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ABSTRACT

The second stage of a followup study examined the life circumstances and adaptive skills of 44 adult former students of Wisconsin classes for the trainable retarded. Results of interviews with the retardates' parents showed that 14 percent more adults had been institutionalized since 1962, 72 percent of the Ss were involved in community programs as compared to the earlier figure of 15 percent, 77 percent of the families were receiving financial assistance, and few parents had made realistic future plans for the retardate. Ss showed strengths in such skill areas as mobility, self-care, and personal adjustment while weaknesses were usually in specific abilities including shopping, reading, and the use of money. Identified were the following needs: systematic analysis and development of local small group homes, coordinated planning between home and public school with greater emphasis on instructional carryover into adulthood, increased parent education, and augmented day care services. Results demonstrated the need for an integrated model of services to the moderately retarded. (CL)

MONOGRAPH SERIES

PROGRAM ACCOUNTABILITY IN SPECIAL EDUCATION

MONOGRAPH NO. 1

AN ELEVEN YEAR FOLLOW-UP OF ADULT FORMER STUDENTS OF WISCONSIN PUBLIC SCHOOL CLASSES FOR THE TRAINABLE MENTALLY RETARDED

1972

A Collaborative Effort

Design and Implementation: Division for Handicapped Children
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SECTION I: INTRODUCTION

In June, 1971 the Wisconsin Association for Retarded Children awarded a grant to the Wisconsin State Department of Public Instruction, Division for Handicapped Children, for the purpose of investigating the adult status and adjustment of former students of special classes for the trainable mentally retarded within the State of Wisconsin.

This follow-up study was designed to be carried out in two phases, consisting of two different groups of former students of state supported classes for the trainable mentally retarded.

Phase I concerns the follow-up of a group of 68 trainable class graduates from the first state supported classes for the trainable retarded. This group was previously followed up in 1962 (Blessing, 1962). The mean age of this group was 28.9 years.

Phase II involves the follow-up of a new sample of approximately 250 more recent trainable class graduates, who have a mean age of about twenty-two years.

The report which follows is a summary of the data obtained from personal interviews with the parents of the Phase I group only. Phase II is expected to be completed in early 1973.

The objective of this study is to obtain some basic information on the total life situation of these moderately retarded adults, including such areas as incidence of institutionalization, extent of adult program involvement, health problems, achievement levels, degree of independence in life style, and, particularly, the adequacy of educational and adult service programs from the point of view of the parents.

The procedure of the study consisted of contacting the parents of this group of moderately retarded adults, and by way of an extensive personal interview, exploring numerous aspects of their son or daughter's current life situation. Although a structured interview schedule was used, much time was also spent in exploring any significant issues which emerged in the interviews.

Much of what follows in this report, in the form of discussions and recommendations, is based on the interviewer's impressions and own conclusions about what needs to be done to improve services to our retarded citizens, rather than on a strictly objective reporting of the statistics gathered.

The descriptive statistical data which was obtained gives us some badly needed preliminary information on what is happening to our trainable class students after they reach adulthood. It is hoped that this report will be useful to the participating state agencies and local parent groups in the development of improved programs and in assuring statewide quality programs throughout the lifespan of our retarded citizens.

It is hoped that these various agencies will look closely at these implications and recommendations and evaluate them on the basis of their own expertise in terms of the potential for improving services.

Much effort has recently gone into the improvement of delivery of services to Wisconsin's retarded citizens and their parents, in the form of Chapter 322 of the State of Wisconsin Statutes. One result of accountability studies such as this should be to explore and document serious areas of need from the point of view of the parents so that priorities can be established for the kinds of services that the parents feel are most urgent.

Whereas Phase I of this study is mostly directed toward identifying issues and obtaining preliminary data, it is anticipated that Phase II which involves a much larger sample will supply more comprehensive and conclusive evidence of the current effectiveness of statewide services to the adult retarded as well as those areas of most prevalent need.

Organization of the Report

Sections II and III which follow are devoted to the reporting of the nature of the sample and to the statistical results which were obtained. Sections IV and V are devoted to the discussion of these results and to an explication of a model for improving lifespan services to the retarded.

SECTION II: THE PHASE I STUDY

Part I: Background of the Sample

The list of names of subjects for the present Phase I sample was taken directly from the previous study conducted by Blessing (1962). This 1962 study was the first follow-up of students from Wisconsin's original state supported classes for the trainable retarded initiated in 1951. At that time, a name list of 134 former TMR students was developed from the Department of Public Instruction's records of class lists. The age range for the sample then was 16-2 to 22-8, with a mean age of 17-9. The I.Q. range was from 29 to 60, with a mean I.Q. of 42.9.

The method for obtaining the data on these subjects was a mail-in questionnaire which was filled out by the parents. From the identified population of 134, 68 completed questionnaires were returned. The questionnaire included a number of questions pertaining to the status of the person; where he was residing, what programs or work he was involved in, total number of years of schooling, main leisure activities, what additional or secondary handicaps were present besides retardation, etc. In addition, the parents were asked for their opinions regarding the educational programs of that time.

The results of that questionnaire lent strong support to subsequent improvement in educational services to the trainable retarded. These changes in policy which came shortly thereafter included extension of trainable classes from half-day to whole-day and extension of the upper age limit of trainable classes from age 16 to 21.

Phase I of this current study is an attempt to go back to the original 1962 sample and, to whatever extent possible, locate these persons who are now on the average 30 years of age, obtain up-to-date information as to their life circumstances and seek input as to current issues regarding adult services to the retarded in Wisconsin.

Part 2: Description of the Sample

An attempt was made to locate the current addresses of all 68 of the subjects from the 1962 study. A request for current addresses was sent out to school district administrators where the subjects were last known to reside. Of the total N of 68, it was found that a current address could not be located for 18 of the original subjects. Of the remaining 50 subjects, we were unable to establish contact with five of these because they did not respond to written requests to participate in the study and did not have any phone listed. An additional single subject was contacted by phone and the parent refused to participate in the study. We were thus left with a remaining sample of 44 subjects.

Although this degree of attrition of subjects from the 1962 study presents some problem in making a completely accurate assessment of what changes have taken place in the sample over the past ten years, the descriptive statistics shown in Table 1 for the two samples are very similar and suggest no obvious bias in this current sample despite the loss of subjects.

Table 1

Comparison of 1962 and 1972 Samples

Total Subjects Accounted For	1962 N=68	1972 N=44
I.Q. Range	29 to 60	29 to 60
$\bar{X}$ I.Q.	42.9	41.5
$\bar{X}$ years attended TMR class	4.0	3.9

Method of Obtaining Data

Letters requesting participation in this current study were sent out to all parents of subjects on the 1962 name list. A follow-up phone call was made to set up an appointment for a personal interview in the parents' home. Nearly 100% cooperation was found when the interviewer had the opportunity to explain the nature of the study over the phone.

Parents interviewed were asked the specific questions contained in the interview schedule (See Appendix A). In addition, every effort was made to explore parents' reactions to current services available to their son or daughter, and, in certain instances, to explain community resources of which they were unaware, such as financial assistance. All parent interviews were conducted by the project coordinator.

For subjects known to be in institutions a questionnaire was devised and sent out to the institutions to be filled out by staff acquainted with the subject (See Appendix B).

SECTION III: RESULTS

The data reported in this section fall into two parts: Part 1 is a report on the life circumstances of these adult retardates. This part includes the following areas:

1. Residential status
2. Presence of secondary physical handicaps and health problems
3. Type and extent of adult program involvement or private employment
4. Extent of financial assistance and medical benefits
5. Private health and life insurance

This information was obtained for the purpose of assessing the current situation of this generation of trainable class graduates and to determine the impact of recent advancements in adult program development and benefit programs authorized by the legislature in the past several years.

