President's Panel on Mental Retardation. Report of the Task Force on Behavioral and Social Research. March, 1964. p. 41

2. Curriculum and Method. Since curriculum and method are so closely related, they will be presented together. Today most educators of the mentally retarded agree that a curriculum must consider two main areas: (1) development of skills in the "tool" subjects, and (2) experiences in the area of living.[63] They disagree, however, on the emphasis these areas should get. Some emphasize the first area and pattern a curriculum after an elementary school program. Some emphasize activities or units of experience. And some try to strike a happy medium. However, no one has empirically tested the relative effectiveness of these approaches, particularly in terms of the criteria of occupational adequacy, personal adequacy, and social competency.

If occupational and personal adequacy and social competency are the ultimate goals in the educational program for retardates, then educational researchers should be asking themselves if the various curricula are, in fact, fulfilling those goals. Time and experience have tested some of the standard curriculum practices, but despite progress, much needs to be done. Examples include: what curriculum content leads to the best post-school adjustment? What kinds of work study programs best prepare retardates for employment? How can a retardate best be taught the necessary skills and attributes for adequate job performance? What curriculum emphasis results in greater academic achievement? In more adequate personal and social adjustment?

A knowledge of the learning characteristics of the retardate would have important implications for both curriculum and method. At present much of educational practice is based on conflicting opinions concerning

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63. Kirk, S. A. & Johnson, O. G. Educating the Retarded Child. Houghton Mifflin, Boston, 1951.

whether or not retardates are quantitatively or qualitatively different from normals. The research in basic learning theory has yielded conflicting results. Therefore, there is a need for more extensive and better integrated investigations to make possible a more complete description of the learning characteristics of the retarded. If this were available, educational practice (curriculum and method) should be influenced.

It would also be extremely useful if some of the results of recent laboratory studies on the learning characteristics of the retarded could be tested in the classroom. In other words, we have to examine the conditions under which and the context within which laboratory findings can be applied in order to facilitate classroom learning.

It is unrealistic to talk about curriculum practices without also being concerned with the methods used to impart the content. We ought to find out through well controlled studies what methods are most effective and with what kinds of children. At present, methods advocated by most special educators are based on speculation. For example, the research on methods of teaching reading to the retarded has not clearly demonstrated the superiority of one method over another. Nor are we clear on what is the best age to begin reading instructions, what are the best materials to use, how effective are teaching machines as a method of teaching reading or any other skill subject.

Systematic research on the teaching of arithmetic is also needed. Generally, studies indicate that retardates achieve at a higher level on the more mechanical, computational skills than on reasoning problems. It has been suggested that this discrepancy probably reflects the methods of teaching arithmetic in classes since it is easier to drill on computational skills than to develop quantitative concepts.[64] Thus, the study

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64. Stevens, H. A. & Heber, R. (Eds.) Mental Retardation - A Review of Research. University of Chicago Press, Chicago, 1964.

of instructional procedures to develop the quantitative thinking ability of mentally retarded children represents a specific area of needed research.

Studies examining the methods of instruction and the development of skills in other areas of the curriculum (music, art, physical education, social studies, etc.) have also been sporadic and discrete. Textbooks, workbooks, and other aids used in teaching content also need to be systematically evaluated.

B. Professional Preparation. Educational researchers ought to be concerned with the selection and training of teachers. We are training more and more teachers of the mentally retarded, but we have no clear-cut evidence as to how to train them or what students develop into the most successful teachers. The same questions should be raised and answered for the training and selection of other professionals who work with retardates.

C. Translation of Basic Research. Basic research in learning, motivation, and personality needs to be translated in educational settings so as to test hypotheses. Current theory and practice in behavior modification ought to be applied in broader terms and in more varied settings. For the most part, the principles of behavior modification have been utilized with institutionalized retardates in hospital settings. And even the research with institutionalized subjects in school settings has been unrealistic. There have been as many experimenters and assistants as there have been children. We ought to find out if the current techniques of modifying behavior by carefully planned schedules or reinforcement are useful in the classroom, and, if they are, how the teacher can be trained to use them.

Bio-medical Research

Research into the causation of any illness or abnormality is a major key to its prevention. According to Masland, a "definite neurological disease" can

be deduced as etiological agent in 25 to 50 per cent of cases of mental retardation.[65] Tarjan states, more conservatively, that with present knowledge it is possible to identify causes in approximately 15 to 25 per cent of cases of mental retardation.[66] In cases of so-called "undifferentiated mental retardation" (mostly with an I.Q. above 50) multiple factors--biological, psychological and socio-cultural--are presumed to be operational and need much more research.

Biomedical research may be divided into three areas: psychiatry; biomedicine; and community health.

A. Psychiatry.

1. How can the physician improve his ability to differentiate those individuals with pure intellectual deficiency from those with severe emotional illness? Clearer points of differentiation between these areas of affliction should be developed, particularly when evaluating young children.

2. What is the etiological connection between childhood autism and mental retardation? Detailed studies are needed of the factors involved and their interplay, e.g., personality of the child, his parents, ancestry, family structure, prenatal influences, genetics, and possible organic involvement.

3. A clearer distinction must be drawn between mental retardation subsequent to childhood autism and a psychosis superimposed on mental retardation. What are the operational factors in the latter case? Are they similar, qualitatively and quantitatively, to those in persons with

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65. Masland, Richard L. Research Profile No. 5: Summary of Progress in Mental Retardation. U.S. Dept. of Health, Education and Welfare. November, 1963. p. 1.

66. Tarjan, George. In Mental Retardation, A Handbook for the Primary Physician. Report of the A.M.A. Conference on Mental Retardation, Chicago, April 9, 1964.

"normal" intelligence?

4. What factors should guide professional decisions regarding institutionalization of the retarded? Consideration has to be given to the effect of community stereotyping, the total family situation, personality of the affected child, stage of development and learning, and adjustment problems in the institution. Studies of these problems have been published but many more factual data are needed. A clear outline and guidance manual should be developed.

5. Numerous definite factors are known which can damage fetal brain development during pregnancy and cause mental retardation (German measles, syphilis, toxoplasmosis, x-ray and atomic irradiation, thyroid deficiencies, vitamin deficiency, smoking, drugs). The question of possible association between maternal emotional stress and improper development of the central nervous system of the fetus should be explored.

