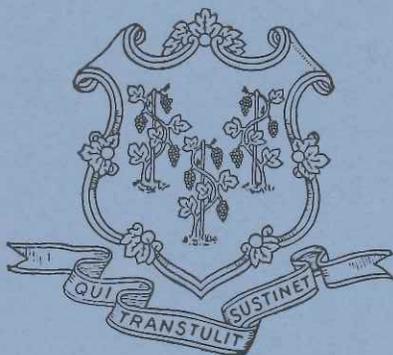


INVESTIGATION OF DEPARTMENT OF MENTAL RETARDATION: CLIENT HEALTH AND SAFETY

Connecticut

General Assembly



LEGISLATIVE
PROGRAM REVIEW
AND
INVESTIGATIONS
COMMITTEE

December 2002

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LEGISLATIVE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE**

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**Investigation of
Department of Mental Retardation:
Client Health and Safety**

DECEMBER 2002

Digest

Department of Mental Retardation: Client Health and Safety

OVERVIEW

- About 1 percent of Connecticut's population, 33,500 persons, is mentally retarded. Less than half, 14,575, are DMR clients.
- Residential services for mentally retarded clients have evolved from institutional settings -- called training schools -- to community settings, including group homes or supporting clients in their own apartments.
- Slightly more than half of DMR's clients live with their families; almost half live in DMR-supported residential settings -- most in Community Living Arrangements (CLAs).
- DMR residential services are not an entitlement; capacity does not meet demand, resulting in a waiting list. There are currently 1,665 people on the waiting list.

CLA Profile

- Currently, there are 771 CLAs providing residential services to 3,428 DMR clients around the state.
 - FY 01 costs for all types of CLAs totaled almost \$400 million. Private providers contracted with DMR receive about two-thirds of all CLA funding, and take care of about 80 percent of the clients. There are salary and staffing gaps between public and private homes -- DMR homes have higher staffing ratios and pay higher wages.
 - Staff turnover is higher in private homes (22 percent) than in public homes (6 percent.)
 - CLAs provide direct care staffing when clients are at home. DMR has initiated a policy requiring all providers to screen potential employees, including criminal background checks.
 - Staff must receive on-the-job training within 30 days of being hired, and must be retrained in most areas every two years.
 - The average age of DMR client living in a CLA is 45, which is 11 years older than the average age of DMR clients overall. As of June 2001, the average length of stay in CLAs was 8.5 years and the median six years.
 - A greater proportion of severely and profoundly mentally retarded clients live in CLAs than live in other settings.
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Residential Program

- Once a referral is made for a CLA placement, a referral form and packet are sent to the potential provider.
- If the provider and referral client and/or guardian agree the placement is acceptable, a transition plan is developed.
- Once a client begins living in a CLA, an overall plan of service is developed for the client. The plan is developed and monitored by the client's Interdisciplinary Team (IDT). The plan must be reviewed at least annually with quarterly updates. Each client has a case manager to oversee the plan and ensure services to the client are appropriate.
- The residential program provider is largely responsible for implementing various aspects of the client's plan, including: access to medical and dental services; health and safety; behavioral issues; transportation; and community participation.
- There are several oversight mechanisms of the client's individual service plan, including regional *program review and human rights* committees.

CLA PROGRAM OVERSIGHT

- The two main ways CLA programs are monitored by DMR are through licensing and inspections, and contract monitoring.
 - Private CLAs are required to have a state license to operate, which must be renewed annually. Public CLAs are "certified" using the same DMR licensing process. Ongoing licensing inspections are to occur at least once every two years.
 - If problems are found at an inspection, DMR issues a citation report and the provider then has 15 working days to submit a plan of correction. Upon approval by DMR, corrective actions must typically be completed within 15 working days. If problems are not corrected or if deficiencies continue, DMR may place the home on a one-year inspection schedule to increase monitoring.
 - DMR has contracts with 81 private provider agencies for CLA services. Each contract is for all services provided to DMR clients by that agency statewide. Contracts are overseen by regional contract monitors.
 - Contracts are annual and coincide with the state's fiscal year. The vast majority of contracts are automatically renewed, unless a provider gives up a contracted service or DMR terminates a contract.
 - Recently, DMR has begun using a new oversight tool called *program integrity*. The intent is to collect and examine all oversight and monitoring results for a particular provider (including DMR homes,) gauge how well it is doing, and recommend adjustments.
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ABUSE AND NEGLECT

- Many persons with mental retardation living in CLAs are vulnerable to the actions of themselves and others, and so a system to address abuse and neglect concerns is needed.
- DMR requires all “incidents” involving clients to be reported, whether or not there is suspicion of abuse or neglect. Reportable incidents range from client injuries to use of restraints and medication errors.
- Connecticut has a multi-agency system – OPA, DCF, DMR, and DSS may be involved -- for reporting on and investigating abuse/neglect allegations involving DMR clients. DMR has two separate tracks for abuse/neglect investigations. In most cases, private providers conduct investigations in their homes, while DMR investigates allegations at DMR homes.
- As of 2000, DMR requires any abuse/neglect investigation involving a residential death be investigated by DMR.
- From FY 92-FY 01, an average of 1,147 abuse/neglect allegations were reported each year, with a substantiation rate of 35 percent. One-third of the allegations related to CLA residents.

POST-DEATH REVIEW

- When a DMR client dies, the agency has a number of policies and procedures in place to review client care both before and at the time of death. Some of these are required by statute, others were put in place early in 2002 by Executive Order 25. Still others DMR implemented over the years as part of department policy.
 - Some actions that can be taken when a client dies are not within DMR’s control. The Office of Chief Medical Examiner may not accept jurisdiction, and/or may decide an autopsy is not necessary. Families have the choice of requesting an autopsy, but may not wish to do so.
 - Regional mortality reviews are *always* conducted if a client was living in DMR-supported setting. In many cases, there is also a state-level review by the Independent Mortality Review Board, created in 1988 and revamped through Executive Order 25 in February 2002.
 - The main focus of the reviews is to ensure the medical and personal care given the client was appropriate and to make recommendations for improvement where applicable.
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ANALYSIS OF DMR DEATHS

- In general, there is a higher death rate among the DMR population than in the general population.
- DMR clients die at an earlier age than in the general population. About 60 percent of the general population dies after age 75; less than 20 percent of DMR clients live that long. The clients in the sample of deaths LPR&IC reviewed were a medically involved group, with many serious illnesses and conditions.
- Connecticut's death rate for its DMR population is similar to Massachusetts and a combined-state average of eight states participating in a national quality improvement project.
- DMR client death rates varied by residential settings -- skilled nursing facilities had the highest rate --at 95 deaths per 1,000. The CLA death rate was 11.2 per 1,000.
- A higher percentage of DMR-client deaths are autopsied than among the general population.
- About 10 percent of all 1,654 DMR clients who died between FY 92 and FY 01 had an abuse/neglect allegations filed in the year prior to death. Only 25 percent of those related to the deaths and 44 percent of those were substantiated.

FINDINGS AND RECOMMENDATIONS

Licensing and Inspections

- A high percentage of CLA licensing inspections occur after the CLA licensing/certification date has expired.
 - The licensing and inspection unit is understaffed and lacks nursing staff, an important component when dealing with a medically fragile population.
 - Public and private CLAs are often not in compliance with the regulatory timeframes for submitting required plans of correction.
 - There was no difference between public and private CLAs in the most common deficiencies cited during inspections.
 - DMR does not use its full range of enforcement tools to ensure compliance with CLA licensing regulations.
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Case Management

- There are no consistent statewide operational requirements for case managers of CLA clients.
- Job expectations and caseloads vary considerably for case managers depending on the regions and whether clients are living in public or private homes.
- It is unclear how recently developed performance evaluation elements will be applied given the practical differences in case management responsibilities.

Human Rights Committees

- There are no consistent statewide guidelines as to how these committees operate or how they make decisions.
- In the absence of guidelines, particularly as they relate to group home settings, it is difficult to determine what forms the basis of committee decisions, especially those affecting client health and safety.

Abuse and Neglect

- Approach to investigating abuse/neglect of DMR clients in CLAs varies, depending largely on whether a client lives in a public or private home.
- Until very recently there was no consistent tracking and follow-up on recommendations resulting from abuse and neglect investigations.
- The Office of Protection and Advocacy has only recently begun to maintain a registry of abuse and neglect reports and actions, a statutory requirement since 1984.
- The current memorandum of agreement between the Office of Protection and Advocacy and the Department of Mental Retardation outlining responsibilities for abuse and neglect investigations was developed in 1992. There is a need to update the agreements to reflect changed roles and functions.

Post Death Review

- The post death review process does not consistently focus on factors beyond a client's medical care before death.
 - DMR has not consistently analyzed mortality data to identify trends, issues or areas for improvement for client health and safety.
 - Regional mortality review committees typically exceeded the 90-day time frame established by DMR policy for submission of their findings and recommendations to the Independent Mortality Review Board.
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- DMR has addressed this issue, notifying regional mortality review committees to conduct reviews more promptly and by late 2002, regional committees were current with mortality review cases.
- The number of deaths classified as accidents varies substantially, depending on the documentation used.

System Coordination

- There is a lack of coordination among the many separate oversight and regulatory tracks DMR uses to monitor itself, its providers, and the services they provide.
- DMR's regional organization structure establishes a service delivery system close to the clients, but oversight functions are split between regional and central offices.
- Communication among staff who perform various oversight functions is not formal nor clearly defined.

Regulatory Enhancements

- There is a need to enhance regulations related to client health and safety in community living arrangements.
- Regulations do not adequately address the spectrum of emergencies that might occur in CLAs.
- DMR needs to begin examining when client health and safety is put in jeopardy by staff who are required to work too many hours without substantial time off.

Residential System Management

- DMR does not have a system in place that collects and maintains data to evaluate whether its clients are living in the most appropriate setting, or whether needs of clients are matched with residential resources and payments
 - DMR's client population is aging and DMR has not yet developed a plan on what types of settings will best meet this population's residential and increasing medical needs.
 - Many CLAs are not equipped or appropriately staffed to address the increasing medical needs of the aging CLA population. There are not enough financial resources in terms of funding the 24-nursing hour nursing staff that would be needed in many more homes, and RN and LPN shortages exist throughout the health care system.
 - DMR does not have an adequate information system to track and manage vacancies in CLAs.
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- The absence of such a system handicaps the regional placement and contracting staff, as well as the budgeting and revenue enhancement staff at DMR central office.
- Long-term vacancies have a financial impact on the state because of lower Medicaid reimbursement, and hamper DMR's ability to reduce the waiting list for residential placement.

Wage Equity

- There is a gap between salaries paid to CLA direct care employees in DMR and private providers, which continues to grow.
 - Pay equity would be incredibly expensive and not realistic given the current economic environment.
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RECOMMENDATIONS

1. Licensing and Inspections. The DMR commissioner shall require all CLA licensing inspections be conducted within the specified regulatory timeframe. The department shall also fully enforce state CLA licensing regulations through appropriate use of its full range of existing enforcement tools, including compliance orders, more unannounced inspections and, if necessary, license revocations. Additional tools, such as fines required through C.G.S. Sec. 17a-227(e), as well as others deemed appropriate by the department, shall also be used to ensure providers fully comply with state regulations on a timely basis.

DMR's licensing and inspection unit shall be responsible for overseeing the entire licensing and inspection process, including complete follow-up to licensing citations issued during inspections. To assist in this function, DMR services and systems unit staff currently used to inspect regional centers shall be transferred to the CLA licensing and inspection unit by July 1, 2003.

DMR licensing inspectors shall incorporate a more interactive approach with provider direct care staff when inspecting public and private community living arrangements. At minimum, this approach should include verbal questions of direct care staff on an as-needed basis to ensure such staff is fully aware of how to handle client health and safety issues, including what actions to take during emergency situations.

At least half of the unit's standard biennial licensing inspections shall be conducted on an unannounced basis (this is in addition to the unannounced follow-up inspections currently conducted by the unit in response to Executive Order 25). On-site follow-up visits by licensing inspectors shall occur for all plans of correction submitted to DMR resulting from inspections. All follow-up visits shall be unannounced and occur within 30 days from the DMR plan of correction approval date, unless an alternate timeframe is required by the department based on the severity of the licensing citation or the provider's approved timetable for fully implementing corrective action.

The department should make full use of its automated licensing and inspection data for management analysis purposes. (The system, however, needs to begin incorporating provider's corrective actions taken to rectify citations issued during inspections and be frequently updated.) The system should be used from an overall management perspective to identify any trends, systemic licensing/inspection issues, and provider compliance with state licensing regulations.

DMR should emphasize compliance and enforcement for its own homes, given inspections of those homes are typically more delayed and plans of correction generally submitted later than private homes.

2. Case Management. DMR should clarify its expectations of the case management function and develop measurable performance standards for its case managers. This should be done with a focus on how best to have consistent reliable information about individual clients.

DMR should standardize case management record keeping statewide, including case management logs.

3. **Human Rights.** The DMR policy on the human rights committees shall be amended to include specific considerations on how the committees shall make their decisions, including the establishment of client health and safety as a primary interest.

4. **Abuse and Neglect.** DMR should continue to maintain its Division of Investigations within the Department of Mental Retardation. The division head should report directly to the commissioner. The division should be responsible for either conducting abuse/neglect investigations or monitoring and reviewing investigations done by private providers. DMR should develop timeframe standards for investigations and track compliance with those standards.

DMR, through its Division of Investigation, shall develop a protocol for monitoring and reviewing investigations done by private providers, including increased monitoring and assuming allegation investigations deemed to be most serious. Among other factors, DMR shall investigate whether staffing was an issue in the alleged abuse/neglect by obtaining actual staffing records for the pertinent times in question. (e.g., was staff working multiple shifts or was full complement of scheduled staff absent?)

All sudden/unexpected deaths shall be screened by the Division of Investigations with the desk audit process DMR began earlier in 2002 to determine if there is suspicion of abuse/neglect. The nurse/investigators conducting those audits should also be available to assist with other abuse/neglect allegations issues in either public or private settings.

Any serious injury reported resulting in hospital or ER treatment shall be submitted immediately to the Division of Investigations, whether or not abuse or neglect has been alleged, and the division shall make a preliminary inquiry as to whether abuse/neglect might have occurred.

All investigations related to deaths where abuse and/or neglect is suspected shall be conducted by the Office of Protection and Advocacy and shall be accompanied by a transfer of the appropriate resources from the Department of Mental Retardation to OPA to conduct such investigations. Further, OPA, in consultation with DMR, shall establish protocols on how such investigations shall be carried out.

OPA and DMR shall develop and institute a new memorandum of agreement, which shall include specific provisions for how OPA will review and monitor completed investigations, and otherwise ensure the agreement accurately reflects the working relationship between the two agencies by June 30, 2003.

Finally, as DMR is apparently desiring that investigation reports should be limited to findings of facts and whether abuse/neglect was substantiated, and should not include programmatic recommendations, DMR should develop a way for the pool investigators to provide input for program improvement, in order to tap their experience. For example,

this could be accomplished by establishing a best practices team from within the pool investigator groups to meet periodically and develop recommendations.

5. Post Death Review. State statutes should be amended to require the Department of Mental Retardation conduct a comprehensive and timely post-death review into the event(s), overall care, quality of life issues, and medical care preceding a client's death. The reviews shall be conducted by the appropriate regional mortality review committee and/or the Independent Mortality Review Board, as determined by DMR.

DMR and the IMRB shall utilize the mortality review database being developed through department's health and clinical services unit to examine client deaths from a broad management perspective. The analysis should be used to identify client health and safety trends, gaps, and areas needing improvement. Any recommendations (including implementation status) stemming from this analysis and those developed through the formalized regional and state-level mortality reviews, should be fully documented by DMR.

DMR shall ensure that any death involving an accident, or where an accident was considered a contributing factor, determined through the mortality review process or the death certificate coding process, shall be categorized as an unexpected, accidental death in all relevant department records.

6. System Coordination. Require the regional contract managers to use the program integrity format and its review components when they conduct their mid-year and end-of-year contract performance reviews. Those components shall include:

- Audits;
- Quality assurance --licensing and inspections, physical plant issues;
- Special protections (e.g., abuse and neglect);
- Individual and family satisfaction;
- Case management;
- Health -- including use of psychotropic drugs and mortality review findings and recommendations; and
- Contract information, including staffing patterns, turnover, and timeliness in filling staff vacancies.

The Quality Assurance Division (QAD) in coordination with the regions shall develop benchmarks for each component area so that the reviews are objective, uniform, measure performance, and produce meaningful, action-oriented results that providers must implement within a reasonable timeframe or enforcement action will be initiated.

Prior to the mid-year and annual reviews being conducted, contract managers shall collect all the relevant information necessary to evaluate each component area as determined by the QAD, analyze the information, evaluate the provider's performance in each component area and prepare a list of findings for review by the Assistant Regional Director prior to meeting with the provider. If there are no concerns in any component area, the findings report shall state such.

The mid-year and annual reviews shall be conducted by the Assistant Regional Director (or directors if the provider is in multiple regions) and all contract managers for that provider. Their participation is mandatory and the reports must be signed by all who conduct the reviews. Participation from central office staff (auditing, operations, and QA) and regional supervisors of case management, health services, and investigations shall be sought but is not necessary to conduct reviews.

A uniform automated tracking system shall be completed by DMR and the results of each review by component area shall be entered on the system by the contract manager and available to all DMR regional and central office staff. Oversight of the tracking system, and its recommendation implementation shall be the responsibility of the Assistant Regional Directors for Private Administration and the Director of the Quality Assurance Division at DMR central office. In concert, they shall ensure timely reviews are conducted, that each component area is addressed and that any recommendations made are implemented in the timeframe given.

For public sector services, DMR shall use the same format, and the reviews shall be conducted with the appropriate DMR residential managers. The directors of each relevant component area (quality assurance, investigations, health services), and a private provider from the appropriate service region shall conduct the reviews.

Enforcement. DMR shall take enforcement action when there a number of concerns raised through the program integrity reviews. For example, if there are more than five component areas where concerns are raised, or one component area where a number of concerns surface, DMR shall put the provider (or its own homes) on a “watch list”, including increased monitoring. If the provider does not adequately address the concern areas by the next review, the provider shall be placed on a partial year contract and continue to be monitored. For its own homes, DMR shall hold the appropriate residential manager responsible for implementing required changes. If problems remain at the next six-month review, DMR shall begin reducing the contract by five percent per-month until compliance is achieved, or the contract is terminated. For its own homes where deficiencies remain, DMR shall begin disciplinary proceedings for those agency personnel deemed responsible for the continuing non-compliance, and/or make appropriate staff changes.

Modifications shall be made to C.G.S. Section 17a-227 to provide for such contract enforcement authority.

7. **Regulatory Enhancements.** Licensing inspectors shall ensure providers’ emergency planning contains how staff should address emergency situations, and shall verify, in addition to document verification, through asking direct care staff what the procedure is for a given emergency situation. Regulations should also require all staff should be trained in CPR, not just one person on each shift. Regulations shall also require that providers be able to produce, upon advance request by DMR, staffing schedules and actual staffing and hours worked for the requested time period.

8. **Staff Hours Worked.** Require that any abuse or neglect investigation or regional or state-level mortality review examine the number of hours staff had been on duty at the time of the incident. Require the department’s Strategic Leadership Center to compile the data

from such reviews. By July 1, 2005, the center shall make a recommendation to the DMR commissioner on whether a policy is needed to limit the number of consecutive hours a staff person can work in both DMR and privately operated homes.

9. **Acuity and Placement.** The commissioner of DMR should make the upgrade of the CAMRIS system a management priority to evaluate appropriate placement of, and payment for, clients in the system. Needs of clients should be evaluated at least every two years to ensure they are in the most appropriate setting.

10. **Aging CLA Clients.** For persons 60 years or older who have had two hospitalizations in a six-month period, DMR shall conduct a review to ensure the residential and medical needs are still most appropriately met in the CLA or whether a residential placement in a skilled nursing facility might be more appropriate.

11. **Vacancy Tracking.** The commissioner of DMR should ensure the development of a tracking system to manage all CLA vacancies is a management priority. The system should be automated, available to both regional and central office staff, and used as a management tool to assist with placement, contract management and revenue enhancement.

12. **Wage Equity.** DMR shall establish as a management priority a longer-term solution that would begin to use the acuity and placement system to develop a prospective approach for payments to providers and what they pay in wages. The ultimate goal of such a system would be to link client need, services, and wages.

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Introduction

The Department of Mental Retardation (DMR) operates and regulates community living arrangements (CLAs), also known as group homes, for persons with mental retardation as one type of residential service available to DMR clients. In March 2002, the Legislative Program Review and Investigations Committee began an investigation into how well the policies and practices of the department and its contracted provider agencies address the safety and physical well-being of DMR clients living in CLAs. The committee investigation was requested by a vote of the Joint Committee on Legislative Management Committee (JCLM) on January 30, 2002. (See Appendix A for the JCLM motion).

The investigation was prompted by a series of articles in the Hartford Courant in December 2001 about deaths of clients in DMR run or funded group homes. The newspaper cited 36 cases as being “linked” to “neglect, staff error, or other questionable circumstances,” noting that this number of deaths represented 10 percent of all the deaths in CLAs over a 10-year period. A central question for the program review committee was whether these deaths resulted from systemic weaknesses in the DMR system.

Methods

To address that central question, the committee analyzed the system from various perspectives. Pertinent DMR statutes, regulations, and policies related to residential programs were reviewed. From these, an array of DMR policies and procedures intended to promote the health and safety of DMR clients were identified and examined. The policies and procedures that occur at each step of the client’s residential program – from individual client placement and planning, through residential program implementation, to home licensing, and provider contracting – were evaluated to understand the health and safety expectations in place. Next, policies, procedures, and practices triggered by events that could indicate a failure to promote health and safety were reviewed—these involve abuse and neglect allegations and how deaths are reviewed.

Committee staff interviewed a number of private and public group home staff on their practices and met with provider associations. Committee staff also interviewed DMR central office and regional staff in various capacities including administration, budgeting, health services, investigations, human resources and information systems. Committee staff accompanied DMR contract monitors and licensing inspectors on site visits and inspections and observed annual contract review meetings, and regional planning and resource meetings.

Program review staff met with personnel in the Office of Protection and Advocacy and Department of Public Health regarding roles and responsibilities impacting DMR clients. In addition staff attended meetings of mortality review committees at both the regional and state levels.

Staff reviewed the general literature on morbidity and mortality among the developmentally disabled populations, and analyzed national and state death-related data. For Connecticut statistics, staff used the Department of Public Health’s death registry, the state’s

official compilation of death certificate and cause information. Staff obtained limited data on deaths among developmentally disabled populations from California, Massachusetts and several other states participating in a quality improvement project whose death data were compiled but without identifying individual states. Staff also reviewed an April 2002 report conducted by a health statistician under contract with DMR. The report contained analysis and findings related to mortality statistics of DMR clients for a six-year period, from 1996 through 2001.

Committee staff also conducted a detailed file review of 177 randomly selected cases of DMR-client deaths in CLAs in all regions. The cases involved about half of all deaths that occurred in group homes during the 10 years from 1992 to 2001. Data were collected on client demographics, residential placement history, health and behavioral issues, cause of death, and processes followed after death. The same information was gathered for the 36 cases cited in the Hartford Courant news articles.

The committee held a full-day public hearing on DMR group home client health and safety in November 2002, with both invited speakers and the general public providing testimony.

Analysis and Findings in Brief

The investigation used a four-step approach that involved looking at overall death rates in the general population compared to the DMR population, and where possible, Connecticut's DMR death rate compared with other states. The ages, residential placements, causes of deaths and contributing factors were examined for all 1,654 DMR client deaths that occurred between FYs 92-01.

An in-depth file review of randomly selected cases of 177 CLA residents who died in the 10-year period of FYs 92-01, along with an examination of the cases cited in the Hartford Courant, were also conducted. Data collected from that file review were compiled and analyzed. The death analyses showed:

1. in general, there is a higher death rate among the DMR population than in the general population, and DMR clients die at an earlier age;
2. Connecticut's DMR population death rate was similar to other states from which numbers were available;
3. the death rate for DMR clients was highest in skilled nursing facilities, followed by Southbury Training School and the regional centers. CLAs had the fourth highest death rate among the seven residential settings compared;
4. as a whole, the persons in the 177 case sample were a medically involved group; and
5. regarding persons in the Hartford Courant cases, while many had medical issues there was a much higher proportion of deaths due to accidents than in the sample.

In some of the 36 cases cited by the Hartford Courant as well as in some of the cases in the program review case file examination, tragic events occurred that but for a different set of circumstances might not have. For example, two people died because they were left alone in bathtubs when they clearly should not have been. Others choked on food or non-food items that should not have been available to them. In its final analysis, the program review committee did not identify any direct systemic cause related to the deaths, meaning that in almost all the cases, there were systems in place to address the risks to these clients, but for one reason or another were not carried out.

After examining the individual death cases and reviewing the current oversight mechanisms in place at DMR, the program review committee concludes the CLA system is regulated and monitored by many different governmental entities (DMR, Office of Protection and Advocacy for Persons with Disabilities (OPA), Department of Public Health (DPH), and the federal Centers for Medicare and Medicaid Services (CMS)). However, there is a lack of cohesiveness and follow-through resulting from any of these reviews. To be the most effective in sending the message that DMR is as serious about client health and safety as it is regarding other aspects of its responsibilities, there must be assurance and accountability from both DMR and its service providers that: 1) deficiencies found are corrected; 2) health and safety measures are practiced; and 3) when an accident or death happens it is thoroughly and objectively examined. Thus the main thrust of committee findings and recommendations in this report is on enhancing oversight effectiveness in areas including licensing and inspections, abuse/neglect investigations and general oversight coordination.

The committee also found that some of the regulations governing CLA operations, especially in the area of emergency planning, are outdated, and recommends enhancements. The committee further determined DMR lacks a comprehensive system to assess client needs and match appropriate resources and also needs to begin addressing the wage equity issue among providers, making recommendations in both those areas.

Report Organization

The report is organized in eight chapters. Chapter I provides an overview of mental retardation and the responsibilities of the Department of Mental Retardation. Chapter II profiles Connecticut's community living arrangements and the DMR clients who live in those settings, while Chapter III describes components of an individual's residential program in a CLA, including planning and review. Chapter IV sets out DMR's oversight mechanisms for CLA residential services, including licensing and contract monitoring. Chapter V focuses on the processes triggered when an allegation of abuse or neglect is made related to a DMR client, while Chapter VI describes the variety of activities that occur when a DMR client dies. Chapter VII presents various analyses of death data related to DMR clients, including the results of the random sample case file review of CLA client deaths. Finally, Chapter VIII contains the committee's findings and recommendations, which primarily focus on improving oversight, enhancing regulations dealing with client health and safety, and strengthening DMR's residential management functions.

Agency Response

It is the policy of the Legislative Program Review and Investigations Committee to provide agencies subject to a study with an opportunity to review and comment on the recommendations prior to publication of the final report. The response from the Department of Mental Retardation is contained in Appendix B.

DMR OVERVIEW

What is Mental Retardation?

- Mental retardation is a disability, not a disease or illness. The definition of mental retardation used in Connecticut statutes, adopted in 1978, still reflects the generally accepted meaning of the disability.
- Mental retardation means a significant subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.
 - *General intellectual functioning* means the results of a general intelligence test (IQ test).
 - *Significantly subaverage* means an IQ of more than two standard deviations below the mean for the test, or 70.
 - *Adaptive behavior* means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group.
 - *Developmental period* means the time between birth and turning 18.
- DMR estimates about 1 percent of Connecticut's citizens, or 33,500, have mental retardation. Currently, 14,575 persons with mental retardation are active DMR clients.
- Table I-1 sets out four commonly used mental retardation levels--mild, moderate, severe, and profound. Since 1921, the American Association on Mental Retardation (AAMR) has been a primary source for defining and classifying mental retardation, measures that have changed over the years as understanding about the condition increased. Since the 1960s, the four-level classification of mental retardation based on intellectual function (IQ test results) has been in general use by the AAMR, although the organization has questioned its use.

Table I-1. Mental Retardation Levels of Severity.		
MR Level	AAMR Severity Classifications	World Health Organization IC-10 Classifications
Mild	IQ -- 50-55 to approximately 70	IQ -- 50-69 In adults, mental age from 9 to under 12 years old. Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.
Moderate	IQ – 35-40 to 50-55	IQ – 35-49 In adults, mental age from 6 to under 9 years. Likely to result in marked developmental delays in childhood, but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.
Severe	IQ – 20-25 to 35-40	IQ – 25-34 In adults, mental age from 3 to under 6 years. Likely to result in continuous need of support.
Profound	IQ below 20-25	IQ – Under 20 In adults, mental age below 3 years. Results in severe limitations in self-care, continence, communication, and mobility.
Source: Mental Retardation Definition, Classification and Systems of Support (10 th Edition, AAMR) and CARC v. Thorne Consent Decree Implementation Plan (Aug. 1985)		

- The World Health Organization International Classification of Diseases (ICD) also classifies diseases and conditions, and has defined, classified, and described mental retardation. The most recent version is the ICD-10, adopted in 1993. The AAMR does not subscribe to the ICD descriptions, in part because it believes the language is “archaic and stigmatizing”; the AAMR also states the use of mental age scores “in current practice is quite limited.” However, these classifications offer informative descriptions related to support needs, albeit generalized, in addition to IQ test scores.

- The use of an intelligence classification for persons with mental retardation as opposed to a classification focus based on a person's adaptive skills and levels of support needed to address deficits is the subject of debate in the mental retardation field. Proponents of reliance on IQ classifications point out the subjectivity and imprecision of support level determinations. Proponents of the skills and needs focus note intelligence scores do not offer a complete picture of an individual. DMR uses both approaches.

Health Issues

- In addition to intellectual and adaptive problems, persons with mental retardation, like people without mental retardation, tend to experience an array of health issues.
 - Some physical and medical issues, though, appear more prevalent among persons with mental retardation, including but not limited to seizure disorders, cerebral palsy, mental illness, scoliosis, and gastrointestinal problems including reflux and constipation.
 - Aspiration pneumonia, where material like food is inhaled into the lungs, is also a common problem especially when coupled with physical disabilities affecting the normal swallowing mechanisms.
 - Ambulation problems affecting some persons with mental retardation and the accompanying inability to do weight-bearing exercise create an increased risk for osteoporosis.
 - Persons with Down Syndrome have heart problems and are more likely to develop Alzheimer's disease, including dementia.

Impact of Services and Supports

- There is a wide range of abilities and disabilities among people with mental retardation. A generally accepted assumption of the field is "with appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve." (AAMR)

Views on Supporting Persons with Mental Retardation

Connecticut and the rest of the United States have evolved on the question of how best to address issues facing people with mental retardation. Connecticut was one of the earliest states to operate training schools in rural settings for these individuals, a cutting edge approach at one time. In the mid-1960s into the 1970s, a movement began for caring for mentally retarded persons in their communities in less institutional settings. One of these settings is the community living arrangement, the focus of this study. Some of the milestones for residential programs for people with mental retardation are included in Table I-2.

Table I-2. History of State-Run Residential Settings for Persons with Mental Retardation in Connecticut.	
1858 – 1961	1961-1978
Connecticut operated schools, known as training schools, in the early 1900s. Mansfield opened in 1915, and by 1934 had a population of 1159 persons, and a waiting list of over 1000. Southbury opened in 1941 to ease demand at Mansfield.	State regional centers began opening in 1961 to address desire for residents to live closer to their families. The first public group home was opened in 1964, and in 1971, private residential facilities began to be licensed.
1978-1984	1984 to Present
CT was sued in 1978 for violating Mansfield residents' federal constitutional and statutory rights. The suit followed U.S. Supreme Court decisions on other states' institutions that began the move to deinstitutionalizing persons with mental retardation. The 1984 consent decree set out a new focus on community integration, normalization, and least restrictive environments. The last resident left Mansfield in 1993.	In 1984, CT was sued for violating Southbury residents' civil rights based on the school conditions. The last several years have seen the rapid growth of private provider CLAs. Earlier efforts to close Southbury were abandoned. Southbury remains open—but accepts no new clients. Its population has decreased from 1,040 in 1992 to 619 as of June 2002. Southbury is currently under the U.S. Department of Justice scrutiny. DMR efforts to provide residential supports have more recently focused on supported living and independent supports.

DMR Responsibilities

DMR was established as an independent state agency in 1975, replacing the Office of Mental Retardation within the state's public health department. By state statute, DMR is responsible for:

- the planning, development and administration of complete, comprehensive, and integrated statewide services for persons with mental retardation, including provision of service to persons with Prader-Willi Syndrome¹ and coordinating services to persons with autism;
- administering and operating Southbury Training School, state regional centers, and all state operated community based residential facilities established for the diagnosis, care, and training of persons with mental retardation; and
- establishing standards, providing technical assistance, and exercising the requisite supervision of all state-supported residential, day, and program support services for persons with mental retardation and work activity programs.

Mission Statement

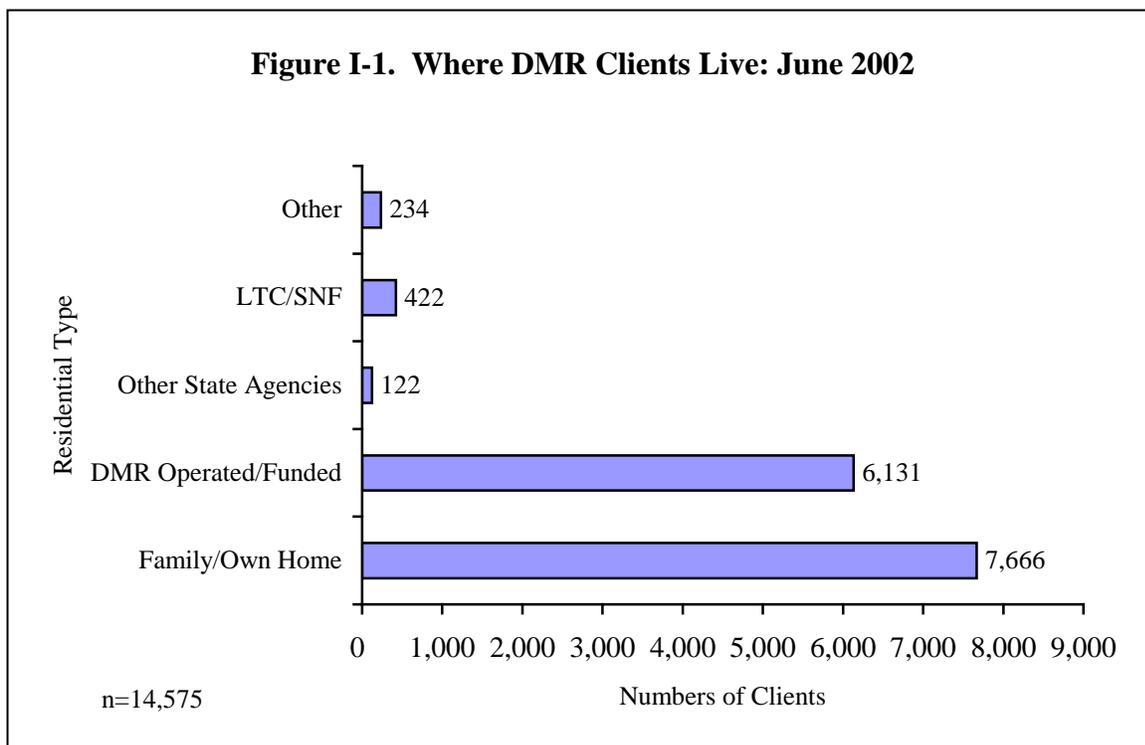
Since 1986, the DMR mission, adopted by the agency, has been to “join with others to create the conditions under which all people with mental retardation experience:

- presence and participation in Connecticut town life;
- opportunities to develop and exercise competence;
- opportunities to make choices in the pursuit of a personal future;
- good relationships with families and friends; and
- respect and dignity.”