The second category of data, Part 2, pertains to the attained competency and personal adjustment levels of this group and reflects their capacity for independent living and the extent to which they have acquired skills usually associated with normal adult level of functioning. This category includes the following skill areas:

1. Mobility
2. Need for supervision
3. Meal preparation
4. Laundry
5. Shopping
6. Money
7. Telling time
8. Use of telephone
9. Speech
10. Reading
11. Spelling
12. Numbers
13. Self-care
14. Personal adjustment

It is recognized that this list of skill areas is somewhat arbitrary and certainly other skills might have been included. The purpose was to obtain some overall picture of how the general handicap of "retardation" is reflected in a variety of skills considered important for the normal adult. The main goal in obtaining this information was to arrive at a descriptive, normative picture of the areas in the life of the adult retardate which suggest dependency on others, and the areas which suggest relative independence from the care of others.

Residential status of the subjects at the time of this survey was obtained and compared with results from the earlier study by Blessing. In order to make comparisons between groups of unequal sizes, the obtained data was extrapolated to the entire group of 80 surveyed in 1962, based on the assumption that the same proportion of changes occurred among the 36 individuals not reported in the 1972 sample. Table 2 below shows the number and percentage reported in each residential category with an additional column added for the reader's convenience in estimating percentage changes between the two survey dates.

Table 2

Frequencies and Percentages of Subjects Living at Home, In Institutions, Independently and Deceased

Status	1962 (obtained)		1972 (obtained)		1972 (extrapolated)		1962-1972 Percentage Change in Sample of 80
	N	%	N	%	N	%	
Living at home	68	85%	23	52%	47	59%	-26%
Living in institution	9	11%	14	32%	20	25%	+14%
Living independently	1	1%	2	5%	3	4%	+ 3%
Deceased	2	3%	5	11%	10	12%	+ 9%
TOTALS	80	100%	44	100%	80	100%	

Comparison of percentages of people in the different categories shows a 26% decrease in the number of subjects living at home and a 14% increase in those living in institutions. Extrapolated 1972 percentages show that more than half of the group continued to live with parents while one out of four was living in an institution. However, if the individual who was placed in an institution in the intervening period but died prior to 1972 is considered, the percentage of people who received institutional care during this time climbs to 26.3% of the sample. Saenger, in his 1957 study of retarded adults living in the community, found that, for a roughly comparable age group, 66% were living at home and 26% had been institutionalized.

Reasons for this increase in institutionalization are not available but one may hypothesize that it reflects both the changing needs of the retarded individuals as they moved from late adolescence to adulthood (average age in 1962 was 18) as well as the decreasing ability of parents to care for them because of increasing age, physical debility or death.

This increase, however, does suggest a closer look at the reasons for institutionalization and an analysis of the content of existing school programs as they relate to developing skills for coping in adult life. Within the extent to which one can justify generalizing from this sample to the adult trainable retarded population of the state as a whole, a number of implications can be drawn regarding needs for residential and day care facilities.

Table 3

Frequency and Percentage of Different Types of Institutional Placements

Type of Placement	N	%
State Colony	7	50%
Private Nursing	2	14.5%
County Hospital	3	21%
Private Institution for Retarded	2	14.5%
	14	100%

B. Presence of Secondary Physical Problems

One of the main purposes for including this question on secondary physical problems was to find out the extent to which retarded adults exhibit chronic physical problems which would require nursing care or medical supervision of the degree usually found in nursing homes and county hospitals. It was felt that this information would have ramifications toward determining the appropriateness of these kinds of medically oriented facilities from the standpoint of cost and type of professional staff. The cost of residential care for the retarded will certainly be exaggerated if the facility includes an emphasis on medical and nursing staff when there may be little need for this type of care.

Table 4 shows the frequency and percentage of all the different types of physical problems which were reported by the parents.

Table 4

Frequency and Percentage of Secondary Physical Problems

Type of Problem	Frequency	Percentage
None	23	59%
Epilepsy (Completely controlled by medication)	2	41%
Epilepsy (Not completely controlled by medication)	4	
Cerebral Palsy	4	
Diabetic	2	
Visually Impaired & Cleft Palate	1	
Cleft Palate	1	
Kidney Disorder	2	
	39	100%

As Table 4 indicates, it is apparent that for this sample, at this time in their life, the significant majority of these individuals exhibit no major physical problems. There were only eight subjects who seemed to have physical problems which would require fairly constant medical or nursing supervision: two diabetics, four uncontrolled epileptics and two cases of kidney disorders.

In general, it was found that the parents reported their son or daughter to be in very good health, with few infections and a low incidence of medical treatment. This finding was particularly true for the mongoloid subjects. A very typical report on the mongoloid cases was that as children there was a high incidence of upper respiratory infections but that this problem disappeared in the late teens, such that in adulthood there were very few mongoloids listed as having secondary health problems. Another finding with the mongoloid subjects was a definite problem with obesity in the late twenties. About 50% of this group was rated as obese by the parent.

C. Prevalence of Medication:

Of the 40 subjects for whom medical information was obtained it was noted that 17 subjects were taking some type of regular medication. Table 5 shows the breakdown with regard to type of medication.

Table 5

Frequency and Percentage of Different Types of Medication

Type of Medication	Frequency	Percentages
None	22	56%
Anti-convulsant	5	13%
Tranquilizers	8	20%
For kidney condition	2	5%
For high blood pressure	1	3%
Thyroid	1	3%
	39	100%

The most interesting observation with regard to medication is that all eight of the subjects receiving tranquilizers are in institutions. It is difficult to draw conclusions from this observation, however, because possibly these institutionalized subjects presented behavior difficulties which resulted in their being institutionalized in the first place. Two parents who saw their son or daughter on regular weekend visits did complain that they felt their son or daughter was "over-tranquilized".

D. Type and Extent of Adult Program Involvement or Private Employment

In 1962, 85% of the subjects living in the community were listed as not being involved in any type of weekday work or activity program. Most of the subjects had been terminated from public school at age 16 and did not have available to them any other kind of community program. Table 6 indicates the progressive change which has taken place in this area of services to the retarded adult over the past decade.

Table 6

Frequency and Percentage of Persons Involved In No Program, In Activity Programs, In Sheltered Workshops, Or In Private Employment While Living in Community

Type of Program	Frequency	Percentage	
Activity Program	10	40%	
Full-time Sheltered Workshop	2	8%	
One-half Sheltered Workshop One-half Activity Program	2	8%	72%
Privately Employed	4	16%	
No Program Involvement	7	28%	
	25	100%	

The combined percentage of subjects who are living in the community who are engaged in full-time activity, full-time sheltered work, combination of the activity and sheltered work, or private employment rose from 15% in 1962 to 72% in 1972.

It should be noted that nearly all of the subjects in this sample are located near high density population centers of the state and consequently have available to them some type of full-time adult program. Therefore, with regard to the seven subjects not involved in a program of any kind, it is a matter of choice rather than a lack of opportunity. From discussions held with the parents of these seven subjects who are at home full-time, some of the reasons for non-involvement that emerged were as follows:

Case 1: A widowed mother feels her son does not like the confusion of the activity program. Also, she complains that attending the program would involve excessive transportation problems each day (program is about 16 miles away). She feels her son is happier at home.

Case 2: Both parents feel daughter is happier at home. Daughter used to attend activity program seven years ago but parents claim she became nervous and refused to continue.

Case 3: A handsome male Negro, living with grandmother, used to attend program eight years ago. Dropped out because of necessity of having to be transported across the City of Milwaukee and the fact that the program required a fee payment for attendance at that time.

Case 4: A family in crisis. Father ill, mother works, serious financial problems. Subject has refused to attend the activity program for the past three years. Parent no longer wished to pay monthly fee, prefers to have son at home.

Case 5: A socially well-adjusted female mongoloid, living on farm with both parents. Parents indicate a transportation problem to program ten miles away. They also feel that the program is mostly arts and crafts and does not include enough practical living skills.

Case 6: A male mongoloid living with both parents on a farm. Mother feels her son has become very difficult to manage. Is not involved in program now because was excluded eight years ago and parents feel he would not be welcome.

