MAINE STATE LEGISLATURE

The following document is provided by the

LAW AND LEGISLATIVE DIGITAL LIBRARY

at the Maine State Law and Legislative Reference Library

http://legislature.maine.gov/lawlib

Reproduced from scanned originals with text recognition applied

(searchable text may contain some errors and/or omissions)

NEEDS OF MIDDLE AGE AND AGING INDIVIDUALS WITH MENTAL RETARDATION OR AUTISM

DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE SERVICES

A REPORT

JANUARY 1, 2000

SUBMITTED TO:

JOINT STANDING COMMITTEE ON HEALTH & HUMAN SERVICES

IN ACCORDANCE WITH
H.P. 82 - L.D. 95
"RESOLVE, DIRECTING A STUDY OF THE NEEDS OF THE ELDERLY POPULATION WITH MENTAL RETARDATION"

HV
3009.5
.A35
N44
2000

LYNN F. DUBY, COMMISSIONER

SUBMITTED BY:

DONALD G. TRITES, PH.D.
CLINICAL DIRECTOR
MENTAL RETARDATION SERVICES

LAW & LEGISLATIVE
REFERENCE LIBRARY
43 STATE HOUSE STATION
AUGUSTA, ME 04333

Index

JUL 17 2000

Executive Summary

H.P. 82 - L.D. 95, Resolve, Directing a Study of the Needs of the Elderly Population with Mental Retardation, required the Department of Mental Health, Mental Retardation and Substance Abuse Services to conduct a study of the needs of middle aged and elderly Mainers with mental retardation. In order to accomplish these tasks, DMHMRSAS appointed a task force that met some nine times to discuss the process of the study and the nature of the report.

Based on the data secured from the Mental Retardation Management Information System, a Case Management survey and selected national information, the task force made the following recommendations:

IV. Recommendations

1. DMHMRSAS and DHS must continue to work together to coordinate the services between the two Departments.

2. The emerging data system in DMHMRSAS that relies on the Medicaid Claims Data from DHS must be improved so that the individuals with mental retardation or autism can be identified through the claims system.

3. The Joint Advisory Committee on Select Services for Older Persons and the Maine Aging Collaborative must have membership from DMHMRSAS that includes staff from the mental retardation section who are in policy making positions.

4. A formal study of the ways in which aging individuals can be cared for in keeping with the value of aging in place needs to be under taken.

5. A format to present waiting list information, including whether an individual has no service or seeks an improved service, the funding implications, and how long individuals have been awaiting services must be developed and data presented to the governor and legislature for use in the development of each biennial budget. This activity must be coordinated with all DMHMRSAS waiting list information.

6. Quality assurance mechanisms and quality improvement mechanisms must be implemented to examine questions of what outcomes have been achieved, what age specific outcomes have been achieved and what level of consumer satisfaction in the aging population has been achieved.

7. Training mechanisms must be established to assist providers to train staff to meet some of the more complex health issues faced by aging individuals.

8. Coordination across all governmental and private agencies that serve aging adults would be furthered by a structure similar to the state level and local level Children's Cabinets.

9. Concerns expressed by case workers about the quality of health care, including issues of dental care, eye care and hearing, and the quality of mental health care as individuals age need to be studied in more detail and plans developed to work with health care professionals and mental health professionals to address the problems identified.

10. Consistent practices across all DMHMRSAS Regions need to be implemented to ensure that appropriate health care directives are in place and whenever appropriate to establish funeral/mortuary trust plans.

11. Employment of individuals over the age of 45 must be a Departmental priority in keeping with the findings of the Maine Medical Center Division of Vocational Services Vocational Audit.

I. Background

H.P. 82 - L.D. 95, Resolve, Directing a Study of the Needs of the Elderly Population with Mental Retardation, required the Department of Mental Health, Mental Retardation and Substance Abuse Services to conduct a study of the needs of middle aged and elderly Mainers with mental retardation. Specifically, the Resolve required the Department to study the following topics:

- The demographic characteristics of the elderly and middle aged population.
- The residential patterns serving this population.
- The services presently provided, those services presently needed and those services reasonably anticipated..
- The number of middle aged and elderly individuals on waiting lists
- The number of middle aged and elderly individuals receiving services in nonresidential community settings.
- The number of middle aged and elderly individuals living in nursing facilities and residential care facilities.
- The number of middle aged and elderly individuals on waiting lists for nursing facilities and residential care facilities.

The Resolve further required that the Department report to the Joint Standing Committee on Health and Human Services on the following:

- The findings of the items above.
- A calculation of how to meet the unmet needs and the anticipated costs.
- Any legislative recommendations
- A plan for coordinated planning between DMHMRSAS and DHS.

In order to accomplish these tasks, DMHMRSAS appointed a task force consisting of the following individuals:

- Donald G. Trites, Ph.D., Clinical Director, Mental Retardation Services, DMHMRSAS
- Jane Gallivan, Program Team Manager, Mental Retardation Services, DMHMRSAS
- Paul Tabor, Training Coordinator, Mental Retardation Services, DMHMRSAS, a member of the Maine Aging Collaborative and a member of the Joint Advisory Committee on Select Services for Older Persons
- Theresa Turgeon, Office of Geriatrics, Mental Retardation Services, DMHMRSAS and a member of the Joint Advisory Committee on Select Services for Older Persons and the Maine Aging Collaborative
- John Baillargeon, Bureau of Elder and Adult Services, DHS and a member of the Joint Advisory Committee on Select Services for Older Persons and the Maine Aging Collaborative

- Cary Kelly, Sebastacook Farms, a member of the Maine Aging Collaborative and a member of the Joint Advisory Committee on Select Services for Older Persons
- Bonnie Jean Brooks, Executive Director OHI, Chair of the Northern QIC and a member of the Maine Aging Collaborative
- Bernadette Albert, ISC Region 1, Mental Retardation Services, DMHMRSAS
- Betsy Kopyc, ISC Region 2, Mental Retardation Services, DMHMRSAS
- Shay Ostrow, ISC Region 3, Mental Retardation Services, DMHMRSAS

This Task Force met nine times to discuss the process of the study and the nature of the report. It was agreed that the basic data for the study was available through the Management Information System maintained by Mental Retardation Services, DMHMRSAS. In addition, Task Force members met with each QIC in the state to advise them of the study and to request their assistance with information gathering. The Task Force also met with members of the Joint Advisory Committee on Aging and the Maine Aging Collaborative to discuss needed services and improved coordination between DMHMRSAS and DHS. In January a Commissioners' Round Table will be held to further the discussion of coordination between the two departments. In order to gather data on the issue of aging care givers, a survey was conducted of all MR case workers. Finally, the DMHMRSAS Office of Geriatrics coordinated the distribution of materials requesting citizen input via a month long toll free call-in process.