¹ A genetic disorder with physical and cognitive problems, including a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity

Who DMR Serves and What Services Provided

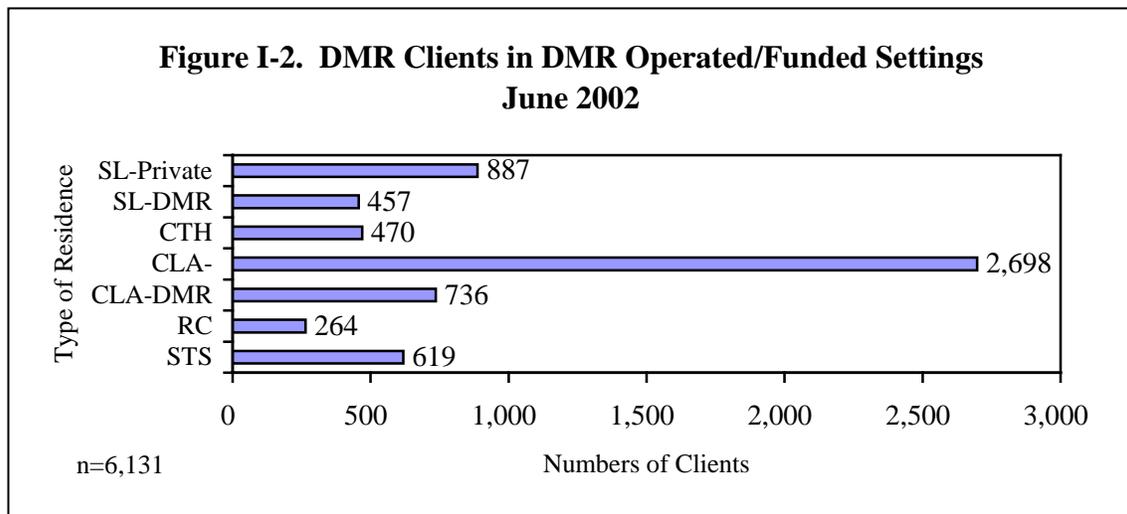
- As of June 2002, DMR served 19,428 people in a variety of ways, with 14,575 as active clients -- 4,448 infants and toddlers participating in the Birth-to-Three program are not considered DMR clients and are not included in any DMR client numbers for the purposes of this study.
- Forty-two percent (6,131) of DMR clients receive residential services from either DMR-operated or funded settings. Figure I-1 shows where DMR clients live.
- Fifty-three percent (7,666) of DMR clients live with their families or on their own
 - DMR services may include day programs (employment or recreational), respite care, and transportation



- Four of 10 DMR clients live in some kind of DMR operated or funded residential setting.
 - Most DMR clients have a day program component (employment or recreational) that they either travel to or that occurs at the residence, in addition to their residential services.
 - People living in CLAs (3,434) constitute 24 percent of all DMR clients.

DMR Operated/Funded Residential Settings

- There are different types of residential settings DMR operates and funds.
 - *Southbury Training School (DMR)*: A large congregate living residence in a campus setting.
 - *Regional Centers (DMR)*: Campus type settings in each region housing from 20-116 people.
 - *Community Living Arrangements (group homes)*: DMR and private providers. Single family homes and sometimes adjoining apartments in which typically three to six people live.
 - *Community Training Homes (private)*: Like foster care homes.
 - *Supported Living (DMR and Private)*: Persons live in own apartments or with others, with less than 24-hour staff services.
 - *Individual Supports (DMR funded)*: A new program, DMR provides an individual support budget, with which a person can fund his/her own residential setting.
- Further descriptions of each type are provided in Appendix C.
- Figure I-2 shows where the 6,131 DMR residential clients live.

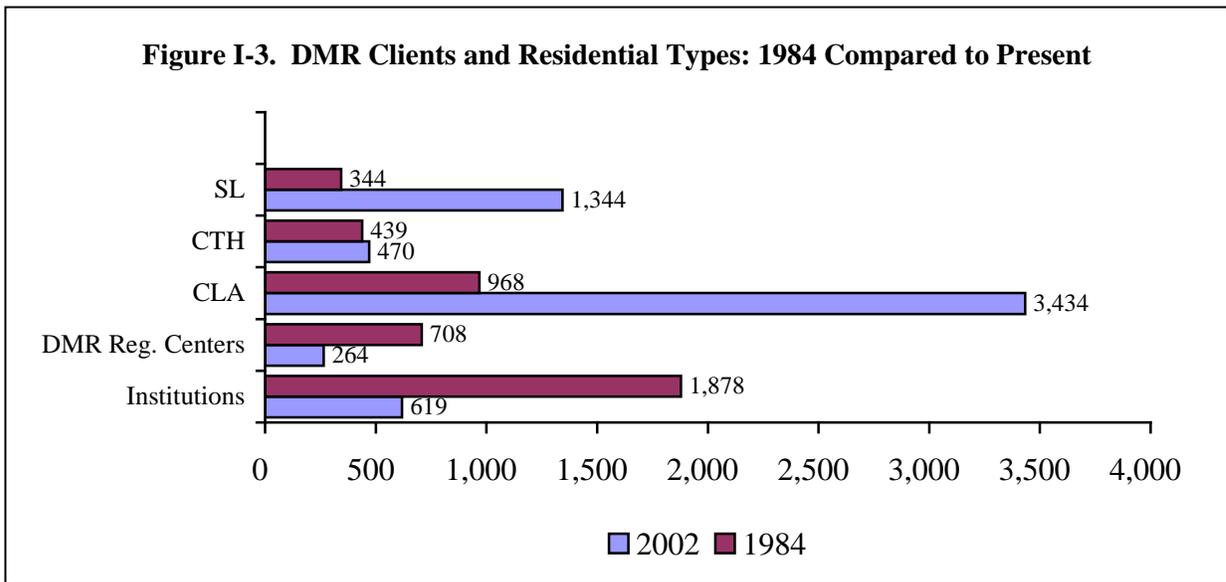


- By far, more DMR residential clients live in CLAs operated by private providers (2,698 -- 44 percent) than any other setting. Conversely, 736 persons (12 percent)

live in DMR-operated CLAs, while the rest live at Southbury, the regional centers, supported living, or community training homes.

How Residential Settings Have Changed

- Figure I-3 compares the number of current DMR run or funded residential types to those in 1984, the year the Mansfield consent decree was settled. The total number of DMR clients in the settings has changed, as well as the mix of residential type.



- In terms of overall growth, the number of DMR clients rose from 10,998 in FY 92 to 14,580 clients in FY 2002, a 34 percent increase.

Organization

- DMR operates with a central office in Hartford supporting five DMR regions that deliver the core services of residential and day programs, along with individual supports through either direct service delivery or contracted providers.
- Figure I-4 maps the five regions – Eastern, Northwest, North Central, Southwest, and South Central.

- *INSERT REGIONAL MAP Figure I-4*

- Figure I-5 shows the current DMR organization. The central office support functions are on the left side, while the regions and functions related to services provided by the regions are on the right side.
- Figure I-6 is a regional organization chart. Until recently, there was no requirement that regions be organized similarly.
- Each region is managed by a regional director and three assistant regional directors, each responsible for one of three main areas -- individual and family support, public services, and private services.
 - Within these areas are case managers assigned to individual DMR clients.
 - Under the private services function, private provider contracts are developed and monitored.
 - Under the public services functions, DMR-operated residential settings are run.
- The Quality Improvement function is part of a new organizational plan, and according to DMR is still being developed. The regional abuse/neglect liaisons, who coordinate private provider abuse/neglect investigations, operate in this unit. (See Chapter V).
- Given the focus of this review is on health and safety in CLAs, it is important to note that organizationally, some key functions like licensing and inspections, and investigations are administered out of the central office, while other oversight functions (e.g., contract monitoring and case management) are carried out by the regions.

Insert Figure I-5 DMR Org Chart

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Figure

I-6

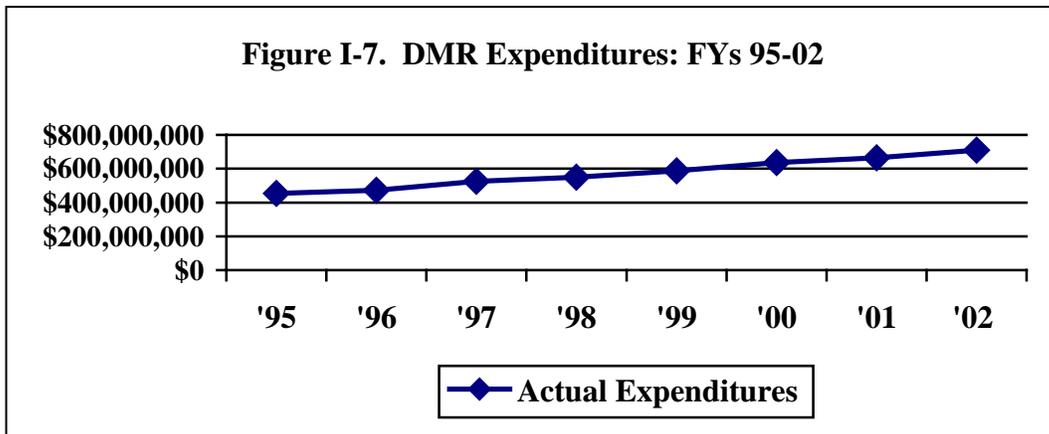
Regional

Org

Chart

DMR Resources

- DMR's total FY 03 budget is \$722 million. Of that total, \$292.4 million (40.5 percent) is allocated for community living arrangements -- including \$192.5 in contract payments going to private providers.
- Figure I-7 shows the growth in the DMR expenditures from FY 95 through FY 02. (See Chapter II for details on CLA expenditures.)



- As of June 30, 2002, DMR employed 4,330 full-time and 1,373 part-time employees. Combining full- and part-time personnel, 137 people (2 percent) work in the DMR central office and 3,628 (64 percent) work in the regions, while 1,938 (34 percent) work at Southbury.

Waiting and Planning Lists

Because DMR residential services are not an entitlement, not everyone who wants or needs a residential placement can get one, resulting in a *waiting list* and a *planning list*.

- The waiting list includes people who seek residential services for the first time from DMR, assuming they either are, or are eligible to be, DMR clients. They are currently living in their family homes or on their own.
- There are also DMR clients already in a DMR residential placement or in some other setting like a nursing home, but need or want to live somewhere else for a variety of reasons. Because of the same resource problem, these people are placed on the planning list.

- As of June 2002, 1,665 people were on DMR's waiting list for residential services.
 - 37 have emergency priority (need placement within 3 months)
 - 573 have Priority 1 status (need placement within one year)
 - 419 have Priority 2 status (need placement within two years)
 - 636 have Priority 3 status (need placement within three years)
- As of the same date, 760 people were currently on the planning list
 - 23 have emergency status; 487 are Priority 1; 116 are Priority 2; and 134 are Priority 3
- There are certain circumstances in which residential placement has to occur, including:
 - court-ordered placement of persons in the criminal justice system;
 - placement of children formerly under the custody of DCF, who have mental retardation, and have "aged out" of DCF jurisdiction; and
 - placement of persons in mental health settings who also have mental retardation.
- DMR also has memoranda of agreement with the Departments of Children and Families and Mental Health and Addiction Services regarding residential services delineating when DMR becomes responsible for former DCF or DMHAS clients.

Other Pressures

- In Olmstead v. L.C., the U.S. Supreme Court held in 1999 that under the Americans with Disabilities Act, states are required to provide the least restrictive setting determined appropriate for a person (e.g., the community), including persons with mental retardation, if that person does not oppose such a setting, and the placement can be reasonably accommodated by the state.
- A lawsuit is pending in Connecticut charging that the waiting list for residential placement and services in Connecticut violates the Americans with Disabilities Act.

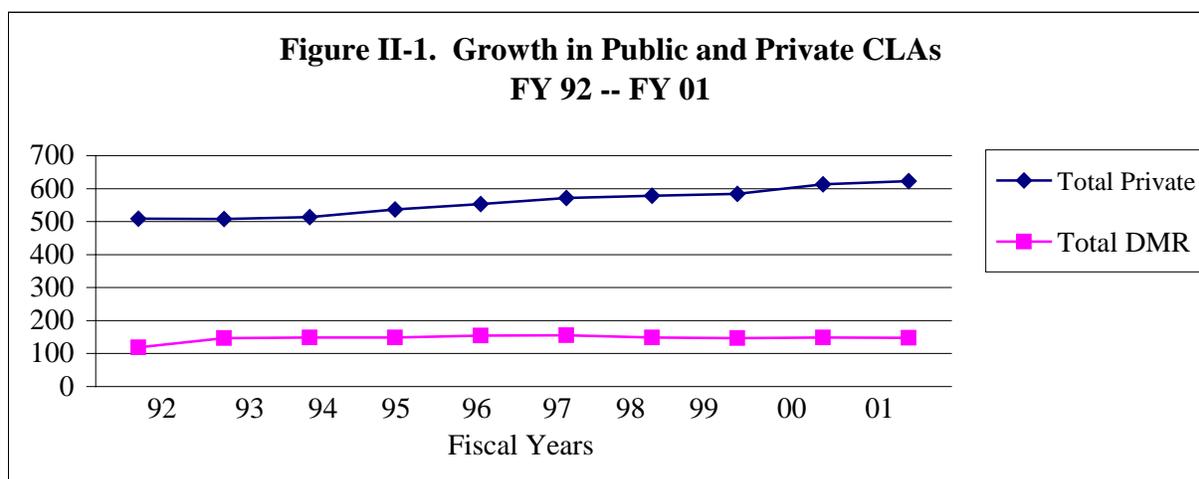
Summary

- The Department of Mental Retardation has evolved into an agency providing or funding residential supports in a variety of settings – (from home to a large institution) — to a broad population of mentally retarded clients with varying health and behavioral issues. The scope of this investigation is to examine how well the department is balancing care for people in their communities while still ensuring their health and safety.

CLA Profile

Providers and Homes

- CLAs are homes where DMR clients reside, located in communities throughout the state.
- CLAs range in size from one to 10 residents, with six being the most common residence size. All have 24-hour staffing.
- There are currently 771 CLAs -- 623 (81 percent) are run by private providers under contract with DMR; 148 (19 percent) are operated by DMR. (See Chapter IV for discussion on contracting of private providers).
- The range in the number of homes per private provider varies widely. The largest operates 78 homes, while a number of providers have only one home each. The top five providers have more than 20 homes each and together manage almost 30 percent of all CLAs statewide. There are 41 providers with four or fewer homes.
- There are 81 private provider agencies -- 17 unionized and 64 non-unionized. DMR homes are unionized.
- Figure II-1 shows the number of homes run by DMR increased from 119 in FY 92 to 155 in FY 97 – or 30 percent. However, between FY 97 and FY 01 the number decreased to 148. Private homes continued to increase during that time, from 509 homes to 623 – or 22 percent.



- CLAs are located in 138 of the 169 towns in Connecticut. Several towns have just one; Windsor has the most with 27.
- CLAs must be licensed by DMR, while DMR’s own homes are “certified” by the department. (See Chapter IV for a discussion of licensing requirements.)
- Sixty-five CLAs are Intermediate Care Facilities for Mentally Retarded (ICF/MR). This designation is issued by the federal Centers for Medicare and Medicaid (much like is done with nursing homes), and entitles these homes to receive Medicaid funding through the state Department of Social Services.
- ICFs/MR are licensed by DMR, but also subject to additional federal regulation and oversight, which in Connecticut is implemented by the state public health department.

Clients (as of June 2002)

Overall Client Capacity

- 3,434 DMR clients live in either public or private community living arrangements
 - 79 percent live in privately run homes (2,698 clients)
 - 21 percent live in CLAs operated by DMR (736 clients)

Clients by Region

- Table II-1 shows the number of CLA clients by region (see Figure I-4 in Chapter I for a listing of towns within each region).
- The North Central region serves the most clients with 1,043 (30 percent), while the Southwest region serves the fewest with 421 (12 percent).
- Over half (54 percent) of the department’s CLA clients reside in the North Central and South Central regions.

Table II-1. CLA Clients by Region		
Region	# Clients in CLAs	Percent of All CLA Clients (n=3,434)
Eastern	594	17.3%
North Central	1,043	30.4%
Northwest	579	16.9%
South Central	797	23.2%
Southwest	421	12.3%
Source of data: DMR Management Information Report, July 2002		

- Table II-2 shows the number and percent of CLA clients by region and whether they reside in private or public homes

Table II-2. Clients by CLA Type				
Region and Number of Total CLA Clients	Clients in Private CLAs	Percent of Clients in Private CLA s	Clients in Public CLAs	Percent of Clients in Public CLAs
Eastern (n=594)	335	56.4%	259	43.6%
North Central (n=1,043)	810	77.7%	233	22.3%
Northwest (n=579)	505	87.2%	74	12.8%
South Central (n=797)	675	84.7%	122	15.3%
Southwest (n=421)	373	88.6%	48	11.4%
Totals (n=3,434)	2,698	78.6%	736	21.4%
Source of data: DMR Management Information Report July 2002				

- Almost 80 percent of DMR's group home clients statewide reside in CLAs operated by private providers.

- The Southwest region has the greatest percentage of clients living in private CLAs (89 percent)
- The Eastern region has the largest proportion of clients living in publicly operated CLAs (44 percent). This is most likely due to towns in this region housing the bulk of clients previously residing in the now-closed Mansfield Training School.

Overall CLA Client Characteristics (as of July 4, 2002 – active clients only)

Summary

- A comparison of CLA client characteristics with those of clients living in all other DMR residential settings, including family homes, shows:
 - both populations tend to be roughly 60 percent male and 40 percent female;
 - CLA clients are older than non-CLA clients, with average ages of 45 and 34 respectively (median ages are 44 and 34);
 - as a proportion of the type of residence, three times as many DMR-CLA clients are profoundly retarded, and twice as many are severely retarded than clients living elsewhere;
 - as a proportion of the type of residence, almost twice as many CLA clients use wheelchairs or have no mobility skills, than non-CLA clients; and
 - almost twice as many CLA clients are blind, compared to non-CLA clients as a proportion of residence type.
- It should be noted, in the client characteristic data given to committee staff by DMR, over 23 percent of mobility and vision data for non-CLA clients were missing, compared to less than one percent for CLA clients.

Sex

- Of the 3,434 clients residing in CLAs, 58 percent are male and 42 percent are female.

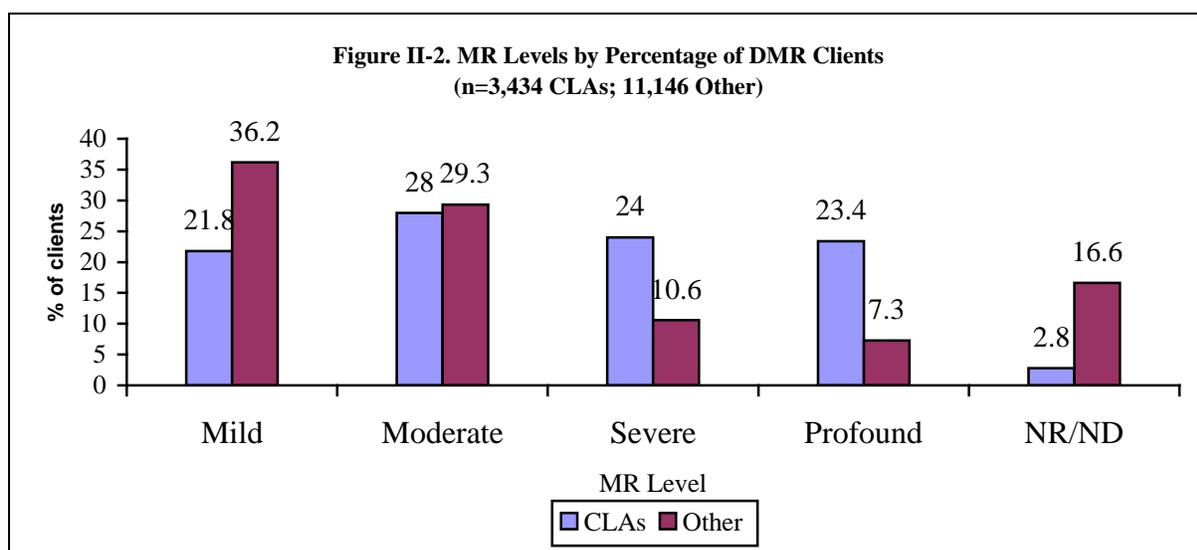
- These percentages are very comparable to DMR’s overall population (excluding CLA clients), where the breakdown is 55 percent male and 45 percent female.

Age

- CLA clients are older, on average, than DMR clients living in other settings.
 - The average age for CLA clients is 45, while the average age for DMR’s total population (excluding CLA clients and including clients living at home) is 34.
 - The median ages are 44 and 34, respectively.

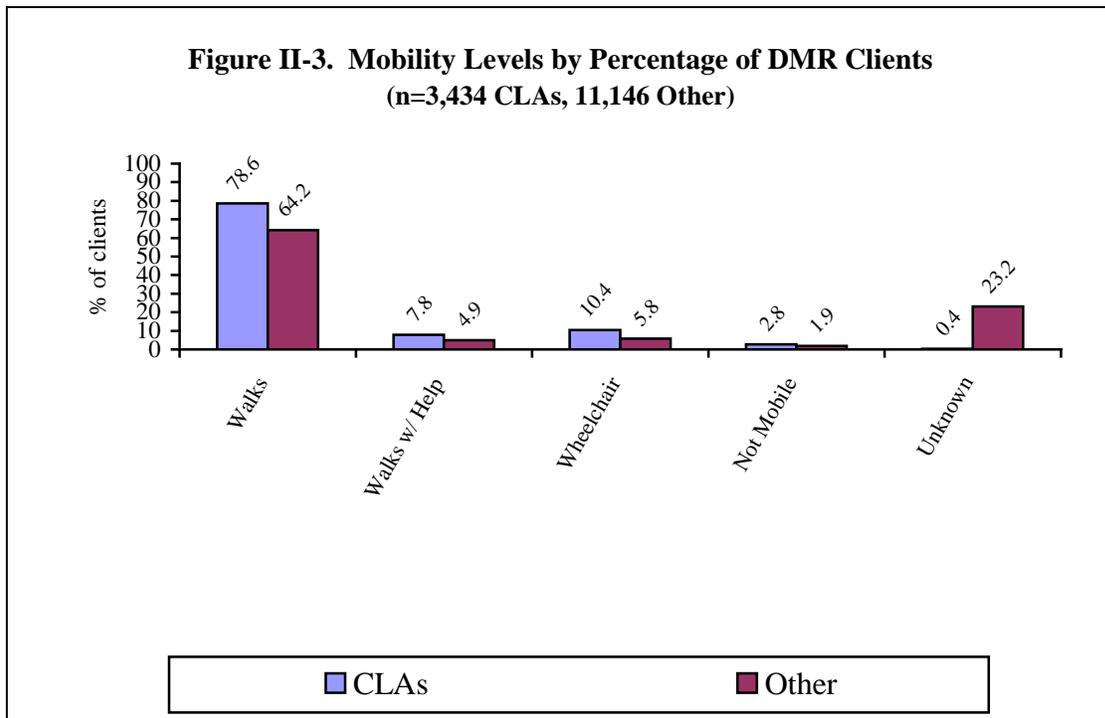
Mental Retardation Level

- Figure II-2 shows the mental retardation severity level (MR level) of CLA clients by percentage. The figure also shows MR levels of DMR clients in all other types of living arrangements (again, excluding CLA clients and including clients living at home). “NR” means the client was not retarded and “ND” means the mental retardation level was not determined.
 - As a proportion of residential type, over three times as many clients with an MR level of “profound” live in CLAs than other living arrangements housing DMR clients, and over twice as many clients have an MR level of “severe.”



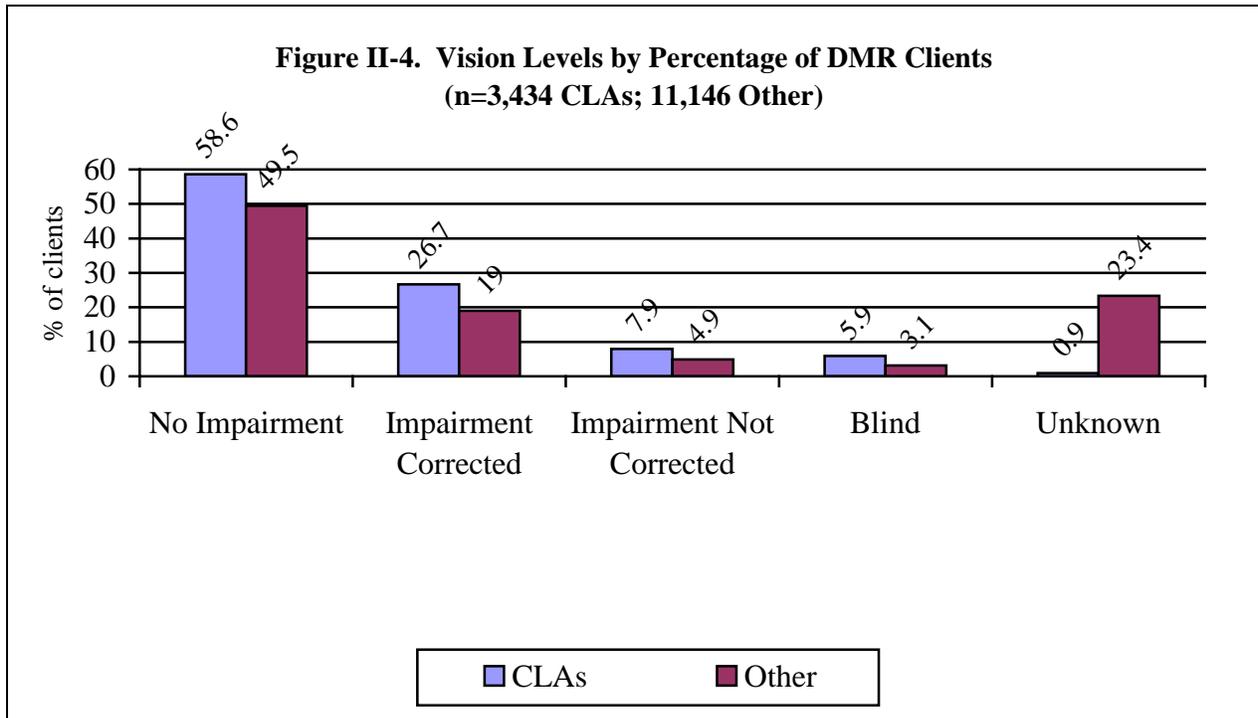
Mobility Level

- Figure II-3 shows the mobility levels of DMR clients living in CLAs by percentages. The figure also shows mobility levels of clients in all other types of living arrangements.
 - Overall, almost 87 percent of CLA and 70 percent of non-CLA clients can walk, either independently or with assistance of a device like a cane or walker.
 - As a proportion of residential type, almost twice as many CLA clients use wheelchairs or have no mobility skills (13.2 percent), than non-CLA clients (7.7 percent.)
 - Mobility data for 23 percent of non-CLA clients were unknown, compared to 0.4 percent for CLA clients.



- Figure II-4 illustrates the visual acuity of DMR’s CLA clients as a separate group and compared with clients living in other settings.
 - Almost 6 percent of CLA clients are blind, compared to 3 percent of non-CLA clients.

- Approximately 60 percent of CLA clients have no visual impairments, compared to 50 percent of non-CLA clients.
- No data exist for 23 percent of non-CLA clients, while less than 1 percent of CLA clients have missing data.



Length of Stay

- The average length of stay in a CLA placement is 8.5 years (as of June 2001). It should be noted, CLAs -- as a residential option -- have only been operating in Connecticut since the late-1980s.
- The median length of stay is six years.

Funding and Expenditures

- Table II-3 shows how CLAs are funded and the total amounts for FY 01.

Table II-3. CLA Funding Sources			
CLA Type	Funding Agency	FY 01 \$m	Medicaid Reimburses
DMR-operated	DMR funds both program and room and board	\$140.5	50% of costs for clients in waiver
Private	DMR funds program portion; DSS funds room and board	\$207.8	50% of costs for clients in waiver
Private ICF/MR	DSS funds all costs	\$37.7	50% of all costs

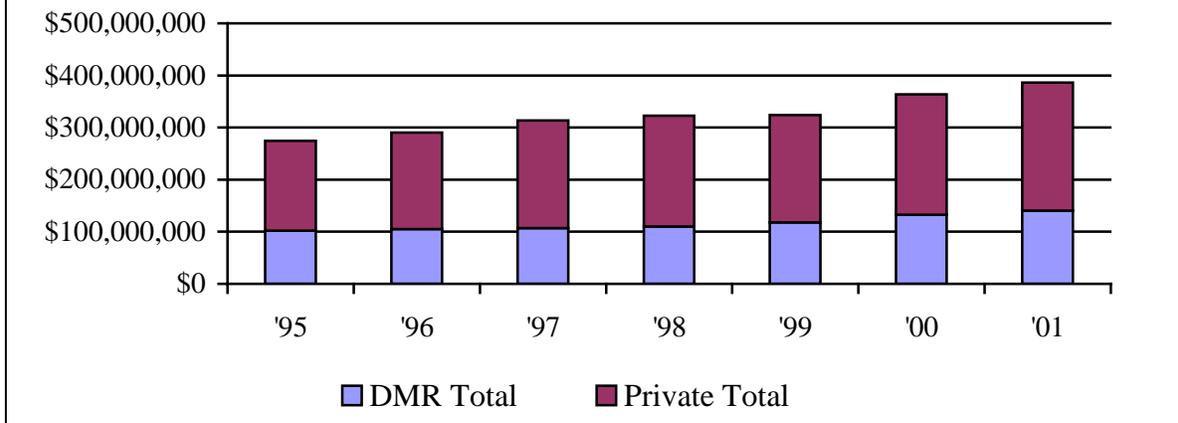
Home and Community Based Waiver Funding

- Ninety percent of the clients who live in CLAs are enrolled in the federal Home and Community-Based Waiver program, which seeks to have Medicaid clients remain in the community, rather than being cared for in institutions.
- Enrollment in the program ensures that Medicaid will reimburse half of the program costs, as well as half of the room and board expenditures. The ICFs/MR group homes are funded entirely through the Department of Social Services, as mentioned above.
- Of the total 2,698 clients living in privately run CLAs, 2,170 (80 percent) are enrolled in the Home and Community Based Waiver program.
- Of the 736 clients living in CLAs operated by DMR, 698 (95 percent) are enrolled in the waiver program.
- CLA clients' medical care is provided in the community. Residents see local physicians, therapists, and dentists at the practitioners' offices. The costs are reimbursed through the individual's Medicaid assistance.

Public and Private Comparison

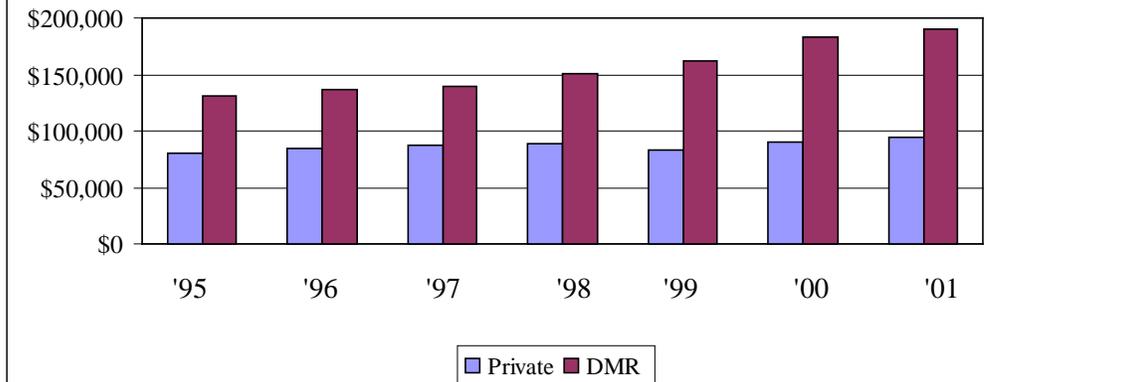
- Figure II-5 shows the total amounts expended on CLAs (both ICF and non-ICF) by both DMR and private providers from FY 95 through FY 01. These expenditures include program, room and board, and other administrative expenses. The private expenditures increased about 34 percent, while DMR expenses grew 32 percent.

**Figure II-5. Total DMR and Private CLA Expenditures
FY 95 - FY 01**



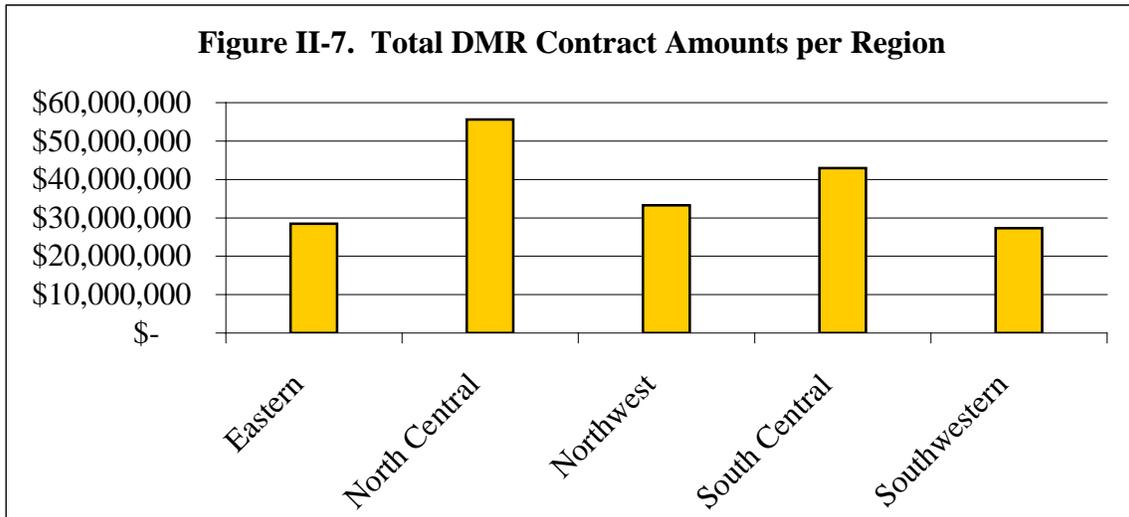
- Private providers receive more of the total funding for CLAs (almost two-thirds); however, private CLAs care for about 80 percent of the clients in those settings.
- In terms of costs per client, DMR expenditures have risen 45 percent in the seven-year period and private provider expenses increased about 19 percent.
- Figure II-6 shows the comparison of the annual cost per client between DMR homes and privately operated homes. In FY 01 it cost about \$95,000 a year to provide services for a client in a private CLA (both ICF and non-ICFs/MR) and about \$190,000 for a client in a DMR CLA -- twice as much.

**Figure II-6. Comparison of Annual Costs per Client in DMR and Private
CLAs -- FY 95 -- FY 01**



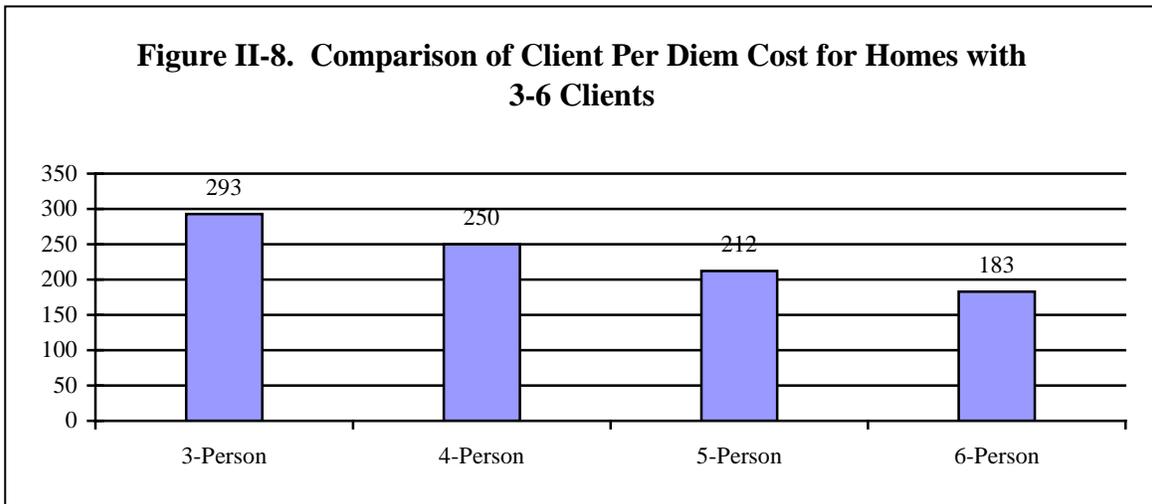
Regional Comparison

- Figure II-7 shows the DMR contract totals to fund privately run CLAs in each region for FY 01. The amounts ranged from \$27.3 million in the Southwest Region to \$55.6 million in the North Central Region. Much of that variation is due to the size of the regions and the number of clients served as discussed above.



- There is variation among the regions in the average *private* annual per-client costs from \$69,688 in the Southwest region to \$89,478 per client in the Eastern region.
- Homes run by unionized providers tend to be more expensive overall than non-unionized. The average daily rate for all homes is \$232; for unionized homes the average cost is \$254 and \$225 for non-unionized homes.
- Older homes and longer-established providers tend to have lower rates than more recently established providers with newer homes. This is due to the fact that newer providers receive initial rates that more closely reflect higher costs while older facilities receive flat percentage increases year after year. Thus, the longer a provider's homes have been operating the greater the gap is likely to be between actual costs and payments made by DMR (similar to the committee's finding in the 2001 Medicaid Rate Setting in Nursing Homes study).

- There is also variation among the *private* CLA per-person program costs based on the number of clients per home. Figure II-8 shows the average daily rate for clients in the most common-sized homes. Generally, the greater the number of clients in a home, the less expensive the daily rate to care for the client. The most expensive is the 3-person home, with a daily cost per person of about \$293.