Case 7: Subject lives in an area where there is a sheltered workshop. Parents feel their son does not have the hand coordination needed to do the kinds of work at the workshop but have not tried to place him there.

These brief case descriptions are given for the purpose of suggesting the diversity in individual situations which for this generation of retardates causes the parents not to consider available programs for their son or daughter. Some consistent themes which emerge from these descriptions are: (1) a sense of concern by parents that their son or daughter is not happy with program; (2) alienation from the community or from the agency sponsoring the program; (3) a real feeling that the content of the programs is not worth the daily problems caused by need for transporting arrangements.

The interviewer's impressions from these seven interviews are that in some cases staying at home does not seem to be detrimental to the individual and the parents probably would not agree to program involvement even with encouragement by an outside agency. Others, however, probably would respond to efforts made by agencies to encourage participation and to help in working out details of transportation. These latter parents really are not satisfied with their son or daughter at home all day and know that this situation may be detrimental to the retarded individual. They are often viewing programs as they were seven or eight years ago and are not aware of improvements in programs, and of financial aids available to offset the cost of transportation and program fees.

There is a small percentage of situations from this age group, perhaps 10% of those living at home, where the parents have become alienated from existing programs and probably would benefit from follow-up and continued contact by local program staff or another interested service agency.

E. Private Employment

With regard to the number of subjects who are privately employed, some explanation is needed relative to the statistics shown in Table 6. Of the twenty-five subjects living in the community it was found that four were privately employed on a full-time basis. However, a closer look at these four subjects suggests that only one could be realistically classified as a trainable level retardate in his developmental years. The other three subjects, despite the finding of low I.Q. ratings in early years, show numerous indications of near normal functioning.

Two of these three, in addition to being privately employed, are married, own their own cars and homes, and manage all of their own affairs independently. The third subject although still dependent on his parents for room and board, has a number of normal social contacts in the neighborhood, and on the basis of social adjustment would probably more correctly be classified as borderline retarded.

Some special note should be taken of the remaining subject who is privately employed and who by most commonly accepted definitions would be classified as a trainable level retardate. This individual, a male mongoloid, has been employed for a continuous five year period at a hospital laundry located in his neighborhood. He is an only child and lives with both parents. The unique aspect of his situation is that his parents, after sending him to schools for several years, decided to undertake the task of training entirely by themselves. Over the years they carefully demonstrated and reinforced all aspects of duties around the house, including laundry, cooking, climbing ladders, yard work. In addition, they patiently and systematically developed reading skills from an early age using flash cards and rote methods. Social skills were developed by involvement in numerous social activities such as dancing, bowling and training at the time relatives or others visited the home.

In early adulthood, the parents felt that their son should be able to do some kind of meaningful work. They contacted Vocational Rehabilitation and after some time they were referred to a janitorial type job involving cleaning restrooms. This job the parents rejected. A chance meeting with a hospital supervisor resulted in his being employed on a trial basis in the local hospital laundry. He passed the trial period and, after the five year period of employment, now earns $2.50 per hour and has demonstrated sufficient awareness of his job and communication ability to train beginning workers on the machines he is familiar with.

It is difficult to draw general conclusions from single case histories. However, it is felt that the uniqueness and success of this one case should be evaluated. First of all, it is possible that this particular subject was a very high level retardate to begin with. The parents, from their observations of other mongoloid persons, felt otherwise. It remains that the training this individual received was highly individualized, with a high degree of sensitivity to the individual's personality and capabilities at every stage of development. In addition, the institutionalized services of his day, in the view of the parents, were not capable of delivering the quality of training or individualized understanding these parents insisted on for their child.

If "success" is defined as normalization and integration into the community, without protective programs or indefinite training class attendance, this case can be viewed as really the only "success" case found in the sample.

Some possible conclusions--

1. The home is the most powerful influence on the young retardate. The training opportunities, both in terms of physical environment, real life learning situations, and the highly reinforcing potential of the parents is generally a source of teaching which has not typically been intensely utilized by TMR programs in the past.

2. The trainable class teacher should be the one to integrate his or her program with a coordinated program of experiences and reinforcements at home.

3. It is felt that a most important aspect of home and school coordination of training is establishing on a continuing basis some specific training goals or objectives, such that parents will know at any point in time what they could or should be doing at home that would enhance and strengthen learning which takes place in school.

4. There is some question as to the appropriateness of assigning the responsibility of job placement for the trainable retarded adult to the Division for Vocational Rehabilitation. A large social service agency, such as Division for Vocational Rehabilitation with a large caseload and serving a wide spectrum of disabilities, may not be in a position to evaluate the individual retardate, his family as a resource, and the immediate community opportunities with the degree of individualization and follow-up which would allow for the most beneficial work placements for the higher level of trainable retarded adults.

A model for training for private employment is developed later in this report (See Section IV, Conclusions and Recommendations).

Thus, in looking at the category of privately employed subjects, only one who was legitimately classified as trainable was found working full-time in a private job. This represents 2% of the total 1972 sample.

Employment in Sheltered Workshops:

With regard to subjects working in sheltered workshops or activity centers, some distinction should be made between these two categories. Many of the subjects listed as being involved in activity programs are involved in some type of contract work for the sheltered workshops associated with these activity centers. However, this work is not on a regular basis, and the primary emphasis in their program is on personal development and recreational activities. The category "Sheltered Workshop" as used here pertains only to those persons whose main activities consist of work for pay on a regular daily basis.

Keeping in mind this distinction, it was found that only two subjects were employed full-time in a sheltered work setting. Two additional subjects were employed half-days in sheltered work programs. These four subjects make up 16% of all subjects residing in the community.

F. Financial Support

Because of recent legislation in Wisconsin providing for medical care for adult retardates, and further recent efforts by WARC to advise parents of the eligibility of their retarded son or daughter to receive categorical financial assistance under Disabled Aid, it was decided to find out how many of the parents were not taking advantage of these benefits despite the efforts to disseminate this information.

Results shown in Table 7 pertain only to those subjects who were residing in their own home and were not privately employed or working full-time at a sheltered workshop.

Table 7

Frequency and Percentage of Subjects Receiving Various Kinds of Financial Assistance (excluding dead, institutionalized and lack of information)

Type of Assistance	Frequency	Percentage	
Social Security Payment	10	45%	
Disabled Aid Payment	4	18%	77%
Social Security and D.A.	3	14%	
Not Receiving Any Benefits	5	23%	
	22	100%	

As indicated in Table 7, approximately 77% of this sample of financially dependent subjects living at home were receiving either Social Security, Disabled Aid or a combination of both. Twenty-three percent were not receiving benefits to which they were entitled. The typical payment was in the range of $90 to $120. Those subjects receiving a combination of Social Security and Disabled Aid were in situations where the Social Security payment fell below the minimal support level established by the County Department of Social Services, and thus the difference was made up by an additional Disabled Aid payment.

In looking at the individual case situations of those families not receiving any financial support for the care of their retarded adult son or daughter, it was found that all of these parents were simply not aware of their ward's eligibility, rather than being unwilling to accept this type of legitimate social assistance. Upon explanation by the interviewer it was observed that the parents in this group were very receptive to applying for disabled aid and simply did not know how to go about making application. An additional observation is that this group of parents was typically the most critically in need of financial help, and, in effect was the most alienated from social and community contacts from which they might have obtained this information.

An overall impression was that nearly all parents who were supporting their adult son or daughter in the home felt that this payment, even though quite small, eased the financial burden and was quite helpful. Most parents only made application for D.A. assistance within the past one or two years, and several expressed dissatisfaction that they were not aware of this source of financial help at the time their son or daughter reached age twenty-one.

G. Medical Insurance Benefits Through Purchases of Services

Table 8 shows the frequency and percentage of subjects who received medical coverage through the Department of Health and Social Services via Purchase of Services.