6. What are the correlates between the various psychological interpretations of "organic brain damage" and objective findings in the individual history, neurological examination, electroencephalogram, and brain pathology?

B. Biomedicine.

1. Genetics

a. Families of the mentally retarded should be studied genetically, in order to identify carriers, to seek out other characteristics associated with the gene, and to give meaningful genetic counseling to the afflicted families. Many such studies have been done for galactosemia and phenylketonuria.

b. Since the chromosome break-through in Down's Syndrome (mongolism), several chromosomal abnormalities associated with mental retardation

have been recognized. Survey studies for chromosomal abnormalities and dermatoglyphics in mental retardation are currently being conducted and will be continued at Faribault State School and Hospital and the University of Minnesota.

2. Etiology and Diagnosis

a. There must be continued search for physical and laboratory evidences which might be the earliest indicators of possible sub-normal central nervous system function. Even as such research continues, the publication and wide dissemination to a variety of health workers of such suspicious or pathognomonic signs would be helpful.

b. In 1934 phenylketonuria was described by Folling as the first metabolic defect associated with mental retardation. During the next thirty years this defect of aminoacid metabolism was thoroughly studied in its genetic, biochemical, clinical, and neuro-physiological aspects. Though comparatively rare (1:10,000 new born), it has become the prototype for research in related fields. More than twenty different types of biochemical defects causing mental retardation have been described. There must be continued search for biochemical defects associated with mental retardation and constant search for clinical methods offsetting their deleterious effects.

c. Intensive review should be made of retarded individuals' records for the past ten years from a major diagnostic center such as the University of Minnesota or Mayo Clinic, where comprehensive evaluations have been made and definitive diagnoses established.

Multidiscipline teams should make complete evaluations of retarded individuals in institutions in order to discover new approaches to treatment, to obtain valuable information concerning the multiply handicapped, etc. A system should be designed to facilitate retrieval

of any component of the complete history, evaluation, and classification. A comprehensive and continuing patient census project by addressograph system has recently been initiated at Faribault State School and Hospital under the Federal Hospital Improvement Program.

3. Neurology and Neuropathology

There is an almost limitless list of possible studies which would aim at identifying factors which might cause improper development of the central nervous system during the segment of the life cycle from conception to birth. Specific problems are under study within the framework of the nationwide Collaborative Perinatal Study, in which various departments at the University of Minnesota are participating.

C. Community Health.

1. In reviewing retarded individuals' records (see 2. c), the following questions should be investigated:

a. When the condition was first suspected, what was done? How might the individual and family have benefited by earlier comprehensive evaluation? What help came from the community and what help might have been sought? What was the disposition and advice at the time the diagnosis was made?

b. The same families should be located to determine whether the retarded member is receiving regular health supervision and appropriate community services, whether he lives with his family, how his present level of functioning coincides with prognostications and, if not, the reason for the discrepancy.

2. Families who have had genetic counseling should be reviewed. Are they better informed, better adjusted? What did genetic counseling mean to them?

3. Attitudes of parents of mentally retarded children toward bearing fur-

ther children. What are the influences on such decisions?

4. Attitudes of Minnesota physicians about working with retarded children and their families should be accurately assessed.

5. Medical schools should be surveyed for content and methods of teaching about intellectual handicaps.

6. What is the nature of the path from the community to the institution? Can it be traversed in both directions?

7. Do home communities maintain relationships with institutionalized patients? By what mechanisms?

8. As Project Head Start broadens to include the younger pre-school age child, more complete health evaluations should be made as a valuable source of information concerning this population. This might be accomplished by a special project setting up teams to perform such evaluations.

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It will be apparent that in many instances each of the four sub-committee reports echoes the ideas of the others with regard to fruitful areas for investigation. The parallel directions of research in the diverse disciplines attests to the fact that mental retardation must be understood, not as an entity, but as the "interplay of the individual with his milieu." Multidisciplinary research does not necessarily involve working as a member of a team, but it may mean working side by side so as to be able frequently to look over the shoulder of a fellow-investigator from another field. The value of such symbiosis cannot be overestimated.

X. PUBLIC AWARENESS

If we are to accomplish our aims in bringing about desired changes in the care and acceptance of the mentally retarded in Minnesota, we must stimulate that heightened public awareness which almost always precedes effective social action. In the words of the American Association on Mental Deficency:

> Broad public awareness, understanding, and acceptance of mental retardation and its many personal and social implications are essential features of a community and state program for the retarded...First, without a recognition and acceptance of the needs of the retarded by at least a substantial part of the community, programs will not be provided...Second, if the retarded are to obtain community adjustment, a wide segment of the community must understand the nature of the difficulties which the retarded face and assume an understanding and accepting attitude...
>
> A misinformed public...can drastically reduce the effectiveness of an enlightened scientific program of training and education...
>
> Not only is there a need to inform the lay public about the nature of mental retardation, but, perhaps more important, the professional elements must become better informed. Public attitude as a whole suffers unduly when those persons whose work brings them in contact with the retarded person and his family are poorly informed as to the essential facts of mental retardation and modern thinking as to what can be done to lessen the handicap. The physician, social worker, educator, lawyer, psychologist, nurse, clergy, all must know mental retardation and have an intimate knowledge of community resources available to the retarded.[67]

The President's Panel states emphatically that educating the public

> is vital to any real progress in every aspect of the retardation problem because public awareness plays a key role in helping to shape the attitudes of legislators and potential workers in the field, as well as helping to stimulate community support and financial backing for the needed expansion and improvements necessary in a wide variety of programs.

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67. Gardner, William I. and Nisonger, Herschel W. A Manual on Program Development in Mental Retardation. Monograph Supplement to the American Journal of Mental Deficiency. Volume 66, No. 4, January 1962

However, the Panel report also points out that a huge task confronts us in

> filling the needs of various professional groups for information and educational materials, and preparing and disseminating more general material for the benefit of special groups and lay publics.[68]

Part of this task is being performed nationally by the National Association for Retarded Children, the American Association on Mental Deficiency, the Council on Exceptional Children, and the United States Department of Health, Education, and Welfare. During 1965 and 1966, the major health campaign conducted by the Advertising Council of America has focused on mental retardation: The campaign is sponsored jointly by the Department of Health, Education, and Welfare and the Joseph P. Kennedy, Jr. Foundation, with extensive support and implementation by the National Association for Retarded Children.