II. Values Position

The Task Force believed that it was important to state clearly the values it believes should guide the development of services for middle aged and elderly individuals with mental retardation served by DMHMRSAS. These values are presented below:

- ☑ All services should be guided by the Principle of Normalization
- ☑ Individuals should be assisted to age in place and whenever possible avoid placement in nursing homes or other institutional structures
- ☑ Supports should be focused on the specific needs and desires of each person
- ☑ Individuals should be assisted to maintain a good standard of holistic health
- ☑ Services should be coordinated between all service providing agencies and departments
- ☑ Individuals should be supported to maintain ties to family and friends
- ☑ Individuals should be respected and provide services in a way that preserves dignity

III. Findings

The findings of the Task Force are presented under the specific topics requested in the Resolve.

A. The demographic characteristics of the elderly and middle aged population.

The Management Information System (MR MIS) maintained by the DMHMRSAS for individuals with mental retardation or autism indicates that there are 4,407 individuals who are

either receiving services, awaiting services or are being assessed for eligibility. Of these, there are some 1,669 individuals at or over the age of 45. All data used in this study are current through November 1, 1999.

Figure 1 below presents the age distribution of the entire 4,407 population. Note that the MR MIS generally maintains information on adults above age 20.

Number of Individuals in other than Closed status by age

Under 20	277
20-24	565
25-29	453
30-34	485
35-39	496
40-44	501
45-49	351
50-54	365
55-59	265
50-64	210
65-69	160
70-74	122
75-79	79
80-84	42
85-89	20
90-94	13
95+	3
Total	4407

Figure 1

Figure 2 below presents the Regional distribution of the population over age 45

Age and Region of all Consumers age 45 and over

	Reg 1	Reg 2	Reg 3	Total
45-49	92	157	117	366
50-54	79	163	129	371
55-59	54	135	80	269
60-64	47	100	64	211
65-69	33	81	48	162
70-74	25	72	26	123
75+	29	91	39	159
Totals	359	799	503	1661

Figure 2

Note: Due to minor data entry omissions the number of individuals reported on varies slightly.

Figure 3 below presents the degree of retardation for the set of 1,669 individuals.

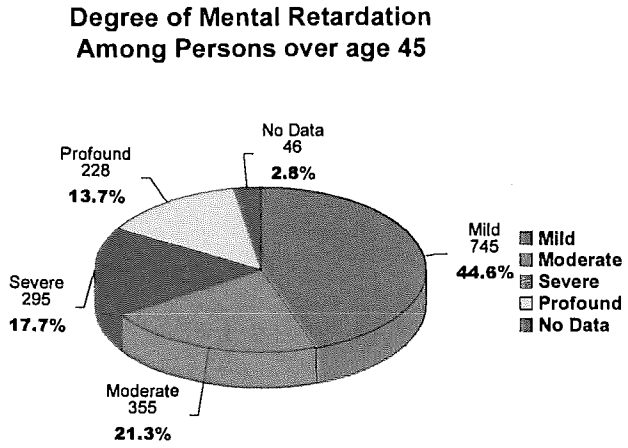

Figure 3

Note: Mild Mental Retardation refers to an IQ between 55-70; Moderate between 40-55; Severe between 25-40 and Profound below 25. These categories were used in the American Association of Mental Retardation definition of mental retardation prior to the definition proposed in the 1992 revision.

Figure 4 below presents the levels of retardation by regional offices.

Levels of Retardation By Sex and Region of Individuals 45 and Over

	No Label	Mild	Moderate	Severe	Profound	Totals
R 1Female	6	79	42	28	15	170
Male	3	78	37	43	23	184
R 2A Female	0	78	28	27	26	159
Male	0	75	32	28	17	152
R 2L Female	8	56	31	24	15	134
Male	19	44	33	22	27	145
R 2T Female	0	43	18	14	6	81
Male	1	38	38	27	7	111
R 3B Female	4	83	35	24	29	175
Male	0	54	42	20	17	133
R 3P Female	1	41	11	13	33	99
Male	0	35	12	17	25	89
Totals	42	704	359	287	240	1632

Figure 4

People with Health Care Directives

	Age 45-59	Age 60+	Totals
Reg 1	48	19	67
Reg 2A	7	17	24
Reg 2L	20	9	29
Reg 2T	2	13	15
Reg 3B	30	7	37
Reg 3P	12	5	17
Totals	119	70	189

Figure 5

People with Mental Health Directives

	Age 45-59	Age 60+	Totals
Reg 1	3	0	3
Reg 2A	0	11	11
Reg 2L	0	0	0
Reg 2T	0	0	0
Reg 3B	5	0	5
Reg 3P	0	2	2
Totals	8	13	21

Figure 6

People with a Will

	Age 45-59	Age 60+	Total
Reg	0	0	0
Reg 2A	2	6	8
Reg 2L	3	4	7
Reg 2T	0	0	0
Reg 3B	0	0	0
Reg 3P	0	3	3
Reg 3P	5	13	18
Total	10	26	36

Figure 7

People with a Mortuary Trust

	Age 45-59	Age 60+	Totals
Reg 1	75	32	107
Reg 2A	57	57	114
Reg 2L	41	32	73
Reg 2T	16	31	47
Reg 3B	42	27	69
Reg 3P	58	54	112
Totals	289	233	522

Figure 8

People with a Funeral Plan

	Age 45-59	Age 60+	Totals
Reg 1	23	15	38
Reg 2A	54	53	107
Reg 2L	31	25	56
Reg 2T	21	19	40
Reg 3B	30	22	52
Reg 3P	32	37	69
Totals	191	171	362

Figure 9

Note: Data for Figures 5-9 are from 88 of 103 case management surveys completed for this study.