Table 8

Frequency and Percentage of Subjects Living at Home Who Have Medical Coverage

	Frequency	Percentage
Have Social Services Medical Coverage	13	52%
Do Not Have Social Services Medical Coverage	8	32%
Private Health Coverage (Through Employment)	4	16%
	25	100%

Basically the same parents who were unaware of Disabled Aid benefits were also unaware of their son or daughter's eligibility for medical coverage. Again it was felt that these families were the ones most in need of this kind of financial benefit and protection against medical expenses.

H. Private Health and Life Insurance

Although the question of the availability of private health insurance for the retarded adult is no longer a vital issue in Wisconsin, it was found that approximately 85% of the parents reported experiencing difficulty obtaining either private health or life insurance for their retarded son or daughter as an adult. Although this question was not pursued in depth, it was apparent that the classification of "mentally retarded" results in significant barriers to obtaining private health and life insurance which are not present for other citizens. It would appear to be a significant legal question as to whether the actuarial statistics for this group are so far divergent from various other citizen groups to allow for prejudicial differences in eligibility.

I. Future Living Plans

In terms of the life span view of the trainable retarded, it is apparent that the single consistent and most important need of these individuals is for some degree of supervision and guidance throughout their lifetime. Although many retarded adults show a considerable degree of independence and capability of taking care of themselves, their ultimate dependence on others in a complex society is inescapable.

Therefore, one of the most significant questions asked of the parents whose son or daughter was living at home was: "What is your long range plan for (subject's name) care and support in the event both parents are unable to provide it?" From the discussion on this question it was apparent that this issue, from the point of view of the parents, was most important.

Table 9 summarizes the responses from parents to the above question.

Table 9

Future Plans for TMR (Excluding dead, institutionalized and lack of information)

Type of Future Plan	Frequency	Percentage
Relative or Sibling	7	30%
Small Group Home	2	9%
Private Church Sponsored Institution	1	4%
Private Nursing Home	3	14%
No Plan at All	10	43%
	23	100%

The above responses regarding long range plans for care seemed to reflect rather tentative plans and, from discussion, it was felt that very few of the parents had really made a firm decision on this matter. This conclusion is supported by the fact that only six out of this total of 23, or about 25%,had actually specified a definite residential placement in a will.

In general, for those subjects still living at home it was found that their parents were not enthusiastic toward any of the currently available residential alternatives for the adult retarded. Many who gave the response of "sibling" or "relative" were conscious of the fact that this plan might not be realistic. A few parents also seemed to hope that their retarded son or daughter would be able to live at their home on his or her own. A further very typical response was that this group of parents were strongly against the prospect of their son or daughter living at a large institution or an "old folks" home, after having adjusted for many years in their own home environment. In most instances parents felt such residential settings were inappropriate.

An attempt was made with each of these parents to sound out their feelings about community based small group homes. It was found that only four parents were aware of the current movement in this direction. Upon explanation of the concept of the group home, most parents expressed very positive opinions of this type of residential placement over current placement alternatives.

Some further points which came out of these discussions were that some parents expressed a desire to keep their son or daughter at home as long as they were able, and others felt it would be desirable to have their son or daughter adjust to a new placement while the parents were still alive and able to assist them in this important adjustment.

In summarizing the interviewer's impressions regarding alternative placements to living at home, it was felt that few parents had made realistic plans. It was an unpleasant subject, made unpleasant mainly because of the current lack in residential facilities which meet not only the needs of a substantial percentage of this population of retarded adults, but also meet the desires and wishes of the parents for their son or daughter to continue to live in a "homelike" environment.

The expansion of public education and adult training and work programs has been based on the philosophy that the retardate should remain in the community. Our philosophy regarding adult residential care, however, is not consistent at this time with this concept of community based services.

Part 2: Results: Adaptive Skills Levels

One of the basic intentions of this study was to determine the degree of independence or freedom from the care of others by this population of retarded adults. With this goal in mind a checklist of specific skill areas was devised to measure the degree of competency of these subjects in a number of different categories of behavior. These areas include mobility, need for supervision, self-care, speech, academics, use of telephone, telling time, meal preparation, laundry, shopping skills, and personal adjustment.

The method of measuring the level of competency within these various areas was to set up a scale with a verbal description of four different levels of competency and then to question the parents about this in each area.

The four levels of competency within each adaptive skill area are arranged in a descending order of difficulty or competency. An example of the technique is the following:

Mobility:	Level 4	Travels about city routinely, understands traffic signals, and hazards of traffic
	Level 3	Travels independently to routine destinations only, understands traffic signal and hazards of traffic
	Level 2	Travels independently in a two or three block radius of home, is trusted crossing streets in residential area
	Level 1	Is not able to cope safely with the hazards of crossing streets, is always accompanied

It is recognized that some of the areas included are more important than others. It was felt that all of the areas are typically found in trainable class curricula and at least on the surface have some contributing value to social functioning.

The method of reporting this data will be to list the four levels for each skill area and then indicate the percentage of subjects scored at each level to the right of that level.

A combined percentage will also be reported: Levels 4 and 3 will be combined, and Levels 2 and 1 combined. This is done for the purpose of evaluating the data with regard to the concept of Independence vs. Dependence; Levels 4 and 3 represent relative independence from the care of others and Levels 2 and 1 represent continued dependence on others.

A discussion of these results will follow the complete listing of the items and the obtained percentages.

Checklist of Adaptive Skills - Percentages of Subjects at Each Level

Item #1: Mobility

55%	20%	Level 4	Travels about city routinely, understands traffic signals, and hazards of traffic
	35%	Level 3	Travels independently to routine destinations only, understands traffic signal and hazards of traffic
45%	28%	Level 2	Travels independently in a two or three block radius of home, is trusted crossing streets in residential area
	17%	Level 1	Is not able to cope safely with the hazards of crossing streets, is always accompanied

Item #2: Need for Supervision

74%	34%	Level 4	Person is left at home alone for a half-day or longer
	40%	Level 3	Person is left at home alone for a period up to two hours
26%	13%	Level 2	Person is left at home alone for a period up to one-half hour
	13%	Level 1	Person is not left at home alone at all

Item #3: Meal Preparation

46%	26%	Level 4	Can prepare own breakfast and lunch, uses stove without direction
	20%	Level 3	Can prepare own breakfast and lunch, uses stove with parent present
54%	34%	Level 2	Can prepare food not involving use of stove
	20%	Level 1	All meals prepared by parent

Item #4: Laundry

32%	26%	Level 4	Can handle all aspects of laundering own clothes, including sorting and running machines independently
	6%	Level 3	Can handle most aspects of laundering, including running machines with parent direction

68%	23%	Level 2	Helps with laundry process but does not run machines
	45%	Level 1	Does not participate in laundry process at all

Item #5: Shopping

42%	25%	Level 4	Goes to store on own, buys groceries, clothes or meals
	17%	Level 3	Goes to store with parent, but makes some purchasing decisions on own
58%	33%	Level 2	Participates in shopping, goes and gets specific items but purchasing decisions made by parent
	25%	Level 1	May accompany parent to store, but is not involved in getting or selecting items

Item #6: Understanding Money

20%	10%	Level 4	Understands money, can identify coins and figure change
	10%	Level 3	Can identify coins and figure change approximately, appreciates value
80%	43%	Level 2	Can identify coins, but doesn't understand value
	37%	Level 1	Cannot identify coins

Item #7: Telling Time

38%	20%	Level 4	Can tell time to the minute
	18%	Level 3	Can tell time to the half hour
62%	22%	Level 2	Knows a few significant times of the day
	40%	Level 1	Does not understand concept of telling time

Item #8: Use of Telephone

32%	29%	Level 4	Able to use telephone without help
	3%	Level 3	Can dial accurately if told number sequence
66%	16%	Level 2	Parent helps in dialing, is able to converse confidently
	50%	Level 1	Does not use phone at all