Staffing

- All CLAs must provide 24-hour, 7-day a week staffing as long as clients are at home. There are no required staffing ratios in any homes. Instead, staffing requirements are based on individual homes, the needs of the clients in a home, the initial licensing application that lays out staffing patterns, and the contracted amounts paid the provider to operate the home.

Screening

- There are no regulatory requirements that staff meet certification or minimum educational levels -- providers may set their own.
- In March 2001, DMR issued a number of human resources policies requiring the following screening measures prior to *hiring new employees* by DMR or private providers (effective date in parenthesis):
 - employer references are checked, and where applicable professional credentials are reviewed and verified (7/1/01);

- a documented review of the Connecticut Registry of Sex Offenders (7/1/01);
 - motor vehicle license and record review to verify that any person who is to transport clients has a valid motor vehicles license (7/1/01);
 - demonstrated employee participation and proficiency in 14 separate areas of staff training (9/1/01); and
 - a documented review of potential employee’s criminal history record. Whenever possible, this history shall be based upon a biometric/fingerprinting analysis conducted by the Connecticut State Police Bureau of Identification (7/1/02).
- If a person is terminated from a provider agency or DMR because of substantiated abuse or neglect, that person’s name must be placed on a registry of persons prohibited from working in direct care services again. Agencies must also screen a potential employee to ensure his/her name does not appear on the registry before the person can be hired. The use of the registry is currently facing a legal challenge and its use is suspended until new regulations can be developed.

Training

- All direct care staff must be *trained within 30 days of being employed and retrained every two years*. New employees must work with other employees until they have received training in:
 - signs and symptoms of disease and illness;
 - communicable disease control;
 - resident basic health;
 - routines of the residents; and
 - emergency procedures of the residents.
- The training content and duration, method of training, and qualifications of the trainers must be documented by the provider. Written summaries of the training content must be available to DMR upon request.

- All direct care staff must be trained within six months, and retrained every two years in the following areas:
 - first aid for accidents;
 - agency policy and procedures;
 - abuse and neglect prevention and reporting (*now required annually*);
 - planning and provision of service; and
 - behavioral emergency techniques.

- At least one staff person for each shift shall be certified in cardiopulmonary resuscitation (CPR), and any person who administers medication shall be certified and possess a valid card attesting to the certification.

- Screening and training of staff is subject to review by a licensing inspector when a home is being relicensed.

- In addition to direct care staff, provider agencies and DMR also employ other persons such as nurses, psychologists, behaviorists, and occupational, speech, and physical therapists. Most of these professionals work on a consultant basis, providing planning, assessment, and monitoring of clients' programs rather than direct care services.

- For some nursing responsibilities, licensed nurses may delegate to direct care staff in certain situations (as explained in Chapter III).

Levels and Salaries

- Committee staff analyzed direct care staffing ratios and salaries for public and private homes for FY 01. These are shown in Table II-4.

 - The resource data show a substantial gap between DMR and the private agencies in the staffing and salaries of DMR and the private providers who operate CLAs under contract. The ratio of staff to clients is higher in DMR homes where it is almost two staff for each client; in private homes there is a better than 1:1 ratio. The numbers of FTEs equal or exceed the number of clients because of the three-shift coverage; it does not mean that each client has one direct care staff taking care of him or her.

 - The salary gap between DMR and private agencies continues to widen -- from a 23 percent difference found in program review's 1992 study of group home staffing to 33 percent in FY 00 to 39 percent in FY 01. In FY 01, private providers expended \$78.5 million in salaries for 2,863 (FTE) direct care staff including substitutes. This translates to an average salary of \$27,397. DMR homes expended about \$48 million for 1,253 (FTE) staff, resulting in an average salary of \$38,369.
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Table II-4. Comparison of Direct Care Resources in DMR with Private Provider Community Living Arrangements (FY 01)		
	Private Providers	DMR
Total Direct Care \$	\$78,450,421	\$48,076,700
Total Direct Care Staff (FTEs)	2,863	1,253
Total Clients in CLAs*	2,347	739
Staff-to-Client Ratio	1 to .81	1 to .58
Avg. Direct Care Salary**	\$27,397	\$38,369

Sources: DMR data on private homes compiled from ACOR; DMR data on staffing and salaries on public homes. Client information from 7/02 Management Information Report. *These numbers do not include staff or clients in ICF/MR homes. There are 345 clients in ICF/MR homes, and 23 “private pay” individuals. DMR states funding and staffing for those clients are not reflected in the numbers in the table. ** Average salary for both private and public CLAs is the total amount paid in wages divided by the total FTEs; thus it is likely higher than the base salary.

Turnover

- Until recently, staff turnover was not information the department requested from private providers. Earlier this year, regional DMR contracting staff began collecting turnover data as part of the contract. However, that data have not yet been analyzed, and it is not clear whether they will be aggregated or will be used in each region as a monitoring tool for individual agencies.
- Recent national figures of staff employed in residential support programs showed a turnover rate of 35.2 percent.² In Connecticut, December 2001 figures collected from 30 private provider member agencies of the Connecticut Community Providers Association indicated a median turnover rate in FY 00 of 22 percent.³
- DMR’s turnover rate among direct care staff, which includes workers at Southbury Training School, regional centers, as well as CLAs and is for both full-time and part-time staff was 6.4 percent in FY 01 and 5.8 percent in FY 02.

² Turnover rate reported from 14 states included in the Core Indicators Project, a quality improvement endeavor sponsored by the National Association of State Directors of Developmental Disabilities Services. This is a similar to the turnover rate program review found in its study of CLAs in 1992.

³ This is similar to the private provider turnover rate of 24 percent program review found in its 1992 study.

RESIDENTIAL PROGRAM

Individual Planning And Placement

- Before a person becomes a CLA resident, there is a series of steps that include:
 - determining a person’s eligibility for services from the department;
 - assessing the person’s needs and prioritizing those needs among others also seeking CLAs;
 - identifying a CLA vacancy; and
 - deciding the identified CLA is appropriate for the person.
- After a person moves into a CLA, another series of activities occur that includes individual program planning, implementation, and monitoring.
- Figure III-1 sets out the key points in the individual placement, planning, and program delivery process.

Request for Service: First-Time Residential Placement Seekers

- Any person with mental retardation seeking residential placement for the first time and who is not already a DMR client must go through an intake process to determine eligibility for services, receive a DMR client number, and be assigned a case manager. Persons already receiving another type of service from the department must also go through the residential assessment process.
- Next, a needs assessment is done of the individual by the case manager and a team with a variety of disciplines (e.g., psychologist, nursing, occupational therapy). This needs assessment seeks to establish the level of residential support needed by the person.

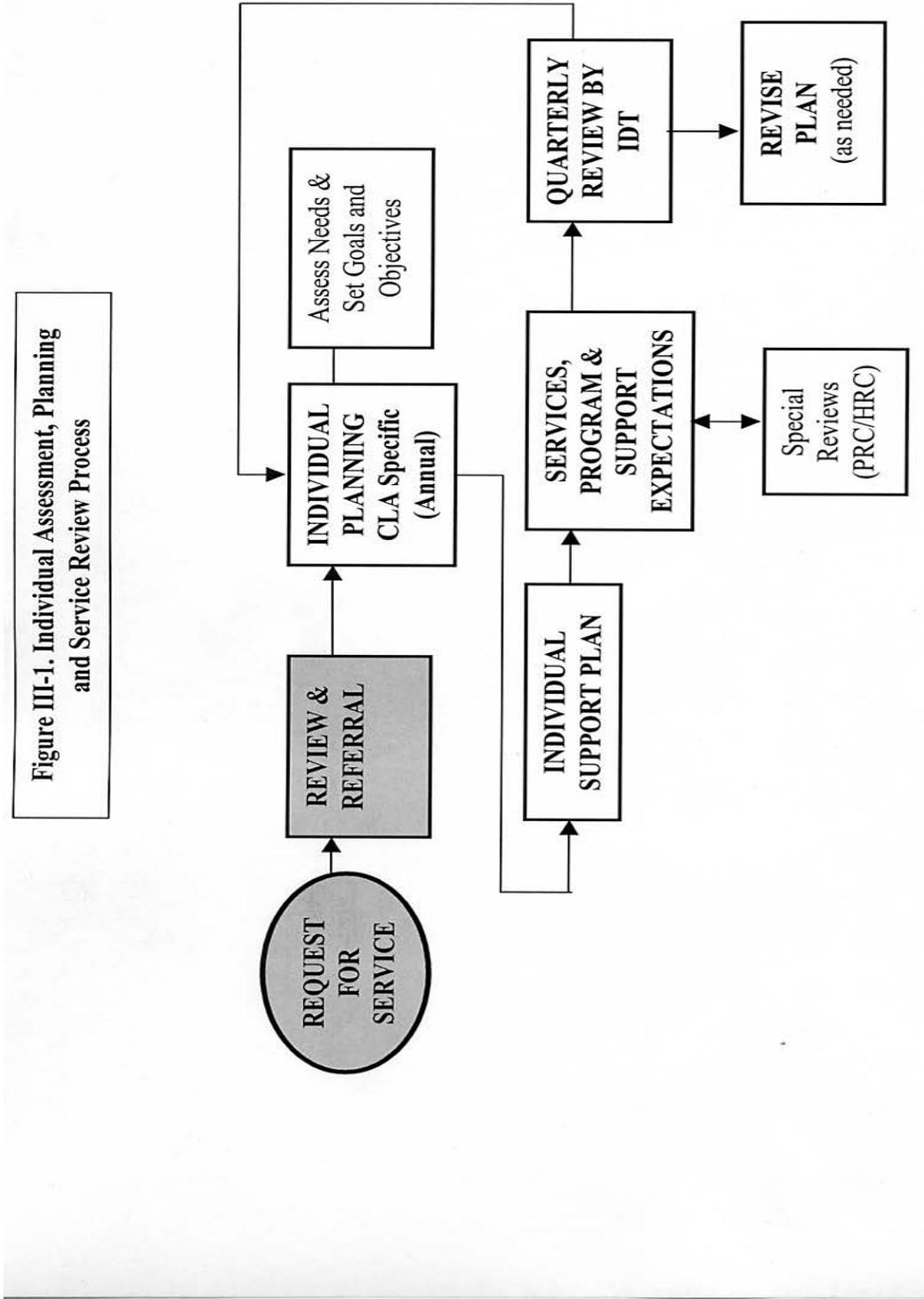


Figure III-1. Individual Assessment, Planning and Service Review Process

Source: DMR

- Written requests for first-time residential placement are prepared by a client's case manager and submitted along with the completed support needs assessment to the pertinent region's Planning and Resource Allocation team (PRAT) for placement on the region's *waiting list*.
- The regional PRATs are appointed by the regional directors and are responsible for receiving residential (and day) program service requests, reviewing and prioritizing DMR client needs for those services, and allocating residential (and day) resources. For residential services, each team:
 - reviews the priority status of persons on the regional planning list at least annually;
 - reviews the status of persons who are deemed waiting list emergencies on a monthly basis;
 - reviews available resources; and
 - matches resources to individual requests and making referrals to providers.
- Each regional Planning and Resource Allocation team establishes a waiting list priority for each person seeking first-time residential placement, based on the individual's present living situation.
 - *Emergency*: need for residential supports and services within three months
 - *Priority 1*: need for residential supports and services within a year
 - *Priority 2*: need for residential supports and services within two years
 - *Priority 3*: need for residential supports and services within three years
- This determination is based on the individual's present living circumstances.

People Already in a Residential Placement Seeking Change: Review and Referral

- DMR clients who are already in a DMR operated or funded residential placement may seek a change in placement. Reasons can include: need for more nursing care; conflict with a housemate; or wanting to be closer to family.
- Case managers for these DMR clients will also submit a written request for a change in placement to the PRAT.
- As with first-time placement seekers, the regional PRAT will make a determination of priority status, using the same scale. However, a separate list is kept for persons who already receive DMR residential support but seek a change – a *planning list*.

Referrals for Possible Placement

- When a placement vacancy becomes available, the PRAT will discuss who from either the waiting list or planning list to *refer* to the provider for consideration.
- The team knows of vacancies in group homes because private providers and DMR-operated homes must inform the team as they occur. Homes also are to provide profiles of each house and their residents for use by the team.
- Clients with emergency waiting list or planning list status must be considered first when vacancies occur.
- There are several factors impacting whether someone will be referred to possibly fill a vacancy, including physical needs, medical needs, and personality. (Such factors may be less crucial if the placement is an emergency)
- When making a referral, the PRAT distributes a client referral form and information packet to a potential provider (as determined by the team). Referrals are to be made within a week of the team meeting.
- Referral packets vary depending on how much available information DMR has about a person. Ideally, the client information packet will contain pertinent current functional assessments, including medical and psychological.

- Providers are encouraged to meet with potential clients and their families (and vice versa) prior to a placement decision to assess how the client could be supported in the home and fit in with the people already living there.
- A provider must inform the team within three weeks regarding its interest and ability to serve the person. The placement decision must also be accepted by the client and/or his guardian or family member.
- Emergency placements may be made outside of the typical planning and resource allocation process, according to DMR policy. In other words, the above process may not happen when a DMR client has no place else to live.

Transition Plan

- Ideally, per DMR policy, a person will move to a new residence within two months after the provider agency and the client have agreed the move is acceptable. Transition planning is needed to ensure the move into the new home and environment is as smooth as possible, and the client's needs will be met despite the change. A written transition plan should be in place to facilitate the move for both the new resident, the housemates, and staff.
- For example, a client may spend a few hours each evening along with a couple of overnights at the new residence during this period of adjustment. This helps assess the client's compatibility with the other residents and enables staff to acquaint themselves with the client's needs gradually. Also, staff from the new home may visit the client in the client's present setting.

Individual Support Plan

- Once a person has been placed in a DMR run or licensed CLA, a planning process focused on that client begins to determine what services would best meet the client's needs and preferences in that setting, and establishes goals and objectives to address those needs and preferences.
- The process results in a written individual support plan, known primarily as the *Overall Plan of Service (OPS)*. The plan covers all aspects of a person's life, including:
 - residential life at the CLA, (referred to as activities of daily living or habilitative services);

- any medical, behavioral, dietary, personal care, and health and safety needs;
 - employment or other day activities; and
 - community involvement.
- The plan is to be reviewed at least annually, with quarterly implementation updates.
 - Each client has an Interdisciplinary Team (IDT) to assist with the planning and implementation of the client’s support plan. The team includes: the client (when possible); the client’s family member, guardian, or advocate; the DMR case manager; staff from the client’s home residence, and any specialists needed (e.g., a behaviorist or speech therapist)
 - The plan is specific to his or her current living situation. It must be developed within 45 days after the move to the CLA, and must be implemented within 30 days of development. (The transition plan is to cover any needs prior to the completion of the OPS.)

Program Implementation

- Once a client has been placed in a CLA, his/her individual plan (the OPS) is kept at his home. It is largely the responsibility of the client’s residential program to implement the plan.
- The major parts of the plan typically include:
 - habilitative services (i.e., activities of daily living);
 - behavioral program (if one is necessary);
 - health and safety needs;
 - day (i.e., vocational or employment) program; and
 - community living.

Habilitative Services

- The habilitative program encompasses two major components for each client: 1) individual activities of daily living -- moving about, eating, dressing, and individual hygiene for him/herself; and 2) his/her participation with household

activities -- assisting with meal preparation, bed-making, clean-up, and the like.

- The residential provider must have a written policy giving employees direction on how the habilitative program will be carried out using sound residential service practices and DMR policies to enhance the client's everyday life.

Behavioral Program

- If a client engages in behavior that is harmful to him/herself or others, or is socially unacceptable, the interdisciplinary team develops a program to reduce the targeted behaviors. (Any medications must be prescribed by a physician.) The residential program must have policies and procedures that will implement the behavioral program through:
 - defining the use of behavior management techniques;
 - obtaining approval from the program review or human rights committees for behavioral plans that include any techniques or strategies for aversive procedures and/or restraints or behavior-modifying drugs;
 - ensuring the use of such restraints is limited by describing when they will be used; that they are designed and used to cause minimal discomfort; that staff are trained in the strategies or techniques; and that the client will be checked at least once every 30 minutes; and
 - ensuring that in a behavioral emergency, the client will be managed using plan-approved techniques before resorting to police intervention or admission to a hospital emergency room or a psychiatric facility. If any of the latter actions must be taken, the residential provider must notify DMR of the action.
 - If a behavioral program is in place, residential program staff are expected to implement the program through the strategies laid out (e.g., redirect the client from the targeted behavior) and are generally required to keep data on the behaviors and program implementation so the IDT can monitor whether the behavior-modifying strategies are having an impact. Residential programs are also required to report to DMR any unusual incidents, including behavior issues. Incident reports are kept on an automated database, and incident data
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are also examined quarterly by the client's IDT when reviewing his or her OPS.

Health and Safety

- A licensed residential facility is statutorily responsible to “insure the comfort, safety, adequate medical care and treatment” of the clients it cares for. By regulation and DMR policy, the residential program must ensure its health and safety practices include the following procedures.
 - Medicines are administered by staff certified by DMR in medicine administration, or that the client can self-administer.
 - Staff are sufficiently aware and trained -- “in-serviced” -- in a client’s health and safety issues to provide needed services appropriately and correctly. In many cases, these functions may be delegated by a registered nurse⁴. The registered nurse must: 1) determine whether it is a function that allows delegation; 2) train all staff who will perform the task; and 3) verify, document, and monitor that they are competent to carry it out.
 - Using a newly developed procedure called “risk-screening”, which case managers must see that the IDT completes, to:
 1. identify clients who may be subject to risks in several health and safety areas – like seizure disorders, severe mobility limitations, and/or swallowing or eating disorders;
 2. determine whether more comprehensive assessments are necessary; and
 3. ensure a plan is in place for those individuals at risk. Assessments will be conducted on all clients currently in CLAs, updated annually (or earlier if a new risk is determined) and when a new client is screened prior to receiving services.

⁴ In January of 1989, the CT Board of Examiners for Nursing issued declaratory ruling concerning delegation of nursing responsibilities. Some clarification regarding the ruling was issued in April 1995, and DMR has issued its own policies to guide implementation.

Medical

- The residential program must provide nursing services – either through its own staff or via RN consulting services -- including coordination, assessment and monitoring and provision of medical services, and planning and implementation of training for direct care personnel.
- A nursing assessment must be conducted for any client living in a CLA. The assessment is conducted within 30 days of placement as part of the client's OPS. It must be updated annually or when a client's health status changes. The RN is responsible for the total plan of nursing care and should be proximately available for on-site visits and available by telephone.
- The residential program is to ensure clients receive medical examinations as indicated by the individual's physician; that any follow-up in the way of exams or testing are carried out; and there exists signed and dated documentation of physician's orders, progress notes, or other medical records that medical attention is provided. Any special health concerns, like a non-ambulatory client requiring repositioning to prevent pressure sores, should be addressed and implemented by the residential provider staff.

Dental

- The residential program must ensure that: *dental exams* occur as required by the dental provider; follow-up or testing occurs as required; signed and dated documentation of dental services by the dental provider is furnished; and ongoing dental care is overseen as written in the orders (e.g., use of special oral rinses; assistance with tooth brushing).

Dietary

- The residential provider must also ensure each client is given adequate nutrition and liquid to meet their needs. Residential staff are responsible for implementing programs requiring:
 - *special diets*, like low cholesterol, specific caloric intake, or a diabetic diet;
 - *special consistency diets* (e.g., ground, pureed, or thickened liquids only); or
 - *adaptive equipment* for eating (like special cups or plates).

Health Oversight

- Each region employs a Health Services Director who is a Registered Nurse. The regional health directors are responsible for the coordination and delivery of health care services (nursing, physical, speech and occupational therapy, and dietary) for clients in publicly run residential programs, ensuring quality medical and dental care are provided in the community, and providing support to private sector agencies and their staff.
- Each regional health services director (HSD) establishes preventive health care programs for individuals in DMR's own residential programs and issues comparable care guidelines for private providers that comply with department policies, medical advisories, and federal and state health care standards. Each HSD also develops in-service (training) programs in health care areas, and meets monthly with private provider nurses on residential health care issues.
- DMR has a Director of Health Services (see Figure I-5 for organizational chart) located at the central office. While the regional health services directors report administratively to the regional directors, the HSDs have a clinical link with DMR's health services director in central office. The regional and state DMR health services directors currently meet at least quarterly to identify issues of health and safety, and develop bulletins and advisories that inform and assist private residential agencies and DMR in providing health and safety for their clients.
- Other advisories may be developed by physicians familiar with persons with developmental disabilities on health issues, and disseminated through DMR's website to providers and the agency. Sometimes, as a result of regional or statewide mortality reviews, (See Chapter VI) a health or safety issue will surface that requires a bulletin or advisory to be issued by the mortality review board. Over the years, DMR has issued 14 bulletins, five nursing standards and associated guidelines, and 22 medical advisories. (See Appendix D for a list).
- DMR's Quality Assurance Division, through licensing inspections and follow-up at each home, ensures these health and safety policies and practices are being implemented. In addition, Quality Assurance may, at times, issue a safety alert as a result of inspection results.

Day Program

- An integral part of a client's individual plan is how they will spend those critical hours during the day – i.e., the work or vocational plan otherwise known as their day program. Almost all CLA clients have some type of day program.
- Typically, a client's day program occurs at another location than his/her residence, although for a minority of clients the day program is operated at the clients' home. Even if the client goes off-site, the residential program must ensure the client gets ready for his or her day program, and often for transporting the person as well.
- Programs vary depending on the client's level of independence.
- In FY 01, 7,985 clients were involved in day programs – 7,028 at privately contracted day programs and 957 at DMR-run services.

Community Living

- A final part of a client's plan is his/her participation in the community. While often a less formal part of an individual's program, the residential provider must ensure this community component occurs. These individual activities might range from helping with household functions – like grocery shopping – to trips to the library or social activities like movies, dances, or community concerts.

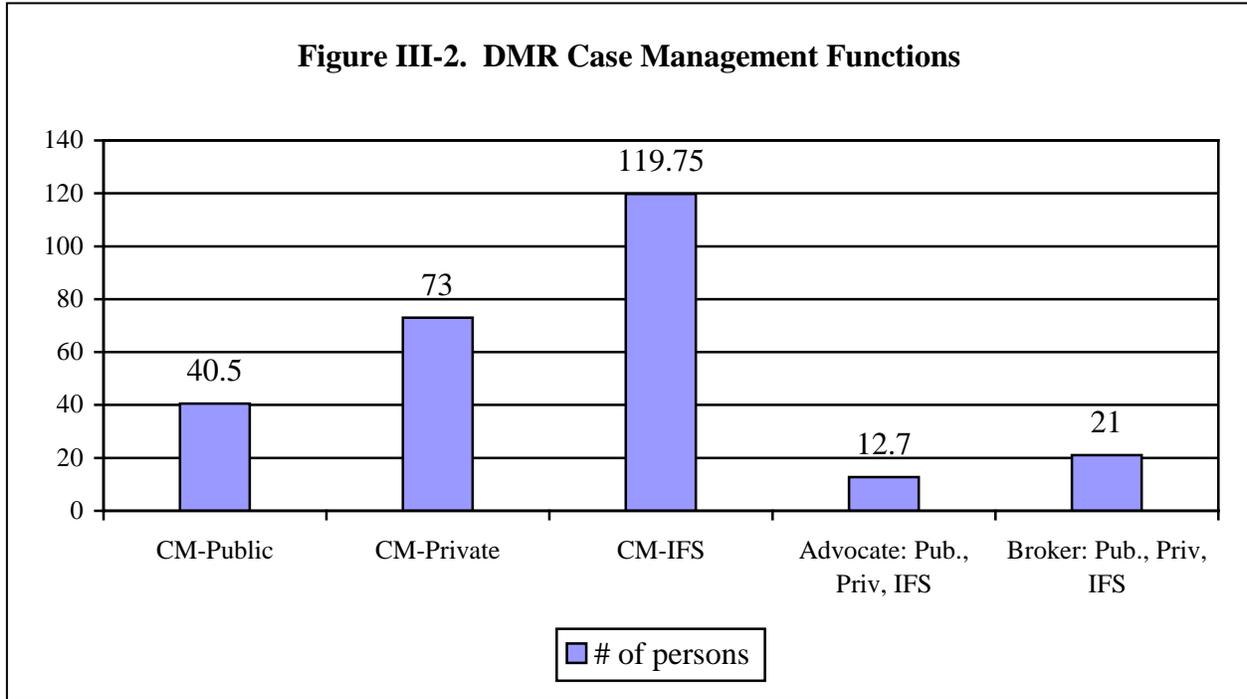
Individual Plan and Program Oversight

- Once a client's plan has been developed and the residential program is implementing it, there are a number of mechanisms in place to ensure the plan is carried out, whether it needs adjustment, and how modifications should be made. Some protections, in the way of regional committee approvals, are put in place to ensure a client's rights are considered in the plan implementation.
- The client's case manager is responsible for ensuring the plan is appropriate and being implemented. If changes need to be made, the case manager is to bring them to the client's IDT.
- Case managers are “responsible for assisting individuals to gain access to department services, managing development, modification, and

implementation of a client's OPS, securing and/or coordinating services, monitoring client progress, maintaining family contact, collecting and disseminating data and information.”

- The case management function occurs at the regional level. In recent years, partly because of changing services and supports DMR provides, case management has been changing.
 - Traditional case managers serve people living in CLAs, CTHs, or supervised living.
 - Since a 7/1/01 regional reorganization, case managers are assigned to clients who are either all in public programs or all in private programs.
 - Case managers for clients in DMR-operated CLAs do more of the actual case manager functions (e.g., coordinate IDT activities and produce the OPS), while case managers for private provider clients are in more of a monitoring role to ensure the private provider performs these activities, depending on the provider.
 - Traditional case managers also serve persons who live at home or on their own, but they have somewhat different functions, and are less involved.
 - Advocates are DMR employees who serve people who are more independent and need less attention. These can be DMR clients living in supported living or with their families or on their own.
 - Brokers, the newest wrinkle related in case management, are DMR employees who assist DMR clients who have individual support budgets.
 - A difference in case management is that one region (Eastern) for DMR-run residential services has 19 program supervisors functioning as Team Leaders, providing case management functions for about 21 individuals each. These people also supervise DMR residential programs.
 - All this variation makes comparing numbers and caseloads difficult. However, as of October 2002, there are 267 DMR employees providing some
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kind of regional case management function: 12.7 are advocates, and 21 are brokers. 233.25 are considered traditional, with 113.5 for CLAs, CTHs and supported living ,and 119.75 for individual and family services.



- Table III-1 shows the CLA case manager caseloads (includes clients in CTHs and SLA) broken down by region and by public or private program. The public client case manager caseload varies by region from 21 in Eastern to 47 in North Central. (As noted above, case management is provided by residential program supervisors in the Eastern region). The private provider case manager caseload also varies, from a low of 46 in Eastern to 60 in Southwest.

Table III-1. Case Manager Caseloads – October 2002.					
Region	Public		Private		Totals
	# Case Managers	Average Caseload	# Case Managers	Average Caseload	
Northwest	5	38.8	15	55.6	20
North Central	9	47	20	54	29
Eastern	19	21	15	46	34
Southwest	5.5	38	9	60	14.5
South Central	2	45	14	50	16
Totals	40.5		73		113.5

Appeals of DMR Services

- Any individual client or his representative can appeal any need evaluation, priority designation, or other CLA service provision decision (e.g. staffing) under the process of programmatic administrative review (PAR). The first level of appeal is to the regional director. If the person disputing the regional decision is still not satisfied, he or she can appeal to the DMR commissioner.
- In the five year period FYs 97-2001, 305 appeals were filed at the regional level. 27 were appealed to the commissioner. In most cases the regional director decision was upheld, but in some, the decision was modified.

Program Review Committee

- Any behavioral program for DMR clients living in public/private provider residential (and day) settings using behavior modifying drugs or aversive procedures must be approved by the applicable regional director prior to its implementation.
 - An aversive procedure is “the planned use of an event that may be unpleasant, noxious, or otherwise cause discomfort to alter the occurrence of a specific behavior or to protect an individual

from injuring individual or others. These procedures include the use of physical isolation, mechanical and physical restraint.”

- Before the regional director makes his/her decision, a Program Review Committee (PRC) must first review the proposed program for clinical appropriateness prior to its use, and make a recommendation to the director.
- The PRC also reviews procedures used during an emergency intervention and monitors their use.
- Each region and the training school has a Program Review Committee, a requirement of the 1985 Mansfield Consent Decree.
- The PRC, appointed by each regional director, is a “group of professionals,” including a psychiatrist, assistant regional managers, executives of contracted agencies, contracted specialists in the disciplines of special education, psychology and medicine, and a representative from the Human Rights Committee. (see below) The committee members elect their own chair and typically meet monthly.
- Clients, parents, guardians, and/or advocates may attend the committee’s meetings, which provide technical assistance to the regional or STS directors pertaining to client program policies.
- The person’s IDT is responsible for preparing information packets to be considered by the PRC. The actual presentation to the PRC can be done by a psychologist or nurse.
 - Informed consent from either the client or guardian is required for use of behavior modifying drugs or aversive procedures
- In reviewing the above, the committee is to ensure that any proposals are clinically sound, supported by proper documentation, and are for uses in accord with DMR policies.

Human Rights Committee

- Any restriction on a DMR client’s civil rights must also be approved by the regional director prior to its implementation (e.g., a person’s privacy right to be in his or her own room without being monitored at all times by a room monitor).

- Before the regional director makes a decision, a Human Rights Committee (HRC) reviews the proposed restriction, and make a recommendation to the director. This is mainly accomplished by reviewing client behavior programs.
 - Each region and Southbury Training School are required to have a Human Right Committee, also a requirement of the 1985 Mansfield Consent Decree.
 - Examples of issues that come to HRCs are use of house alarms, audio room monitors, locked bathrooms, closets, sharp utensils, cleaning supplies, or locked refrigerators and cabinets, dating guidelines, restrictions and/or supervision, search and removal of personal property, and sedating medications prior to medical and dental appointments
 - The committee is made up of six to ten people who serve three-year terms. By DMR policy, the regional director was to make the first appointments when the HRCs were first created; after that, the committee makes appointments to fill vacancies. Members are to include a physician, a lawyer and at least one parent (and no DMR employees). The regional director or designee is supposed to attend all committee meetings in a liaison capacity. A DMR regional staff member is assigned to assist the committee in its work.
 - The committee considers the following questions.
 - What is the purpose for the proposed restriction?
 - Is it a safety issue, and why? Because of person's age, health, or medical condition; type or pattern of behavior; environmental issue beyond control of provider?
 - What less intrusive/restrictive means have been attempted to address problematic behavior?
 - Has the impact of the restriction been assessed on housemates, and have all housemates/guardians agreed to restriction?
 - Is the restriction needed at all times?
 - What are the criteria for discontinuing the restriction?
-

DMR OVERSIGHT OF CLAs

There are two major ways DMR oversees CLAs and the services they provide:

- licensing and inspections of privately operated homes and certification and inspections of facilities operated by DMR; and
- contract monitoring of provider agencies and homes operated by them.

These oversight mechanisms are described in this chapter.

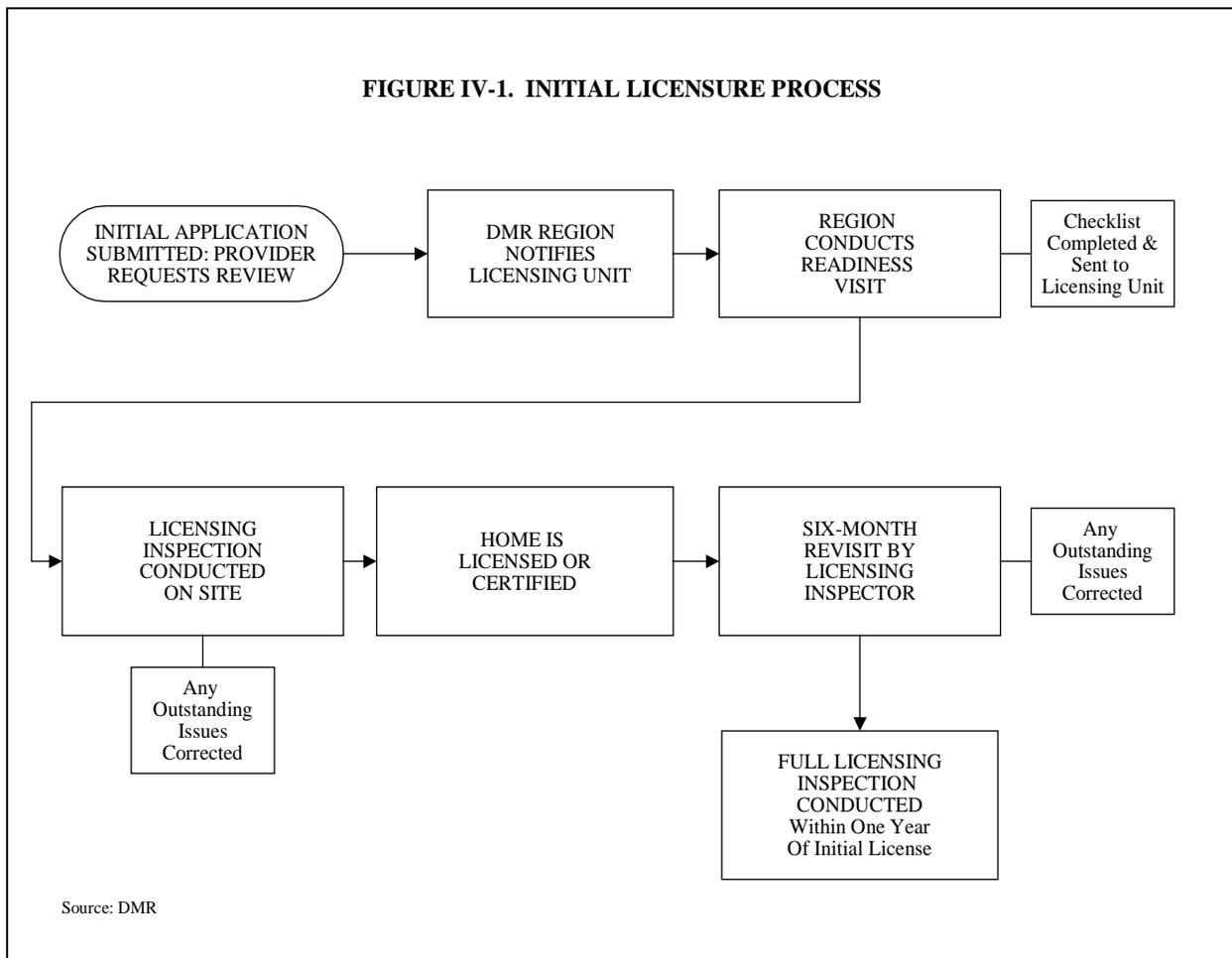
Licensing and Inspections

Background

- All privately run CLAs are required to have a state license and undergo periodic inspections by DMR. Inspections are to occur at the initial licensing/certification stage and at least biennially thereafter. Inspections and the licensing process help ensure the implementation of DMR health and safety regulations, as well as program-oriented regulation, for the overall health and safety of CLA residents.
- CLAs operated by DMR are “certified” rather than licensed, since they are operated by the state. State-run CLAs go through the same inspection process as private homes.
- State licensing regulations outline basic standards for operating a group home, including home safety, emergency planning, staff training, individual client records, financial records, agency policies and procedures, and compliance with local fire and building code requirements.
- Licensing and inspections are DMR central office functions within the Quality Assurance Division (QA). There are six inspectors (each with caseloads of roughly 130 homes) and one supervisor responsible for licensing and inspecting the roughly 780 CLAs statewide. The inspectors’ backgrounds vary (although none is a registered nurse.) All inspectors have experience working with the developmentally disabled population.