B. A presentation of the residential patterns serving this population

Individuals with mental retardation or autism who are 45 or over and who need residential supports are served in a variety of service designs. The variety of designs and the pattern of individuals receiving specific service types can be seen in Appendix A.

Housing

	Receives	Needs	Total
45-49	290	40	330
50-54	307	34	341
55-59	231	19	250
60-64	185	11	196
65-69	142	10	152
70-74	108	12	120
75+	143	6	149
Total all age	1406	132	1538

Figure 10

Percentage Receiving Housing by Age Group			
	Receives	#in Cohort	%Receiving
45-49	290	336	86.31%
50-54	307	371	82.75%
55-59	231	269	85.87%
60-64	185	211	87.68%
65-69	142	162	87.65%
70-74	108	123	87.80%
75+	143	159	89.94%
Percentage Needing Housing by Age Group			
45-49	40	336	11.90%
50-54	34	371	9.16%
55-59	19	269	7.06%
60-64	11	211	5.21%
65-69	10	162	6.17%
70-74	12	123	9.76%
75+	6	159	3.77%

Figure 11

From the above charts it can be seen that 1406 individuals age 45 or older are receiving housing supports (approximately 85%). In additions 132 or 8% need housing supports. The cost to meet that need is estimated at $2,904,000 in seed dollars.

The information below presents the Regional data on those receiving or needing housing supports.

Figure 12

Figure 13

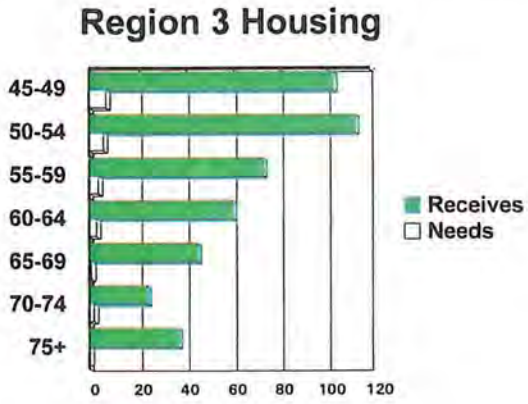

Figure 14

C. A Presentation of the Day and Employment Patterns for this Population

Day Program

	Receives	Needs	Total
45-49	224	25	249
50-54	138	20	158
55-59	89	13	102
60-64	68	10	78
65-69	43	7	50
70-74	21	1	22
75+	48	6	54
Total all ag	631	82	713

Figure 15

People Receiving Employment or Education by age

	Employment	Education
45-49	58	16
50-54	63	18
55-59	34	8
60-64	17	5
65-69	11	1
70-74	4	0
75+	4	2

Figure 16

People Needing Employment or Education by Age

	Employment	Education
45-49	29	6
50-54	19	5
55-59	11	3
60-64	9	3
65-69	4	2
70-74	1	0
75+	1	1

Figure 17

The data above indicates that 82 individuals need a day program and an additional 74 need employment services. An estimate of the cost to provide those services would be $1,060,800 in seed cost.

The data on employment, however, seems suspect. Figures 18 and 19 below present another way of interpreting the employment data.

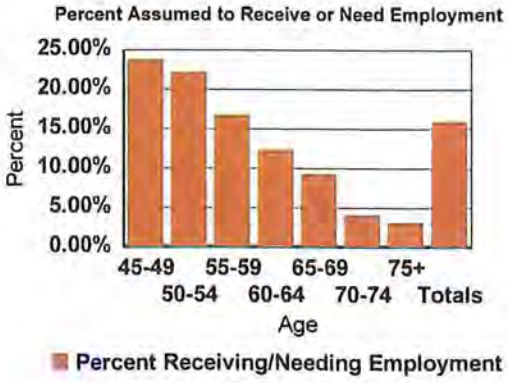

Figure 18

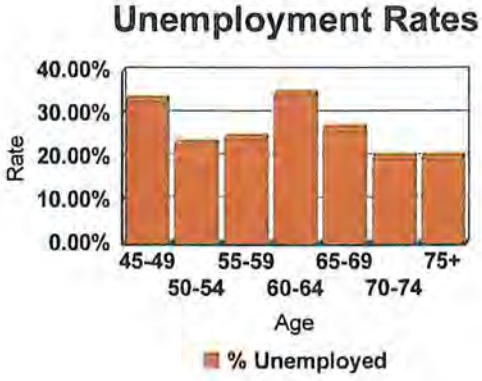

Figure 19

The assumption that only 16% of individuals above the age of 45 "need" any employment service seems significantly out of line with assumptions made at the national level. In addition, unemployment rates, as displayed in Figure 19, seem unacceptably high. These data may reflect the assumptions held by some case workers or service providers about who is capable of being employed and should be closely examined in keeping with the audit of vocational services completed by the Maine medical Center's Division of Vocational Services.

D. The number of middle aged and elderly individuals living in nursing facilities and residential care facilities and the number of middle aged and elderly individuals on waiting lists for nursing facilities and residential care facilities.

Nursing Facilities

	Receives	Needs	Total
45-49	16	3	19
50-54	24	0	24
55-59	22	1	23
60-64	29	1	30
65-69	19	1	20
70-74	27	0	27
75+	49	0	49
Total	186	6	192

Figure 20

Figure 20 indicates that few individuals need nursing level of care who are not already receiving those services. It should also be noted that long term care can be and is being provided to this population without extensive use of nursing facilities. Of the 186 individuals who receive nursing home care, 122 or 66% live in a general nursing home, while 64 or 34% live in an ICF/MR nursing facility. Policy makers in the long term care field should note that tying dollars and staff to these facilities will make the continued use of other options of care more difficult.

