Speaker Pro Tem

GREGORY D. STUMBO
Majority Floor Leader

WOODY ALLEN
Minority Floor Leader

JODY RICHARDS

SERVICES TO ADULTS WITH MENTAL RETARDATION IN KENTUCKY

PREPARED BY:

Yair G. Riback, Ph.D.
and
Gerard Donovan

RESEARCH REPORT NO. 234

Legislative Research Commission
Frankfort, Kentucky
March, 1988

This report was prepared by the Legislative Research Commission and paid for from state funds.

FOREWORD

This study was mandated by the 1986 Regular Legislative Session. It directed the assessment of services to adults with mental retardation and the need for additional services of particular interest to those who graduate from the educational system, which provides for them, under PL 94-142, until they turn twenty-two.

Our thanks are extended to the Cabinet for Human Resources and the many other agencies and individuals who assisted us by providing information and shared their concerns with the research staff. The list is too long to mention all of them individually.

Special thanks to Commissioner for Mental Health and Mental Retardation, Dennis Boyd, Ms. Denise M. Keene, President-Elect of KARC, and Mr. Graeme Hopple, President S/LTRC, who reviewed the draft of the report and sent us useful remarks.

The study was conducted by LRC staff, Yair G. Riback and Gerard Donovan. Gwyn Boyd and Gail Mathers typed the study.

Vic Hellard, Jr.
Director, LRC

The Capitol
Frankfort, Kentucky
February, 1988

NOTE: By its nature, the following study must use generalizations and statistical data which often obscure the personal circumstances of the individuals involved. Since the study cannot include individual histories, we would like to take this opportunity to salute the individuals we have interviewed, many of whom have fought hard to overcome barriers and difficulties.

Further, we would like to add that we realize that some of the terminology we have used, although generally accepted, might prove offensive to some. If this is the case, we offer our apologies.

Yair Riback, Ph.D.
Gerard Donovan

TABLE OF CONTENTS

FOREWORD i
TABLE OF CONTENTS iii
LIST OF TABLES, CHARTS AND MAPS iv
EXECUTIVE SUMMARY vii

I. BACKGROUND OF THE STUDY 1

Previous LRC Studies 2
Defining Mental Retardation 3
The Population Of Persons with Mental Retardation and Its Distribution 6
Discussion 12
Recommendation 12

II. SERVICES TO THE MENTALLY RETARDED 15

Introduction 15
What Services are Needed 16
How Many Need Services 21
Service Agencies and Clients 28
Regional Services 30
Intermediate Care Facilities 40
Long Term Care Homes 48

III. MONEY MATTERS 51
Sources of Funds Available to the MR 51
Costs, Allocations, Budgets and Expenditures 53
How Much More Will It Cost? 55
Kentucky Compared With Other States 59
Discussion of Recommendations 69

IV. OTHER ISSUES 71

Legal Issues 71
Recommendations 71
Zoning and Group Homes 72
Abuse and Neglect 75
"Turning 22" 75
State Use Law 78
Work Habilitation Services 78
Mental Retardation: Challenge for Corrections 80

FOOTNOTES 83
APPENDICES 85

LIST OF TABLES, GRAPHS AND MAPS

TABLES:

1. Levels of Retardation by IQ Scores and Percentage of Total Population. 4
2. Summary of Major Characteristics of Mental Retardation 5
3. Degree of Retardation, Educational Classification and Commonly Estimated Percentages 7
4. Estimated Numbers of Adults with Mental Retardation in Kentucky. 7
5. Estimated Numbers of Persons with Mental Retardation in Kentucky by Region, Age and Level of Retardation 9
6. Population of Persons with Mental Retardation and Developmental Disabilities in Kentucky 10
7. Rank Order of Primary and Secondary Diagnoses Reported for the MR/DD Population 11
8. U.S. and Kentucky Number of Persons with Mental Retardation Based on the Assumption that They Comprise 3% of the Population. 12
9. Array of Direct Services for the Retarded 17
10. Array of Services 19
11. Estimated Number of Persons Needing Any Ongoing Special Services Due to Mental Retardation. 22
12. Estimated Number of Persons with Mental Retardation in Need of Community Residential Services 22
13. Estimated Number in Need of Community Residential Service by Level of Support in Kentucky 23
14. Persons in Need of Services by Services, All Regions 25
15. Projected Need of Adult Employment and Training Services for Persons nLabeled Mentally Handicapped in Kentucky. 26
16. Estimate Service Needs by Region (All Ages). 27
17. 1986, Persons by Region and by Service (CHR) 33
18. Number of Adults Served by Service Area in Each Region 34
19. Daily Cost in Three Types of Care Facilities for Persons with Mental Retardation 47
20. LTC Home: Room, Board, and Medical Sources of Payment. 49
21. 1986 Allocations by Source of Funds. 54

22. LRC 1984 Estimates of Recipients/Expenditures for MR/DD Services Through MH/MR Boards Projections Based on Passage of H.B. 33 56

23. CHR Cost Estimates 57

24. Closing Service Gaps in Essential Services (Adults) 58

25. Statewide Allocations of MH/MR Boards, Division of Mental Retardation 60

26. Comparisons of Regional Allocations 61

27A. MR/DD Expenditures for Institutional Services as a Percentage of Personal Income, Ranked by State: FY 1984 62

27B. MR/DD Expenditures for Community Services as a Percentage of Personal Income, Ranked by State: FY 1984 62

28. United States MR/DD Expenditures for Institutional and Community Service as a Percentage of Personal Income, Ranked by State: F.Y. 1984 63

29. MR/DD Expenditures for Institutional and Community Services as a Percentage of the Total State Budget, Ranked by State: FY 1983 64

30. MR/DD Institutional and Community Services Expenditure Per Capita, Ranked by State: FY 1984 65

31. State Comparison of Rates of Residential Service Per 100,000 of the General Population in 1982 66

32. Mental Retardation Services, 1983 Budgeted Per Capita 66

33. Report of Handicapped Children and Youth Existing in Kentucky Educational System During the 1985-86 School Year 67

34. Report of Anticipated Services Needed by These Handicapped Children and Youth in Kentucky for the 1986-87 School Year 68

CHART:

Organizational Chart: Department for Mental Health and Mental Retardation Services 32

MAP:

Kentucky Mental Health/Mental Retardation Districts—1987 31

APPENDICES

1. Definitions of MR and Related Disabilities 85
2. Definition of Services Provided by the State 93
3. Service Needs and Their Priority Ranks as Presented in the Seven Counties Plan 125
4. Five Years of Funds for the MR by Regions 133
5. Legislative Research Commission Fiscal Analysis Note 151
6. CHR Cost Projections 159
7. A Comparison of Two Cost Projections 167
8. Partial List of Legislation and Regulations Which Affect the M.R. 183
9. Massachusetts Turning 22 Law Three Years Later, 1986 187
10. Regional Service Agencies Which Serve Various Client Groups (including MR) 199

EXECUTIVE SUMMARY

Are services to the adults with mental retardation adequate?

This study's major finding is that while existing services are adequate, they reach only a small part of the population of adults with mental retardation.

The data which was available is skimpy, not only in that different sources disagree but they also often rely on estimates and projections whose accuracy can be challenged. For example, while it can be safely stated that the majority of the adults with mental retardation are underserved and reside in long-term care facilities, the estimates of their number range from 3,478 to 7,696.

The commissioner of the Department for Social Insurance, when asked how many adults with mental retardation are in LTCF, responded by a letter (August 20, 1987) that "the Department for Social Insurance does not have means to identify residents in long-term care facilities by diagnosis . . . . Staff from this office [the Department of Social Insurance] contacted staff in the Department for Medicaid Services and the Department for Social Services. Staff of those Departments also indicated that there is no computer system in their Departments to identify residents by diagnosis." Thus, short of site visits to review the 30,784 long-term care residents, there seems to be no way to know how many of them are adults with mental retardation.

While the study makes several recommendations, it can not determine how many people require service or what services they should receive.

Such a decision cannot result from a study. It is an administrative and budgeting decision. This study could only point out the problem.

The present service system is full to capacity and can hardly accommodate more clients. This problem is more acute in some rural areas for which the ICF/MR are an essential alternative.

The study also points out the difficulty of making accurate cost projections. It was discussed in some length that cost estimates are highly speculative and that four different estimates were offered, ranging from $6.5 million to about $164 million in additional costs. Thus the study cannot make any recommendation for a specific amount but only state that more resources are needed.

The major findings and conclusions are:

- There is no accurate data and all figures are estimated.
- There are up to 10,500 adults with mental retardation who do not receive services.
- Residential services of all kinds now serve about 1,500 individuals.

- Only a small part of the adults with mental retardation are served, while the great majority who need services are not receiving them. Most of the former are in long-term care facilities.

- By CHR figures the average SGF per individual served in the community is $27,655 in ICF and $13,221 in long-term care (CHR long-term ombudsman).

Most services which are offered are federal programs and the state must adhere to their rules. Dollars in the communities are limited and little money can support only a small number of people.

While the present study was underway, a CHR Task Force was preparing its own recommendations to implement KRS Chapter 347. With a larger staff and better access to information, they are in a better position to make more specific recommendations.

There are, however, three groups urgently in need of funding:

- Those who are on waiting lists and not receiving services;

- Those who will be deinstitutionalized as a result of a judicial review of their case; and

- Those who will need services as they graduate.

Intermediate Care Facilities received less attention in this study but they are essential for many severe and profound cases and they are, in the eyes of many, more stable than community services. It is the opinion of these researchers that these facilities should be strengthened in order to be able to accomodate those who need them. It must not be the case that those who need this type of service will not be able to find it. Should the number of beds be increased? We cannot tell without more accurate information and it is up to CHR to make a case for that.

The study has recommended an annual growth rate to meet the needs of school graduates and for additional programs. Such rate is hardly sufficient but essential.

The gaps between the number of people served and those on waiting lists are also large and the reasons for this are different from region to region. Some indicated that there is no use having waiting lists. Others say that such lists do not reflect the actual need for services.

Concerns about the community-based services' ability to meet the needs of the severe and profound cases have been expressed. It should also be noted that community-based services which are a relatively new approach, still lack in experience to provide for clients over many years and through life transitions.

At the same time, as much as the community-based services profess to serve the severe and profound, we have seen quite a few who seem to be at the moderate or even mild levels. This is not a negative condition by itself, because it is the conclusion of the study that the determination of the residential setting ICF or community should be made on the basis

of the individual's condition. To this end there should also be some revisions of the statutes (see Chapter IV).

The finding is that there is a substantial number of adults with mental retardation who are not served and are in long-term care facilities. Their condition is not known. There is a need to determine the fate of those people. It is not up to this study to tell what should be done about them, but we are concerned about the magnitude of the problem and recommend that CHR examine it and present a plan which will, at least prevent more people from being placed in long-term facilities, and explore the feasibility of eliminating the problem.

CHAPTER I

BACKGROUND OF THE STUDY

In its 1986 regular session, the Kentucky General Assembly requested the Legislative Research Commission to study services to adults with mental retardation in the state (SCR 57).

While the implementation of federal law PL 94-142 guarantees services to people with mental retardation and to those who suffer from other developmental disabilities (DD) during their school years, the General Assembly was concerned about the continuity of service for individuals turning 22. SCR 57 directs the study to this portion of the population; others are touched upon only incidentally.

The resolution directed the Legislative Research Commission to study the necessity for services for adults with mental retardation to assess current services and to study the need for additional services. The report which follows is submitted to the Kentucky General Assembly as a response to that directive.

The 1986 session also passed a comprehensive bill (HB 53, codified as KRS Chapter 347), known as "the bill of rights", for persons with developmental disabilities, of which the adults with mental retardation are part. While this bill, along with other state laws affecting people with mental retardation, will be discussed in Chapter IV, its passage is a recognition of the necessity for services to the adults with mental retardation and DD, and is thus one response to the first question presented for this study.

It should be noted, however, that while KRS Chapter 347 recognizes the rights of persons with developmental disabilities to lead as nearly normal a life as they can, it does not mandate that the state provide needed services. In its first section, KRS Chapter 347 states that the service system needs improvement and provides guidelines for service; it also lists some essential services and recognizes the DD person's right to lead as normal a life as possible. It calls for the development of a comprehensive plan to provide those services and make those rights an obligation of the state. But in its last section, it says:

> The responsibilities of the cabinet for human resources, the education and humanities cabinet and the department of education to carry out the provisions of this Act shall be limited to the amount of funding appropriated to carry out the provisions of this Act. When such funds are exhausted no action shall be taken to compel the provision of additional services. [KRS Chapter 347(7).]

Examining those two actions of the General Assembly itself provided an answer to the first research question presented for this study.

1. Are services to the adults with mental retardation necessary?

   Yes. KRS Chapter 347 recognizes their necessity and provides service delivery guidelines and lists essential services. In July 1987, the Cabinet for Human Resources (CHR) established a task force to prepare an implementation plan.

This report concentrates on the second question:

2. Are services adequate, and are more services needed?

   Services reach only a small portion of the population. Community-based services, while adequate for the most part, face budgetary and regional problems (e.g. weak economy, transportation). Essential services are available in most regions. Institutional care remains an essential modality.

The rest of this report is an elaboration of this point.

Previous LRC Studies

In 1951 the LRC conducted its first study relating to the adults with mental retardation. At that time adults with mental retardation did not have many options:

> Kentucky recognizes her responsibility for the mentally deficient in two ways. One—through provision of institutional care for the feeble-minded at the Kentucky Training Home. The other—by subsistence grants to pauper idiots.[1]

Not only has such offensive terminology been dropped, but other changes have made the treatment and options more humane and more responsive to human dignity and rights.

Without community alternatives back in the fifties, the grim picture of those days is apparent by the fact that custodial services were the only option available besides the "subsistence grants to pauper idiots."

> The Kentucky Training Home, formerly the State Institution for the Feeble-minded, is located at Frankfort. Its object is to provide mental and physical training for the feeble-minded; actually, its service is primarily custodial. It is the only public institution of its kind in the State. However, Kentucky State Hospital at Danville cares for about 150 of the most difficult cases.[2]

A second study, recommends closing the Kentucky Training Home, after 98 years, and placing those who have nowhere to go in 'carefully chosen and supervised foster homes.[3] If this recommendation had been carried out, 906 residents would have been released, 212 more than the facility's official bed number.

> It is remarkable that there were 1,200 mentally subnormals in State mental hospitals which are not designed to rehabilitate them. While this problem does not exist at present, the MR still seem to live with the consequences of being attached to the mentally ill.[4]

Unfortunately, people with mental retardation still are treated as though they are mentally ill. Their institutionalization is legally equivalent to the confinement of the mentally ill.

Sometime between 1958 and 1974, the Kentucky Training Home was finally closed; a 1974 study makes no mention of it, but some old problems seem to have remained. The study recommended closing the Outwood facility. Its renovation was estimated to require $5 million and the recommendation was to build a new facility which would function "in such manner that it will be readily assimilated in the community."[5] A new, modern facility now operates in Dawson Springs.

It is worth noting that the Cabinet for Human Resources originally planned to replace Outwood's run down buildings with a new one to house about 400 people. The Kentucky Association for Retarded Citizens (KARC) won a lawsuit against CHR and, as a result, the new Outwood facility houses only 88 people. KARC wished to direct more money to community programs, however, money trimmed from institutional budgets does not necessarily go into community programs.

In 1974 the community comprehensive care system was already in place and offered these basic services: inpatient, outpatient, partial hospitalization, consultation and education, information screening and referral rehabilitation.

Another study, *Mentally Retarded Offenders in Adult and Juvenile Correctional Institutions*, LRC RR #125, 1975 will be reviewed in Chapter IV.

Defining Mental Retardation

Mental retardation is a term which is used to describe many human conditions with different, often unknown, causes. KRS 202B.010 defines a person with mental retardation as:

> . . . a person with significant subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

This definition was based on one by the American Association on Mental Deficiency, which was adopted by most of the states.

A recent trend is to deemphasize the diagnosis and base the definition upon a person's ability to provide for his basic personal needs and define them as persons who are unable to provide for their basic personal needs for food, clothing, or shelter, or to make

rational or responsible decisions concerning their welfare, or to understand that they lack this capacity.

A person is considered mentally retarded if all three conditions exist:

1. **Subaverage general intellectual functioning.** This is measured by what commonly is known as IQ scores. The intelligence scale, in spite of criticism about its validity, is the only measure which gives a standard and more or less objective measure of retardation (Table 1). This scale is the basis of the distinctions of retardation levels. The divisions of the various levels, however, are artificial cutting points and should be taken as statistical benchmarks. The individual's true condition must remain paramount to test scores.

TABLE 1

LEVELS OF RETARDATION BY IQ SCORES
& PERCENTAGE OF TOTAL POPULATION

Retardation Level	IQ Range	Educational Classification	% of Total Population
Borderline	70-84	Not considered persons with mental retardation	
Mild	55-69	Educable	2.7
Moderate	40-54	Trainable	.18
Severe	25-39	Totally Dependent	.10
Profound	Below 25	Totally Dependent	.05
TOTAL PERSONS WITH MENTAL RETARDATION			3.0%

2. **Deficits in Adaptive Behavior.** This criterion relates to the consequences of mental retardation and is the basis for the educational classification of persons with mental retardation in Table 1.

3. **Manifested during the developmental period.** The onset of mental retardation is at the early age of human development and it is a permanent, incurable condition.

Table 2 summarizes the major characteristics of each classification.

It is generally anticipated that mild cases, with some training, are capable of independent living in the community and holding competitive employment. Moderate cases, with more intensive training, can live in group homes, but would require some ongoing supervision and support to do so. They can also work in sheltered workshops. Some of the severe and profound adults with mental retardation, who often have secondary physical handicapping conditions, can participate in activity centers and live in group homes, while others would require more intensive care.

TABLE 2

SUMMARY OF MAJOR CHARACTERISTICS OF MENTAL RETARDATION

IQ Level	% of persons with MR and General Characteristics	Adaptive Behaviors
Mild (55-69)	89% are mildly retarded. Capable of competitive employment and independent community living.	Exercises care for personal grooming, feeding, bathing and toileting. Goes about home town with ease; communicates complex verbal concepts and understands them; carries on everyday conversation, but cannot discuss abstract or philosophical concepts; interacts cooperatively or competitively with others and initiates some group activities, primarily for social and recreational programs; can be sent to several shops to make purchases; can make change correctly; may earn living but has difficulty handling large amounts of of money without guidance; can cook simple foods, prepare simple meals; as an adult, can engage in semi-skilled or simple skilled jobs; initiates most of his own activities; conscientious about work and assumes much responsibility but needs guidance for tasks with responsibility for such major tasks as health care, care of others, and a complicated occupational activity.
Moderate (40-54)	6% are moderately retarded. Can work in sheltered workshops; with guidance may live in group homes.	Feeds, bathes, dresses self; may prepare easy foods; may wash and/or iron and store own clothes; good body control; good gross and fine motor coordination; may carry on simple conversation; uses complex sentences; recognizes words; may interact cooperatively and/or competitively with others; may be sent on shopping errands for several items without notes; may make minor purchases; adds coins to dollar with fair accuracy; may do simple routine household chores.
Severe (25-39)	5% are severe or profoundly retarded. Often also have physical handicaps. Some may participate in group activities, live in group homes. Others need more intensive care.	Feeds self adequately with spoon and fork; can put on clothes; may tie shoes; bathes self with supervision; is toilet trained; can run, skip, hop, dance; may participate in group activities spontaneously; may be sent on simple errands and make simple purchases, may prepare simple foods; can help with simple household tasks; makes efforts to be dependable and carry out responsibilities.
Profound (below 25)	(Percentage with severe)	May feed self with spoon or fork; tries to bathe self but needs help, partially toilet trained; may hop or skip; may have speaking vocabulary or over 300 words and use gramatically correct sentences; may use gestures to communicate needs; understands simple verbal communication; participates in group activities and simple group games; interacts with others in simple play and expressive activities.

SOURCE: Adapted from: "Deinstitutionalization and Institutional Reform" by R. C. Scheerenberger, Charles C. Thomas, Publisher, 1976.

These general characteristics describe a widely diversified population with a broad range of capabilities and conditions.

It must be emphasized that all three conditions must be met for a person to be classified as a person with mental retardation. There are cases of individuals with low IQ who are socially adjusted, or individuals with normal IQ but impaired social behavior; neither of these types fits the definition. Also, there can be individuals who meet these two criteria but whose difficulties began at a later age (e.g., a result of illness or an accident).

It is equally important to emphasize that mental retardation is a permanent condition which is not amenable to treatment and not curable. Persons with mental retardation will remain so for the rest of their lives.

While it is not difficult to recognize severe and profound retardation cases, it is more difficult to determine the moderate and mild cases, because socio-economical and environmental factors are involved. Such determination is often judgmental and arbitrary and suffers from various biases. There have been cases in the news of children diagnosed as having mental retardation with learning disabilities, while in fact they merely suffered some physical handicap (e.g., hearing, sight or speech impediment). A recent case which received national attention was of a woman of normal intelligence who was confined to a facility for persons with mental retardation for many years because of undetected deafness.

Judgmental factors are even more acute when criteria of adaptive behaviors are used. Some individuals can well be judged as unadjusted to certain environments (e.g., school), while fully adjusted to their natural environment. There is a recent tendency, as in the State of Hawaii, to de-emphasize personal traits and put more emphasis upon the consequences of their condition.

Appendix #1 provides a comprehensive definition of persons with mental retardation and related conditions.

The Population of Persons with Mental Retardation and Its Distribution

One difficulty of gathering information for the present study was the lack of reliable data, an issue discussed in later sections. The present section uses only estimates of the prevalence of persons with mental retardation based on rates which are acceptable by most of the sources reviewed.

Estimates of the prevalence of mental retardation range from as low as 1% of the total population to as high as 3% (excluding borderline cases). This study uses the 3% estimate, which is used by most of the sources reviewed. The Kentucky Division for Mental Retardation in its annual plan, "Kentucky on the Move: Toward True Community Services" (Kentucky CHR, Department for Mental Health and Mental Retardation, June 1987), uses a .9% based on a 1973 study.[6]

Table 3 presents the rates used by this study:

TABLE 3

DEGREE OF RETARDATION, EDUCATIONAL CLASSIFICATION, & COMMONLY ESTIMATED PERCENTAGES

Degree of Retardation	Educational* Classification	I.Q. (Stanford-Binet)	Percent Total Population	Percent of Retarded Population
Mild	Educable	55-69	2.67	89.0
Moderate	Trainable	40-54	.18	6.0
Severe	Totally Dependent	25-39	.10	3.5
Profound		Under 25	.02	1.5
TOTAL	—	—	3.00	100.0

Source: President's Committee on Mental Retardation (1972)

*This classification is not used by CHR but rather by the Department of Education.

Table 4 presents estimates of the population of adults with mental retardation in Kentucky by applying Table 3 rates to Kentucky's demographic data.

TABLE 4

ESTIMATED NUMBERS OF ADULTS WITH MENTAL RETARDATION IN KENTUCKY (Population base: 3,814,400)

Total number of retarded	114,300 (all levels)
Total number under 5 years old	12,931
Total number 5—19	33,643
Total number 20—64	57,216
Total number 65 and over	10,642
Total number with mild retardation	102,759
Total number with moderate retardation	6,865
Total number with severe retardation	4,005
Total number with profound retardation	1,716

Assuming that all the profound and severe cases need services and only half of those at the moderate level require services, the estimated number of people in need of services is anywhere from 9,150 to 15,600. The high estimate includes all people with moderate retardation and 3% from the mild. The number of adults can be estimated between 6,450 and 10,920. Other assumptions yield different figures and the estimates must be taken as merely showing the magnitude of the problem and not as exact figures.

Table 5 presents the distribution of the population of persons with mental retardation by age and level of retardation among the 14 regional service centers. (Note that inconsistencies between Tables 4 and 5 are due to different sources, a problem mentioned other places as well.)

The research literature also indicates that there are geographical areas of higher concentration of persons with mental retardation; the statistical estimates do not reflect this. For example, there is no data about alleged isolated communities in Kentucky with higher retardation rates.

Up to 66% of the persons with mental retardation also have an additional developmental disability of some kind (Table 6). While the diagram is sufficient to present the magnitude of the problem, a more detailed rank order of secondary diagnoses is presented in Table 6.

While no breakdown of secondary conditions was available to us, the prevalence of secondary conditions was studied by several researchers. One such breakdown is presented in Table 7 to illustrate the nature and prevalence rates of secondary diagnosis.

Such data suggests that destinctions between adults with mental retardation and other DD are meaningless because often these two groups are one and the same. Policies and plans should regard them as such; KRS Chapter 347 is a step in that direction.

TABLE 5

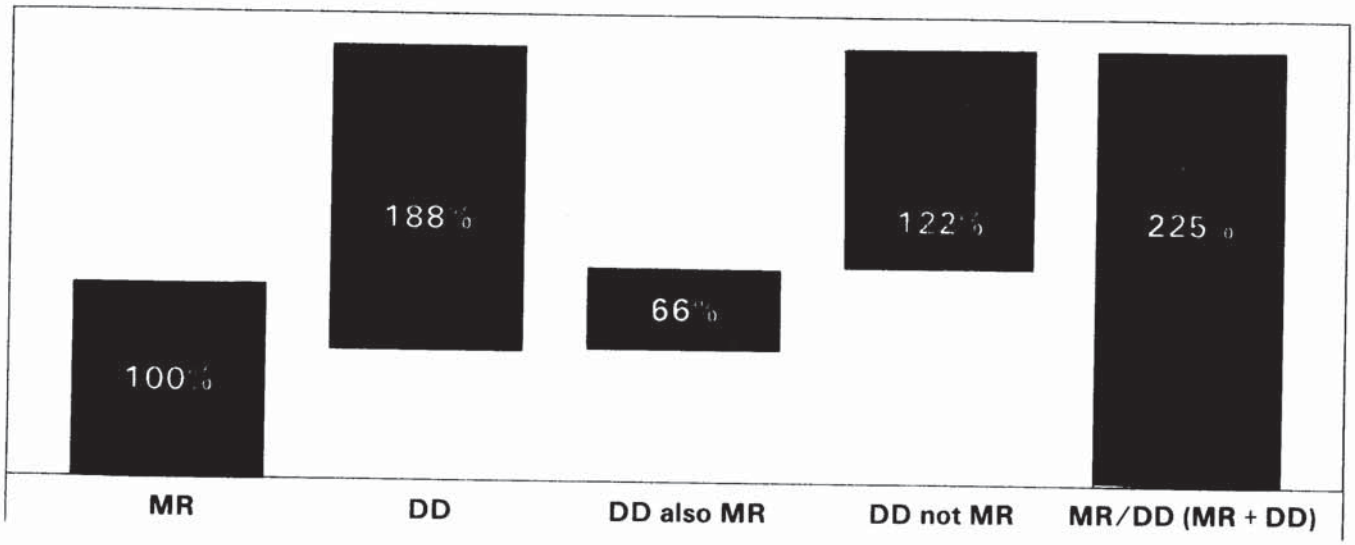
ESTIMATED NUMBERS OF PERSONS WITH MENTAL RETARDATION IN KENTUCKY BY REGION, AGE AND LEVEL OF RETARDATION

Region	Population	Total MR	Age				Adults (all conditions)	All Age Levels			
			Under 5	5-19	2064	65+		Mild	Moderate	Severe	Profound
1	193,859	5,816	657	1,710	2,908	541	3,449	5,223	349	204	87
2	207,555	6,227	704	1,831	3,113	579	3,692	5,592	374	218	93
3	208,751	6,262	707	1,841	3,131	582	3,713	6,623	376	219	94
4	242,195	7,266	821	2,136	3,633	676	4,309	6,525	436	254	109
5	227,527	6,826	721	2,007	3,413	635	4,048	6,130	410	739	102
6	819,073	24,572	2,777	7,277	12,286	2,285	14,571	22,067	1,474	860	369
7	326,833	9,805	1,108	2,883	4,903	912	5,815	8,805	588	343	147
8	56,286	1,689	191	497	845	157	1,002	1,517	101	59	25
10	217,965	6,539	739	1,922	3,269	608	3,877	5,872	392	229	98
11	202,378	6,071	686	1,785	3,035	565	3,600	5,452	364	212	91
12	144,651	4,339	490	1,276	2,169	404	2,573	3,896	260	152	65
13	246,822	7,405	837	2,177	3,703	689	4,392	6,650	444	259	111
14	184,632	5,539	626	1,628	2,769	515	3,284	4,974	332	194	83
15	582,811	17,484	1,976	5,140	8,742	1,626	10,368	15,701	1,049	612	262
KENTUCKY TOTAL	3,914,400	114,432	12,931	33,643	57,216	10,642	67,858	102,759	6,865	4,005	1,716

TABLE 6

POPULATION OF PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES IN KENTUCKY

(all ages and conditions)



SOURCE: Based on CHR Annual Plan (op Cit)

TABLE 7

RANK ORDER OF PRIMARY AND SECONDARY DIAGNOSES REPORTED FOR THE MR/DD POPULATION

Primary Diagnosis:	Frequency*	%
Mild MR	104	23.9
Moderate MR	97	22.3
Severe MR	53	12.2
Schizophrenia	44	10.1
Behavior disorder	31	7.1
Other	28	6.4
Unspecified MR	21	4.8
Other psychosis	16	3.7
Developmental disability	14	3.2
Profound MR	9	2.1
Affective-depressive disorder	9	2.1
Alcoholism	2	.5
Other physical disability	2	.5
Not reported	3	.7
TOTAL	433	

Secondary Diagnosis:	Frequency	%
Behavior disorder	107	24.6
Mild MR	68	15.6
Other	40	9.2
Schizophrenia	37	8.5
Moderate MR	31	7.1
Other psychosis	29	6.7
Affective-depressive disorder	21	4.8
Other physical disability	15	3.4
Developmental disability	12	2.8
Unspecified MR	11	2.5
Severe MR	10	2.3
Alcoholism	7	1.6
Drug Abuse	3	.7
Profound MR	2	.5
Deafness	2	.5
Not reported	38	8.7
TOTAL	433	

SOURCE: Parkhurst, R., "Need Assessment and Service Planning for Mentally Retarded—Mentally Ill People" in Handbook of Mental Illness and the Mentally Retarded, F.J. Menoluscino and J.A. Slack (eds.) Premium Press, 1986.

S. C. Plog and M. B. Santamour[7] project the incidence of persons with mental retardation to the 1990's and, not surprisingly, conclude that there will be a larger population of adults with mental retardation (Table 8). While the figures in Table 8 are of incidence rates which are different from the previously used prevalence rates, they illustrate the trend of growth. Plog and Santamour also discuss the consequences of the post-industrial society upon mental retardation.

TABLE 8

U. S. & KENTUCKY NUMBER OF PERSONS WTH MENTAL RETARDATION
BASED ON THE ASSUMPTION
THAT THEY COMPRISE 3% OF THE POPULATION (in thousands)

	1970		1980		1990	
AGE	U.S.	Ky.	U.S.	Ky.	U.S.	Ky.
Under 5	515	8	651	10	731	12
5-15	1,341	21	1,189	19	1,512	24
16 +	4,289	69	4,820	77	5,518	88
TOTAL	6,146	98	6,860	109	7,759	124

Discussion

A recent study[8] points out that there is a lack of information about the prevalence and incidence of handicapped people. The authors point out several problems which make an accurate count difficult—among them: information is fragmented and different sources use different statistics. Sometimes, they say, different reports have conflicting data. Different segments of the population might have different incidence rates. With the implementation of PL 94-142, regarding the right to an education of all handicapped children, they say, more accurate information will become available about school-age children. This report concurs with their conclusions.

While this report does not recommend an all-out effort to develop a data base to capture all cases of people with mental retardation, it recommends a gradual effort to start developing such data.

Recommendation

It is recommended that an information system about handicapped children in all categories be developed in such a way that it can evolve into a comprehensive information system which would follow the person with mental retardation beyond graduation. To do this, CHR and the Department of Education should coordinate their information systems.

After several years, a complete system will evolve. Efforts toward such a system should be coordinated between the Cabinet for Human Resources and the Department of Education.

The Martini/MacTurk Study also indicates that some disabilities are better known than others, but still many mild cases of persons with mental retardation are diagnosed as merely learning disabilities. Presently, the only nearly complete data, due to PL 94.142, is gathered by the public school system. Thus, the data gathered by the Department of Education is the most feasible for projecting future needs. This approach is the least expensive one for building a more complete information system. Such an approach is also recommended by I. Rowitz, in "Guidelines for the Development of a Uniform Mental Health Data Reporting System" (*Journal of Mental Health Administration* #9, 1982).

CHAPTER II

AVAILABLE SERVICES

Introduction

The paramount characteristic of persons wih mental retardation is the fact that most of them who receive services will remain dependent upon the system for the rest of their lives. Mental retardation is a non-curable condition. Most of the persons with mental retardation can learn to function within the limitations of their conditions and many can become productive and active members of the community. But in order to do so, they always will need various degrees of support and guidance. With proper support many can participate in society at large and use the same facilities as everyone else. The support which is provided to them is commonly referred to as "services."

The state assumes responsibilities for services to the persons with mental retardation, mainly by the default of others. Often those who would seem the appropriate caretakers, for a variety of reasons, simply cannot assume that role. In this respect, community-based services are an attempt to put the responsibilities for the persons with mental retardation back in the community.

Those who are dependent upon some residential setting, or upon other services, will remain so for many years to come. It is a concern of this study that the service system has not yet acquired experience in effecting smooth transition of clients from one stage of life to another and is not yet geared to accommodate people in mid-life or late-life. The research team saw only a handful of people at these ages; the majority seem to be young adults.

There is a constant "supply line" of new people who graduate annually from the educational system. While it is not possible to know exactly how many of them will require services, the fact remains that more people demand services every year, while those who already are served will stay in the service system for many more years.

In addition, there is a need to accommodate a yet unknown number of people who might be released from institutions as a result of a ruling in Samuel Doe, et al, versus Elbert Austin, Secretary (U.S. District Court for the Western District of Kentucky at Louisville, C 82-0738-L9A). By some estimates their number is up to 350 people. The total number of people currently in community-based residential arrangements is about 450 and it is doubtful if such expansion is possible without more resources, but responding haphazardly to a court order without a comprehensive plan can prove expensive in the long run.

While much discussion is mainly devoted to community-based services, the intermediate care facilities for persons with mental retardation (ICF/MRs) are an essential

part of the service system, and remain a viable alternative, especially for severe and profound cases and those from rural areas where community resources are scarce and spread over large distances.

What Services Are Needed

There are several models in the literature which describe the various services needed for persons with mental retardation. As in other human services areas, it is difficult to determine the need for services by merely translating individual needs into a service plan and at the same time satisfying the requirements and restrictions imposed by various funding sources. In many instances individuals are caught in a bureaucratic web that delays their access to needed services. This often results from the conflicts between individual needs, a generalized service plan, and eligibility requirements of the funding sources. This study refrains from dealing with KRS Chapter 347, which was the subject of a governor's task force.

A comprehensive approach to services for persons with mental retardation was developed by the 1962 President's Panel on Mental Retardation (Table 9). It displays an array of services which takes into account the entire life span of the person with mental retardation.

Other service models available in the literature[9] indicated that a major barrier to retaining the person with mental retardation within their most natural environment, their own family, is often the fact that the retarded person seriously interferes with family life. Other family problems, even those unrelated to the person with retardation, interfere with their ability to care for him. Elderly parents often can no longer care for their adult children with mental retardation.

A comprehensive need assessment in Kentucky[10] identifies many needs of developmentally disabled adults but it would be hard to translate their findings into a service plan.

Often the terms used by service providers to describe their services are confusing terminology. Appendix 2 attempts to address this difficulty by offering definitions and a brief description of the services offered in Kentucky, and a summary of the eligibility requirements and the conditions under which they can be delivered.