Item #9: Speech Articulation

66%	20%	Level 4	Essentially normal articulation
	46%	Level 3	Some articulation errors, but is understandable
34%	29%	Level 2	Definite speech problems, is difficult to understand at times
	5%	Level 1	Severe speech problems, is frequently difficult to understand for parent

Item #10: Reading

13%	5%	Level 4	Able to read magazine or newspaper with understanding of passages of interest
	8%	Level 3	Able to read comic book and simple messages
87%	27%	Level 2	Able to read only isolated words and signs
	60%	Level 1	Reads only alphabet or less

Item #11: Spelling

11%	3%	Level 4	Prints letters and messages, own spelling
	8%	Level 3	Able to spell some words needs help with sentence construction
89%	35%	Level 2	Able to spell name
	54%	Level 1	Prints only alphabet or less

Item #12: Numbers

34%	7%	Level 4	Formal arithmetic, adding
	27%	Level 3	Counts effectively above ten objects
66%	46%	Level 2	Counts effectively below ten objects
	20%	Level 1	Little or no number sense

Item #13: Self-care Skills (Only two levels of response, either independent or requires help)

A.	Toileting	Independent	89%	Need Help	11%
B.	Bathing	Independent	84%	Need Help	16%
C.	Shaving (M)	Independent	80%	Need Help	20%

D. Menstrual Care (F)	Independent	91%	Need Help	9%
E. Dressing	Independent	87%	Need Help	13%
F. Brushing Teeth	Independent	90%	Need Help	10%

Item #14: Personal Adjustment

86%	70%	Level 4	Personal adjustment is excellent, is cooperative, helpful and gets along well with others
	16%	Level 3	Personal adjustment is good, is usually cooperative but occasionally resists requests or needs reminding
13%	8%	Level 2	Personal adjustment is fair, has some bad days when expresses unhappiness and uncooperativeness
	5%	Level 1	Personal adjustment is poor, has frequent episodes of temper, is often not cooperative, difficult behavior

Discussion of Adaptive Skills

In a very general overview of the Adaptive Skills results, one can highlight those areas which show a majority of the subjects classified as independent and which areas showing a majority of subjects as dependent. These are as follows:

Independent	Dependent
Mobility	Meal Preparation
Need for Supervision	Laundry
Speech	Shopping
Self-care	Money
Personal Adjustment	Telling Time
	Telephone
	Reading
	Spelling
	Numbers

In looking over these two lists it is apparent that the weakest areas for this group involve specific learned skills, many of which have some academic component. On the other hand, those areas which are strongest involve more generalized learning and would be considered most important with regard to the real demands the retarded individual places on his or her environment.

It is felt that these findings lend strong support to the view that a good percentage of moderately retarded adults do show: 1) a good social adjustment; 2) a capacity for being on their own for significant periods of time; 3) a capacity for looking after their own bodily needs; and 4) understand and avoid hazards in and away from home.

The following section will look more closely at each skill area and point out some of the observations and remarks made by the parents to these particular items.

Discussion of Specific Adaptive Skill Areas

Item #1: Mobility

In discussing this question, two significant points emerged. First of all, some parents made the point that although they had been urged by their son or daughter's teachers to work toward mobility skills such as taking the bus to the activity center, they felt there was too great a risk involved and thus they have resisted this recommendation.

Secondly, parents in medium to large city neighborhoods stated that whereas they used to allow considerable freedom for their son or daughter to travel about in the neighborhood, because of the change in neighbors and the increased amount of traffic, they no longer felt it was safe to allow this kind of freedom. Thus, the question of mobility for this population is affected by the overall stability of city residential areas from the point of view of the parents.

The issue of mobility skills requires some further analysis in terms of its importance for the trainable retarded adult. The capacity of the retarded adult to safely use the city bus to get to an activity center may be a determining factor as to whether he attends at all. In certain instances, unless transportation is provided, dependency in this area will ultimately involve the willingness on the part of the parent to transport on a daily basis.

Item #2: Need for Supervision

The basic rationale for this question was that the trust implicit in leaving the person at home unsupervised reflects other aspects of the person's competencies: such as his or her capacity for avoiding safety hazards, finding constructive activities, taking care of bodily needs, and knowing how to respond to some degree of emergency situations.

A rather frequent statement by parents was not their concern about their son or daughter behaving appropriately, but rather their fear of strangers coming to the door. Typical instructions to the person were not to answer the door and not to use the stove.

Item #3: Meal Preparation

It was found that about 80% of this sample living at home were able to prepare some of their own meals but that less than half were allowed to use the stove. The major concern expressed by parents was that teaching the person to use the stove would increase the risk when they were left at home alone. Thus, in <u>certain</u> instances where subjects were taught the use of a stove in school, the parents actually disapproved of this practice and consequently did not reinforce this learning at home. For the more permissive families, where cooking was typically taught at home in the early teens, a great deal of trust about use of the stove developed over the years.

Some families, while not allowing use of the stove, did encourage use of a hot plate with the dial marked at medium heat or else set up an electric fry pan for use by their son or daughter.

In summary, while some of the fears of parents with regard to use of stove have some basis, as far as safety considerations, particularly with gas stoves, it would seem that some of these dangers could be circumvented by use of color marked dials on the stove, or use of appliances having a limited heat range.

Item #4: Laundry

The results in this area were of interest in that there is very little safety risk in helping with the laundry process and yet it was found that only 32% of the subjects had actually become involved in running washers and dryers. This skill has much potential as a practical learning situation, probably within the capabilities of most adult retardates. (It should be noted that the only privately employed subject was employed in a laundry and had had extensive practice and training in this area at home.) Parents, in general, seemed to feel this was "Mother's job", and just did not view this work as appropriate for their retarded son or daughter.

Item #5 and #6: Shopping and Understanding Money

This area was difficult to assess accurately. In general, it was found that 42% had had some experience in either buying their own things, or making some purchasing decisions with parents. The 25% in Level 4 actually had gone to some store, usually a neighborhood grocery, and purchased items on their own. Not this many (only 20%) understand monetary values, however, and usually the parents assisted in providing a list of items to be purchased and the approximate amount of money for purchase.

Item #7: Telling Time

About 38% of the subjects showed an understanding of telling time. It was found that some subjects had learned how to tell time by rote without really understanding the number concepts involved. That is, they were able to "label" the correct time without being able to cognitively manipulate the numbers in any way. Others were able to identify significant times of day such as meal times, time to be ready for bus, etc.

Item #8: Use of Telephone

The majority of subjects seemed to have little experience with the appropriate use of the telephone. The main problem in development of this skill seemed to be in handling the number sequencing accurately. One parent found that the use of a push button type phone facilitated the acquisition of this skill.

Item #9: Speech Articulation

Although most of the subjects were indicated as having some speech articulation difficulties, 66% were felt to be understandable nearly all the time. The differentiation between Levels 3 and 4 and Levels 1 and 2 was based on whether the parents indicated that they themselves at times had difficulties understanding the speech of their son or daughter.

Items #10, #11 and #12: Reading, Spelling and Numbers

As expected, these three academic areas showed a rather low rating of competency. Some impressions of significance which emerged were as follows:

1. There was actually little attempt made to teach these skills either at home or school.
2. A number of parents remarked that they felt learning capacity had improved up into the twenties, and that possibly as adults their son or daughter could learn to read. However, at this later age they had no real direction in how to go about teaching them.
3. Many subjects who had learned to print their name and spell a few words in school have lost this learning in adulthood because of lack of usage and importance in their daily life.
4. Many of the subjects seemed to have some usable number concepts under ten, but these skills also had little practice or reinforcement in adulthood and tended to become extinguished.
5. Teaching basic academic skills can probably be accomplished by rote techniques, but this learning will be lost if it is not related to real life situations in the adult life of the retardate that will strengthen this learning.