E. Projected Costs of Meeting Existing Day and Residential Needs

As noted above the cost of meeting Day Program needs, including employment services, for individuals over age 45 is estimated at $1,060,800 in seed cost. The cost of meeting existing residential need is estimated at $2,904,000 in seed cost.

If reasonable steps are not taken to meet those existing needs, both the need for residential and day supports will continue to grow as projected in Figures 21 and 22 blow.

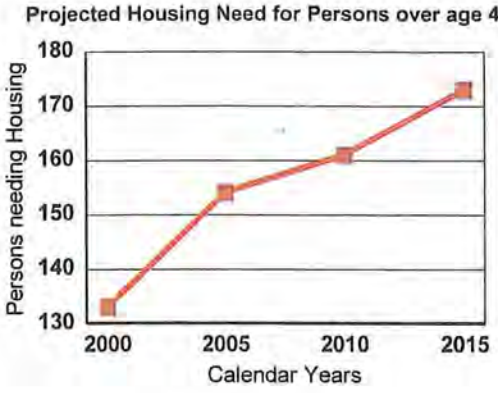

Figure 21

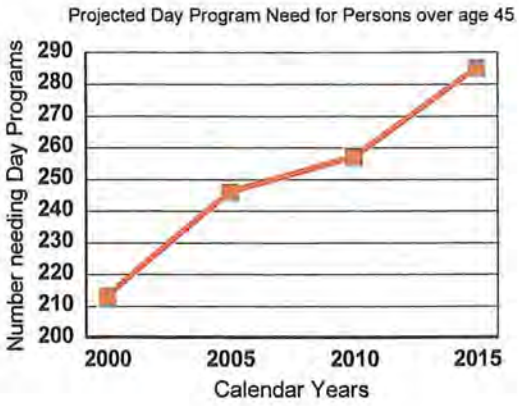

Figure 22

F. Present and Future Problems with Aging Care Givers and Staff Availability

Estimates of the size of the American population over the age of 65 indicate that over the next 30 years the number of individuals over that age will increase substantially. Figure 23 presents one such estimate:

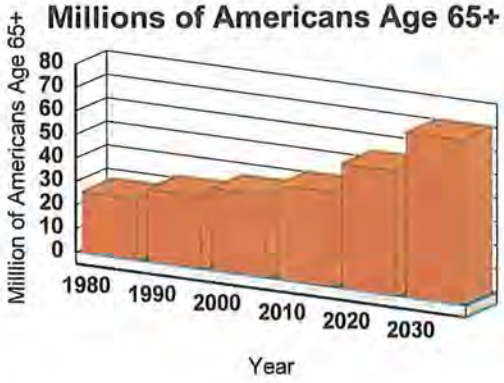

Figure 23

Given that increase in population, the pressure on all services for older individuals will also increase substantially. That increase will exacerbate the shortage of staff for all programs and will create a severe problem in all human service programs.

In addition, within Maine, the number of individuals presently served by aging care givers is already a significant issue. Estimates of the scope of that problems taken from the case management surveys (88 of 103 reporting) are as follows:

How many people on your case load are currently living with or dependent on a care giver who is age 50-60?	
Reg 1	46
Reg 2A	109
Reg 2L	45
Reg 2T	72
Reg 3B	52
Reg 3P	39
Total	363

Figure 24

How many people on you case load are currently living with or dependent on a care giver who is age 60+?	
Reg 1	59
Reg 2A	78
Reg 2L	32
Reg 2T	83
Reg 3B	55
Reg 3P	30
Total	337

Figure 25

The present problems in locating staff for new or existing services already present in some sections of the state, together with the growth in the general aging population and the number of aging care givers who will have to be replaced soon presents a picture of potential crisis within the service system. These issues will require significant attention and soon.

IV. Recommendations

1. DMHMRSAS and DHS must continue to work together to coordinate the services between the two Departments.

During the course of this study an example of the lack of coordination between DHS funding of Home Health Services under Medicare and Medicaid and DMHMRSAS funding under the Home and Community Based Waiver (HCBW). A father who had been caring for his son with mental retardation had declined significantly in his physical health due to diabetes. Despite receiving the maximum number of hours of home health services an despite the involvement of his daughters in providing 24 hours of support and despite the placement of the son in a day program in a local nursing home, the supports eventually collapsed. The result was a family situation in collapse and a father and son separated and placed in two different locations. The inability to identify this situation early on and the inability for representatives from the two department to find a coordinated strategy resulted in a high cost solution that was not truly satisfactory to anyone.

Coordination of services will require significantly greater contact between the two departments at the policy and operations levels. In addition, service providers will need to be brought together so that needs can be dealt with in a way that is satisfactory to the individuals involved and cost effective.

Action Steps

1A. A Commissioners' Forum on the topic of Aging is scheduled for January 5, 2000 to answer questions and begin the process of greater coordination.

1B. A meeting between the Mental Retardation Staff of DMHMRSAS and the staff of the Bureau of Elder and Adult Services of DHS has been set for January 20, 2000 to identify areas of mutual concern and establish an agenda for future collaboration.

1C. Ongoing meeting between the two departments continue on the subject of the Home and Community Based Waiver, the primary funding vehicle for MR services. Maine's Waiver expires in 2000 and these meetings will establish the new waiver format.

1D. Meeting are now being established for further coordination of data systems between DMHMRSAS' SIDI Project and the Medicaid Data System utilized by DHS. The focus of these new meetings will be the further development of the Mental Retardation Management Information System. This will be supported by major Federal funding.

1E. Continued meeting between DMHMRSAS and the Maine Aging Collaborative and the Joint Advisory Committee on Select Services for Older Persons are scheduled. Policy level representatives to these two gropes will be appointed in keeping with recommendation 3 below.