The plan of the Kentucky Cabinet for Human Resources[11] outlines the principles under which services should be provided. The overall principle is individually responsive services in three essential categories:

> To fully implement this individualized approach it has to be built into service need identification, the classification system, and the service design. The use of the essential services concept will allow a more appropriate translation of client need into client services. This would be true not just for residential and habilitation services, but for all services. There are three essential services:

TABLE 9

ARRAY OF DIRECT SERVICES FOR THE RETARDED

Life Stage	Components of Special Need: Physical & Mental Health	Shelter Nuture Protection	Intellectual Development	Social Development	Recreation	Work	Economic Security
Infant	Specialized medical follow-up Special diets, drugs or surgery Home nursing	Residential nursery Child Welfare services	Sensory stimulation	Home Training Environmental enrichment			
Toddler	Correction of physical defects Physical therapy	Foster care Trained baby sitter	Nursery school Classes for slow learners		Playground programs		
Child	Psychiatric care Dental care	Homemaker service Day care	Special classes-educable Special classes-trainable Religious education Short stay home Work-school programs Boarding school Speech training	Day camps Residential camps	Scouting Swimming		Disabled child's benefits
Youth	Psychotherapy	Occupational training	Social clubs Vocational counseling-Personal adjustment training	Youth groups	Selective job placement		Health insurance
Young adult	Facilities for retarded in conflict	Half-way house Guardianship of person Long-term residential care	Marriage counseling Bowling		Sheltered employment Total disability assistance Sheltered workshops Guardianship of property		
Adult		Group homes Boarding homes	Evening school Evening recreation	Social supervision		Life annuity or trust	
Older adult	Medical attention to chronic conditions					Old age assistance OASI benefits	

*Not included are diagnostic and evaluation services, or services to the family; the array is set forth in an irregular pattern in order to represent the overlapping of areas of need and the interdigitation of services. Duration of services along the life span has not been indicated here.

SOURCE: The President's Panel on Mental Retardation (1962).

Access: Families and persons with mental retardation need someone they can contact who can provide information about services and who has the means to make services available to the client and their family. This would include assessment of the need and planning to meet the need. It would also include continuous follow-up to maintain the access.

Supervision: Supervision is having the responsibility for the care and safety of the person with mental retardation. Persons with mental retardation, to whatever degree possible, should be allowed to be independent of supervision. The parents or other family are natural means of meeting that responsibility when the person is dependent. The greatest need of the family is to have the service system share that responsibility. To determine what degree is the responsibility of the family or other resources and what degree is the responsibility of the service system is service planning.

Training: The belief that persons with mental retardation can learn and grow is the force behind the need for training. This service is an extension of the family function and is one of society's major goals for its citizens. Many families lose hope in this area and many do not have the skills necessary to accomplish this task. Society has met a portion of its responsibility through mandatory school attendance. The service system has to determine what other portion is the responsibility of the service system and what is the responsibility of private enterprise, volunteers, and other resources.

A truly responsive, accessible system should address these basic service needs for all persons with mental retardation and their families. It may be that, for some, through personal and private resources a major portion of these needs are met and these families will need few services from the system. Many other persons need services from the service system for only a short time. Others need intensive services life long. Providing services in this manner does not dictate the setting, does not establish predetermined criteria, nor predetermine the amount of service needed by the client.[12]

The three service areas are broken into an array of services (Table 10) and the plan makes 21 implementation recommendations.[13]

With that, the upcoming task force report of implementing KRS Chapter 347 and other studies, enough recommendations have been made about improving services. This study cannot offer many new ones but stresses the need for a fresh policy. For this end it provides background information and points out some weaknesses in the service system.

TABLE 10

ARRAY OF SERVICES

Prevention:
- Education & Consultation
- Program Research & Development

Access Service:
- Case Management
- Advocacy
- Interagency Coordination
- Transportation

Supervision:
- Crisis
- Respite
- In-home Support
- Staffed Residences
- Group Homes
- Facilities

Training:
- Work/Adult Habilitation & Training
- Supported Employment
- Early Intervention
- Preschool
- Leisure & Recreation
- Adult Education
- In-home Training
- Behavior Management

SOURCE: CHR MR/DD Plan, June, 1987

Another plan judged as outstanding in its approach and organization was reviewed by the research team; it is explicit and concrete. The mission and philosophy of the Seven Counties Three Year Plan (1987) is presented through a clear and concise statement of principles:

Mission, Philosophy, and Organizational Goals:

The mission of services delivery system of a Mental Retardation/Developmental Disabilities Program is to enhance the status, image, and development of people who are mentally retarded and developmentally disabled.

We believe that the programs and services designed to accomplish this mission must be consistent with the following philosophical underpinnings:

1. Adherence to the principle of normalization, which makes " available to the

mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969).

2. Provision of services in the least restrictive manner possible.

3. Respect for and facilitation of the social and emotional bonds between disabled citizens and other members of our community.

4. Acknowledgment of the rights of disabled citizens.

5. Provision of services in a manner which maximizes opportunities for meaningful interactions between disabled and non-disabled persons.

6. Awareness of and respect for the unique contributions which disabled persons offer to other citizens and the community as a whole.

Such mission and philosophy can best be implemented through attainment of the following organizational goals:

1. Development of a working partnership between the community and the service delivery system.

2. Development of leadership to initiate and maintain networks of support and assistance for mentally retarded and developmentally disabled citizens of the region.

3. Development of meaningful involvement for consumers and consumer representatives in planning, monitoring and evaluation of services.

4. Development of mechanisms through which to provide meaningful accountability to the community for the public resources utilized in the accomplishment of the mission.

5. Development of an array of individualized services which are implemented in community-based and integrated residential, educational, vocational, and recreational environments.

6. Reduction of attitudinal barriers.

7. Efficient utilization of human and material resources available within the community.

8. Development of additional resources within the community to assist in the accomplishment of our mission.

9. Assurance of protection for the legal and human rights of persons with mental retardation/developmental disabilities.

10. Development of appropriate and usable management information systems that will allow effective monitoring of the efficiency of services.

The Seven Counties Plan prioritizes and translates those statements into specific needs (Appendix 3), identifies service gaps and outlines action goals along with completion dates.

Of special interest are the Seven Counties services for rural areas (Appendix 3, #4). Their involving many community agencies and other interested parties in the planning process is also commendable. This, however, is not to say that other regions don't have good plans. This report recommends that those regions who wish to improve their planning process examine the Seven Counties plan.

How Many Need Services

When it comes to determining how many should be served, where they are, or who currently gets what services, information is skimpy, with many discrepancies existing among different information sources. Thus, deciding the number of people who need which service is a guessing game. Had there been reliable data, service gaps could be identified and costs estimated. Unfortunately, it is not available. The estimate of the number of people who need services and how many receive them is not reliable. One reason for this is the fact that many agencies which provide services do not restrict them to adults with mental retardation. Many clients receive multiple services that are often counted more than once.

In the absence of a direct needs assessment study to determine the number of people in need, most planning in Kentucky is based on a study done by M. F. Hogan[14] in a western Massachusetts region. Despite the demographic differences, there is no reason to believe that a similar study in Kentucky would yield much different results from the Hogan study, and the cost of such effort could thus not be justified. Table 11 presents the estimated rates and number of people who need services based on that study. The estimated number of "people in need" is two times higher than estimated above. The reason seems to be that all moderate and unspecified percentages of mild cases are included in Hogan's estimates.

TABLE 11

ESTIMATED NUMBER OF PERSONS NEEDING ANY ONGOING SPECIAL SERVICES DUE TO MENTAL RETARDATION

Age Group	Age Specific Rate of Need	Estimated Number of Kentuckians in Need of Services
Birth to 2	.66%	2,970
3 thru 21	.68%	7,400
22 and up	.53%	11,600
TOTAL	.59%	21,970

In his study Hogan makes the following statement:

The community service movement is built on a foundation of residential services. It is particularly strange, therefore, that there is little useful data on the need for community residential services.[15]

Table 12 estimates the number of people in need for residential services.

TABLE 12

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION IN NEED OF COMMUNITY RESIDENTIAL SERVICES

Age Group	Hogan Rate*	Estimated Number of Kentuckians in Need of Community Residential Services
Birth to 2	9.38%	680
3 to 21	9.09%	
22 and up	61.71%	7,158
TOTAL		7,838

*percentage out of the population of adults with mental retardation

Deducting from the estimated 7,838 individuals who need residential services, the 1,006 who are in ICF/MRs and in private institutions and the 452 in community living arrangements, there are 6,380 people still in need of residential services, which is 81% of the people in need.

The levels of care for those in community residential living depends upon their condition. Applying Hogan's rates of levels of residential support to the estimated number of people who need residential care results in the figures presented in Table 13.

TABLE 13

ESTIMATED NUMBER IN NEED OF COMMUNITY RESIDENTIAL SERVICE BY LEVEL OF SUPPORT IN KENTUCKY

Level of Support & Definition (service continuum)	% of People Needing This Support	Estimated Number of Persons in Ky. In Need of This Level of Support
Minimal supervision Periodic & backup support for persons with independent self-help skills but needing some community living help	44%	3,625
Moderate supervision Regular support & training (e.g., 1:8 to 1:4 ratio) for people who have basic self-care skills but need help in managing around their home	15%	1,352
Supervised training Regular on-site supervision (e.g. 1:4 to 1:2 ratio) for people needing some assistance and much training in self-help skills	22%	1,900
Supervised living Intensive on-site supervision (e.g. 1:2 to 1:1 ratio) for people needing considerable or total assistance & training in self-help skills	10%	960
TOTAL:		7,837

A breakdown by the categories used in Table 13 of those who presently live in the community in Kentucky is not available.

While residential arrangements are the backbone of the community-based services, it is the variety of day programs which determines the quality of life of the persons with mental retardation in the community. According to Hogan, 77.6% of the persons with mental retardation require some kind of day programs. Using the Hogan rates, the CHR Plan estimated service needs in Kentucky, which are indicated in Table 14.

TABLE 14

PERSONS IN NEED OF SERVICES BY SERVICES, ALL REGIONS

Existing Service Classification	Hogan Numbers Served	Estimated # Service Classification	In Need Applying Hogan to Ky.	Gaps
Crisis Intervention (MH Facility)	5 Pls	Crisis	76 Pls	5 Pls
Case Management	8,346[a]	Coordination	22,400	14,054
Respite	787[b]	Respite	3,800	3,013
Habilitation		Community Day Program		
Work Service Adult Hab. & Tr. Supported Emp.	2,891	Adult employment/ training	6,992	4,101
Preschool	252[b]	Not Identified		
Early Intervention	482[b]	Early Intervention	1,216	734
Residential	1,458	Residential	8,360	6,902
Group Home Com. Tr. Home Staffed Res. (Daily & Periodic) Cluster AIS-MR	452			
ICF-MR & Other Private Facilities	1,606[c]			
Leisure Recreation	235[b]	Social/Recreational Support	4,066	3,831
In-Home Support	332	Not Identified		
Not Identified		Adult Education	3,572	3,572

[a]All clients reported on Client Summary, assuming all receive CM.
[b]Fee for service figure, not specifically identified on Client Summary form.
[c]Provided by Institutional Care Division & Health Plan.

SOURCE: CHR Plan, op. cit.

Finally, according to Hogan, 58% of the persons with mental retardation population need employment services, while 42% can find means of their own, with or without the assistance of their family. Table 15 presents Hogan's rates as they apply to Kentucky.

TABLE 15

PROJECTED NEED OF ADULT EMPLOYMENT AND TRAINING SERVICES FOR PERSONS LABELED MENTALLY HANDICAPPED IN KENTUCKY

Level of Supervision and Description	% of Need According to Hogan	Number of Persons Needing this Support
No special employment/training service	42%	4,872
Semi-independent Emp. Job placement, support & stabilization in competitive employment for person with ability to work on task, few interfering behaviors	15%	1,740
Minimal supervision Minimal shelter & some training (e.g., 1:12 to 1:8 staff ratio) for persons who can work on task at about 25% productivity rates	17%	1,972
Moderate supervision More intensive support (e.g., 1:8 to 1:6 staff ratio) for persons with some interfering behavioral or medical needs and whose productivity is less than 25%	9%	1,044
Intensive supervision Intensive training & supervision (e.g., 1:4 to 1:1 staff ratio) for persons with substantial skill deficits (e.g., very limited self-help skills) or significant behavioral/medical needs	16%	1,856
TOTAL needing some assistance:	58%	6,728
TOTAL:		11,600

Applying the Hogan rates to each of the state's regions would indicate that large gaps exist between estimated needs and number of people served (Table 16). Even though the accuracy of this estimate can be challenged, the existence of large gaps seems indisputable.

TABLE 16

ESTIMATE SERVICE NEEDS BY REGION
(ALL AGES)

Type of Service and Level of Support	# In Need Per 100,000*	Total # in KY in Need**	# of People Served (All the State)***	Estimated Number of People in Need**** REGION #1	#2	#3	#4	#5	#6	#7	#8	#10	#11	#12	#13	#14	#15
CRISIS INTERVENTION	2	76	5	4	4	4	5	5	16	7	1	4	4	3	5	4	12
CASE COORDINATION	590	22,400	8346	1,121	1,239	1,239	1,416	1,357	4,838	1,947	330	1,286	1,192	856	1,457	1,092	3,440
RESPITE	100	3,800	787	190	210	210	240	230	820	330	56	218	202	145	247	185	583
COMMUNITY RESIDENTIAL	220	8,360	452	418	462	462	528	506	1,820	726	123	480	444	319	543	407	1,283
No resident services	370																
Minimal Supervision	97			184	204	204	233	223	795	320	54	211	196	141	240	179	566
Moderate Supervision	34			65	71	71	82	78	279	112	19	74	69	49	84	63	198
Supervised Training	49			93	103	103	118	113	402	162	27	107	99	71	121	91	286
Supervised Living	40			76	84	84	96	92	328	137	27	87	81	58	99	74	233
COMMUNITY DAY PROGRAMS		216															
Infant Stimulation	32	1,216	834	61	67	67	77	74	262	106	18	70	65	46	79	59	187
Spec. Ed in School	242	9,186		460	508	508	581	557	1,984	799	136	528	489	351	598	448	1,411
Employment and Training		6,992	2,891														
No. Spec. Employment and Training	132			251	277	277	317	304	1,082	436	74	288	267	191	326	244	770
Semi-Independent Employment	47			89	99	99	113	108	385	155	26	102	95	68	116	87	274
Minimal Supervision	55			105	116	116	132	127	451	182	31	120	111	80	136	102	321
Moderate Supervision	30			57	63	63	72	69	246	99	17	65	61	44	74	56	175
Intensive Supervision	52			99	109	109	125	120	426	172	29	113	105	75	128	96	303
TRANSPORTATION		4,712															
Adapted	30			57	63	63	72	69	246	99	17	65	61	44	74	56	175
Special Transportation Assistant	94			179	197	197	226	216	771	310	53	205	190	136	232	174	548
SOCIAL-RECREATIONAL SUPPORT		4,066	235														
Highly Specialized	47			89	99	99	113	108	385	155	26	102	95	68	116	87	274
Moderate	60			114	126	126	144	138	492	198	34	131	121	87	148	111	350
ADULT EDUCATION (SPECIALIZED)	94	3,572		179	197	197	226	216	771	310	53	205	190	136	232	174	548

*Rates in Hogan's Study
**Estimated by the MR Plan, 1987
***MR 1987 Plan
****Hogan rates as applied to the region's population

Service Agencies and Clients

Several state agencies, fourteen regional comprehensive care centers, and numerous non-profit or for-profit agencies are involved in providing services to the adults with mental retardation directly or indirectly. This section summarizes the roles of the major agencies.

Of the many state agencies involved in providing services to the adults with mental retardation, two CHR divisions have major responsibility. The state MH/MRs plan cites their mission, which is defined in the Governor's executive order 84-599 (see chart).

- **Division of Mental Retardation:** The Division shall, among other things, provide support to Community Mental Health/Mental Retardation Boards and their subcontractors; assist in the allocation of State General Funds and Federal funds for mental retardation services; monitor contracts with providers of mental retardation services; collect and disseminate data relating to mental retardation services; disburse special equipment funds to the mentally retarded; and provide administrative support to the Developmental Disability Council; provide monitoring, technical assistance, training and public information services relating to mental retardation; establish service definition criteria; provide crisis management services; provide coordination between community mental health/mental retardation boards and other mental retardation agencies and the public; and develop a residential services manual.[16]

- **Division of Institutional Care:** The Division of Institutional Care . . . . shall provide residential services necessary for a complete service system for persons with a mental illness or who are mentally retarded. The Division shall, among other things, provide programs for acute forensic psychiatric services; forensic services; hospitals and schools for persons with mental retardation; alcohol abuse facilities; and alternate care facilities; provide budgeting and fiscal services, personnel and staffing services; technical assistance, data collection, analysis and presentation; standards for residential services; coordination with regional mental health/mental retardation boards and local agencies; and monitoring of contracted services provided at residential facilities.[17]

- **The Regional Centers:** The Division for Mental Retardation contracts with the fourteen regional Mental Health/Mental Retardation Boards for direct services (see map).

The boards in turn provide direct services or contract with service agencies (most of them non-profit). Those agencies receive federal and state funds through the regional boards but also can raise other funds.

The departmental plan provides a summary of the statutes which establish the community-based Comprehensive Care Centers (CCC) as follows (KRS 210.370 through 210.550):

- Recruit and promote local financial support for their programs.

- Promote, arrange and implement working arrangements with other service providers in their areas.
- Review and recommend the annual plan and budget.
- Administer the community mental health and mental retardation programs.

The Department for Mental Health and Mental Retardation Services is required to:

- Allocate to the Boards available funds for disbursement in accordance with their annual plans and budgets.
- Review the program budgets and planned expenditures.
- Issue rules and regulations in regard to the governing boards' eligibility for state funds and approve fee schedules.
- Perform periodic reviews to determine the quality, efficiency and effectiveness of services provided by each board.

It is not within the scope of this study to examine this structure. For the most part, we find it adequate. Whatever problems there might be do not necessarily result from the deficiency of the system but more likely from budgetary or other problems.

However, there is a built-in conflict between functioning in case management which has strong advocacy aspects and being a service agency at the same time. When regional CCC's act in both these capacities, the conflict of interests diminishes their advocacy roles.

In addition to the community-based services, the state operates four facilities which specialize in serving the adults with mental retardation:

Central State ICF/MR (50-bed capacity)
Oakwood ICF/MR (420-bed capacity)
Hazelwood ICF/MR (220-bed capacity)
Outwood ICF/MR (operated under contract) (80-bed capacity)
Total number of beds: 770

There are also five private institutions:

Cedar Lake Lodge (76-bed capacity)
Excepticon (180-bed capacity)
Higgins Learning Center (56-bed capacity)
Panorama (58-bed capacity)
Wendel Foster Carter (63-bed capacity)
Total beds in private institutions: 433.

More detailed treatment is in a later section.

The CHR plan provides the following totals:

Community residential arrangements	452
In home support	332
Total in community-based residential arrangements	784
ICF/MRs and other private facilities	1,006
GRAND TOTAL	1,790
In private institutions	433
TOTAL All residential arrangements of all kinds:	2,223

It is safe to assume that this is a reliable, unduplicated count.

With only 2,223 people accounted for, where are the majority of the people? The Office of the Long-Term Ombudsman in CHR estimates that 25% of long-term beds are occupied by young and old adults with mental retardation. That is 7,696 beds out of a total of 30,784 (the CHR plan puts the percentage at 11.3%, but their estimate of 2,800 seems to be too low, as it applies to only 24,779. It is safe to state that the number is somewhere between 3,478 and 7,700. This study estimates their number as 5,589 (average between high and low estimates).

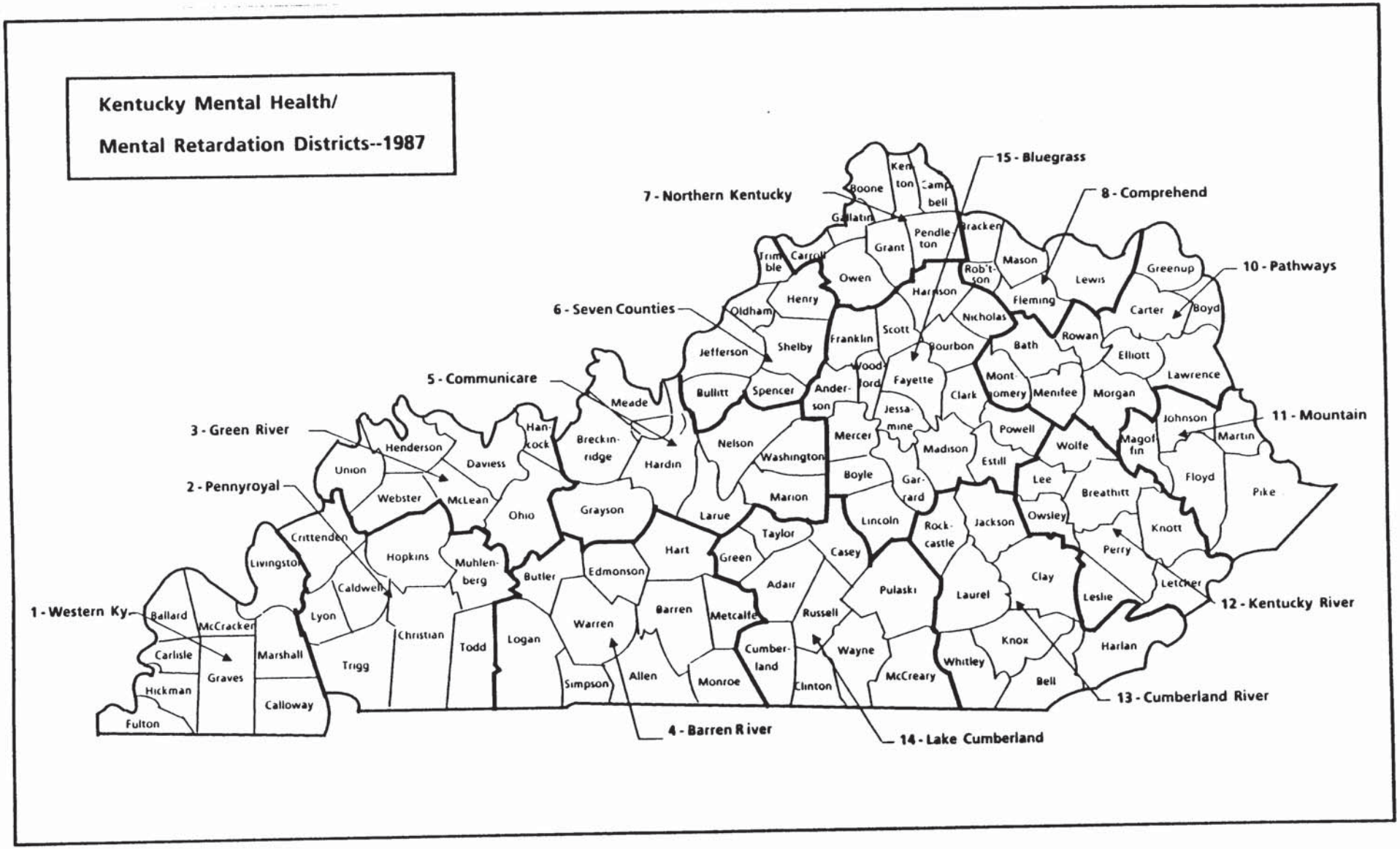
This figure also agrees with Hogan's estimate of a total bed need of 7,837; CHR accounts for 2,223, leaving 5,614 unaccounted for, which is close to our 5,589 estimate.

There is no easy way to figure out how many of those are capable of community living. Many, no doubt, have deteriorated, due to the lack of proper services, making such change impossible; this study therefore urges that efforts be made to prevent future placement of persons with mental retardation in long-term beds, unless such placement is warranted by their conditions. CHR should examine the feasibility of removing them to the community or other appropriate facilities for persons with mental retardation.

Regional Services

This section presents the services in each region. First, there is a table based on CHR data of the total number of people, of all ages who receive services (Table 17).

Table 18 presents the number of adults served either directly by the regional centers or their subcontractors. Information for this table was provided by the regional MR/DD Directors. This table and Appendix 10 also contain the list of regional affiliates provided for this study. The table also includes the number of people on waiting lists. Some regions, however, do not maintain waiting lists because there are no openings within the forseeable future. This table and Appendix 10 also provide a list of regional service subcontractors as provided for this study.


Kentucky Mental Health/
Mental Retardation Districts--1987
1 - Western Ky
2 - Pennyroyal
3 - Green River
4 - Barren River
5 - Communicare
6 - Seven Counties
7 - Northern Kentucky
8 - Comprehend
10 - Pathways
11 - Mountain
12 - Kentucky River
13 - Cumberland River
14 - Lake Cumberland
15 - Bluegrass
Ballard
McCracker
Carlisle
Graves
Marshall
Hickman
Calloway
Fulton
Trigg
Lyon
Caldwell
Crittenden
Livingston
Christian
Todd
Logan
Warren
Simpson
Allen
Monroe
Barren
Metcalfe
Cumberland
Clinton
Russell
Wayne
McCreary
Pulaski
Hopkins
Muhlenberg
Butler
Edmonson
Hart
Green
Taylor
Adair
Casey
Larue
Marion
Washington
Nelson
Hardin
Grayson
Ohio
Webster
McLean
Union
Henderson
Daviess
Hancock
Breckinridge
Meade
Jefferson
Oldham
Shelby
Spencer
Bullitt
Henry
Trimble
Carroll
Owen
Gallatin
Boone
Kenton
Campbell
Grant
Pendleton
Bracken
Robertson
Mason
Harrison
Nicholas
Fleming
Lewis
Greenup
Carter
Boyd
Rowan
Bath
Montgomery
Menifee
Morgan
Elliott
Lawrence
Johnson
Martin
Magoffin
Floyd
Pike
Knott
Perry
Letcher
Harlan
Leslie
Clay
Knox
Whitley
Bell
Laurel
Rockcastle
Jackson
Owsley
Breathitt
Lee
Wolfe
Powell
Estill
Madison
Garrard
Lincoln
Boyle
Mercer
Anderson
Franklin
Scott
Woodford
Fayette
Clark
Bourbon
Jessamine

ORGANIZATIONAL CHART

Department for Mental Health & Mental Retardation Services

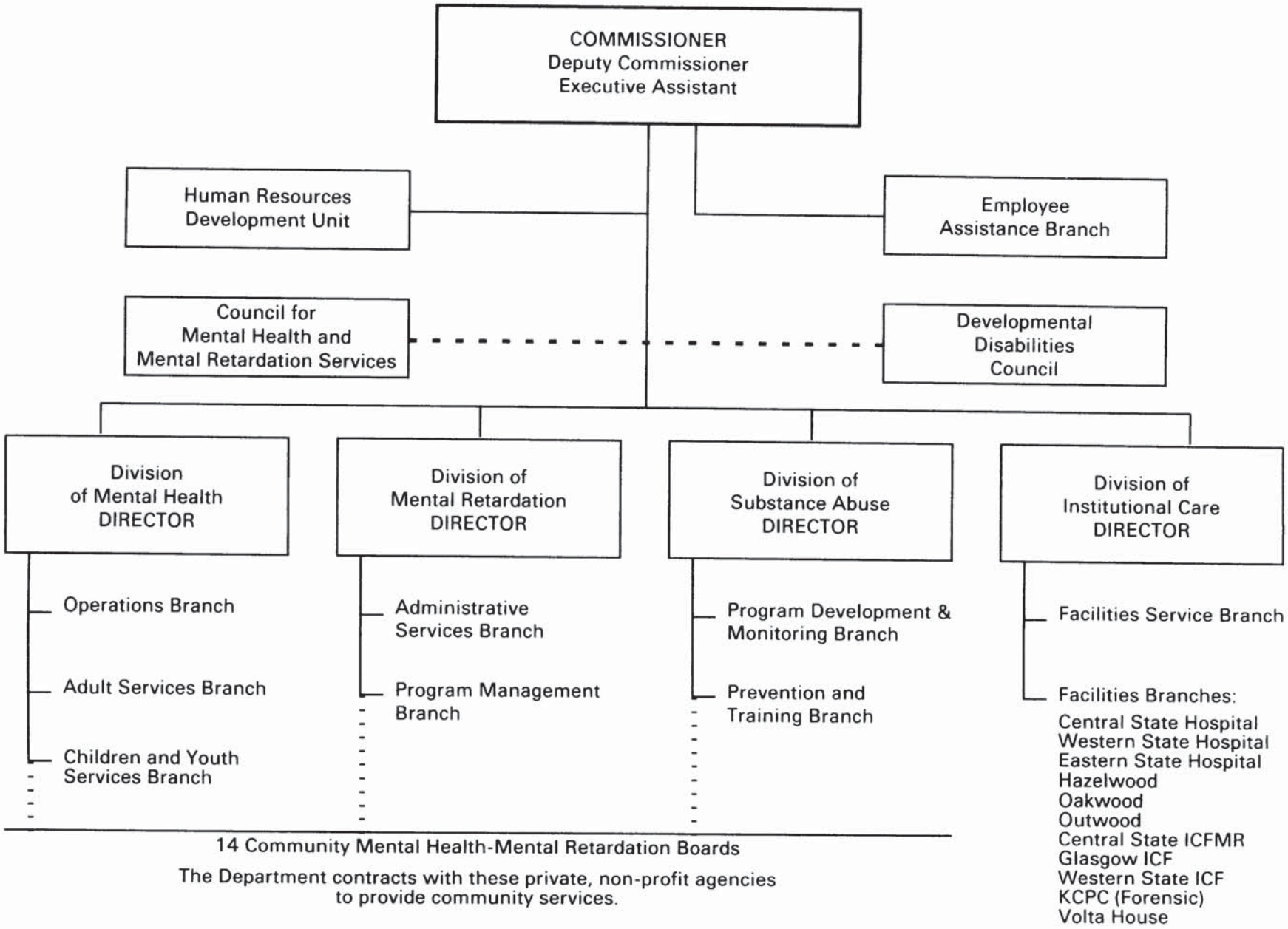


TABLE 17

1986 PERSONS BY REGION AND BY SERVICE (CHR)

Existing Service Classification	Reg. I Numbers Served	Reg. II Numbers Served	Reg. III Numbers Served	Reg. IV Numbers Served	Reg. V Numbers Served	Reg. VI Numbers Served	Reg. VII Numbers Served	Reg. VIII Numbers Served	Reg. X Numbers Served	Reg. XI Numbers Served	Reg. XII Numbers Served	Reg. XIII Numbers Served	Reg. XIV Numbers Served	Reg. Numb Serv
CRISIS INTERVENTION	NI	NI	NI	NI	NI	NI	NI	NI	NI	NI	NI	NI	NI	NI
CASE MANAGEMENT	236	53	222	8	25	0	305	69	443	145	138	217	48	238
RESPITE	51	89	0	24	37	46	10	19	51	0	0	0	11	55
HABILITATION														
Work Service Adult Hab. & Training Supported Employment	101	65	91	141	136	207	115	35	158	100	47	140	46	165
Preschool	51	33	0	0	31	20	3	0	0	2	0	135	19	58
Early Intervention	42	22	42	76	16	94	10	55	77	35	42	152	37	12
RESIDENTIAL														
Group Home	0	0	0	0	12	10	10	6	0	0	0	0	0	0
Com. Tr. Home	0	0	0	0	0	0	0	5	0	0	0	0	0	0
Staffed Re. (Daily & Periodic)	0	0	7	0	2	26	0	0	0	0	0	0	0	14
Cluster	0	0	0	0	0	0	0	0	0	0	0	0	0	0
AIS-MR	21	17	49	13	20	43	20	25	23	0	0	23	23	27
ICF-MR & OTHER PRIVATE FACILITIES														
LEISURE RECREATION	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
IN-HOME SUPPORT	18	18	41	20	19	56	25	14	20	0	0	19	43	47

TABLE 18
NUMBER OF ADULTS SERVED BY SERVICE AREA IN EACH REGION

Number of Adults Served by Service Area in Each Region

	Region One			Region Two			Region Three		
	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List
RESIDENTIAL									
Group Home			20	49					
Supervised Apartments		16					50 slots		11
Independence Apartments		21*							
Client With Another Family		19	Included in sup. apts.				6 8		2 5
VOCATIONAL									
Voc/Day Habilitation	45	131 plus Included in voc/hab	20	30					
Sheltered Workshop				130	50 plus	NNP	46	10/ 257 plus	25
Supported employment				5*					
SUPPORT									
In-Home Support	NNP		8	18			90	25	
Case Management	195			208			90*		
Respite	194			99			90	90	
Short									
Long									
Leisure/Recreation	NNP						90	396	
Parent Support Group									
DEVELOPMENTAL									
Speech							Included in Leisure/Rec.	Included in Leisure/Rec.	
Physical Therapy									
Home Health Aides									
Clinic									
Testing/Counseling									
EDUCATION									
ELDERLY MR Services									
ADVOCACY									

*also, alternative living units available for 25

*will do 5 this year

*D.D. Case management serves 120

**This is either the total number served by affiliates or only the number they are contracted to serve under their contract with the comp care center.

***Number not provided - service exists but number not provided.

****Blanks indicate that no information indicates whether service offered or not.

Number of Adults Served by Service Area in Each Region

	Region Four			Region Five			Region Six		
	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List
RESIDENTIAL	12*					35		100	880
Group Home	3			8					
Supervised Apartments	4			5					
Independence Apartments				NNP					
Client With Another Family				NNP					
VOCATIONAL								400	6300
Voc/Day Habilitation	158		50	NNP					
Sheltered Workshop	39								
Supported employment	9**							NNP	
SUPPORT								345	1400
In-Home Support				NNP				NNP	
Case Management	199			NNP			1170*		
Respite	40							NNP	
Short				NNP					
Long				NNP					
Leisure/Recreation				NNP				NNP	
Parent Support Group	15							NNP	
DEVELOPMENTAL				NNP				325	1700
Speech				NNP					
Physical Therapy				NNP				NNP	
Home Health Aides				NNP					
Clinic				NNP					
Testing/Counseling				NNP					
EDUCATION								NNP	
ELDERLY MR Services									
ADVOCACY									

*in alternative living units

**only funded at 50% level

*serving 1,170 clients of 2,660 requesting services

Number of Adults Served by Service Area in Each Region

	Region Seven			Region Eight			Region Ten		
	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List
RESIDENTIAL			137			10			7
Group Home		19			8		6		
Supervised Apartments		21			25		20		
Independence Apartments		7			included in sup. apts.				
Client With Another Family					NNP		25		
VOCATIONAL				NNP					
Voc/Day Habilitation		116*	137**	80		5	NNP		15
Sheltered Workshop		NNP					NNP		
Supported employment		NNP							
SUPPORT									
In-Home Support		43		18					
Case Management	NNP			162			300*		
Respite		NNP		50			NNP		
Short									
Long				NNP					
Leisure/Recreation		NNP							
Parent Support Group									
DEVELOPMENTAL		15		NNP					
Speech									
Physical Therapy									
Home Health Aides									-
Clinic									-
Testing/Counseling	NNP***						NNP		
EDUCATION									
ELDERLY MR Services	NNP			24					
ADVOCACY		NNP							

Many are being served in the region that don't come through Comp Care

*full time employment for 3

**needing day program

***includes psychological, outpatient counseling and behavior management

*serve approximately 300 but they are not just adults

Number of Adults Served by Service Area in Each Region

	Region Eleven			Region Twelve			Region Thirteen		
	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List
RESIDENTIAL	(new)5*		NNP	(new)*		10	3		23*
Group Home							16		
Supervised Apartments							25		
Independence Apartments							included in sup. apts.		
Client With Another Family							25		
VOCATIONAL							4-6**		
Voc/Day Habilitation				NNP			343		92
Sheltered Workshop	124**		25	120			120 plus		
Supported employment				NNP			8***		
SUPPORT	235						20		20
In-Home Support							20		20
Case Management	150-175			NNP			800		43
Respite									
Short									
Long							45		43
Leisure/Recreation									
Parent Support Group									
DEVELOPMENTAL									
Speech									
Physical Therapy									
Home Health Aides									
Clinic									
Testing/Counseling							/NNP		
EDUCATION									
ELDERLY MR Services									
ADVOCACY	NNP						NNP		

73.3 growth rate over 1986 fiscal year

*just certified

**Three programs in horticulture

*have slots for 25

*identified 30 to 38 in need

**at Appalachian Computer

***by December

Number of Adults Served by Service Area in Each Region

	Region Fourteen			Region Fifteen		
	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List	No. Adults Comp. Care Serves	No. Adults Subcontractor Serves	Combined Waiting List
RESIDENTIAL	NNP		13			84
Group Home				NNP	NNP	
Supervised Apartments						
Independence Apartments						
Client With Another Family						
VOCATIONAL						
Voc/Day Habilitation	NNP		60			100
Sheltered Workshop					450	
Supported employment				NNP	NNP	
SUPPORT						
In-Home Support	NNP		20*	NNP	NNP	10
Case Management	NNP		75	NNP		26
Respite	NNP			NNP	NNP	
Short						
Long						
Leisure/Recreation	NNP			NNP	NNP	
Parent Support Group						
DEVELOPMENTAL				NNP	NNP	
Speech		NNP				
Physical Therapy		NNP				
Home Health Aides						
Clinic						
Testing/Counseling						
EDUCATION						80
ELDERLY MR Services						
ADVOCACY						

*In-Home training

SOURCE INFORMATION: Information received from the CCC.