Item #13: Self-Care

Although the very high rating of independence in this section on self-care skills may not reflect with complete accuracy some partial help or direction by parents, the results were considered very positive in terms of the overall capability of this population to look after their own personal hygiene. It is felt that, in general, there was little evidence of a degree of dependency which would amount to nursing care. It should be noted that most cases of dependency were residing in institutions, but that not all of the subjects residing in institutions were dependent on others for daily assistance in these areas of self-care.

Item #14: Personal Adjustment

This area, though not really well classified as a skill, does reflect on the freedom from others in supervising the person's interaction with other people. In this sense, the concept of independence in personal adjustment is felt to be valid. As seen in the table, 86% of the subjects showed good to excellent personal adjustment. Again, most of the poor ratings were for subjects placed in institutions, but not all of those in institutions showed behavior or personal adjustment problems requiring extensive supervision. About half of the institution sample were considered to be capable of adjusting to a small group home.

SECTION IV: CONCLUSIONS AND IMPLICATIONS OF THE DATA

At the outset of this summary, one must acknowledge that the data contained in this report cannot be considered completely conclusive or definitive in terms of describing this total generation of moderately retarded persons in Wisconsin. The problems in sampling described earlier necessitate some caution in taking a strict statistical view of these results. It is felt, however, that these results are highly suggestive of the characteristics of this population and must be considered our best evidence to date of what has happened to this group.

Because much of the effort in this study was spent on personal interview with the parents, not clinical style evaluation of the retardates themselves, it was intended that the main focus would be on exploring issues and feelings with parents, while at the same time gathering some fundamental data on the subjects as previously described in Section III.

The following recommendations are considered the most important by the interviewer based on an examination of the data and the impressions gained from discussions with these parents.

Need for Local Residential Facilities

Probably the most single important and obvious conclusion that emerges from this survey is that of the pressing need for a state-wide system of appropriate community based residential settings for the substantial percentage of higher functioning moderately retarded adults.

Residential alternatives for the adult retarded have in the past been based almost solely on a model of medical-nursing service. With the exception of local private nursing homes and county hospitals, residential placement has necessitated the removal of the retarded from proximity to family, relatives and friends, and a significant alteration in life style from that experienced in his or her home.

There are a number of findings contained in the data of this survey which would argue against the medical-nursing care model which is implicit in the current residential alternatives, i.e., state colonies, hospitals and homes, private nursing homes and private institutions for the retarded.

1. 80% of the adult retarded in this sample were reported as having no chronic physical disability requiring medical or nursing supervision.

2. 75% of these subjects were reported as being capable of taking care of personal hygiene with only minimal direction.

3. 86% of this sample was reported as demonstrating a good to excellent personal adjustment and not demonstrating difficulties in management.

4. 74% were considered responsible enough to be left at home alone for periods of two hours or more.

In summary, there is a substantial proportion of this population, though not all, whose needs could apparently be met in residential settings which have a minimum of supervisory personnel and which do not emphasize a medical or nursing basis of service.

The above data suggests the feasibility of a substantial number of moderately retarded adults being served in non-medical settings. There were numerous other impressions from parent comments which point to the desirability of a community based small group-home concept.

1. The community based residential concept would permit a more flexible admission policy, and thereby truly provide a service to the parents. Short-term, intermittent and part-time placements could allow for a continuing involvement of family and relatives with the adult retardate, while at the same time providing some relief from the otherwise constant demands for care and supervision.

2. Continued family involvement would be encouraged because of geographical proximity to the person.

3. Community based residential care would provide a continuity of life experience and allow for continuation of activities and friendships which have been developed over the years. The problem of adjustment to the more highly structured environment of the large institution would be eliminated.

4. Parents in general are very disheartened about current residential alternatives. They are against "commitment" and also feel that placement in a nursing home for the aged would not be appropriate for the needs of their son or daughter.

5. The locally based residential setting would provide parents, from the early stages of the development of their retarded child, with some definite behavioral goals to work toward in order to ensure their son's or daughter's acceptance and optimum adjustment within such an adult placement.

In summary, there is much evidence obtained from these interviews which points to the feasibility and desirability of the local small group-home concept.

At the present time in Wisconsin there are several communities which have already constructed, are in the process of constructing, or are in the beginning planning stages for construction of residential facilities of the type being considered here. The complex task of planning and locating funds has, as in the days of the first parent sponsored classes for the trainable retarded, been assumed by parent members of local Associations for Retarded Children and the Wisconsin Association for Retarded Children. Sources of funds for these facilities at this time appear to be limited to federal grants and local voluntary fund raising drives.

The current lack of state government participation in these projects points to a serious lack in a comprehensive and humanistic philosophical position by the State of Wisconsin toward serving the life span needs of the moderately retarded citizen.

A further basic social question is whether the parents are entitled to have an appropriate local residential option for their retarded son or daughter upon their reaching 21 years of age. This question again calls for a statement of philosophy by state government.

On practical grounds, it is believed that a great deal of potential in the development of the community based group-home movement will be lost without the State's active participation over the next few years.

It is obvious at this time that there is a tremendous amount of duplication of planning and fund raising effort by local ARC groups. There is a strong likelihood that without systematic state supported planning and contribution to construction, many of these projects will be undermined by the necessity of cost-cutting. The result will necessarily be less than optimum facilities for many years to come.

With the above discussion in mind, the results of this study point strongly to the following recommendations:

1. That state government study the feasibility of financial aid and support of local efforts toward construction of community based residential units for its retarded citizens.

2. That a portion of this aid go toward funding a systematic analysis of this concept, exploring matters of cost efficiency, site selection, potential for enriching the adult life of the retarded, optional architectural design, projected usage, and impact on demands for currently available high cost residential care.

IMPLICATIONS FOR PARTICIPATING AGENCIES

Implications for Department of Public Instruction

Because this generation of former TMR students received relatively little special class training and have been out of school for so long, it was not feasible to obtain direct parent evaluation of current public school programs. However, a number of educational implications did emerge from these interviews with parents.

1. Home-school Coordination of Training: Classification of Objectives

Discussion with some parents pointed to some serious lack of coordination of objectives and training efforts between parents and school or activity center programs. In some cases it was found that parents were not in favor of instruction in certain areas involving safety risks. These included use of stoves, training in riding city buses and use of power tools.

These discrepancies in training objectives between home and school emphasize the important need for clarification of developmental objectives and discussion with parents of any reservations they might have. Discussion of these matters would also include techniques for minimizing risks.

This problem area also points to a more general but very important aspect of home-school coordination; that of the mutual reinforcement of developmental gains between home and school. Parents should be informed of new skills learned at school so that they can provide similar learning opportunities at home with appropriate reinforcement of newly acquired skills.

2. Improved Reporting Systems

The need for close coordination between home and school points to the advisability of more frequent reporting of operationally defined and easily communicable educational objectives of the school. Such frequent reporting will require the development of concise and efficient reporting techniques which do not require extensive or inordinate teacher time.

3. Carry Over of School Instruction Into Adulthood

There was some evidence of a lack of carry over into adulthood of previously learned skills. Usually the skills which seemed to drop out of the person's repertoire in later life were school taught behaviors related to academics, such as name printing and basic sight word reading vocabularies.

This problem of previously learned skills being extinguished points out a vital need for establishing curriculum goals which have a high probability of usage and reinforcement in adulthood. In addition, and particularly in the case of academics, it may be well to look toward developing learning habits and providing adult opportunities which will tend to ensure usage in after school years.

In the case of reading skills, for example, the establishment of personal libraries of read-a-long cassette tapes may allow the adult retardate to continue to learn sight words and to have available on a daily basis a motivating source of instruction. As an aside, many parents reported that they felt their son or daughter continued to develop intellectually up until 30 years of age.

4. More Flexible Programming for the Moderately Retarded

This implication relates to the current policy of segregated TMR classes. Recently a great deal of attention has been paid to the concept of "mainstreaming", or integration into the regular school program of special students, using flexible programming based on individualization of training needs. The basic idea is to program each student to engage in activities and associations which are of maximum benefit to him, and to avoid the inherent problems of rigid classification of students, i.e., labeling.