On the State level, the Minnesota Association for Retarded Children has assumed a major responsibility for public education, working through its field representatives, local chapters, and the printed word. The Department of Public Welfare has been active and is becoming more so. The Jaycees, Mrs. Jaycees, and United Commercial Travelers have each taken mental retardation as a major project for the year. Local groups which concentrate considerable effort and resources on helping the mentally retarded in Minnesota are Civitan, Veterans of Foreign Wars auxiliary, American Legion auxiliary, and Epsilon Sigma Alpha philanthropic sorority.

Nevertheless we have only scratched the surface. Many people are not even certain about what mental retardation is.

> The American public seems to lump all the mentally retarded into one commonly held stereotype: the person with absolutely not one whit of intelligence. Even the slightly retarded are thought of in this manner.[69]

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68. President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. October, 1962. p. 157-8

69. From an attitude study by Dorly D. Wang, sponsored by Woods School, Langhorne, Pennsylvania. In Newsletter. President's Committee on the Mentally Handicapped. January, 1963.

> Intensive public information and re-education is needed before the negative failure stereotype concept of mental retardation is eradicated and the new positive hopeful approach is substituted. This will involve a public awareness of the new dimensions of mental retardation as a fluid, relative concept, rather than as a static, immutable one. 70

A 1962 survey of public information and attitudes of 900 Minnesotans, sponsored by the Minnesota Association for Retarded Children, revealed that the public in general has a very limited understanding of mental retardation. Only one person in ten demonstrated "specialized" information about retardation, while one-fifth of the respondents confused retardation with a variety of other mental and physical disorders. Slightly less than half believed that the retarded are also mentally ill. Further, many respondents harbored misconceptions about the causes of mental retardation (e.g., 28 per cent cited external conditions such as "sinful living","too much worry", etc.) and had little, if any, information about physical and mental capabilities of retardates. Even those who were able to relate mental retardation to some kind of mental deficit displayed superficial knowledge which indicated "misunderstandings or vague suppositions". Nearly one-third of the people sampled could not identify a single State or local service for the retarded. Yet about seven out of ten objected to the idea of caring for the retarded at home.

On the professional level, the situation is often little better. Consider these statements about three key professional groups:

> Communicating information to the <u>practicing physician</u> is not...simple... Any educational effort faces the built-in resistance of many physicians, both because of their pessimistic attitude toward the disease in general and because of the personal feelings of anxiety and guilt such patients may arouse. 71

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70. President's Panel on Mental Retardation. <u>Report of the Task Force on Education and Rehabilitation</u>. August. 1963. p. 24

71. <u>Mental Retardation, A Handbook for the Primary Physician</u>. Report of the American Medical Association Conference on Mental Retardation. Chicago, April 9-11, 1964. p. 152

> Employers with the highest levels of education tended to have the least favorable opinions of the job abilities of the retarded. The amount of factual knowledge employers had of mental retardation seemed to have little bearing on their attitudes toward the retarded. Somehow employers have to be made to feel that the retarded can work, and work well.[72]

> The shortage of adequately trained teachers is a major deterrent to the expansion of programs for the retarded. Colleges training such persons report 10-20 positions available per graduate. At least 50,000 new teachers are needed. Three out of four retarded children are not in special classes due in part to lack of adequately trained teachers.[73]

It is not surprising, then, that the task force on Public Awareness decided to operate on two assumptions: (1) efforts to inform the public, or specific publics, about mental retardation up until now have been largely unsuccessful, and (2) development of effective methods of communication would be the major task.

Members felt that it was desirable to prepare as specific and detailed a plan as possible, with clearly stated directions on how to translate the plan into action.

It was also decided that, while it is certainly important to reach "the people", task force efforts should center on specific professional publics. This decision was predicated on unanimous agreement with the President's Panel that "intensive indoctrination for specific professional personnel would lay a broad base for future public education in this area." Further, voluminous public opinion research supports the notion that

> It is a common mistake to think of the Public as one massive, monolithic assemblage. No money-spending, vote-casting, good-buying unit of more than 100 million adult Americans waits as one vast audience to be molded into 'public opinion'. We the People consist of many publics, of many kindred interest groups, and of unorganized groups with like and unlike preferences...[74]

Accordingly, a tentative list of key professional "priority publics"

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72. From an attitude study by Dr. Julius S. Cohen, Syracuse University. In Newsletter. President's Committee on Mentally Handicapped. September, 1963.

73. National Association for Retarded Children. "Make Teaching Retarded Children Your Career." (Pamphlet).

74. Cutlip, Scott N. and Center, Allen H. Effective Public Relations. Prentice-Hall, 1964. p. 66

was drawn up as follows:

1. Physicians
2. Clergymen
3. Employers and labor representatives
4. Teachers of teachers
5. Teachers
6. Teachers of psychologists, social workers, and other menbers of service professions
7. School superintendents and administrators
8. School boards
9. Public Health Nurses
10. Public officials
11. Lawyers and judges
12. Church groups throughout the State
13. Homemaker clubs
14. Parents not being reached
15. Volunteers
16. Non-white minority group representatives
17. Mass media

It was decided that the best way to canvass professional publics would be through a series of information workshops where representatives of the various publics would share their ideas with the Public Awareness committee in a round table disucssion. Task force members hoped, in this way, to find out from each of the key publics what kinds of information they need or wish to have; the effectiveness of public education, past or present, in getting the message to them; what role they can play in evolving messages and methods; how we might best help them. It is evident that this type of involvement is in itself a potent way to foster awareness and interest in mental retardation. (The effect of "influentials" in molding opinion within their groups has been well documented in public opinion research, including the Minnesota Association for Retarded Children attitude survey mentioned above.)

Because of their obviously central role in caring for the mentally retarded person and his family, physicians were designated as the first key public. Workshops were also held with school superintendents, clergymen, employers, and "teachers of teachers". In each instance, a wide range of interests and problems was presented. It was clear that the need for information is overwhelming. On-

the-spot mutual education was accomplished through an exchange of ideas which also resulted in a rich pool of recommendations. The workshops will be continued throughout the implementation period.