Source: Information received from the CCC.

Differences in the figures amplify the problem of data reliability. Differences occur sometimes even within a single source. Comparisons between Table 17 and Table 14, both from CHR, and Table 18, reveal the following differences in state totals:

	Table 17* (all ages)	Table 14* (all ages)	Table 18* (adults)***
Case Management	2,022	8,346	3,284
Respite	393	787	473
Work Habilitation	1,547	2,891	1,576*
All Residential	396	452	467*
Leisure & Recreation	0	235	486*
In-Home Support	340	332	214

*Table 14 presents estimated number of people in need. Tables 17 and 18 are of people served.
**Indicates adult services
***This includes people who are served both by the Comp Care Centers and their affiliates.

This study cannot reconcile the differences.

Differences in services among regions can be, in part, explained by regional socio-economic development. For example, Northern Kentucky (Region 7) has manufacturing, transportation, and outreaching interstate roads and its Comp Care has many affiliates, private providers and other community resources. Most importantly, it has strong parent groups and successful fundraising activities. On the other hand, Region 10, in the northeastern part of the state, is primarily rural and half mountainous. Its only urban areas, with the exception of some development in Rowan and Montgomery counties, are Boyd county's Ashland, Huntington, and Ironton metropolitan areas. Carter, Elliot, and Lawrence counties are dominated by the coal industry, with about 10% unemployment.

In most rural areas there are limited opportunities for job placement; there are transportation problems, a shortage of private providers, and meager community resources.

In response to the researchers' questions, the MR/DD directors identified needed services which do not presently exist in their region or are inadequate:

7 directors indicated the need for more recreation or day programs.
3 for more case management.
3 for more AIS/MR services.
4 for more transportation services.
9 for a formal transition program.
9 for more residential slots.

6 for more rehabilitation programs.
8 for more employment opportunities.
2 for more services for the adults with mental retardation with behavioral problems.
2 for higher salaries for workers (this was mentioned as a major problem in other regions).
4 for in-home training.
4 for services to aging adults with mental retardation.

INTERMEDIATE CARE FACILITIES

This section covers state and private ICF/MRs and concludes with some concerns expressed by parents. The Cabinet for Human Resources, through the Department for Mental Health and Mental Retardation Services, Division for Institutional Care, has responsibility for three of the four main state operated ICF/MRs; the fourth is operated by Res-Care Health Services.

Services in the ICF/MRs include:

1. Psychological services.
2. Social services.
3. Program services.
4. Speech and hearing therapies.
5. Physical and occupational therapies.
6. Recreation services.
7. Nursing services.
8. Dietary services.
9. Vocational services.
10. Foster grandparent services.

According to the Division of Institutional Care:

> Admissions to state MR facilities are initiated by family, guardian or legal committee through local community MH/MR centers. The community MH/MR center information, screening, and referral service in each of the fourteen (14) community MH/MR center regions evaluates the possibility of all community programs and processes referrals. An interdisciplinary team at the state level evaluates the appropriateness of admission to an institution and makes placement decisions. State ICF/MR/DD programs are designed to serve primarily individuals with profound and severe retardation and they offer basic training in living/survival skills. Individuals with mental retardation having primarily psychiatric problems are served by the psychiatric hospital system. General admission criteria include residing in Kentucky and age (only individuals over 5 years of age are considered for placement).[18]

The Hazelwood ICF/MR in Louisville is a 220-bed state facility. It is in an old tuberculosis hospital and is lacking many needed accommodations. The total number of residents at the facility is 216. Hazelwood is unique to this state in providing residential ser-

vice for non-ambulatory individuals. 206 of the residents are profoundly retarded, 7 are severely retarded, and 3 are moderately retarded.

All 216 are non-ambulatory, 138 have seizure disorders, and 216 have speech and language disorders. There is one court ordered admission. The average age of the residents is 34. The oldest is about 60. Some of the adults work in the work activity center doing production work and are paid accordingly. Two work off the premises.

The residents of Hazelwood share rooms with one to three people. Each person has a bed, wardrobe, and a chest. The rooms are decorated individually to suit the taste of the resident or their family.

Hazelwood does not have as many young admissions as they used to because there are many more services in the community, including less restricted schools. Some of the school age residents go out to public school. Others of that age go to county classrooms within the facility. The reason for this is that their physicians do not feel they could survive transportation. Programs in Hazelwood consist of:

1. Education
2. Vocational training
3. Physical Therapy
4. Recreation
5. Occupational Therapy
6. Speech and Language Acquisition
7. Independent Living Skills

The school/vocational enrollments are:

45 Public School
21 Public School at Hazelwood
35 Vocational Training at Hazelwood
160 Adult Module Programs at Hazelwood

The number of residents discharged in 1985-86 was 14. They were discharged to:

1 Foster Care
1 Skilled Nursing Facility
9 Direct to Home
3 Died while on leave
The average length of stay for those discharged was three years.

Oakwood ICF/MR is a modern 420-bed facility located in Somerset. Currently, there are 416 residents. Oakwood opened in 1972 and consists of 26 buildings. The buildings are arranged in a village configuration, with cottages bordering the outside and the inner building serving for educational, vocational, and leisure activities. These buildings include administration, service/maintenance, a community center (housing the gymnasium, stage, and indoor-outdoor swimming pool), an educational complex, a 21 bed infirmary, and an activity center.

225 of the residents are profoundly retarded; 136 are severe; 41 moderate; and 19 are mildly retarded.

There are 13 non-ambulatory residents, 180 residents with seizure disorders, 101 with epilepsy, and 229 with speech and language disorders. There are three court ordered admissions.

Residents' bedrooms have large windows; most are carpeted. Residents live two to a room. Each apartment contains an activity/classroom, a living room area, and dining area. All areas have been newly furnished, carpeted, painted, and color coordinated, throughout.

Programs consist of:

1. Self-Help Training
2. Functional Living Skill Training
3. Speech/Language/Total Communication Programs
4. Behavior Programming
5. Physical or Occupational Therapy
6. Vocational or Horticulture Training
7. Swimming Lessons or Aquatic Skills
8. Recreation and Leisure Skill Training
9. Socialization Skill Training
10. Counseling

The school and vocational enrollments include 71 residents in public school and 416 attending educational training at the facility.

The number of residents discharged in 1985-86 was 66:

10 AIS/MR
52 Direct to Home
1 Deceased
1 Private Licensed Facility
1 Skilled Nursing Home
1 Transfer to Another State Facility

For those discharged, the average length of stay was 8 years, 4 months, for long-term care and 23 days for short-term. Many of Oakwood's residents are not yet ready for community programs. The clients are mostly in their twenties, with a minimum age of six. Oakwood has a waiting list of 20 to 30 persons.

Outwood ICF/MR is a modern 80-bed facility located in Dawson Springs. It currently has 77 residents. The breakdown by retardation level is:

Forty-three are profoundly retarded, 27 severe, and 5 moderate. There are two blind residents whose level of retardation is not specified.

There are eight that are non-ambulatory, 28 have seizure disorders, and all have speech/language disorders. Two are deaf and eight are partially or totally blind. Forty-two have behavioral disorders. There are four court-ordered admissions.

Living quarters are apartment-style, with two clients sharing a bedroom. Each apartment has its own multi-purpose recreation room, as well as dining room and outdoor patio, complete with grill and picnic setting. Apartments are part of a duplex arrangement and share a kitchen and service area. We have no information on what their programs consist of.

The school and vocational enrollment include 51 in Day Training/Pre-Vocational and 26 in Work Activities Center. No residents are eligible for public education.

There were 17 discharged in fiscal year 1985-86. Sixteen were discharged to respite and 1 to Glasgow ICF. The average length of stay for those discharged was 23 days for respite. The ICF transferee stayed 17-1/2 years.

Private facilities:

Cedar Lake in LaGrange is a modern non-profit licensed ICF/MR/DD with 76 residents:

Eight are profoundly retarded, 31 severe, 24 moderate, 10 mild, 2 are borderline cases and 1 is of average intelligence.

There are five residents who use wheelchairs. There are 14 residents with seizure disorder and 47 with speech/language disorders. There are no court-ordered admissions and no school age residents.

Residents live in semiprivate rooms. Each suite has four or five bedrooms, one to three bathrooms and a living room and dining room/kitchen.

Programs consist of:

1. Four Work Options
2. Recreation Services
3. Living Skills
4. Ancillary Services—Occupational, Therapy, Speech Therapy, Physical Therapy, and Psychology/Behavior Management
5. Self-Help/Domestic Skills Training
6. Social Services/Counseling
7. Religious Services

There are no "school" classes because Cedar Lake serves adults.

No residents were discharged in 1985. Three residents were discharged in 1986; one to his private home and the others to a licensed family care home. Their average length of stay was 10 years, 2 months.

Wendell Foster Center, Incorporated, is a modern, private, non-profit facility with 63 beds located in Owensboro. Wendell Foster is the only facility within the Commonwealth of Kentucky specializing in residential training and therapy for children and adults with cerebral palsy. Its clients are six years of age or older. Fifty-one of the residents have mental retardation.

Seven are profoundly retarded, 16 severe, 17 moderate, and 11 are mildly retarded.

Forty-four are non-ambulatory, 37 have seizure disorders, and 63 have speech/language disorders. There are no court-ordered admissions.

Residential rooms at the Wendell Foster Center provide quarters for four residents and have an attached bathroom. Hospital beds are used because of the amount of resident needs and staff lifting requirements. All rooms have exterior windows. Emergency calls are available at each bed site and in each bathroom. They are both audio and visual.

Programs consist of:

1. Self-Help
2. Communication/Language Therapy
3. Physical Therapy
4. Occupational Therapy
5. Recreation/Leisure Time
6. Citizenship Training/Community Awareness
7. Health Education

The school and vocational enrollments include twelve that are in public school and five that are attending educational training at the Center.

Wendell Foster had 14 discharges in 1985-86:

3 AIS Programs
3 Group Home
3 Personal Care Home
1 Skilled Care
1 Deceased
2 Parents Home
1 Family Care Home
1 College

Of those discharged, the average length of stay was about 11 years.

Panorama is a modern, for-profit ICF/MR/DD agency located in Bowling Green. The total number of persons with mental retardation at the center is 58 of school age or older.

Five of them are profoundly retarded, 12 severe, 22 moderate, and 19 mildly retarded.

All are ambulatory, 21 have seizure disorders, and 39 have speech/language disorders. There are no court-ordered admissions.

The semi-private resident rooms are similar to dormitory rooms. Panorama's programs consist of group therapies in the areas of:

1. Psychological Counseling
2. Behavior Management
3. Speech/Language Therapy

4. Recreation
5. Occupational and Physical Therapy
6. Developmental Training

The school and vocational classes include sex education, laundry, cooking, health and first aid. They have 22 residents in public school.

Panorama discharged 10 residents in 1985. They were discharged to:

3 Home
4 AIS Programs
1 Foster Home
1 Home of the Innocents
1 Saddlebrook Apartments

Panorama discharged 13 residents in 1986. They were discharged to:

6 Home
2 AIS Programs
2 Foster Homes
2 Children's Treatment Center
1 Higgins Learning Center

The average length of stay for those discharged was two years in 1985 and four years in 1986.

Excepticon-Lexington Campus is located in Lexington. It is a private, for-profit ICF/MR/DD located in the center of a residential area that includes single-family housing, apartments, townhouses, and a shopping center. Excepticon's capacity is 180 and it is serving 179 adults 18 or older with mental retardation.

Twenty-seven are profoundly retarded, 74 severe, 43 moderate, and 34 mildly retarded.

All residents are ambulatory, 29 have seizure disorders, and 90 have speech/language disorders. There are no court-ordered admissions.

Residents reside in six apartments on a campus. Thirty residents live in each building, 15 on either side of two common living rooms and a counselor/program aide "station." Almost all bedrooms are semi-private, and each building has two private bedrooms.

Programs consist of all residents receiving training provided by the facility school and vocational enrollment includes:

1. 36 individuals now working at the Excepticon Workshop Corporation at 281 Big Run Road, Lexington;

2. 7 currently competitively employed in the Lexington community;

3. 45 attending the Satellite Center at 145 Constitution Avenue, Lexington, a community-based day program providing training in cooking and other housekeeping skills, independent traveling, social/leisure skills, shopping, utilizing community resources, etc.;

4. 30 residents attending an on-campus federally-licensed work activities program providing training and employment in janitorial/housekeeping skills, dining room/"bus boy" service, time and money management, etc.;

5. 61 residents attending on-campus Learning Centers entitled Work Preparation, Daily Living, and Social/Leisure. Residents rotate through each center for training in vocational, independent living, and leisure skills.

Two residents attend public school.

Eight residents were discharged in 1985. as follows:

4 Home
1 Quest Farm
1 Personal Care Home
1 Psychiatric Facility
1 Another ICF/MR

Those discharged in 1985 had an average length of stay of 3-1/2 years.

Seven residents were discharged in 1986, as follows:

1 Home
1 AIS Program
2 Personal Care Homes
1 Psychiatric Facility
2 Nursing Home

The average length of stay for those discharged in 1986 was 9-1/2 years.

Higgins Learning Center is a private, for-profit ICF/MR/DD located in Morganfield. Residences are dormitory style. Its 56 residents are school age or older, the average age being 20. Their retardation levels are: Five severely retarded, 14 moderate, 27 mild, 3 borderline, and 3 of unspecified level.

Fifty-five of the residents are ambulatory, one is in a wheelchair, 20 have seizure disorders, 23 have speech/language disorders/delays, and three are severely autistic.

Higgins has the reputation of handling school-age residents with behavioral problems. About 20 percent of the admissions are court-ordered. They get the clients that AIS cannot manage. Medicaid has told Higgins that the high functioning client of an IQ of 65 or over may not be disabled enough to be in their facility. Yet Higgins knows something is needed for the high functioning person with mild mental retardation that has behavioral behavior problems. Realizing that a lot of their clients get expelled from school, Higgins has formulated its own day program for those that are sent home.

Higgins has students in high school and elementary school including trainable mentally handicapped classrooms and supported employment. Many of Higgins' out of district students attend public school and tuition adds up. Since Higgins no longer has the extra funds for tuition, they have left the tuition issue for the parents and school to resolve.

The school/vocational enrollments:

26 Public School (1 Mainstreamed, 21 TMH, 4 SPH)
12 Sheltered Workshop (4 Sheltered Workshop, 7 Activities, 1 Evaluation)
18 Center Day Programming

Seventeen residents were discharged in 1985, as follows:

8 AIS Program
1 Personal Care Home
4 Home
2 Sheltered Apartment
2 Facilities More Structured than Higgins

Seven residents were discharged in 1986, as follows:

6 AIS Program
1 Sheltered Apartment

The average length of stay for those discharged in 1985 was almost four years and for those discharged in 1986 three years.

The chairpersons of the parent groups of Hazelwood, Outwood and Oakwood expressed the following concerns, including that their children should not be moved into community residential programs because an institution, to them, is the least restrictive environment.

Their major concerns are:

1. Community programs are not monitored enough.

2. Planned budget cuts may result in reduction of institutional care. The LRC budget review subcommittee report (1988-90 general fund budget limitation options record) recommended a total reduction for Hazelwood for the FY 1988-89 of $987,000 and $672,800 in FY 1989-90.

3. They suggest a review of the existing moratorium on ICF/MR beds.

4. The number of persons needing institutional care is increasing each year and the waiting lists are growing.

5. Outwood could handle many more persons if additional cottages were added; presently the facility has been cut to 80 residents.

6. More programs are needed to keep the adults with mental retardation in ICF/MRs and in nursing homes busy. (Having programs for adults with mental retardation within long-term care facilities where adults with mental retardation constitute about 25% of the population could also create problems.)

7. The idea of the courts annually reviewing institutionalized persons with mental retardation is disturbing, since the average person does not have the knowledge or direct experience to make such decisions. Moreover, such legal processes will involve valuable staff time and will take professional time from the residents' care. They would be traumatic for the residents and their families and perhaps result in adults with mental retardation being put out in the street.

8. ICF/MRs should be upgraded.

9. Monitored group homes need to be funded.

Long-Term Care Homes

The last group of care facilities, with the largest number of persons with mental retardation but without mental retardation services, is the Long-Term Care Homes (Nursing Homes). There are 30,784 LTC beds in Kentucky with 3,478 to 7,696 of them occupied by old or young people with mental retardation. Applicants for LTC facilities are not screened for mental retardation; therefore, their exact number and their retardation levels of age are not available (as is indicated elsewhere in this report).

Long-term care clients whose care is funded by Medicaid must be diagnosed for a major medical problem other than mental retardation. Recently, Medicaid started enforcing this requirement in Kentucky. Such enforcement means that many of the persons with mental retardation without such a major medical problem can be removed from the LTC Medicaid beds without guarantee of alternative placement.

Ninety-five percent of the long-term care facilities are privately owned, and the remainder are owned by county government or a nonprofit organization. These homes are often called Nursing Homes, Personal Care Homes, or Family Care Homes. These LTC homes vary in accommodations. Within most of them there is a variety of client beds which offer different levels of care. The higher level of care beds are funded by Medicare for the first 20 days and by Medicaid for the remaining care period. The lower level of care beds are SSI and state funded.

The lower cost of room and board in long-term care homes, the moratorium on ICF/MR construction, and the limited community programs may explain the large number of persons placed in LTC facilities. This lower cost for LTC room and board is shown in Table 19.

Unlike ICF/MR., skilled and intermediate care beds have a cap on the amount of room and board paid by Medicaid. Medicaid does not pay room and board for personal and for family-care beds; it is paid through SSI check for those eligible. Some clients do not receive enough SSI and the state supplements what their SSI does not cover.

Medicaid pays much more than room and board for LTC homes. It pays both indirect and direct medical services for those eligible for Medicaid in skilled and intermediate care beds. It also pays medical services through medical cards for SSI individuals in personal and family care beds. This information is summarized in Table 20.

TABLE 19

DAILY COSTS IN THREE TYPES OF CARE FACILITIES
FOR PERSONS WITH MENTAL RETARDATION

Long-Term Care Homes	State ICF/MR	Private ICF/MR/DD
Skilled Care Bed $54*	Central State $173	Wendell Foster $109
Intermediate Care Bed $38*	Outwood $155	Panorama $85
Personal Care Bed $17	Hazelwood $126	Cedar Lake $76
Family Care Bed $14 in private home	Oakwood $100	Higgins $71
		Excepticon $70

*Medicaid cap on room and board.
LTC figures are estimates.

SOURCE: Kentucky Cabinet for Human Resources for 7/1/87.

TABLE 20

LTC HOME: ROOM, BOARD AND MEDICAL SOURCES OF PAYMENT

Skilled and Intermediate Care Beds:	Personal Care Beds:	Family Care Home Beds:
Room and Board Paid by Medicaid if eligible	Room and Board Paid by SSI if eligible	Room and Board Paid by SSI if eligible
Indirect & Direct Medical Services Paid by Medicaid	Medical Services Paid by Medical Card (with SSI)	Medical services Paid by Medical Card (with SSI)
Cost Higher for Non-Medicaid Clients	Cost may be Higher for Non-Medicaid Clients	Cost may be Higher for Non-Medicaid Clients

The present ICF/MR and the community-based services cannot accommodate the persons with mental retardation presently in LTC Homes. For this reason, the feasibility of comp care centers providing some in-home services to persons with mental retardation in LTC residents must be examined. However, it doesn't seem fair to overlook the non-

retarded in the same facilities. Presently, four comp care centers intervene into personal care homes offering only consultation and staff training. Such services are not covered by Medical Assistance and most community mental health centers have eliminated personal care home consultation programs because of the cost involved and limited reimbursement.

CHAPTER III

MONEY MATTERS

Sources of Funds Available to Persons with Mental Retardation

Understanding the funding patterns for persons with mental retardation requires the knowledge of where the money comes from. In this section the funding sources and their eligibility requirements are presented.

Federal Funds: (All Medicaid benefit programs—individual, group, institutional, etc.—are 72.2% federally funded with a state match of the remainder, as of October 1, 1987).

- **AIS/MR Alternative Intermediate Services for the Mentally Retarded:** This is Medicaid money ("waiver") for which some of the rules were waived to pay for non-institutional residential care. The Medicare Waiver Program has its own policies, procedures and regulations and the documentation of services is per service staff note. Billing is based on cluster maximum and annualized upper limits per client and by minimum-maximum for certain services within the project. The reimbursement is by a fixed fee for services which is set by administrative regulation. This is a major funding source (resulting from the Home and Community Living Amendments, 1982), which allows the use of Medicaid money for community services. The state must receive approval for its plan (renewed every 3 years), which allows for a mixture of services. The clusters are the administrative units for the AIS/MR. There can be up to 25 in community group homes and up to 25 in residential services (the state has a toal of 17 clusters, servicing 765).

- **DDA—Developmental Disability Act:** This is considered seed money for new projects. In some cases it can be a continuing allotment.

- **ICF/MR—Intermediate Care Facilities for the Mentally Retarded:** These are funded through Medicaid institutional funding, third party payments and private care.

State General Fund:

- **MRSGF (Mental Retardation State General Fund):** This is a project of continuation money which is adjusted for inflation. It also can be used as a crisis fund for individual clients in need. This source of funds attempts to respond to regional needs to supply missing services. Payments are made on a daily basis. This also includes **SGFS (State General Fee for Service)** A maximum amount can be earned annually by providing services at a rate adjusted for inflation. Most of this fund goes into adult day habilitation. Services are monitored by the division and documented on per-service basis or by a weekly summary note.

- **ESEA—Elementary and Secondary Education Act:** This is support service money to the school districts for aid and materials for clients enrolled in school.

Other funds available to the MR:

- **Medical Card:** Medicaid funded health care card. Some persons with mental retardation are eligible.

- **Section 8:** A federal program administered by local agencies which pays in part or in full for rent and utilities for eligible low income people.

- **Chapter I:** Federal money which CHR receives from the Department of Education for partial funding of the infant stimulation program.

- **Foster Grandparent Program:** (no further information about this was provided).

- **Supplemental Security Income—SSI:** A federal program that provides monthly payments to aged, blind, and disabled people who have little or no resources and income. The program is administered by the Social Security Office but the funds are not Social Security funds. SSI is funded through the U.S. Treasury from taxes collected by the U. S. Government. Eligible recipients include adults with mental impairments that prevent them from doing any substantial gainful work, or children with mental impairments that are comparable in severity to one that would prevent an adult from working. The impairment must be expected to last at least 12 months or to result in death. One's sources of income affect his eligibility for SSI. An eligible applicant's resources cannot exceed $1,700 for a single person and $2,550 for a couple. Personal monthly income cannot exceed $336 for an individual or $504 for a couple. Not all resources are considered, however. Homes and a few other types of resources are exempt, and recipients are permitted up to $65 a month of earned income plus one-half of earned income over $65 a month, or if there is no unearned income, $85 of earned income plus half of the remainder.

  SSI has many work incentives, including trial work. During this trial period, the person can continue receiving disability checks for 9 months, no matter how much he earns. After completion of these 9 months, the work or services performed will be considered, to determine whether the individual is engaging in substantial gainful employment. A gauge for this is whether earnings are at least $300 a month. These are just a couple of the work incentives. In Kentucky SSI recipients are eligible for Medicaid, which can pay health care expenses. SSI recipients may also be eligible for food stamps.

- **Department for Social Services—DSS:** Persons with mental retardation are sometimes eligible for D.S.S. benefits, but not because of their mental retardation. D.S.S. funds residential services, Children's Treatment Center, emergency shelter, child protection, special needs adoption, day care, and homemaker services. D.S.S. can subcontract with regional MH/MR boards for services, mainly in urban areas.

- **Department for Employment Services:** The Department for Employment Services funds the Committee on Employment of the Handicapped through the JTPA. Some funds can be channeled through the regional CCC.

- **Department of Health:** The Department of Health funds lab work for some persons with mental retardation.

- **Department of Education:** The Department of Education funds classroom units for exceptional children through the foundation program. Additional special education is funded by Public Law 94-142, the Education for all Handicapped Children Act. The Department of Education's special education services are provided to qualified students from the ages of 5 through 21. Preschool and kindergarten special education students are served by federal grants, though some of these students attend regular kindergarten.

- **Vocational Education:** Vocational Education services include programs for the disadvantaged and handicapped in local high schools, liason projects between vocational education centers and high schools on high school campuses, and post-secondary institution programs.

- **Vocational Rehabilitation:** Through the Carl Perkins Act, the federal government and the state match funds for vocational rehabilitation programs that serve the developmentally disabled. The funds flow through the Department of Education. These funds also provide for the Carl Perkins Evaluation Center. Vocational Rehabilitation programs begin in 12th grade (following an earlier evaluation). The state receives a grant for supported employment through Vocational Rehabilitation.

- **Local Funds:** KRS 210.440 to 210.480 allow for local taxes to be levied for the handicapped. On January 18, 1988, CHR reported that at least two districts levy this special tax.

Local funds can also be received through direct fundraising efforts or from community fundraising organizations (e.g., the United Way). Information about those amounts is incomplete. In some cases there is a reluctance to submit this information, because successful local fundraising is often "rewarded" by cuts in state allocations, according to local agencies and state officials.

Costs, Allocations, Budgets and Expenditures

With so many funding sources, each with different requirements, it is not possible to know how much money persons with mental retardation actually are receiving. The only amount which can be determined is the money allocated through the Division for Mental Retardation to the MH/MR boards and the funds spent for ICF/MRs. Other funds which benefit persons with mental retardation are not necessarily identified as such (e.g., SSI funds). These funds come to them because of other eligibility criteria (e.g., low income, age, etc.).

In 1986 the SGF contributed 46.8% of the $22,400,721 for community-based services, as shown in Table 21.

TABLE 21

1986 ALLOCATIONS BY SOURCE OF FUNDS

SGF	10,490,843	46.8%
DDSA	723,759	3.2%
ESEA	411,119	1.8%
AIS/MR	10,775,000	48.1%
TOTAL	22,400,721	

Table 25 provides a breakdown of these allocations by the regions and by services, while Appendix 4 provides such allocations for each of the 14 regions by program areas in the last five years.

There seems to be a certain disparity in allocations among the regions, which is augmented by the fact that larger urban areas tend to attract certain numbers of persons with mental retardation from other regions. Such an observation was also made by several people who were interviewed and is supported by findings in other research. No data to support this was presented. To check such a claim, regional allocations were compared to the size of the population and per capita rates (Table 26).

Comparisons of the percentage point difference between the regions' population and their funding levels shows:

1. Bluegrass: -5.0 percentage points difference
2. Seven Counties: -4.9 percentage points difference
3. Northern Kentucky: -1.5 percentage points difference
4. Mountain: -1.2 percentage points difference

(This means that the Bluegrass regions received 5% less in funds than its share of the population).

On the positive side are:

1. Comprehend: + 3.4 percentage points difference
2. Pathway: + 3.3 percentage points difference
3. Green River: + 2.6 percentage points difference

The first group also receives lower per capita allocations:

State Average SGF:	$2.75	All Funds: $5.87
Bluegrass SGF:	1.97	All Funds: 3.94
7 Counties SGF:	1.97	All Funds: 4.5
Northern Kentucky SGF:	2.34	All Funds: 4.83
Mountain SGF:	4.16	All Funds: 4.68

The other groups have higher than state average per capita allocations:

State Average SGF:	$2.75	All Funds: $5.87
Comprehend SGF:	8.16	All Funds: 19.85
Pathway SGF:	5.28	All Funds: 9.41
Green River SGF:	1.93	All Funds: 9.69

But while the overall numbers of people with mental retardation and allocations are positively correlated, the lower share of the three largest urban areas (45% of the state population receives 33.6% of the funds allocated to people with mental retardation) needs to be examined because of the large number of people such differences affect.

It should be noted that while Region VIII receives the highest per capita allocations, it has higher overheads and transportation costs, due to its rural character and smaller population.

How Much More Will It Cost?

Once again, projecting future expenditures is made difficult by the unreliability of the data.

As a case in point, two estimates of the costs of implementing HB 33 (which passed in the 1986 regular session as HB 53 and was codified as KRS Chapter 447) were made in 1984, one by LRC staff and the other by CHR.

The LRC Fiscal Impact Analysis estimated the 1986 expenditures at $29,427,200 of which $6,551,000 was additional funding, (Table 22 and Appendix 5). The Division of Community Services for Mental Retardation estimated a need for $186,195,152, a mere $156,767,952 difference (Table 23 and Appendix 6).

TABLE 22

LRC 1984 Estimates of
Recipients/Expenditures for MR/DD Services Through
MH/MR Boards Projections Based on Passage of HB 33*

# Type Recipient	FY 1983 Expenditures	FY 1984 Expenditures	FY 1985 Expenditures	Program Growth Rate	FY 1986 Expenditures	Program Growth Rate
6.687: Existing Rec.	$15,215,400	$15,976,200	$16,775,000	—	$17,613,700	—
30: MR/DD Fac. Increase	N/A	N/A	955,700	—	1,003,500	—
3,444: Additional Services to Existing Rec.	N/A	N/A	1,660,500	10% (344)	3,491,900	20% (689)
521: MH/MR Board Waiting Lists	N/A	N/A	545,000	10% (52)	1,145,800	20% (104)
5,599: No Services	N/A	N/A	2,939,400	10% (560)	6,172,300	20% (1,120)
Total Program Costs:	$15,215,400	$15,976,200	$22,876,200	—	$29,427,000	
Total Additional Funding:	N/A	N/A	$6,900,000	—	$ 6,551,000	

*All expenditures are calculated on Fiscal Year 1982-83 cost data adding a 5% inflationary increase each fiscal year and an additional 10% each year in client growth levels.

(LRC, 84 BR 23-746)

TABLE 23

CHR COST ESTIMATES

Service	# To Be Served	Unit Cost	Total Cost
Residential	3,313	$11,592/yr.	$38,405,952
Education	300	$ 1,500/yr.	$ 450,000
Vocational	11,558	$ 7,200/yr.	$83,217,600
Support	13,760		
Case Mgt.	13,760	$ 1,500/yr.	$20,640,000
Therapies	9,632	$ 2,000/yr.	$19,264,000
Respite	13,760		
Intensive	10,320	$ 1,920/yr.	$19,814,400
Non-Intensive	3,440	$ 1,280/yr.	$ 4,403,200
	Support Total	$64,121,600	
	Grand Total	$186,195,152	

Reasons that accurate estimates cannot be done are:

- there are no clear definitions of a "service" or a service unit.
- duplicated counts of people.
- inability to come up with a reliable number of people served.
- inability to determine how many will be served in the future.

The Division for Mental Retardation states that since the expansion of the state's service system would require identification and inclusion of all eligible people a five-to-ten-year plan would be required. In Appendix 6, the CHR Secretary explains a few reasons for the difference in the estimates.

This study cannot support either of these two estimates. The recipients of the two estimates, being concerned about the large differences, asked a third party to settle the difference and have them evaluated; none was more authoritative than Dr. Michael Hogan himself. Dr. Hogan stated that all such estimates should be "taken with a grain of salt" (Appendix 7). He provided yet another estimate, setting additional costs for implementing HB 53 at $44,316,500 (Appendix 7, p. 6).

The authors of the present study estimate that, based on the reported number of people served and cost allocations provided by the Division for Mental Retardation, the "service gaps" can be closed at an additional cost of $31,089,354 (Table 24).

TABLE 24

CLOSING SERVICE GAPS IN ESSENTIAL SERVICES (ADULTS)

Service	Cost Per Unit Served	Close the Gap CHR (Hogan Figures)	Costs Based on This Study Population Estimate**	1986 Allocations	Additional Costs
Case Mgt.	$ 62	$ 871,348	$ 673,940	$ 519,310	$ 154,630
Respite	105*	1,512,526	$1,141,350	395,385	744,965 (ST + CT)
Work Habilitation	1,786	7,324,386	10,483,820	5,163,980	5,319,840
Residential (community based)	2,945	17,363,720	3,840,280	1,330,946	2,509,334
Leisure/ Recreation	541	2,072,571	2,921,400***	127,055	2,794,545
TOTAL		29,144,551	19,060,790	7,536,676****	11,523,114
Other Services			14,864,045	19,566,240*****	
TOTAL				22,400,721	31,089,354

*This is the cost per potential client; actual cost per client served is $502.

**This study used the conservative estimate of 10,878 people with mental retardation in need of services.

***Assuming only half of the population will use this service.

****The difference between this and the $22,400,721 allowed is used for other services and/or other age groups.

*****These are the costs for other services allowing the same ratio of expenditures as in 1986.

The four estimates of costs to serve the entire adults with mental retardation population (over 1986 expenditures) are:

CHR 1984 estimate	-	$163,794,431
LRC 1984 estimate	-	6,551,000
M. Hogan estimate	-	44,316,500
Present LRC estimate	-	31,089,354

With such differences the only thing that can be stated is that there is a need for more funds. The majority of the adults with mental retardation are not served and their numbers increase every year. It is up to the legislature to decide how to respond to this

challenge. In residential services alone there are as many as 7,000 adults with mental retardation in long-term care facilities whose needs are not met. This study cannot recommend what to do about them, but merely state that they exist.

But there seems to be no doubt that the present system, both community-based and ICF/MR is full to capacity and cannot absorb any significant number of additional people without more funds.

Kentucky Compared with Other States

A national study of MR/DD spending places Kentucky in the 47th and the 48th places in respect to total MR/DD spendings in the years 1986 and 1984.[19] The study, however, combines expenditures for MR and DD of all ages, thus making it impossible to determine how Kentucky stands in expenditures for adults with mental retardation. It would seem safe to assume that it is not much better. Kentucky also ranks low by all other criteria in the Braddock study.

Table 27 shows Kentucky in the 49th place in percentage of personal income (.075%) allotted to ICF/MR. Kentucky fares somewhat better when it comes to community-based services; with .06%, it is in 38th place. It is not clear if private funds are included, nor does the $27,398,251 include the $12,317,316 which Kentucky provides to private ICF/MR.

Kentucky also does not fare well when MR/DD allocations as a percentage of total state budget are compared: It is 4th from the bottom with .8% (with .42% going to institutional care and .38% for community-based programs. Table 29).

With $11.5 per capita annually, Kentucky is 3rd from the bottom in expenditures. Only Wyoming spends less; Nevada ties with Kentucky. Per capita, Kentucky is last among the states in institutional expenditures ($6.0) and the 12th from the bottom in community care ($5.5) (Table 30).

A 1982 study made by the Tennessee Department of Mental Health comes to similar conclusions when comparing Kentucky and 11 southern states. It is worth noting that according to this study, Kentucky spends $6.86 for institutional care and $3.77 for ICF/MR per capita (Table 32).

Another study which compares residential services places Kentucky 48th in the number of residential services per 100,000 of the general population (Table 31).

It is not possible to determine if those studies compare the same figures in each state. It is not clear how the Tennessee study could include community-generated revenue when such figures were not available for the present study. The unreliability of data has already been noted, but the similar conclusions reached by different studies indicate a reason for concern.