It is suspected that at least to some extent the same arguments against strictly segregated programs which have been used in the case of the educable mentally retarded also apply to the trainable retarded child. This is felt to be particularly true for the higher level functioning trainable retarded student. The question must be raised as to whether the legal cut-offs between TMR and EMR class attendance is not resulting in less than optimum programming for a certain percentage of higher functioning trainable class students.

5. The Public School's Role in Preparing Moderately Retarded for Employment Outside the Sheltered Workshop Concept

The data from this study seem to verify that very few trainable class graduates have attained positions in private industry. The data further indicate that few of these moderately retarded are able to meet the demands of the kinds of work typically found in the sheltered workshop.

One could take two views of this situation. One might conclude that the ability levels of the moderately retarded are so uniformly limited as to preclude attempts at training for any kind of employment outside of a self-contained program.

A second view, however, would suggest that the abilities of this group are not uniformly low, that there is variation in ability levels within and between individuals, and that the basic inhibitors to employment are an absence of carefully selected work options and an absence of training efforts directly geared to those specific work options.

It is felt in most cases it would be unrealistic for the schools to attempt to train the moderately retarded in a specific skill area and to then expect the retardate and his or her parents to secure employment for that individual on a competitive basis.

If, however, *semi-protected* work opportunities were solicited and established within the community, and if secondary and adult training programs were geared to train for specific work in these settings, it is believed that a significant percentage of moderately retarded citizens would perform adequately. The vocational work-oriented program for upper age TMRs in Walworth County is an exemplary program encompassing a number of these program concepts.

The implication for the public schools would certainly be to explore the potentials for the work-study concept for the older moderately retarded students, with particular emphasis on the role of a teacher-counselor who would have released time to establish and supervise semi-protected work opportunities in the community which are particularly well suited for the retarded.

Some of the conditions for success of a program of this kind might be as follows:

1. That opportunities should be solicited in settings which would at the outset be expected to show an understanding and acceptance of the disability of retardation, e.g., hospitals, nursing homes, child care centers.
2. That the solicitation of work settings be a coordinated effort of the schools, DVR, Day Care program staff, and the local ARC's.
3. That the schools' training programs be coordinated with those of adult training programs. This would be especially important for those individuals who continue to mature socially in their twenties, after attendance at the public school program is completed.
4. That there be imaginative efforts to encourage employers to establish hiring of the retarded as an ongoing program. This might include flexible wages based on productivity, and possibly some salary reimbursement for other employees involved in supervision or on-the-job training.

It is not suggested that the schools would be able to increase the rate of private employment of the retarded on their own. Rather, it would require a coordinated effort of all agencies currently charged with the responsibility of service to the adult retarded.

One important further consideration would be that if such efforts were designed for those students currently designated as low EMR, it would seem a relatively simple matter to offer these same opportunities to the higher functioning individuals now designated as TMR.

6. Impact of Community Based Group Home Movement on Public School Curriculum

In the past many TMR class curricula were lacking in the specification of behavioral objectives for the TMR graduate, particularly at the secondary level. This situation was due in part to the fact that most TMR students graduated to a long-term stay at home, or else to commitment to institutions. Neither situation made any specific demands on the schools in terms of specific behavioral attainments desirable upon graduation.

This situation is changing. The development of the concept of semi-independent living in a minimally supervised group home holds the potential for establishment of some very specific behavioral objectives based on admission criteria as well as desirable skills for participation in such living arrangement.

It would seem important that public school programs begin to focus on the changing scene in adult opportunities for the retarded, and to identify those skills which will be of most importance to the successful adjustment of adults within a semi-independent living situation.

It may be advisable to establish communication with those community residential centers just getting underway to obtain recommendations for instructional goals which will have maximum importance to ultimate group home adjustment.

Implications for WARC

In reflecting on the individual family situations and the overall results of this study, two points related to the role of WARC seem to stand out.

1. Although the majority of parents of retarded adults seem to be up-to-date on current information related to legislative acts which benefit the retarded, it is felt there is still a significant percentage of parents who are unaware of recent improvements and current movements in adult services. We are referring specifically to that percentage of parents who were not aware of Disabled Aid and Medical Card benefits as well as those who were not aware of the current community based group home movement.

With this particular group of older parents there seemed to be a certain degree of discouragement regarding future improvements in services. Many had been very actively involved in the initial efforts to secure public school classes for their retarded child. However, in the end their child actually benefited from only a few years of the classes after they were begun. These parents frequently dropped out of involvement with local ARC's and thus lost their most important information source.

Thus it is suggested that there is a need for a more systematic method of insuring that all parents of retarded individuals receive up-to-date and authoritative information on new benefits, pending legislation and current issues requiring parent opinion and support.

This information source might be most logically in the form of a WARC bulletin, mailed out to all parents who have given permission to be placed on a master address list. Besides containing information on vital issues, the bulletin could be used as an information gathering survey system, as well as a parent education forum.

In addition, by providing parents with names and addresses of their state and national legislators at crucial times of pending legislation, the lobbying power of the parents should be effectively increased. The main purpose of the master address list would be to continue to involve parents who are no longer active in local ARC's.

2. In view of the urgent need at this point in time for usable information regarding the numerous questions related to optimum development of the community based group-home concept, it might be advisable to devote a portion of all of WARC research funds to <u>pre-selected</u> topics for study; this approach would be in place of awarding grants for research topics submitted to WARC.

Suggested study topics might relate to economic considerations, projections of usage, optimum architecural design in relation to the potential uses of the building, site selection and exploration of the group-homes as centers for recreation, volunteer activities, parent training, etc.

Implications for Day Care Services

Day Care Service is providing financial support and quality guidelines for numerous adult activity and sheltered workshops throughout the State. Recent years have seen a significant effort to expand services to the adult retarded and to improve the quality of existing programs.

In general, the parents' reactions to these programs were quite favorable. Very few parents were able to make specific criticisms or suggestions for improvement of their local programs. A few, however, did express the following negative comments:

1. In Milwaukee, several parents expressed the view that programs were too centralized. They offered the suggestion of more branch or area centers in order to reduce problems in transportation.

2. Parents from several different areas expressed a desire to see more adult practical living skills taught with a de-emphasis on recreational or craft type activities.

3. Several parents expressed some strong feelings that their son or daughter was not well suited for the kinds of work available to them in the sheltered workshop programs. They expressed some frustration over the fact that there were no work opportunities available locally which would better fit in with their son or daughter's interests or abilities.

It is felt that this third criticism, although expressed by relatively small percentage of parents, carries the most important implication for improvement of adult work programs. A basic source of work opportunities in the sheltered workshop concept is that of subcontracts involving assembly or packaging to manufacturers. Because many of the moderately retarded lack the requisite degree of eye-hand coordination, they frequently are not able to participate on a full-time basis in this type of work.

A fundamental question to be asked is: Should not the work opportunities of the moderately retarded be related to the strengths and abilities of the individual, and not be determined by a rather limited work source which may involve activities which are not always well suited to the moderately retarded individual?

This question leads to the more basic issue of segregated versus integrated models for adult programming. An extensive discussion of these two models follows in the concluding section of this report.

Implications for Department of Vocational Rehabilitation

For this particular sample of adult moderately retarded it was found that the major impact of DVR services related to its involvement in the Sheltered Workshop evaluations at the time of the retardate's initial involvement at the Workshop-Activity center.

Only three parents reported actually having talked with a DVR counselor. A significant number of parents had either not heard of DVR or were unaware of how to contact a DVR counselor.

In reviewing this situation, it is important to also look at the total picture of DVR services and policies and how they relate to the specific circumstances of the moderately retarded adult.

Because of the very extensive involvement of DVR with a large spectrum of disabilities, its coordinating function between existing training programs and available work opportunities within the community, its policy of case closure, and the voluntary nature of its client involvement, it may be questioned whether or not DVR should be the primary source of state effort at securing the optimum work opportunities for the moderately retarded.