The recommendations which grew out of them are as follows:

Public Awareness Recommendations

1. Physicians

   a. Regional diagnostic facilities should function as repositories for information concerning (1) mental retardation in general and (2) referral resources in the community. County medical society offices should likewise be utilized in this manner.

   b. Medical schools should stress the process of normal growth and development, as well as significant deviations from the norm, in undergraduate and post-graduate courses. If structured along biochemical, genetic, or other such specific lines of inquiry, post-graduate programs dealing with mental retardation may be more effective in attracting intelligent, scientifically-oriented young people into the field.

   c. Regional diagnostic centers should coordinate the necessary network of communication among doctors, parents, teachers, psychologists, and social workers, to relieve the physician of the often formidable obstacle of trying to keep in touch with all of the persons involved in a diagnostic workup.

   d. A questionnaire which would suggest to parents the "right" questions to ask a doctor would facilitate parent counseling for both parent and physician.

   e. Local Associations for Retarded Children should play an important role in effecting communication between physicians and parents.

   f. A Statewide mailing should be sent to those Minnesota physicians whose

work might be expected to bring them in contact with the mentally retarded and their families, e.g., general practitioners, pediatricians, etc. Such a mailing might include the recent American Medical Association Handbook entitled Mental Retardation, a comprehensive list of community resources, and a compilation of standards of normal growth and development. Alternatively these materials could be distributed at appropriate county or State medical society meetings.

2. School Administrators

a. Schools should make use of local newspapers to publicize and promote special education. Stories and pictures should concentrate on improvement in abilities of various children who are enrolled in special classes.

b. School newspapers and bulletins published by elementary schools should devote space to special class activities.

c. The State Department of Education should employ additional consultants to inform, promote, and advise regarding special education classes in all regions of the State.

d. Elementary principals, guidance counselors, psychologists, and parents were identified as effective pressure groups whose aid should be enlisted in bringing to the attention of school superintendents the desirability of special education programs and increased psychological services.

e. In-service training programs for school faculty and administrators should be widely promoted by State special education consultants; educational television should be utilized to reach a wider audience of school personnel.

f. The Department of Educational Administration at the University of Minnesota should be requested to include information pertaining to special education in their curriculum. Other groups who would also benefit from exposure to this information are teachers of non-academic subjects and

directors of secondary education.

g. The editors of the Minnesota Education Association Journal should be contacted and requested to devote regular space to issues relating to special education.

3. Clergy

a. Seminary training should include clinical experience with mentally retarded patients and course material which deals with problems of the retarded and their families.

b. Programs of religious instruction for the retarded should be developed by churches and religious organizations, on an interdenominational basis whenever feasible.

c. Short-term workshops on mental retardation should be planned for clergymen throughout the State. These might take various forms: (1) Three or four day sessions at the State institutions for the retarded. These would include ward visits and presentation of clinical material. (2) A series of two or three hour luncheon meetings, possibly as part of the curriculum of the United Theological Seminary. (3) All-day interfaith meetings comparable to the one sponsored this year by the Missouri Synod of the Lutheran Church. (4) Bus tours to the State institutions for both clergymen and congregation.

d. Directories of community referral resources should be distributed to clergymen.

e. Clergymen should offer informed counsel to parents and other lay persons about mental retardation.

f. The clergy should avail itself of its unique opportunity to educate, inform, and foster rapport with families of the handicapped through the medium of sympathetic and knowledgeable sermons.

g. Clergymen should actively encourage their congregations to participate as

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STATE OF MINNESOTA

volunteers in religious education and other activities geared for the retarded.

h. Articles on mental retardation written for clergymen, by clergymen, should be placed in key religious periodicals.

i. Simple publications about mental retardation, written clearly in words easily understood by laymen, should be gathered together and disseminated to clergymen throughout the State. Ideally such materials should be available at the workshops mentioned in (c) above.

4. Employers

a. The new National Association for Retarded Children motion picture, "Selling One Guy Named Larry", should be widely shown to service clubs, professional organizations, business and industrial groups, unions, management organizations, personnel managers, and supervisors in business and industry. Screening should be accomplained by a brief discussion and distribution of explanatory printed materials. An attempt should be made to arrange for television viewing as well.

b. Communication with employers should be channeled through the Division of Vocational Rehabilitation and the school rehabilitation coordinators.

c. Verification and confirmation of retarded employees' success, as described by satisfied employers, should be exploited as the best advertisement for employing the retarded.

d. The State's leadership in providing a special Civil Service classification for retarded persons should be publicized as a model.

5. Teachers of Teachers

a. The Department of Public Welfare is preparing a packet of supplementary curriculum materials about mental retardation suitable for high school and college teachers. It is important that this packet receive wide distribution and promotion.

b. Community resource directories of the Department of Public Welfare and Education, which are valuable sources of referral information, should be widely distributed to teachers and to teachers of teachers.

c. Colleges should consider sharing staff in order to remedy the shortage of persons qualified to teach courses on exceptional children.

d. A series of seminars for "teachers of teachers", taught by teachers and other professionals who are currently working with the retarded, should be planned.

e. It is the ethical responsibility of teachers of teachers to sensitize students to the need for special teachers. Students who are preparing to become teachers of normal children should be educated concerning the retarded child. Those who express an interest in special educational should be encouraged to consider the possibility of graduate training. Direct student contact with handicapped persons and community resources will foster involvement and may often have to substitute for specific courses on the exceptional child, because of the dearth of persons qualified to teach such courses at an undergraduate level.

f. Directors of volunteer programs should seek out high school and college students as a means of fostering involvement and interest.

g. Volunteer programs at colleges and universities should include service at the State institutions for the retarded. Similar programs should be planned in which volunteers would work with educable retarded in the Twin City area.

h. Student volunteer groups might meet with mental retardation experts in campus workshops.

i. The Student National Education Association and other college civic and religious organizations should be utilized as focal points for stimulating student involvement.

j. Department of Public Welfare bus tours to institutions for retarded should be planned for students and educators. Such trips should also include Twin City facilities, such as special classes, day care centers, residential facilities, etc.

k. A one sheet bibliography of books and pamphlets about mental retardation should be prepared for teachers and distributed statewide.

l. Library lists for high schools and colleges should be prepared by competent authorities and distributed for student use.

m. Films on mental retardation should be widely used in high school and college classrooms. Annotated lists of available films on mental retardation should be sent to teachers of teachers.

n. A recruiting film should be created by the State Department of Special Education.

XI. LAW

This summary of the activities of the task force on Law is in the nature of an interim report, since the work of the task force will be continued during the two year implementation period.