TABLE 25

Statewide Allocations of MH/MR BOARDS
Division of Mental Retardation

SGF	WESTERN	PENNY	GREEN	BARREN	NCTRL	7 COUNT	N KY	COMP	PATH	MOUNT	KY RIVER	CUMB RIV	LAKE CUMB	BLUE GRASS	STATE
Respite Ext	16000			9775	26764	62132		25000	55292			2000	11991		208954
Work Adult Hab	155310	339888	132978	496386	566944	304429	454629	210000	718832	618240	197392	275437	300868	549986	5321319
Preschool	700	186913			63669	139755	10523					24371 7	67893		713170
Early Int. (CD)				167413	29583							159861		165390	522247
MR Cluster									68121						68121
Group Home (A)					142326	109798	201026	85000							538150
Staff Res			55911			244263								150251	450425
Comm. Tr. Homes								24000							24000
Group Home (C)															0
Clinic	2200	25000		1044	8000	45002	5751					24740			111737
Off-Home							300					2843			3143
Off-Apt. Living															0
Off-In Home						109751	6001	10000					20773	95974	242499
Off-E. Int. (HB)								14528	50902	45860	19420	4945	16605		152260
Off-Other															0
Staff Res. (per)															0
Respite ST	10000			5608	3197	11582		6771	25000			13594	3998		79750
SUBTOTAL A	184210	551801	188889	680226	840483	1026712	678230	375299	918147	664100	216812	727137	422128	961601	8435775
Case Management	72360	51000	79435	80000			62536	41000	137669	74616	63491	33819	72887	144441	913254
Cons/Ed	32906			6635		139026			28649		1085	2866			211167
In-Home Support						30000									30000
Behavior Mgt		9866											20000		29866
Respite		33210	22151												55361
Supp. Emp			46659			275579	24592						26442		373272
Early Int.		3952													3952
Leisure/Rec.	16940		47230			27080									91250
Residential Ser.			10000			65700	24756								100456
SS & E						73331			89586						162917
AISMR										87500	25000			87500	200000
Spec. Proj			28696		25923	17000		41759			103000				216378
SUBTOTAL B	122206	98028	234171	86635	25923	627716	(111884)*	82759	255904	162116	192576	36685	119329	231941	2275989
TOTAL SGF	306416	649829	423060	766861	866406	1654428	678230	458058	1174051	826216	409388	763822	541457	1193542	10711764
DDA															
Preschool			48495			51185	21541	43779		25144	39678		26370		256192
Case Mgt	14686	42666		14686	14686		14282		65700			14686		56366	237758
Special Project	23121					33350			63909			23265		10465	154110
Employment														8772	8772
TOTAL DDA	37807	46775	73670	14686	14686	96684	35823	68535	129609	25144	39678	37951	26370	75603	723021
TOTAL ESEA	45030	39500	37758	28440	16590	54581	33838	18170	33614	43389	21140	96775	11906	107612	588343
AISMR (est.)	750000	600000	1500000	600000	750000	1800000	750000	600000	750000	250000	250000	600000	750000	1250000	11200000
TOTAL MR	1139253	1336104	2034488	1409987	1647682	3605693	1497891	1144763	2087274	1144749	720206	1498540	1329733	2626757	23223120
MRSGF (rev)	160236	168132	281208	293909	315167	1010042	484900	241617	609111	404564	260651	222434	361631	821300	5634902
COMP CARE (rev)	146180	481697	141852	472952	551239	644386	193330	216441	564940	421652	148737	541388	179826	372162	5076782

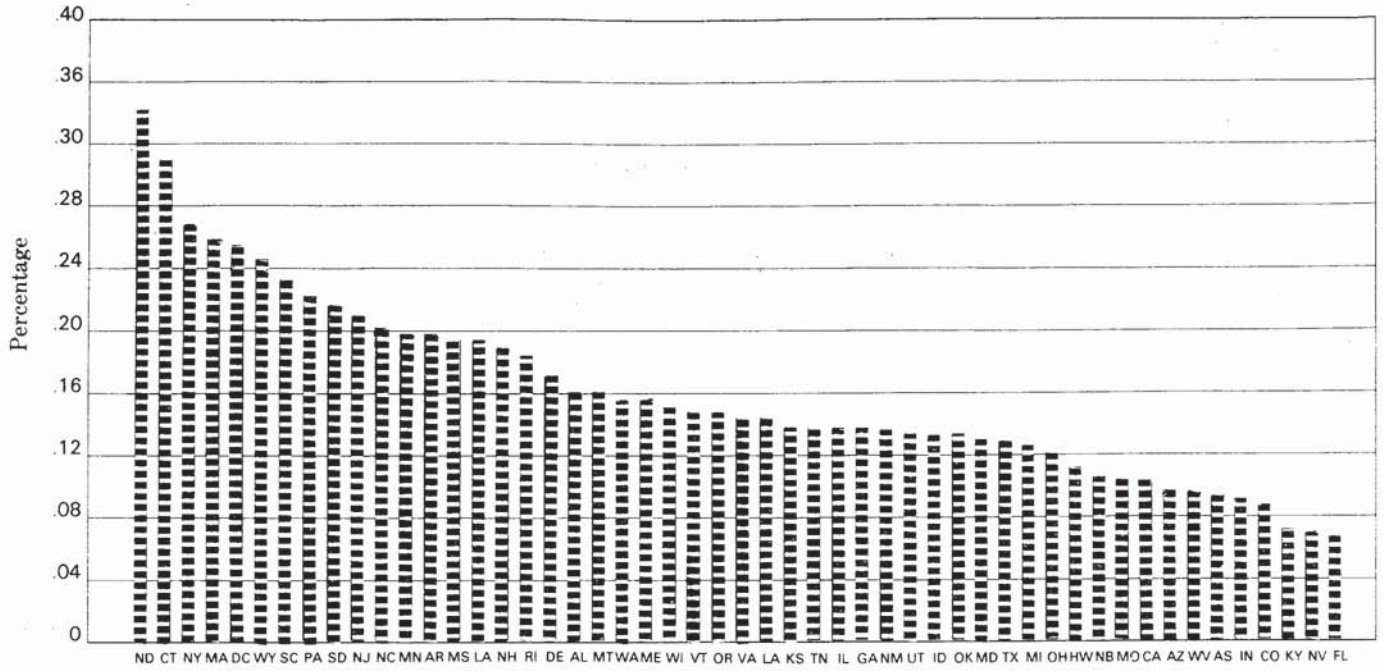
TABLE 26

COMPARISONS OF REGIONAL ALLOCATIONS

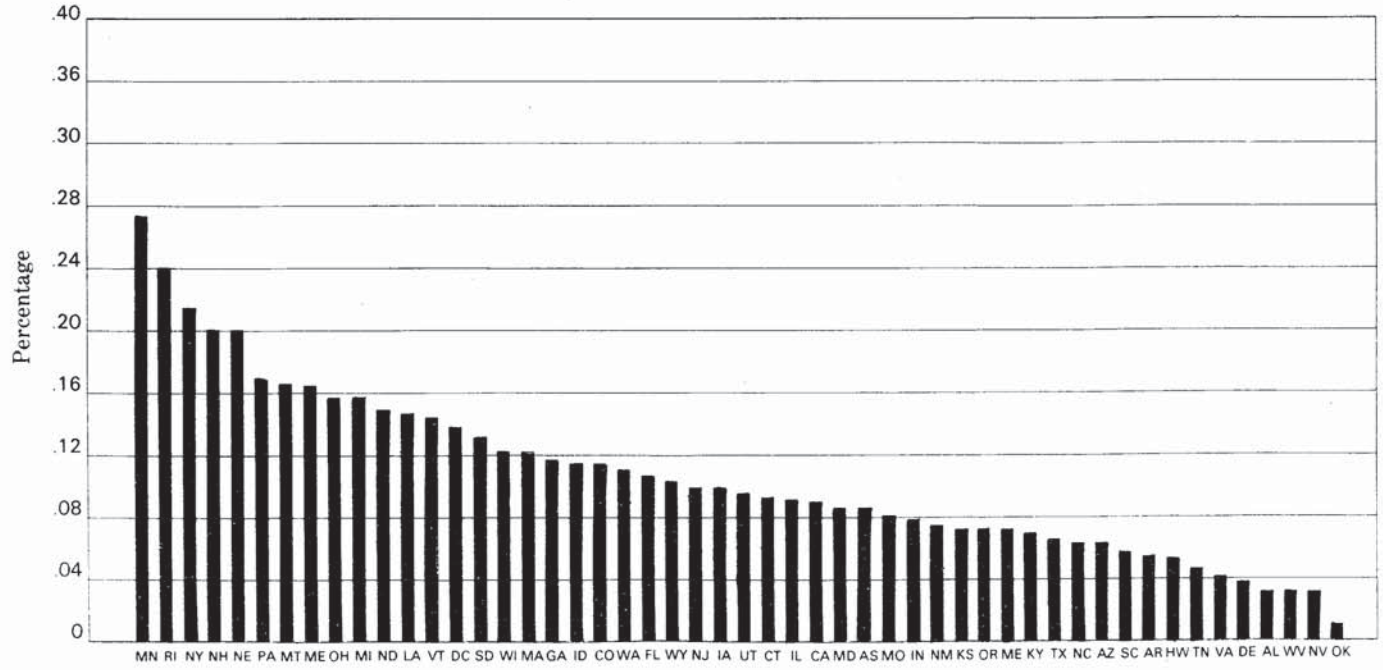
	Region	Region of State Population	% of State MR Allocations	Total Fund Per Capita	SGF Per Capita
I	Western	5.0	5.3	$6.47	$2.11
II	Pennyroyal	5.4	5.8	6.07	2.92
III	Green River	5.4	8.9	9.69	1.93
IV	Barren River	6.3	5.6	5.23	2.59
V	Comunicare	5.9	7.1	7.14	3.67
VI	Seven Counties	21.3	16.4	4.5	1.97
VII	Northern Ky.	8.5	7.0	4.83	2.34
VIII	Comprehend	1.5	4.9	19.85	8.16
X	Pathways	5.7	9.0	9.41	5.28
XI	Mountain	5.3	4.1	4.68	4.16
XII	Ky. River	3.8	3.8	6.01	3.90
XIII	Cumberland River	6.4	6.4	5.94	3.10
XIV	Lake Cumberland	4.8	5.4	6.64	2.32
XV	Bluegrass	15.2	10.2	3.94	1.97
	ALL REGIONS	100	100	$5.87	$2.75

Table 27

MR/DD Expenditures for Institutional Services
As a Percentage of Personal Income,
Ranked by State: FY 1984



MR/DD Expenditures for *Community** Services
As a Percentage of Personal Income,
Ranked by State: FY 1984



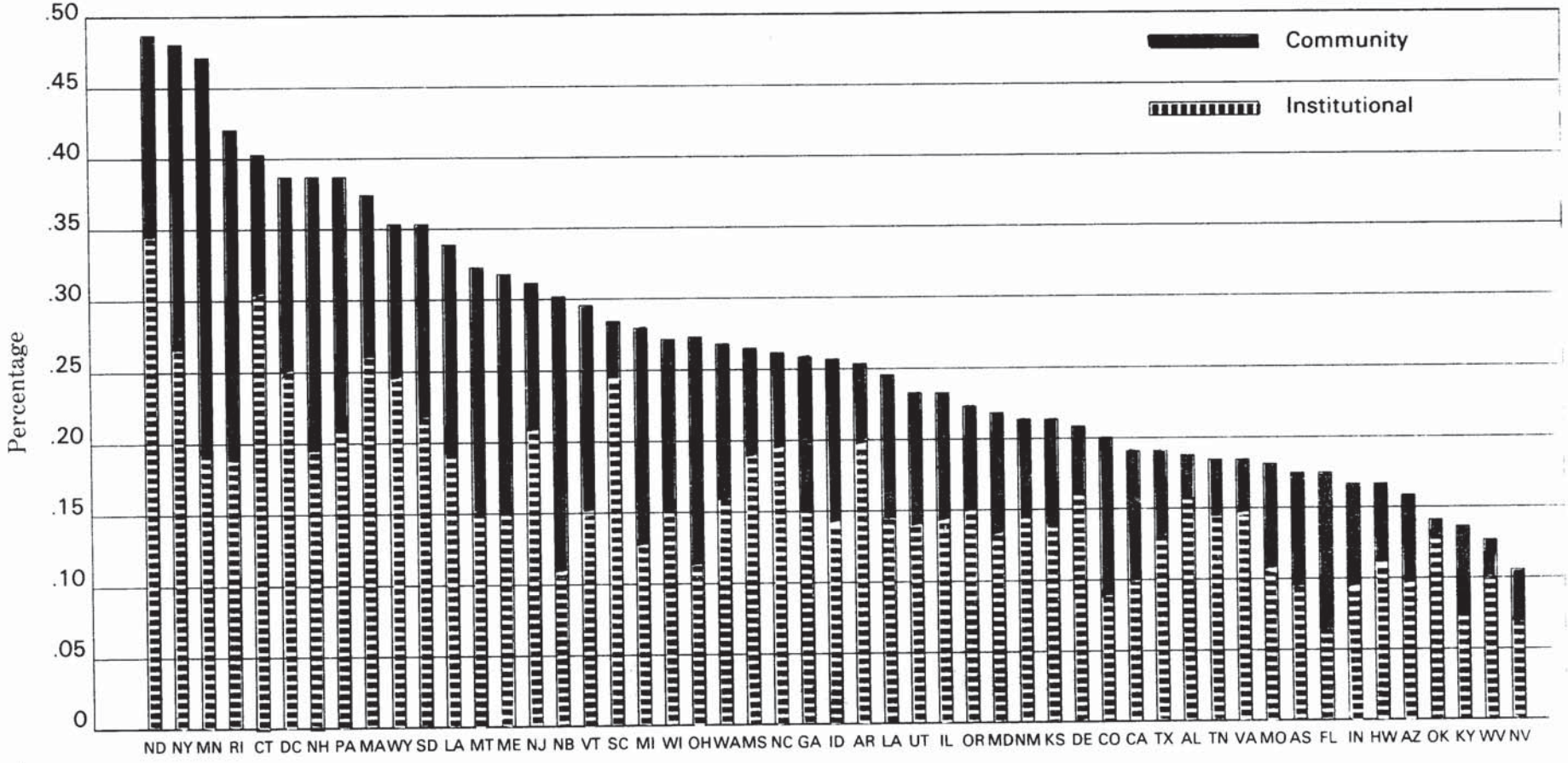
*Excludes SSI, SSDI, Special Education & Local Expenditures

SOURCE: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Table 28

UNITED STATES

MR/DD Expenditures for *Institutional & Community** Services as a Percentage of Personal Income, Ranked by State: FY 1984



*Excludes SSI, SSDI, Special Education & Local Expenditures

SOURCE: Barddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Table 29

MR/DD Expenditures for *Institutional & Community* Services as a Percentage of the Total State Budget, Ranked by State: FY 1983

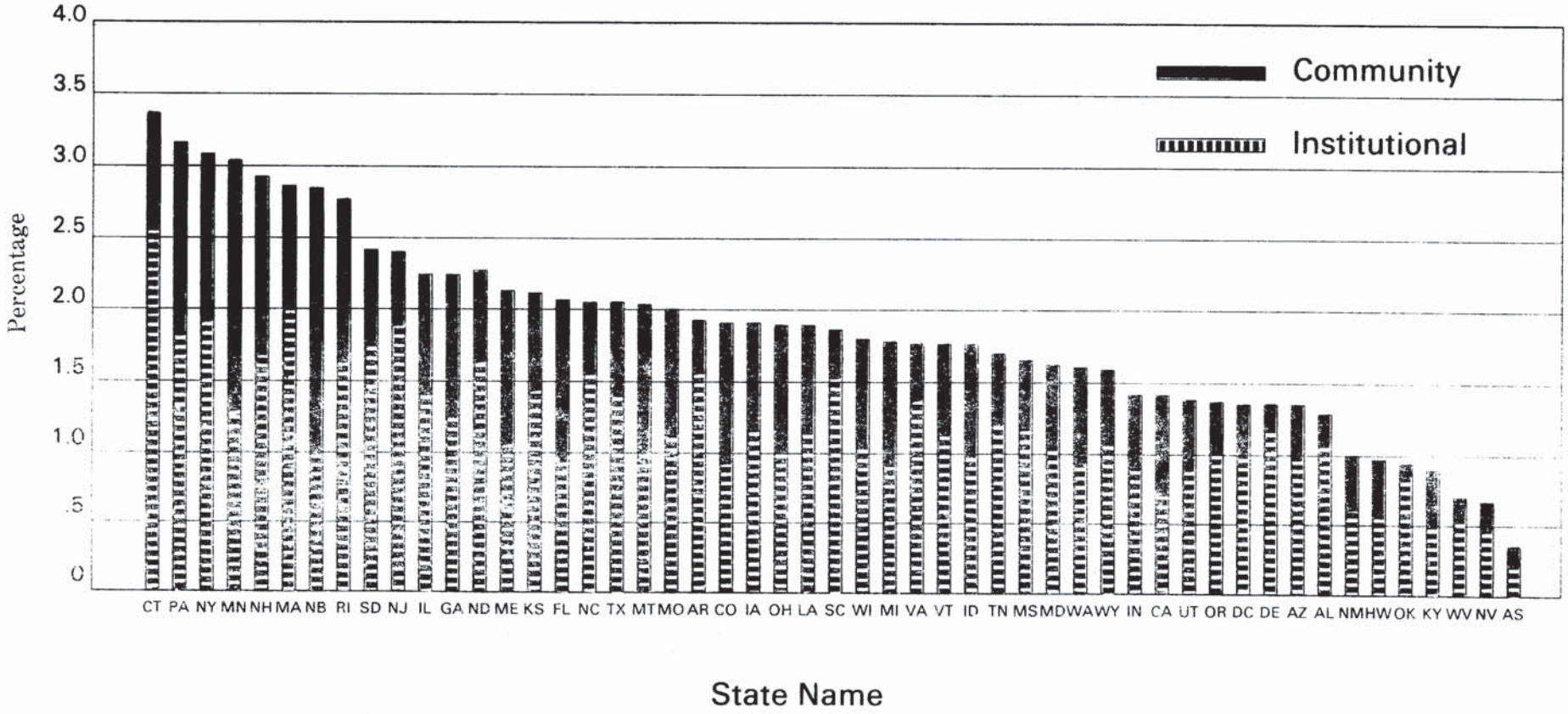
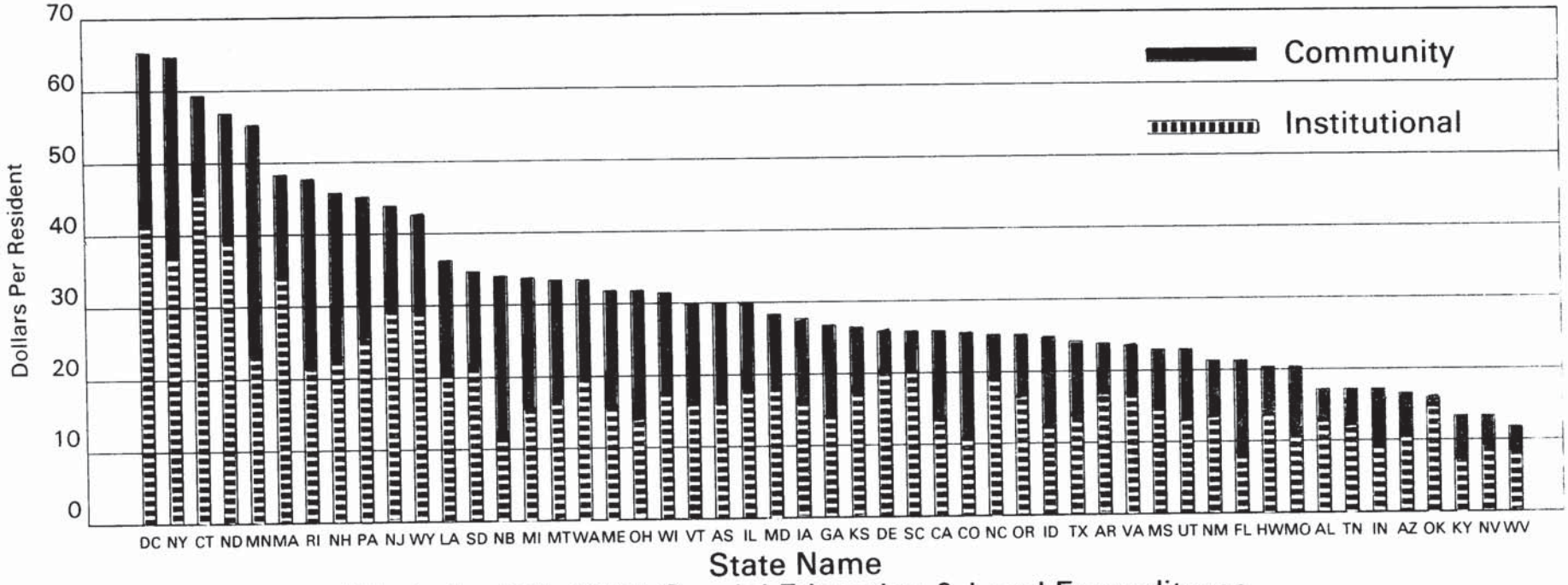


Table 30

MR/DD *Institutional & Community** Services Expenditures Per Capita, Ranked by State: FY 1984



*Excludes SSI, SSDI, Special Education & Local Expenditures

SOURCE: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

TABLE 31

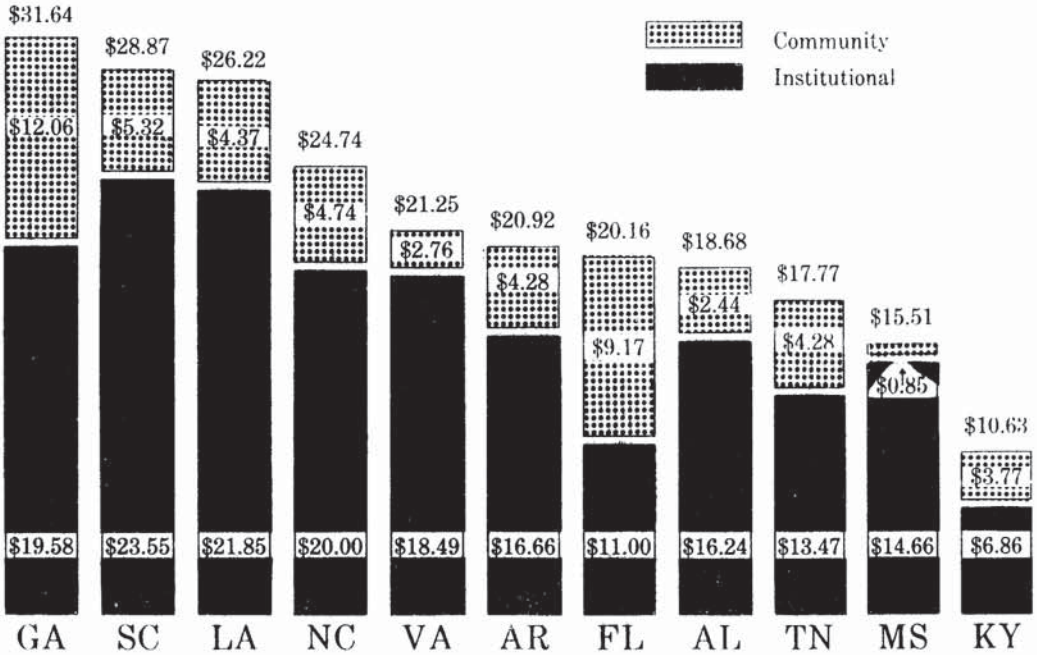
STATE COMPARISON OF RATES OF RESIDENTIAL SERVICE PER 100,000 OF THE GENERAL POPULATION IN 1982

Ten Lowest Rates of All Types Residential Care for Persons with Mental Retardation		Lowest Rates of Residential Care for Persons with Mental Retardation, 15 or Fewer Beds	
50) Nevada	(34.16)	50) West Virginia	(2.7)
49) Alabama	(49.27)	49) Oklahoma	(2.9)
48) Kentucky	**(50.72)**	**48) Kentucky**	**(4.8)**
47) West Virginia	(52.92)	47) Louisiana	(6.1)
46) Arkansas	(56.62)	46) South Carolina	(6.1)
45) Arizona	(60.60)	45) Illinois	(6.3)
44) New Mexico	(62.25)	44) Texas	(7.4)
43) Georgia	(63.07)	43) Alabama	(7.7)
42) Indiana	(72.40)	42) Virginia	(8.0)
41) North Carolina	(73.78)	41) Arkansas	(8.3)
National Avg.	(105.2)	National Avg.	(21.9)

SOURCE: Hauber, F. A., Bruininks, R. H., Hill, B. K., Lenkin, C. K., and While, C. C. (1982), National Census of Residential Facilities, Minneapolis: Center for Residential and Community Services, Department of Educational Psychology, University of Minnesota.

TABLE 32

MENTAL RETARDATION SERVICES 1983 BUDGETED PER CAPITA (including community generated revenue)



SOURCE: Tennessee Department of Mental Health and Mental Retardation *Breakthrough*, Vol X, No. 4, Fall 1982.

TABLE 33

REPORT OF HANDICAPPED CHILDREN AND YOUTH EXITING
THE KENTUCKY EDUCATIONAL SYSTEM DURING THE 1985-86 SCHOOL YEAR

Basis of Exit	HANDICAPPING CONDITION/AGE											
	MENTALLY RETARDED											
	1-5	6-11	12	13	14	15	16	17	18	19	20	21
(A) Graduation with Diploma	X	X	X	X	X	X	3	119	417	243	90	18
(B) Graduation Through Certificate of Completion/Fulfullment of IEP	X	X	X	X	X	X	1	1	29	15	17	89
(C) Reached Maximum Age	X	X	X	X	X	X	7	4	3	1	1	57
(D) Dropped Out	0	3	0	1	2	9	233	125	102	36	9	17
(E) Status Unknown	0	24	5	6	7	26	42	15	17	8	4	1
(F) TOTAL (of rows A-F)	0	27	5	7	9	35	286	264	568	303	121	182

SOURCE: U.S. Department of Education, Office of Special Education and Rehabilitative Services Special Education Programs

TABLE 34

REPORT OF ANTICIPATED SERVICES NEEDED BY THESE HANDICAPPED CHILDREN AND YOUTH IN KENTUCKY FOR THE 1986-87 SCHOOL YEAR

	HANDICAPPING CONDITION/AGE								
	Mentally Retarded								
	Less than 16	16	17	18	19	20	21	Over 21	Total
(a) Counseling/Guidance	125	107	96	168	105	43	38	29	711
(b) Evaluation of MR Services	7	80	80	197	64	21	33	12	494
(c) Physical/Mental Restoration	2	5	8	33	15	15	10	1	89
(d) Vocational/Training Services	16	119	132	277	142	59	39	14	798
(e) Transitional Employment Services	3	45	43	163	55	38	39	13	399
(f) Vocational Placement	10	82	87	181	103	33	29	14	539
(g) Post Employment	6	22	33	113	72	23	27	8	304
(h) Maintenance	6	18	20	66	51	24	35	10	230
(i) Transportation	41	16	15	67	28	20	36	3	226
(j) Family Services	17	34	30	46	36	23	27	8	221
(k) Independent Living	1	20	20	50	37	24	36	20	208
(l) Residential Services	0	3	2	5	7	7	8	21	53
(m) Interpreted Services	0	0	0	0	0	0	0	0	0
(n) Reader Services	0	0	0	1	3	1	0	0	5
(o) Technological Aids	1	1	5	12	10	6	6	0	41
(p) Other Services*	1	4	9	27	26	11	17	0	95
(q) No Special Services	9	20	25	25	8	7	4	2	100
TOTAL (of rows A-F)	163	438	446	1019	484	209	188	83	3030

*Specify other Services: 1. Work Activity Center 2. Student Workshop

SOURCE: U.S. Department of Education, Office of Special Education and Rehabilitative Services Special Ed. Programs

Discussion of Recommendations

The inadequacies of the data available for the present study have already been pointed out. The consequences could mean major problems for planning and budgeting, as suggested by the tremendous differences in cost estimates in Chapter III.

The gaps between the number of people served and those on waiting lists are also large, and the reasons for this differ from region to region. Some have indicated that waiting lists are useless. Others say that such lists do not reflect the actual need for services.

Concerns about the community-based services' ability to meet the needs of the severe and profound cases have been expressed. It should also be noted that community-based services are a relatively new approach, thus lacking in experience to provide for clients over many years and through life transitions. Some parents of persons with mental retardation in facilities have expressed their concern about the long-term stability of community-based services, suggesting that institutions are more stable in the long run and less susceptible to budget cuts, policy changes or economic fluctuations, and that they can be better monitored and are better suited to provide for difficult cases.

At the same time, as much as the community-based services profess to serve mainly severe and profound cases, we have seen quite a few of their clients who seem to be at the moderate or even mild levels. No related data was provided. This is not a negative condition by itself, because it is the conclusion of the study that the choice between placement in a residential setting, ICF or community should be made on the basis of the individual's condition.

The finding is that there is a substantial number of adults with mental retardation who are not served and are in long-term care facilities. Their condition is not known. There is a need to determine their fate. We are concerned about the magnitude of the problem and recommend that CHR examine it and present a plan which will, at least, prevent more people from being placed in long-term facilities.

CHAPTER IV

OTHER ISSUES

Legal Issues

The Resolution which ordered this Study (SCR 57, 1987) did not include a review of judicial matters. However, such matters affect services and a few comments seem in order. Appendix 8 lists major federal and state laws which affect the persons with mental retardation. Recently, CHR also reviewed judicial matters and made several recommendations for change.[20]

The statutes do not seem to recognize that mental retardation and mental illness are different phenomena and that persons with mental retardation have a life-long, incurable condition. Further, mental retardation itself is a generic term which includes a wide range of conditions from mild to severe or profound. The statutes are not flexible enough to accommodate their diversity by treating all conditions equally. Without a statute of their own, persons with mental retardation are treated as mentally ill (KRS 202A and 202B) or as part of the broader category of the developmentally disabled (KRS 347).

Commitment of persons with mental retardation into an institution suggests that they are mentally ill, since the dictionary defines commit as to place officially in confinement or custody. A more fitting term to use is "entrusted," which suggests caring. The difference is not merely semantic. The law by which persons wth mental retardation are committed to an ICF was written to fit the mentally ill, with little recognition of the unique characteristics of persons with mental retardation, and it was, in turn, derived from criminal procedures. In part, it intended to protect the mentally ill from institutional horrors, as such facilities once permitted.

Judge Allen recently ordered[21] (presently under appeal) a periodic review of all cases of persons with mental retardation in ICFs. Protection and Advocacy estimates that 300-400 individuals could be released from ICF/MR into the communities "even if there are no places for them to go." This study has previously stated that indeed most of them have no place to go. The community-based service system is full to capacity and without additional funds, and relaxing zoning restrictions, most of those released will have no place to stay.

Recommendations

It is recommended that no person should be discharged from one place to another unless there is a guarantee that he will receive at least a comparable level of care and that his basic needs will be met.

Any review of a case should take into consideration the interests and welfare of the individual and the recognition that mental retardation is a permanent and incurable condition.

Even the aforementioned CHR review of KRS 202A and 202B, while offering valuable revisions, is mainly concerned with "proper" hospitalization procedure, as the title of those recommendations implies; they fall short of recognizing the unique phenomenon of mental retardation. Mental retardation is not an illness, ICFs are not hospitals, nor are they places of confinement. They are, with all their shortcomings, the product of an organized attempt by the society to create an environment where persons with mental retardation can live, and for many of them it is the "least restrictive environment," which provides for their basic daily needs, and where they can enjoy programs and services which otherwise would not be available, or accessible for them. This is especially true in rural areas.

Protection and Advocacy attorneys indicated that probably many adults with mental retardation will be released to places where service will be available; however, they said, the courts can only release them. The courts do not determine where they will go. Facilities are obliged to release them, but not obliged to make residential arrangements. The writers of this study are concerned about the hardship that can be caused to discharged individuals without the guarantee of continuation of care.

Decisions about the best interest of an individual should be left to professionals who are better equipped to evaluate what is best for his welfare than judges, juries or advocates.

It is not just the persons with mental retardation who will bear the burden of such periodic reviews; the institutions must provide transportation, professional escorts, and professional time to appear in court. Parents and guardians also will have to appear. Protection and Advocacy attorneys will spend much time, too, and so will judges. Protection and Advocacy has already indicated the need for more funds for such reviews.

And there are questions of who will serve as advocate for those released from institutions without a place to go, or those who will slip away from the system. The plight of the released mentally ill is not encouraging.

The following recommendation is made:

> CHR should review all statutes which affect services to persons with mental retardation to recommend changes to accommodate their special characteristics.

Zoning and Community Living

KRS Chapter 100 enables counties and towns to have their own zoning ordinances. Quite often local laws conflict with deinstitutionalization of the adults with mental retardation or other groups. Neighborhoods where house prices are more affordable

and which have less restrictive rules tend to have larger numbers of group homes. As community placement continues, other groups of handicapped people (DD, mentally ill, substance abusers, juvenile delinquents) also compete for the same locations.

In the course of the present study, the researchers have heard repeatedly about the difficulties of establishing such group homes within communities. Some zoning restrictions limit groups to 3 residents. Groups are sometimes kept small to avoid federal requirements (e.g., sprinklers, special exits) and the additional expenses they entail.

The situation is summarized by a national study of zoning issues:[22]

> Implementation of policies promoting deinstitutionalization of the mentally retarded, developmentally disabled, and mentally ill (hereinafter collectively referred to as the "disabled") [and other groups] and placement of these persons in community based residential settings infringes upon local government's control over land use within its boundaries.
>
> From the local government perspective, however, the community residence or group home in a residential area is an anathema. Residents fear that these homes will depress property values and destroy neighborhood tranquility. Accordingly, zoning authorities have employed a variety of methods to exclude this locally unwanted land use.
>
> Typically, the local zoning ordinance will designate certain areas of the municipality as "single family residential" zones either expressly prohibiting group homes or imposing burdensome special conditions upon such uses. The exclusionary nature of these zones is often premised upon restrictive definitions of "family" which limit occupancy in such zones to persons related by blood, marriage, or adoption. Private landowners have embodied similarly limited definitions of "family" in deed restrictions to prohibit the establishment of groups homes. Alternatively, group homes are sometimes classified as boarding or rooming houses, permissible in commercial but not residential zones. Another approach is to treat group homes as akin to hospitals or nursing homes and limit them to zones permitting such uses.

While federal courts have not yet definitely determined whether the exclusion of the adults with mental retardation from residential zones violates their constitutional rights to due process and equal protection, other court decisions, such as Judge Allen's ruling, have upheld their right to live in the least restrictive environment.

It seems that the adults with mental retardation are caught between the hammer and the anvil. Their "right" to normalization will "free" some of them into communities where their "right" to live in the manner by which they can survive is not recognized.

The Steinman study further says:

> In Village of Belle Terre v. Boraas, a federal court upheld the constitutionality of a local zoning ordinance restricting land use in single family dwellings [see Steinman for case citations], the ordinance defined family as one or more persons related by blood, adoption or marriage, or up to

> two unrelated persons living and cooking together as a single housekeeping unit. Rejecting claimed violations of equal protection and rights of travel, association, and privacy asserted on behalf of six unrelated commuter college students leasing a house in the village, the Court found the ordinance to bear a rational relationship to the legitimate governmental purpose of preserving family values and needs and to involve no deprivation of any fundamental right . . . . The Court in Moore v. City of East Cleveland, invalidated on due process grounds a city housing ordinance limiting occupancy of a dwelling unit to members of a single family. "Family" was restrictively defined to include only certain, but not all, categories of individuals related by blood or marriage. The plaintiff had been convicted under the ordinance for sheltering an "illegal occupant", her grandson.

More important are the conclusions and recommendations made by federal courts, with which this study can only concur.

> The complex and technical manner in which this large and diversified group is to be treated under the law is very much a task for legislators guided by qualified professionals and not by, perhaps, ill-informed opinions of the Judiciary. In accounting for the diversity in needs and abilities of the mentally retarded, government bodies must retain a certain amount of flexibility and freedom from judicial oversight in shaping and limiting their remedial efforts.
>
> Further, the court observed, the distinctive legislative response, both in Congress and the state legislatures, to the plight of the mentally retarded underscores their unique problems and evidences a consciousness by the lawmakers which belies a continuing antipathy or prejudice and a corresponding need for more intrusive oversight by the judiciary.[23]

Since community living is a major aspect of normalization of adults with mental retardation (and the other groups) there seem to be no alternatives but to consider the following questions:

> a. Whether the policy of deinstitutionalization preempts local zoning prerogatives;
>
> b. Whether state agencies or licensed non-profit corporations which provide governmental services to handicapped people are immune from local zoning requirements in establishing and operating group homes; and finally,
>
> c. Whether the residents of a group home constitute a family.

Unless the legislature resolves these, and related issues, deinstitutionalization can have disastrous results to the individuals involved.

So far, thirty-four states have enacted legislation authorizing, to various degrees, the location of group homes in residential areas.[24]

Abuse and Neglect

The research staff has no indications of any cases of abuse or neglect. On the contrary, the ICF and the numerous group homes which were visited seemed to be clean and well maintained and their residents well treated. This opinion was reinforced by interviews with staff, parents and residents.

However, there were a few comments made about possible abuse in two forms of living arrangements: (1) in nursing homes where the persons with mental retardation often are "at a low" status; and (2) in community placement where one or two persons with mental retardation are placed with a family, "and are washed and cleaned whenever an inspector comes." While such abuses may occur, the researchers have not witnessed any. It is true, however, that ICFs are more amenable to unannounced inspections and visitations by family, and some parents indicated that they have "better peace of mind" about them.

It is recommended that this issue be reviewed by CHR and corrective measures be taken as necessary.