Pre-License Inspection Process

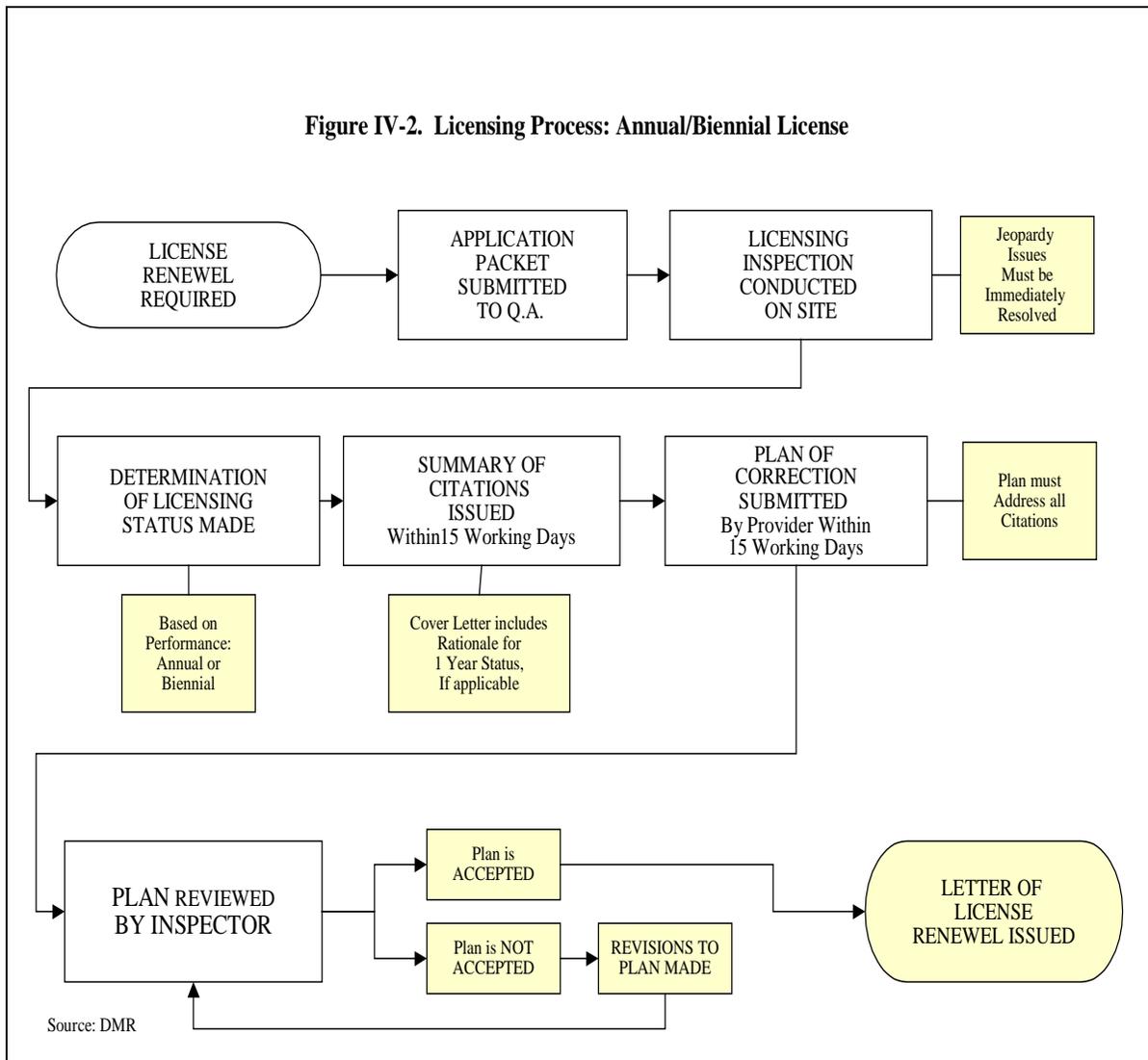
- Figure IV-1 shows the process for obtaining an initial license to operate a group home.
- A provider must first submit an application to operate a group home. A preliminary inspection is then conducted by regional staff before a full inspection by the department's central licensing unit. The information is to be forwarded to the licensing unit at least 10 days prior to the anticipated open date of the facility.
- A licensing inspector reviews the information for completeness and accuracy before going to the home and conducting the initial licensure inspection. This inspection is conducted prior to residents moving into the home.



- Upon a successful initial inspection, a private home is given an operating license, while DMR-operated homes are “certified.” This allows clients to move into the home. The inspector may revisit the home within six months of operation to conduct another review. If deficiencies are found, the provider is responsible for making the necessary corrections.

Post License Inspections and Renewals

- Figure IV-2 illustrates the license renewal process.



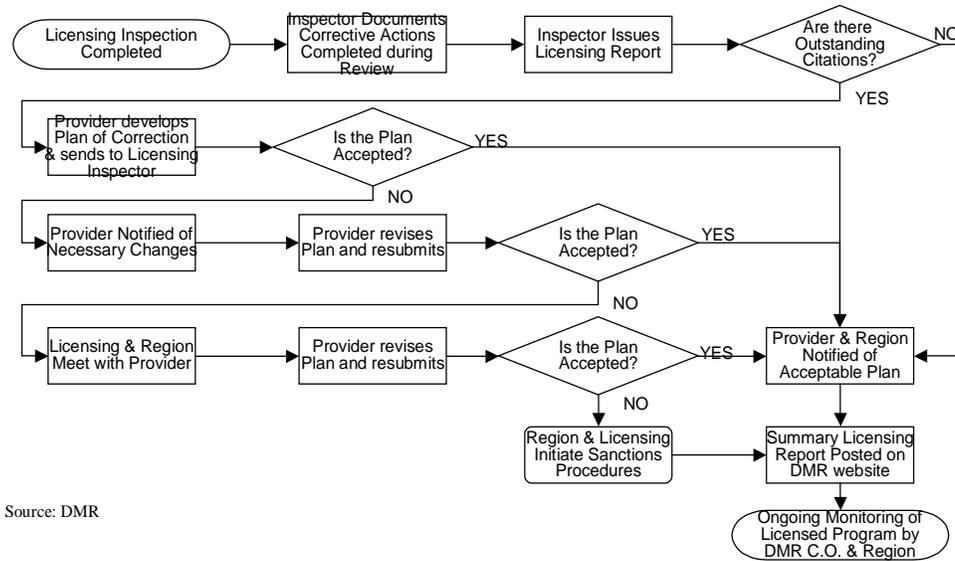
- Within one year of the initial inspection another full inspection is typically conducted for public and private homes. The inspection includes a check of the overall safety of the house and grounds, a review of the required files kept by the provider (medical information, residential logs, client information), and interaction with clients, if available. At this point, the inspector decides whether to recommend the next inspection be conducted one or two years from that time. The recommendation goes to the central office licensing supervisor and Quality Assurance Division director who make the final determination.
- Licenses must be renewed every year, with renewal applications submitted to the licensing unit.
- Full site inspections are made at the time of license renewal in the biennial inspection cycle. All site inspections at the time of license renewal are announced to the providers.
- Regular site inspections typically occur within two months before the license expiration date.
- Inspections usually take a day to complete and typically include: 1) a sample document review of client program, financial, medical, and incident records; 2) an environmental check, including physical plant and water temperature; 3) fire safety/emergency procedures; and 4) reviewing staff training records.

Plan of Correction

- Figure IV-3 outlines the steps taken when an inspection results in deficiencies on part of the provider.
- Deficiencies found during an inspection must be reported to the provider within 15 working days of the inspection. Issues found during an inspection involving the immediate health and/or safety of the clients (e.g., staffing complement too low) must be rectified while the licensing inspector is at the home. Generally, inspectors highlight the inspection results at an exit interview held at the end of the inspection.
- After the provider receives the inspection results from DMR, a plan of correction must be developed by the provider and submitted to the licensing unit within 15 working days. A plan of correction is to include:
 - a remedy for correcting individual citations;
 - the person/position responsible for implementing the plan;

- the identification of a system in place in order to prevent the inspection deficiency from occurring in the future; and
- an implementation and/or completion date.

Figure IV-3. Issuance and Acceptance of Licensing Plan of Correction (Draft)



- All plans of correction are reviewed by the DMR licensing supervisor and the QA director for approval. A subsequent plan is required if the first one is not approved.
- If a second correction plan is unacceptable, the inspector and a regional representative (typically the contract manager and an assistant regional director) meet with the provider to discuss any outstanding issues. A revised plan is submitted and if not approved, sanctions may be initiated, including an increased inspection schedule, a compliance order (requiring such measures as increased/specific training, a reduction in capacity, or increased staff support), or revoking a home's license. DMR informed the committee the vast majority of corrective plans are approved and additional sanctions used infrequently.

Monitoring

- After the plan of correction is approved, DMR determines which corrections can be verified through documentation submitted from the provider to the licensing inspector and which citations will need a department site visit to verify the proper corrections have been made.
- The licensing unit then sends a copy of the correction plan, indicating the citations requiring on-site verification, to the assistant regional director for appropriate action.

Private Sector Monitoring

- On-site monitoring for urgent matters relating to client health and safety, as determined by the licensing unit, is conducted immediately by the unit's inspectors. For all other matters, the DMR regional staff will verify corrective action has been taken at the time of the next formal site visit by the contract manager (described later in this Chapter.)
- The *contract manager* has been the contact person responsible for conducting the on-site monitoring. The process, however, recently changed whereby the DMR licensing inspector is responsible for conducting the monitoring visit for all urgent health and safety issues.
- The regional contract manager is to report the on-site visit results to the DMR licensing inspector. The inspection report, with the accompanying plan of correction, is used to determine if the provider has successfully corrected the citations. If additional action is needed, the licensing inspector will contact the contract manager.

Public Sector Monitoring

- The process for monitoring plans of correction for public homes is comparable to that for private homes, with several differences. Since contract managers are not responsible for public homes, a DMR residential manager makes the necessary monitoring visits to public homes. DMR requires residential managers not be responsible for their own homes, and that another residential manager -- as determined by the licensing unit -- conduct the necessary monitoring visits.

Unannounced Inspections

- Licensing inspectors began conducting unannounced inspections at the beginning of 2002. Each inspector is required to select two homes per month and complete a “revisit” inspection to ensure providers are implementing actions detailed in their plans of correction. Homes are chosen based on recent inspections and plans of correction.

Administrative Review

- Providers may request an administrative review by the QA director if they disagree with any part of their inspection results, including their one-year inspection status. The review offers providers an opportunity to be heard by the department’s QA director. DMR notes approximately four appeals have been made in the past 10 years.

Licensing and Inspection Activity

- Table IV-1 outlines licensing and inspection data for FYs 97-02.

Table IV-1. DMR Licensing and Inspection Activity: FYs 97-02							
FY	Initial Inspections	Inspections Conducted Resulting in a 2-Yr Status	Inspections Conducted Resulting in a 1-Yr Status	Revisits	Special Monitoring	Compliance Orders	License Revocation
1997	33	279	68	54	0	0	0
1998	68	251	60	25	6	1	0
1999	32	404	54	1	3	0	0
2000	53	353	35	5	2	0	0
2001	41	359	19	6	2	0	0
2002	26*	346	23	51	0	0	0
*Through April 2002							
Source of data: DMR							

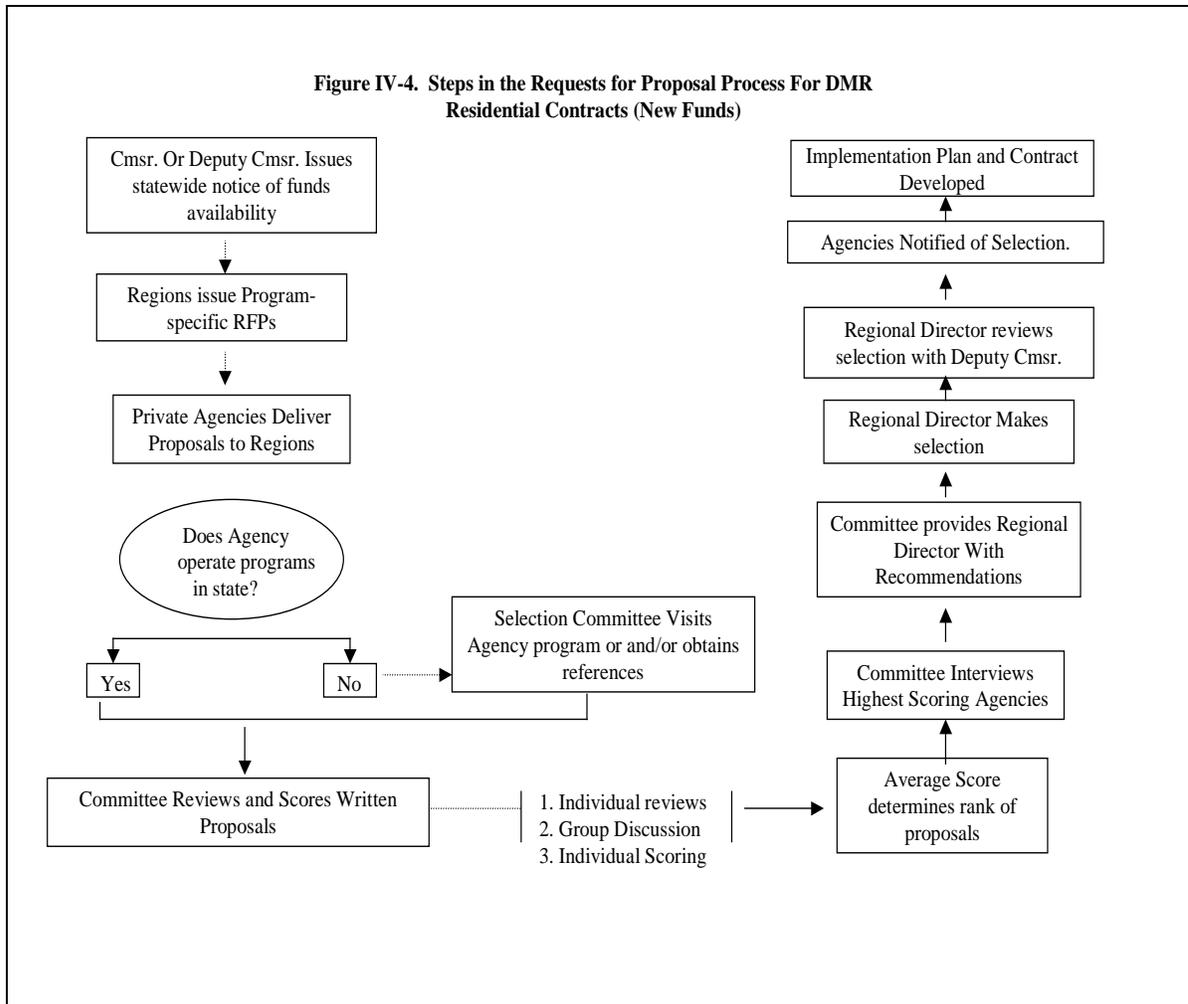
Contracts and Contract Monitoring

- DMR has statutory and regulatory authority to contract with private provider agencies for provision of services, including residential services, to DMR clients.
- DMR currently contracts with 81 agencies to provide residential services to almost 2,700 clients. Each provider has one contract which covers all the CLAs and other programs offered by that agency.
- Responsibility for contracting – including issuing the initial contract, contract monitoring, and contract renewal -- is primarily a regional function, although there is a central office role under the Director of Operations, and each contract is signed by the department's budget director.
- Staffing assigned to the contract management function varies among the regions – from six persons in the Southwest region to 10.5 full-time equivalent positions in the Northwest region.
- DMR contracts are issued for 12-month periods and coincide with the state's fiscal year.
- New contracts are issued only when there is new funding allocated from the legislature or when a provider agency terminates all or part of its contract. The vast majority of contracts are renewals and not initial contracts.

New contracts

- When new money becomes available, or when a new provider is being sought to take over an existing program, DMR follows the state's request for proposal process (RFP) as shown in Figure IV-4.
- Once the RFP is issued, a regional selection committee is appointed by the Regional Director, Assistant Regional Director, and Regional Self-Determination Coordinator (whose major role is to ensure client choice and independence in all processes). Once responses to the RFP are received (typically within 60 to 90 days), the selection committee reviews bids, and scores them using a statewide standard scoring scheme.
- Included in the RFP is specific information about the clients who will be served in the new home, or who already live in the home that is changing providers.

Figure IV-4. Steps in the Requests for Proposal Process For DMR Residential Contracts (New Funds)



- The standards evaluated include a provider's:
 - previous performance record (may include a site visit to another program);
 - organization and staffing patterns;
 - overall budget and cost effectiveness; and
 - proposed financing and operations for the RFP services.

- Once the scoring is complete, the selection committee interviews the top agencies – typically the top three -- makes its final selection, and refers its recommendation to the Regional Director. The Regional Director reviews the selection and rationale with the Deputy Commissioner of DMR. Once completed, the region notifies the selected agency and final terms and conditions are negotiated. Agencies not selected are notified within 48 hours.

Contract Renewals and Amendments

- Once a contract has been issued it is renewed annually thereafter, except under rare circumstances where a provider gives up a contract (partially or entirely), or unless DMR takes action to reduce or terminate a contract. (See Table IV-3 later in this Chapter for such actions.)
- Each spring, as part of the contract renewal process, the provider and DMR regional contract staff discuss the contract and provision of services. Typically, increases in the contract are limited to percentage increases authorized through the state budget process.
- Contract discussions focus mainly on performance and meeting goals and objectives rather than on financial aspects because increases in overall contracts are established by the legislature via the budget. DMR also holds mid-year reviews with the contracted agencies, emphasizing services rather than financial matters.
- Cost settlements – recoupments to DMR because of overpayments – are adjusted at the time of contract discussions. Repayments to DMR are generally made through a reduction in the DMR payments to a provider over the ensuing three months, and generally limited to recoupment of 50 percent of the overpayment. DMR also has authority to reduce funding when utilization falls below 85 percent if the provider cannot adequately justify the reduced occupancy. DMR stated it has not used this authority.
- A contract can also be adjusted during the year with contract amendments. These may be for one-time expenditures for a set period of time or expansions to the contract, which would build in those expenses for ensuing years. Amendments are often attributable to the increasing needs of a specific client or clients, and the necessity to add staffing or other resources to address those needs.

- Table IV-2 shows amendment activities over the past three fiscal years. While some of these amendments are for contracts with agencies that provide other than residential supports, most of the amended amounts deal with community living arrangements.

Table IV-2. Contract Amendment Activities FY 99 –FY 01				
FY	# of Agencies	# of Amendments	Total \$ Amendment Amounts	Total DMR Contract \$ for CLA services
99	74	229	\$2,299, 944	\$171,779,524
00	78	302	\$2,949,809	\$172,659,749
01	89	265	\$3,978,565	\$178,938,702
Source: DMR Contract Operations Center				

Contracts and Monitoring

- Each contract includes:
 - a generic human services contract portion;
 - a section setting forth specific *requirements for day and residential services* including quality assurance, reporting and auditing requirements; and
 - a section outlining requirements for *all DMR contracted programs* which include requirements that providers: allow DMR access to its programs; maintain minimum training of staff, report all incidents as required, and not suspend or discharge clients from a program without DMR review and approval;
 - Attachment A, which includes specific contractual obligations for CLAs (see Appendix E for a listing);
 - agreed-upon performance objectives for the contract year;
 - a workforce analysis for affirmative action purposes; and

- a financial summary of the contract, including number of persons to be served in residential and day programs.
- Provider agencies submit annual “operational plans” for all their major residential and/or day programs. DMR contract monitoring personnel use the plans submitted as a guide for how a provider agency intends to operate its programs and expend its funding.
- Contract managers monitor the provider’s performance in a number of ways:
 - A *contract monitoring book* is kept on each provider agency operating in that region, which includes the contract, amendments, licensing information including deficiencies and plans of correction, reports of abuse/neglect, and the resulting investigations.
 - *Site visits* are conducted at least twice a year -- one announced and one unannounced – and monitors complete a site visit form, documenting visit findings.
 - Mid-year and year-end *performance reviews* are conducted by the monitors, which are included in the contract monitoring book and discussed in a limited way at contract renewal.
 - Contract monitors have also begun (as of 7/1/02) requiring providers to report on *staffing levels in each CLA*.
 - Conduct *follow-up on providers’ corrective action plans* resulting from licensing inspections.
- A private provider agency must also submit annually to DMR its audited consolidated operational report (ACOR), which is a retrospective look at the provider’s actual revenues, costs, and client data for the preceding year. The data from the ACOR are used for any cost settlements (mentioned above).

Contract Enforcement

- Contract issuance and adjustments can be used by DMR as an enforcement tool with private providers. Table IV-3 shows contract actions from FY 97 through FY 02. The most common contract enforcement action is to place the provider on a partial year contract (typically six months). During this time, DMR increases monitoring and oversight to ensure concerns are being addressed before returning the provider to a full-year contract.

- More rarely, a contract is terminated by DMR. As the table shows, in only 12 instances was a contract tied to residential services (either regional or statewide) ended by DMR. In two other cases, DMR recouped funds that were disallowed from agency principals and reduced management fees. In 11 other cases, the provider ended the service or merged with another agency.

Table IV-3. Contract Actions FY 97 – FY 01					
	Unsatisfactory Service	Financial Concerns	Financial and Service	Other Reasons*	Total
Contract Terminated (state)	2	4	3	11	20
Contract Terminated (region)	3	0	0	0	3
Partial year contract	1	3	3	2	9
Other Action	0	2	0	0	2
Total	6	9	6	13	34
*Other reasons typically include that the provider ended that program or merged with another program. Source: DMR					

Other Enforcement

- Rarely, cases involving private providers are sent to the Office of the Attorney General or the State’s Attorney for enforcement for fraud or misuse of funds. In one case, the Attorney General’s office was successful in recovering \$1.25 million from one private provider who fraudulently billed for client services.
- Obviously, the same tools cannot be used to enforce standards in DMR homes; those CLAs are not under contract and individual auditing requirements. If there are problems at certification inspections, inspectors will issue citations, plans of correction are submitted and reviewed as with provider homes, and some DMR homes have been put on a one-year certification schedule.
- Twenty-five percent of DMR homes are also subject to unannounced site visits by DMR residential managers of homes other than ones they normally oversee.
- However, if problems continue to exist in a home, DMR as the employer can take personnel actions against its employees. DMR furnished data on disciplinary actions taken against its employees over an 18-month period, but “reason” categories were not refined enough for the committee to determine

whether failing to meet or maintain certification standards was a cause for discipline.

Program Integrity

- A new oversight tool was implemented by DMR two years ago. The process is aimed at providing a “holistic” picture of the overall quality of services and management practices and examines the oversight results for selected providers.

Purpose

- “Program Integrity” (PI), as the process is named, is coordinated by the DMR central office to consolidate and integrate the system’s various information sources regarding service quality and integrity.
- The PI process integrates and reviews information about a provider’s (or providers’) services, including the following areas: 1) financial, 2) contract, 3) health, 4) quality assurance, 5) special protections, 6) individual/family, and 7) case management.
- DMR utilizes the PI review process to ensure programs and services are in compliance with departmental policies and practices. The process is designed to:
 - assess agency programs and practices;
 - provide direction and recommendations to regions or ensure service standards with those providers; and
 - promote consistency across regions in contract review, management, and enforcement activities.

Team Membership

- A core team consisting of central office and regional representatives conducts program integrity reviews. Members from the central office include the directors of:
 - Quality Assurance (chairperson);
 - Audit;
 - Investigations;
-

- Health Services; and
- Operations Center.
- Regional members include:
 - the regional director; and
 - optional members as appropriate (e.g., assistant regional director, health services director, quality improvement director, contract managers, and the abuse/neglect liaison.)

Reviews Conducted

- The PI process can evaluate any provider(s) DMR licenses, certifies, or funds, including facilities operated by the department. Any provider(s) identified as having a program performance concern by a core team member can be scheduled for a PI review. A PI review may examine a single agency or multiple agencies covering different regions. To date, DMR has conducted seven program integrity reviews covering 35 agencies statewide. Most of the reviews have been of private agencies; one review was done of all public facilities in the South Central region in mid 2002. Another PI review of all public homes in the Eastern region was pending at the time this study was completed.

Reporting and Monitoring

- The current process includes a final report developed by the PI team at the conclusion of a review containing:
 - agency description;
 - financial status and issues;
 - physical plant and fire safety;
 - abuse/neglect information;
 - program review and human rights committees issues;
 - program/service issues;
 - health and clinical issues; and
 - other (e.g., management).
- The PI report identifies existing or potential conditions/patterns regarding organizational performance that have or may have harmful effects on DMR clients. Any necessary internal system changes to DMR's oversight process are also identified.

- PI reports are distributed to the applicable regional director, members of the core team, the DMR deputy commissioner, and the pertinent agency director. All applicable agencies are responsible for implementing any recommendations contained in the PI report. The regional director is responsible for ensuring implementation and periodically reports progress to the deputy commissioner, who has ultimate implementation responsibility.
- An automated system is currently under development to track implementation efforts of PI review recommendations.

ABUSE AND NEGLECT

Background

While a primary goal of DMR is to support as much independence as possible for its clients, most if not all persons with mental retardation living in CLAs are vulnerable to the actions of themselves and others, and may not have the independent tools to either protect themselves or articulate what happened to them to others. Thus a system to address abuse and neglect concerns is needed.

All DMR clients, including those residing in CLAs, the focus of this study, have the statutory right to “be protected from harm and receive humane and dignified treatment which is adequate for his needs and for his development to his full potential at all times...”⁵

Also, the 1985 Mansfield consent decree, which laid the blueprint for growth in community living in the 1980s, required the development and implementation of abuse/neglect policies and procedures, to carry out the decree principle that “DMR will not tolerate abuse of persons who are mentally retarded.”

The Mansfield-prompted policies and procedures, effective in 1986, were operative until March 2002 when DMR established a new policy. The new policy is similar in substance, but is more specific about procedures, including tracking investigation outcomes.

What is Abuse and Neglect?

- In very general terms, the difference between abuse and neglect is whether someone intended to harm or not. A finding of abuse requires intent.
- “Abuse” under the state statute pertaining to most abuse/neglect cases involving persons with mental retardation *is the willful infliction of physical pain or injury or the willful deprivation by a caretaker of services which are necessary to the person’s health or safety.*
 - Under DMR policy, abuse also includes the use of offensive language or an act to provoke or upset an individual or to subject him or her to humiliation or ridicule.
- “Neglect” under the same statute *is a situation where a person with mental retardation either is living alone and is not able to provide for himself the*

⁵ C.G.S. Sec. 17a-238(b)

services which are necessary to maintain his physical and mental health OR is not receiving such necessary services from his caretaker.

- DMR policy also uses a term “programmatically neglect”, which means the failure to provide oversight in developing or implementing an individual’s program that ensures an individual’s well-being and safety.
- Because of the different agencies and statutes involved with abuse/neglect allegations related to persons with mental retardation, different definitions have existed over the years, though those differences have been minimized recently due to DMR policy amendments.

Abuse/Neglect Response System

There are four components of an abuse/neglect response system: prevention; reporting; investigation; and resolution.

Prevention

General program operations

- DMR policy states all service programs for DMR clients are to “undertake activities” to prevent abuse.
- A DMR client’s Interdisciplinary Team is to “identify in the plan services required to prevent the individual from engaging in or being subjected to abuse/neglect.”

Training

- All DMR employees and private provider employees who serve DMR clients are trained annually in the recognition, prevention, and obligation to report abuse/neglect. Supervisors are also trained to ensure the statutory reporting requirements are met and that no retaliation for reporting occurs.

Incident Reporting

- DMR requires all “incidents” involving clients to be reported on DMR forms, whether or not there is suspicion of abuse or neglect. Reportable incidents range from client injuries of any severity, including self-inflicted injuries, use of restraints (outside of an approved program), and unusual incidents

including calls for fire or police service and missing clients, to medication errors.

- Incident reports can serve as a warning the potential for abuse/neglect exists.
- DMR case management supervisors and individual case managers receive copies of incident reports about a week after they are submitted to the regional quality improvement directors for review and data entry. Case managers are to be informed of any significant incidents immediately in order to make sure any appropriate action is taken.
- An allegation of abuse or neglect related to an incident is to be noted on the incident form, in which case a whole separate reporting and follow-up procedure comes into play. A description follows.

REPORTING AND INVESTIGATION

In Connecticut, there is a multi-agency system in place for reporting and investigating abuse/neglect allegations involving DMR clients. Within DMR itself, there are two separate tracks for abuse/neglect investigations, depending on whether the service provider in question is private and under contract with DMR, or DMR itself.

- While DMR in reality either monitors, reviews, or conducts most of the abuse/neglect investigations related to persons in CLAs, there are other state agencies with statutory authority and responsibility for these investigations. In part this is because people with mental retardation, due to age or other characteristics, also fall under other agency jurisdictions.
- In addition, the Office of Protection and Advocacy for Persons with Disabilities (OPA) has had, since 1984, the authority and responsibility for abuse/neglect investigations involving persons with mental retardation between the ages 18 to 59.
- Table V-1 summarizes the statutory responsibilities of the various state agencies.

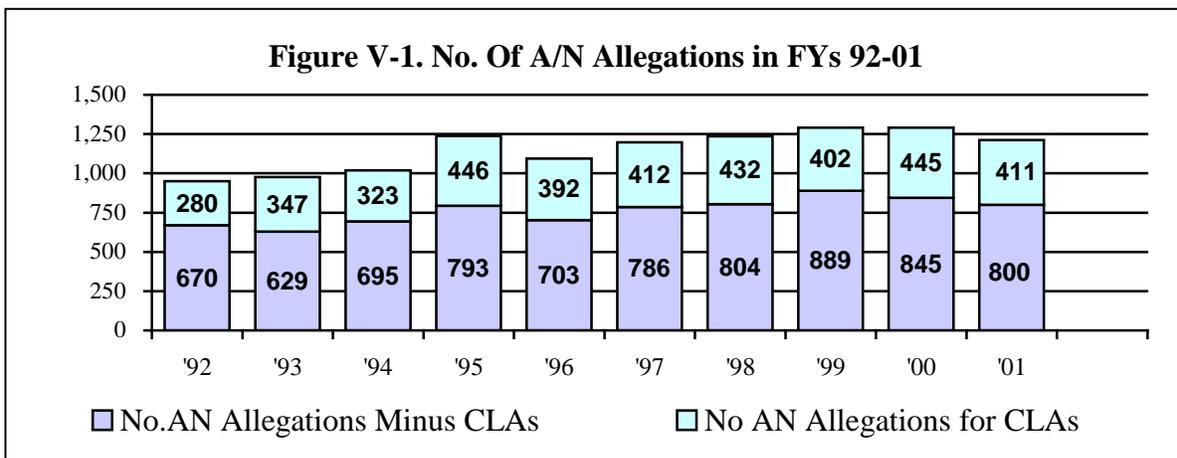
Table V-1. State Agencies with Abuse/Neglect Investigation Authority	
<i>Agency</i>	<i>Jurisdiction and Practice</i>
Office of Protection and Advocacy for Persons with Disabilities (OPA)	<p>Adults with mental retardation aged 18 to 59</p> <p>While OPA receives all allegations, DMR actually conducts or requires its private providers to conduct investigations related to DMR clients in residential or day settings, and submits these investigations to OPA for review. OPA investigates abuse/neglect allegations pertaining to people living with their families or on their own.</p>
Department of Children and Families (DCF)	<p>Children up to 18 years old, including children with mental retardation</p> <p>DCF investigates allegations pertaining to children who are DMR clients and shares the investigation results with DMR. DMR may also do its own investigation, but usually does not.</p>
Department of Social Services (DSS)	<p>Adults 60 and older, including adults with mental retardation</p> <p>DMR conducts these investigations and shares the results with DSS.</p>
Department of Public Health (DPH)	<p>Any care complaint related to a facility or person licensed by DPH, including those from persons with mental retardation</p> <p>Persons with mental retardation use hospital, nursing home, and licensed medical professional individual services; any abuse/neglect allegations regarding a facility or person licensed by DPH are investigated by DPH. These cases typically arise by DMR requesting an inquiry by DPH. DPH conducts the investigation and sends DMR a final report</p>

A Note About OPA

- OPA first acquired the responsibility to receive and investigate complaints of *abuse* related to persons with mental retardation in 1984. Two years later, *neglect* complaints were added to OPA’s charge. Certain persons, including DMR and private provider direct care workers, physicians and nurses, are mandated to report any suspicion of abuse and neglect to OPA (similar to the mandated reporter laws for children and elderly people).
- Based on the 1984 legislative history, it seems clear OPA was to have a prominent role as the receiver and independent investigator of abuse/neglect allegations for persons with mental retardation between the ages 18-59, including, but not limited to, DMR clients. Proponents referred to the benefits of “third party intervention” in abuse cases. At the time, though, OPA representatives said they would need more resources for the new function. OPA was never staffed to handle the investigation task by itself.
- Thus, though almost all abuse and neglect allegations related to DMR clients must be reported to OPA, from the beginning, OPA and DMR have operated with an understanding that splits investigations among them, as described in Table V-1. (DMR signed a memorandum of agreement with OPA, DCF, and DSS in 1992 to coordinate agency efforts).

Volume of Allegations and Outcomes

- Figure V-1 shows the number of abuse/neglect allegations related to DMR clients for each year over a 10-year period ending FY 01. Over that period, there was an average of 1,147 abuse/neglect allegations reported each year. The yearly totals ranged from a low of 950 in FY 92 to a high of 1290 in FY 2000, a 36 percent increase. FY 2001 showed a slight decline.

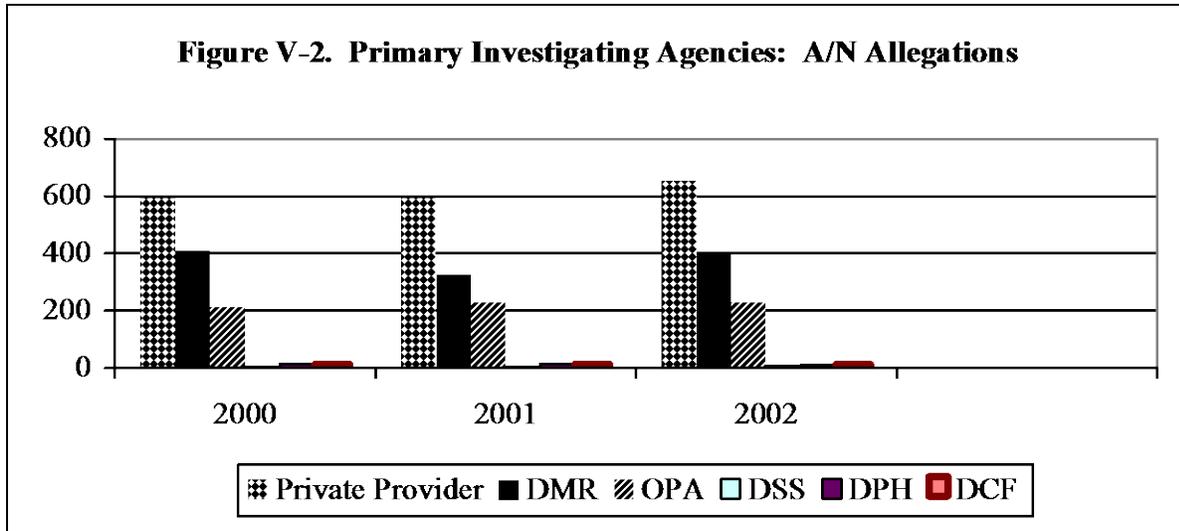


- Table V-2 displays a DMR Client-to-Allegation ratio calculated for all DMR clients, DMR clients living in CLAs, and DMR clients not living in CLAs. (The latter two add up to the first).
 - The ratio was calculated by dividing the total number of clients in a given category as of June 30 of each year by the number of allegations pertaining to that client category for the same year. The results show how many clients in that category there are for every one allegation. Thus, in 1992, when looking at all DMR clients, there were 12 clients for every one allegation.
- It is unclear why DMR clients living in CLAs appear more likely to be the subject of abuse/neglect allegations than DMR clients not living in CLAs. The fact CLAs are more regulated and have more staff than some settings DMR clients live in might generate increased reporting.

Table V-2. DMR Client-to-Abuse/Neglect Allegation Ratio: Different Settings										
FYs 92-01										
DMR Client Type/Fys	92	93	94	95	96	97	98	99	00	01
All DMR Clients	12:1	12:1	12:1	10:1	11:1	11:1	11:1	10:1	11:1	12:1
Living in CLAs	10:1	9:1	9:1	7:1	8:1	8:1	7:1	8:1	7:1	8:1
Not Living in CLAs	12:1	13:1	13:1	11:1	13:1	12:1	12:1	12:1	12:1	14:1
Source of Data: DMR										

- Each bar in Figure V-1 on the previous page is divided to show the portion of abuse/neglect allegations related to CLA residents compared to all other DMR clients. On average, 34 percent of all abuse/neglect allegations related to CLA residents compared to 66 percent of the allegations involving all other DMR clients.
 - In comparison, on average CLA residents over same period made up 25 percent of all DMR clients. (Again, there may be more incidents prompting allegations pertaining to CLA residents or there may be increased reporting of incidents not reported in other settings.)

- The portion of total abuse/neglect allegations that are subsequently substantiated averaged 35 percent in the 10-year period ending FY 2001.
- Figure V-2 shows the number of abuse/neglect investigations conducted by or under the jurisdiction of the various agencies mentioned in Table V-1.



- Most investigations are conducted by private providers. From FY 2000 through FY 2002, private providers averaged 613 investigations as the primary investigating agency, compared to 379 conducted by DMR (DMR also conducts investigations related to persons 60 or older under the jurisdiction of DSS). OPA in the same time period averaged 314 investigations each year as the primary investigating agency. Some of the DMR investigations may include private provider cases, but the great majority relate to DMR settings.
- Combining the private provider investigations and the DMR investigations gives a rough view of the number of investigations OPA monitors. (The number will be overstated because some of these investigations do not fall under OPA jurisdiction due to type of charge or age of alleged victim.)