A major effort was involved in the compiling of all existing State laws pertaining to the mentally retarded, together with pertinent court decisions and opinions of the attorney-general. This time-consuming work was accomplished under the supervision of Robert Levy, Ll.B., professor of law at the University of Minnesota and Vice-Chairman of the task force, and was financed with mental retardation planning grant funds. The task force will study these laws, develop position papers on various aspects of the law, and recommend draft legislation to appropriate State departments for submission to the legislature.

Proposed legislation has already been drafted to change the distribution of cost of residential care between county and State, so that the State would assume 100 per cent of the cost of care regardless of whether the individual is placed in a State or in a private residential facility. (See Residential Care task force report.)

In April, 1965, Mr. Levy published in the Minnesota Law Review (Volume 49, Number 5) an article entitled "Protecting the Mentally Retarded: An Empirical Survey and Evaluation of the Establishment of State Guardianship in Minnesota". This article is a portion of a comprehensive study which Mr. Levy has recently completed. The project office distributed copies of the entire study to probate judges and county welfare executives throughout Minnesota, as well as to the Planning Council.

Suggested changes in commitment and guardianship laws are being carefully studied by the task force as well as by the Mental Health Planning Council and the Minnesota Bar Association. Governor Rolvaag has appointed a task force member,

the Honorable Harold Schultz, Judge of the Second District Court of St. Paul, as his consultant in matters concerning possible revisions or amendments of Minnesota's commitment and guardianship laws.

A quantity of information has been gathered regarding the so-called "defective delinquent." Professional literature on the subject has been thoroughly surveyed, other states have been queried as to their handling of the mentally retarded delinquent, and many involved and informed persons in State and local Departments of Welfare and Corrections in Minnesota have been interviewed at length. One of the responsibilities of the Law task force during the implementation period will be to review and discuss this wealth of material in order to make recommendations as to how Minnesota can best cope with the problem.

Appendix A

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Appendix B

SURVEY OF RETARDED PERSONS IN MINNESOTA
November, 1964

Basic to definitive State planning are data on retarded persons--number, age, degree of retardation, and place of residence. In an attempt to secure this information in Minnesota and to gain insight into data-keeping problems, the questionnaire which appears on pages 197 & 198 was sent to all County Welfare executives. Information was also obtained from the State Department of Education and Division of Vocational Rehabilitation.

Our thought was that county welfare departments would know about the majority of the retarded population at large and probably about all of those in residential care facilities. The State Department of Education is aware of another large segment of the retarded population which is included in special classes and vocational rehabilitation caseloads. Many others are known to none except their parents.

Seventy-three of the eighty-seven county welfare directors responded. * Data are tabulated in original form. Not all questionnaires were completely filled out, and in many instances totals were inconsistent.

The many discrepancies encountered in compiling and tabulating the data probably invalidate the results. However, the survey is published to illustrate the need for refinement of our record-keeping procedures. The information it contains may be used only if carefully qualified.

Some of the requested items, notably the intelligence test scores, are not kept routinely in family reporting systems. Individual caseworkers had to make time-consuming hand counts of their caseloads in order to provide us with data.

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* Those counties which did not respond were: Benton, Blue Earth, Clearwater, Cottonwood, Jackson, Morrison, Olmsted, Rice, Sherburne, Stearns, Steele, Todd, Watonwan, and Wright.

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In Hennepin County, the large number of cases prohibited doing this. The State Department of Public Welfare does keep child welfare statistics for Hennepin County, but not by the categories necessary for planning. Their figures are presented separately from those for the balance of the State.

School districts report much of the requested information to the State Department of Education. Because the Department does not keep data in a central location or in a conveniently retrievable form, a volunteer spent many hours tabulating from the raw statistics supplied. Addresses do not always identify county of residence nor indicate whether persons are residing in boarding homes, their own homes, or other facilities. School districts often transcend county lines, making an unduplicated count impossible.

Division of Vocational Rehabilitation records are not kept according to degree of handicap, and there are always questions about whether retardation is the primary or secondary handicap. Counselors have persons coming and going in their caseloads who are retarded at one time but who after rehabilitation assume their places in society and are no longer so identified. As of February 28, 1965, there were 513 mentally retarded persons over age 16 in Division of Vocational Rehabilitation active caseloads.

The items at the bottom of the questionnaire were asked only of welfare directors. Answers ranged from "I don't know what you mean" to several pages of thoughtful comment. Although many answers were repeated by a number of respondents, the tabulation disclosed a great variety of responses.

The problems of definition and methods of diagnosis are forcefully called to attention by the answers to questions 1 and 3. A host of other issues are pinpointed in the balance of the replies.

It would not appear to be difficult to develop a data-keeping system useful for State planning. Information is available but is structured for individual department use so far as data processing is concerned. With a few additions to

present reporting systems, periodic checks could be made of known retardates in the State.

* * * * * *

1. <u>What does your agency use as a working definition of retardation?</u>

Definition found in Subdivision 6 of 525.749, Minnesota statutes.

If (the person) is lacking intellectual development that is associated with or the basis of personal and social inadequacy.

If child cannot do regular school work.

Any person who is so diagnosed by recognized authority.

Below normal I.Q. (from psychological tests) and unable to attend school classes.

I.Q. under 80.

A person who functions at an intellectual level below that of the average person.

I.Q. under 90.

I.Q. of 70 or lower.

State psychologist's definition, as determined by exams.

Referral from the physician in ability to keep up with school work, parent's statements and psychological tests.

Official disorder with commitment or institutionalization.

Educable and below.

Condition meaning impaired or incomplete mental development and unable to master environment.

Unable to function without assistance.

That found in manual on Mentally Deficient and Epileptic, page 5, Section 2b.

Evaluation by Mental Health Clinic or Child Development Center.

I.Q. of 75.

Persons functioning well below usual mental levels.

Persons considered retarded only if they have been committed as mentally deficient.

Any person other than a mentally ill, so mentally defective as to require supervision, control or care for his own public welfare.

No definite definition.

Legal commitment.

Medical diagnosis of retardation.

An individual's lack of intellectual capacity hindering his or her ability to conceptualize, thus, impairing self-support, self-direction, etc. which would be in keeping with normal expectations for his or her chronological age group and necessitating supervision to cope with their environment.