"Turning 22"

The Massachusetts "Turning 22 Law" was one impetus to the present study. Thus, its brief outline is in order.[25]

The "Turning 22 Law" provides a two-year transitional planning process for habilitative services for severely disabled young adults who will lose their entitlement to special education upon graduation or by turning 22. It is a transition plan from the educational system into the adult service system. The intent of the law is to provide a continuation of services to those who traditionally did not fit into any agency. A transitional agency is assigned to manage each individual through the "turning 22" process and to develop the transitional plan.

The law establishes a Bureau of Transitional Planning and a Transitional Advisory Committee which monitors the planning process and ensures that each individual has an appropriate service plan. Its primary purpose is to establish a transition between the educational system and the community-based services. This is done through an interagency and interdisciplinary planning approach. People receiving SSI & SSDI funds based on their own disability, and those legally blind are eligible. The other criterion, for those who don't meet one of these two, is whether the person can work more than 20 hours per week in a competitive environment. A Transitional Agency is designated for each individual and it is

responsible for bridging the gap between the two systems by case management functions. Appendix 9 is a report of the Massachusetts three-year implementation experience.

Should Kentucky enact a similar law?

Probably not. While "Turning 22" is an excellent law, which can alleviate the plight of many individuals, the Kentucky system, at present, cannot commit itself in the manner which is implied by the Massachusetts law.

When asked, most regional directors agreed that, while it is a good idea, we don't need it because they either already provide some of its elements in case management, or can't provide these services anyway. Similar opinions were expressed by some CHR people.

A small task force of CHR personnel and others, which was established in the course of this study to examine the "Turning 22" law, came to the following conclusions:

TRANSITION: Persons with severe disabilities under the age of 22 receive special education entitlement services from local schools. The majority of these individuals will need continued services after leaving school. However, in Kentucky, no planning occurs prior to graduation or reaching age 21 that addresses the need for transition to adult services and there is no coordinated assistance in obtaining those services.

Some key issues are:

1. Who are considered in need of "transition"?
2. Who is responsible?
3. When should the process begin?
4. What should be provided that will accomplish the goal of appropriate transition?

There are other approaches (besides the Massachusetts model), or models, that seek to address the issue. For example, it is suggested that a thirteenth year be added to the educational process specifically designed to concentrate on preparation for leaving.

The primary response to this issue by Kentucky has been a Transition Project; a federal grant project secured by the Department of Education and subcontracted to the Human Development Institute at the University of Kentucky. The project has studied the issue and has held a major organizing conference. Local school district representatives were brought together to focus on the approach their local district will take. Two other similar conferences are planned prior to the conclusion of the grant in October. The Department of Education has responded to the need for follow-up on this activity and has assigned a staff person to the issue of transition.

Conclusions:

1. **A data base must be established.** The scope of the need is just not known. At present, there are 18,000 plus students in special education. All will not need transition services, but no effort has been made to identify who does need transition. Also, there is no effort underway to identify what does happen to those who leave the entitlement service. A tracking process should be a part of the data base.

2. **Kentucky needs to establish a position on who should receive transition.** Eligibility criteria would be established if a program was put in place, but the question now is how broad the commitment should be.

3. **Kentucky needs to establish who is responsible for providing transition.** Kentucky could choose the Massachusetts model that establishes a new administrative structure.

   Another option would be to establish responsibility for "sending" and "receiving." The sender (education) would have specific responsibility for preparation, need identification and assurance of appropriate transfer. The receiver would be responsible for providing primary services, linking to other services, and follow-along.

   A third consideration could be the use of the existing law that established a "Bill of Rights" (HB 53). The designated agency responsible for the administration of HB 53 could be the responsible agent for transition, being one function among many to provide comprehensive services.

4. **Additional resources are essential to meet the needs.**

A recommendation on which of the options to adopt in Kentucky should come from CHR rather than from a legislative study.

As indicated earlier, the Kentucky service system adequately serves those clients it has, but is hardly capable of handling a greater demand for services without additional resources. With people graduating from school each year, services must expand at rates that match the increase in the number of those eligible.

The Department of Education Report for the 1985-86 school year provides information about handicapped graduates. The report provides statistical data about various handicapping conditions, but it does not indicate the total number of persons with mental retardation, since persons with mental retardation can be classified according to some other handicaps. Table 33 presents the number of graduates by age and the basis for their exit from school. It can be safely assumed that most of those graduating at age 20 and 21 are more severely retarded than those graduating at the regular age of 18 or 19. It also can be assumed that those graduating with a diploma are higher functioning than others. Thus, of the 606 graduates with mental retardation (19 and over), 134 are assumed to be severely handicapped. With the many unknowns that plague this study, it is not possible to know how many of them will require services, but only a few can be served at present. More students graduate from school every year, at about the same rate.

The Department of Education estimates that 1,807 1985-86 graduates will need 3,030 service slots; of these 53 will require residential services (Table 34).

While the service list used by the Department of Education does not match that of CHR, it is not known how many people are eligible for service and how many will actually request services, but the figures are sufficient to indicate the growing pressure on the service system to accommodate an ever growing demand. Fifty-three needed residential slots represent 11.8% of the existing community-based residential population and 3.6% when the ICF are included.

The service system, in all of its facets, must be responsive to this growing need, and must grow at least by an annual rate of 5%. This rate must continue until the system can meet growing demands for services and until the number of people exiting due to death or retirement equals the number of newcomers. Since services to the persons with mental retardation are lifelong, such a growth rate should continue for many years.

State Use Law

According to KRS 45A.470, Kentucky state agencies must give first preferences in purchasing goods or services to prison industries and second preference to the industries for the blind and other severely handicapped. To qualify, such industries must be non-profit agencies of the severely handicapped, which includes the adults with mental retardation.

Unlike some other states, Kentucky does not link the Purchasing Division and the agencies of the severely handicapped. It does not provide for a committee to facilitate purchases of products or services of the severely handicapped, nor does it create a non-profit agency to facilitate the distribution of orders.

Presently agencies of the adults with mental retardation need to develop their own distribution agency which will act as a contact with the state's Purchasing Division.

Until such an agency is created, agencies of adults with mental retardation need to develop their own strong selling effort. They need to contact the Purchasing Division as entrepreneurs and vendors and make the Division aware of their services, products and prices.

There are simple jobs, such as assembling parts, that are well-suited for industries of adults with mental retardation for which alternate employees are hard to find. At the same time, small businesses sometimes feel disadvantaged in competing with prison industries or with the severely handicapped for this simple work. This is not only because the latter have preferential sales, but also because they have lower wages and overhead, which can make them more competitive.

Work Habilitation Services

Employment opportunities for the adults with mental retardation include sheltered workshops and competitive employment, which are also offered to the other DD persons.

There are 17 sheltered workshops in addition to the workshops listed in Table 18. These are the workshops under Vocational Rehabilitation. They serve 450 persons, of whom 80 to 90 have mental retardation. Fifty percent of their funding is from actual work performed. Vocational Rehabilitation (through the Department of Education) pays the remaining $2,200,000 for the workshops. Supplemental funding comes from the United Way, donations, contributions, and sometimes local government. JTPA also funds some sheltered workshops. Workshops provide evaluations, training, work, and a component for the lower functioning. The earnings are below minimum wage, job termination is low, and job security is high. The work setting is not integrated.

The latest trend is competitive employment with integrated employment at competitive wages. Included in this is supported employment. Among the supported employment providers is Project ASSET (Approach to Statewide Supported Employment Transition). ASSET was created recently when Kentucky received a five-year federal grant of seed money for supported employment. It also receives money from the Developmental Disabilities Council and the Department of Mental Health and Mental Retardation Services. The federal grant is managed by Project ASSET under the Kentucky Office of Vocational Rehabilitation. The grant structure defines supported employment as renumerative work, 20-40 hours per week, generally minimum wage in an integrated work setting, for individuals who are severely handicapped and require ongoing support on the job for an extended period.

As of August 1987, ASSET's nineteen funded projects had spent roughly $393,182 of the money granted to them. Although this is nearly three times the amount of wages earned ($137,779), it is important to keep in mind that as additional people become employed, wages will continue to increase, while the rate of spending will remain basically the same. For example, the $61,227 in wages earned in the second quarter of this year was nearly $25,000 more than the $36,427 earned in the first quarter. Project ASSET likes to point out that if you divide the amount spent by the number currently working, the average per person ($3,674) compares favorably to the estimate by the Division of Mental Retardation for cost of day services per client ($3,500—$4,000).

Furthermore, ASSET says that persons in supported employment earn much more than persons in traditional day services, such as sheltered workshops and work activity centers. The 107 individuals now placed in jobs are earning more wages, paying more taxes, and receiving less in social security benefits than they were before they were placed.

The problems lie in the low number they serve, job security, and the client's average length of stay on the job. Forty-nine individuals were working at the beginning of 1987. Ninety-two new placements have been made in this year. There have been twenty-four job terminations in 1987. It is difficult to calculate an average stay on the job, but the number is low and job termination is high.

When organizations apply for a grant from ASSET, they must include in their proposal a plan for finding other funding sources to continue their program after ASSET funding ends. The funded programs have to this date been able to find such funding from a variety of sources, which have included the local Comprehensive Care Centers, other OVR programs, local United Ways, and local governments. Even with this guarantee, job security is questionable.

There are three models of supported employment: individual job coach, enclave, and work crew. The degree of integration differs according to the model. The individual job coach is the most integrated and the work crew probably involves the least integration. Of the 107 individuals working on June 30, the breakdown was as follows:

77 (72%) in individual job coach
16 (14%) in enclaves
14 (13%) in work crews

Of the 107 individuals working on June 30, ninety-seven had mental retardation as a disability. The level of retardation breakdown was as follows:

Borderline Intellectual Functioning: 13
Mild Mental Retardation: 54
Moderate Mental Retardation: 27
Severe Mental Retardation: 3

These figures demonstrate that Project ASSET hardly meets the federal requirement of serving adults with severe mental retardation.

There is some question as to whether supported employment can adequately serve the large number of adults with mental retardation.

Competitive employment for the adults with mental retardation can include more than restaurants and hotels. It can include manufacturing that is unlike that of a sheltered workshop. This is a new development and Louisville is fortunate to have Custom Manufacturing, modeled after Minnesota Diversified, the internationally sought model. Custom Manufacturing employs about 200 handicapped, including adults with mental retardation. Wages have gone from 16 cents an hour in 1981 to $3 an hour in 1986. Paid vacations and some sick benefits are also incentives for the workers.

About 15 percent of the company's work force is non-handicapped, providing a model to employees and aiding the organizational structure of the company.

Unfortunately, if the handicapped worker makes too much, he becomes ineligible for social security benefits covering medical care.

Custom Manufacturing offers janitorial services, pipe-cleaner manufacturing, assembly/packaging, microfilming and light gauge metal fabrication. It operates as a small business under short-term or long-term contracts with both local and national firms.

In 1981, Custom Manufacturing Services Inc., then a sheltered workshop, was receiving about 80 percent of its operating income from federal and state subsidies through programs designed to employ the handicapped. This year, still nonprofit, the firm will only receive about 16 percent of its income from federal and state sources.

Mental Retardation: Challenge for Corrections

(This section was prepared by Leonard Miller, PSY.D.,
Director, Division of Mental Health, Corrections Cabinet.)

A 1975 report prepared by the Kentucky Legislative Research Commission (RR #125) suggested that a new secure institution be built to accommodate mentally retarded and borderline adult inmates in the Commonwealth's prison system. This report was prophetic in anticipating the need for a "special needs" institution in Kentucky. In 1981 the Luther Luckett Correctional Complex, adjacent to the Kentucky State Reformatory, opened and ushered in a new era for offenders with unique needs. The Luther Luckett Correctional Complex was and remains unique in the nation. It is comprised of a 480-bed close

security prison adjacent to a 97-bed maximum security forensic psychiatric hospital. Until the Complex opened, Kentucky had no institution specifically designed and staffed to accept inmates who, because of developmental, psychiatric, and other disabilities, could not function within the inmate populations at The Reformatory or The Kentucky State Penitentiary.

As stated earlier, the 1975 Legislative Research Commission report focused on the needs of the mentally retarded inmate. However, mental retardation seldom occurs in isolation. Especially in correctional populations, mental retardation is frequently encountered in a complex matrix of mental illness and/or maladjustment, medical problems (notably epilepsy and varied neurological dysfunctions), and pervasive cultural deprivation. Hence rarely is one speaking **only** of mental retardation. Also, since the 1975 report, drug abuse has become prevalent in our society and chronic in offender populations. The diagnostic dialectic of mental retardation versus major mental illness versus organic dysfunction from substance abuse has emerged as a major one of contemporary corrections. The picture is further confused by the phenomenon of deinstitutionalization. The practical implication of the latter is that persons who a decade ago would have been treated in mental hospitals are now diverted to the criminal justice system.

Correctional mental health practitioners have responded to the above complexity by adopting more complex, sophisticated diagnostic models. For example, the dually diagnosed client has become commonplace at facilities such as Luther Luckett. To avoid unnecessary stigmatization the Corrections Cabinet has utilized the umbrella term "special needs," as opposed to "mentally ill" or "retarded." Inmates with varied and mixed disabilities are represented in the population at Luther Luckett.

The 1975 report alluded to above rightly raises the issue of test scores as valid indices of mental retardation in a prison setting. Note that both a measure of intelligence as well as one of adaptive functioning is needed to warrant a diagnosis of mental retardation. A group measure of intelligence (such as the BETA) is used for screening purposes. Persons scoring below a cutoff point are then referred for an individually administered intelligence test, usually the Wechsler Adult Intelligence Test, Revised. Group administered tests are not sufficient to render a definitive intelligence quotient. Since the hectic pace of a reception center is not optimal for test administration, low scores (particularly in group administered measures) must be validated, that is, checked by an instrument such as the WAIS-R. There is a need for more psychologists in the reception center to meet the complex diagnostic needs of many exceptional persons entering the correctional system.

After increased diagnostic services, the most pressing need of mentally retarded inmates is for specialized educational and habilitative programs. This would involve a new cadre of correctional personnel as well as "real work" programs, of the sheltered workshop variety, suited to the aptitudes and needs of the retarded. The Legislative Research Commission's 1975 report is correct in observing that the disbanded Operation RESTORE Vocational Rehabilitation program never meaningfully addressed the needs of developmen-

tally disabled inmates. Following the report's plea for interagency cooperation in meeting the needs of Kentucky's mentally retarded inmates, an ideal solution might be for the Corrections Cabinet to collaborate with the Division of Mental Retardation and Vocational Rehabilitation to begin training programs, sheltered workshops, and other programs in specialized settings such as Luther Luckett. Obviously, without provision for placement and follow-up after release, such programs would be futile; this cannot be overemphasized.

In November, 1987, the Director of Mental Retardation, a Legislative Research Commission representative, and the Director of Mental Health for the Kentucky Corrections Cabinet attended a week-long national planning conference for developing a systemic, interagency plan to address the needs of incarcerated mentally retarded citizens. As the 1975 report states, such interagency approaches comprise the only legitimate hope of mentally retarded inmates in Kentucky for a better future.

FOOTNOTES

1. "Welfare, The Training Home, Staff Report to the Committee on Functions and Resources of State Government", LRC RR #23, October 1951, p. 1.

2. Ibid, p. 1.

3. "Homes for Retarded Children", LRC RR #60, 1958, p. 33.

4. Ibid, p. 33.

5. "Society's Stepchildren: The Mentally Retarded", LRC RR #12, 1974.

6. CHR plan Op. cit. p. MR-7.

7. "The Year 2000 and Mental Retardation," (Plenum Press, N.Y., 1983).

8. "Issues in the Enumeration of Handicapping Conditions in the United States," by: L. Martini & R. H. MacTurk in *Mental Retardation*, Vol. 23 #4, August, 1985, pp. 182-185.

9. R. C. Scheerenberger, "Deinstitutionalization and Institutional Reform" (Charles C. Thomas publisher, 1976, pp. 137-138).

10. Adult Services Planning Counsel, University of Kentucky, April, 1986.

11. Kentucky on the Move: Toward True Community Services, Ky. Cabinet for Human Resources, June, 1987.

12. Ibid. p. MR-14.

13. Ibid. pp. MR-23 through MR-29

14. M. F. Hogan, "Comprehensive Community Services", *Mental Retardation*, 1982.

15. Ibid. p. 15.

16. Ibid. p. 10.

17. Ibid. p. 10

18. CHR Plan, op. cit.

19. "National Study of Public Spending for Mental Retardation and Developmental Disabilities", the *American Journal of Mental Health*, Vol 9L, No. 1, 1987.

20. "Recommendations from MH/MR Judicial Task Force on KRS 202A, 202B and 504," CHR, January, 1987.

21. U.S. District Court for the Western District of Kentucky, C 82-0738 L(A) Samuel Doe et al v. Elbert Cuisting, Secretary.

22. Lester Steinman, "The Effect of Land Use Restrictions on Establishment of Community Residences for the Disabled: A National Study", *The Urban Lawyer*, Vol. 19, #1, Winter 1987).

23. Steinman op. cit.

24. Steinman op. cit: Bates M.V. "State Rezoning Legislations: A Purview," Wisconsin Council on Developmental Disabilities, Madison, Wisconsin, August, 1985).

25. Massachusetts General Laws, Chapter 71B, commonly known as "Chapter 766—the Special Education Law," passed in December 1983.

APPENDIX 1

Definitions of MR and Related Disabilities

A principal authorative source for defining mental retardation and other mental disabilities is the "Diagnostic and Statistical Manual of Mental Disorders" published by the American Psychiatric Association (DSM-III) (3rd edition, Washington, D.C., APA, 1980). The manual acknowledges that:

> Although this manual provides a classification of mental disorders, there is no satisfactory definition that specifies precise boundaries for the concept 'mental disorder' (also true for such concepts as physical disorder and mental and physical health). Nevertheless, it is useful to present concepts that have influenced the decision to include certain conditions in DSM-III as mental disorders and to exclude others.

Definitions of mental retardation and related disabilities (source: "The Legal Rights of Handicapped Persons, Robert L. Burgdorf, Jr., 1980).

Mental Retardation (MR)

Defined: "Significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifested during the developmental period." American Association on Mental Deficiency, *Manual on Terminology and Classification in Mental Retardation,* (Grossman, H., ed., (1974)). Adaptive behavior along with I.Q. scores are the key factors in evaluating the degree of mental retardation.

Subcategories:

(a) Mild mental retardation — I.Q. score between 50-70 (85 percent of all mentally retarded persons).

(b) Moderate mental retardation — I.Q. score between 35-50.

(c) Severe mental retardation — I.Q. score between 20-35.

(d) Profound mental retardation — I.Q. score below 20.

Causes:

(a) Genetic defects

(1) Down's syndrome — results from the presence of an extra chromosome (47 instead of 46); evidenced by a number of unusual physical and mental characteristics.

(2) Phenylketonuria (PKU) — a hereditary defect that results in the inability of the body to properly metabolize a particular amino acid (phenylalanine). Once the amino acid builds up in the blood, it causes damage to the brain resulting in mental retardation.

(b) Prenatal damage to the fetus

(1) Infectious disease (*i.e.*, rubella, syphillis, or meningitis) contracted by the mother during pregnancy.

(2) Glandular disorders in the mother.

(3) Poor prenatal care.

(4) Nutritionally deficient diet.

(5) Use of certain drugs during pregnancy.

(6) Excessive X-rays.

(7) Damage to the fetus caused by accidents or other physical injury during pregnancy.

(c) Perinatal damage to the fetus (injuries during the birth process)

(1) Lack of oxygen during delivery.

(2) Prolonged labor.

(3) Unusual stress.

(4) Physical injury to the fetus.

(5) Premature birth.

(d) Postnatal injuries

(1) Serious injuries to the head.

(2) Metabolic disorders and glandular imbalances.

(3) Shock.

(4) Some childhood diseases.

(5) Serious illnesses (*i.e.*, encephalitis and meningitis).

Treatment:

PKU's damaging effects may be avoided by a special diet. Otherwise, educational and vocational programs are available to maximize the potential of mentally retarded persons and enable their integration into society as much as possible.

Additional Information:

Association for Retarded
Citizens — U.S.
2501 Avenue J
Arlington, TX 76011

American Association on Mental
Deficiency
1719 Kalorama Road, N.W.
Washington, DC 20009

Joseph P. Kennedy, Jr.,
Foundation
1701 K Street, N.W.
Suite 205
Washington, DC 20006

Emotional Disturbance and Mental Illness (MH)

Defined: Disorders of the mental processes, usually evidenced by inappropriate behavior and inability to function in society.

Causes: (a) Organic — Those conditions associated with some identifiable physical cause (*i.e.*, senility resulting from hardening of the arteries in the brain) involving a physical change in brain structure.

(b) Functional — A non-organic cause, but indicated by some cognitive or behavioral abnormality.

(1) Psychophysiological Reactions — Conditions in which an emotional disorder engenders physical symptoms (*i.e.*, pain) even though no actual physical disorder or illness can be found.

(2) Psychosis — Major emotional disorder with derangement of the personality and loss of contact with reality, often with delusions, hallucinations, or illusions (*i.e.*, schizophrenia).

(3) Neuroses — An emotional disorder that can interfere with a person's ability to lead a productive life but is less serious than psychosis (*i.e.*, phobias and depression).

(4) Personality Disorders — Conditions that do not involve being out of touch with reality but occur when an individual's personality seems to differ significantly from the societal norm (*i.e.*, sexual deviance).

Treatment:

(a) Standard Measures

(1) Administration of drugs and dietary supplements

(2) Psychotherapy

(3) Hypnosis

(4) Various techniques of behavior modification

(b) Extreme Measures

(1) Shock therapy

(2) Psychosurgery

Miscellaneous:

No meaningful distinction can be made between the terms *mental illness* and *emotional disturbance.* Yet, there exists some tendency to use the latter term more in regard to children in the education context. *Insanity,* a legal term, is broad and somewhat ambiguous, referring to unsoundness or derangement of the mind, without regard to its cause. *Autism* is a behaviorally defined syndrome. The essential features are typically manifested prior to 30 months of age and include disturbances of (1) developmental rates and/or sequences; (2) responses to sensory stimuli; (3) speech, language and cognitive capacities; and (4) capacities to relate to people, events and objects.

Additional Information:

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2932

American Psychiatric Association
1400 K Street, N.W.
Washington, DC 20005

National Society for Autistic Children
1234 Massachusetts Ave., N.W.
Washington, DC 20005

Defined: Impairments of the bones, joints, muscles, and the motor (efferent) nerves which transmit impulses from the brain and spinal cord to the muscles.

Causes:

(a) Disease — about one-half of these handicaps.

(b) Birth defects — about one-third of these handicaps.

(c) Accidents — about one-sixth of these handicaps.

(d) Specific conditions

(1) Paraplegia: paralysis (sometimes with loss of feeling) or loss of use of both legs and frequently of the entire lower body as well; often results from spinal cord damage.

(2) Quadriplegia: paralysis or loss of use of all limbs of the body, frequently with loss of sensation; usually the result of damage to the upper vertebrae of the spine.

(3) Cerebral Palsy: motor-skill and posture impairments resulting from a nonprogressive defect or damage of the brain.

(a) Spastic type: characterized by spasms or tightening of the muscles and exaggerated stretch reflexes.

(b) Athetoid type: refers to uncontrolled movements and purposeless muscle tension.

(c) Atactic type: characterized by a staggering gait with poor balance, and coordination.

(4) Poliomyelitis (infantile paralysis): an acute, contagious, viral disease, largely eradicated by widespread immunization with Salk and Sabin vaccines, causing motor paralysis and atrophy of skeletal muscles.

(5) Muscular Dystrophy: a group of related, possibly hereditary, muscle diseases characterized by a progressive weakening and atrophy of the muscles that are deprived of vital protein, and the muscle fibers are gradually replaced by fat and connective tissue.

(6) Multiple Sclerosis: chronic disease characterized by the formation of patches of hardened tissue in the brain and spinal cord which interfere with the nerve pathways in those areas. The effects vary with the parts of the nervous system affected.

(7) Spina Bifida: a birth defect that consists of a gap or

spinal column, which can cause permanent paralysis, loss of sensation, and loss of bowel and bladder control.

(8) Congenital absence, incompleteness or malformation of limbs: imperfect formation of the body during the fetal period.

(9) Arthritic handicaps: diseases of the joints of which there are more than 100 types, characterized by pain, stiffness, and inflammation of the affected joints.

(10) Amputation: the removal of a limb or other bodily appendage. The greatest percentage of leg amputations are the result of blood vessel disorders, such as arteriosclerosis.

(11) Dwarfism: a significant underdevelopment of the body resulting from abnormal fetal development, hormonal irregularities, nutritional deficiencies, or other disorders occurring during the growth process.

(12) Others: Parkinson's disease, injuries during birth, amyotrophic lateral sclerosis, myasthenia gravis, hunchbacking conditions, osteomyelitis, tumors, meningitis, some forms of diabetes, and veneral diseases.

Treatment:

Devices to deal with these handicaps include wheelchairs, canes, crutches, walkers, prosthetic devices (artificial body parts), ramps, and specially adapted automobile controls.

Additional Information:

National Association of the
Physically Handicapped
76 Elm Street
London, OH 43140

Paralyzed Veterans of America
801 18th Street, N.W.
Washington, DC 20006

American Orthotic and Prosthetic Association
717 Pendleton Street
Alexandria, VA 22314

National Spinal Cord Injury
Association
149 California Street
Newton, MA 02158

United Cerebral Palsy
Association
66 East 34th Street
New York, NY 10016

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019

National Multiple Sclerosis
Society
205 East 42nd Street
New York, NY 10017

Learning Disabilities

Defined: A disorder in one or more of the basic psychological processes involved in understanding or using spoken or written language, manifested by a significant discrepancy between intellectual ability and actual achievement in any of the areas of listening, thinking, speaking, reading, writing, spelling, or performing arithmetic computations. Examples include dyslexia, hyperactivity, hypoactivity and developmental aphasia. However, learning problems attributable primarily to visual, hearing, or motor handicaps, mental retardation or emotional disturbance, or environmental, cultural, or economic disadvantages are not considered learning disabilities.

Causes: Organic brain dysfunction and unknown reasons.

Treatment:

Educational programs, special diets, and drug treatment.

Additional Information:

Association for Children and
Adults with Learning Disabilities
4156 Library Road

Epilepsy

Defined: A chronic brain disorder characterized by recurrent seizures. A seizure is an abnormal electrical discharge by nerve cells in the brain which typically results in an interruption of consciousness and may also cause involuntary convulsive movements in the muscles. Yet, seizures caused by something external to the brain itself (*i.e.*, hypoglycemia — low blood sugar) do not constitute epilepsy.

Causes: Brain injuries before or during birth, brain tumors and abscesses, nutritional deficiencies, fever, certain diseases, congenital disorders, and head wounds. Often, the cause is unknown.

Treatment:

Anticonvulsant drugs

Additional Information:

Epilepsy Foundation of America
4351 Garden City Drive, Suite 406
Landover, MD 20785

APPENDIX 2

Definition of services provided by the state and the conditions under which they can be delivered (provided by the Department for Mental Retardation, the Cabinet for Human Resources). By the time this report was published, a few changes took place. Those were not included due to the late date they were received. All references to PL 95-602 should be changed to PL 98-527.

Respite Care - Extended

Respite Care - Extended, more than 24 hours and generally less than thirty days, for individuals with mental retardation and/or developmental disabilities in or out of their normal residential environment for the temporary relief either of the individual, the family and/or the providers. Out of the home respite care may be provided in a variety of settings.

Conditions

1. All services must be provided in accordance with the Individual Habilitation Plan or Individual Service Plan.

2. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

3. A per contact staff note shall be used to document billable services. If five (5) consecutive days of respite are provided to one client, either a per contact or at least a weekly summary staff note shall be used to document billable services.

HABILITATIVE

Work/Adult Habilitation Services

Services designed to provide an employment-oriented program of meaningful work training to adults with mental retardation/developmental disabilities. These services are to enable individuals served to either move into competitive employment or other work training programs. Meaningful work must be provided. Components of this service shall include an evaluation to assess the individuals vocational functioning level and a supervised work/training experience that will promote physical capacities, psychomotor skills, interpersonal and communicative seeking skills, productive skills, knowledge of work practices, work-related skills, and employment opportunities.

Some individuals may be involved in work services on a full time basis while other individuals may be involved in work services for only a few hours a week, spending most of their day in adult habilitation services, goal-oriented program of developmental and therapeutic services designed to develop, maintain, increase or maximize an individual's independent functioning.

The components of this service meet a wide range of individual client needs and may include behavior shaping, social integration, self-care, communication skills development, travel training, community utilization, health maintenance, adult education, client rights, and referral to ancillary services.

CONDITIONS

1. The program shall employ a minimum of two supervisory staff for the first 15 clients or fewer.

2. When there are over 15 clients in the program, one additional employee must be in direct client service for each additional group of 15 or any part thereof.

3. Services must be provided in accordance with an Individual Service Plan specifying services to be rendered.

4. Services must be available a minimum of six (6) hours per day (excluding transportation time), five (5) days per week, 12 months per year less customary holiday.

5. These services cannot be billed for eligible clients receiving vocational evaluation, personal and work adjustment training and job placement services through contract with the Office of Vocational Rehabilitation.

6. Weekly summary staff notes shall be used to document billable services.

7. The program shall be located in a non-residential setting.

8. The program must comply with state and federal wage and hour regulations.

Preschool

These are services which are provided to children who are emotionally disturbed, mentally retarded and/or developmentally disabled. Services are delivered in a preschool center to any of the three above listed groups of children in either integrated or segregated settings.

The service is designed to develop basic precognitive skills, which are primarily psychomotor with specific stimulation to areas in which delay in development is manifest; and to provide developmental experiences and training to aid the child in adapting to the demands of daily living. Program areas include self-help, motor, social, communications, and cognitive skills.

CONDITIONS

1. Preschool may be provided to children from birth to compulsory school age.

2. The preschool center must operate at least three hours per day, three days a week.

3. Child-staff ratio is to be determined by the age, developmental level, and specific handicap of children; however, there shall be at least one teacher and an assistant with every group of children regardless of group size.

4. There shall be at least one additional staff member working directly with children for each increment of six children with handicapping conditions. It should be noted this is a minimum staff ratio based on four and five year olds. A higher staff to child ratio is recommended for younger and/or more children with multiple handicapping conditions.

5. No one teacher is to have a teaching load of more than 24 children per week.

6. All service models must meet the standards section of the Department for Mental Health and Mental Retardation Services, Division of Mental Retardation, "Early Childhood Program Standards and Guidelines," (Chapter I Services).

7. Services must be provided in accordance with a person's Individual Education Plan, Individual Habilitation Plan or Individual Service Plan.

8. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

9. Either a per contact or a weekly summary staff note will be used to document billable services.

10. Those early childhood centers that meet the minimum definitions set by the Division of Licensing and Regulations for child day care must be licensed in accordance with KRS 199.892-199.896. (i.e. those centers that also furnish child care.)

RESIDENTIAL

Community Training Homes

The provision of supervision, assistance, protection or personal care to adults (18 years of age or older) with mental retardation and/or developmental disabilities in a family home setting. Services are provided by a member (or members) of the family.

CONDITIONS

1. A home will serve no more than three persons at a time.

2. A home will be a private residence not used for any other residential services.

3. Services must be provided in accordance with a person's Individual Service Plan or Individual Habilitation Plan.

4. All clients who are to receive Developmental Disabilities (DD) funded service (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD charges.

5. Either a per contact or weekly summary staff note shall be used to document billable services.

Group Home

Services designed to provide a comprehensive training oriented living experience in a group home setting for from four to eight persons with mental retardation and/or develpmental disabilities.

CONDITIONS

1. The group home shall meet all regulations as promulgated by 902 KAR 20:078 which provides the licensure requirements for the operation of group homes and the services to be provided.

2. Group home services must be provided in accordance with a person's Individual Habilitation Plan or Individual Service Plan.

3. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

4. Either a per contact or at least a weekly summary staff note shall be used to document billable services.

Community Residential Services (MR)

Staffed Residence
(Daily)

Staffed residence is a residential support service for persons with mental retardation and/or developmental disabilities. Supervision and/or general assistance is provided by trained staff. Each unit must have its own bath and kitchen facilities and can be occupied by no more than three clients. The staff person providing supervision may live in the unit or must provide at least daily supervision of that unit.

CONDITIONS

1. A staffed residential unit must be residential in nature and must be in an appropriately zoned area.

2. Services must be provided in accordance with a person's Individual Habilitation Plan or Individual Service Plan.

3. A staff member must maintain regular contact to provide whatever assistance is necessary to maintain a placement.

4. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

5. Either a per contact or at least a weekly summary staff note shall be used to document billable services.

   Residential support services provided less frequently than daily (e.g., twice a week) to a client living in a residential unit should be billed under Staffed Residence (Periodic).

Community Residential Services (MR)

Staffed Residence
(Periodic)

Residential support services are designed to provide as-needed, periodic (less than daily) assistance and supervision to persons with mental retardation and/or developmental disabilities in a residential setting. Supervision and/or general assistance is provided by trained staff. Each unit must have its own bath and kitchen facilities and can be occupied by no more than three clients. The staff person providing supervision shall provide periodic on-site assistance. The amount of assistance will depend upon the individual needs of the client(s).

CONDITIONS

1. At least a monthly contact in place of residence must be provided for each receiving staffed residence services.

2. The client's residence must be residential in nature and must be in an appropriately zoned area.

3. Services must be provided in accordance with a person's Individual Habilitation Plan or Individual Service Plan.

4. A staff member must maintain regular contact to provide whatever assistance is necessary to maintain a placement.

5. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

6. A per contact staff note shall be used to document billable services. If five consecutive days of residential support services are provided to one client, either a per contact or at least a weekly summary staff note shall be used to document billable services.

   Supervision provided daily to a client living in a staffed residential unit should be billed under Staffed Residence (Daily).

Cluster Service

A basic organizational unit of a residential service providing individualized environments and supports for persons with mental retardation and/or developmental disabilities. Each cluster consists of one core residence and several alternative residences which are administratively attached to the core residence. The core may function to evaluate client needs, administer the alternative residences, monitor alternative residences and provide program support.

CONDITIONS

1. Services must be provided by qualified mental retardation staff and under the supervision of qualified mental retardation staff as defined in this manual.

2. A single alternative living unit may serve no more than three clients at a time.

3. Services must be provided in accordance with a client's Individual Service Plan or Individual Habilitation Plan.

4. Residential services must be provided in a core residence, group home, private residence or apartment.

5. Services are restricted to persons with mental retardation and/or developmental disabilities.

6. All clients who are to receive developmental disabilities funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD clients.

7. Either a per contact or at least a weekly summary staff note shall be used to document billable services.

8. Once AIS/MR (medicaid funded) services are implemented this category is restricted to those clients previously reimbursed under New Neighbors who are not determined eligible for medicaid AIS/MR reimbursement. No new clients may be billed under this category without prior written authorization.

OUTPATIENT

Early Intervention - Center Based

Center-based intervention services include developmental experiences, training, and education provided to children (birth to school age) with mental retardation and/or developmental disabilities. Program areas include self-help, motor, social, communications, and cognitive skills. Both the child and other family members participate in this program on a regular basis. The child and his/her family visit the center on a regular basis, generally once or twice a week for one to three hours.

CONDITIONS

1. All service models must meet the standards sections of the Department for Mental Health and Mental Retardation Services, Division of Mental Retardation, "Early Childhood Program Standards and Guidelines," (Chapter I Services).

2. A center-based trainer, one full time equivalent (1.0 FTE), may have an active case load of no more than 30 children and their families.

3. Some portion of the program must be direct face-to-face infant and parent (guardian) contact.

4. Services must be provided in accordance with a person's Individual Education Plan, Individual Habilitation Plan or Individual Service Plan.

5. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

6. A per contact staff note shall be used to document billable services.

Early Intervention - Home-Based

Home-based intervention services include developmental experiences, training and education provided to children (birth to school age) with mental retardation and/or developmental disabilities. Program areas include self-help, motor, social, communication, and cognitive skills. Staff visit the child and his/her family in the child's home on a regular basis, generally twice a week for one to three hours.

CONDITIONS

1. All service models must meet the standards section of the Department for Mental Health and Mental Retardation Services, Division of Mental Retardation, "Early Childhood Program Standards and Guidelines," (Chapter I Services).

2. A home trainer (1.0 FTE) may have an active case load of no more than 30 children and their families.

3. The contact is face-to-face with the infant and parent (adult).

4. Services must be provided in accordance with a person's Individual Education Plan, Individual Habilitation Plan or Individual Services Plan.

5. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

6. A per contact staff note shall be used to document billable services.

Respite Care - Short Term

Respite Care - Short Term is more than one hour and less than 24 hours for individuals with mental retardation and/or developmental disabilities in or out of their normal residential environment for the temporary relief either of the individual, the family and/or the providers. Out of the home respite care may be provided in a variety of settings.

CONDITIONS

1. All services must be provided in accordance with the Individual Habilitation Plan or Individual Service Plan.

2. All clients who are to receive Developmental Didsabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

3. A per contact staff note for each date of service is required.

In-Home Support

These are services designed to help maintain the person with mental retardation and/or developmental disabilities in their own home. This service includes in-home training and personal care provided to recipients living in non-specialized residential settings such as family homes, apartments, etc. (other than alternative living units within AIS/MR clusters).

A. In-Home Training

Services designed to facilitate the acquisition of language and communication, sensory-motor, social and self-help.

B. Personal Care

Service designed to assist and training in ambulation, dressing toileting, grooming, feeding, and bathing.

CONDITIONS

1. Services must be provided in accordance with an Individual Service Plan or Individual Habilitation Plan.

2. Services are restricted to persons with mental retardation and/or developmental disabilities.

3. All clients who are to receive Developmental Disabilities (DD) funded services (P.L. 95-602) must be certified DD eligible during the first three months entry into the service and an Individual Habilitation Plan number must accompany all DD bills.

4. A per contact staff note shall be used to document billable services.

51-59 Outpatient

Services to clients provided for less than three hours on an individual or group basis.

1. (52) Diagnostic: Services such as psycho-social, psychological, and/or psychiatric evaluations provided to any patient/client in the outpatient service system prior to setting a treatment plan.

2. (53) Treatment: Therapeutic interaction between qualified professional staff and a client for the purpose of reducing or eliminating the presenting problem or for the purpose of maintaining a previously achieved reduction or elimination of such a condition.

   Services may be provided in a center-based (51) clinic or off-site visits, such as: (a) (56) Licensed Personal Care Home; (b) (57) Home (family-dwelling setting); (c) (58) hospital; (d) (59) other.

CONDITIONS

Mental Health

1. Services must be rendered by qualified mental health staff.

2. Mental Health outpatient services are limited to the following modalities/techniques:

   --marital counseling
   --family counseling/therapy
   --individual counseling/psychotherapy
   --group counseling/psychotherapy
   --speech therapy provided by a qualified speech therapist
   --expressive or play therapies
   --chemotherapy, i.e. the administration of a psychotropic medication by center staff.

Mental Retardation

1. Mental Retardation Outpatient Services must be provided in accordance with an individual service plan and are limited to the following modalities/techniques for clients with Mental Retardation and/or Development Disabilities:

   --Psychometric Services: Services rendered by qualified psychologist or psychometrist including administration of various psychological tests designed to determine one or more of the factors in the individual's mental ability such as intelligence, special abilities and disabilities, manual skill, vocational aptitudes, interests and personality characteristics.

   --Behavior Management: Precisely planned systematic application of behavior change methods designed to reduce the incidence of inappropriate aggressive behaviors, self-abusive behaviors and/or extremely withdrawn behaviors. Services are delivered by qualified mental retardation staff and may not include the use of aversive consequences. Behavior management through medication is excluded.

--Counseling: Services provided to clients on an individual basis for the purpose of problem solving, and community and personal adjustment. When the client is a child with mental retardation/developmental disabilities, counseling may be provided with the family on behalf of the client for such things as behavior management, family adjustment, implementation and follow through of training and/or stimulation programs.

--Expressive Therapies: Social skill development, and reduction of aggressive, self-abusive, or withdrawn behaviors, not associated with mental illness when provided by registered expressive therapists using techniques unique to those disciplines.

--Speech Therapy: When provided by a qualified speech therapist.

--Occupational Therapy: When provided by a qualified occupational therapist.

--Physical Therapy: When provided by a qualified physical therapist.

2. A per contact staff note shall be used to document billable services.

Alcohol and Drugs

1. All outpatient substance abuse services shall be provided in accordance with 902 KAR 3:050, Section 3.

Diagnostic

1. Clients must have a presenting problem of alcohol abuse or drug abuse or be an immediate family member of a person with an alcohol abuse or drug abuse problem.

2. Services should result in the setting (or amending) of a Treatment Plan.

3. Reimbursement will be made for the following non-medical diagnostic services:

   a. alcohol/drug use and problem history;
   b. psychosocial evaluation;
   c. mental status examination;
   d. psychological evaluation; and
   e. documentation of a diagnostic impression.

4. Reimbursement will be made for the following medical diagnostic services:

   a. psychiatric evaluation;
   b. history and physical examination; and
   c. documentation of client's diagnosis of alcohol or drug abuse.

GRANTS

Job Development/Job Placement Services

Job development/job placement services are designed to provide assistance to adults with mental retardation/developmental disabilities which will help to identify, obtain and maintain employment. These services will be provided on an organized, planned basis and may include but not be limited to: an evaluation process to assess vocational capabilities and needs for job preparation, training and placement, a supervised work experience to allow individuals to adjust to the work environment, training to reach proper work habits, job seeking and job survival skills, placement, and follow-up services. Job development/job placement services may also include: contacting employers to identify job opportunities, providing job analysis, job modification, assisting employers to identify and eliminate barriers to employment, educating and training prospective disabilities and vocational implications.

CONDITIONS

1. A job development log shall be maintained indicating prospective employers contacted, contact person, date and results of contact.

2. A written placement plan shall be developed for each individual served in job placement.

3. Documentation shall be maintained which indicates client participation in the decision process for his or her placement on a job site.

4. Records of individuals who have been placed in employment shall contain the following information:

   A. Placement of employment
   B. Job title
   C. Rate of pay and fringe benefits
   D. Date of employment
   E. Name of immediate supervisor at the work site
   F. Employment follow-up reports
   G. Monthly progress notes.

5. Job development/job placement service funds shall not be used for client wages.

6. Job placement follow-up services shall be limited to one year from the date of placement.

7. Quarterly reports of the job development/job placement program will be submitted to the Division of Mental Retardation.

Case Management

Case Management is the provision of services to or on behalf of a client with mental retardation and/or developmental disabilities as will assist him/her in gaining access to needed social, medical, educational and other services. The desired outcome of case management is to assist the individual to become more independent, and includes:

1. Follow-along services which ensure, through a continuing relationship between agency or provider and a person with mental retardation and/or developmental disabilities and the person's relatives, guardians, or significant others, that the changing needs of the person and the family are recognized and appropriately met; and

2. Coordination and monitoring of services which provide support, access to other services, information on programs, and services, and client's progress.

Case management involves various levels of service from infrequent follow-up contacts in order to make sure needs are being met, to comprehensive program planning and coordination.

Case Management Functions

The following functions are the main activity areas in which a case manager would be involved. The duties describing each area should not be considered an exhaustive list. All actions taken under each area require thorough documentation to provide an accurate account of a client's habilitation and the case manager's actions.

1. Information gathering and disbursing: a) Ongoing identification of individuals' needs and services/service agencies to satisfy those needs. If resources are not available to meet a particular need of a number of individuals, then this situation should be explained to the administrators of the agency. b) Gather information on individual clients, i.e., evaluation results, education, family. c) Maintain a resource directory of the avaiilable services and agencies in the service areas. d) Provide information to clients, families or representatives, and service agencies when appropriate.

2. Service Planning: a) Development of the individual Service Plan (ISP) or Individual Habilitation Plan (IHP). b) Determine an individual's eligibility for case management and other required services. c) Preservice consultation with clients or appropriate representatives.

3. Coordination: a) Match clients with available services. b) Refer clients to other services and delivery agencies. c) Arrange for services not readily available. d) Coordinate a client's service to facilitate maximum benefit with minimum distress.

4. Monitoring: a) Monitor the ISP/IHP and delivered services to ensure the client's needs are being adequately met. b) Provide follow-along services to identify any new or unexpected problems that may occur. c) Revise the ISP/IHP when necessary to reflect changes in client status.

CONDITIONS

1. Staff persons providing case management services must have a B.A. Degree in the human services field and a minimum of two years experience working with persons with mental retardation is recommended.

2. Staff persons providing case management services must attend at least one case management training session sponsored by the Division of Mental Retardation.

3. All clients receiving case management services will have an assigned case manager. Any case management service documented by a staff note by any staff other than the assigned case manager must be co-signed by that client's assigned case manager.

4. Case managers will arrange for service, and when no other service resource is available, may provide services directly to assist the client. Case management will support, not supplant, other programs and services.

5. Case management services cannot be delivered in group settings.

6. Case management services do not include routine transportation (i.e., transportation to workshop, preschool, etc.).

7. A per contact staff note shall be used to document case management services.

8. Case managers will maintain appropriate documentation. This may be either a service ticket or a daily log entitled "Case Management" and will indicate the name of the client receiving case management services as described above, the date, and the name and title of the staff rendering the service. If other than either of these is utilized, a waiver must be obtained.

9. DD funded case management staff must provide the following.

   a. Evaluate and certify eligibility of clients to receive DD funded services.

   b. Develop Individual Habilitation Plan within the first three months of entry into DD funded services.

   c. Review and update Individualized Habilitation Plans.

   d. Serve as an advocate for the client in conformity with P.L. 95-602, Section III.

   e. Services must be in accordance with an Individual Habilitation Plan.

   f. An Individual Habilitation Plan number must accompany all DD bills.

Leisure/Recreation Services

Leisure/Recreation services include training for leisure/recreation skills development and participation in leisure/recreation activities for persons with mental retardation and/or developmental disabilities. Activities are to be heterogeneous grouping and integrated activities using generic, community based services. Teaching independent as well as group use of leisure time is included in this service. The goal of training should be to teach the skills necessary for independent pursuit of leisure/recreation activities.

Groups may involve people that do not have any handicapping conditions and are not clients of the center for the purpose of having integrated group activities.

CONDITIONS

1. Services must be provided in accordance with a person's Individual Habilitation Plan, Individual Service Plan or Individual Education Plan.

2. Services can be billed only for Community Mental Health/Mental Retardation Center clients with mental retardation and/or Developmental Disabilities.

3. The funds reimbursed for this service may not be used to pay for client's participation in leisure/recreation activities (e.g. cannot pay for client's bowling, admission to movies, etc.)

4. For adults, these services are limited to services that are provided after center's normal working hours. They may be provided during the evenings and on weekends.

5. Documentation of staff involved, recipients and activities required.

Consultation - Mental Health/Mental Retardation

The process of interaction between a center staff person (consultant) and representative(s) of another organization or individual practitioner (consultee) to assist the consultee, to impart mental health, or mental retardation knowledge, skills or attitudes, and to aid the consultee in carrying out his/her agency mission(s).

CONDTIONS

1. Refer to Program Limitations for Reimbursement applicable to all services.

2. Documentation of staff involved, recipients and subject is required.

Education - Mental Health/Mental Retardation

Imparting information to the general public, to segments of the population, or to special target groups to promote a better understanding of mental health, mental disorders, mental retardation and developmental disabilities, or to achieve improved attitudes or behavior.

CONDITIONS

1. Documentation of staff involved, recipients and subject is required.

2. Education services provided as a part of a prevention plan are not billable under the category of education.

APPENDIX 3

Service needs and their priority ranks as presented in the seven counties plan.

APPENDIX #3

Service needs and their priority ranks as presented in the seven counties plan.

Developmental Service Need

Priority Rank	Identified Need
1	A central agency which parents can contact, which would provide: -case management -social services -referrals to programs and services -facilitate parent to parent contacts
2	More availability and support for community daycare centers and preschools, which would include: -available consultants -additional assistance/assistants (e.g., Foster Grandparents) -ongoing staff training
3	Parent subsidies when families are not eligible for existing forms of assistance (e.g., Medical card, purchase of care), which would be applied to: -tuition -purchase of equipment -therapies -counseling
4	Family support programs and get-togethers for purposes such as: -training/informing extended family members/friends, neighbors -parent advocacy training -sibling groups
5	Hospital related services and programs which would provide: -parent support and direction services at time of birth/diagnosis -education for medical personnel regarding developmental disabilities, the effectiveness of early intervention, and community resources for children and their families
6a	Provide services to children who are considered "at risk" for developmental disabilities, but who do not meet the current MR/DD eligibility criteria
6b	More services available in the rural area
7	Assistance with transportation to community programs and therapy appointments
8	Availability of home-based services for families who choose this type of program, which would include: -early intervention -training and information for extended families and friends
9a	Consistent, well-organized follow-up program for high-risk infants after they leave neonatal intensive care
9b	Parent administered direction services and support network

Priority Rank	Identified Need
10	In-home support services, including respite for non-disabled children
11	Emergency and crisis intervention services
12	Legal assistance, and financial planning for future schooling
13	More availability of adaptive equipment, both in funding and through a "lending library" system for used equipment

2. Family Support Services

Priority Rank	Identified Need
1	In-home services which would provide: -assistance with lifting, carrying, bathing; assistsance with personal care; behavior management/counsultation; home-based physician care; physical and occupational therapy consultations; homemaker services
2	Vocational/nonvocational Day Program which would include supported employment and day program appropriate to age
3	Expanded respite care program to include: better trained providers; more available/accessible providers; ability to respond to emergency situations; provision of extended respite for periods of more than 24 hours; and emergency residence - which could be accessed at any time
4	Financial subsidies for families who are not eligible for forms of assistance such as a medical card, special services and equipment funding, etc. in order to assist with the cost of equipment; therapies; attendant care; transportation; deaf interpreters; home adaptations; a source of income for disabled adult
5	Child care programs, especially: Summer program availability and full day; expanded after school program to serve more significantly involved children and teenagers.
6	Socialization experiences to include: Social group - especially for teenagers; companionship with peers who are not disabled; recreation/leisure services that include transportation
7	Parent support and education to include; support groups to prepare individuals for independent living; parent training/education; guardianship/estate planning assistance; sexuality counseling for individuals and families

3. Residential Service Needs

Priority Rank	Identified need
1	Well coordinated, centralized delivery of services that provides: knowledge of available services; assistance in accessing; continuum of services; establishment of linkages and cooperation amongst agencies
2	Flexible funding not tied to a model
3	Appropriate day programs
4	Mechanism to help families start to think of ways to meet residential needs in the community (not equal to a facility bed) and develop circle of support to accomplish
5	Establish philosophical underpinnings, including right to live in the community
6	More services for persons with profound/multiple needs, who may be non-ambulatory
7	Services for older adults
8	Housing subsidies
9	Mechanism to provide training and/or on-going supports in independent living, including: travel, training, homemaker services, meal preparation, cleaning, and shopping
10	Support services - occupational and physical therapies, respite, medical care, counseling, case management/linker
11	Relationship building - recreation, friendship, opportunities for spiritual growth
12	Intervention before crisis
13	Self-advocacy
14	Guardianship and payee (if needed)

4. Service Needs in Rural Areas

Priority Rank	Identified Need
1	Central, local contact person/agency to provide information about services, coordination, and monitor/follow-up client participation.
2	Transportation
3	Local ownership of, and advocacy for, the need for availability of services for all age groups and disabilities
4	More services within the rural counties
5	Parent-to-parent contact for support and information
6	Residential services; apartments and shared small residences
7a	Additional providers/vendors for services
7b	Adequate funding for existing services.
8	Respite services for all ages
9	Homebased services for infants and toddlers who are MR/DD
10	Vocational and non-vocational day services for severely retarded adults.
11a	Local medical attention and treatment services
11b	Summer recreation programs
11c	Assistance to elderly citizens with disabilities

5. Vocational and Adult Day Services

Priority Rank	Identified Need
1	Centralized clearing house to: - coordinate referrals, services information (news letter, directory), and information about people (registry) - fulfill quasi-legislative role - provide planning function and fund procurement - enhance public relations and change attitudes to open doors to industry - recruit talented people to work in programs
2	Sufficient funding to support existing programs
3	Additional job placement providers
4	Commitment on the part of the local government to hire people who are handicapped
5	Programs for people who are severely handicapped
6	Transportation

APPENDIX 4

Five Years Allocation of Funds for the MR, by Regions

APPENDIX 4

Five Years Allocation of Funds for the MR by Regions

HFK 4-1-87
WESTERN
REGION I

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.	5505	5805	6225	20140	16000
Work Adult Hab	12500	141832	154790	181465	155310
Preschool		51658	16800	16800	700
MR Cluster					
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	2838	2000	7280	3501	2200
Early Int. (CB)	44015	41536	61110	61115	59800
Off-Personal					
Off-Apt. Living		500			
Off-Hospital					
Off-In Home					
Off-E. Int. (HB)					
Off-Other					
Ap. Living (per)					
Respite-ST	23498	16809	10000	10000	10000
SUBTOTAL 1	88356	260140	156205	293021	244010
GRANTS					
Case Management	21643	28142	26165	41274	72360
Consultation 1	18139	10156	29903	32490	32906
Consultation 2					
Education 1	5000	4000			
Education 2					
Job D/P1					
AISMR	112500			15960	16940
Leisure/Rec.					
SHELTERED WK. SHOP					
SS & Equipment					
Preschool/EI	5000				
SUBTOTAL	162282	42298	56068	89724	122206
TOTAL SGF	250638	302438	3122773	382745	366219
TITLE XX (100%)	202107				
CASE MGT.		13987	14686	14686	
EARLY INT.					
SPECIAL PRO.					
TOTAL DDSA	12148	13987	14686	14686	37807
TOTAL ESEA	35980	33241	33490	39234	35340
TOTAL AISMR (est)	394841	674869	747169	800000	800000
TOTAL MR	895714	1024535	1107618	1236665	1239363
MRSGF	225041	107541	$112,919.00	$160,236.00	$160,236.00

HFK 5-5-87
PENNYROYAL
REGION II

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.					
Work Adult Hab	200000	257696	$330,000	$376,153	$339,888
Preschool	61863	125000	$153,000	$170,000	$86,913
Early Int. (CD)			$13,000	$29,000	$51,000
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	7585	6000	$2,500	$2,500	$2,500
MR Cluster					
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In Home					
Off-E. Int. (HB)					
Off-Other					
Apt. Living (per)					
Respite-ST					
SUBTOTAL 1	269448	388696	$498,500	$577,653	$580,301
GRANTS					
Case Management					
Consultation 1	2652				
Consultation/ED			$827		
Education 1	895				$800
Education 2					
Job D/P1					
AISMR	244736	100000			
Leisure/Rec.					
Residential Serv.					
BEHAVIOR MGT.			$9,866	$9,866	
RESPITE				$33,210	$33,210
Preschool/EI				$3,957	$3,957
SUBTOTAL	248283	100000	$827	$47,033	$47,833
TOTAL SGF	517731	488696	$499,327	$624,686	$628,134
TITLE XX (100%)	252561				
CASE MGT.		29057	$30,783		
EARLY INT.		13139	$11,883		
SPECIAL PRO.					
TOTAL DDSA	$44,819.00	42196	$42,666	$42,666	$42,666
TOTAL ESEA	$49,444.00	41318	$36,222	$32,547	$31,000
TOTAL AISMR (est)		285061	$521,077	$650,000	$650,000
TOTAL MR	864555	857271	$1,099,292	$1,349,899	$1,351,800
MRSGF	$351,947.00	222737	$117,572	$168,132	$168,132

HFK 4-4-87
GREEN RIVER
REGION III

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.		132978	132978	132978	132978
Work Adult Hab					
Preschool					
MR Cluster					
Group Home (A)	31696	31000	66565	55911	55911
STAFF RESIDENCE					
Comm. Tr. Homes					
Group Home (C)					
Clinic					
Early Int. (CB)					
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In Home					
Off-E. Int. (HB)					
Off-Other					
Apt. Living (per)					
Respite-ST					
SUBTOTAL 1	31696	163978	199543	188889	188889
GRANTS					
Case Management	$47,544.00	47544	42824	41358	79435
Consultation 1			22800	23484	23484
PINOCCHIOS					
Education 1			24075		10000
Apt. Living-Ind			22500		
Job D/P1		22500	27860	23175	23175
SUPP WORK			43279	47230	42230
Leisure/Rec-KyVac	19250	13879			5000
Leisure/Rec-Marc					
WORK ACT-				28696	28696
TAMERLANE		16388			
AISMR	173750			25153	
Preschool/EI				22151	22151
RESPITE		2618	5285		
SUBTOTAL	240544	102929	188623	211247	234171
TOTAL SGF	272240	266907	388166	400136	423060
TITLE XX (100%)	159480				
CASE MGT.		13986	16725	16725	
EARLY INT.		32200	31770	31770	
SPECIAL PRO.		2221	20480		
TOTAL DDSA	54304	48407	68975	48495	48495
TOTAL ESEA	46972	40191	41925	22954	22630
TOTAL AISMR (est)	992922	1297712	1527917	1600000	1600000
TOTAL MR	1525918	165321	2026983	2071585	2094185
MRSGF	292240	114173	$223,304.00	$258,284.00	$281,208.00

HFK 6-23-87
BARREN RIVER
REGION IV

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.	3410		3744	$4,600	$5,775
Work Adult Hab	48759	477400	496713	$540,236	$496,386
Preschool					
MR Cluster	16780	20717			
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	162	207	2438	$930	$1,044
Early Int. (CB)	44053	25197	26288	$34,405	$167,413
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In Home					
Off-E. Int. (HB)					
Off-Other					
Apt. Living (per)					
Respite-ST	1310	1335	1050	$1,755	$1608
SUBTOTAL 1	114474	524856	530233	581926	672226
GRANTS					
Case Management					$80,000
Consultation 1			3868	$4,246	$6,635
Consultation 2					
Education 1					
Education 2					
Job D/P1					
AISMR		50000	75000		
Leisure/Rec	2200				
Residential Serv.					
SHELTERED WK SHOP					
SS& Equipment					
Preschool/EI				$29,432	
SUBTOTAL	2200	50000	78868	33678	86635
TOTAL SGF	116674	574856	609101	615604	758861
TITLE XX (100%)	399000				
CASE MGT.		13987	14686		
EARLY INT.					
SPECIAL PRO.					
TOTAL DDSA	12148	13987	14686	$14,686	$14,686
TOTAL ESEA	50937	50157	36185	$19,084	$14,389
TOTAL AISMR (est)			185236	$500,000	$650,000
TOTAL MR	578759	639000	845208	1149374	1437936
MRSGF (revenue)	125317	136433	161433	$143,909	$293,909

HFK 5-6-87
NORTH CENTRAL
REGION V

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.			4887	14293	18668
Work Adult Hab	23918	416448	470064	549544	575040
Preschool	54310	30671	56547	78514	63669
MR Cluster					
Group Home (A)	115444	95979	93730	90066	142326
Staff Residence	15890	50551	24059	23473	26682
Comm. Tr. Homes					
Group Home (C)					
Clinic	9808		6849	4523	8000
Early Int. (CB)		5000	14712	22192	29583
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In Home					
Off-E. Int. (HB)					
Off-Other					
Apt. Living (per)					
Respite-ST			5113	15668	3197
SUBTOTAL 1	219370	598649	675961	798273	867165
GRANTS					
Case Management					
Consultation 1	8410				
PRESCHOOL		5000			
Education 1	4023				
RESPITE		10000			
Job D/P1			25168	25923	25923
Project Learn					
Leisure/Rec					
AISMR	62260				
PROJECT ADMIN SP-		3468			
SS& Equipment					
Preschool/EI		20000			
SUBTOTAL	74693	38468	25168	25923	25923
TOTAL SGF	294063	637117	701129	824196	893088
TITLE XX (100%)	406968				
CASE MGT.		11833	14686	14686	14686
EARLY INT.		2154			
TRANSITION PRO.		23122			
TOTAL DDSA	17564	37109	14686	14686	14686
TOTAL ESEA	11209	13102	13525	13525	13020
TOTAL AISMR (est)	402610	624164	746927	800000	800000
TOTAL MR	1132414	1329492	1476267	1652407	1720794
MRSGF (REVENUE)	184729	127434	$149,13400	$255,167.00	$315,167.00

HFK 6-10-87
SEVEN COUNTIES
REGION VI

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite	15000		8186	$66,432	$62,132
Work Adult Hab	9863	337928	312283	$355,127	$304,429
Preschool	70650		35153	$115,522	$139,755
MR Cluster					
Group Home (A)		188984	196054	$99,825	$109,798
Apt. Living	22848	80476	95266	$240,744	$244,263
Comm. Tr. Homes					
Group Home (C)					
Clinic	23000	17128	23550	$26,403	$ 45,002
Early Int. (CB)		101253	15000		
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In Home			89430	$108,116	$109,751
Off-E. Int. (HB)	15668	255581	68180		
Off-Other					
Staff Res. (per)	37590		35540	$23,000	$11,582
Respite-ST	50000	36684	31405		
SUBTOTAL 1	244619	788034	910047	1035169	
GRANTS					
Case Management					
Consultation/Ed	126615	128241	227209		$139,026
In-Home-Support		177934		$30,800	$30,800
Education 1		17000	17000		
P. Burkhead		13139	13130	$33,739	
Job D/P1		96670	182225	$234,881	$275,579
SP RESIDENTIAL	193750				
Leisure/Rec		21267	31367	$26,975	$27,080
Residential Serv.		100000	60000	$65,700	$64,700
SPECIAL PROJECT	90221	15936			
Parent Outreach				$17,000	$17,000
Preschool		34920		$161,119	$0
SUBTOTAL	410586	605107	530931	$570,214	
TOTAL SGF	655205	1393141	1440978	$1,605,383	$1,581,897
TITLE XX (100%)	629479				
PRESCHOOL			51185		
SPECIAL PRO/ED		48748	89557		
SPECIAL PRO/VOC.		121356	28793		
TOTAL DDSA	109630	130685	130685	$203,884	84535
TOTAL ESEA	106634	90465	96620	$63,307	34410
TOTAL AISMR (est)	1029840	1781466	1727510	$1,700,000	$1,700,000
TOTAL MR	2530788	3395757	3395793	3572574	3400842
MRSGF (REVENUE)	660205	704864	772020	$1,010,042	$1,010,042

HFK 4-5-87
NORTHERN KENTUCKY
REGION VII

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.			5644	$12,610	$0
Work Adult Hab	48071	374044	374537	$447,929	$454,629
Preschool	10476	10476	10220	$10,526	$10,523
MR Cluster					
Group Home (A)	140528	140528	136554	$140,650	$140,642
Apt. Living					
Comm. Tr. Homes					
Group Home (C)	60267	60267	58609	$60,367	$60,384
Clinic	4800	4630	5300	$5,511	$5,751
Early Int. (CB)					
Off-Personal					
Off-Apt. Living			119	$124	$300
Off-Home			7820	$6,770	$6,001
Off-In Home					
Off-E. Int. (HB)					
Off-Other	4750		$400.00	$416	$0
Apt. Living (per)					
Respite-ST		1150	1745	$4,397	$0
SUBTOTAL 1	268892	591095	600948	$689,300	$678,230
GRANTS					
Case Management	45452	22000	28000	$36,218	$62,536
Consultation 1	165				
Consultation 2					
Education 1	65				
Education 2			23876	$24,592	$24,592
Job D/P1					
AISMR	75000				
Leisure/Rec					
Residential Serv.				$8,280	$0
CIT ADV	9926				$30,000
Dual Diagnosis					
Preschool/EI					
SUBTOTAL	130608	22000	51876	$69,090	$117,128
TOTAL SGF	399500	613095	652824	$758,390	$795,358
TITLE XX (75%)	323195				
CASE MGT		13474	14282	$14,282	
INFANT STIM.		20643	21541	$21,541	
SPECIAL PRO		34591			
TOTAL DDSA	68848	68708	35823	$35,823	$35,823
TOTAL ESEA	$39,255.00	33989	33036	$35,823	$26,040
TOTAL AISMR (est)	498175	532971	622960	$700,000	$700,000
TOTAL MR	1328973	1248763	1344643	$1,530,036	$1,557,221
MRSGF (REVENUE)	340005	330121	$345,711.00	$430,144	$463,900

HFK 6-9-87
COMPREHEND
REGION VIII

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.	5000	7412	12948	18910	25000
Work Adult Hab	13486	210406	178701	199597	210000
Preschool					
MR Cluster					
Group Home (A)	96287		86317	96196	85000
Apt. Living	19000				
Comm. Tr. Homes	8541		20700	23094	24000
Group Home (C)					
Clinic	1000	3000	2370	2884	0
Early Int. (CB)					
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home	10000		6112	8224	10000
Off-E. Int. (HB)	14335	18544	16856	18658	14258
Off-Other					
Apt. Living (per)					
Respite-ST	4000	3460	5303	7800	6771
SUBTOTAL 1	171622	242822	329307	375383	
GRANTS					
Case Management	13098	28702	27755	40005	41000
Consultation 1					
Consultation 2					
Education 1					
Education 2					
Job D/P1					
AISMR					
Leisure/Rec					
Residential Serv.					
SHELTERED WK SHOP					
AGING PROJECT		1277	36225	39550	41759
Preschool/EI					
SUBTOTAL	13098	29979	63980	79555	
TOTAL SGF	184720	272801	393287	454938	457788
TITLE XX (100%)	170328				
CASE MGT		332			
EARLY INT.		41694	43779	43779	
COMM TNG HOME SP.		4743			
TOTAL DDSA	66415	46769	43779	43779	43779
TOTAL ESEA	16797	15639	13180	9675	14260
TOTAL AISMR (est)	382721	481636	509618	600000	600000
TOTAL MR	820981	816845	959864	1108392	1115827
MRSGF (REVENUE)	230484	230846	222196	241617	241617

HFK 5-8-87
PATHWAYS
REGION X

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.		24000	20000	55292	55292
Work Adult Hab	346	558655	683653	708832	718832
Preschool					
MR Cluster			65000	78121	68121
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	4729				
Early Int. (CB)		3560			
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home					
Off-E. Int. (HB)	65000	85000	129000	114621	50902
Off-Other					
Apt. Living (per)					
Respite-ST		6000	10000	25000	25000
SUBTOTAL 1	70075	677215	907653	981866	918147
GRANTS					
Case Management	45000	53201	64680	64680	137669
Consultation 1				25411	28649
Consultation 2					
Education 1	3000				
Education 2					
Job D/P1					
AISMR	75000				
Leisure/Rec					
Residential Serv.					
SPECIAL PROJECT	81949				
SS& Equipment	60000	60000	60000	89584	89586
TRAINING		20000	20000		
SUBTOTAL	264949	133201	144680	179675	255904
TOTAL SGF	335024	810416	1052333	1161541	1174051
TITLE XX (100%)	452281				
CASE MGT	$60,762.00	62600	65730	65730	
SS&E	$45,271.00	73724	110237	47503	63909
EARLY INTER					65730
TOTAL DDSA	$106,033.00	136324	175967	113233	129639
TOTAL ESEA	$31,250.00	36591	29839	25695	23250
TOTAL AISMR (est)	$482,585.00	719102	776880	800000	800000
TOTAL MR	1412514	1695681	2035019	2100469	2126940
MRSGF (REVENUE)	259914	357174	534174	606775	609111

HFK 5-8-87
PATHWAYS
REGION X

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.		15000	20000	55292	55292
Work Adult Hab	346	497260	683653	708832	718832
Preschool					
MR Cluster			65000	78121	68121
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	4729				
Early Int. (CB)		3560			
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home					
Off-E. Int. (HB)	65000	105000	129000	114621	50902
Off-Other					
Apt. Living (per)					
Respite-ST		15000	10000	25000	25000
SUBTOTAL 1	70075	635820	807653	981866	918147
GRANTS					
Case Management	45000	53201	64680	64680	137669
Consultation 1				25411	28649
Consultation 2					
Education 1	3000				
Education 2					
Job D/P1					
AISMR	75000				
Leisure/Rec					
Residential Serv.					
SPECIAL PROJECT	81949				
SS& Equipment	60000	60000	60000	89584	89586
Division Tr.		20000	20000		
Not Spread		67000			
SUBTOTAL	264949	200201	144680	179675	255904
TOTAL SGF	335024	836021	1052333	1161541	1174051
TITLE XX (100%)	452281				
CASE MGT	$60,762.00	62600	65730	65730	
SS&E	$45,271.00	73724	110237	47503	63909
EARLY INTER					65730
TOTAL DDSA	$106,033.00	136324	175967	113233	129639
TOTAL ESEA	$31,250.00	36591	29839	25695	23250
TOTAL AISMR (est)	$482,585.00	719102	776880	800000	800000
TOTAL MR	1412514	1721286	2035019	2100469	2126940
MRSGF (REVENUE)	259914	357174	534174	606775	609111

HFK 4-1-87
MOUNTAIN
REGION XI

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.					$0
Work Adult Hab	114080	623446	600741	$637,000	$618,240
Preschool	26122	18720	659		
MR Cluster					
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic					
Early Int. (CB)	213				
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home					
Off-E. Int. (HB)				$41,238	$45,860
Off-Other					
Apt. Living (per)					
Respite-ST					
SUBTOTAL 1	140415	642166	601400	$678,238	$664,1000
GRANTS					
Case Management	38886	24720	35150	$57,452	$74,616
Consultation 1					
Consultation 2					
Education 1					
Education 2					
Job D/P1				$62,500	$87,500
AISMR					
Leisure/Rec					
Residential Serv.					
SPECIAL PROJECT	43000				
RESPITE			9925	$23,881	$0
EARLY INTERVENTION				9526	
SUBTOTAL	81886		54601	143833	162116
TOTAL SGF	222301	642166	656001	$822,071	$826,216
TITLE XX (100%)	539033				
CASE MGT		13157	13256	$13,256	
EARLY INT.		10790	11888	$11,888	$25,144
SPECIAL PRO.					$33,713
TOTAL DDSA	28144	23947	25144	$25,144	$58,857
TOTAL ESEA	17619	9226	7272	$3,426	$25,730
TOTAL AISMR (est)					$200,000
TOTAL MR	802900	676536	688417	$850,641	$1,110,803
MRSGF (REVENUE)	222291	188256	226906	$379,564	$404,564

HFK 5-5-87
KY RIVER
REGION XII

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.					
Work Adult Hab		167762	174399	$205,775	$197,392
Preschool					
MR Cluster					
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	1369	1734	1192	$2,303	$0
Early Int. (CB)					
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home					
Off-E. Int. (HB)	26782	21254	17513	$48,852	$32,779
Off-Other					
Apt. Living (per)					
Respite-ST					
SUBTOTAL 1	28151	190750	193104	$256,930	$230,171
GRANTS					
Case Management	36106	20723	63588	$66,602	$50,132
Consultation 1	488	972	2683	$2,377	$1,085
Consultation 2					
Education 1	422	218			
WORK ACT/PERRY			100000	$103,000	$103,000
Job D/P1					
AISMR				$125,000	$25,000
Leisure/Rec					
Residential Serv.					
SHELTERED WK SHOP					
SPECIAL PROJECT	43608				
Preschool/EI		27447			
SUBTOTAL	80624	49360	166271	296979	179217
TOTAL SGF	108775	240110	359375	553909	409388
TITLE XX (100%)	158168				
CASE MGT		37789	9514	$9,514	
EARLY INT.			30164	$30,164	
COMM TNG HOME SP		4113			
TOTAL DDSA	44555	41902	39678	39678	39678
TOTAL ESEA	17748	16281	10621	$10,278	$13,950
TOTAL AISMR (est)					$200,000
TOTAL MR	329246	298293	409674	6038865	663016
MRSGF (REVENUE)	94426	91963	196963	360651	260651

HFK 5-6-87
CUMBERLAND RIVER
REGION XIII

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.	18030	3701			
Work Adult Hab	99809	321382	256259	$256,259	$275,437
Preschool	5472	241140	236548	$236,548	243,717
MR Cluster	30467	16808			
Group Home (A)	60259	9320			
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic	57059	31718	29585	$27,488	$24,740
Early Int. (CB)	68948	112649	74296	$177,111	$159,861
Off-Personal					
Off-Apt. Living					
Off-Home	6756		3266	$3,266	$2,843
Off-In-Home					
Off-E. Int. (HB)		16282	15775	$26,465	$4,945
Off-Other					
Apt. Living (per)					
Respite-ST					$15,594
SUBTOTAL 1	346800	753000	615729	$727,137	$727,137
GRANTS					
Case Management	15190	21271	22941	$22,941	$33,819
Consultation 1	2948	630	2866	$2,866	$2,866
Consultation 2					
Education 1	845	3941			
Education 2					
Job D/P1					
AISMR		85000			
Leisure/Rec					
Residential Serv.					
SHELTERED WK SHOP					
SS& Equipment					
Preschool/EI					
SUBTOTAL	18983	110842	25807	$25,807	$36,685
TOTAL SGF	365783	863842	641536	$752,944	$763,822
TITLE XX (100%)	431746				
CASE MGT		13987	14686	$14,686	
EARLY INT.					
SPECIAL PRO.					
TOTAL DDSA	12148	13987	14686	$14,686	$14,686
TOTAL ESEA	83088	77020	89688	$73,316	$75,950
TOTAL AISMR (est)		196681	627084	$650,000	$650,000
TOTAL MR	892765	1151530	1372994	1,490,946	$1,504,458
MRSGF	284288	343870	$161,653.00	$222,434	$222,434

HFK 5-5-87
LAKE CUMBERLAND
REGION XIV

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	FY 88 ALLOCATION
FEE-FOR-SERVICE					
Respite-Ext.	3406	4963	4963	$11,991	$11,991
Work Adult Hab		113999	198999	$206,000	$300,868
Preschool	1799	35659	35659	$46,734	67,893
MR Cluster					
Group Home (A)					
Apt. Living					
Comm. Tr. Homes					
Group Home (C)					
Clinic					
Early Int. (CB)	15337	10344	10344	$30,654	$0
Off-Personal					
Off-Apt. Living					
Off-Hospital					
Off-In-Home					
Off-E. Int. (HB)	12028	5545	5545	$20,773	$20,773
Off-Other					
Apt. Living (per)					
Respite-ST	180	74	74	$3,998	$3,998
SUBTOTAL 1	32750	170584	255584	$336,815	$422,128
GRANTS					
Case Management	50000	45000	50000	$58,200	$72,887
Consultation 1					
Consultation 2					
Education 1	7517				
Education 2					
Job D/P1			25672	$26,442	$26,442
AISMR					
Leisure/Rec					
Residential Serv.	131250				
BEHAVIOR MGT					$20,000
SS& Equipment					
Preschool/EI					
SUBTOTAL	188767	45000	75672	$84,642	$119,329
TOTAL SGF	221517	215584	331256	$421,457	$541,457
TITLE XX (100%)	173376				
PRESCHOOL		8924	9370	$9,370	
CASE MGT		13987	14687	$14,687	
EARLY INT.		2203	2313	$2,313	
TOTAL DDSA	43443	25114	26370	26370	26370
TOTAL ESEA	14698	21406	25486	$10,278	$7,750
TOTAL AISMR (est)	618175	816847	748803	$800,000	$800,000
TOTAL MR	1071209	1078951	1131915	1,258,105	$1,357,577
MRSGF (REVENUE)	191376	104611	193973	$241,631	$361,631

HFK 6-9-87
BLUEGRASS
REGION XV

MENTAL RETARDATION

SGF	FY 84 ALLOCATION	FY 85 ALLOCATION	FY 86 ALLOCATION	FY 87 ALLOCATION	CATEGORIES	FY 88 ALLOCATION
FEE-FOR-SERVICE						
Respite-Ext.			8875	5535		
Work Adult Hab		310191	357509	397509	RESPITE-ST	
Preschool	102103	113786	99570	170668	RESPITE-24	
WORK SERVICES					IN-HOME	
Group Home (A)					LEIS/REC	
STAFF RESIDENCE	21010	54289	69967	69355		
Comm. Tr. Homes					IN HOME SUPPORT	95974
Group Home (C)						
Clinic	11791	31512	6349			
Early Int. (CB)					ST RES-per	
Off-Personal					ST RES-24	
Off-Apt. Living					HATTON	
Off-Hospital						
Off-In-Home			19115	21700	RESIDENTIAL	150251
Off-E. Int. (HB)	7343					
Off-Other						
STF RESID (per)	4416	15274	37596	43308	PRESCHOOL	
Respite-ST	10503	24555	27002	34964	E INT-CB	
					E INT-HB	
SUBTOTAL 1	157166	549607	625983	743039	EDUCATIONAL	165390
GRANTS						
Case Management	62800	34731	31135	66084		
Consultation 1	3100					
WK ACTY MARC		17500			AD HAB	
Educational					SUPP EMP	
COMM. TR HOME		16000			SP-ESTTILL	
Job D/P1	595600	99945	127603	143179	SP-CONEX	
AISMR	80920			62500		
Leisure/Rec		37584	32969	36890	ADULT TRAINING	549986
ADULT DAY HAB				26050		
BEHAVIOR MGT SP		5000	12000	22000	BEH MGT	
SPEC PRO	80927				CASE MGT	
PROJECT ADMIN SP		5535				
SPEC PRO—ESTILL			35000	35000	CASE MANAGEMENT	144441
SUBTOTAL	287307	216295	203707	391703		
TOTAL SGF	444473	765902	829690	1134742	TOTAL SGF	1193542
TITLE XX (100%)	319450				MRSGF	821380
PRESCHOOL		42904	19098			
CASE MGT		37777	37268			
MARC		14151	34784			
COPES			15000		COMMUNITY CARE	372162
TOTAL DDSA	90858	94832	87062	56366		
TOTAL ESEA	80049	52946	76356	89076		
TOTAL AISMR (est)	597603	779715	814117	1000000	AISMR	1200000
TOTAL MR	1532433	1693395	1807215	2280184	TOTAL MR	2552535
MRSGF (REVENUE)	360426	425921	551274	762380		

APPENDIX 5

Legislative Research Commission Fiscal Analysis Note

COMMONWEALTH OF KENTUCKY
GENERAL ASSEMBLY
1984 REGULAR SESSION

LEGISLATIVE RESEARCH COMMISSION
FISCAL ANALYSIS NOTE

APPENDIX 5

MEASURE

(X)84 BR No. 286 (X) House Bill No. 33

( )Resolution No. ( )Amendment No.