1F. Through the efforts of DHS, a DMHMRSAS representative was invited to present to the Joint Standing Committee on Health and Human Services as the Committee considered questions of long term care. The meeting scheduled on January 20 should establish a format for his continued involvement between DHS and DMHMRSAS on the topic of long term care. DMHMRSAS will appoint a representative with experience in services to individuals with mental retardation to participate with others in state government in the planning of long term care.

2. The emerging data system in DMHMRSAS that relies on the Medicaid Claims Data from DHS must be improved so that the individuals with mental retardation or autism can be identified through the claims system.

There has been great progress in the past two years in coordinating data systems between the two departments. Additionally, the most recent meeting with Federal officials show great promise for significant financial support for improving the data systems available in the mental retardation/autism field. However, at the present moment, there is not an ability to limit the data searches and assessments to just those individuals who have mental retardation or autism. As a result, it is not possible at the present time to identify those individuals with mental retardation or autism who are Medicaid eligible and who are not part of the DMHMRSAS MIS system. Because of that, projections of future need do not include some number of individuals who are at present unknown to DMHMRSAS.

Action Steps

As noted under recommendation 1, mental retardation data systems development has been identified as the next step in the Federally funded activity between the two departments. There is little doubt the recommendation 2 will be one of the top priorities. A meeting to begin this work was held on December 21, 1999.

3. The Joint Advisory Committee on Select Services for Older Persons and the Maine Aging Collaborative must have membership from DMHMRSAS that includes staff from the mental retardation section who are in policy making positions.

Membership on the two Committees has included active participation from DMHMRSAS. However, there has not been a direct connection between either of these two Committees and the Policy Council of DMHMRSAS.

Action Steps

A representative from the DMHMRSAS Policy Council to these two groups has been appointed. This will help to establish within the department the topics of aging and mental retardation as significant policy issues.

4. A formal study of the ways in which aging individuals can be cared for in keeping with the value of aging in place needs to be under taken.

The projections of continuing and future staffing problems, the fiscal impact of property held by providers should some facilities become financially difficult or impossible to maintain, the need to explore other staffing models as partial solutions to the present and future staffing crisis all need careful study. DMHMRSAS is in the process of developing plans for a research and evaluation capacity that should be used in conjunction with DHS and university centers to study these issues now. To delay such studies will simply guarantee that future crisis will occur and be difficult to address. In order to avoid pending crisis situations there needs to be immediate planning around those situations involving aging care givers. In addition, the issue of aging care givers must be routinely examined.

Action Steps

4A. The Mental Retardation Team of DMHMRSAS will be asked to begin work now with private service providers to explore present and future options.

4B. The Research and Evaluation Team will be apprised of this important need and a study designed as soon as possible. This should include a review of any relevant literature in the field.

5. A format to present waiting list information, including whether an individual has no service or seeks an improved service, the funding implications, and how long individuals have been awaiting services must be developed and data presented to the governor and legislature for use in the development of each biennial budget. This activity must be coordinated with all DMHMRSAS waiting list information.

As the waiting list needs for services at all age levels have become an obvious biennial issue, DMHMRSAS has presented information on the size of the need and the cost to meet that need. The format for the presentation of that information, however, should be standardized and coordinated with other Departmental waiting list presentations so that accurate comparisons to the past and accurate projections into the future can be made. Once this is done, the housing needs of middle age and elderly individuals must be addressed.

Action Steps

Commissioner Duby has coordinated the development of coordinated waiting list presentation, including funding projections. This work will be continued and further developed for presentation of the 2001-2002 biennial budget.

6. Quality assurance mechanisms and quality improvement mechanisms must be implemented to examine questions of what outcomes have been achieved, what age specific outcomes have been achieved and what level of consumer satisfaction in the aging population has been achieved.

Quality Improvement and Quality Assurance mechanisms for the Department have been designed over the past two years. These have included careful development of outcome measures and tools that has involved Departmental staff, families and consumers and providers of services. Implementation of the designs has begun and will become a standard part of the examination of the success areas of weakness of the systems of care. Consumer satisfaction surveys are now being used in the MR system at the time of personal planning and in conjunction with contract renewals.

Action Steps

The Quality Improvement data dealing with older adults will be examined for specific actions needed to be taken to improve the quality of services to older adults.

7. Training mechanisms must be established to assist providers to train staff to meet some of the more complex health issues faced by aging individuals.

As some individuals already being served in private agencies have aged the complexity of some health conditions has required the knowledge of more sophisticated medical interventions, such as tube feeding, ostomy care and even more careful health or medical monitoring. This has required private providers to secure additional training for their staff and at times has required the hiring of staff with specific medical training or experience.

Action Steps

7A. DMHMRSAS should survey the provider community to establish base line information on what types of services are presently being offered, how training was secured and what assistance would prove helpful in these situations.

7B. Based upon these data, DMHMRSAS should establish a task force to develop and implement any needed training protocols or policies.

7C. The Committee responsible for this report should continue and make this its initial focus.

8. Coordination across all governmental and private agencies that serve aging adults would be furthered by a structure similar to the state level and local level Children's Cabinets.

Because there are both State level policy issues and very practical local issues, action is needed at both levels to coordinate services more effectively. The models established at the State and local levels by the Children's Cabinet should be followed to focus work on adults, especially adults who are aging.

Action Steps

The Committee has written to Commissioners Duby and Concannon requesting their support for such an adult level "cabinet."

9. Concerns expressed by case workers about the quality of health care, including issues of dental care, eye care and hearing, and the quality of mental health care as individuals age need to be studied in more detail and plans developed to work with health care professionals and mental health professionals to address the problems identified.

In the survey completed by the DMHMRSAS Case Workers a number of concerns about health and mental health care were expressed. These included concerns that some individuals who were aging were not receiving attentive care from professionals, that stigma about aging was being added to stigma about mental retardation and resulting in less than adequate care and that particular needs of older individuals were not being thought about for those with mental retardation.