A person who, because of limited intellectual ability, cannot meet the problems of daily living.

Adult M.R. and child M.R. defined as such only after psychological evaluation.

Obviously mentally retarded.

Includes individuals whose I.Q. is below 70 on two psychological examinations plus a medical evaluation and history of inadequate social adjustment.

Unemployable and school drop-out because of M.R.

A lack of intellectual development that is associated with, or the basis of, personal or social inadequacy.

2. <u>At what point do you meet retardates?</u>

Whenever the problem comes to our attention either by referral from school, physician, family, other interested individuals or when this problem is found in a family with whom we are having contacts for other reasons.

When they come to the agency for service or financial assistance.

Referral from courts.

Referral from psychologists.

..., pastors, public health nurses may bring a pre-school child to our attention. Neighbors, police may bring an adult to our attention.

Usually pre-school.

When the family feels a need to "do something" about the retarded person.

... at birth when profoundly retarded child is referred by pediatrician; etc., up to the time of adulthood; when family is unable to continue planning.

At the point of request for service. We initiate contacts as an agency if there are complaints of community concern.

Usually when the child begins to have trouble keeping up in school.

When their specific problems arise.

Doctors could refer them to us sooner.

ARC meetings, parents, Crippled Children's Clinic.

Varies usually according to severity of condition.

At the time the family faces a financial crises.

Usually at the "panic point."

Before guardianship--ARC, etc.

Referral by outside sources, and through Crippled Children's Services.

When they come to our attention and a service is required.

Officially upon commitment to State guardianship or entrance to institution.

Referrals by ..., law enforcement officers and any other references, including casual comments, where we might suspect there might be a retard.

When parents ask for help in getting child into special class.

Upon referral from any source.

3. <u>How are retardates diagnosed in your county?</u>

Psychological, social, medical, and perhaps neurological and psychiatric study.

State psychologist whose services are available to us quarterly. With infants, a pediatrician's diagnosis is acceptable. Older children are diagnosed in school for special class placement.

Studied clinically and tested by a certified psychologist.

School and Duluth Mental Hygiene Clinic.

By I.Q. tests administered by schools.

Principally by the mental health center.

Considered only potential retardates until they have actually appeared before the Probate Judge during a commitment hearing.

..., University Hospitals, private agencies.

Diagnosed by ..., Hennepin County General Hospital, diagnostic resources, agency psychologist, etc.

Child Development Center, etc.

..., Crippled Children's Clinic.

..., Psychological Education Clinic, Vocational Rehabilitation, various workshop programs, speech therapy clinic, etc.

Compete physical, neurological, intelligence usually; medical diagnosis alone in serious birth defects.

Medical examinations purchased from private facilities.

Mayo Clinic, Rochester....

Medical and social histories.

... and our own judgement.

4. What do you feel are the gaps in services for retardates in your county?

Sheltered workshops for training and employment; social opportunities for older retardates; local day care facility.

Difficulty in securing boarding homes for retarded children.

Lack of vocational as well as other general educational opportunities in area schools for retarded children.

Lack of integrated learning opportunities (segregated classrooms for retardates).

Inadequate genetic counseling to parents having had or likely to have retarded children.

Inadequate professional personnel functioning in early detection and diagnosis of mentally retarded.

Lack of school facilities to train them to any degree of usefulness. (Children and adults both)

Fulltime day care centers, specialized foster homes.

Speech training, guardianship of funds, coordination.

Diagnosing pre-schoolers; schools are not required to report retardates to our agency.

Casefinding.

Institutional space.

Community placement resources and facilities for the trainable.

State financial assistance for care of the retarded is needed.

Special classes for educable and trainable.

More casework staff for providing services; ongoing training program for staff--there are many recent developments in the field, and workers are not kept abreast of these developments.

Additional leisure time activities including group work for retardates.

Services could be made available if we could gain parental acceptance of the fact of retardation.

Need for a multidisciplinary community center for evaluation, treatment, and research under central auspices for thorough services to the retardate.

No mental health clinic.

Summer programs.

Lack of communication in terms of creating a better degree of community understanding.

No ARC.

Making plans for those who are discharged from Faribault and Owatonna as there are no facilities to train them to take outside work.

Volunteers.

5. <u>What administrative problems should the Planning Council study?</u>

More permissive legislation on the State level to obtain funds without the necessity for matching funds. It would also seem significant that in terms of human values, all States should come under the Mental Health Compact Law.

There should be county and State sharing in the cost of private institutionalization. Parents are penalized financially if they don't use public facilities. County agencies are paying full costs in private facilities.

Study should be given to the possibility of eliminating the legal commitment of persons as mentally deficient. Local and State services and facilities should be available to all, and should not be dependent on whether a person has been placed under State guardianship.

Clarification as to the effect on the civil right of persons committed as mentally deficient.

The difficulty of obtaining an individual to act as guardian of estate for an adult retardate.

Need for mechanics of employing a professionally trained person to work with retardates covering all phases of their community and family adjustment including employment and recreation.

Emphasis on Federal-State-County relations.

Rules such as the feasibility of admission to the State hospital without commitment to State guardianship.

Regarding diagnostic and child care problems on a load level--there should be some middle ground or mutual participation rather than the either/or situation of local care.

Court procedures, collections.

The Department of Public Welfare should give us an idea of when and why they expect relatives to contribute, both for Mentally Deficient and Mentally Ill.

Clarification of responsibility of the State as guardian of the person and the authority that is vested in that guardian; definition of the responsibility of the county as an agent of the State.

Ways of obtaining institutional space, State and/or Federal partial reimbursement to counties for payment of boarding home care for retarded as for other State wards.

Education of physicians who advise parents not to take baby from hospital, but have child placed in institution immediately when, actually, child could very well be at home.

Criteria for admission to State hospitals.

Township relief and Aid to the Disabled maximum as it affects the retarded adult.

Interpretation of the changing philosophy of the care of the mentally retarded to other professionals (medical and legal profession).

Would it be possible to require parents to have their children submit to mental testing at the request of M.D. or the school?

Empty the State schools and hospitals of those that can live in a community.

Revise court procedures to make it easier for commitment.

Our Probate Judge does not believe in commitment (Stevens County).

Requirement of doctor in making determination of retardation should be examined more closely.

Do away with "notice of service." Collections should be the responsibility of each county as families usually feel more responsibility toward local authority.