CLA Investigations: Separate Tracks for Public and Private

- The largest number of abuse and neglect investigations involve DMR clients living in DMR operated or funded residential placements. Who actually conducts the investigation depends on a number of factors, but for the most part, private providers are required by DMR to conduct investigations of abuse/neglect allegations involving DMR clients living in their homes, while DMR employees investigate allegations at DMR homes. One recent change in the last two years is that any abuse/neglect allegation involving a client death is now always investigated by DMR.
- Separate DMR administration and monitoring structures for investigations conducted by the private sector and DMR have been in place since the mid-nineties at DMR. Until the central office Division of Investigations was created, abuse/neglect investigations were managed primarily out of each region. Now the Division of Investigations is responsible for DMR home investigations, while the regions are still primarily managing the private sector investigations. Just recently (October 2002), DMR created a new central office investigator position within the Division of Investigations to coordinate private sector investigations to parallel its central review process of DMR investigations.

Training

- All DMR employees serving as investigators have completed training on investigating abuse/neglect allegations in DMR settings, either conducted by outside groups or in-house by DMR regional staff. Investigators in the private sector may also participate in those training sessions. More recently, a week-long investigations course taught at the State Police Training Center is offered to both public and private provider investigators, and the ultimate goal of the department is to have all investigators receive the State Police training

Investigation Process

- Figure V-3 sets out the process for investigations at DMR operated CLAs, and Figure V-4 sets out the process for investigations at CLAs operated by private providers. The processes are very similar, and mostly differ by who does the investigations and how those investigations are reviewed within DMR.





DMR Operated CLAs

- The Division of Investigations, located in the DMR central office, is responsible for ensuring the investigation of allegations of abuse/neglect related to group homes operated by DMR. The division, established in 1997, has been headed by a captain of the Connecticut State Police on loan from the Department of Public Safety since May 2000.
 - There are five lead investigators in the division, who are physically assigned to regions. They either conduct public investigations themselves or assign and monitor investigations done by DMR employees who are “pool investigators”.
 - The pool investigators are DMR regional employees who have full-time responsibilities in other areas of the department, but have volunteered to conduct abuse/neglect investigations on a part-time basis. As of November 2002, the regions’ pools consist of between 29 to 63 people each. Included in the pool are specialists, such as nurses and psychologists.
 - As Figure V-3 shows, the process begins when a report of suspected abuse is made to OPA. OPA gathers preliminary intake information about the allegation, and faxes the intake information --within hours or at most a day of receiving it-- to DMR, specifically the Division of Investigations and the pertinent regional A/N liaison.
 - In addition to the mandated reporter law, DMR policy requires employees to report suspected acts of abuse or neglect to their supervisors immediately. Failing to do so can result in disciplinary action.
 - Supervisors must report any cases involving suspected assault or sexual abuse to the appropriate law enforcement authorities.
 - If the person suspected of abuse is an employee, under DMR policy, that person is immediately placed on leave until the conclusion of the investigation.
 - In most cases, one or two of the pool investigators will be assigned the investigation. Their completed investigation will be reviewed by a lead investigator and in some regions the abuse/neglect liaisons, and then submitted to OPA unless further investigation is needed.
-

Private Provider CLAs

- The private provider investigations process for CLAs is intended to be similar to the investigations of DMR-operated homes, with the major difference being that in most cases, private provider personnel conduct the investigations. The other main difference is the oversight of the investigations -- each DMR region has an employee serving as an Abuse/Neglect Liaison, responsible for coordinating and monitoring private provider investigations.
 - In some cases, DMR and/or OPA determine a private provider should not investigate itself. Examples of reasons can include the allegation involves senior agency management, or the allegation is part of a pattern of complaints. In those cases, the Division of Investigations takes responsibility for the case, and either a lead investigator conducts the investigation or it is assigned to the pool investigators.
 - Regional personnel involved with the private provider's contract will be informed of the allegation and investigation.
- As with public home investigations, any private provider employee alleged to have abused a DMR client must be put on administrative leave pending the conclusion of the investigation.
- Once a private provider completes the investigation, the report is usually sent to the A/N liaison for review for completeness, and then to OPA. Sometimes private providers send their reports directly to OPA.

OPA Review

- When OPA receives investigation reports for DMR or private facilities, it reviews them for completeness. OPA will send the report back if additional information is needed. If OPA finds the report complete, it can either agree or disagree with the abuse/neglect finding, as well as make recommendations.
- OPA has a goal of having investigations completed within 60 days after intake, and will send a letter to the DMR liaison inquiring as to the status of the investigation after 60 days. If an adequate response is not forthcoming, OPA writes to the commissioner.

- Table V-3 shows the number of completed monitored investigations by OPA for calendar years 2000 and 2001, and 10 months of 2002. It also shows how often OPA disagrees with DMR/private provider findings of abuse/neglect substantiation.

Table V-3. Number of OPA- Completed Monitored Investigations and Disagreement with Findings			
	# of Completed Monitored Investigations	# of disagreements over findings	Percent
CY 2000	898	61	6.9%
CY 2001	637	65	10.2%
CY 2002 (as of 10/1)	715	81	11.32%
Source: Office of Protection and Advocacy for Persons With Disabilities			

Investigation Outcomes and Follow-Up

- Any abuse/neglect investigation is to determine whether the allegation of abuse or neglect can be substantiated or not. In addition, other recommendations can be made, if necessary, to address:
 - any client-specific issues, which may include a protective services plan required by OPA, if abuse/neglect are substantiated (a protective service plan is required to prevent any further harm to the individual);
 - any programmatic or administrative issues going beyond the individual client (e.g., safety alerts); and
 - personnel actions, although recommendations specific to individuals are not typically made as part of an investigations report. DMR handles such issues for its CLAs through its human resources processes, and leaves personnel decisions for private providers up to them (except see discussion of Registry below.)

- If OPA determines a protective service plan is needed as a result of any abuse/neglect investigation, it will “refer” the case to DMR, which is required to submit a plan to OPA within 15 days of the referral. OPA then monitors compliance.
- Until March 2002, there was no statewide procedure at DMR setting out who was accountable for ensuring abuse/neglect recommendations were followed and how implementation was to be tracked. It appears there was no requirement for a provider to make a written response to DMR about how it planned to address investigation findings and recommendations.
- Effective March of this year, DMR established a standard statewide monitoring system for abuse/neglect investigation recommendations for both the private and public sectors.

Private CLA Tracking

- For private sector facilities, the regional director is to review all investigation reports. Within seven days after the regional director’s review, the A/N liaison is to request from the private provider a written response regarding the status of actions taken on the recommendations. The response is due within 30 days of the request.
- If the provider doesn’t respond in the required timeframe, the contract manager is to meet with the provider to determine recommendation compliance status, including insuring a compliance plan is in place if needed.
- Under the new procedure, actual recommendation compliance is monitored through site visits of the contract managers (see Oversight Chapter).
- A new database has been established to facilitate the tracking of recommendation implementation. Upon receipt of the final investigation reports, the regional A/N liaisons are to enter all the recommendations and produce monthly reports on their implementation status. These reports are to go to the regional Quality Improvement director, other division directors, the lead investigator assigned to the region, and the regional director.

Public CLA Tracking

- For public facilities, within seven days after the A/N liaison’s (or designee’s) review of the completed abuse/neglect investigation, the AN liaison is to request in writing, from the residential manager and the public programs

director, recommendations to address the investigation findings. They are to respond in writing within 30 days.

- If the response is not timely, the regional director is notified and a compliance plan will be required.

DMR Registry

- In 1997 the legislature required DMR to establish a registry to identify people who had been fired for either abuse or neglect of a DMR client. The purpose of the registry was so prospective employers would not hire anyone on the list for direct care work. Due to issues of due process (e.g., a person's right to a hearing), the registry has not been used pending acceptance of regulations to address the due process problem.
 - Employers were first requested to submit referrals to the registry in July 1999.
 - As of 8/31/02, 235 names were referred (three people were referred twice).
 - Private Sector Referrals: 160 (67.2 percent)
 - Public Sector Referrals: 78 (32.8 percent)
 - Of the 235 referrals, there are currently 30 names on the list.
- To use the registry, an employer would contact DMR, and after establishing the employer's identity, DMR would through confidential facsimile transmissions inform the employer if a prospective employee was on the list.

DMR Personnel Actions

- From July 2001 through September 30, 2002, 37 DMR employees were disciplined for either client abuse, client neglect, or client verbal abuse.
 - For client abuse, four employees were fired and one was suspended
 - For client neglect, 26 were disciplined—four were fired, 21 were suspended, and one received a written warning

- For client verbal abuse, six were suspended.

Sudden/Unexpected Deaths: Special Abuse/Neglect Review

- In March 2002, DMR instituted a new step in its post-death review for sudden or unexpected deaths of DMR clients who lived in DMR residential settings. Described in the Chapter on post-death activities, it is noted here because its main purpose is to determine, as quickly as possible post-death, if there are any suspicions of abuse or neglect that need investigation. If the review indicates a suspicion of abuse or neglect, the case is reported to OPA (if the case falls under its jurisdiction), and goes through the process described above. The reviews are conducted by two nurse investigators.

POST-DEATH REVIEW

Background

- Because of the nature of mental retardation, DMR often serves people throughout their entire lifetimes.
 - During FYs 92-01, an average of 165 DMR clients died each year, for a total of 1,654 client deaths.
 - 388 (23 percent) of these deaths involved clients living in community living arrangements, for an average of 39 client deaths per year.
- DMR policy states the department “has a responsibility to the citizens it serves to ensure quality services including health care. One way to ensure quality is to receive timely notification of the death of every individual served by the department and to review the care provided for these individuals served prior to their deaths.”
- The department has a number of policies, procedures, and practices in place to review the care of DMR clients who die. Some of these are required by statute, some have recently been required by a governor’s executive order, while others have been put in place through department policy and procedure.
- The post-death steps include the following:
 - reporting all deaths of DMR clients to DMR regardless of residential setting;
 - determining whether the place of death needs to be secured and collection of all records that will be needed for a post-death review;
 - conducting a regional and state medical/health care review for certain deaths depending on the client;

- reporting certain deaths to the Office of the Chief Medical Examiner;
 - encouraging family members to consent to autopsies in certain deaths;
 - conducting an immediate desk audit of all sudden/unexpected deaths to determine whether an abuse/neglect report should be made;
 - conducting a review by Fatality Review Board for Persons with Disabilities (this is separate from the Independent Mortality Review Board as discussed later in this chapter); and
 - conducting a root cause analysis for selected deaths by DMR upper-level management.
- Descriptions of these processes follow.

Executive Order 25

- Executive Order 25, put into effect February 2002, made several changes to the reporting and oversight procedures regarding deaths of DMR clients. (Appendix F provides a copy of the order.)
 - In general, the order requires DMR to report all deaths of its clients to the Office of Protection and Advocacy (OPA).
 - It replaces the previous Medical Quality Assurance Board with the Independent Mortality Review Board (IMRB), with similar functions as the MQAB, but with a revised membership. As described in Appendix F, the new board includes the additional membership of the state medical examiner, commissioner of public health, two members appointed by the OPA executive director, and a private provider representative jointly appointed by the DMR commissioner and OPA director to members from the previous MQAB (members may include designees).
 - Further, it requires the IMRB to submit annual reports to the governor and legislature outlining trends, analysis, and recommendations.

- Finally, the order creates a Fatality Review Board for Persons with Disabilities appointed by the governor to investigate the circumstances surrounding untimely deaths warranting a full and independent investigation as determined by the OPA director.
- Executive Order 25 also made changes in other areas of DMR oversight, by increasing the frequency of unannounced visits to public and private facilities, and requiring providers to post their inspection reports either on the internet or within their facilities.

Post-Death Procedures

- Table VI-1 outlines the steps to be taken by DMR following all deaths of residential clients.
 - Every death is to be reported immediately to the individual's family, the DMR regional director (or designee), and the regional health services director.
 - A DMR case manager/other assigned staff is required to file a death report with the DMR central office, within one working day following the death.
 - For every death not under the statutory jurisdiction of the Office of Chief Medical Examiner (which is the majority of cases), DMR policy is to encourage an autopsy, except in certain specified circumstances.
 - Every death is reviewed by the appropriate regional mortality review committee, and may be reviewed by the Independent Mortality Review Committee if it meets certain criteria.
- Different steps are required if the death is considered sudden or unexpected, as opposed to expected.
 - DMR's current policy on sudden/unexpected deaths, first established in June 2001, and revised in March 2002, applies to all persons served in residential programs licensed, operated, or funded by DMR, and people who die while participating in a DMR operated or funded day program, or receiving respite services in a DMR owned or operated facility.

Table VI-1. Checklist Following a DMR Client Death.

Responsibility	Expected Death/DNR	Sudden/ Unexpected Death	When	Who's Responsible (During Bus Hours)	Who's Responsible (After Business Hours)
Obtain detailed info surrounding death. Clarify 911 status and any police involvement	√	√	Immediately	Central Office	CO On-Call Manager
Notify family/guardian, DMR regional/STS director, DMR health services director/STS medical director, regional abuse/neglect coordinator, client's case manager or supervisor	√	√	Immediately	Provider	Provider/Regional On-Call System
Regional Director/designee ensures all appropriate parties have been notified	√	√	Immediately	Regional Director/designee	Regional Director/designee
Notify state/local police and ensure preliminary investigation happens. Notify DMR Dir. of Invest. if police do not initiate or decline investigation	N/A	√	Immediately	Regional Director/designee	On-Call Manager
Secure environment, and individual's/agency's records	N/A	√	Immediately	Regional Director/designee	On-Call Manager
Notify Office of the Chief Medical Examiner		√	Immediately	Health Services Director/designee	On-Call Manager
Pursue autopsy consent from next of kin if OCME declines case and assist with arrangements	√	√	Immediately	Health Services Director/designee	On-Call Manager
Notify Commissioner		√	Immediately	Regional Director	On-Call Manager
Commissioner/designee and Regional Director determine if Immediate Safety Assessment Visit required		√	Immediately	Regional Director	On-Call Manager
Notify Regional Director of Health Services	√	√	Immediately/ as directed	Health Services Director	On-Call Manager
On-site safety visit conducted using specified form; distribute forms as required		√	Within 8 hrs. of death	Regional Director/Central Office	On-Call Manager
Notify Commissioner	√		Next Working Day	Regional Director/Central Office	On-Call Manager
Notify DMR Special Protections Coordinator (SPC) via telephone or fax, using death report form. (Copy of report sent to regional health director)	√	√	Next Working Day	Case Manager/Other Assigned staff	On-Call Manager

Responsibility	Expected Death/DNR	Sudden/ Unexpected Death	When	Who's Responsible (During Bus Hours)	Who's Responsible (After Business Hours)
SPC notifies Nurse Investigators of the death			Immediately	Special Protections Coordinator	
In case of a child's death, the SPC notifies the Office of Child Advocate	?	√	Immediately	Special Protections Coordinator	
Notify DMR-CO Quality Assurance Director		√	Next Working Day		On-Call Manager
Notify DMR-CO Health and Clinical Services Director		√	Next Working Day		On-Call Manager
Notify DMR-CO Director of Investigations		√	Next Working Day		On-Call Manager
Notify Case Manager	√	√	Next Working Day		On-Call Manager
Notify Regional Abuse/Neglect Liaison		√	Next Working Day		On-Call Manager
Notify Regional Lead Investigator, as appropriate		√	Next Working Day		On-Call Manager
Complete DMR death report; distribute copies as required	√	√	Next Working Day	Case Manager	On-Call Manager
Letter to family/guardian re: autopsy results, as appropriate	√	√	Within 5 Days	Health Services Director	On-Call Manager
Letter to family/guardian re: mortality review process	√	√	Within 5 Days	Health Services Director	On-Call Manager
Regional Mortality Review (issues findings/recommendations)	√	√	Within 90 Days	Regional Mortality Review Committee	
State Independent Mortality Review Board (issues findings/recommendations)	As Applicable	√			
DNR=do not resuscitate order Source: DMR					

- It does not apply to people living on their own, with their families, or who have individual support agreements.

Expected Death Defined

- A death is expected if a client has a terminal illness, dies of a condition related to a previous diagnosis, or has a “do not resuscitate” (DNR) order.

Sudden/Unexpected Death Defined

- A sudden or unexpected death is a death:
 - not expected or anticipated according to any previously known terminal medical diagnosis;
 - resulting from an accident (e.g., car accident, fall, choking), even if the person had a known terminal condition;
 - due to a suspected/alleged homicide or suicide; or
 - suspected/alleged to be due to abuse or neglect.

Sudden/Unexpected Death Process

- Sudden or unexpected deaths require immediate local or state police notification and investigation, unlike expected deaths.
 - The DMR Director of Investigations is to be contacted by the regional director/on-call manager if police fail to initiate or decline immediate investigation (a new March 2002/June 2001 feature).
- The environment, documents, and records associated with a sudden or unexpected death are immediately secured and a preliminary review is conducted, as determined by the regional director (a new March 2002/June 2001 feature), and in conjunction with any police investigation.
- The commissioner and regional director decide if a safety assessment is necessary to ensure health and safety of other individuals at the place of death. The safety assessment gauges the safety of other DMR clients and staff at the location of the death. Results are immediately/directly communicated to the regional director who informs the commissioner (a new March 2002/June 2001 feature).

- The Office of Chief Medical Examiner (OCME) is notified by the regional health service director/designee to determine if the death requires a statutorily mandated investigation and possible autopsy. If OCME determines the death does not require such investigation, it will decline jurisdiction (described below).
- Upon OCME declining jurisdiction, the regional health service director is to pursue consent for autopsy from the client's next-of-kin or person who assumes custody of the body for burial.
- One of the two DMR nurse investigators is immediately notified of the death by DMR central office personnel (a new March 2002 feature). The nurse investigator conducts a medical desk review to determine if there is a need for further review or investigation, by talking to appropriate parties and reviewing preliminary documents.
 - If no further review is needed, the case will be referred to the regular mortality review process.
- If further review is needed, the nurse investigator will obtain additional records for examination. Based on this review, if:
 - abuse/neglect is suspected, the case will be referred to the abuse/neglect system for investigation;
 - system deficiencies are identified or suspected, the case will be referred for an expedited mortality review; or
 - no issues are raised, the case will be referred for a regular mortality review.

Cause of Death Investigations and Autopsies

- Regarding decisions about autopsies for its clients, DMR is not the sole decision-maker. State laws related to the Office of Chief Medical Examiner dictate when it must take jurisdiction, and then potentially conduct an autopsy as part of a death cause investigation. (Appendix G summarizes the general OCME process). In cases where OCME does not take jurisdiction, the family of the deceased makes the decision of whether to have an autopsy done.

DMR Policy

- By DMR policy, each regional health service director or designee is required to contact the OCME in all sudden/ unexpected deaths of residential clients occurring in that region.
 - A specific form with all pertinent client/death information must be completed prior to telephoning OCME by whoever calls, to document what information was given. Included in the information must be the circumstances of the death (e.g., where the person was found, anything unusual), because this is in part what OCME bases its decision to take the case. The relevant DMR regional health service director must receive a copy of the form by the next working day following contact with state medical examiner's office. If jurisdiction is declined by OCME, DMR procedures for requesting an autopsy from a hospital pathology department are followed, as described below.
 - DMR policy strongly encourages autopsies in the following situations:
 - sudden and/or unexpected death;
 - unexplained or unwitnessed deaths;
 - death involving an earlier accident or trauma;
 - death involving questionable contributing factors;
 - death not due to previously diagnosed condition or disease; or
 - if a case involves abuse or neglect allegation, even if the case meets DMR criteria not requiring autopsy, as outlined below.
 - By DMR policy, the Office of the Chief Medical Examiner is to be notified of all DMR client deaths involving the situations above.
 - DMR policy does *not* require an autopsy if the individual:
 - received regular medical supervision and had a previously diagnosed terminal illness (e.g. metastatic cancer), progressive condition (e.g. congestive heart failure, renal or liver failure), degenerative process, or serious medical condition whereby death is normally expected and diagnosis has been well documented.
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- A request for an autopsy is made – whenever possible – by a person who has had a pre-existing relationship with client’s family. Consent is obtained from client’s next-of-kin as defined in statute, or other person specified by state law.
- Documentation of efforts to obtain consent is to be entered into the client’s DMR master file.

Payment for Autopsy

- Payment for autopsies is not available from Medicare, Medicaid, or Social Security. Autopsies may cost up from \$2,000 -\$3000. Thus, the following sources must be sought for payment:
 - the deceased client’s medical insurance plan;
 - the hospital pathology department where the client died or routinely received medical care and an autopsy is performed for clinical or medical interest purposes;
 - the person giving consent for the autopsy (the person assuming custody of the deceased client’s remains is also responsible for burial costs);
 - DMR, under the following circumstances:
 - payment authorization was obtained from the Regional Director/designee prior to request for, and performance of, the autopsy or
 - autopsy request was made by DMR designee based on guidelines described above; and
 - OCME, if that office accepts jurisdiction of the case and performs the autopsy.
- Autopsy results are to be sent to the regional health service director in the region where the client resided. The appropriate regional director must notify client’s next-of-kin and review results with family members, if requested. A

copy of the notification letter becomes part of client's mortality review file, as discussed below.

Mortality Review Policy and Process

Policy

- In 1988, DMR issued its first policy on mortality review. When first established, the deaths of all clients for whom DMR had direct or oversight responsibility for medical care were to be subject to mortality review “as a means of monitoring and evaluating the quality of health care provided to the deceased client and to improve ongoing health care delivery for clients.” The regional mortality review committees and the statewide medical quality assurance board were both to review events and medical care preceding a client's death.
- DMR issued a revamped mortality reporting and review policy and procedures on March 2002. While the policy statement is quite similar to the original 1988 one, the 2002 policy seems to broaden the scope of the review. Mortality review is “one means of monitoring and evaluating the quality of health care and overall care provided to individuals served by the department. Mortality reviews shall also include a review of the quality of life issues and mission principles such as dignity and respect.”

Process

- There are two separate levels of mortality review at DMR:
 - all DMR client deaths are reviewed by one of five regional mortality review committees operating out of each region, depending on where the client lived. (Southbury Training School has its own committee); and
 - some of these deaths are subsequently reviewed by the statewide Independent Mortality Review Board, if certain criteria are met, as described below.

Regional Mortality Review Committee

- The regional mortality review committee examines the client's overall care, quality of life issues, and health care preceding the death.
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- Mortality review committees are appointed by regional directors.
 - At minimum, the regional committee includes:
 - the regional health service director (who chairs committee);
 - a director or supervisor of case management for the region;
 - the region’s quality improvement director;
 - a registered nurse who is not a DMR employee; and
 - a client advocate who is not a DMR employee.
 - The mortality review process is designed to identify issues or concerns that may have compromised a client’s medical, health, or overall care. The reviews are also intended to develop corrective actions, where appropriate, and reduce future risk.
 - Case managers are responsible for pulling together the necessary/required documentation “in a timely fashion” for the committees to conduct their reviews. Typically, a registered nurse at the regional level coordinates the review for the committee, including making the necessary contacts, ensuring the mortality review packet is complete and distributed to members, and providing any necessary follow-up on part of the committee. The information for review typically includes staff logs, nurses notes, medical information, and case manager notes.
 - Upon discussing the details of a client’s death, the regional committee is required to detail its findings, recommendations, or actions on a specified DMR form, including whether:
 - medical and personal care was timely and appropriate;
 - medical specialists were used appropriately; and
 - any systemic issues exist from the case.
 - The regional health services director is required to notify the client’s next-of-kin and/or legal guardian upon completion of the committee’s review and discuss the committee’s findings/recommendations if requested.
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- The form is to be sent to the Independent Mortality Review Board (IMRB) within 90 days of the death (the regional chairperson is required to notify the IMRB chairperson and explain why any report cannot be made within the 90-day timeframe.) The report is to include:
 - supporting documentation (e.g. death certificate, autopsy report); and
 - documentation showing whether committee closed the case the regional level or if review by the IMRB is required.
- When a DMR client residing out of state dies, his or her service shall request the state where the client died conduct an investigation and submit its findings to the IMRB. If no investigation is conducted, the IMRB may provide for an independent investigation.

Independent Mortality Review Board (State)

- The state-level Independent Mortality Review Board (IMRB) exists to provide an independent review of a DMR client’s death by qualified professionals unrelated to the client’s DMR service region. (The IMRB was formerly the Medical Quality Assurance Board. Its composition and role were changed with Executive Order 25.)
- A case is automatically referred to the IMRB from a regional committee if:
 - the case involved an allegation of abuse or neglect;
 - the OCME accepted jurisdiction;
 - an autopsy was performed;
 - the client’s death was sudden or unexpected;
 - the death was unexpected and unrelated to a previously diagnosed medical condition;
 - the findings/recommendations of the regional mortality review committee were significant and may have statewide significance; or
 - the regional committee is “unsure” of whether to refer the case to IMRB.
- Board members are appointed by the DMR commissioner and include the following members or their designees:
 - DMR Director of Health and Clinical Services;

- DMR Director of Quality Assurance;
 - DMR Director of Investigations;
 - State Medical Examiner;
 - A medical doctor appointed jointly by the commissioner and the OPA executive director;
 - Commissioner of Public Health;
 - two individuals appointed by the OPA executive director; and
 - a private provider jointly appointed by the commissioner and OPA director.
- The following non-voting staff may provide assistance and support to the board, as necessary:
 - a regional health services director;
 - a regional case management director/supervisor;
 - the Southbury Training School medical director; and
 - the central office Special Protections Coordinator.
- The main functions of the board are to:
 - ensure local mortality reviews fully evaluate health care, overall care, and quality of life issues, and make recommendations and identify corrective actions as appropriate;
 - recommend an independent investigation of any death;
 - review findings/recommendations of abuse or neglect allegations relevant to the individual’s care and make additional recommendations, as needed;
 - identify incidents requiring a more comprehensive review using “root cause analysis” (described below) and review any resulting findings/recommendations;
 - identify specific regional issues needing additional attention and make recommendations;
 - identify systemic issues requiring statewide actions;
 - refer issues or concerns to other state agencies for investigation (e.g., DPH for investigation of medical practitioners and
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facilities licensed by DPH, including hospitals and nursing homes);

- send findings and recommendations to the appropriate regional health services director who is responsible for notifying families/guardians of the IMRB review and sharing the results if requested; and
 - recommend issues for policy, procedure, directive, or advisory development and implementation.
- The department’s policy is to have the board send its reviews/recommendations to the DMR commissioner within 30 days upon completion of the review, for the commissioner’s approval or disapproval.
 - Beginning early 2002, the IMRB is required to submit reports to the governor and legislature’s public health committee identifying trends, results of analyses, and recommendations for system enhancements. The reports are to be submitted at least annually.
 - The board is to meet at least quarterly to review cases.
 - In addition to the cases sent to the board from regional mortality review committees, it must review at least 10 percent of cases closed at the regional level/STS. The board is to document such reviews.
 - When either the IMRB or DMR commissioner determines corrective actions are required, the regional (or STS) director or the executive director of the affected private provider is responsible for developing a plan to implement those actions in a timely fashion. The plan may include, but is not limited to, the following:
 - professional education;
 - increased resources;
 - facility and equipment improvements;
 - new or revised policies or procedures;
 - corrective actions specific to the event, facility, or program; or
 - staff training or retraining.
 - The board is to review implementation of all corrective plans or follow-up on recommendations put forth by the board, including results of any investigation
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done by other departments and/or agencies. The board is to document its review and any subsequent actions.

- The board is to provide feedback to regional mortality review committees regarding outcomes of its recommendations or corrective action plans.
- All IMRB and regional mortality review committee reports are confidential under state law. Any request for release of a report(s) must first be reviewed by the department's commissioner, health and clinical services director, and legal and government affairs director.
- The department's health and clinical services director is required to collect and analyze mortality statistics in each region and the Southbury Training School. Such information, in conjunction with the mortality reviews, may be reviewed by the IMRB to provide the basis for further quality assurance initiatives.

Fatality Review Board

- Executive Order 25 established a Fatality Review Board for Persons with Disabilities (FRBPD) in addition to the IMRB. The board is to investigate the circumstances surrounding untimely deaths that the OPA believes warrant a full and independent investigation.
 - The OPA executive director can refer a particular case to the FRBPD before the IMRB completes its review to facilitate a timely investigation.
 - The FRBPD is chaired by the OPA executive director, and includes the following members appointed by the governor:
 - one law enforcement professional with a background in forensic investigations;
 - one mental retardation professional;
 - the Chief State's Attorney or his designee;
 - two medical professionals; and
 - the DMR commissioner/designee serves as a non-voting liaison to the board.
 - As of May 2002, OPA and DMR entered into an "information sharing" Memorandum of Understanding (MOU). The MOU outlines the following five areas the two agencies have agreed upon regarding the sharing of information surrounding untimely deaths of DMR clients.
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- DMR must make all documents collected, obtained, or maintained by the department in connection its mortality review process available for inspection and, upon request, copies must be provided to OPA for the purposes and activities of the fatality review board.
 - All DMR client records and any records obtained/maintained by the department for administering or monitoring the quality of DMR/contracted services provided by DMR/contractors, must be available to OPA for the purposes of the FRBPD.
 - DMR will cooperate with any investigation conducted by the fatality review board, including access to records and other information in accordance with state and federal law.
 - OPA and the fatality review board agree to maintain and provide access to records obtained for the purposes of the fatality review board in accordance with applicable state and federal laws.
 - OPA and the fatality review board agree to share findings made and records obtained by the board with the IMRB, consistent with the purposes and activities of the IMRB.
- As of November 2002, the fatality review board is compiling information for 121 DMR deaths referred to OPA since January 2002. A summary report will be developed by OPA and presented to the fatality review board at its November 2002 meeting. OPA has also received two death cases from DMR for the fatality review board to begin preliminary investigations regarding the deaths.

Root Cause Analysis

- In mid-2001, DMR initiated a practice called “root cause analysis.” Root cause analysis is used in special circumstances for the purpose of “eliminating or reducing risk of future unusual incidents that could result in the untimely death or serious injury to a DMR client.” It is a formal analytic process designed to help identify underlying factors that have contributed to or have directly caused a major adverse event or systems failure. The goal of root cause analysis is a full and complete discovery of the factors surrounding an

untimely death or serious injury. The process is conducted by the DMR central office.

- Root cause analysis follows a prescribed process and is always conducted by a team of individuals familiar with the incident under review, departmental policy, and program requirements, and the root cause analysis process itself. The results are typically used to guide and direct changes to processes, the environment, and human behavior with the goal of preventing or reducing future adverse events.
- OPA also receives a copy of the root cause analysis report and DMR implementation plan within 30 days of the DMR executive management team review.
- A written summary of the report must be posted on the DMR website for a minimum of 90 days.
- The root cause analysis process is not designed to replace traditional review and investigation procedures or existing mortality review processes. Any formal reports resulting from the root cause analysis process will protect the privacy rights of individuals and will not disclose client, family, guardian, or staff names, or any other identifying information.
- DMR has conducted four root cause analyses of deaths to date.

ANALYSIS OF DMR DEATHS

- There are a number of ways to analyze the deaths of DMR clients that have occurred over the past 10 years – FY 92- FY01. Program review used a four-step approach in its analysis of the deaths.
- First is a broad look at the numbers of DMR death and rates of deaths in comparison to deaths in the general population, and other including by cause of death and by age group, as well as a comparison.
- Second, a somewhat in-depth look at all 1,654 deaths of DMR clients that occurred between FY 92 and FY 01 – the 10-year period outlined in the committee’s scope of study.
- The review includes whether there had been a report of neglect or abuse, whether an autopsy had been done, and what the causes and contributing factors to the deaths were. DPH was able to match and provide death registry data for 1,572 of the 1,654 DMR-client deaths.
- Committee staff conducted a very detailed examination and data collection effort of one-half of all CLA deaths that had occurred in all DMR regions over the last 10 years.
- Staff performed an equally intense review of the 36 death cases contained in the December 2001 Hartford Courant articles.
- Each area of analysis will summarize methods used and a summary of the analysis and conclusions.

Overall Deaths in General Population and Among DMR Clients

- Many studies, publications, and reports indicate death rates are higher (and death occurs earlier) in developmentally disabled populations than in the general population. Table VII-1 below shows the death rate is higher.
- Table VII-1 shows the number of deaths in Connecticut among the general population and the death rate per 1,000 for the population compared to the number and crude rate in DMR client population. The data are available for the overall population based on calendar years 1992-1999, and for the DMR population from FY 92 through FY 01. The table shows that DMR’s death rate, when taken of its whole population, shows narrow fluctuation.

Table VII-1. Deaths and Death Rates in General Population and DMR Population				
Year	# of Deaths in CT (overall population)	Death Rate per 1,000	# of Deaths in DMR population	Deaths per 1,000⁶
1992	28,224	8.6	140	11.5
1993	28,938	8.8	146	11.4
1994	29,242	8.9	163	12.3
1995	29,438	8.9	153	11.1
1996	29,541	9.4	165	11.7
1997	29,405	8.9	164	11.3
1998	29,619	9.0	158	10.7
1999	29,314	8.9	180	11.9
2000	No data		204	13.8
2001	No data		181	11.9

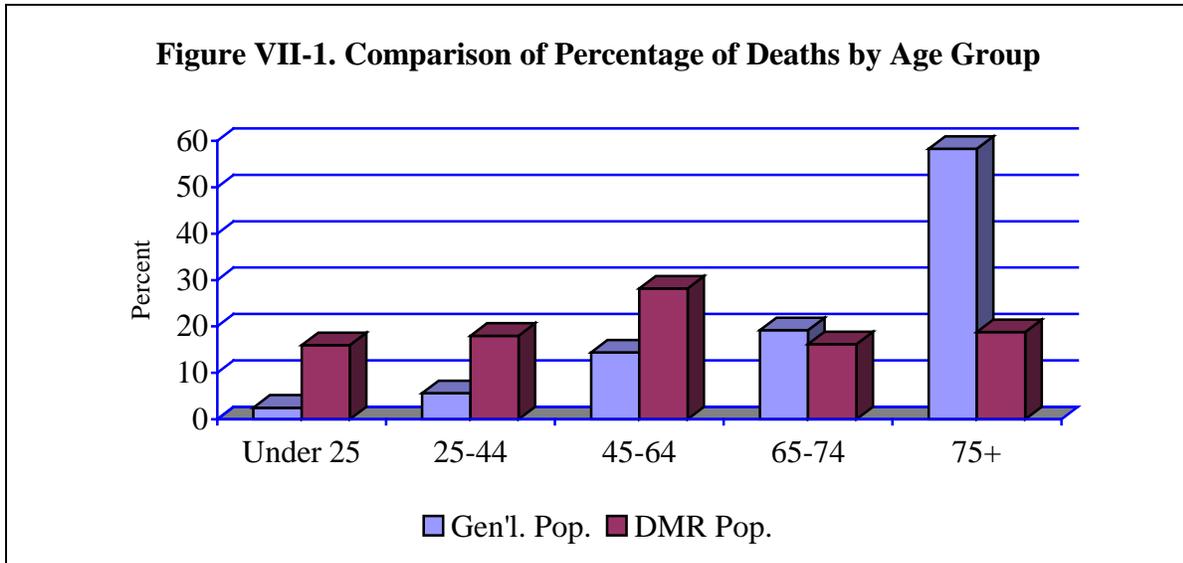
Source: Department of Public Health, Division of Vital Statistics (CT population death statistics). DMR provided fiscal year data on death numbers and population to calculate death rates

Table VII-2. Breakdown by Age Category of Deaths in General Population and DMR Populations				
Age Category	General Population 1992-99		FY 92-FY 01	
	Number (n=233,722)	Percent	Number (n=1,654)	Percent
Under 25	5,884	2.5%	272	16%
25-44	12,994	5.6%	303	18%
45-64	33,583	14.4%	468	28.2%
65-74	44,948	19.2%	275	16.2%
75+	136,313	58.3%	307	18.8%
Age not known			29	

Source: DPH for the General Population statistics and DMR CAMRIS for the DMR data

⁶ To calculate the rate for DMR deaths: DMR deaths/DMR population X 1,000. DMR population used as the denominator is the number of active clients receiving services from DMR for that given year.

- Figure VII-1 shows deaths by age category, and as the graph illustrates, DMR deaths occur much earlier than in the general population. For example, more than one-third of the DMR population deaths occur before age 45, while less than 10 percent of the general population dies before that age. However, while almost 60 percent of the general population live to 75 years or older, fewer than 20 percent of the DMR population live that long. As will be discussed later, many DMR clients have significant health conditions that compromise their longevity.



Other States

- Mortality data among the developmentally disabled population are not readily maintained by most states, and comparing among the few states that keep the data is problematic because the definitions of eligible clients and reporting of deaths to the appropriate agency varies from state to state.
- With these cautionary notes, Table VII-3 presents FY 99 death data from the Core Indicators Project⁷, which collected and aggregated data from eight states and calculated an average death rate per 1,000. This rate is compared with Connecticut's rate for FY 99.