Action Steps

9A. The Committee should follow up with case workers on these issues and develop an a specific plan to address these issues.

9B. Work being done by the ad hoc group to develop a more focused effort on mental health issues of individuals with mental retardation will also focus on this issue.
9C. Work needs to be done with mental health professionals to encourage more active participation with individuals who have mental retardation or autism.

10. Consistent practices across all DMHMRSAS Regions need to be implemented to ensure that appropriate health care directives are in place and whenever appropriate to establish funeral/mortuary trust plans.

Examination of the MIS data suggests that there is some inconsistency about these issues across regions.

Action Steps

Contact with the newly formed mental retardation team will be made and a specific request that they examine this issue for an appropriate response.

11. Employment of individuals over the age of 45 must be a Departmental priority in keeping with the findings of the Maine Medical Center Division of Vocational Services Vocational Audit.

The data for the MR MIS on employment is quite disappointing. As noted above almost 78% of those over age 45 are apparently being judged as not being able to benefit from employment. Of those judged to be employable, an unemployment rate in excess of 25% is reported. The Maine Medical Center Audit of the Department has suggested a major refocusing of efforts in this area. This is important for all those who are middle age and older, as well as for those who are younger.

Action Steps

11A. Information on this issue has already been given to DMHMRSAS staff who are actively involved in focusing Departmental actions and policies on employment.

11B. Meetings between DMHMRSAS and Vocational Rehabilitation continue and must also address the implications of these data.

11C. The Maine Advisory Committee on Mental Retardation has received two presentations on employment from Maine Medical Center and will be meeting with Department officials on January 3, 2000 to discuss these issues further.

11D. The Committee that prepared this report should continue to monitor work in this area.

12. Educational opportunities and meaningful retirement options must be created for those individuals who desire them.

The information, though fragmentary, on the MR MIS suggests that educational opportunities are not being seen as a major priority for older individuals with mental retardation. At the present time there is no clear information available on retirement options for aging individuals with mental retardation. In addition, given the lack of life experiences that many individuals with mental retardation have had, it is difficult for them to select from options that they may know little about.

Action Steps

Case workers and providers should be surveyed about these issues by the Committee and appropriate follow-up actions taken.

Appendix A

The following figures present the detail of the present pattern of residential support received and needed in each of the 3 Regions and totally for the state as a whole.

Region I	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg I
	Receives	Receives	Receives	Receives	Receives	Receives	Receives	Receives
Housing Type								
Independent Living	8	7	5	5	3	1	1	30
Live with Own Parents/relative	8	6	4	0	1	0	0	19
Boarding/Lodging home	0	0	0	1	0	1	3	5
Supportive Living	10	5	4	3	4	0	1	27
Supportive Living - Waiver	10	10	4	3	1	0	0	28
Congregate Living	0	0	1	0	0	0	0	1
Personal Support	2	2	0	0	0	0	0	4
Adult Foster Home - Unlicensed	0	1	1	0	0	1	2	5
Adult Foster Home - Licensed	0	0	1	2	2	0	0	5
Adult Foster Home - Waiver	21	24	14	13	8	9	6	95
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	4	4	6	3	5	5	3	30
Boarding Care - Waive	1	1	0	3	1	1	2	9
Boarding CAre - regular	3	1	1	1	0	1	1	8
ICF/MR Group	2	3	3	2	0	0	0	10
ICF/MR Nursing	0	0	0	2	0	0	0	2
General Nursing Home	0	1	2	3	2	5	6	19
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	0	0	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	0	0
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	0	0	0	0	0	0	0	0
Out-of-State residence	0	0	0	0	0	0	0	0

Figure A1
Region 1 Residential Services Received

Region 2	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg 2
	Receives	Receives	Receives	Receives	Receives	Receives	Receives	Receives
Housing Type								
Independent Living	13	13	16	10	8	4	2	66
Live with Own Parents/relative	23	18	9	3	6	4	3	66
Boarding/Lodging home	1	1	1	0	0	1	1	5
Supportive Living	1	7	2	2	1	0	1	14
Supportive Living - Waiver	5	3	4	3	4	0	3	22
Congregate Living	1	0	0	0	0	0	0	1
Personal Support	0	2	1	2	0	2	0	7
Adult Foster Home - Unlicensed	2	5	5	3	9	2	3	29
Adult Foster Home - Licensed	3	6	4	4	5	6	3	31
Adult Foster Home - Waiver	34	38	29	16	14	7	8	146
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	15	16	22	21	11	17	26	128
Boarding Care - Waive	2	1	1	0	0	0	0	4
Boarding CAre - regular	2	1	1	1	2	1	0	8
ICF/MR Group	6	4	5	2	1	2	1	21
ICF/MR Nursing	5	6	7	7	3	3	1	32
General Nursing Home	5	9	5	10	6	11	28	74
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	0	0	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	1	1
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	0	0	0	0	0	0	0	0
Out-of-State residence	0	0	0	0	0	0	0	0

Figure A2
Region 2 Residential Services Received

Region 3	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg 3
	Receives	Receives	Receives	Receives	Receives	Receives	Receives	Receives
Housing Type								
Independent Living	16	12	8	4	4	2	2	48
Live with Own Parents/relative	19	13	9	7	1	2	1	52
Boarding/Lodging home	1	1	0	0	0	0	0	2
Supportive Living	2	5	4	1	0	0	1	13
Supportive Living - Waiver	11	9	8	6	3	1	2	40
Congregate Living	0	1	0	0	0	0	0	1
Personal Support	0	0	0	0	0	0	0	0
Adult Foster Home - Unlicensed	1	3	2	4	1	3	2	16
Adult Foster Home - Licensed	1	3	3	4	3	0	1	15
Adult Foster Home - Waiver	37	36	24	18	12	2	4	133
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	8	14	7	7	11	6	6	59
Boarding Care - Waive	0	0	0	0	0	0	0	0
Boarding CAre - regular	2	2	0	2	2	0	2	10
ICF/MR Group	2	5	0	0	2	0	1	10
ICF/MR Nursing	4	5	6	4	2	2	5	28
General Nursing Home	2	3	2	3	4	6	9	29
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	0	0	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	0	0
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	0	0	0	0	0	0	1	1
Out-of-State residence	0	0	0	0	0	0	0	0