SUBJECT/TITLE Developmental Disabilities Bill of Rights

SPONSOR Representative Gerta Bendl

NOTE SUMMARY

Fiscal Analysis: X Impact; No Impact; Indeterminable Impact

Level(s) of Impact: X State; Local; X Federal

Budget Unit(s) Impact: Department for Health Services

Fund(s) Impact: X General; Road; X Federal;

Restricted Agency (Type); ; (Other)

FISCAL SUMMARY

Fiscal Estimates	1983-84	1984-85	1985-86	Future Annual Rate of Change
Revenues (+/-)				%
Expenditures (+/-)	-0-	+$6,900,000	+$6,551,000	15%+ for 8 yrs
Net Effect				%

MEASURE'S PURPOSE:
Creates a bill of rights for the developmental disabled population requiring services and planning for services by the Cabinets for Human Resources and Education.

PROVISION/MECHANICS:
All functions, personnel, funds, equipment, facilities and records necessary to carry out the provisions of this act will be in the Cabinet for Human Resources and Education and Humanities Cabinet. HB 33 establishes rights for developmentally disabled persons, including definitions of specific services and terms. It requires the Cabinet for Human Resources and the Education and Humanities Cabinet jointly to develop, implement and report on a plan to serve the DD population.

FISCAL EXPLANATION:

I. Estimated Kentucky Developmental Disabled Population In Kentucky: 50,864/Target Population: 20,774

The Kentucky Developmental Disabilities (DD) Planning Council estimates there are 50,864 developmentally disabled citizens in the Commonwealth based on national projections. However, the target population who need and may request services is a sub-population of that total number. For purposes of this fiscal note, 20,774 individuals are assumed as requiring some amount and type of service. This number is based on the Massachusett's research done by Michael F. Hogan which shows that .59% of the population needs some assistance from a community service system due to functional problems. The fiscal impact of this measure is calculated to represent 20% of the total estimated cost in the 1984-86 biennium and is further explained in Section III.

II. Target Population - 20,774 Persons

A. Current Client Load - 14,654 Persons

From figures made available by the Cabinet for Human Resources and Department of Education, there are 1,560 individuals residing in Mental Retardation/Developmental Disabilities institutional facilities, 2,800 in nursing homes, 6,687 served by the Mental Health/Mental Retardation boards and 3,607 served by the Kentucky Department of Education (PL 94-142). This gives a total of 14,654 currently receiving some type of service. Of these clients, it is anticipated that 3,474 persons would request or require additional services under this legislation. (23%)

a. Current Client Load Additional Services Estimates - 3,474

1) Individuals Seeking Entry to MR/DD Facilities: 30

HB 33 addresses the developmentally disabled individual's right to the least restrictive appropriate level of care. This level of care may be in a MR/DD institution. Presently, there are 30 individuals awaiting an institutional placement. Twenty-five individuals are waiting to be admitted to Oakwood and five waiting to enter various other mental retardation facilities. Should these individuals be placed today, it would cost $75 per day at Oakwood and slightly more (approximately $100) at the other facilities.

If these 30 individuals stayed in the facilities for one year, the cost would be $866,900. This figure is exclusive of capital construction costs; it assumes that the beds would be made available in existing facilities.

2) Individuals Receiving Minimal Amount of Support Service from the MH/MR Boards: 3,444

From the MR/DD reports for Fiscal Year 1982-83, 3,243 individuals received "hard" services, labelled residential placement, vocational or educational services. The remaining 3,444 received some support services, probably case management (the average cost per recipient for a year was $155; which is an average of 10.8 instances of service per year).

Based upon current utilization patterns, if these 3,444 individuals were to receive additional services, 12% would receive residential services, 54% vocational services and 34% educational services. The new cost of providing this level of service, based on Fiscal Year 1982-83 expenditures, for 3,444 individuals is $15,078,800.

B. Estimated DD Population Not Receiving Services - 6,120 Persons

From the Hogan Research, 20,774 individuals are estimated needing assistance. 14,654 individuals receive some service, which leaves 6,120 in need but not receiving services.

a. MR/DD Individuals on Existing MH/MR Board Waiting Lists: 521

From an analysis of existing reporting forms, there are 521 individuals waiting to receive services. 274 people need residential serivces, 353 need vocational and 63 need educational services. (Note: some persons need more than one service.)

The cost to serve this population is higher than the average cost of serving current recipients as more residential placements are requested. The average cost per recipient is $9,516, total new cost of providing these services to the 521 waiting is $4,957,600 (based on Fiscal Year 1982-83 expenditures).

b. MR/DD Individuals Not on Waiting List, Not Receiving Services (Based on Hogan Research): 5,599

If those MR/DD individuals who are in need of some level of service but have not requested or been made eligible for services, would request service due to the passage of HB 33, the cost of providing the same degree of service as those 3,243 recipients would by $25,388,900 (based on Fiscal Year 1982-83 costs). This figure was derived by assuming that their needs were similar to the existing service recipients. That is:

12% (672) need residential services,
54% (3,024) need vocational services,
34% (1,904) need educational services, and
all need support services of at least 10.8 instances of service each year ($155 Fiscal Year 1982-83).

III. Projections of Expenditures Based on Passage of HB 33

HB 33 is an entitlement bill, which would give the DD population the right to certain services and may place greater demands on the Commonwealth to provide defined services. This fiscal note attempts to give an estimate of the number of people needing services. All groups discussed in this analysis represents 9,594 individuals needing services, costing an estimated $46,292,300 (Fiscal Year 1982-83).

However, a realistic prediction of the number of people requesting services suggests a gradual increase in service demand. In calculating phased implementation of HB 33, three additional factors are taken into consideration. These are: 1) The availability of trained service providers and existing resources (i.e. sheltered workshops, supervised living situations) is presently limited and would have to be developed over several years; 2) The demand for services would gradually increase as community awareness about existing services grew; and 3) Finally, reappraisal and assessment of recipient needs and service plans would require additional staff effort and time. Therefore, the projected expenditures based on HB 33 would also gradually increase.

Table I shows the estimated increase through Fiscal Year 1985-86, with new funding being allocated for the first time in Fiscal Year 1984-85. The increase in service provision to those not served and those presently underserved would be 10% in Fiscal Year 1984-85. Fiscal Year 1985-86 shows a 20% growth over the Fiscal Year 1982-83 figures. Based on these estimates the program will expand 10% yearly with an additional 5% yearly inflationary increase.

TABLE I
Recipients/Expenditures for MR/DD Services Through
MH/MR Boards Projections Based on Passage of HB 33*

# Type Recipient	FY 1983 Expenditures	FY 1984 Expenditures	FY 1985 Expenditures	Program Growth Rate	FY 1986 Expenditures	Program Growth Rate
6,687: Existing Rec.	$15,215,400	$15,976,200	$16,775,000	-	$17,613,700	-
30: MR/DD Facilities Increase	N/A	N/A	$955,700	-	$1,003,500	-
3,444: Additional Services to Existing Rec.	N/A	N/A	$1,660,500	10% (344)	$3,491,900	20% (689)
521: MH/MR Board Waiting Lists	N/A	N/A	$545,600	10% (52)	$1,145,800	20% (104)
5,599: No Services	N/A	N/A	$2,939,400	10% (560)	$6,172,300	20% (1,120)
Total Program Costs	$15,215,400	$15,976,200	$22,876,200	-	$29,427,200	
Total Additional Funding	N/A	N/A	$6,900,000	-	$6,551,000	

*All expenditures are calculated on Fiscal Year 1982-83 cost data adding a 5% inflationary increase each fiscal year and an additional 10% each year in client growth levels.

DATA SOURCE(S) Bill Draper & Paris Hopkins, CHR; Billie Downing, DOE; Hogan Report

NOTE NO: 23 PREPARER Mary C. Yaeger REVIEW DATE 1/17/84

LRC 84
BR 23-746

APPENDIX 6

CHR Cost Projections

APPENDIX 6 - CHR COST PROJECTIONS

THE SECRETARY FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT 40601

January 19, 1984

Honorable Joseph P. Clarke, Jr.
Chairman
House Appropriations and Revenue
Capitol Annex
Frankfort, Kentucky 40601

Dear Chairman Clarke:

As requested by Representative Long, I am forwarding for your information the Cabinet's most recent cost projections for implementation of HB 33. Since our projections differ significantly (CHR estimate $37,239,034 over the biennium compared to $13,451,000 LRC staff estimate) from those projected by your staff, I have asked staff in the Division of Community Services for Mental Retardation to review the LRC fiscal note of January 18, 1984, and comment to me on their differing approaches. Their reply is summarized below.

The LRC cost estimate varies in several ways from the Cabinet for Human Resources calculations:

- CHR total mental retardation target group is smaller (17,740 versus 20,774) and is based on the percentage of people with mental retardation estimated to be included in the total 50,864 developmentally disabled population (Kentucky Developmental Disabilities Planning Council three year plan/Gollay and Associates HEW study).

- Under the LRC category of "current population", it is not appropriate to reduce the target group by 3,243 receiving "some type of service". The average cost of service at present for this group is approximately $4,263/person/year and this population includes some very mildly handicapped people.

  A full range of services for a developmentally disabled individual can range from $15,000 to $25,000/year.

- It is also not appropriate to reduce the target population by the 3,607 people served by Department of Education. First, they represent all levels of handicapped children and youth served under P.L. 94-142, not the severely impaired developmentally disabled category. Secondly, they do not now receive all the services necessary for them or available under HB 33. Some few will need residential care; many will need respite, case management and therapies such as occupation, physical, speech, etc.

- Within the 3,474 people included by LRC as "needing additional services", 30 are scheduled to go to an ICF-MR facility. The remaining 3,444 currently receive an average of only $155/year of service compared to our estimate of $15,000 to $25,000/year necessary for developmentally disabled client. Use of the 1982-1983 average cost figure, inclusive of all levels of mental retardation, i.e., mainly mild and moderate, as a per diem for the 3,444 people is not appropriate and under estimates need.

- Given that the target population reduction group was too high though including underserved, with necessary additional dollars attached, the remaining 6,120 "not receiving services" is too low.

- Overall, the major factor in different cost projection outcome between CHR and LRC is the use by LRC of 1982-1983 average cost figures, which represented only partial services to a group that was not mainly developmentally disabled, but previously included mild and moderate levels of retardation. As noted to LRC when supplying the 1982-1983 figures requested, the $15,000 to $25,000 range is much more applicable to developmentally disabled clients than our previous expenditure patterns for all known clients.

As you will see from our estimate, we believe it could cost as much as $186,000,000 to fully serve 13,760 people with a developmental disability related to mental retardation. This averages approximately $13,500/person/year and is consistent with our experience in the AIS-MR community services program.

It should be noted that LRC staff did not project cost associated with developmentally disabled conditions other than mental retardation.

We concur with the intent of HB 33 and applaud the goals it addresses, but it cannot be implemented unless funded realistically. Adequate funding would be vitally necessary given the inclusion of guaranteed legal redress offered in cases where the act is violated.

Sincerely,

E. Austin, Jr.
Secretary

cc: Representative Marshall Long
Representative Gerta Bendl

Analysis of Cost for H. B. 33

(Developmental Disabilities)

Prepared By: Division of Community Services
for Mental Retardation

January 12, 1984

Introduction: HB 33 requires that a comprehensive system of services and care be made available to people in Kentucky with Developmental Disabilities (DD). DD refers to a condition of developmental and/or physical impairments, manifested before age 22, which results in substantial functional limitations in at least three areas of life activity identified in the proposed legislation. The definition contained in HB 33 parallels the language of the Federal DD act, Public Law 95-602.

The purpose of material presented below is to estimate the probable cost associated with enactment of HB 33.

General Information: Developmental Disability as defined includes handicapped people within four general categories of impairment, i.e., mental retardation, sensory, physical or serious emotional disturbance.

A substantial majority of people served in Kentucky who are certified as eligible for DD have a diagnosis of mental retardation, i.e., over 75%. The most authoritative study for use in predicting expected incidence rates for Developmental Disabilities is one prepared for Health, Education and Welfare by Gollay and Associates. That study predicts that 1.2% of the state's population would be eligible as Developmentally Disabled, and further would indicate the following distribution within that 1.2%:

- Developmentally Disabled with Mental Retardation 35%
- Developmentally Disabled with serious emotional disturbance 10.42%
- Developmentally Disabled with sensory impairments 17.17%
- Developmentally Disabled with physical impairments 37.43%

Obviously, our state focus is primarily on mental retardation, since more than 75% of those served are mentally retarded compared to an expected 35%. Since the DD Council staff are attached to the Division of Community Services for Mental Retardation (DCSMR) and the primary service providers with DD funds are the Mental Health/Mental Retardation Boards, it is reasonable to assume that many people with physical, sensory or emotional impairments are not identified and/or served under this present system.

The most recent DD plan, i.e. FY 1984-1986, predicted that 50,684 people would be eligible in one of the four major categories of impairment. Gollay's statistics would predict that 17,740 people from that group would be mentally retarded.

To effectively use Gollay's figure, the current mental retardation totals in public and private ICF-MR, nursing homes plus the (capacity) of the AIS-MR program must be subtracted. Therefore the mental retardation population, alone, to be served under the proposed legislation would be 13,760 individuals.

It is highly probable that not all people in the group of 13,760 would require all services available. Best predictions of number in the eligible population who would require service have been used to multiply by average annual cost of needed/guaranteed services. A modification of the Hogan Consumer-Centered Planning Project data was used to determine number per service category. Yearly cost of service was generated through reference to and application of existing similar services now provided.

Population Calculations:

Estimated Kentucky DD population (Gollay & Associates Study)	50,684	
Impairment Categories Within Population		
- Developmentally disabled with mental retardation		35.0%
- Developmentally disabled with emotional disturbance		10.42%
- Developmentally disabled with sensory impairment		17.17%
- Developmentally disabled with physical impairment		37.43%
35.0% mentally retarded population	17,740	

17,740	
- 770	ICF-MR
16,970	
- 430	Private ICF-MR
16,540	
-2,200	Nursing Home
14,240	
- 480	AIS-MR (capacity)
13,760	Population to be served

Cost Calculations:

Service		# to be served	Unit Cost	Total Cost
Residential	24%	3,313	$11,592.50/yr.	$38,405,952
Education	2%	300	$ 1,500/yr.	$ 450,000
Vocational	84%	11,558	$ 7,200/yr.	$83,217,600
Support	100%	13,760		
-Case Mgmt	100%	13,760	$ 1,500/yr.	$20,640.000
-Therapies	7%	9,632	$ 2,000/yr.	$19,264,000
-Respite	100%	13,760		
-Intensive	75%	10,320	$ 1,920/yr.	$19,814,400
-Non-Intensive	25%	3,440	$ 1,280/yr.	$ 4,403,200
			Support Total	$64,121,600
			Grand Total	$186,195,152

Conclusions:

The total projected cost for the mental retardation portion of the total DD population is $186,195,152, or an average per person cost of $13,531.62/person/year. Since the capacity of the state's delivery system to add on such an increased capacity would not allow immediate identification and inclusion for all people, a phased in plan over five to ten years in duration would be required. Education and Support services could most likely be added in the shortest period, while additional time would be required for necessary residential and vocational programs. Should a five year plan be attempted, the average yearly expenditure of '84 dollar figures, would be $37,239,034/year, or more realistically, $18,619,517 for a ten year phase-in activity.

It is not within the scope of the Cabinet for Human Resources or the Division of Community Services for Mental Retardation to project the cost for the 54% of the DD population that is impaired in either physical or sensory development. The fourth group DD with serious emotional disturbance, would likely generate a similar cost/year as the mental retardation population. Overall, if the cost is similar to that for mental retardation services across all impairment categories, a total cost of approximately $582,000,000 would result.

APPENDIX 7

A Comparison of Two Cost Projections

The Commonwealth of Massachusetts
Executive Office of Human Services
Department of Mental Health
160 North Washington Street
Boston, Massachusetts 02114

Gus J. Callahan, Jr., Ph.D.
Commissioner

AREA CODE (617)

February 10, 1984

Ms. Helen Clevenger
Chairperson
Bill of Rights Committee
Commonwealth of Kentucky

Dear Ms. Clevenger:

I am writing to comment on the Developmental Disabilities Bill of Rights (House Bill No. 33) which your committee has worked on. I have had the opportunity to review the bill and believe it is a well conceived piece of legislation. Some problems that we now have with services in Massachusetts--such as difficulty for clients in making the transition from school to adult services--might be averted if we had such legislation.

However, I understand there is legitimate concern in Kentucky about the price tag for the services the bill would require. Ms. Peach, of the Office for Public Advocacy, has asked me to review for you the cost estimates done be the Legislative Research Commission (LRC) and the Cabinet for Human Resources (CHR). On a separate occasion, I had the opportunity to discuss this problem with Mr. Stone of the Division of Community Services.

The need for and projected costs of social services are always difficult to anticipate with certainty. Apparently I have become involved in this issue because of the work we did here in Massachusetts when confronted with the same need for long range planning. Our work, supported by a National Significance grant from the federal Developmental Disabilities Office, was a comprehensive needs assessment of mental retardation service needs. We attempted to locate and determine the service needs of every mentally retarded person in Western Massachusetts (population about 800,000). I have attached a copy of an article that describes our project. We are flattered that the LRC has in part relied on our efforts in projecting Kentucky service needs. I will try to review the validity of the LRC conclusions.

The CHR has not relied on our study, but has produced different statistical projections based on the excellent work of Elinor Gollay and her colleagues, Since the conclusions reached by the LRC and CHR are so different, I will also presume to comment on the CHR methodology. Finally, I have done my own assessment of the likely service needs and costs. This should be taken with a grain of salt since I am not familiar with the details of the Kentucky scene. However, I believe a "third opinion" might be useful in evaluating the approaches that have been used.

I) Comments on LRC Fiscal Analysis Note (1/17/84)

A. Overall, the LRC analysis is careful and reasonable, although I feel it may be faulty in some details. The method involves projecting overall needs based on our study, and then determining likely costs for the currently unserved and underserved populations. The method of anticipating that unserved and underserved people will have service needs something like those of the clients who are now getting adequate assistance is quite reasonable.

1) Some might justifiably argue that the unserved and currently unknown population is likely on the average to need less intensive services than current clients. This would reduce the LRC estimated costs. However, I feel that the conservative approach used by LRC is a good one.

2) On the other hand, it might be that the unserved and currently unknown population is on the average more needy than current clients. The CHR analysis argues this (see Secretary Austin's letter of January 19). I do not believe this scenario is likely. Therefore, I do not believe the huge cost increases anticipated be CHR are likely. In my experience, the clients now being served are likely to be in programs partially due to their greater needs. While some current programs need to be upgraded, especially for the clients of the MH/MR Boards who now get "minimal services," the LRC approach to anticipating this need is more reasonable. There is a danger of intruding too much into family life for those people who are being nurtured and cared for by their families, but for whom a comprehensive service package might seem desirable.

B. As CHR correctly notes, LRC did not calculate the likely need for new services for those developmentally disabled people who are not mentally retarded. It is clear that there is not much data on the needs of this group. I believe it is easier to over- than underestimate the needs of this population. The largest group of developmentally disabled persons aside from the mentally retarded is persons with physical impairments. Most of these individuals are mentally competent, and those who are not are included in the mentally retarded group which has been planned for. Most of the services for other mobility impaired people involve adaptations of generic services (accessible housing and transportation, etc.). Other services such as personal care attendants for the small number of people with extreme physical impairments are potentially Medicaid reimbursable.

I believe that the fact that 75% of the current DD eligible people served in the Commonwealth are mentally retarded casts a useful light on this problem. Since again I believe it is likely that the most needy persons are probably known to the system, the LRC figures should be adjusted upwards by some factor for non- mentally retarded

developmentally disabled persone who will need new services. I feel a 10-15% upwards adjustment is perhaps realistic.

II) Comments on CHR Cost Projections (1/19/84 letter and attachments of Secretary Austin)

A. It is my professional judgement that the CHR projections are drastically overstated. I should note that I am not privy to the materials used by CHR to develop per client costs, but it is this area that concerns me the most. If the per client costs are justified, then perhaps the CHR projections are reasonable. In my view, the major problems are:

1) Residential services. The average projected cost ($11,592.50 per client per year) is quite expensive. Perhaps this assumes that all residential supports would be provided in staffed programs such as group homes or staffed apartments. This in my view is an overly expensive and less than ideal approach. Particularly for persons now living at home, a residential services strategy that provides in home supports as a first priority is suggested. When out of home placement is essential, the first alternative should be to develop a family type or shared living placement such as foster care (which can be appropriate for very disabled persons if the back-up services are provided). This is both cost-beneficial and often more relevant. I believe that up to 50% of all residential services can be provided using such models. In particular, the use of intensive family supports can contain costs, prevent long term placements, and help keep families together.

My second concern about the per client cost figure for residential services is that it assumes that unserved and unknown people are likely to need the more structured programs. I feel it is likely that many of the most needy people are already receiving ICF-MR or other residential services.

2) Education services. I would assume that this bill would not increase state education costs for school aged children, due to the service entitlement under PL94-142. Other increased education costs for younger children might result, and I comment on this below.

3) Vocational services. In my judgement, both the anticipated number of vocational service clients and the per client costs are too high. I know of no system that provides vocational assistance to so many mentally retarded citizens, especially at such costly levels. The level of need anticipated is 80% higher than we found in Massachusetts. Perhaps this many persons of all developmental disabilities may need some vocational assistance, but it would certainly not be at such intensive levels. Our research found that only about 10% of the mentally retarded population needs such intensive vocational assistance (e.g. $7200 per client per year). Our recent experience with the model vocational programs

developed by Dr. Tom Bellamy at the University of Oregon has convinced us that less expensive programs--if well conceived and managed--are effective for even the most disabled populations.

For most developmentally disabled persons, programs such as assistance with job finding, transitional employment support, or minimally subsidized competitive employment are appropriate. The per client per year cost for these programs should be in the $1000-$3000 range.

4) Support services. Here also, I believe the per client cost estimates (and to a lesser extent the estimated numbers to be served) are too high. As a "for instance", the intensive respite program could at this funding level provide 16 days per year per client of 24 hour one-to-one aid at $5 per hour--to over 10,000 persons. There are certainly some individuals and families who could use this type of help. However, if the services are to be provided based on an ISP that is developed and negotiated with the consumer and family, the need will not be this high. Here in Western Mass., our DMH funded respite services are quite extensive, and cost about $1 per capita per year. Since Social Services provides some respite services for children with developmental disabilities, and since some expansion could be justified, I feel the figure might by doubled to $2 per capita per year. This would be about a third of the CHR estimate.

- I also believe the case management figures are too high. Here, we also anticipated that in an "ideal" system every client would need case management assistance. Experience has not supported this assumption. Large numbers of developmentally disabled persons do fine without case management, or with infrequent aid (which apparently the MH/MR Boards now provide). I would certainly not argue that no increase in the program will be needed, however. Here in Western Mass., our extensive case management/service coordination programs cost about $2 per capita per year, and I believe this is close to fully adequate.

B) In some ways, the CHR analysis, in my view, may be superior--or at least the methodology is sound except for the overestimates of cost and need for some categories. The number of mentally retarded people estimated to need some assistance is actually less in the CHR approach than in the LRC analysis, since the more conservative Gollay figures about the incidence of substantial mental retardation. Also, as CHR points out, the needs of developmentally disabled persons who are not retarded must be considered. With these important notes, I judge the CHR cost estimates on the whole to be quite exaggerated.

III) Alternative Need and Cost Projections

To provide an independent "third opinion" on the likely costs of this legislation, I did my own analysis by applying the result of our study to the Kentucky population. Because I do not know the Commonwealth in any detail, I feel these projections should certainly not supplant the analyses done in Kentucky. However, this type of "validation" approach may shed light on the merits of the LRC and CHR projections.

I have attached a copy of an article which describes our work in some detail. In addition to the points noted in the article, I should reinforce the following:

1) The study was quite extensive. As described, we made every effort short of a door to door survey to locate mentally retarded people who could benefit from services.

2) The results describe the needed community services for all retarded people--including those now in our state institutions, nursing homes, etc. If the decision is made to continue to provide institutional services for some people, then the overall need for community services can be reduced.

3) The need for services that we describe is, if anything, on the high side. Our figures on the number of people in need were obtained by using the highest need results from among the five different service Areas in Western Mass. In other words, since the Springfield Area documented a higher need for services to children aged birth to three, we used their data for this age group. This is explained in the article. We felt this was appropriate given our goal of describing the professionally ideal service system. Likewise, where we found people who were unserved, we included the services which we felt they could benefit from. Given this approach, I feel that the figures we came up with are realistic and perhaps a little on the high side. When figuring costs, this is probably the way to go.

To construct a picture of anticipated needs and costs for Kentucky, I relied on Tables 3 and 4 in the paper. These tables present not just the total number of persons needing residential or vocational services, but the number needing services at each level of assistance or cost. Therefore I used these figures in conjunction with the Kentucky population (which I understand to be about 3.5 million) to develop need rates for each type of service. If I have seriously under- or overestimates the state population, the figures will be in error. Next, I factored in a per client per year cost figure for each service type. Most of these back-up cost factors or estimates are attached.

For educational services, I expect (see above) that school aged children are receiving adequate PL94-142 services. However, I have counted

on additional costs for early childhood developmental services for children aged birth to three (1100 children at $2500, or $2,75 million per year).

For support services, cost projections are more subjective. This is not addressed in the article although we did look at the issue. My method was to compute the cost of all of the support services we now provide in Western Mass. (where the system is quite well developed) and add a factor of about 50% for clients who may be unserved. The result is an estimate of $900 per client (all clients--obviously some individuals would use more and some less) for these services. I should note that many of these services are Medicaid fundable, and the $900 per client figure is only the state cost.

Using this approach (you may want to look at the back-up tables) I computed the total cost of a fully implemented program at $83,906,000. Since this is only the cost for mentally retarded persons, I then added a 15% factor for other developmentally disabled persons. The assumptions behind this are discussed above. This would make the total state cost of a fully comprehensive DD program $96,492,800. (This assumes no Medicaid offset.) Since the method covers all persons including those now served, the cost increase may be determined by subtracting all current state costs from this figure (both the LRC and CHR "bottom lines" use this approach).

I am not privy to the costs of the nursing home or ICF-MR services now being provided. Assuming that the state cost of the nursing homes is $6000 per client per year, and the state cost of the ICF-MR program is $12000 per client per year, the costs would be as follows:

TOTAL ESTIMATED PROGRAM COST: MR	$83,906,000
ESTIMATED COST FOR OTHER DD PERSONS	$12,585,900
TOTAL PROGRAM COST	$96,491,900
MINUS: MH/MR BOARD FUNDING	($15,215,400)
ESTIMATED NURSING HOME STATE SHARE	($16,800,000)
ESTIMATED ICF-MR STATE SHARE	($20,160,000)
ESTIMATED ADDITIONAL COST: BILL 33	$44,316,500

Since I have worked on this very hurriedly, I hope my math is right! Also, the nursing home and ICF-MR costs are only gross guesses or estimates. But if these figures are in the ballpark, then I conclude the overall cost is much more likely to be in line with the LRC than the CHR estimates.

I would agree with both estimates that five to ten years are needed to phase the program in appropriately, having had experiences with trying to do too much too quickly. I also concur strongly with Secretary Austin that support services could be phased in quicker--although obviously a mix is needed in any particular year.

There are a number of other factors which cushion the projected costs. One is the very sound approach of building services on the individual service plan. Although this bill would provide an entitlement to services, it is not a blanket approach like the social insurance programs whose costs are escalating. The services that clients would be entitled to are those which would be professionally determined--with the participation of the consumer and possibly his/her family--to be needed. This is another reason for initiating the support services as a first priority. In my experience, an appropriate array of these services can often prevent the use of the more expensive alternatives.

A second major feature is that the Legislature retains control over the appropriation process and over funding levels. Although the right to appropriate services would clearly lead to a need for more resources, this would not be open ended. The phased in approach suggested in the LRC analysis is indeed the right way to go, and would imply a gradual ability to assess precisely what the cost increases would be. The program could certainly be adjusted by the Legislature if needs be. However, it is my best professional judgement that the extreme cost increases anticipated by the CHR are most unlikely if the program is implemented as currently drafted.

Finally, it may be that a better targetting of federal programs might reduce the overall state cost while providing the full program. An expanded Omnibus waiver of Medicaid requirements--focussing on providing appropriate and less restrictive alternatives for qualified ICF-MR residents--could provide an opportunity to serve more clients with the same funding level.

In sum, it is my feeling the bill is programmatically and fiscally sound and philosophically progressive. Your Committee deserves credit for its work, and I hope that you are rewarded by passage of the legislation. I hope my comments are useful, and am sorry that some of the back-up materials I have attached may seem a little disorganized. I had to work quickly against your deadlines. Please feel free to contact me if you have questions.

Sincerely,

Michael F. Hogan, PhD.

BACK-UP WORKSHEETS FOR NEED AND COST ESTIMATES

COMPARISON OF CHR AND HOGAN ESTIMATES *

SERVICE	NUMBER IN NEED		ANTICIPATED COST PER CLIENT/YEAR		TOTAL COST (in thousands)	
	CHR	Hogan	CHR	Hogan	CHR	Hogan
RES	3313	7,700	$11,593	$5,314	$38,406	$40,906
EDUC	300	1,100	$1,500	$2,500	$450	$2,750
VOC	11,518	6,440	$7,200	$3,345	$83,218	$21,543
SUPPORT	13,760	20,774	$4,660	$900	$64,122	$18,697
TOTAL	13,760	20,774	$13,531	$4,039	$186,195	$83,996 **

* The CHR estimates of need are for the additional (unserved or underserved) clients. The Hogan estimate is of total need for mentally retarded clients

** due to addition error discovered after this "went to press," the total cost reported in the analysis is actually $83,906,000

NEED ESTIMATES FOR RESIDENTIAL LEVELS

STATE POPULATION	NEED LEVEL	RATE OF NEED	NUMBER IN NEED	NUMBER PER SERVICE TYPE					
				Staffed	model cost	total cost	In-home or foster care	model cost	total cost
3.5 mil.	minimum	.00097	3395	3395	$1104	$3748080	--	--	--
3.5 mil.	moderate	.00034	1190	595	$5800	$3451000	595	$2250	$1338750
3.5 mil.	training	.00049	1715	858	$13390	$11488620	857	$2750	$2356750
3.5 mil.	living	.00040	1400	700	$21211	$14847700	700	$5250	$3675000
3.5 mil.	total	.00215	7700	3851	--	$33,535,400	3849	--	$7,370,500

total residential: $40,905,900

PROGRAM COST MODELS

RESIDENTIAL MODELS ASSUMPTIONS	minimum sup'n	moderate sup'n	supervised training	supervised living
salaries	$10,000	$10,000	$10,000	$10,000
staff levels for each model	1:15 ratio	1:6 with sleep-in	1:3 with sleep-in	1:2 with sleep-in
relief staff factor	NA	1.72	1.72	1.72
fringe	15%	15%	15%	15%
other than direct staffing costs	20%	20%	20%	20%
program size	in own housing	6	6	6
annual client contribution (e.g.SSI)	NA	$2250	$2250	$2250
PER CLIENT COST	$1104	$5800	$13390	$21211

NEED ESTIMATES FOR VOCATIONAL LEVELS

STATE POPULATION	NEED LEVEL	RATE OF NEED	NUMBER IN NEED	COST/ CLIENT	TOTAL COST
3.5 mil.	Semi-ind.	.00047	1645	$1500	$2467500
3.5 mil.	Min. Sup'n.	.00055	1925	$3000	$5775000
3.5 mil.	Mod. Sup'n.	.00030	1050	$4000	$4200000
3.5 mil.	Int. Sup'n.	.00052	1820	$5000	$9100000
3.5 mil.	Total	.00184	6440	--	$21542500

OTHER BACK-UP DATA FOR COST ESTIMATES INCLUDED

1) In-home support or foster care models were projected for 50% of the population anticipated to need residential services. The costs were calculated as follows:

Supervision level	Estimated weekly cost of supports or home provider stipend plus back-up services	Estimated annual/client cost	Estimated SSI contribution to offset cost
Minimum sup'n.	Not applicable. All persons with this level of need projected to live in their own housing (or family), with staff follow-up and assistance provided with a 1:15 caseload.		
Moderate sup'n.	$86.50	$4500	$2250
Sup. Training	$96.15	$5000	$2250
Sup. Living	$144.25	$7500	$2250

2) Early childhood education services were anticipated to be needed by 1100 children in the state, using the rate of need from Table 4 of the attached chapter. A per child per year cost of $2500 for these programs was used to estimate the cost.