In order to maximize the possibility of employment for the moderately retarded, it would seem necessary for the following conditions to exist:

1. That a variety of potential work settings be contacted and solicited with regard to their desire to employ retarded individuals under externally supervised conditions.
2. That the training institutions be closely involved in the coordination of their efforts with the demands of the work settings which are involved, and further be involved in the evaluation and assessment of particular individuals for particular jobs.
3. That persons involved in locating placements also become involved in the supervision of placements to whatever extent is indicated.
4. That the persons involved in locating work settings have an intimate knowledge of both the local community and its potential resources, as well as of the retarded individual and the wishes of his or her family.

It is suspected that these conditions, particularly conditon #3, go far beyond the statewide potential of DVR as it is presently conceived.

SECTION V: A PROPOSAL FOR AN INTEGRATED MODEL OF SERVICES TO THE MODERATELY RETARDED

The intent of this section is to explore our past model of life-span services for the moderately retarded and to propose a new model which incorporates some of the conclusions of this study as well as the current progressive trends in improved services to the retarded.

The results of this study strongly support the view that the current state and local services to the moderately retarded child and adult are based almost exclusively on a rigid model of <u>segregated</u> programs. A main characteristic of the segregated model is relatively inflexible programming and limited options as the moderately retarded person develops into adulthood. A further characteristic of the segregated model is that it usually involves labeling and classification as an essential part of segregating procedure.* There is an emphasis in the segregated programs approach on maintaining group size in order to secure reimbursement by governmental agencies, frequently at the expense of vigorous attempts to secure the best possible situation for the individual retardate.

The following schematic illustration shows the traditional life-span options for the moderately retarded:

The Segregated Model of Services to the Moderately Retarded

Residential Options	Schooling	Community Services
(Options usually involve legal committment and segregation from local community)	(School programs based upon too rigid classification schemes segregated with large difference in program content between two adjoining levels of programming, e.g., TMR vs. EMR)	(Adult community programs)
1. State Colonies	1. Day Care School Programs	1. Activity Centers
2. County hospitals	2. Public School TMR Programs	2. Sheltered Workshop
3. County and Private Nursing Homes for Aged	3. Possible EMR Placement	
4. Private Institutions for Retarded	4. Public or Private **Training School** Placement in School Age Years	
5. Adult Foster Home		

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* A policy which is in opposition to that of the Wisconsin Association of Retarded Children as stated in the organization's publication "Policy Statements on the Education of Retarded Children."

Although this model has in part met the needs for the more seriously disabled trainable class students in the past, at this point in time it is felt there are a number of forces operating which suggest a need for change in this model for future generations of retarded children. These forces are:

1. Increasing public enlightenment and acceptance of the retarded.

2. Increasing knowledge on the part of parents and their desire for a better education, more "normalized" adult life for their retarded son or daughter, and more residential options which resemble the kind of living environment they have had in their years at home.

3. Expanded and improved educational programs, and particularly improvements in training technology, allowing for more intensive goal-oriented training.

The segregated model of services has its historical foundations in some serious basic misconceptions about the potential of most moderately retarded and, subsequently, about the proper way of dealing with mental retardation as a "social problem." These misconceptions include: 1) relatively short life span; 2) should be kept at home during school years or sent away to a state institution; 3) should be treated in a protective manner because social judgment will never be developed.

In a number of parent interviews it was found that the above misconceptions were frequently given as "recommendations" by the family physicians of this generation of retarded subjects.

Although current programs for the retarded have gradually and progressively demonstrated a rejection of these original misconceptions, our thesis here is that the basic philosophy behind many programs and services for the present day moderately retarded child and adult still reflects the historical model of segregated programming.

An Integrated Model of Services

The integrated services model contains several basic concepts which the investigator believes to be an improvement over the traditional model and which appears to be in accord with the feelings of parents as expressed in the interviews.

1. That school programs for the moderately retarded should provide a flexible continuum of program content and involvement with other mildly retarded and normal children which allows each individual to develop maximum potential both academically and socially. Segregated programs for the moderately retarded frequently involve an arbitrary cut-off decision which results in a radically different program from the next succeeding program. This arbitrary cut-off involves labeling and a concurrent significant reduction in behavioral expectations.

2. That adult residential options should also reflect a continuum of available living environments which take into account varying degrees

of need for medical and other kinds of supervisory personnel. The results of this study indicate that a large percentage of retarded adults living at home, as well as some subjects now living in institutions, would be able to adapt to local residential settings which would be more homelike and require less costly medical and supervisory personnel.

The continuum of residential options should also reflect the parents' desire to remain in close contact with their retarded son or daughter and to be able to enrich their life by more frequent participation in family activities. This can only be accomplished via community based residential settings with flexible policies of "admission" and "release".

3. That adult work options be expanded to take into account the significant variations in skills, interests and social development that are exhibited by this adult population. It is felt that the concept of "semi-protective" employment in various work settings, public and private, should be added to the current option of the Activity Center and the Sheltered Workshop toward the end of increasing the alternatives for meaningful adult activity.

At this time it is felt that there are several barriers to the implementation of an integrated model of services.

1. The too frequently locally applied arbitrary distinction of TMR and EMR which does not recognize the compatability of training needs between higher functioning TMR and lower functioning EMR students.
2. The absence of work training programs which include personnel whose role is devoted to seeking out feasible work options in the community and coordinating these work options with secondary and adult training programs.
3. The absence of a comprehensive plan at the state level to explore all the potentials of the community based residential facility and to coordinate the current efforts by various parent groups throughout the state.

A suggestion for actions by various state agencies which would serve to remove these barriers includes the following:

1. Department of Public Instruction policy provides for some flexibility in the cut-off I.Q. scores for TMR versus EMR class placements. Although there are no explicit barriers to implementing a flexible program continuum which would tend to integrate higher functioning moderately retarded with lower functioning mildly retarded children, it is felt there should be stronger encouragement of local school districts to develop such a continuity of instruction throughout the full range of mental retardation which would tend to erase the TMR-EMR distinction.

The emphasis in individual evaluation should shift from intelligence evaluations to behavioral-functional evaluations derived from the program's curriculum, and supervised by an inter-disciplinary team consisting of teachers, psychologists and special education supervisors.

Thus it is felt that the Department of Public Instruction should encourage a new level of local program flexibility which would take into account the compatability of training needs of some individuals in the general I.Q. range of 40 to 65, and to discourage the continued practice of a sharp division between TMR and EMR programs.

2. A re-examination of policy by agencies currently involved in adult services for the purpose of shifting of some funds and personnel to support local efforts to increase work options through semi-protective employment for the retarded requiring some supervision, but not segregation.

3. Substantial involvement of state government at this time in the planning, developing and funding of locally based and controlled adult residential facilities based on the concepts of community integration, minimal supervision, and semi-independent living.

In conclusion, the implications and recommendations described in this and the preceding section should be considered a basic summarizing statement of what the parents of this generation of retarded persons feel should be the course of improved services to retarded children and adults. The one consistent theme which emerged from these numerous personal contacts was that of a desire for programs which allow for the greatest opportunity for development of the *unique* capacities and interests of their particular child rather than their child having to fit into programs which are limited in opportunities for effective individualization.

References

Blessing, Kenneth R., Ph.D. Follow-Up Survey of Former Trainable Mentally Retarded Enrollees, *Bureau Memorandum*, December 1962

Saenger, G. *The Adjustment of Severely Retarded Adults in the Community*. New York State Interdepartmental Health Resources Board, Albany, N.Y., October 1957, 176 pp.

APPENDIX A

Interview Schedule - Parent Form

If reader is interested in copies of the schedule, please contact:

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126 Langdon Street
Madison, Wisconsin 53702

APPENDIX B

Questionnaire - Institute Form

If reader is interested in copies of the schedule, please contact:

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