⁷ The Core Indicators Project is a quality improvement endeavor sponsored by the National Assn. of State Directors of Developmental Disabilities Services. Eight states furnished their mortality data to the project with the understanding the individual states would not be identified.

Table VII-3. Comparison of Deaths per 1,000: Connecticut and Core Indicator States -- FY 99	
Connecticut Rate/1,000	Core Indicator States Rate/1,000
11.9	11.06

- In Table VII-4, the FY 00 death rate in California is compared with Connecticut's rate. Although Connecticut's rate per-1,000 client population is substantially higher than California's, factors like death reporting and population differences (California population includes all developmentally disabled persons, broader than Connecticut's) might contribute to such variation.

Table VII-4. Comparison of FY 00 Mortality Rates of DMR Population: Connecticut and California			
Connecticut		California	
Deaths	Rate/1000	Deaths	Rate/1000
204	13.8	1,469	8.74

- The committee obtained death rate data from the Massachusetts Department of Mental Retardation for the calendar years 1996 through 2000. Table VII-5 compares the Massachusetts' death rates of its DMR client population with Connecticut's for the same time period.

Table VII-5. Comparison of Mortality Rates of DMR Population: Connecticut and Massachusetts -- Calendar Years 1996-2000					
Massachusetts			Connecticut		
Year	Deaths	Rate/1000	Year	Deaths	Rate/1000
1996	232	14.8	1996	166	11.8
1997	242	14.0	1997	164	11.3
1998	257	13.7	1998	144	9.7
1999	237	11.6	1999	195	12.9
2000	322*	13.5	2000	206	14.0

* Massachusetts DMR indicates the increase in 2000 is due to including deaths of DMR clients in nursing homes for the first time

Sources: Massachusetts and Connecticut Departments of Mental Retardation

Causes of Death

- Some causes of death are similar to those in the general population; others appear to be more common to the developmentally disabled population. Because the age-span of developmentally disabled persons is often shorter, the onset of some causes of death frequently appear earlier as well.
- Table VII-6 below shows the five leading causes of death among the general population nationally, in Connecticut, and among the state's developmentally disabled population for the latest available national and state data.

Table VII-6. Causes of Death: A Comparison by Population		
U.S. (2000) n=2.4 million	Connecticut (1999) n=29,314	CT Developmentally Disabled (2000) n=204
1. Heart diseases (30.3%)	1.Heart disease (32.5%)	1. Heart disease (28%)
2.Malignant neoplasms (cancer) (23%)	2. Malignant neoplasma (23.9%)	2 Pneumonias and other respiratory diseases (19.1%)
3. Cerebrovascular diseases (7%)	3. Cerebrovascular disease (6.6%)	3 Malignant neoplasms –cancer (10.7%)
4. Chronic lower respiratory disease (5.2%)	4. Chronic lower respiratory disease (4.8%)	4. Congenital /chromosomal disorders (7.3%)
5. Accidents and unintentional injuries (4.1%)	5. Accidents and unintentional injuries (4.1%)	5. Diseases of central nervous system (5.3%)
Sources: Centers for Disease Control Preliminary Death Report (2000); CT Department of Public Health Death Registry Data 1999; and DMR Death data coded (ICD-10) from death certificate data		

- Heart disease is the leading cause of death in all three populations.
- In the national and state general populations, cancer is the second cause of death, while in the Connecticut's developmentally disabled population, pneumonias and other respiratory disease is the second leading cause. Two reasons are cited for the less frequent occurrence of cancer among the mentally retarded:

- their shortened life spans mean fewer years for cancers to develop;
- they are less likely to be exposed to, or engage in, cancer-causing risks.

Aspiration Pneumonia

- The federal Centers for Disease Control in its *2000 Preliminary Death Report* indicates that “pneumonias due to aspiration of food or liquids” was among the top 15 causes of death for the first time ever. The report noted this cause of death is concentrated among the elderly and results from aspirating material into the lungs.
- This is also common cause of death among the developmentally disabled population. As the table above indicates, pneumonias and respiratory problems were the main cause of death for about 19 percent.
- The specific pneumonia caused by aspirating food or other materials into the lungs was a cause of 17 of the 204 deaths in 2000, or slightly more than 8 percent.
- As both the general and developmentally disabled population ages, aspiration pneumonia has grown as the primary cause of death in both populations. Table VII-6 shows the growth in the numbers in both populations. While aspiration pneumonia is cause of death in a very small percentage of general population deaths, it is increasing.
- Aspiration pneumonia, as a percentage of DMR-client deaths, is also increasing, although again with small numbers that ratio can swing dramatically from one year to the next. But there is recognition that this population -- especially more severely and profoundly retarded persons -- experience a higher possibility of swallowing problems and aspiration, and as they age this risk increases substantially.

Table VII-7. Aspiration Pneumonia as the Primary Cause of Death				
	# General Population	% of Deaths	# DMR Population	% of Deaths
1992	154	.54	3	2.1
1993	133	.45	3	2.0
1994	169	.57	5	2.9
1995	181	.61	3	1.9
1996	184	.62	4	2.4
1997	195	.66	6	3.6
1998	254	.85	1	.63
1999	342	1.16	11	6.1
2000	No data		17	8.37
Total			43	

Accidents

- Identifying accidental deaths can be problematic depending on who, when, how and what documentation is used to label the cause “accidental”. Program review used the death certificate information maintained at the Department of Public Health as the determining factor in all DMR deaths over the 10-year period. The analysis showed of the 1,572 DMR-client deaths with death certificate data:
 - 43 deaths were considered accidental;
 - one a suicide;
 - five homicides;
 - one undetermined;
 - one unknown; and
 - the remainder were natural causes.

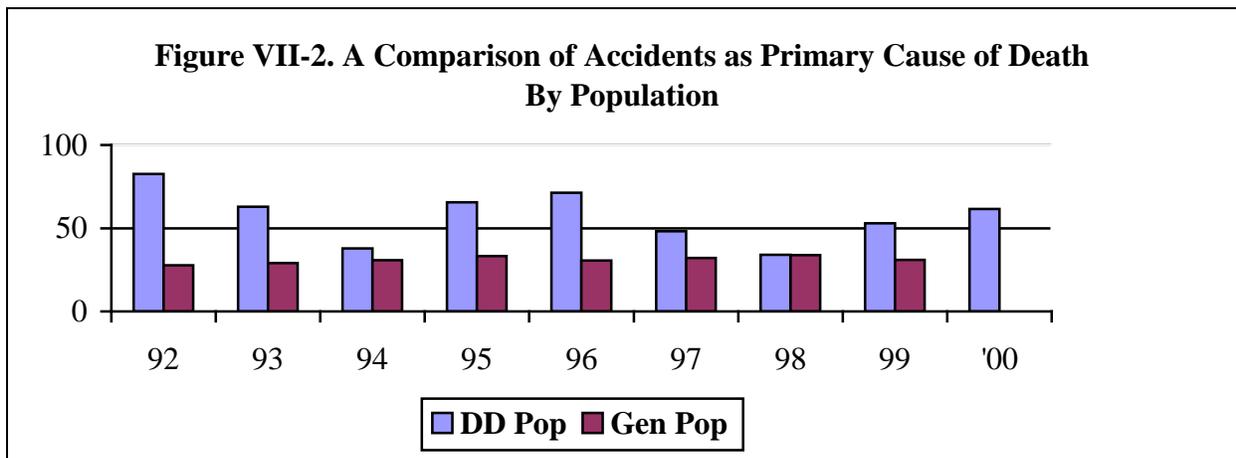
Using these accident data shows that only 3.2 percent of DMR-clients deaths over a 10-year period are accidents.

- A broader definition of accidental deaths yields a larger number. Program review staff examined 1,572 deaths for which there were death certificate data and included any accident code⁸ that was listed in any field (up to nine are used in any death record) labeled as a contributing cause to death. The committee acknowledges this is a broad definition of accidents but one that may more accurately depict the type of accident that occurs among the disabled population. For example, if a client chokes, rather than dying

⁸ Accident codes are specific numerical codes within the International Classification of Diseases codes (edition 9 and 10) that signify an accident.

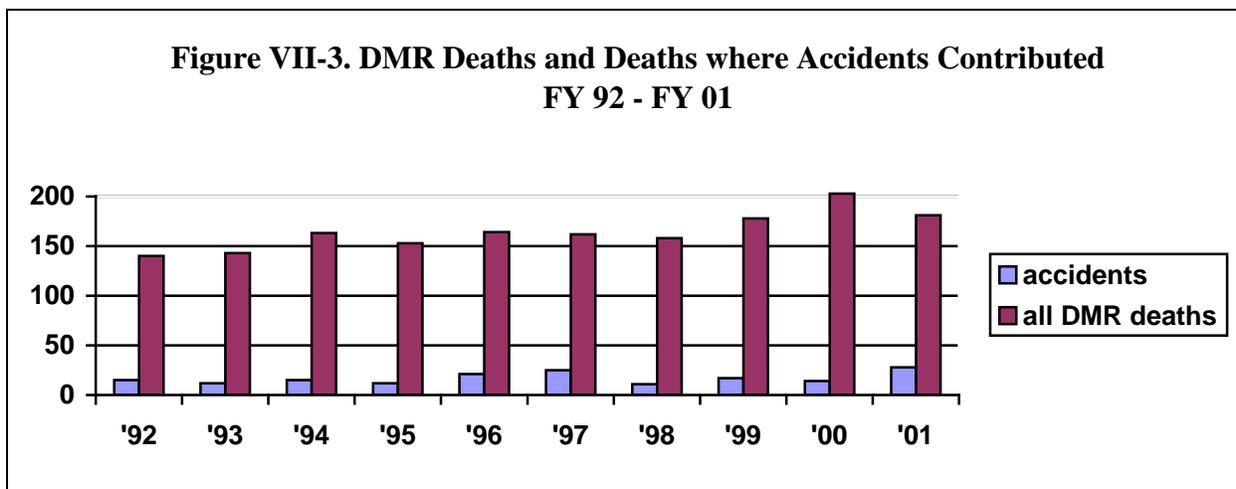
instantly, the client may die of other causes -- like respiratory failure -- a few days or even weeks later.

- Using the broad definition of accidents contributing to death shows that 170, or about 10 percent of the DMR-client deaths had an accident as a contributing factor.
- Defining accidents as a *primary cause of death* (an accident code is listed first on the death certificate) is used to determine accident rates in the general population. Using this definition shows that accidental deaths occur more frequently among the developmentally disabled population than among the general population, as shown in Figure VII-2 (Data for the general population were not available for 2000. The way the data are kept for general Connecticut population is (# of deaths/(number of population/1000)) *100. Staff used the same calculation for DMR death rates



- Figure VII-3 shows the actual number of DMR-client deaths where accidents (broad definition) contributed to death each year compared with the total number of DMR-client deaths. As shown:
 - the number of accidents is small—between 11 and 28 annually;
 - because the numbers of DMR deaths overall are small, the accidental deaths as a percentage can be somewhat large (e.g., 10-15 percent);
 - there is volatility in the number of accident-contributing deaths that occur from year to year—in FY 97 there were 25; in FY 98 there were 11, a drop of more than 50 percent. Again, this is a problem when dealing with small numbers of the DMR-client deaths.

**Figure VII-3. DMR Deaths and Deaths where Accidents Contributed
FY 92 - FY 01**

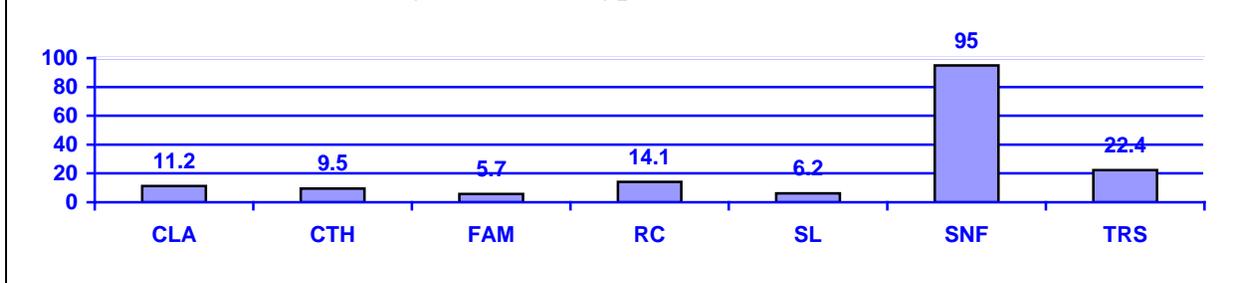


- Accidental deaths (broad definition) for FY 92-FY 01 occurred in all residential settings:
 - 36 of 388 deaths in CLAs (9.2%)
 - 6 of 53 deaths in CTHs (11.3%)
 - 28 of 363 deaths in family homes (6.8%);
 - 25 of 369 in SNFs (6.7%)
 - 6 of 185 at Southbury Training School (3.2%)
 - 14 of 56 in Regional Centers (25%) and
 - 4 of 70 deaths in supported living (5.7%).

Comparison of Death Rates by Residence Type

- Figure VII-4 shows the average annual death rate per 1,000 over the FY 92-FY 01 period. The population is the number of unique persons in that setting each year added for the 10-year period.

**Figure VII-4. Average Annual Death Rate:
by Residence Type FY 92 - FY 01**

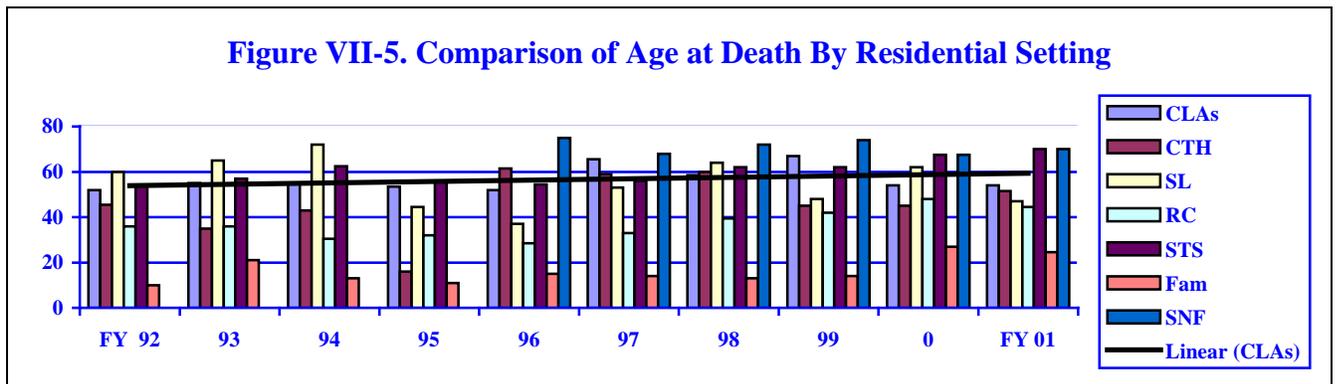


As the figure shows:

- The highest average rate of death occurred in SNFs, 95 per 1,000. SNF clients are older in general and frailer and more medically involved, and SNF clients died at an older age – 70 in FY 01.
- Southbury had the 2nd highest death rate -- an average of 22.4 per 1,000 during the period. Southbury's population is the oldest among DMR residential settings -- 53 in FY 01. Southbury residents are also older at death -- 70 in FY 01.
- Regional Centers had the next highest death rate at 14.1 per 1,000. The regional centers take care of a younger population – median age was 37 in FY 01 – and persons died younger there (median death age was 44 in FY 01). But the centers also take care of the most severely retarded population – more than 80 percent of their population in FY 01 was severely or profoundly retarded.
- CLAs had a 10-year average annual death rate of 11.2 per 1,000. CLA median age in FY 01 was 44, the median age at death was 54. The CLA population is fairly evenly distributed among the different severity levels of a mental retardation.
- The 10-year death rate was lowest in families -- at 5.7 per 1,000. The median age of a client who died with family in FY 01 was 24.5, and the median age of a client living at home was 20.
- Because of the small numbers of deaths and populations in any of these settings, the death rate can fluctuate dramatically from year to year. In FY 95, the CLA death rate was 8.1, in FY 96 it had doubled to 15, by FY 97 it had dropped by a third to 10.2. (Appendix H presents the number of DMR client deaths by fiscal year and residential type for FYs 92-02.)

Age of Clients at Death by Residential Setting

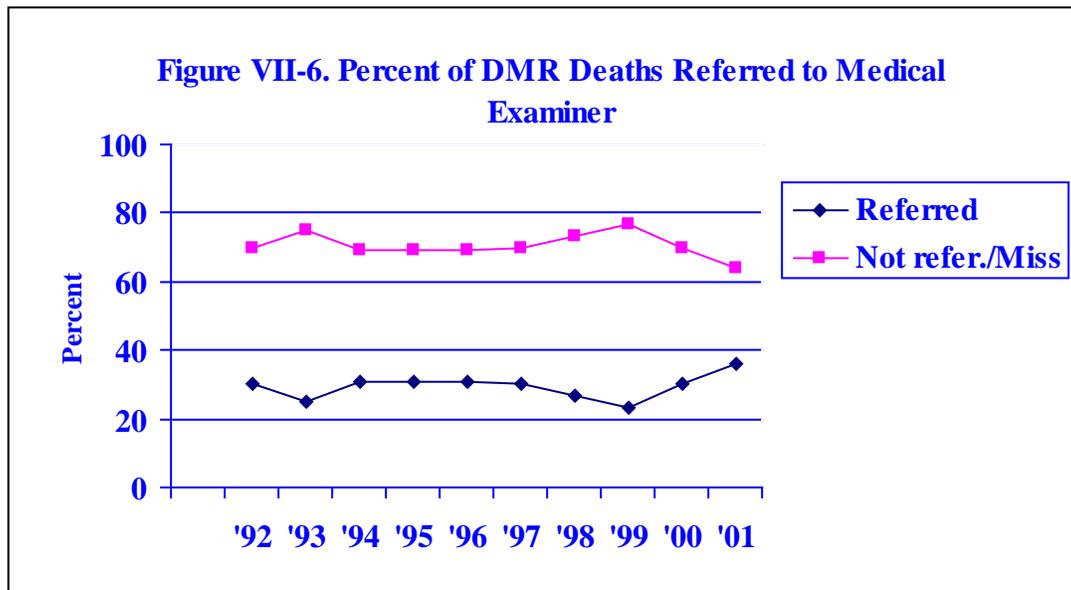
- Figure VII-5 shows the median age for persons who died in various residential settings. Information from the figures is mentioned in the discussion above. The conclusions related to age are:
 - persons who die in nursing homes are older –70 in FY 01 (there are no nursing home age data before FY 96)
 - persons who die at Southbury are also older – 70 in FY 01
 - persons who die at regional centers are younger, but their population is also younger
 - persons who died in CLAs were younger in FY 00 and FY 01 than they had been in FY 97, 98 and 99
 - there is great variation from year to year in the median age at death by residential setting, because the numbers are small
 - people who die with their families are the youngest, but they are also the youngest population in any residential setting



Referral to Medical Examiner

- Chapter VI described referral to medical examiner process. Figure VII-6 shows the number of DMR cases that are referred to a medical examiner. Because a death is sent for examination by a medical examiner does not mean the examiner will accept jurisdiction or that an autopsy will be done.

Approximately 30 percent of DMR's cases have been sent to a medical examiner during the period examined.



Autopsies

- The process for obtaining an autopsy was explained in the previous chapter. Autopsies need not be performed by a medical examiner; they can be performed by a hospital's pathology department. However, in most cases there must be a request for an autopsy and the family must give consent. The table below shows the number and rates of autopsies for deaths in the general population compared with autopsies of DMR deaths for 1995 – 2001.

Table VII-8. Comparison of Autopsy Rates Among General Population and DMR Population Deaths				
Year	<i>General Population Deaths</i>		<i>DMR Population Deaths</i>	
	# of Autopsies	% of Deaths	# of Autopsies	% of Deaths
1995	2,217	7.5%	38	24.0%
1996	2,159	7.3%	25	15.2%
1997	2,209	7.5%	25	16.0%
1998	2,181	7.3%	17	12.1%
1999	2,118	7.1%	30	12.2%
2000	No data		23	11.6%
2001	No data		14	15.0%

Source: DPH for general population data, DPH death registry and DMR CAMRIS data for DMR population data

- Connecticut's autopsy rate is fairly high compared with other states.⁹ Of the 19 states responding to the survey question on autopsies:
 - Washington state indicates 35 percent of its deaths had autopsies;
 - Colorado stated 25 percent, and Vermont between 20-25 percent;
 - Indiana 14.5 percent and *Connecticut 14 percent*; and
 - Florida between 10-20 percent; Rhode Island and Arkansas each at 10 percent; and
 - The other 10 states said the percent was unknown or below 5 percent.

Abuse/Neglect Allegations

- 159 (9.6 percent) of the 1,654 DMR clients who died from FY 92-FY 01 were the subject of 193 abuse/neglect allegations in the year before they died. (Most allegations had no connection to the client deaths).
- 45 percent of the allegations were substantiated.
- Table VII-9 shows the breakdown of allegations by residential setting.
- 53 percent of the allegations pertained to persons living in CLAs, while persons living in CLAs only made up 23 percent of the 1,654 deaths. Forty-five percent of the suspicions were substantiated.
- Out of the 388 CLA clients who died, 53 had abuse/neglect allegations reported, or one allegation for every seven people. For the 185 people living at Southbury Training School when they died, 23 allegations were made—1 allegation for every eight people.
- As with the death numbers, the abuse/neglect numbers are low so small changes can make significant percentage changes.

⁹ July 2002 survey conducted for the California Department of Developmental Services; 24 states responded, not all answered every question.

Table VII-9. Abuse/Neglect Allegations In Year Before Death for 1,654 DMR Clients Who Died in FYs 92-01 By Residential Type

Resident Type	# of Allegations (# of people)	# Substantiated (% of allegations)	# Unsubstantiated (% of allegations)	Blanks
CLA	100 (83)	45 (45%)	47 (47%)	8
CTH	9 (7)	3 (33%)	4 (44%)	2
FAM	7 (7)	3 (43%)	3 (43%)	1
RC	21 (14)	11 (52%)	9 (43%)	1
SL	6 (6)	2 (33%)	4 (67%)	0
SNF	17 (14)	10 (59%)	6 (35%)	1
TRS	23 (20)	9 (39%)	11 (48%)	3
Others	10 (8)	4 (40%)	4 (40%)	2
TOTALS	193 (159)	87 (45%)	88 (46%)	

Source: DMR CAMRIS

- In 31 deaths (1.9 percent of total deaths), abuse/neglect was suspected and recorded on the initial death report filed immediately after the death.
- Twelve of these allegations were substantiated.
- seven were not substantiated.
- nine allegations reported immediately were not entered into the abuse/neglect portion of the DMR database (based on other information, seven cases did have abuse/neglect investigations).
- Twenty (1.2 percent of total deaths) others had an abuse/neglect report made within one week of their deaths.
 - At least eight of these were related to the deaths, but were not reported on the death report at the time of death. Many of these people had accident/injury or unusual incident reports related to their deaths, but abuse/neglect was not suspected per these reports.
 - Five of the eight were substantiated
 - Three were not substantiated (but OPA disagreed with one finding)
 - One involved a drug interaction issue that was addressed without an abuse/neglect finding

- There are several categories of cases that are investigated
 - Neglect
 - Physical Abuse
 - Sexual Abuse
 - Psychological Abuse
 - Verbal Abuse
 - Incidents of Unknown Origin
 - Other

- Out of the 193 allegations, the most common category was neglect – 126 (65%) of the total, with 66 relating to CLA residents. The next most common was physical abuse at 30 allegations (16%), with 14 relating to CLA residents.

Program Review Sample of CLA Death Cases

- This review was prompted in large part by media accounts of specific deaths of DMR clients living in CLAs, citing 36 as “questionable”. (A summary profile of these cases is contained in Appendix I.) To put those deaths in context, the program review committee staff picked a random sample of 177 DMR clients living in CLAs who died during the ten year period FY 92 through FY 01. This number represents half of the CLA deaths in that ten year period (excluding the cases cited in the media). The sample was picked to reflect the differences in regional death numbers.

- Information was gathered from the sample about some of the client’s demographics, where the client lived, the client’s health conditions, cause of death, and processes after death. The same information was gathered about the cases cited in the Hartford Courant.

- Table VII-9 presents the results of the PRI death sample as well as the cases cited in the Hartford Courant. The case file review analysis led to several findings.

- As a whole, the persons in the PRI sample were a medically involved group.
 - Thirty-nine percent had between five and seven medical diagnoses before death, with a full 30 percent having 10 or more diagnoses.

- Forty percent of the PRI sample had a seizure disorder; 19 percent, hypertension; 12 percent, Alzheimer’s disease; and 12 percent, cerebral palsy.
 - Fifty-one percent of the people in the PRI sample were taking between five and eight different prescription medications.
 - Twenty-three percent of the sample had a feeding tube inserted.
 - Twenty-nine percent spent time in hospice care or at a nursing home before death, while thirty-eight percent spent between four and 91 days in a hospital before death.
- The cases cited in the Hartford Courant had a much higher proportion of deaths involving accidents than the PRI sample.
 - Forty-seven percent of the Hartford Courant cases were determined to be accidents, compared to 3 percent of the PRI sample.¹⁰
 - A higher percentage of autopsies were done for the Hartford Courant cases (61% compared to 24%), and of those, over half were conducted by the Office of Chief Medical Examiner, evidence of sudden and unexpected death circumstances.
 - 22 percent of the Hartford Courant cases involved choking in contrast to eight percent of the sample (although the committee notes the choking rate from the sample is considerable).

¹⁰ As noted in the table, these data are based on information in DMR mortality review files and due to several factors, program review uses these data with caution. Also, see the earlier discussion about accident –reporting related to deaths.

Table VII-10. Analysis Results of Program Review Committee Staff Sample (deaths occurring in Community Living Arrangements between FYs 92-01) and Comparison to 36 Death Cases Highlighted in the <i>Hartford Courant</i> (December 2001)		
Note: Percentages are rounded	Committee Staff Sample (n=177 unless indicated)	Hartford Courant (n=36 unless indicated)
Residence at time of death		
Public CLA	21%	31%
Private CLA	75%	56%
Other	5%	14%
Sex		
Male	51%	64%
Female	49%	36%
Age		
Minimum	23 years	12 years
Maximum	94 years	74 years
Average	58 years	42 years
Median	57 years	38 years
0-29 years	5%	31%
30-49 years	28%	42%
50-59 years	20%	11%
60-69 years	20%	14%
70+ years	28%	3%
Mental Retardation Level		
Mild	23%	22%
Moderate	17%	17%
Severe	20%	19%
Profound	33%	39%
Not Retarded	1%	0%
Missing	7%	3%
Place of Death		
Hospital	60%	78%
Group Home	27%	14%
Skilled Nursing Facility	6%	0%
Hospice	5%	3%
Other (family home, respite, etc.)	2%	3%
Regional Center	1%	3%
Region Where Death Occurred		
North Central	38%	14%
South Central	23%	8%
Northwest	18%	22%
Eastern	17%	13%

Note: Percentages are rounded	Committee Staff Sample (n=177 unless indicated)	Hartford Courant (n=36 unless indicated)
Southwest	5%	17%
Number of Diagnoses per Client		
1	1%	11%
2	3%	9%
3	3%	23%
4	9%	6%
5	14%	11%
6	12%	6%
7	13%	0%
8	5%	6%
9	8%	11%
10+	30%	17%
Missing	2%	3%
Common Diagnoses		
Seizure Disorder	40%	33%
Hypertension	19%	Hypothyroidism 17%
Alzheimer's Disease	12%	
Cerebral Palsy	12%	17%
Gastro/Intestinal	11%	31%
Osteoporosis	11%	
Spastic Quadriplegia	8%	
Anemia	7%	
Hiatal Hernia	7%	
Chronic Obstructive Pul. Dis.	6%	
Hepatitis B	6%	
Down Syndrome	15%	11%
Feeding Tube	23%	11%
Number of Medications per Client (prescription only)		
0	1%	0%
1	5%	11%
2	7%	19%
3	11%	11%
4	8%	14%
5	12%	6%
6	12%	6%
7	15%	6%
8	12%	11%
9	6%	3%

Note: Percentages are rounded	Committee Staff Sample (n=177 unless indicated)	Hartford Courant (n=36 unless indicated)
10+	8%	11%
Missing	2%	3%
Time in Placement at Time of Death		
<1 Year	18%	19%
1 to <2 Years	8%	8%
2 to <3 Years	7%	17%
3 to <4 Years	7%	8%
4 to <5 Years	7%	3%
>5 Years	49%	39%
Inconclusive from file	4%	6%
Avg. time in placement	5.6 years	5.5 years
Median time in placement	5.1 years	3 years
Was 911 Called at Time of Death		
Yes	47%	75%
No	41%	22%
Inconclusive from file	12%	3%
Was Family/Guardian Notified about the Death		
Yes	87%	94%
No	0%	0%
Inconclusive from file	13%	6%
Elapsed Time When Family was Notified of Death		
	n=154	n=34
Day of death	83%	92%
Next Day	7%	
2 days after death	2%	
10 days after death	1%	
11 days after death	1%	
Missing dates	6%	8%
Was Autopsy Discussed with Family/Guardian (not formally recorded by DMR; information taken from general file)		
Yes	28%	94%
No	12%	
Inconclusive from file	59%	6%
Was Autopsy Conducted		
Yes	24%	61%
No	76%	39%
Inconclusive from file	1%	0%
Who Conducted Autopsy		
	n=42	n=22
Hospital	79%	36%
Chief Medical Examiner's Office	21%	59%

Note: Percentages are rounded	Committee Staff Sample (n=177 unless indicated)	Hartford Courant (n=36 unless indicated)
Was a Regional Mortality Review Conducted		
Yes	100%	100%
No	0%	0%
Elapsed Time from Date of Death to Regional Mortality Review		
<6 Months	40%	44%
6 Months to <1 Year	44%	42%
1 Year to <2 Years	14%	11%
>2 Years	2%	1%
Inconclusive from file	1%	3%
Was a State Mortality Review Conducted		
Yes	51%	97%
No	47%	3%
Inconclusive from file	2%	0%
Elapsed Time from Regional Mortality Review to State Mortality Review		
	n=90	n=35
<6 Months	77%	77%
6 Months to <1 Year	14%	20%
1 Year to <2 Years	2%	3%
>2 Years	7%	0%
Inconclusive from file	7%	0%
Did Client Have a Do Not Resuscitate Order at Time of Death		
Yes	58%	28%
No	31%	61%
Inconclusive from file	11%	11%
Cause of Death (as determined by the regional mortality review process)		
Pulmonary, Respiratory, Lungs	29%	56%
Cardiac	26%	8%
Cardio-Pulmonary	12%	11%
Cancer	8%	0%
Sepsis/Sepsis Shock	3%	6%
Renal	2%	0%
Seizure	2%	3%
Gastro/Intestinal	2%	0%
Other	7%	17%
Missing	1%	0%
Choking Involved with Death?*		
Yes	8%	22%
In Hospital for One or More Days		
	n=99	n=16
1-3 days	32%	38%

Note: Percentages are rounded	Committee Staff Sample (n=177 unless indicated)	Hartford Courant (n=36 unless indicated)
4-7 days	14%	44%
8-14 days	18%	13%
15-21 days	14%	0%
28-91 days	21%	0%
Days in Hospice Care At Home	n=29	n=0
1-3 days	10%	
4-7 days	10%	
8-21 days	31%	
22-35 days	14%	
36-91 days	17%	
Over 92 days	17%	
Days in Hospice Care at Hospital/Hospice Center	n=9	n=0
1-17 days	100%	
Days in SNF	n=13	n=0
1-3 days	8%	
4-7 days	8%	
8-21 day	38%	
22-35 days	8%	
35-91 days	23%	
Over 91	15%	
Was Death an Accident? **		
Yes	3%	47%
No	85%	44%
Blank	12%	8%
<p>* The data on choking were based on a review of the circumstances of the deaths, in addition to the identified cause of death. Sometimes the cause of death just identifies the end result of choking, such as cardiac arrest.</p> <p>**These data are based on information found in DMR mortality review files. Due to changing ways of collecting this information and apparent inconsistencies in filling the forms out in the time period of the file review, committee staff uses the data with caution. They do show, though, the high percentage of accidents in the cases the Hartford Courant highlighted compared to other CLA deaths.</p>		

FINDINGS AND RECOMMENDATIONS

This chapter contains the findings and recommendations of the program review committee based on its investigation into the health and safety of DMR clients living in community living arrangements. As the preceding chapters show, the committee investigation included a review of the current oversight mechanisms in place at DMR as well as analyses of data related to DMR client deaths. In its review, the committee determined, as other studies and reports have indicated, death rates are higher and deaths occur earlier in developmentally disabled populations, including Connecticut's DMR clients, as compared to the general population. Further, in terms of specific deaths reviewed, the program review committee did not identify any direct systemic causes for the deaths, meaning that in almost all the cases, there were systems in place to address the risks to these clients. For one reason or another, though, the systems were not carried out.

After examining individual death cases and reviewing the current oversight mechanisms in place at DMR, the program review committee concludes the CLA system is regulated and monitored by many different governmental entities (DMR, Office of Protection and Advocacy for Persons with Disabilities (OPA), Department of Public Health (DPH), and the federal Centers for Medicare and Medicaid Services (CMS)). However, there is a lack of cohesiveness and follow-through resulting from any of these reviews. To be the most effective in sending the message that DMR is as serious about client health and safety as it is regarding other aspects of its responsibilities, there must be assurance and accountability from both DMR and its service providers that: 1) deficiencies found are corrected; 2) health and safety measures are practiced; and 3) when an accident or death happens it is thoroughly and objectively examined. Thus the main thrust of the committee findings and recommendations presented below is to enhance oversight effectiveness.

The committee oversight enhancements affect the following areas: 1) CLA licensing and inspections; 2) individual oversight tools, including case management, human rights committees, and abuse/neglect policies and procedures; 3) post-death review; 4) and overall coordination of the oversight system. In addition, regulatory enhancements pertaining to DMR client health and safety are recommended to strengthen the regulations. Finally, the committee recommends DMR develop a system to assess client needs and match appropriate services, a key feature in optimizing client health and safety, and begin to develop a provider payment approach based on client needs that could, among other objectives, address current wage equity issues.

OVERSIGHT: LICENSING AND INSPECTIONS

FINDINGS

- *A high percentage of licensing inspections of public and private CLAs are occurring after a provider's license/certification has expired (see Appendix J for a full analysis.)*
 - *The licensing and inspection unit is understaffed and lacks staff with a nursing background, an important component in dealing with an increasing medically fragile population.*
 - *Public and private homes are typically not complying with the regulatory timeframe for submitting required plans of correction outlining how citations will be rectified following licensing inspections.*
 - *Public homes are more likely to submit their required plans of correction later than private providers.*
 - *Almost all plans of correction for public and private providers, however, are acceptable to the DMR licensing unit on first submittal without further modification.*
 - *There were no differences among public and private homes in the top five regulatory categories cited during inspections for the period analyzed by committee staff (see Appendix J for the full analysis.) Note: the regulatory categories encompass a broad range of areas where inspectors can cite providers as being deficient. Specific licensing citations (e.g. excessive water temperature) are made within the context of a broader regulatory category.*
 - *DMR does not utilize its full range of enforcement tools to ensure compliance with CLA licensing regulations. Although the use of one-year inspection cycles (the most "stringent" licensing enforcement tool currently used by the department) has declined since FY 97 from 20 percent to roughly 6 percent in FY 02, its use still indicates providers are not fully complying with licensing requirements.*
 - *The focus of biennial licensing inspections is on announced visits with an emphasis on reviewing documentation maintained by the provider.*
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- *The program review committee considered other models for overseeing licensing, inspections, and enforcement, but determined maintaining the function within DMR with enhanced staffing and improved inspection follow-up and enforcement was the best option.*
- *DMR is not consistently using its relatively extensive automated licensing database to examine the licensing/inspection process for community living arrangements from a broad management perspective.*

Background

State regulations require annual license renewals and biennial inspections of public and private community living arrangements to help ensure the health and safety of DMR clients living in CLAs. Providers are required to submit timely plans indicating how they will rectify any citations resulting from inspections, who will be responsible for implementation, and when the problem(s) will be corrected. Until recently, there was no mechanism to independently verify all plans were implemented until the next inspection in two years. The department has several enforcement tools to ensure compliance with state regulations. DMR also has a relatively extensive automated database system tracking most of the key elements of the licensing/inspection process.

Problems

Inspections for almost two-thirds of public homes and 40 percent of private homes occur after an operating license has expired. (See Appendix J for more detailed analysis.) Given most licensing inspections occur once every two years, late inspections extend an already lengthy time period between inspections, allowing possible client health or safety problems to go undetected for longer timeframes. Licensing data further show public and private providers are not adhering to the regulatory timeframe for submitting their plans of correction. The plans outline a provider's actions to rectify citations found during a licensing inspection. Further, public homes typically take three weeks longer than private homes to submit their required plans of correction. Untimely, late plans of correction lengthen the time to rectify inspection citations, unnecessarily extending the potential for client health and safety problems. The department also does not use its full range of enforcement actions to ensure compliance by providers, as highlighted earlier in the report.