3) Vocational program options for each level of need were costed out based on the staffing levels included in Table 5 of the attached chapter. The resulting per client per year costs are as follows:

Supervision level	Anticipated per client per year costs
Semi-ind. employment	$1500
Minimal supervision	$3000
Moderate supervision	$4000
Intensive supervision	$5000

Some increase in the per client cost figures here may be appropriate for the higher levels of supervision, but these are reasonable planning figures.

APPENDIX 8

Partial List of Legislation and Regulations Which Affect the MR

APPENDIX #8

Partial List of Legislation and Regulations
Which Affect the MR

KRS 202A — Hospitalization procedures of the mentally ill which also apply to the MR.

KRS 202B — Hospitalization procedures of the mentally retarded. Subsection .040 sets five conditions for involuntary hospitalization.

KRS 347 — "Bill of Rights" of the developmentally disabled. While comprehensive in its scope, it limits the responsibilities of state agencies to the availability of funds.

KRS 210.470 — Allows counties which participate in establishing MH/MR services to establish MH/MR taxing districts.

KRS 210.370 to 210.460 — Requires review and evaluation of the mental retardation services and report to the Secretary for Human Resources, the administrator of the program, and, when indicated, the public, together with recommendations for additional services and facilities.

KRS 157.312 — Authorizes the establishment of a kindergarten in the common schools.

KRS 157.221 — Provides that the State Board of Education shall create a bureau of education for exceptional children in the State Department of Education, separate from any other existing bureau, to supervise and direct a state program for exceptional children in the Commonwealth.

KRS 157.224 — Establishes that "the Commonwealth of Ky. is committed to providing a comprehensive educational program for its exceptional school-age children through KRS 157.221..."

KRS 158.090 — Under this statute a local Board of Education has the authority, with State Board approval, to establish and maintain a kindergarten program for children 4 to 6 years of age, regardless of handicapping condition.

KRS 158.100 Relates to the provision of services to children birth through 21. Provides for an approved 12-grade school system service for all children under 21. It also places the responsibility upon the district of residence to either maintain an approved elementary and secondary school service or contract for the provision of those services.

KRS 210.400 Sets forth the authority and duties of the Regional Board.

707 KAR 5:050 Provides for the operation of public kindergarten units receiving Minimum Foundation Funds.

P.L. 93.112 Title One of the Rehabilitation Act of 1973. Services within the Department of Education are in compliance with this act. Sections 503 and 504 of the Rehabilitation Act of 1973 and amendments of 1974.

P.L. 93.567 Amendment to P.L. 93.112.

P.L. 94.203 Establishes the Protection and Advocacy Division.

P.L. 94.142 The Education for All Handicapped Children Act.

P.L. 95.602 Revised the Rehabilitation Act and redefines the developmentally disabled population and gives a revamped Kentucky Developmentally Disabled Planning Council strong new direction. Amends P.L. 94.103.

P.L. 98.527 The Federal Developmental Disabilities Act of 1984, it mandates the Developmental Disabilities Planning Council.

2175n

APPENDIX 9

Massachusetts Turning 22 Law Three Years Later, 1986
(Implementation Report)

APPENDIX #9

Massachusetts Turning 22 Law
Three Years Later, 1986.
(Implementation Report)

– the Turning Point

MASSACHUSETTS' TRANSITION LAW

Michael S. Dukakis, Governor
Philip W. Johnston, Secretary
Mary Ann Walsh, Director
Executive Office of Human Services

TURNING TWENTY-TWO LAW - THE TURNING POINT

Laura is a 22 year old young woman with severe cerebral palsy. For the past several years she has resided at a private rehabilitation center funded through her local school system. Financial support from the school system ended when Laura passed her twenty-second birthday. Laura needs total care; she cannot speak and has very limited mobility. As Laura approached the age of 22, there was no existing model on which to base a plan for her long term residential needs. She needed both a day program and residential care.

Through an interagency planning team consisting of Laura, Laura's mother, and local school personnel, as well as the four human service agencies with the potential to serve Laura, a plan was developed. The Massachusetts Rehabilitation Commission's Independent Living Unit took responsibility for creating a transitional living program so that Laura's unique needs could be met and her progress enhanced. Today, Laura is living in a community setting and is aiming toward independent living.

The success of Laura's situation along with hundreds of other young adults with severe disabilities has not always been so positive. Chapter 766, Massachusetts' special education law, has been providing educational programming for special needs students for over ten years. Thousands of students, regardless of their disability, have received an array of services provided by local schools. The special education entitlement program cared for all the individuals either until graduation or their twenty-second birthday, whichever came first. However, approximately 10% or 600-800 members of the special education population continue to need some form of services and support.

Although students are well served until the age of 22, there was often a break and interruption of services before individuals entered the adult service system. The function of the "Turning Twenty Two" program is to eliminate that break and to coordinate planning so that the transition to adult services is not impeded. Until Turning 22 there was no standard statewide plan to assist students whose multiple and severe needs may require programs from as many as five separate human service agencies. Today the Bureau of Transitional Planning guides and coordinates the efforts of these agencies to make the individuals' transition from special education to work with adult human services as efficient as possible.

MASSACHUSETTS' TURNING TWENTY-TWO LAW

In December, 1983, Governor Michael S. Dukakis signed the nation's first transition law. Chapter 688, known as "The Turning 22 Law," was developed by parents, advocates and

educators to provide for a two year planned transitional process for severely disabled young adults who will lose their entitlement to special education upon graduation or reaching the age of twenty-two.

This law creates a Bureau of Transitional Planning and a single point of entry into the Adult Human Services system by developing an Individual Transitional Plan (I.T.P.) which documents the adult service needs and responsible state agencies for every person who is found eligible for Chapter 688

The "Turning 22 Law" is not a continuation of Chapter 766. This law was designed for the more severely disabled person who, if provided appropriate support services, will continue to learn and develop throughout his or her life. It was not intended for the many students who have received special education services and are now able to enter competitive work situations and lead independent lives as adults.

Chapter 688 serves students with a variety of special needs. Many of these individuals may have a combination of several disabilities which can include: mental illness, head injury, autism, mental retardation, cerebral palsy, blindness, and deafness. Out of 3,000 clients currently receiving transitional planning, the BTP has approved 1,000 Individual Transitional Plans. The analysis of these plans suggests disabilities fall into three general categories: mental retardation- 74%, emotional/behavioral disturbances- 55%, and medical/physical limitations- 39%. Approximately 700 students with severe handicaps become eligible for Chapter 688 transitional planning every year.

A disabled individual may be eligible for Chapter 688 planning and service if all of the following criteria are met. He or she must be:

1. presently receiving special education services,
2. in need of continuing services after special education,
3. unable to work 20 or more hours per week in competitive employment.

Individuals who already receive Supplementary Security Income (SSI) or Disability Income (SSDI) are automatically eligible for Chapter 688 services. Individuals who are not eligible for SSI will be reviewed by the Chapter 688 Eligibility Unit at the Massachusetts Rehabilitation Commission to determine their ability to work 20 or more hours per week in competitive employment. If the client is deemed ineligible, then he or she has the right to appeal the decision.

BUREAU OF TRANSITIONAL PLANNING

In order to oversee the development of ITP's and to monitor the actual delivery of service, the Executive Office of Human Services (EOHS) opened the Bureau of Transitional Planning (BTP) on October 1, 1984. The BTP has been operational for two years, and already is transitioning over 3,000 clients. The BTP oversees and maintains centralized case tracking and ITP development, and monitors the agencies' service delivery system, program development, and Chapter 688 related budgets.

The BTP is the administrative and organizational backbone of Chapter 688's actual implementation. The Bureau assists 270 local school districts to identify disabled students for Chapter 688 transitional planning and refer them to the appropriate local state agency. Each agency, mandated to serve Chapter 688 clients, has a BTP liaison in every one of their local offices. The liaison is responsible for case work and ITP development. There are 40 Department of Mental Health offices, 40 Department of Social Services offices, 30 Massachusetts Rehabilitation Commission offices, 6 Massachusetts Commission for the Blind offices, 1 Department of Public Health office and 1 Massachusetts Commission for the Deaf and Hard of Hearing office. Altogether, a network of 118 BTP liaisons across the state facilitate the transitional process for Chapter 688 clients.

The BTP works closely with the Department of Education and local public and private schools to enhance their understanding of transitional issues and assist in the development of transition programs within the school system. The BTP also works closely with the Turning Twenty-Two Coalition, a parent and advocacy organization, and the State Legislature to promote their understanding of client service needs and program costs, with support for adequate state budget appropriations.

SCHOOL TO WORK - TRANSITION PROCESS

Agencies mandated to serve Chapter 688 clients include: The Massachusetts Commission for the Blind (MCB), the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), the Massachusetts Rehabilitation Commission (MRC), the Department of Public Health (DPH), the Department of Mental Health (DMH), and the Department of Social Services (DSS). Out of a total of 3000 referrals, 66% are referred to DMH, 26% to MRC, 2% to MCB, 2% to DSS, 1% to MCDHH, and 3% to DPH.

How The System Works

The system is Area Based and designed to allow a person to remain where his or her family lives. The process is as follows:

The local school district, through the 766 evaluation team, makes the decision that the person may need aditional services beyond graduation or turning 22. The student and/or his parents may request the referral, but it must go through the local school district.

The local school district forwards the case to the appropriate human services agency, two years prior to the termination of a student's special education. In most cases, the agency the case is forwarded to is designated as the transitional agency.

The Transitional Agency opens a client case file and assists with a referral to the Social Security Administration or the Chapter 688 Unit at the Massachusetts Rehabilitation Commission to establish eligibility.

The Transitional Agency is responsible for developing an Individual Transitional Plan. Other appropriate human service agencies, school system personnel, the family, and the person who is disabled, participate in the development of the plan.

The Plan is approved by the Executive Office of Human Services and is signed by the Secretary. The Individual Transition Plan must be completed 6 months before the person finishes his or her education.

INDIVIDUAL TRANSITION PLANS

Every Chapter 688 eligible client receives a written Individual Transition Plan (ITP) developed by a multi agency planning team. The ITP is the prototype used across Human Services Agencies to identify a clients' residential, day and support service needs. ITP's are also an important source of data on Turning 22 clients. Aggregated ITP's provide client demographics for program development, budget planning, and long term planning for this profoundly disabled population. Services to which Turning 22 clients are referred fall into three distinct categories as outlined below. Appx. 7

Day services

All clients in the Turning 22 Program (including residential clients) receive day services of some type. Figure 2 shows a breakdown of these services. Short term services (8.0%) are competitive employment placements which are time limited training or vocational school programs. Vocational training (48.0%) is long term training in either a sheltered workshop or in an integrated industry based setting like supported employment. Day activity (26.0%) and Work Activity

(18.0%) are the traditional non-employment related programs for clients assessed to be in need of more basic training such as communication and daily living skills.

The costs for day programs vary as shown in Figure 3. The costs for short term and vocational training programs which can lead to competitive employment are significantly less than the day and work activity types of programs which are highly structured environments. The cost of all day programs is substantially less than residential programs.

Residential Services

Turning 22 clients in need of residential programs are frequently the most disabled clients. Some of the clients require total care in a very structured environment. Most of these clients also attend day programs in addition to receiving intensive residential care. Figure 4 shows a breakdown of the differect types of residential services to which Turning 22 clients have been referred. Temporary residential services (3.3%) are time limited transitional residences in which a client can become independent in a short period of time. A cooperative apartment (13.3%) is a setting in which the client takes most of the responsibility for household tasks with minimum staff supervision. Community residences (26.7%) and staffed apartments (43.3%) are in greatest demand. The clients who are referred to these programs require full time staff supervision but are capable of some responsibility for household tasks. A residential facility (13,3%) is a highly structured, self contained environment where clients are closely supervised.

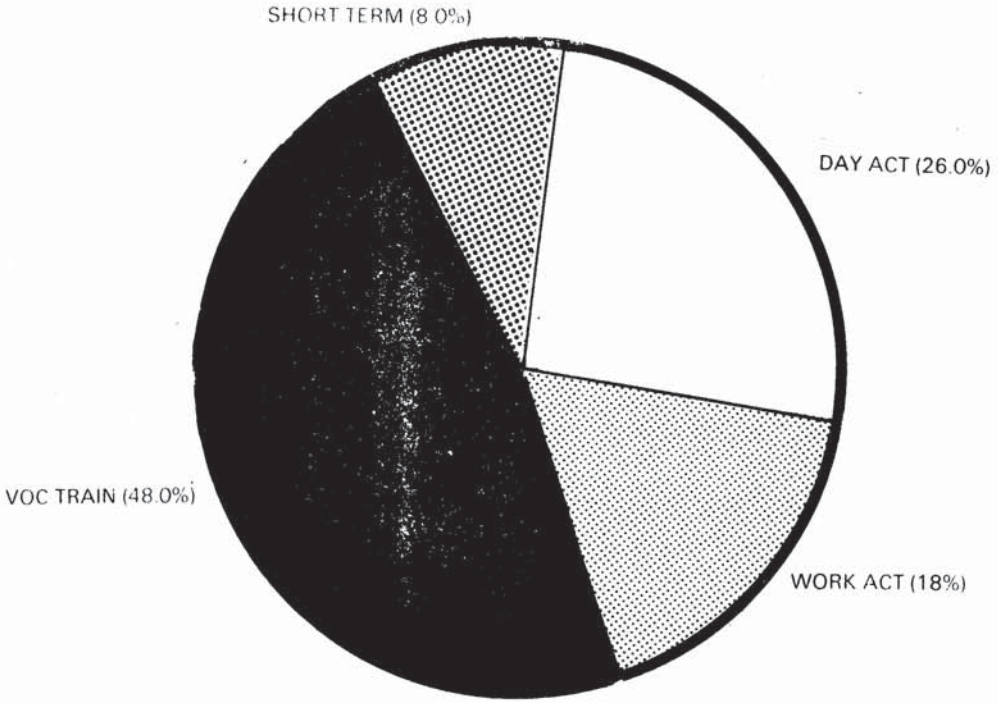
Figure 5 indicates the cost per client for residential services only. These costs are far higher than the day services.

Ancillary services

A variety of ancillary services are required by Turning 22 clients to assist them in their day and or residential programs. These services can include but are not limited to transportation, therapeutic services, medical services, interpreter services and adaptive equipment. These services have a wide range of costs but make up less than 15% of the total costs for this population.

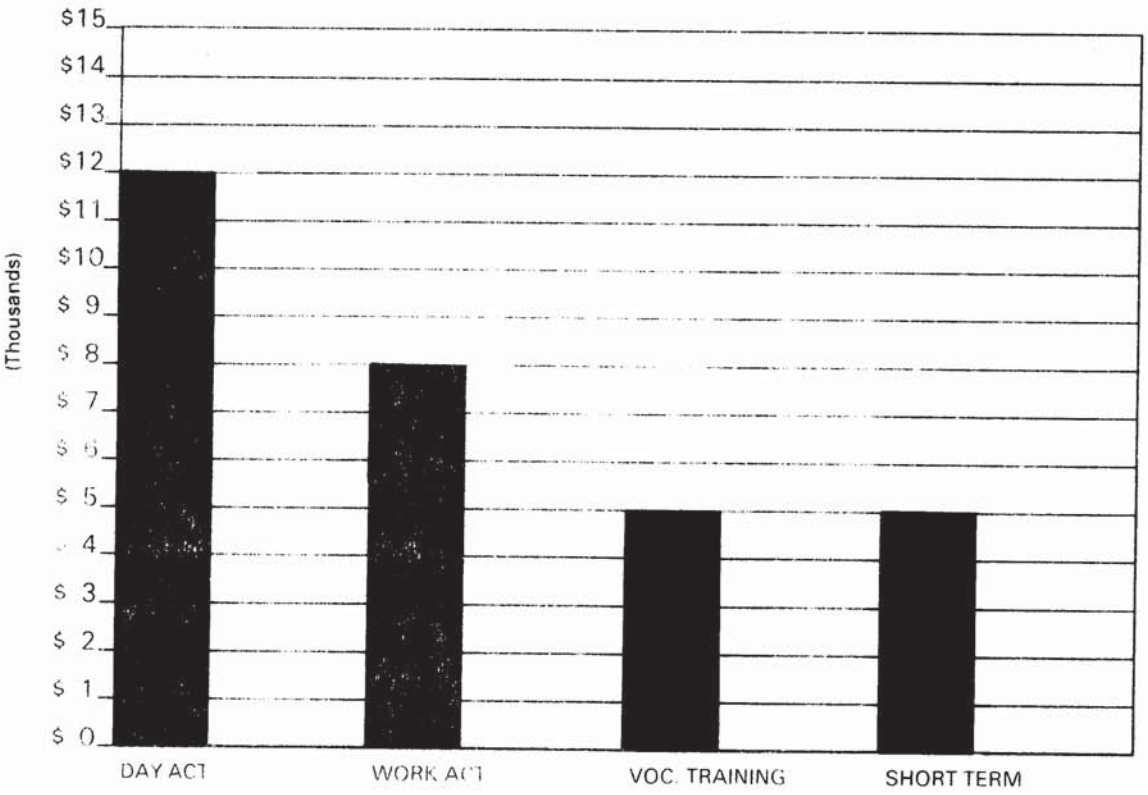
TURNING 22: TYPE OF RESIDENCE

150 TOTAL CLIENTS



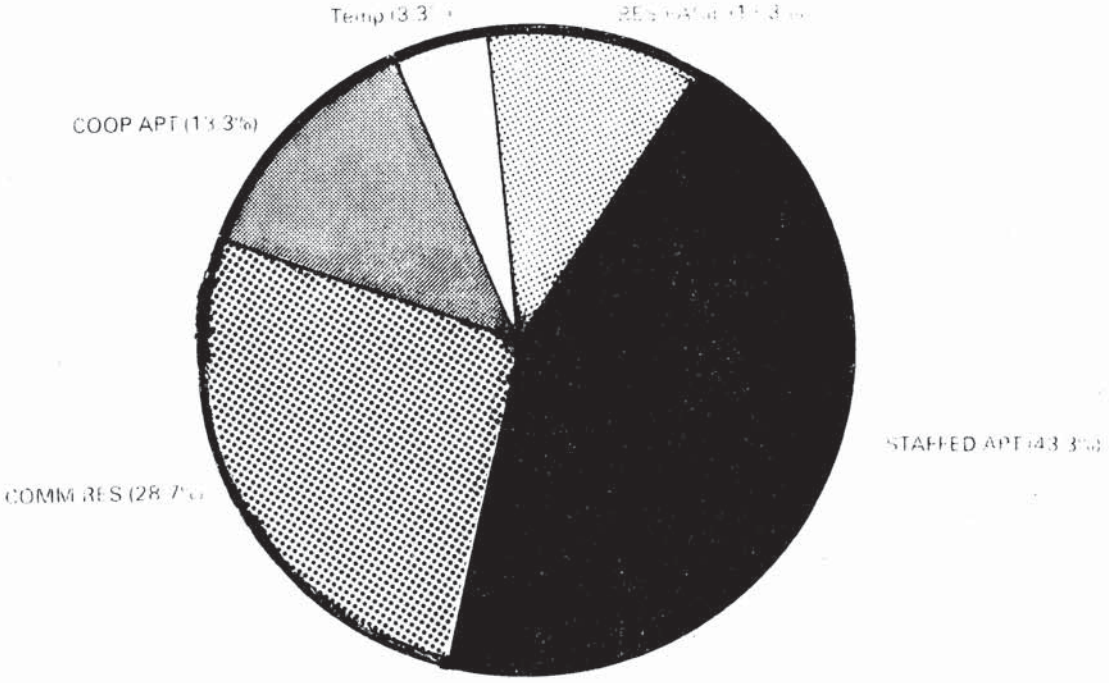
TURNING 22: ANNUAL COST PER CLIENT

DAY SERVICES ONLY



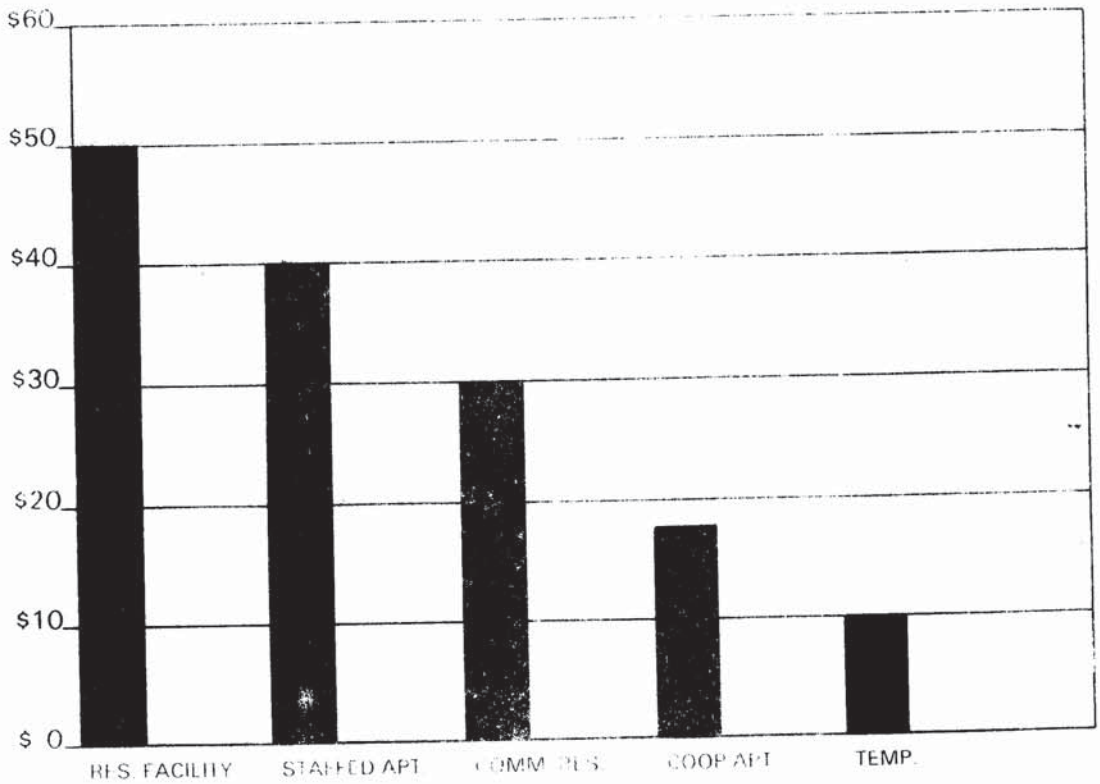
TURNING 22: TYPE OF RESIDENCE

150 TOTAL CLIENTS



TURNING 22: ANNUAL COST PER CLIENT

RESIDENTIAL SERVICES ONLY



LONG TERM PLANNING PRINCIPLES

The passage of the Turning 22 law has necessitated a closer look at agency responsibility for clients, and at the critical need for program development within the adult human services system. Beyond the need for agency assignment are the more complicated issues of how services will be designed, delivered, funded and evaluated for the hundreds of severely disabled clients entering the adult system in the years to come. The need for the development of innovative programs and new methods of delivering services to new clients is becoming increasingly critical as the multiple and long-range service needs of the Turning 22 population are identified.

Key Planning Principles

The following planning principles outline policy directions for the growth of the Turning 22 program. These principles represent a model for program development for the next five years.

- The ability of the family to care for disabled family members should be maintained and supported through program policy.

- Clients of the Turning 22 Program should have access to a continuum of care, which extends from community-based programs in clients' homes to total institutional care.

- Families should, whenever possible, contribute financially to the cost of treatment for their family member. A sliding fee or some other mechanism should be provided to ensure this is done equitably.

- Planning for residential services should occur on an interagency basis, and should maintain, as much as possible, the client's proximity to his or her home community.

- Planning for day service should be focused on the creation of a range of employment options whenever possible. The supported employment model which stress integrated work in an integrated setting should be key in long term employment planning.

- Services should be coordinated between the agencies and through the case management process to ensure that the best use of resources is achieved.

- Consistency in treatment of clients with similar needs should be a major goal of inter-agency cooperation. This goal is particularly important in case management delivery models and those which use functional assessment tools as a basis for service delivery.

CONCLUSION

Chapter 688, the Turning Twenty-Two law, has energized the disability community in Massachusetts. The entire state is observing growth of a planned approach for transitioning of students with severe disabilities from school to work with community living settings. As pioneers in the field of transition, the BTP has laid the groundwork for a successful future. Chapter 688 is not an entitlement to adult services, but client programs have been granted a solid budget for FY'87. The budget has increased 750%, from two million dollars in FY'85 to seventeen million dollars in FY'87. Over 1000 individuals will have been served by this fiscal year end, in a variety of work and residential settings.

Just 10 short years ago, Massachusetts took the lead with Chapter 766, the nation's first law to guarantee a public education to students with special needs. Together Massachusetts faces a major challenge, to make Chapter 688 the acclaimed critical success which Chapter 766 has become.

Turning Twenty-Two is the Turning Point.

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region I Subcontractor Providers for Adults:				
J.U. Kevil Memorial Foundation Center	Mayfield	Voc/Day Habilitation	45	
West Kentucky Easter Seal Center	Paducah	Voc/Day Habilitation	29	
Work Activities Training Center	Murray	Voc/Day Habilitation	29	20
Marshall County School for Exceptional Children	Benton	Voc/Day Habilitation	28	
Riverwood Group Home	Paducah/McCracken	Residential	8	
Willow Apartments	Mayfield	Residential	8	6
Region I Private Providers for Adults:				
Paducah Transit Authority	Paducah/McCracken	Transportation	4-5	
West Kentucky Diagnostic Center	Murray/Calloway	Comprehensive Diagnostic Service	100	
Murray State University Resource Library	Murray/Calloway	Lending Library		
Paducah Community Resource Lending Library	Paducah/McCracken	Lending Library		
Dixie G. Hopkins	Murray/Calloway	Speech	110	
Kelly's Psychiatric Clinic	Lone Oak/McCracken	Psychological Screening	400	
Private Residence	Fulton/Fulton	Residential	6	
Mississippi River Opportunity Council Inc.	Fulton/Fulton	Transportation (Fulton-J.U. Kevil)	6-12	
Hickman Co. School System	Clinton/Hickman	Transportation (Hickman-J.U. Kevil)	10-14	
Murray/Calloway Transit System	Murray/Calloway	Transportation (Calloway-Graves Co.)	1	
Region II Subcontractor Providers for Adults:				
Pennyroyal Industries	Princeton	Sheltered Workshop		
Opportunity Workshop	Greenville	Sheltered Workshop		
Trace Industries		Sheltered Workshop	50+	
Region II Private Providers for Adults:				
Vocational	Madisonville/Hopkins	Vocational Rehabilitation	6	
Vocational	Eddyville/Lyon	Vocational Rehabilitation	11	
Vocational	Princeton/Caldwell	Vocational Rehabilitation	6	
Vocational	Hopkinsville/Christian	Vocational Rehabilitation	7	
Vocational	Cadiz/Trigg	Vocational Rehabilitation	9	
Vocational	Greenville/Muhlenberg	Vocational Rehabilitation	13	
Transportation	Elkton/Todd	Vocational Rehabilitation	11	
Transportation	Madisonville/Hopkins	PACS	12	
	Hopkinsville/Christian	PACS	20	

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region III Subcontractor Providers for Adults:				first come first served
Hugh Standefur Training Center	Henderson	Sheltered Workshop	160	25
Opportunity Center	Owensboro	Sheltered Workshop	73	
Tamarline	Ohio County	Sheltered Workshop	24	
Pinocchios	Beaver Dam	Work (Vocation)	10	
Region III Private Providers for Adults:				
Higgins Learning Center	Morganfield/Henderson	ICFMR/DD	30 (age 19 & up)	14
Special Olympics	All Counties	Recreation		
Speech Therapy	Owensboro/Daviess	Speech Therapy		
Green River Intra-Transit Systems	All Counties	Limited Transportation to Elderly and Handicapped		
Owensboro Transit System	Owensboro/Daviess	Transportation for Elderly, Physical & Mentally Handicapped		
Wendell Foster Center	Owensboro/Daviess	ICFMR/DD (Primarily CP with some degree of retardation)	50 (age 19 & up)	10
Region IV Subcontractor Provider for Adults:				
Cave Lake Workshop	Glasgow	Sheltered Workshop	39*	
Exceptional Industries	Bowling Green	Sheltered Workshop	9	
Project Eagle	Logan/Simpson, Buller	Supported Employment		
Upjohn Home Health		Home Health and Personal Care		
Region IV Private Providers for Adults:				
Panorama	Bowling Green	ICF/MR	2 (age 19 & up)	10
Region V Subcontractor Providers for Adults:				
No affiliates.				
Region V Private Providers for Adults:				
Breckinridge County Adult Activity Center	Hardinsburg/Breckinridge	Adult Training	12	
Community Action	All Counties	Transportation	200	

*23 CC clients

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region VI Subcontractor Providers for Adults:				
Council for Retarded Citizens	Jefferson, Oldham & Bullitt Counties	Respite Care, Parent Outreach, Attendant, Personal Care, Home Health, Respite Care, Periodic Recreation, Residential	50	
Options for Individuals	Louisville	Attendant, Personal Care, Home Health, Residential, Community-based Day Services		
Shelby County Respite Program	Shelbyville	Respite		
Physical Therapy Service	Louisville	Physical Therapy		
College for Living	Louisville	Education		
Community Employment	Crestwood	Job Placement, Training, and Volunteer Placements	50	
Community Living	Louisville	Residential		
Custom Manufacturing Services	Louisville	Vocational Evaluation, Training and Volunteer Placements	200	
Highland Opportunity Workshop	Louisville	Vocational Evaluation, Work Adjustment, and In-House Sheltered Employment	50	
Louisville Diversified Services	Louisville	Sheltered Workstations, Individual Placement, Training and Non-Vocational Adult Day Services		
Southwest Center for DD	Louisville	Sheltered Employment and Adult Day Services	50	
St. Columba	Louisville		40	
Region VI Private Providers for Adults:				
Goodwill Industries of Kentucky, Inc.	Louisville/Jefferson	Vocational		
Kentuckiana Center for Education, Health, & Research, Inc.	Louisville/Jefferson	Speech and Education		
Ky. Industries for the Blind	Louisville/Jefferson	Vocational		
Bridgehaven	Louisville/Jefferson	Vocational		
Jewish Vocational Services	Louisville/Jefferson	Vocational		
Dorman Vocational Training Center	Shelbyville/Shelby	Vocational		
Ky. Easter Seal Society	Louisville/Jefferson	Speech Therapy & Physical Therapy		
Cedar Lake Lodge	LaGrange/Oldham	ICFMR/DD	66 (age 19 & up)	102

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region VI Private Providers Continued:				
Caretenders, Inc.	Louisville	Attendant, Personal Care, Home Health		
Community Health Services	Louisville	Attendant, Personal Care, Home Health		
Quality Care Home Care Service	Louisville	Attendant, Personal Care, Home Health		
Spaid Private Duty Nursing	Louisville	Attendant, Personal Care, Home Health		
Upjohn Health Care Services	Louisville	Attendant, Personal Care, Home Health		
Visiting Nurse Association of Louisville, Inc.	Louisville	Attendant, Personal Car, Home Health		
We Sit Better, Inc. of Louisville	Louisville	Attendant, Personal Care, Home Health		
Home and Health Care Services	Louisville	Attendant, Personal Care, Home Health		
Home Care Partners	Louisville	Attendant, Personal Care, Home Health		
Metro Parks and Recreation	Louisville	Rec, Leisure		
Family Care	Louisville	Residential		
Residential Care Services	Louisville	Residential		
Region VII Subcontractor Providers for Adults:				
United Home Care		In-Home Support, Developmental	7*	
Easter Seal		Developmental	15*	
BAWAC	Florence	Voc./Day Habilitation	23*	
Short/Long-Term	Newport	Residential and In-Home Support	36*	
Redwood	Ft. Mitchell	Vocational/Day Habilitation	26*	
New Perceptions	Newport	Vocational/Day Habilitation	64*	
The Point	Covington	Work/Vacation		

*These figures are only the clients comp care contracts to have served by the affiliates.

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region VII Private Providers for Adults:				
Citizens Advocacy of Northern Kentucky	Covington	Advocacy		
Northern Kentucky Easter Seal Center	Covington	Speech Therapy	750	
Northern Kentucky Transit	Florence	Transportation		
Region VIII Subcontractor Providers for Adults:				
Community Training Homes		Residential		
Region X Subcontractor Providers for Adults:				
No affiliate providers for adults				
Region X Private Providers for Adults:				
Geiger Easter Seal Speech & Hearing Center	Ashland/Boyd	Evaluation for all Communication Disorders		
King's Daughter's Hospital	Ashland/Boyd	Physical Therapy		
Louisa Community Hospital	Louisa/Lawrence	Physical Therapy		
Stark Community Center	Olive Hill/Elliott	Adult Activity		
Region XI Subcontractor Providers for Adults:				
No Subcontractors				
Region XI Private Providers for Adults:				
Highlands Regional Hospital	Prestonsburg/Floyd	Physical Therapy		
Pikeville Methodist Hospital	Pikeville/Pike	Physical Therapy		
Our Lady of the Way	Martin/Floyd	Physical Therapy		
McDowell ARH	McDowell/Floyd	Physical Therapy		
Magoffin County Mini-Homes 2	Salyersville/Magoffin	Residential		
Floyd County Mini-Home	Prestonsburg/Floyd	Residential		
K. Krigger	Prestonsburg/Floyd	Speech Therapy		
Eastern Ky. Voc. Rehab.	Thelma/Johnson	Psychological Screening		
Paintsville Hospital	Paintsville/Johnson	Physical Therapy		
Voc. Rehab. Center	Thelma/Johnson	Vocational		

APPENDIX 10

Regional Service Agencies Which Serve Various Client Groups (including MR)

Name	City/County	Type	Total Served	Total Unserved
Region XII Subcontractor Providers for Adults:				
No Subcontractors				
Region XII Private Providers for Adults:				
No Private Providers according to information provided				
Region XIII Subcontractor Providers for Adults:				
No Subcontractors				
Region XIII Private Providers for Adults:				
Corbin Sheltered Workshop	Corbin/Whitley	Sheltered Workshop		
Harlan Sheltered Workshop	Harlan/Harlan	Sheltered Workshop		
Middlesboro Sheltered Workshop	Middlesboro/Bell	Sheltered Workshop		
Region XIV Subcontractor Providers for Adults:				
No names provided				
Region XIV Private Providers for Adults:				
Caprice Industries	Somerset/Pulaski	Work Activity	25	
Lake Cumberland Home Health	Somerset/Pulaski	Early Intervention, In-Home Support, and Speech Therapy	20	
Lake Cumberland Home Health	All Counties	Physical Therapy		
Cumberland Area Transit System	Russell Springs/Russell	Transportation	40	
Region XV Subcontractor Providers for Adults:				
No names provided				
Region XV Private Providers for Adults:				
Opportunity Workshop of Lexington	Lexington/Fayette	Sheltered Workshop	130	
Exception-Lexington Campus	Lexington/Fayette	ICFMR/DD	179 (age 19 & up)	7
Quest Farm	Georgetown	Farming Residence	11	20