Voluntary admissions to institutions should be available with "sign in" by legally responsible relatives.

Examining Boards at mental deficiency hearings should include a certified psychologist rather than two medical doctors.

Reasonable definition of retardation and commitment.

Revision of social history.

Why is commitment necessary for institutional placement?

Dual guardianship when child is dependent child, financial guardian for State ward, marriage of wards.

More facilities so people committed as mentally retarded can be admitted at a more rapid pace.

Community resources.

6. At what point do you meet administrative and legal problems and what are your suggestions for their solution?

Administrative problems are dealt with when a need for services becomes apparent for which agency structure as it exists is not able to cope with the need. Expansion of the program of the agency of the community is made through board action or community participation.

Usually at time of commitment, drop guardianship and State participate in care of case locally.

... with the help of the county attorney, Probate Court, Department of Public Welfare, and families of retardates.

Meet problems when they occur and solve according to Department of Public Welfare Manual and county court procedures.

Only problem is lack of staff to expand services.

Do away with Guardianship Law.

Problems when part of ward's estate is in the Department of Public Welfare, part in State institution, and part in county.

With Old Age Survivor Insurance benefits being paid to the family and the county being held responsible for payments for cost of care because the family will not release the funds.

Suggest the admission procedures be simplified for State institutions.

Suggest possibility that court commitments be done away with.

Legal problems arise sometimes when a retardate is accused of crime. The easy way too frequently is to attempt emergency entrance into a State institution without regard for the accused person's right to a trial.

We meet specific problems at an acute stage due to a shortage of staff. Improved and increased casework could be expected as a result of increased financial participation by the State department.

State should share in costs of retardates cared for in community (boarding care).

Administrative problems to find resources for persons with special needs before emergency rises; better understaning with Department of Public Welfare to admit certain individuals to a State institution; after the emergency arises, the person is institutionalized without difficulty.

One was met preparing this report. How accurate is this count of State wards?

Department of Public Welfare, Mental Deficiency Section should have a social history guide that corresponds to Family Rehabilitation Method. Caseworkers shouldn't have to use 2 or 3 different social history guides found in 2 or 3 different places for various disorders encountered.

Suggest that Family Rehabilitation Method definition of mental retardation be broadened to include those so diagnosed.

... suggest (in an attempt to resolve problems) clarification of the guardianship responsibility and the county's responsibility in the ongoing work with a ward.

Parents feel they no longer have financial obligation once a child has been committed to guardianship. The solution to this probably is through casework and a better understanding between parents and agency.

What to do with retardates who cannot live in their own home and cannot be admitted to a State institution.

Under staffing of State institutions.

Clarify need for presence of county attorney and guardian ad litem.

Special Education Department needs more staff to give more advice and help on local level. Needs more specially educated facilities in secondary schools.

Problems are with handling of wages of employed wards. Must all wages and Social Security payments be paid into Social Welfare Fund?

Under what conditions can committed persons change their legal settlement? Where families have a child committed as mentally deficient and later move to another county or State, it seems unreasonable to have the family establish legal settlement elsewhere but to have the children retain legal settlement different from his parents.

Problems have arisen because the Department of Public Welfare did not keep county informed of changed policies.

TABULATION OF DATA OF RETARDED PERSONS IN MINNESOTA

State of Minnesota

Number of retardated under guardianship? 8,355*
Number of retardates not under guardianship? 3,231

AGE**	SEX**		DEGREE**				MULTIPLY** HANDICAPPED	LOCATION**					
	M	F	Educable IQ.50-80	Trainable IQ.25-50	Dependent Under 25	Unknown		Own Home	Board. Home	Nurs. Home	State Inst.	Private Inst.	Others
Under 5	180	148	169	93	74	172	127	286	115	1	41	52	9
5 - 14	1116	770	898	691	322	306	366	930	192	1	757	134	45
15 - 24	1059	790	1,040	618	291	183	333	858	120	7	275	31	57
25 - 34	611	458	589	429	121	134	199	540	85	2	641	4	50
35 - 44	522	510	570	406	97	139	155	516	74	9	593	7	41
45 - 54	421	419	456	340	68	128	114	393	70	21	479	3	44
55 - 64	252	279	318	221	38	112	84	271	79	35	299	2	24
65 +	100	165	191	108	20	57	41	121	63	72	114	2	12
TOTALS	4261	3539	4,231	2,906	1,031	1,231	1,419	3,915	798	148	3,899	235	282

* Department of Public Welfare records show 10,892 as of 6-30-64.
** Excludes Hennepin County.

EDUCATION DEPARTMENT DATA

Educable	6,803
Trainable	483
Total	7,286

1. What does your agency use as a working definition of retardation?
2. At what point do you meet retardates?
3. How are retardates diagnosed in your county?
4. What do you feel are the gaps in services for retardates in your county?
5. What administrative problems should the Planning Council study? (i.e. Laws, rules, court procedures, etc.)
6. At what point do you meet administrative and legal problems and what are your suggestions for their solution?
7. Do you use volunteers as part of your agency program for the retarded?

TABULATION OF DATA OF RETARDED PERSONS IN HENNEPIN COUNTY

COUNTY Hennepin

Number of retardates under guardianship? 1,877
Number of retardates not under guardianship? 99

AGE**	SEX**		DEGREE**				MULTIPLY** HANDICAPPED	LOCATION**					
	M	F	Educable IQ 50-80	Trainable IQ.25-50	Dependent Under 25	Unknown		Own Home	Board. Home	Nurs. Home	State Inst.	Private Inst.	Others
Under 5			--	--	--	--	--	103	76	--	23	3	13
5-14			--	--	--	--	--	253	73	--	271	57	5
21-24	14	17	21	10	--	--	1	169	43	--	266	22	13
25-34	8	16	15	9	--	--	1	19	5	--	--	--	--
35-44	13	14	23	4	--	--	6	24	3	--	--	--	--
45-54	4	6	9	1	--	--	2	8	1	--	--	--	1
55-64	1	4	2	3	--	--	1	4	1	--	--	--	--
65 +	1	1	1	1	--	--	--	1	1	--	--	--	--
TOTALS	41	58	71	28	--	--	11	581	203	--	560	82	32

1. What does your agency use as a working definition of retardation?
2. At what point do you meet retardates?
3. How are retardates diagnosed in your county?
4. What do you feel are the gaps in services for retardates in your county?
5. What administrative problems should the Planning Council study?
   i.e. Laws, rules, court procedures, Federal-State-County relations, collections, etc.
6. At what point do you meet administrative and legal problems and what are your suggestions for their solution?
7. Do you use volunteers as part of your agency program for the retarded?