Causes

During the years analyzed, the department's licensing unit functioned with six inspectors responsible for licensing and inspecting close to 800 public and private CLAs operating statewide. (The unit hired an additional inspector in mid-2002.) Executive Order 25 (February 2002) further required the licensing unit conduct unannounced inspections, of which close to 170 such inspections are anticipated annually. This equates to a ratio of roughly one inspector for every 85 homes when calculated on an annual basis. The department's quality assurance director

and licensing unit supervisor concur licensing inspectors should have annual caseloads of between 60-70 homes.

To deal with the understaffed licensing unit, DMR initiated a process requiring regional contract monitors to conduct follow-up “visits” to ensure plans of correction are properly implemented. The process, however, has not been completely operationalized at present. DMR further takes the position that available enforcement tools, such as compliance orders, issuing fines, or revoking providers’ licenses, should not be used to require compliance from providers. Instead, the department’s practice is to work with providers to ensure compliance.

Effects

Overdue inspections and late plans of correction run contrary to state regulation, compromise the overall integrity of the licensing and inspection process, and may lead to increased client health and safety risks. A lack of full enforcement to ensure provider compliance, along with consistent management analysis of the licensing/inspection system using available automated information to oversee system performance and detect areas for improvement, only exacerbate the issues.

Remedy

Provide a licensing and inspection system that is timely, geared toward complete compliance on the part of public and private providers through enhanced staffing, uses the available and appropriate automated information for continuous management oversight, and is results-oriented.

RECOMMENDATIONS

The DMR commissioner shall require all CLA licensing inspections be conducted within the specified regulatory timeframe. The department shall also fully enforce state CLA licensing regulations through appropriate use of its full range of existing enforcement tools, including compliance orders, more unannounced inspections and, if necessary, license revocations. Additional tools, such as fines required through C.G.S. Sec. 17a-227(e), as well as others deemed appropriate by the department, shall also be used to ensure providers fully comply with state regulations on a timely basis.

DMR’s licensing and inspection unit shall be responsible for overseeing the entire licensing and inspection process, including complete follow-up to licensing citations issued during inspections. To assist in this function, DMR services and systems unit staff currently used to inspect regional centers shall be transferred to the CLA licensing and inspection unit by July 1, 2003. (See Appendix J for further discussion.) DMR licensing inspectors shall incorporate a more interactive approach with provider direct care staff when inspecting public and private community living arrangements. At minimum, this approach should include verbal questions of direct care staff on an as-needed basis to ensure such staff is fully aware of how to handle client health and safety issues, including what actions to take during emergency situations.

At least half of the unit's standard biennial licensing inspections shall be conducted on an unannounced basis (this is in addition to the unannounced follow-up inspections currently conducted by the unit in response to Executive Order 25). On-site follow-up visits by licensing inspectors shall occur for all plans of correction submitted to DMR resulting from inspections. All follow-up visits shall be unannounced and occur within 30 days from the DMR plan of correction approval date, unless an alternate timeframe is required by the department based on the severity of the licensing citation or the provider's approved timetable for fully implementing corrective action.

The department should make full use of its automated licensing and inspection data for management analysis purposes. (The system, however, needs to begin incorporating provider's corrective actions taken to rectify citations issued during inspections and be frequently updated.) The system should be used from an overall management perspective to identify any trends, systemic licensing/inspection issues, and provider compliance with state licensing regulations.

DMR should emphasize compliance and enforcement for its own homes, given inspections of those homes are typically more delayed and plans of correction generally submitted later than private homes.

Rationale

The committee believes centralizing the complete CLA inspection function, enhancing inspection staff, and fully utilizing enforcement tools will lead to a more coordinated, timely, and effective inspection process. Actual follow-up to providers' plans of correction by central licensing staff will help ensure providers are actually complying with their plans, while "closing the loop" of the inspection process. Licensing inspectors will be fully aware of how well providers are complying with licensing regulations.

The recommendations also require inspectors to conduct more questioning of staff during inspections. This element gives inspectors a baseline understanding of how well direct care staff understands what to do in different situations, including emergencies, regarding client health and safety.

The proposed staff being transferred from the Service and Systems Enhancement Unit to the Licensing and Inspections Unit includes three registered nurses. Given no CLA licensing inspectors are registered nurses, having this experience in the licensing unit will provide a medical perspective to the process that does not exist. Enhanced staffing within the licensing unit not only centralizes the entire licensing function within the unit, but better equips the unit to oversee additional responsibilities for DMR services currently not licensed but requiring oversight for federal reimbursement purposes.

OVERSIGHT: CASE MANAGEMENT

FINDINGS

- *Currently, there are no consistent statewide operational requirements for case managers for CLA clients.*
- *Case managers for persons living in public homes have smaller caseloads and different job expectations than many case managers for persons living in homes run by private providers. Private home case manager responsibilities and caseloads also vary by region (as highlighted earlier in the report.)*
- *For clients living in private provider homes, the DMR case manager is the only department representative solely focused on the individual.*
- *DMR recently developed a set of performance evaluation elements for case managers, yet it is unclear how they will be applied given the practical differences among DMR case manager responsibilities.*

Background

Case managers have been and continue to be described by DMR as the central focus of the individually oriented support system for DMR clients. Over the years, the DMR case manager role has differed depending on the client setting, in response to increases in the DMR population without similar increases in case managers. Also, additional functions have been added to the role.

Having a case manager for every DMR client is at the core of the individually focused service and support system—that there is a person working in the interest of an individual DMR client, and involved in the client’s life. As the service and support structure of DMR has changed, so have DMR expectations of case managers. This report noted many private agencies provide case management services for DMR clients, while the actual DMR case managers are in more of a monitoring role.

DMR is aware the role of case managers is problematic. While in the early days of community living, very detailed guidelines related to aspects of the case manager function were prepared and used, those guidelines are now viewed as out of date. In 1995, DMR commissioned a study to evaluate the functions of case managers, although no direct changes resulted from the study. In recent months, DMR has been working on clarifying case manager roles by revising job responsibilities and performance evaluation goals, still in draft form. Over the years, the case management function is managed at the regional level, which has allowed for regional differences.

While there are no state required case manager standards for client contact, the federal targeted case management program, which provides funding specifically for case management, requires a minimum of some contact related to a client every month (This could be a phone call to the home or day program) and actual physical contact with the client every quarter.

Problem

DMR case managers are not equally involved in the lives of their clients, and that involvement level is dependent on where people live (i.e., public or private CLAs) as opposed to differences in support needs. Because of this situation, DMR's reliance on the case manager system as the front line for identifying needs and programs to meet those needs, particularly in the health and safety area, is questionable.

Cause

The changing structure of the DMR service and support system, including the private/public home mix along with the regional approach.

Effect

The confidence in DMR's understanding of the needs (and changing needs) of its clients in group homes is weakened when the connection between case managers and individual clients is diminished.

Remedy

Establish statewide standards for all case managers and ensure their implementation.

RECOMMENDATIONS

DMR should clarify its expectations of the case management function and develop measurable performance standards for its case managers. This should be done with a focus on how best to have consistent reliable information about individual clients.

DMR should standardize case management record keeping statewide, including case management logs.

OVERSIGHT: HUMAN RIGHTS COMMITTEES

FINDINGS

- *Human rights committees operate under a general policy statement established in 1986, prior to the growth in community living settings. The absence of consistent statewide guidelines, in particular as they relate to group home settings, including the need for getting consent from other*
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residents, can lead to different results from different committees, affecting client health and safety.

Background

The human rights committees are regional committees designed to review program proposals that might infringe upon a person's human or civil rights (e.g., whether using a room monitor would be an undue invasion of a person's privacy). These committees were required by the Mansfield consent decree. No statewide procedures were ever developed to guide the work of the regional human rights committees (see pages 44-45 for background.)

Problem

These committees can be a pivotal part in the decision making about aspects of a individual's program relating to health and safety. With no guidelines in place, it cannot be determined what forms the basis of the committee's decisions. The nature of the decisions coming from the various regional committees is not tracked by DMR; thus there is no assessment of whether the committees are consistent in their recommendations.

Effect

There is no way of knowing if regions are balancing health and safety issues related to potential human rights violations in the same way.

RECOMMENDATION

The DMR policy on the human rights committees shall be amended to include specific considerations on how the committees shall make their decisions, including the establishment of client health and safety as a primary interest.

OVERSIGHT: ABUSE AND NEGLECT

Findings

- *The approach to investigations involving DMR clients in CLAs is inconsistent, and largely dependent on whether a person lives in a public or private setting.*
- *There was no central DMR management accountability for abuse/neglect investigations until 1997—and that only applied to public homes until October 2002, when a partial connection to private provider investigation review was established.*
- *There has been no consistent standardized approach to tracking and following up on recommendations from abuse and neglect recommendations until recently.*

- *OPA within the last year has begun tracking information about abuse/neglect cases in an automated format, which will allow it to maintain the statewide registry of abuse/neglect reports and actions it has been required to maintain since 1984, but until recently had not.*
- *The interagency memorandum of agreement between OPA and DMR (and other agencies with jurisdiction over abuse/neglect) was executed in 1992, just as community living settings were expanding.*

Background

Since 1984, OPA has had a central statutory role in receiving and investigating allegations of abuse and neglect pertaining to DMR clients age 18-59, the large bulk of DMR clients, but was never funded to conduct all investigations. Per an interagency memorandum, OPA and DMR have divided up the function, with DMR responsible for investigations of DMR clients in residential or day program settings, and OPA responsible for investigations of people living in family homes or on their own. OPA meets its statutory obligation through an oversight role by reviewing the investigations done by DMR (and private providers) to determine if OPA agrees with the conclusions. DMR has five full-time investigators in its division of investigation. However, most investigations related to public settings are done by DMR employees with other full-time responsibilities, while investigations related to private settings are done primarily by the private providers. (See Appendix K for current caseload information and comparative abuse/neglect substantiation information)

Problem

There is no consistent, coordinated approach for abuse/neglect investigations relating to DMR clients. The lack of central management responsibility not only prevents meaningful administrative control over issues such as timeframes and completeness, it also can create conflicts of interest within regions between addressing abuse/neglect concerns about private agencies while also supporting them as service providers.

Cause

The system has developed over the years in an ad hoc way, over a time period when the nature of the DMR service system has changed dramatically.

Effect

From the point of view of the individual client, the nature and quality of the investigation should not be dependent upon whether the person lives in a DMR-run group home or a private provider home. A differentiated system not only increases the chances problems might slip by, but also inhibits the recognition of any patterns or trends.

Remedy

The management accountabilities need to be clearly identified for all abuse/neglect investigations pertaining to DMR clients in all residential and day settings.

RECOMMENDATIONS

DMR should continue to maintain its Division of Investigations within the Department of Mental Retardation. The division head should report directly to the commissioner. The division should be responsible for either conducting abuse/neglect investigations or monitoring and reviewing investigations done by private providers. DMR should develop timeframe standards for investigations and track compliance with those standards.

DMR, through its Division of Investigation, shall develop a protocol for monitoring and reviewing investigations done by private providers, including increased monitoring and assuming allegation investigations deemed to be most serious. Among other factors, DMR shall investigate whether staffing was an issue in the alleged abuse/neglect by obtaining actual staffing records for the pertinent times in question. (e.g., was staff working multiple shifts or was full complement of scheduled staff absent?)

All sudden/unexpected deaths shall be screened by the Division of Investigations with the desk audit process DMR began earlier in 2002 to determine if there is suspicion of abuse/neglect. The nurse/investigators conducting those audits should also be available to assist with other abuse/neglect allegations issues in either public or private settings.

Any serious injury reported resulting in hospital or ER treatment shall be submitted immediately to the Division of Investigations, whether or not abuse or neglect has been alleged, and the division shall make a preliminary inquiry as to whether abuse/neglect might have occurred.

All investigations of deaths where abuse and/or neglect is suspected shall be conducted by the Office of Protection and Advocacy and shall be accompanied by a transfer of the appropriate resources from the Department of Mental Retardation to OPA to conduct such investigations. Further, OPA, in consultation with DMR, shall establish protocols on how such investigations shall be carried out.

OPA and DMR shall develop and institute a new memorandum of agreement, which shall include specific provisions for how OPA will review and monitor completed investigations, and otherwise ensure the agreement accurately reflects the working relationship between the two agencies by June 30, 2003.

Finally, as DMR is apparently desiring that investigation reports should be limited to findings of facts and whether abuse/neglect was substantiated, and should not include programmatic recommendations, DMR should develop a way for the pool investigators to provide input for program improvement, in order to tap their experience. For example, this could be accomplished by establishing a best practices team from within the pool investigator groups to meet periodically and develop recommendations.

Rationale

Clarifying and elevating management accountability for overseeing DMR investigations will enhance the importance of abuse/neglect investigations and lessen concerns about conflict of interest perceptions. The program review committee considered the idea of establishing OPA as the sole investigator of all allegations of abuse/neglect, but determined such a recommendation would be unworkable at this time. First, the resource demands for conducting all such investigations could not be met by simply moving positions from DMR to OPA, and would require new funding. Second, the exact staffing needs are not known at this time.

While there are five investigators dedicated full time under the Division of Investigations, most investigations are done by either DMR employees who have other full-time responsibilities or by private provider staff. In order to adequately staff OPA to handle all the investigations, a workload analysis would have to be conducted to determine the full time equivalent (FTE) persons needed to perform investigation work currently.

However, the committee strongly believes that in death cases where abuse and/or neglect is suspected it is crucial that objectivity in conducting investigations can be assured, and therefore recommends the Office of Protection and Advocacy be responsible for carrying out inquiries where such deaths are involved. Removing that responsibility from the service agency, DMR, should eliminate any perception such investigations are not conducted thoroughly and objectively. Recognizing this should not involve a great number of cases, the committee recommends the appropriate level of resources be transferred from DMR to OPA to staff this role, and the two agencies consult and develop protocols on how these investigations be conducted.

It is also important OPA continue its oversight role of all investigations of abuse and neglect of DMR clients and that OPA's role is clarified in a revised memorandum of agreement.

OVERSIGHT: POST DEATH REVIEW

FINDINGS

- *The post death review process for DMR clients living in community living arrangements does not consistently examine health and safety factors beyond a client's medical care, resulting in a systemic weakness in the process.*

- *DMR has not consistently analyzed mortality data of client deaths on an aggregate basis to identify trends, issues, or areas for improvement regarding client health or safety.*
- *Client mortality files reviewed by committee staff typically lacked specific documentation indicating recommendations developed through the regional or state level mortality review processes were fully implemented.*
- *The committee staff's analysis of DMR client mortality files also determined the regional mortality review process exceeded by an average of five months the DMR policy to submit committee findings, recommendations, and actions to the Independent Mortality Review Board (IMRB) within 90 days of the death. DMR, however, has placed an emphasis on ensuring regional mortality reviews are conducted more promptly, and notes all regions are now up-to-date with their reviews. This was evident in the IMRB meetings attended by committee staff. (Committee staff examined a random sample of 177 cases involving the deaths of DMR clients living in group homes over a 10 year period.)*
- *A varying numbers of death cases examined by committee staff were classified as accidents, depending on which documentation was used in the files.*

Background

All deaths of clients living in community living arrangements must be reviewed by a regional mortality review committee. A state-level Independent Mortality Review Board also exists to review all sudden or unexpected deaths, deaths referred from the regional mortality committees, and a sample of all deaths occurring in a given year. DMR policy and Executive Order 25 (effective February 2002) require the post death review process to “examine events, overall care, quality of life issues, and medical care preceding a client’s death.” The IMRB is also to make recommendations for systemwide improvements or training to enhance client care and reduce risk. The central office of DMR is developing a comprehensive database of client mortality information, which includes about two recent years’ worth of data.

Problems

Program review committee staff’s analysis of mortality files (as documented above) and its observations of regional and state mortality review committee meetings, concludes:

- the post death review process for CLA clients focuses on clients’ medical care, with limited examination of the other required components;

- although the department’s “root cause analysis” process is designed to examine the various factors leading to a client’s death, it is a relatively new, resource-intensive process that has not been extensively used to date; and
- DMR’s does not analyze client mortality information on an aggregate basis to identify trends in causes of death or contributing factors, or client health and safety areas needing improvement at either the regional or statewide level. (The department notes it will soon begin such an analysis using its newly developed mortality database.) The result is a gap in the mortality review process because there is no single mechanism that comprehensively examines the collective key elements related to a client’s medical care and overall personal care, as well as mortality trends in the DMR client population.

Causes

A mortality review process that does not fully examine all factors leading to or causing client deaths due to delays in review of cases and the lack of an integrated, automated database.

Effects

Without a complete and timely post death review of a client’ overall care, quality of life issues, and medical care, the post death review processes of the regional mortality review committees and the Independent Mortality Review Board do not result in a comprehensive examination of the factors surrounding a client’s death. As a result, underlying problems potentially affecting client health and safety may go undetected and unrectified by DMR.

Remedy

Ensure the mortality review processes conducted by the regional morality review committees and the IMRB examine all required factors relating to a CLA client’s death, and that DMR consistently analyzes client morality information. At minimum, this should include examining group home staffing at the time of death, any outstanding corrective actions to licensing citations, information sent to the chief medical examiner’s office, and any other factors deemed necessary by DMR. For deaths involving abuse or neglect allegations, the post-death review process will have access to abuse/neglect investigations, including analysis of the provider’s staffing at the time of the alleged incident (see recommendation on abuse/neglect on page 125.)

RECOMMENDATIONS

State statutes should be amended to require the Department of Mental Retardation conduct a comprehensive and timely post-death review into the event(s), overall care, quality of life issues, and medical care preceding a client’s death. The reviews shall be conducted by the appropriate regional mortality review committee and/or the Independent Mortality Review Board, as determined by DMR.

DMR and the IMRB shall utilize the mortality review database being developed through department's health and clinical services unit to examine client deaths from a broad management perspective. The analysis should be used to identify client health and safety trends, gaps, and areas needing improvement. Any recommendations (including implementation status) stemming from this analysis and those developed through the formalized regional and state-level mortality reviews, should be fully documented by DMR.

DMR shall ensure that any death involving an accident, or where an accident was considered a contributing factor, determined through the mortality review process or the death certificate coding process, shall be categorized as an unexpected, accidental death in all relevant department records.

Rationale

The program review committee believes the mortality review processes at the regional and state levels provide the mechanism whereby a full review and analysis of a client's death can and should occur. The processes need to be comprehensive, timely, and results-oriented. Requiring a statutory provision to this effect should help ensure such reviews are conducted in a complete and expeditious manner. An additional analysis by DMR and the IMRB examining client mortality information from a macro perspective, making any necessary recommendations, following up on their implementation status, and fully documenting this process will provide the department an opportunity to develop or modify client health and safety programs and services.

OVERSIGHT: SYSTEM COORDINATION

FINDING

There is a lack of coordination among the many separate oversight and regulatory tracks that DMR uses to monitor itself and its providers and the services they provide.

Background

DMR has, over the years, initiated many oversight tools to regulate providers taking care of DMR clients. In its testimony at the committee's November 19, 2002, public hearing, DMR indicated it had 30 separate oversight tracks. Many of these first came into place when DMR began contracting with private agencies to operate community living arrangements after DMR closed or significantly down-sized its two training schools. Other oversight mechanisms were added since the early 1990s to address problems as they surfaced.

Problem

There is no consistent or uniform way DMR uses all of the information collected through these oversight tools to comprehensively assess, evaluate, and manage the department's own services and those provided by its contracted agencies. DMR has initiated a "program integrity" system at the central office, but over the three-year period since the program's inception, has

only conducted 35 reviews of private agencies and one DMR region; not frequent enough to provide meaningful accountability.

Cause

DMR's regional organizational structure establishes a service delivery system that is close to the clients, but the oversight mechanisms are split between the regions and central office. Further, communication among the staff who perform the various oversight functions – contract management, licensing, auditing, and investigations – is not clearly defined nor formalized.

Effect

Because oversight mechanisms are varied and carried out by many different central office and regional staff, there is a lack of coordination in using the oversight information produced in the most effective way – to improve services or take enforcement action. Further, the central office approach – program integrity -- while providing a valuable framework, does not occur often enough to be effective.

Remedy

Provide a data-driven, results-oriented system that effectively collects and regularly analyzes comprehensive information from the various oversight mechanisms and uses the information to ensure DMR and provider accountability.

RECOMMENDATION

Program Integrity. Require the regional contract managers to use the program integrity format (see Appendix L) and its review components when they conduct their mid-year and end-of-year contract performance reviews. Those components shall include:

- **Audits;**
- **Quality assurance --licensing and inspections, physical plant issues;**
- **Special protections (e.g., abuse and neglect);**
- **Individual and family satisfaction;**
- **Case management;**
- **Health, including use of psychotropic drugs and mortality review findings and recommendations; and**
- **Contract information, including staffing patterns, turnover, and timeliness in filling staff vacancies.**

The Quality Assurance Division (QAD) in coordination with the regions shall develop benchmarks for each component area so that the reviews are objective, uniform, measure performance, and produce meaningful, action-oriented results that providers must implement within a reasonable timeframe or enforcement action will be initiated. (See Appendix M for benchmarks suggested by the program review committee.)

Prior to the mid-year and annual reviews being conducted, contract managers shall collect all the relevant information necessary to evaluate each component area as determined by the QAD, analyze the information, evaluate the provider's performance in each component area and prepare a list of findings for review by the Assistant Regional Director prior to meeting with the provider. If there are no concerns in any component area, the findings report shall state such.

The mid-year and annual reviews shall be conducted by the Assistant Regional Director (or Directors if the provider is in multiple regions) and all contract managers for that provider. Their participation is mandatory and the reports must be signed by all who conduct the reviews. Participation from central office staff (auditing, operations, and QA) and regional supervisors of case management, health services, and investigations shall be sought but is not necessary to conduct reviews.

A uniform automated tracking system shall be completed by DMR (see Appendix M) and the results of each review by component area shall be entered on the system by the contract manager and available to all DMR regional and central office staff. Oversight of the tracking system, and its recommendation implementation shall be the responsibility of the Assistant Regional Directors for Private Administration and the Director of the Quality Assurance Division at DMR central office. In concert, they shall ensure timely reviews are conducted, that each component area is addressed and that any recommendations made are implemented in the timeframe given.

For public sector services, DMR shall use the same format, and the reviews shall be conducted with the appropriate DMR residential managers. The directors of each relevant component area (quality assurance, investigations, health services), and a private provider from the appropriate service region shall conduct the reviews.

Enforcement. DMR shall take enforcement action when there a number of concerns raised through the program integrity reviews. For example, if there are more than five component areas where concerns are raised, or one component area where a number of concerns surface, DMR shall put the provider (or its own homes) on a "watch list", including increased monitoring. If the provider does not adequately address the concern areas by the next review, the provider shall be placed on a partial year contract and continue to be monitored. For its own homes, DMR shall hold the appropriate residential manager responsible for implementing required changes. If problems remain at the next 6-month review, DMR shall begin reducing the contract by five percent per-month until compliance is achieved, or the contract is terminated. For its own homes where deficiencies

remain, DMR shall begin disciplinary proceedings for those agency personnel deemed responsible for the continuing non-compliance, and or make appropriate staff changes.

Modifications shall be made to C.G.S. Section 17a-227 to provide for such contract enforcement authority.

Rationale

The committee believes this recommendation places the responsibility for comprehensive provider evaluations with the appropriate staff and their supervisors in the region. By requiring information for each component area be examined and tracked will mandate that the reviews be thorough, uniform, and consistent, and set accountability for maintaining standards.

Requiring specific staff to collect all information for these component areas, analyze it, and meet at least twice a year to conduct the reviews, will ensure there is additional objectivity in the reviews, that cross-regional experience is considered in the evaluation, and that comprehensive information on each provider's performance is reviewed on a frequent basis.

Requiring a tracking system that recommended actions be implemented within a certain period of time and that the tracking system be overseen by regional and central office management, will enforce service accountability for both private agencies and DMR.

Conducting these reviews twice a year places a comprehensive, objective approach on an oversight system already in place, rather than adding a new level of monitoring and ensures that review, analysis and follow-up happens often enough to be meaningful.

Further, because service provision, contracting for service, and regulatory authority, including licensing and inspections all occur within the same agency, there is a tendency for those functional lines to sometimes blur. Requiring mandatory, stepped-up enforcement actions to be taken against private providers and its own regional residential supervisory staff removes the subjectivity and delays that can sometimes occur with oversight and achieving compliance.

REGULATORY ENHANCEMENTS: EMERGENCY PLANNING

FINDING

There is a need to enhance a number of the regulations related to client health and safety in Community Living Arrangements.

Background

Many of the regulations concerning CLAs were put in place in 1992, and many of those adopted at that time were modeled after the federal ICF/MR regulations, which were initiated in the 1970s. These regulations had a heavy emphasis on environmental inspections, and emergency planning was centered around fire drills and evacuation requirements.

Problem

Because the regulations and licensing inspections concerning emergency planning focus on fire and evacuations, this is where providers and regulators have also placed their attention, even though these may not be the cause of most of the emergencies that occur in CLAs. Further, the requirement that only one staff person per shift be trained in CPR appears inadequate, given the medical needs of clients in CLAs, and that often shift coverage in a CLA consists of only one or two persons.

Cause

Outdated regulations that do not adequately address the spectrum of emergencies that might occur in CLAs.

Effect

Providers develop emergency plans to respond to regulations, and not to the most likely emergencies. As a result, CLA staff may be ill-prepared to deal with some types of emergencies.

Committee staff reviewed 213 case files of DMR-client deaths between FY 92 and FY 01. In about half the cases --127-- some type of issue related to the medical or personal care of the client was noted. This ranged from relatively minor deficiencies in staff or case management documentation and record-keeping to more serious problems where staff did not properly follow guidelines for appropriate client care like diet or food consistency or use of safety equipment. (See Appendix N.)

In a substantial number of the 127 cases, staff appeared ill-prepared to deal with the emergency at hand. Seventeen cases involved a CPR issue, where staff was either not trained to perform CPR, or there were questions about whether staff began or performed CPR. In 14 cases, calling 9-1-1 was not done, or was done after calling someone else (e.g., a nurse or house manager). In several cases, staff on duty appeared to panic in an emergency situation, perhaps indicating inadequate training. These situations involved finding clients unresponsive, not breathing, or choking. In no case did the committee find inadequate preparation in evacuating clients in case of fire, etc, surrounded a death.

In addition, in more than 30 cases, it appeared from the file review that key information about each client was not always communicated to emergency medical service personnel or hospital staff. Finally, documentation on staffing and hours worked is not routinely collected as part of any post-death review or abuse and neglect investigation.

Remedy

At a minimum, require that provider emergency plans and training include when to: 1) call 9-1-1; 2) call police; 3) start CPR; and 4) perform the Heimlich maneuver. Providers should also practice these emergency situations frequently in the home so that staff are prepared. Providers should also ensure key critical information on each client is summarized and in written format that can be given to emergency response personnel and or/hospital staff. Providers

should also be able to produce, upon DMR request, actual staffing and consecutive hours worked for an established time period in any CLA.

RECOMMENDATION

Licensing inspectors shall ensure providers' emergency planning contains how staff should address emergency situations, and shall verify, in addition to document verification, through asking direct care staff what the procedure is for a given emergency situation. Regulations should also require all staff should be trained in CPR, not just one person on each shift. Regulations shall also require that providers be able to produce, upon advance request by DMR, staffing schedules and actual staffing and hours worked for the requested time period.

REGULATORY ENHANCEMENTS: STAFF SCHEDULING

FINDING

DMR needs to examine when health and safety is put in jeopardy by staff who are required to work too many hours without time off.

Background

No labor laws exist to protect workers (other than minors, handicapped persons and elderly) from being required to work limitless hours straight. By contract, there are limitations as to situations in which DMR or providers can call an emergency requiring mandatory overtime. However, one of these situations is when a staff member does not show up for his/her scheduled shift, and the employer

Problem

When staff are required to work too many hours without adequate time off, their capacity to be alert and attentive to the client is diminished, and client health and safety can be compromised.

Cause

Private providers cite a shortage of staff, especially staff an employer can call as substitutes when "back-up" coverage is needed (e.g., when someone calls in sick for an assigned shift). DMR, which has higher staff ratios in its homes than most private homes, also faces shift coverage issues when a staff person cannot work his/her assigned shift, requiring someone else to be held over from the previous shift.

Effects

The problem may be exacerbated when staff who are continually asked to work mandatory shifts quit the job, creating higher turnover and adding to staff coverage problems. Clients may be put at risk by staff who are tired and not alert. At least one of the death cases reviewed by program review staff involved a staff person working many hours without adequate time off.

No data exist on the number of hours staff work in any straight time period. Further, no one has been examining staff issues (except in isolated cases), as part of the abuse and neglect system or the mortality review process to determine whether work schedules may contribute to health and safety issues.

Remedy

Begin collecting appropriate data on staffing circumstances when an incident of abuse/neglect or a death occurs. Based on what the data show, DMR should determine whether to establish a policy that limits the number of consecutive hours a staff person works without a significant period off-duty.

RECOMMENDATION

Require that any abuse or neglect investigation or regional or state-level mortality review examine the number of hours staff had been on duty at the time of the incident. Require the department's Strategic Leadership Center to compile the data from such reviews. By July 1, 2005, the center shall make a recommendation to the DMR commissioner on whether a policy is needed to limit the number of consecutive hours a staff person can work in both DMR and privately operated homes.

Rationale

This will begin to provide a body of data to establish whether staff fatigue or overload from working many hours without time off pose greater risk of harm or death to clients.

RESIDENTIAL SYSTEM MANAGEMENT: ACUITY AND PLACEMENT

FINDING

DMR does not have a system in place that collects and maintains data to evaluate whether its DMR clients are living in the most appropriate setting, or whether needs of clients are matched with residential resources and payments.

Background

DMR went from an agency that serviced its clients in one type of setting to one that provides services to clients in a variety of settings. But the department's system to track the acuity of clients and whether they remain appropriately placed is deficient. Ten years ago, when the community living arrangement model was relatively new, the program review committee found the lack of acuity measures to assess whether clients were appropriately placed. The agency has not improved its data collection, and without that data any evaluation of clients' medical, behavioral, and social needs occurs on an ad hoc basis.

Problem

Without a system that collects and maintains needs assessment information that is evaluated on some ongoing basis, DMR cannot determine whether its clients remain in the most appropriate residential placement, nor can it readily assess client acuity and link those needs to provider pay for various levels of care. This means a client who may not need the level of staffing and care in a given CLA is there because it is where the vacancy occurred. Further, clients who are elderly and whose medical needs have intensified may no longer be able to be taken care of in a CLA, jeopardizing their health and safety as well as others in the home.

Cause

DMR moved its clients from institutional settings to the community in a relatively short period of time. Its data system (CAMRIS) was created to maintain information on the class members in the Mansfield consent decree. The system has been expanded and modified, but remains inadequate to manage a placement and payment system for more than 6,000 residential clients and a waiting list of 1,600.

Effect

Initial placement rests with each region's Planning and Resource Allocation Team, and ongoing assessment is the responsibility of an interdisciplinary team. Both are conducted on an individual basis, not on a system basis to ensure all clients continue to be in the most appropriate setting and the system is serving as many clients as possible in the most cost effective way.

Remedy

DMR should enhance its client information system to provide essential data on needs, and develop an ongoing evaluation system to ensure clients are in residential settings matching their needs in the most cost-effective manner. Developing such a system requires that DMR recognize it is responsible for managing and overseeing an entire residential and payment system, as well as serving individual clients. DMR acknowledges this and is now working with a health statistician to begin developing needs indicators and assessment measures for residential placement.

RECOMMENDATION

The commissioner of DMR should make the upgrade of the CAMRIS system a management priority to evaluate appropriate placement of, and payment for, clients in the system. Needs of clients should be evaluated at least every two years to ensure they are in the most appropriate setting.

RESIDENTIAL SYSTEM MANAGEMENT: AGING CLIENTS

FINDING

DMR's client population is aging and DMR has not yet developed a plan on what types of settings will best meet this population's residential and increasing medical needs.

Background

DMR's population is aging, as is the population in general. Fifteen percent of DMR's CLA population is 60 or older. As discussed above, many of DMR's clients have significant medical problems in addition to their mental retardation. Some of these conditions grow worse with age, while others first present when a client gets older (e.g., Alzheimer's with Down Syndrome).

DMR recognizes its population is getting older. In 1997, the department looked at altering Southbury Training School to make at least a portion of that facility a certified skilled nursing facility (SNF) to accommodate clients as they became more medically fragile. That idea was quickly abandoned as the costs to STS's physical plant to become a SNF would have been prohibitive.

DMR, at the beginning of 2002, established a task force to examine the issue of its aging clientele. It is still working on recommendations to propose to the DMR commissioner as of the completion of this study.

Problem

As persons in CLAs age they often experience medical problems difficult for the direct care staff in the CLA to properly address. Based on the file review conducted by committee staff of DMR-client deaths in CLAs, a number of clients who died had extremely serious medical problems. Fifty-eight percent had Do Not Resuscitate (DNR) orders, some of the DNR orders followed the client back to the CLA after a hospitalization. Twenty-three percent of the clients who died in CLAs had had a feeding tube inserted at some point prior to death.

Only 21 of the 771 CLA homes have 24-hour nursing services. In all others, nursing services are consultative or provided on a less than 24-hour basis. As discussed in the briefing, many nursing services can be delegated, but as these tasks become more medically oriented and

complicated, it seems less likely nurses will want to delegate such duties, given the RN is ultimately responsible for ensuring the persons are trained and competent before delegating, or that direct care staff will be able or willing to have these duties assigned them. Further, as nursing shortages face the entire health care delivery system, it may not be possible to provide 24-hour staffing at many more homes, even if the DMR residential system had the funding available for such enhancements.

Cause

CLA clients are aging in place and many homes are not equipped or appropriately staffed to address increasing medical needs. There are not the financial resources in terms of funding the 24-hour nursing staff that would be needed in many more homes, and RN and LPN shortages exist throughout the health care system.

Effect

At least one provider has already stated it will no longer be able to care for clients with DNRs or certain tubes if the home does not already have 24-hour nursing care. In other cases, from committee staff's file review, direct care staff seemed ill-prepared to deal with clients with DNRs, especially in emergencies. If staff are not trained or prepared to give certain medical care to medically fragile clients, the clients' health and safety are put at risk, as well as those of other residents in the home.

Further, as more financial resources go to provide nursing services and other enhancements to support aging CLA residents who have increasing medical issues, fewer openings and monies are available for clients on the waiting list.

Remedy

Skilled nursing facilities in the community provide a residential and medical alternative to community living arrangements that can no longer furnish the kind of care needed by elderly, medically fragile clients.

RECOMMENDATION

For persons 60 years or older who have had two hospitalizations in a six-month period, DMR shall conduct a review to ensure the residential and medical needs are still most appropriately met in the CLA or whether a residential placement in a skilled nursing facility might be more appropriate.

Rationale

The 1987 federal OBRA law requires a two-level preadmission screening before anyone believed to be mentally retarded or developmentally disabled is admitted to a skilled nursing facility, even for a short-term stay. DMR does the second-level screening in Connecticut.

DMR will continue to be required to do these second-level screenings, and will be a check to ensure no one is being placed who does not require nursing home level of care.

Further, Connecticut's mentally retarded population in skilled nursing facilities declined 10 percent from 1996-2000¹¹. It is now 12 per 100,000 general population, about the national average of 13. The committee believes DMR has been a strict SNF gatekeeper, especially where clients from DMR-funded or operated facilities are concerned.

However, the committee believes returning medically fragile persons to a CLA without appropriate medical staffing can be potentially harmful to the client, as well as the other residents and staff in the CLA. Enough financial and medical staff resources simply do not exist to provide all the enhancements needed at CLAs. Skilled nursing facilities provide an alternative that addresses a client's medical needs when those become of great concern.

RESIDENTIAL SYSTEM MANAGEMENT: CLA VACANCIES

FINDING

DMR has no good information system to track and manage its vacancies in CLAs.

Background

As discussed above, DMR's residential placement system is mainly a regional function. There is a philosophical and practical emphasis on trying to ensure referrals to CLAs are appropriate so a client will "fit in" with the other residents in the home and the client's placement will become permanent. It is not a system where people are expected to be moving in and out, instead it is one that assumes long-term stability.

The state funding of CLAs also banks on stability in the system. The vast majority of CLAs (other than ICFs/MR and DMR CLAs) are funded by DMR on a yearly contract basis, not a person-day basis, although federal Medicaid reimbursement for the Home and Community Based Waiver program does fund on a person-day basis.

When a vacancy becomes available in one of the CLAs, staff in the region are notified. Each month the regional staff send an "attendance" report to the central office on the number of clients in each private CLA.