Figure A3
Region 3 Residential Services Received

Region 1	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg 1
	Needs	Needs	Needs	Needs	Needs	Needs	Needs	Needs
Housing Type								
Independent Living	1	0	0	0	0	0	0	1
Live with Own Parents/relative	0	0	0	0	0	0	0	0
Boarding/Lodging home	0	0	0	0	0	0	0	0
Supportive Living	0	3	1	1	0	0	0	5
Supportive Living - Waiver	5	3	1	0	1	1	0	11
Congregate Living	0	0	0	0	0	0	0	0
Personal Support	3	1	0	1	0	0	0	5
Adult Foster Home - Unlicensed	0	0	0	0	0	0	0	0
Adult Foster Home - Licensed	0	0	1	0	0	0	0	1
Adult Foster Home - Waiver	3	2	0	1	0	0	0	6
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	0	0	0	0	0	0	1	1
Boarding Care - Waive	0	0	0	0	0	0	0	0
Boarding CAre - regular	0	0	0	0	0	0	0	0
ICF/MR Group	0	0	0	0	0	0	0	0
ICF/MR Nursing	2	0	0	0	0	0	0	2
General Nursing Home	0	0	0	0	0	0	0	0
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	0	0	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	0	0
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	0	0	1	0	0	0	0	1
Out-of-State residence	0	0	0	0	0	0	0	0

Figure A4
Region 1 Residential Services Received

Region 2	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg 2
	Needs	Needs	Needs	Needs	Needs	Needs	Needs	Needs
Housing Type								
Independent Living	0	0	0	0	0	0	0	0
Live with Own Parents/relative	0	0	0	0	0	0	0	0
Boarding/Lodging home	1	1	0	0	0	0	0	2
Supportive Living	2	4	1	1	0	1	2	11
Supportive Living - Waiver	2	4	2	0	1	0	0	9
Congregate Living	0	0	0	0	0	0	0	0
Personal Support	0	0	0	1	0	0	0	1
Adult Foster Home - Unlicensed		0	0	0	0	0	0	0
Adult Foster Home - Licensed	1	1	0	0	2	0	0	4
Adult Foster Home - Waiver	10	6	4	2	3	7	2	34
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	0	2	1	0	0	0	0	3
Boarding Care - Waive	0	0	0	0	0	0	0	0
Boarding CAre - regular	0	0	0	0	0	1	0	1
ICF/MR Group	1	0	0	0	0	0	0	1
ICF/MR Nursing	0	0	1	0	1	0	0	2
General Nursing Home	0	0	0	1	0	0	0	1
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	1	0	0	0	0	0	0	1
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	0	0
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	1	2	2	0	0	0	0	5
Out-of-State residence	0	0	0	0	0			0

Figure A5
Region 2 Residential Services Received

Region 3	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total Reg 3
	Needs	Needs	Needs	Needs	Needs	Needs	Needs	Needs
Housing Type								
Independent Living	0	0	0	0	0	0	0	0
Live with Own Parents/relative	0	0	0	0	0	0	0	0
Boarding/Lodging home	0	0	0	0	0	0	0	0
Supportive Living	1	2	1	1	0	0	0	5
Supportive Living - Waiver	2	0	1	1	0	1	0	5
Congregate Living	0	0	0	0	0	0	0	0
Personal Support	0	0	1	0	0	0	0	1
Adult Foster Home - Unlicensed	0	0	0	0	0	0	0	0
Adult Foster Home - Licensed	1	0	0	0	0	0	0	1
Adult Foster Home - Waiver	2	3	1	1	1	1	0	9
Child Foster Home	0	0	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0	0	0
Boarding Care - PNMI	0	0	0	0	0	0	0	0
Boarding Care - Waive	0	0	0	0	0	0	0	0
Boarding CAre - regular	0	0	0	0	0	0	0	0
ICF/MR Group	0	0	0	0	0	0	0	0
ICF/MR Nursing	1	0	0	0	0	0	0	1
General Nursing Home	0	0	0	0	0	0	0	0
Hospital	0	0	0	0	0	0	0	0
Residential Treatment - MR	0	0	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0	0	0
Residential Treatment - Other	0	0	0	0	0	0	0	0
Temporary Shelter	0	0	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0	0	0
Correctional Halfway House	0	0	0	0	0	0	0	0
Other Housing	0	1	0	0	0	0	0	1
Out-of-State residence	0	0	0	0	0	0	0	0

Figure A6
Region 3 Residential Services Received

	Total Reg 1		Total Reg 2		Total Reg 3	
	Receives	Needs	Receives	Needs	Receives	Needs
Housing Type					0	0
Independent Living	30	1	66	0	48	0
Live with Own Parents/relative	19	0	66	0	52	0
Boarding/Lodging home	5	0	5	2	2	1
Supportive Living	27	5	14	11	13	6
Supportive Living - Waiver	28	11	22	9	40	3
Congregate Living	1	0	1	0	1	0
Personal Support	4	5	7	1	0	1
Adult Foster Home - Unlicensed	5	0	29	1	16	1
Adult Foster Home - Licensed	5	1	31	13	15	2
Adult Foster Home - Waiver	95	6	146	24	133	7
Child Foster Home	0	0	0	0	0	0
Child Foster - waiver	0	0	0	0	0	0
Boarding Care - PNMI	30	1	128	3	59	0
Boarding Care - Waive	9	0	4	0	0	0
Boarding CAre - regular	8	0	8	2	10	0
ICF/MR Group	10	0	21	0	10	1
ICF/MR Nursing	2	2	32	2	28	0
General Nursing Home	19	0	74	1	29	0
Hospital	0	0	0	1	0	0
Residential Treatment - MR	0	0	0	0	0	0
Residential Treatment - MH	0	0	0	0	0	0
Residential Treatment - Other	0	0	1	0	0	0
Temporary Shelter	0	0	0	0	0	0
Correctional Facility	0	0	0	0	0	0
Correctional Halfway House	0	0	0	1	0	0
Other Housing	0	1	0	4	1	1
Out-of-State residence	0	0	0	0	0	0

Figure A7
Totals for Regions 1,2 and 3 of Residential Services Received and Needed

Appendix B

The following Figures present the series of general needs recorded in the MR MIS for each Region and the State wide totals.