SIGNATURE

Appendix C

SUMMARY OF COURSES RELATED TO MENTAL RETARDATION OFFERED BY COLLEGES AND SEMINARIES IN MINNESOTA

Department	NO. of Letters Sent	Replies
SOCIOLOGY The University of Minnesota offers seven graduate courses and seven undergraduate courses which study the problem in considerable depth. Two schools offer courses touching on mental retardation. Three offer nothing pertinent.	30	6
PSYCHOLOGY One school offers one course wholly on mental retardation. Four include the subject in broader courses. Three offer nothing pertinent.	30	8
EDUCATION Five schools offer special teacher training. One school touches briefly on the subject. Three schools offer nothing applicable.	30	9
SOCIAL WORK Two schools offer courses that touch on mental retardation. Three schools offer nothing specifically related to mental retardation.	30	5
MEDICINE No response received.		
SCHOOLS OF NURSING Eleven schools offer courses that touch on the subject, but there are no courses devoted wholly or in part on mental retardation. Fourteen schools offer no courses in this area, nor do they indicate that they even discuss the subject.	50	25
SEMINARIES No seminary offers anything applicable.	4	2
BIBLE COLLEGES Nothing applicable.	2	1

Appendix D

SUMMARY OF RESPONSES TO SURVEY CONDUCTED BY VOLUNTEER SERVICES AND PUBLIC AWARENESS TASK FORCE, NOVEMBER, 1964. *

1. Describe briefly the nature and scope of your volunteer program.

Volunteers are usually used to help provide a link between patient and community. They work in any area of the hospital or mental health center where additional help is needed. The volunteer works with patients under the guidance of psychologists, social workers, nurses or a volunteer coordinator. Volunteers are also recruited for county institutions and other facilities used by welfare clients and their families.

2. What kinds of work do volunteers do?

Volunteers may help in any of the following activities of a given hospital or State school: social service, recreation, handicraft, ward religious services, beauty shop, sewing, tour guiding, birthday parties, etc. In every hospital volunteers participate in the one-to-one visiting program. They may staff the patient clothes shop or direct youth activities such as scouting. In one hospital volunteers staff a nursery for children of volunteer mothers. Another State school trains its volunteers to administer tests under the direction of the psychology department. Still other volunteers attend infants, counsel in home and financial management, sell craft products, or take patients to places of interest outside the hospital. Frequently patients visit in the homes of volunteers.

3. What are the responsibilities of the volunteer?

Generally, the responsibilities of the volunteer are to help the staff provide treatment for a patient and to help the patient develop his potential to the highest possible level. The volunteer has the same responsibilities toward a patient as does any employee of the hospital or school. Volunteers in the county welfare departments are expected to cooperate with the staff in providing needed services and in maintaining relationships with institution case workers. Volunteers are expected to maintain ethical standards regarding confidentiality of information about clients or patients.

4. How are volunteers recruited?

Volunteers are recruited with the help of community groups, such as Associations for Retarded Children, Mrs. Jaycees, and church organizations, or by the volunteer coordinator or hospital staff members. Speaking engagements, personal communication with members of community groups, radio, newspapers, and institutional newsletters have all been effective in recruiting volunteers. The working volunteer has been found by many to be the best means of recruiting other volunteers. Also helpful have been college teaching staffs, veterans' service organizations and Welcome Wagon Hostesses.

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* Questionnaires were sent to each of the State institutions for the mentally retarded and mentally ill, to the Community Mental Health Centers, and to The Ramsey and St. Louis County Welfare Departments.

5. What standards are used in selecting volunteers?

One county welfare department utilizes personal interviews and completed volunteer information forms in selecting volunteer workers. A Community Mental Health Center employs volunteers who are both professionals and prominent in the community. One of the State schools has a minimum age of 14 years and insists that a volunteer's chief motive for working be his willingness to help others; the volunteer coordinator interviews candidates and discourages those he feels would not make good volunteers. Hastings State Hospital requires that four hours of orientation precede a volunteer assignment and that the volunteer be able to take a regular assignment.

6. What training is available for volunteers?

Some agencies offer general orientation, followed by supervised orientation in the area in which the volunteer will work. Some of the kinds of training available are: a short session with the Director of Remotivation; a meeting with the administrator and medical director; monthly conference with staff department heads; orientation to the hospital provided by the volunteer coordinator.

7. What goals are set for volunteers?

The over-all goal of the volunteer as well as of the hospital staff is to add something needed to the patient's life, to help create a program and a climate of acceptance which permits the retardate to become as adequate, independent, and happy as his physical, emotional, and intellectual capacities allow. Important goals for the volunteer himself are to make the most of his opportunity to work in a helping capacity, and to gain insight into mental retardation and its treatment.

8. What is the quality of volunteer work?

The quality of the volunteer's work ranges from fair to excellent. Poorer volunteers have a tendency to drop out of the program. Very good quality of work is noted when the volunteer is assigned a job according to his interests. For the most part, volunteers were described as "suprisingly good", "generally the best", "superior", "high", "excellent".

9. Who evaluates the work of volunteers?

The volunteer services coordinator, the case worker, supervisors, department head, the staff member to whom the volunteer is assigned, requesting department, and the Clinical Planning Committee all help in the evaluation of the volunteer worker.

10. What problems center around the use of volunteers?

The staff finds it difficult to take enough time to help volunteers get a good start on an assignment. Finding an important job with which a volunteer will be satisfied and making the volunteer feel that the service he offers, small though it may be, is important, is also a problem. Other problems cited were: lack of staff initiative in requesting volunteers; emotional involvement of volunteers; transportation of student volunteers from colleges to State hospitals; impressing the need for consistancy on the volunteer;

overcoming staff resistance so that enough work will be assigned to the volunteer; reluctance of some volunteers to provide individual help as well as to join in group activities; and the tendency of volunteers to socialize among themselves instead of with the patients.

11. Who conducts the volunteer program?

The individual department to which the volunteer is assigned, or in the case of the 10 State institutions, the volunteer services coordinator.