Total Reg 1		
Receives	Needs	
16	6	Family Support
11	4	Planned Respite
159	15	Vacation
199	2	Family Contact/Visitation
18	4	Homemakers
2	0	Parent Support/Skill Training
266	1	Representative Payee
130	5	Money Management
116	40	Funeral Planning
175	6	Guardianship/Conservator
8	1	Legal Services
65	4	Self Advocacy Training/Support
316	18	Individual Support Coordinator
137	0	Religious/Spiritual Opportunity
225	15	Recreation
203	14	Transportation
38	0	Sexuality Education
26	1	Emmergency Prevention Plan
6	0	Other Personal Services
53	7	Correspondent

Figure B1

Total Reg 2		
Receives	Needs	
77	1	Family Support
90	5	Planned Respite
370	7	Vacation
535	8	Family Contact/Visitation
40	4	Homemakers
4	0	Parent Support/Skill Training
688	2	Representative Payee
344	2	Money Management
236	67	Funeral Planning
484	13	Guardianship/Conservator
19	1	Legal Services
89	4	Self Advocacy Training/Support
722	10	Individual Support Coordinator
351	3	Religious/Spiritual Opportunity
584	13	Recreation
590	7	Transportation
41	0	Sexuality Education
73	1	Emmergency Prevention Plan
24	4	Other Personal Services
111	37	Correspondent

Figure B2

Total Reg 3		
Receives	Needs	
44	8	Family Support
65	7	Planned Respite
155	10	Vacation
317	8	Family Contact/Visitation
21	3	Homemakers
3	0	Parent Support/Skill Training
435	1	Representative Payee
222	8	Money Management
177	34	Funeral Planning
304	7	Guardianship/Conservator
30	1	Legal Services
89	12	Self Advocacy Training/Support
435	6	Individual Support Coordinator
222	1	Religious/Spiritual Opportunity
312	9	Recreation
359	6	Transportation
33	0	Sexuality Education
51	1	Emmergency Prevention Plan
22	8	Other Personal Services
71	45	Correspondent

Figure B3

Total All Regions		
Receives	Needs	
137	15	Family Support
166	16	Planned Respite
684	32	Vacation
1051	18	Family Contact/Visitation
79	11	Homemakers
9	0	Parent Support/Skill Training
1389	4	Representative Payee
696	15	Money Management
529	141	Funeral Planning
963	26	Guardianship/Conservator
57	3	Legal Services
243	20	Self Advocacy Training/Support
1473	34	Individual Support Coordinator
710	4	Religious/Spiritual Opportunity
1121	37	Recreation
1152	27	Transportation
112	0	Sexuality Education
150	3	Emmergency Prevention Plan
52	12	Other Personal Services
235	89	Correspondent

Figure B4

Appendix C

The Figures below present general data from the MR MIS on Medical and Therapeutic Needs

Total Reg 1		
Receives	Needs	
304	1	Medical
31	0	Home Health
248	7	Dental
39	2	Dental IV Sedation
40	0	Occupational Therapy
58	0	Physical Therapy
89	1	Psychiatric Evaluation
115	1	Psycho-Active Med. Review
88	2	Psychology - Evaluation
37	2	Counseling
33	0	Behavioral Consultation
229	1	Vision
71	0	Adaptive Equipment
51	8	Environmental Modification
8	0	Family Planning
8	2	Other Clinical/Ancillary Services
21	3	Other Mental Health Service
46	0	Crisis Team Access

Figure C1

Total Reg 2		
Receives	Needs	
723	4	Medical
67	0	Home Health
522	17	Dental
45	4	Dental IV Sedation
102	1	Occupational Therapy
124	2	Physical Therapy
162	3	Psychiatric Evaluation
221	2	Psycho-Active Med. Review
309	5	Psychology - Evaluation
70	9	Counseling
93	2	Behavioral Consultation
538	4	Vision
184	4	Adaptive Equipment
168	9	Environmental Modification
5	0	Family Planning
29	0	Other Clinical/Ancillary Services
30	2	Other Mental Health Service
62	1	Crisis Team Access

Figure C2

Total Reg 3		
Receives	Needs	
364	4	Medical
37	3	Home Health
271	27	Dental
34	6	Dental IV Sedation
47	0	Occupational Therapy
62	2	Physical Therapy
98	5	Psychiatric Evaluation
139	6	Psycho-Active Med. Review
104	6	Psychology - Evaluation
41	14	Counseling
41	2	Behavioral Consultation
272	10	Vision
128	2	Adaptive Equipment
94	4	Environmental Modification
4	0	Family Planning
42	6	Other Clinical/Ancillary Services
21	1	Other Mental Health Service
73	0	Crisis Team Access

Figure C3

Total all Regs		
Receives	Needs	
1391	9	Medical
135	3	Home Health
1041	51	Dental
118	12	Dental IV Sedation
189	1	Occupational Therapy
244	4	Physical Therapy
349	9	Psychiatric Evaluation
475	9	Psycho-Active Med. Review
501	13	Psychology - Evaluation
148	25	Counseling
167	4	Behavioral Consultation
1039	15	Vision
383	6	Adaptive Equipment
313	21	Environmental Modification
17	0	Family Planning
79	8	Other Clinical/Ancillary Services
72	6	Other Mental Health Service
181	1	Crisis Team Access

Figure C4