Periodically, DMR's central office issues a report back to the region on vacancies in CLAs that have not been filled in more than 60 days.

¹¹ State of the States in Developmental Disabilities: 2002 Study Summary, D. Braddock et al, February 2002.

Problem

The service system for placement of clients and refilling vacancies is a regional one. Managing the contracts for providing those services is also a regional responsibility, but administering the system to maximize Medicaid reimbursement is largely a central office role. Their objectives may sometimes work at cross purposes, but neither has a good tracking tool for managing vacancies and ensuring they are filled appropriately and promptly.

The residential system is generally stable, with private CLA utilization calculated by DMR at about 95 – 98 percent for FY 01 and FY 02. However, there are vacancies. In FY 01, the average monthly vacancies in private CLAs across all regions was 56 (2.5%) and in FY 02 was 30 (1.2%). Some of these vacancies are open for long periods of time, a few as long as a year.

Cause

DMR's residential placement system is expected to place its clients in what is anticipated to be a permanent home. DMR's funding of the CLA system fosters this permanent placement; providers' DMR rates are not reduced when they experience a vacancy. Contractual language allows DMR to make reductions when a provider's utilization rate slips below 85 percent, but DMR has not exercised that option, believing it would place a provider in financial hardship.

Further, regional placement teams want to ensure the placements they make work out, so they may take longer to fill a vacancy than if the placement is for a short-term stay, or a financial consequence were at stake.

Effect

Neither the central office nor the regional offices have a tracking system for managing vacancies in the system. The department cannot provide -- without massaging a lot of different reports from different systems -- data on how many vacancies there are, where they are, or how long they have been vacant.

The absence of such a system handicaps the regional placement and contracting staff, as well as the budgeting and revenue enhancement staff at the central office. Without such a system, placement teams may lose track of vacancies, or contract managers overlook long-standing vacancies a provider has when contract performance reviews are conducted.

Long-term vacancies have a financial impact on the state because of the lack of Medicaid reimbursement. DMR, in one of its periodic utilization reports to the regions, stated vacancies over 60 days cost the state slightly over \$2 million in lost federal match for the period September 2000 to August 2001.

Further, with as many as 1,600 persons on the waiting list, there should be emphasis in making appropriate placements, but also making them quickly.

Remedy

Create a vacancy tracking system, for all CLAs -- private and public, and ICFs/MR -- to assist with residential placement, contract management and revenue enhancement.

RECOMMENDATION

The commissioner of DMR should ensure the development of a tracking system to manage all CLA vacancies is a management priority. The system should be automated, available to both regional and central office staff, and used as a management tool to assist with placement, contract management and revenue enhancement.

Rationale

This will provide a first-step in the ability to maximize placement resources, and fill vacancies more quickly. It will also provide readily available information to contract managers so they can better monitor provider performance in a key service area

WAGE EQUITY

FINDING

There is a gap between salaries paid to CLA direct care employees in DMR and private providers, which continues to grow.

Background

Nineteen percent of CLAs (148) in the state are operated by DMR and staffed with state employees. Many of these homes were opened for Mansfield clients when that institution closed. The DMR homes were also staffed with former Mansfield employees, who by contractual language had to continue to be employed. The salary structure for those DMR workers was begun in institutional settings, where staff was generally well compensated.

Also, to accommodate the transfer of former Mansfield clients into the community, the state began to contract with private agencies to operate group homes (CLAs) and employ their own staff as direct care workers. Private providers now operate 81 percent (623) of the CLAs.

The growth in CLAs has been in the private sector, from just over 500 homes in FY 92 to 623 homes currently. Meanwhile, the number of DMR homes has decreased in the past five years from 155 to 148.

As discussed above, DMR rates for CLAs are set when the home is first opened; DMR contracts with private providers are not renegotiated based on costs. Instead contracts are renewed annually, but monetary changes to contracts are generally limited to across-the-board percentage increases appropriated in the state budget.

Problem

The pay scales for DMR direct care employees are generally much higher than for private sector workers. A February 2002 DMR assessment of wage disparity shows the average wage differential is more than \$9 an hour between the DMR CLA worker and the direct care aide in private group homes. (See Appendix O.)

There is also a significant pay scale differential among the private provider agencies, with larger unionized agencies paying much better wages than smaller providers. The same assessment shows an almost \$5-an-hour difference between average direct care wages for private providers and the highest-paid private provider aides.

Generally, across-the-board percentage increases tend to perpetuate any existing wage gaps.

Cause

There is no one established pay scale for direct care workers providing residential services to DMR clients because staff work for many different employers – one public, the rest private -- and their wages are established in a variety of ways, at varying points in time.

First, DMR direct care staff are in a job classification series – Mental Retardation Worker -- that governs mental retardation workers in a variety of settings, including CLAs. The classifications were established many years ago (updated in 1988), and the pay increases are negotiated between the state and the union when the contracts expire. The current four-year contract runs until 2005. The compensation plan tied to the contract pays a Mental Retardation Worker 1, -- at step one (entry level) -- \$16.55 an hour, effective July 1, 2002.

Sixteen private providers, including the largest -- Connecticut Institute for the Blind -- are also unionized. Their workers' pay is also negotiated and established by contract; the entry-level wage for the highest paid private provider is about \$13.70 an hour and increases to \$14.48 after one year.

Other providers are not unionized and wages are not collectively bargained; providers pay what they are able given the contracted increases, and the employment market.

Effect

The flat percentage increases given to private providers tend to perpetuate the wage differentials.

The lower salaries among the private providers create instability in staffing, with turnover among private providers at about 22 percent compared to 6 percent among DMR direct care staff.

The bifurcated service delivery system has festered resentment among many private agencies, which maintain that they and their staffs are doing the same work as DMR employees for less pay.

Remedy

Pay equity among the many direct care staff is one remedy, but would be incredibly expensive and not realistic given the current economic environment.

The DMR assessment on wage disparity indicates the annual costs to bring just direct care workers in private CLAs to the DMR levels would be about \$72 million. The annual costs to bring all private CLA direct care workers to the top-paid private provider staff would be about \$31 million. (Amounts include wages and mandatory benefits.)

A special allotment of state budgeted funds dedicated to a low-wage pool has been enacted in the past. (FY 97 was the last time a low-wage pool budget allocation was implemented for DMR providers). However, this does not completely address the wage differential, and offers a somewhat temporary solution. This approach can also be costly and difficult to monitor to ensure that any allocations in fact increase low-wage workers' salaries. (To bring 51 homes that have a daily rate of less than \$120 per client to a per diem of \$120 would cost \$1.3 million)

Further, there are no good data linking rates paid to providers and lower and higher paid workers. One intuitively believes providers with higher rates pay higher salaries, but the system does not provide data to make that determination.

RECOMMENDATION

Given the current economic environment, the committee makes no recommendation on addressing pay equity. Instead, the committee recommends that DMR establish as a management priority a longer-term solution that would begin to use the acuity and placement system to develop a prospective approach for payments to providers and what they pay in wages. The ultimate goal of such a system would be to link client need, services, and wages.

APPENDICES

Appendix A: JCLM Motion

Joint Committee on Legislative Management

Motion to Request an Investigation of the Department of Mental Retardation

To request the Legislative Program Review and Investigations Committee, pursuant to C.G.S. Sec. 2-53g(a)(5)(B), to conduct an investigation into how the Department of Mental Retardation ensures the safety of its clients in DMR run or regulated community living arrangements. In conducting the investigation, the Committee shall examine the role of the agency's policies, procedures, practices, staffing and training as they pertain to the safety of DMR clients, examine the agency's interaction with clients' families, including their legal representatives, concerning access to information on incidents endangering the safety of clients, and examine selected cases of untimely deaths to determine whether there are systemic weaknesses amenable to legislative remedy.

Approved 1/30/02 by the Joint Committee on Legislative Management

APPENDIX B: AGENCY RESPONSE



JOHN G. ROWLAND
GOVERNOR

STATE OF CONNECTICUT
DEPARTMENT OF MENTAL RETARDATION



OFFICE OF THE
COMMISSIONER

February 5, 2003

Michael L. Nauer, Director
Connecticut General Assembly
Legislative Program Review and Investigations Committee
State Capitol, Room 506
Hartford, CT 06106

Dear Mr. Nauer,

The Department of Mental Retardation wishes to thank the staff and committee members for their very thorough and thoughtful analysis of the many systems Connecticut has put in place to protect and safeguard our citizens with mental retardation. Although we do not agree with each and every finding and recommendation contained within the committee report, we do believe it represents an objective and sound appraisal of our oversight systems. We are particularly pleased that "...the program review committee did not identify any direct systemic cause related to the deaths..." and that "...in almost all the cases, there were systems in place to address the risks to..." our clients. Individuals with mental retardation, like everyone else, sometimes experience health complications or other unanticipated events that can lead to death. In fact, and as noted by the committee, the persons served by DMR, especially those living in structured residential programs, represent a population with very complex and significant medical and disability-related conditions that unfortunately contribute to a higher mortality rate than that of the general population at large. The mortality rate in the Connecticut DMR however, is not unusual or unexpected when compared to other states.

The committee has focused its findings and recommendations on a variety of strategies to enhance the effectiveness of our oversight practices. The department certainly recognizes that continual improvement should always be a goal within any governmental entity and commits to strengthen our risk prevention and service oversight systems. However, it is very important to formally note that the Connecticut DMR currently has one of the most comprehensive systems of risk prevention and group home oversight anywhere in the country. For example, our mortality review process was not only one of the very first in the U.S., but continues to serve as a model for many other states who are only now establishing such a system. Our unique relationship with the Connecticut State Police, while only briefly mentioned in the report, provides DMR with extremely competent and professional unbiased third party oversight of the abuse and neglect investigation process.

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This process is directed by an independent, trained and experienced senior officer of the State Police. We also have implemented a number of other oversight enhancements, including the use of root cause analysis, program integrity team review, clinical nurse investigation of deaths, more unannounced visits and reviews of group homes, web posting of licensing inspection results, and the publication of a very comprehensive and detailed annual mortality report. I believe these examples represent evidence of our commitment to assuring that review and oversight practices are thorough and open to exacting scrutiny.

The recommendations of the committee have been carefully evaluated. I am pleased to note that many of them represent initiatives and activities we have already implemented. Planning is underway for some, and others can reasonably be implemented over time. A number require more study. There are also recommendations we cannot support at this time and a substantial number that, although good ideas, will require significant increases in funding and/or personnel if they are to be properly instituted. In fact, preliminary estimates indicate that at least \$2 million of new funding would be necessary to begin to meet the requirements contained in this latter group. Given the existing and projected budgetary constraints we all face, as well as personnel losses associated with recent staff reductions and a potential early retirement program, it would be unreasonable to expect we could proceed with this latter cluster of recommendations at the present time.

More specifically, the department has already initiated or is planning to implement the following committee recommendations (if current staffing levels and budgets remain in place):

- Director of Investigations reporting to the Commissioner
 - Desk audits of all deaths in DMR operated or funded settings
 - Publication of mortality data re: trends, gaps and improvement strategies
 - Participation (or pre-review) by regional administrators for all provider contract reviews
 - Clarification of the roles and responsibilities of case managers
 - Standardization of case manager records
 - Use of the program integrity model by regions
 - Use of data-driven benchmarks (starting with abuse/neglect and injury data) when reviewing providers
 - Use of level of need as a basis for evaluating the appropriateness of services
 - Expansion of emergency preparedness
 - Investigations unit review of serious injuries
 - Methods to elicit recommendations for program improvement from pool investigators
 - Guidelines for Human Rights Committees
 - Revision of the DMR/OPA Memorandum of Agreement
 - Submission of staffing information by providers to DMR whenever requested
 - Standard enforcement practices for public CLAs
-

- Increasing the percentage of unannounced licensing inspections
- More systematic enforcement practices for operators of private CLAs
- Automated tracking system for CLA vacancies

A number of the committee recommendations represent enhancements or changes that cannot be accomplished within existing resources or are not consistent with what the department believes are efficient use of the resources it has or can reasonably anticipate in the near future. In addition, changes to the existing legal authority of DMR may be necessary to address those recommendations associated with enforcement practices for private provider services. Consequently, at this time we cannot commit to implementation of the following:

- Milestones for tracking abuse/neglect investigations
- Protocols for monitoring private provider abuse/neglect investigations
- Tracking IMRB recommendations
- Transferring the Service and Support Enhancement unit personnel to the licensing unit
- Revision of the Q.A. database to include corrective actions and tracking of follow-up status
- Transferring staff or funding to the Office of Protection and Advocacy to conduct separate investigations for those deaths associated with suspected abuse/neglect due to the lack of discrete resources dedicated to this function.
- Using more punitive enforcement practices, use of monetary fines and staged reduction in funding for private operators of CLAs
- Requiring review of staffing in every abuse/neglect investigation
- Implementing a wide range of new activities and responsibilities for the licensing unit
- Redesigning the Q.A. database to perform management analyses
- Expanding areas of review by regional and central mortality review committees, including staffing
- Coding changes for unexpected and accidental deaths
- Uniform automated contract performance management system
- Formal study of the relationship between staffing and both abuse/neglect and mortality
- Requiring CPR certification for all staff
- Evaluating elderly clients with medical needs for transfer to long-term care facilities

The department is fully committed to building on an already solid and comprehensive system. The department cannot, however, commit to practices that place additional demands on a shrinking workforce at a time of great uncertainty with regard to future financial and human resources.

Finally, we believe it is important to acknowledge that the department's oversight responsibilities extend far beyond the residents of community living arrangements and we must strive to assure limited resources are fairly and reasonably allocated to these other important activities.

Once again I thank the committee and its staff for conducting an objective and thoughtful review of our department. My staff and I are always available to provide additional information or answer any questions regarding the issues raised by your review.

Sincerely,

A handwritten signature in black ink, appearing to read 'Peter H. O'Meara', written over a large, loopy circular flourish.

Peter H. O'Meara
Commissioner

Appendix C: DMR Residential Service Descriptions

The Department of Mental Retardation, through each region, enters into contractual arrangements with private providers, or agreements with families or service recipients, to offer or to support community residential supports and services for eligible individuals. The residential supports and services include:

- ***Community Living Arrangements***

DMR owned, operated, or licensed community residences for individuals who have mental retardation and who need continuous supervision. Services are direct care and habilitative. These homes typically are for six or fewer individuals, although some homes may serve up to 15 people.

- ***Supported Living Services***

Supports tailored to assist persons with mental retardation to live in their own homes in the community. The department does not license these homes.

- ***Community Training Homes***

Families or individuals licensed by DMR to share their homes with and provide support for up to three persons who are eligible for DMR services. In addition, regions may contract with provider organizations or individuals to provide management and recruitment, training and a variety of supports and interventions.

- ***Habilitative Nursing Facilities***

Services are 24-hour nursing care for children or adults who have multiple, serious physical and/or medical conditions. Facilities are licensed by DMR. They are owned or leased and operated by the provider organization or individual.

- ***Private Residential Schools***

Facilities providing education/vocational and residential programs for persons eligible for DMR services up to 22 years of age. The facilities are owned, or leased, and operated by the provider and are licensed by the appropriate regulatory agency.

- ***Campus Setting***

Campus settings are large congregate living residences operated, licensed, or funded by DMR for individuals with mental retardation who need extensive and continuous supervision and services.

- ***Individualized Supports***

Individually tailored supports to assist persons with mental retardation to live in their own home, family home or other home in the community. These supports may be delivered in the home or community and may include personal assistance, adaptive skill development, adult educational supports, transportation, social and leisure skill development, respite, parent training, environmental modifications, clinical and medical supports and adaptive equipment and supplies not covered by insurance, support planning, coordination and administration. The person or his or her family has a person-centered supports agreement that includes an individual plan describing the supports and services to be obtained or provided and anticipated outcomes to be achieved. The person or his or her family has an individualized budget with portable funds and the person or his or her designee controls the distribution of the funds and resources. Individualized supports may include self-directed supports or enhanced family supports.

- Self-directed supports are designed to meet the needs of the individual and enhance consumer empowerment, personal development and choice and control over life decisions and are provided in the person's own home or other home in the community.
- Enhanced family supports assist families to care for and support their family members who have mental retardation to live in the family home. The supports required by the family exceed assistance provided through the department's other family support programs and may include intensive supports to meet the medical, behavioral, or physical needs of individuals who wish to remain in their family homes.

Source: DMR Regional Protocols: Residential Supports and Services (Effective 7/93; revised 3/95; 7/99)

Appendix D: DMR Health-Related Advisories and Bulletins Currently on DMR Website

DMR Health Bulletins

Number	Subject
2002-1	RECALL: Infected Chicken/Turkey; Listeriosis
99-2	Response to Health Emergencies
99-1	MQAB Systemic Issues (Atrial Fibrillation; GastroEnterologic Assessment
98-4 R	Bed and Siderail Safety Document has attachments - see Regional Contact at top of page. (Revised October 2000)
98-3	Winter Health Issues
98-2	Herbal Treatments and Food Supplements
98-1	Health & Safety: Summer Activities
97-2	DNR Orders for Individuals Receiving Respite Services
97-1	Medication Ordering Guidelines for DMR Licensed or Operated Facilities (Revised July 1999)
96-2	Rubber Glove Disposal (June 21, 1996)
96-1	Summer Health Issues (June 21, 1996)
95-2	Guidelines for Nurse Delegation to Community Training Home Provider Designees Document has attachments - see Regional Contact at top of page.
95-1	Possible Adverse Drug Interactions (November 30, 1995)

**DMR NURSING STANDARDS
AND ASSOCIATED NURSING GUIDELINES**

Number	Standard
99.1	Medication Administration by Licensed Staff Associated Guideline: Sanction Guidelines for Nursing Medication Errors
97.1	Nursing Delegation to Unlicensed Staff (Document has attachments - see Regional Contact at top of page.)
96.3	Nursing Documentation (Document and Associated Guideline have attachments - see Regional Contact at top of page.) Associated Guideline: Nursing Documentation Guideline
96.2	Nursing Process Components
96.1	Nursing Process

DMR MEDICAL ADVISORIES

Number	Subject
2000-2	Monitoring for Abnormal Involuntary Movements (Tardive Dyskinesia Screening) (rev. #86-3, #92-1)
2000-1	Infection Control (rev. #89-2)
99-4	End of Life Decisions to Withhold and/or Withdraw Medical Treatment
99-3	Interpretive Guidelines for the DMR Regulations Concerning the Administration of Medication by Certified Unlicensed Personnel (rev. #89-1, 93-1, 97-1)
99-2	Family Health History
99-1	Guidelines for Management of Dysphagia
98-8	Routine Preventive Care for Persons with Mental Retardation
98-7	Recommendations to Prevent Aspiration Pneumonia
98-6	Guidelines for Neurological Care of DMR Clients with Epilepsy (rev. #88-3)
98-5	Standards for Multiple Psychotropic Drug Use (rev. 11/98)
98-4	Health Promotion and Disease Prevention in Older Adults
98-3	Practical Guidelines for Care of Persons with Down Syndrome and Dementia
98-2	Guidelines for Management of Clients with Vancomycin Resistant Enterococci in DMR Operated or Funded Facilities or Programs
98-1	Guidelines for Management of Clients with Methicillin Resistant Staphylococcus aureus in DMR Operated or Funded Facilities or Programs
97-3	Guidelines for Prevention of Bloodborne Pathogens (HIV & HBV) for DMR Clients
97-2	Advance Directives for DMR Clients
92-2	Monitoring the Use of Psychotropic Medication Prescribed for DMR Clients (UNDER REVISION) (rev. #86-4)
91-4	Reporting Deaths of DMR Clients to the Office of the Chief Medical Examiner (rev. #88-2)
91-3	Autopsies (rev. #88-1)
91-2	Unlabeled Use of Medications for their Behavior Modifying Effects for DMR Clients (rev. #86-1)
91-1	Neuroleptic Dose Reduction
87-2	Withholding Cardiopulmonary Resuscitation of Terminally Ill DMR Clients

Appendix E: Contract Obligations

1. Staffing patterns must conform to the staffing worksheet form in the Operational Plan. A generalized, sample weekly schedule of the program's staffing pattern must be presented to the region each year when the contract is renewed. A revised schedule must be sent whenever the staffing pattern is changed during the contract period. Proposed changes from this pattern must be approved by DMR prior to its implementation.
2. The Contractor will ensure that direct staff are trained in a minimum of the following areas: OPS, Medication, Bloodborne Pathogens, DMR Policy, First Aid, CPR, the DMR Mission, and Principles of Active Treatment, Abuse/Neglect Prevention, Sexual Abuse Prevention, and Behavioral Techniques based on the needs of the participants. The Contractor will have sufficient certified staff to administer medication to meet the needs of the participants. Training documentation shall be available. Documentation should include a complete listing of current staff working in DMR funded programs and the status of training in the preceding areas. Please include the most recent date of training/certification, expiration date, and anticipated date of renewal if known.
3. The Contractor will conform to the DMR Operational Guideline regarding new placements by providing the region with a written decision within the specified timeframe.
4. Unusual incidents or occurrences affecting a person being supported shall be reported to the Region in a timely manner. Incidents of abuse or neglect, serious injury, loss of home and missing person and other serious matters shall be reported to the Region immediately. Other State and municipal agencies shall be notified at the same time. If necessary, the Regional on-call system shall be accessed by the provider.

Copies of all Unusual Incidents, Accident/Injury, and Restraints will be forwarded to the DMR Regional Office using procedures and forms provided by DMR.
5. The Department of Mental Retardation endorses the ability of individuals funded under this contract to control their lives as well as their resources and make effective choices about their supports and desired outcomes. If any individual currently funded by DMR in Supported Living or Day Services requests a change in type of supports they receive, or does not feel that the provider is meeting their needs, the Department will make every effort to meet their request. The method to reach this outcome is as follows: The individual with his family and friends will have the opportunity to change or redesign the supports for the individual to reach the preferred outcome or procure the supports with existing resources. If the individual chooses to leave the provider, the individual will be assigned a specified amount of money from the provider's current contract (negotiated between the region and the provider) and the contract will be reduced by that amount. The region will then seek the necessary supports to meet the individual's needs.
6. No person will be discharged or suspended from a program without the review of an IDT meeting and approval of the Region Contract administration.
7. All providers shall participate in mid term and annual meetings with DMR.
8. DMR Regional staff shall be granted access to day and residential sites, and records for the purpose of routine site visits.
9. Prior approval is required to add or transfer a person into or within any DMR program.
10. Providers must notify the DMR Case Manager in writing, of entitlements, changes, receipt of lump sum payments and loans from the Contractor. Current or outstanding loan amounts, reasons and re-payment plans must be indicated, with written updates twice a year to the DMR case manager.
11. The Contractor will submit to Contract Administration a Participant Change Form within five (5) days of any Residential or Day program change.

Appendix F: Executive Order 25

Appendix G: Office of Chief Medical Examiner: Investigations and Autopsies

C.G.S. Secs. 19a-400 through 19a-415

State Statute and Regulations

- By state statute, “all law enforcement officers, state’s attorneys, prosecuting attorneys, other officials, physicians, funeral directors, embalmers and other persons shall promptly notify” the OCME of any death “coming to their attention which is subject to investigation by the OCME.”
- The OCME must investigate the death of anybody, including a DMR client, in the following categories:
 - violent deaths, whether apparently homicidal, suicidal or accidental;
 - sudden or unexpected deaths not caused by a readily recognizable disease;
 - deaths under suspicious circumstances;
 - deaths of persons whose bodies will be cremated;
 - deaths related to disease resulting from employment or to accident while employed; and
 - deaths related to disease that might constitute a threat to public health.
- A threshold question, then, is whether the circumstances of the death fit under one of the mandatory categories requiring investigation. The OCME ultimately makes that decision. If OCME accepts jurisdiction, and determines an autopsy is necessary, the OCME makes arrangements for transportation of the body.
- The main purpose of an OCME investigation is to determine cause and manner of death, and certify that on a death certificate. It is up to the OCME to decide whether an autopsy is needed to make that determination. Other sources of investigatory information include the findings at the death scene and any laboratory analysis (e.g., toxicologic, serologic). Sometimes the circumstances of the death and an external examination of the body “allow a medical examiner to conclude with reasonable certainty that death occurred from natural causes or obvious traumatic injury.”

- By regulation, all deaths in institutions have to be reported to the OCME by phone immediately by regulation if the death occurs:
 - in one of the categories above;
 - within 24 hours of admission;
 - in a sudden and unexpected fashion;
 - during or related to a therapeutic or diagnostic procedure;
 - in an operating room or recovery room; or
 - there is evidence of abuse or neglect in causing the death.
- By regulation, when any death subject to OCME investigation occurs, the police having primary responsibility for the death investigation are to immediately telephone the OCME and give information.
- In cases of apparent homicide or suicide, or of accidental death, the cause of which is obscure, the scene of the event is not to be disturbed until authorized by the CME or his authorized representative. In these cases, the chief medical examiner, or his representative, shall view and take charge of the body without delay.
- Operationally, the OCME has six physicians located at its Farmington offices, where autopsies are actually performed. The OCME also uses the services of approximately 80 physicians, called assistant medical examiners, around the state. While deaths may be reported directly to the Farmington office, these assistants often are the initial contact for the OCME from local police, hospitals, and others, and make the determination whether a particular death requires the OCME to take jurisdiction.

Appendix H: Deaths by Residential Type: FYs92-02

Type/FY	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	TOTAL
CLA	18	30	27	26	49	34	50	37	60	57	53	441
CTH	4	5	5	5	6	9	6	4	4	5	3	56
CTO	3	0	1	5	3	1	0	0	0	0	2	15
FAM	35	43	39	38	28	33	27	49	43	28	31	394
HAB	2	2	1	0	1	1	0	0	1	0	1	9
HOS	0	0	1	1	1	2	2	1	0	1	0	9
ICF	7	5	8	6	4	7	3	5	9	7	11	72
IL	2	0	2	2	3	4	3	9	2	2	4	33
MH	1	0	1	0	0	0	0	0	0	0	0	2
OR	0	0	2	0	0	0	0	1	0	2	2	7
RC	6	6	6	4	6	7	2	8	7	4	12	68
RCH	4	1	4	1	4	3	4	3	1	5	3	33
SL	5	4	3	12	5	3	8	5	15	10	6	76
SNF	29	32	47	38	34	42	31	37	43	36	36	405
TRS	20	15	16	15	20	16	22	19	18	24	15	200
No Res.*	4	3	0	0	1	2	0	2	1	0	0	13
Total	140	146	163	153	165	164	158	180	204	181	179	1833

* Means no residential type coded
Source of Data: DMR

Appendix I: DMR Case Summaries

Summaries of DMR Death Cases Identified as Questionable by the Hartford Courant in Its December 2001 Series on DMR Group Home Deaths

- The Hartford Courant identified as questionable 36 deaths of DMR clients living in group homes. These deaths spanned a ten-year period—three people died in 1991, one in 1992, four in 1993, four in 1994, seven in 1995, two in 1996, five in 1997, two in 1998, three in 1999, and five in 2000.
- The program review committee staff reviewed the mortality review files for each death, as well as any abuse/neglect investigations related to the deaths. From this review, the staff prepared summaries of each case, which are attached.
- Each summary gives some very brief facts about each person -- age, level of mental retardation, number of medications the person was taking at time of death, the number of diagnoses the person had prior to death, and where the person was living at time of death. The person's cause of death is also noted.
- In the remainder of the summary, there is a brief description of the events leading up to the person's death, a tally of what post-death actions were taken, and a description of any outcomes of these actions. The summary concludes with program review staff comments based on its review.
- Individual identifying information such as the client's name or birth date is not included in the summaries in keeping with the confidentiality provisions related to DMR client records, the mortality review process, and the abuse/neglect investigation process.

Glossary of Acronyms/Terms Used in Summaries

A/N= Abuse/Neglect

CAMRIS= the main client database at DMR

DNR = Do Not Resuscitate Order

DK = Don't Know

DPH=Department of Public Health

ER=Emergency room

FDA=Food and Drug Administration

HRC=Human Rights Committee

ICU=Intensive Care Unit

IDT=Interdisciplinary Team

OCME=Office of Chief Medical Examiner

OPA=Office of Protection and Advocacy for Persons with Developmental Disabilities

OPS=Overall Plan of Service

Pica= An eating disorder characterized by the repeated eating of non-food substances

PRC=Program Review Committee

RMRC=Regional Mortality Review Committee

STS=Southbury Training School

Demographics

Age: **29** MR Level: **Mild** # Meds: **7** # Diagnoses: **2** Public/Private Home: **Private**

Cause of Death: *Acute Thioridazine Intoxication*

Events Leading to Death

- After client came home from work, she told staff she was going to rest in her bedroom and for staff to wake her for dinner
- When staff went to get client, she was found on floor, unresponsive
- Nursing notes say staff ran to call 911 but panicked and did not perform CPR
- Client died from an adverse drug interaction (a new drug given to the client was only on the market for six months and was not contraindicated with the client's current medications)
- Client lived at group home for approximately five years

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- On August 1, 1995, chief medical examiner said death was due in part to new drug apparently interfering with body's metabolism by artificially raising the levels of client's other drugs to potentially toxic levels; advised DMR to take steps to notify all appropriate people
- DMR issued a medical alert on same day as medical examiner's findings to all regional directors, regional health service directors, and licensing staff
- Medical examiner reported incident to FDA as an "adverse drug reaction"
- DMR determined it was not possible for the prescribing physician or other medical personnel to predict the outcome
- DMR issued a Health Bulletin (November 30, 1995) regarding psychotropic drugs and possible interactions
- Death review noted several systemic issues

Program Review Committee Staff Comments

- Regional mortality review was unclear why client's psychotropic meds changed to the new drug and why case manager was not notified timely of psychiatric change
- Temporary approval for psychotropic med change not reviewed by program review committee (PRC). Client's psychiatrist who prescribed med change sat on client's PRC and a representative on the client's human rights committee also sat on PRC and was administratively employed by the provider agency
- State mortality review recommendation to develop an easy-to-use chart re: drug interactions was determined too complex by a DMR consulting psychiatrist and thus never developed

Demographics

Age: 74 MR Level: Mild # Meds: 9 # Diagnoses: 9 Public/Private Home: Private

Cause of Death: Myocardial Infarction

Events Leading to Death

- Client lived in group home for three years prior to death
- Entered hospital for hip surgery one month before death, diagnosed with moderate cardiac enlargement
- Later admitted to emergency room with leg pain; diagnosed with broken leg; went into cardiac failure during operation; died later that night

Post Death Actions

	Yes	No
Family Contacted	X	
Autopsy		X
A/N Investigation		X

	Yes	No
Police Investigation		X
Regional Mortality Review	X	
State Mortality Review	X	

	Yes	No
Personnel Actions Recommended		X
Other Enforcement Actions Recommended		X
Lawsuit Filed		X
DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review committee said client's death was not unexpected, due to cardiac status and that group home provided excellent care and good quality of life
- State mortality review board accepted local findings

Program Review Committee Staff Comments

- Client entered hospital on two separate occasions with a broken hip and a broken leg near the time of death. No abuse/neglect investigation information was in the client's file and the regional and state mortality reviews did not question these incidents, which they could have given the timing of the incidents relative to the client's death.

Demographics

Age: 29 MR Level: Moderate # Meds: 2 # Diagnoses: 4 Public/Private Home: Private

Cause of Death: Multiple Blunt Force Injuries

Events Leading to Death

- Due to inclement weather, provider decided to use public train transportation rather than drive to a planned outing for clients
- Client, said to be “lacking in strong traffic safety skills” and having compulsive behavior, became excited on train platform when a train approached, ran to the platform’s edge, and had to be redirected by staff
- Client ran a second time and staff was unable to physically control him and he fell onto the tracks in front of an oncoming train
- 911 was called, CPR administered, and client taken to hospital but died of multiple trauma
- Client lived in group home for 14 months

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Provider conducted an abuse/neglect investigation – found staff followed safety procedures and did all they could during the situation
- Regional mortality review committee said provider’s investigation was monitored by OPA, which stated its satisfaction with results; committee noted client’s lack of traffic safety skills was addressed by staff using proven procedures, the incident was unexpected and appropriately dealt with by staff, and that staff are commended for exemplary efforts
- State mortality review board accepted the regional committee’s findings
- OPA did not substantiate neglect or make any recommendations

Program Review Committee Staff Comments

- Although the client had compulsive behavior and did not exhibit “strong traffic skills,” the regional death review process determined these areas had been addressed through supervision and redirection at the time of the incident, which worked well in the past with this client.
- The death review process also determined the incident was unexpected and dealt with appropriately by staff. The state mortality review process agreed with these findings.
- Committee staff questions, however, whether more staff attention should have been given addressing the client’s behaviors after the first incident of him running toward the train tracks and having to be restrained/redirected by staff. Otherwise, provider staff did all it could to help client. A difficult situation.

Demographics

Age: **25** MR Level: **Mild** # Meds: **1** # Diagnoses: **3** Public/Private Home: **Private**

Cause of Death: *Multiple Blunt Force Injuries as a Result of Motor Vehicle Accident*

Events Leading to Death

- Client was annoyed after a mid-evening confrontation with staff; went to bedroom
- 2 staff were on duty and scheduled until 10 p.m.; 1 staff person left at 9:20 p.m.
- 2 off-duty staff came to the house for a brief period from 9:40-9:45 p.m. (one claimed to have seen what he thought was the client in his bedroom during that time)
- Client left the house and was spoken to twice by town resident at a public place at approximately 9:45 p.m.; the town resident called 9-1-1 – the DMR investigation determined the client left the residence no later than 9:10 p.m.
- Alarm system in the house was not activated
- Client stole and then crashed a car and was fatally injured
- Client lived at group home for 2 ½ years

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	(not indicated in file)		Police Investigation	X		Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed	X	
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional and state mortality reviews called death an accident
- DMR investigation substantiated provider neglect; made multiple recommendations, including obtaining criminal histories before hiring direct care staff
- OPA both agreed and disagreed with several of the DMR investigation findings regarding substantiated neglect or abuse. OPA also made several protective service/systemic recs.
- Staff now go through criminal background checks
- Provider eventually lost contract for this home and all other homes in this region
- Lawsuit settled for “several hundred thousand dollars”

Program Review Committee Staff Comments

- Staff not aware client was missing for at least six hours, including after a formal shift change less than an hour after investigation determined client left house
- Provider did not get formal DMR approval prior to installing alarm, nor was there a record of formal staff training or written operations relating to the system, including regions of the house routinely bypassed by staff
- A rebuttal to the investigation report from the provider noted all provider staff were trained in using the alarm system; also noted the department’s licensing inspectors never cited the provider due to a lack of training on the alarm system despite regular DMR inspections
- Why did DMR permit an asleep 3rd shift staff given clients’ “need for supervision” based on their documented behaviors
- DMR investigation found provider’s personnel practices deficient in staff screening, hiring, evaluation, and discipline (disputed by the provider rebuttal) – unclear what department’s oversight role is in these areas

Demographics

Age: 37 MR Level: Severe # Meds: DK # Diagnoses: DK Public/Private Home: Private

Cause of Death: Asphyxia, Secondary to Foreign Body in Throat

Events Leading to Death

- After 26 years at Southbury, the client moved to a one-person private group home specifically designed for his needs, with the expectation at least one other client would later move in
- Less than one month later, the client died as a result of a choking incident –he grabbed food allegedly in sizes exceeding the client’s food guidelines, ran away from staff, and choked
- Staff called 911 and tried to intervene doing Heimlich Maneuver and CPR before emergency help arrived; ambulance took client to hospital where he died
- Client had a 1:1 supervision requirement, meaning he was to be within an arm’s reach of a direct care staff person at all times while the client was awake

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed	X	
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- A lawsuit filed by the client’s family is pending and the provider has submitted a written rebuttal to the DMR investigation report
- A DMR investigation was conducted and cited neglect on part of provider management for not ensuring staff were adequately inserviced on client’s food prep guidelines (currently disputed by provider)
- Regional and state mortality reviews were conducted – both accepted the DMR investigation findings and recommendations
- The provider has so far agreed to inservice all appropriate staff on any specific food prep guidelines for clients, and will record attendants’ signatures, titles, and training dates – as recommended in the DMR investigation report; any other personnel or programmatic actions are pending the result of the lawsuit
- OPA agreed with the DMR investigation findings of substantiated neglect and made a recommendation for DMR to ensure upon the transition of any client with specific food guidelines that formally documented procedures be in place and that such guidelines are given to the new provider prior to the transition process.

Program Review Committee Staff Comments

- The DMR investigation cites 12 different documents available to the provider where the client’s behaviors (re: grabbing food/running) and food guidelines were noted in information between STS and provider – the provider is disputing the investigation results
- Although the same DMR client transition processes used in moving Mansfield residents are to be used for Southbury residents, including the transition of this client, it is unclear whether the new provider was fully aware of client’s food guidelines as part of the transition process.
- The regional mortality review committee gives conflicting answers as to whether care before the client’s death was appropriate; the regional review process was also held three weeks *before* DMR’s investigation report was completed, which DMR reports is not unusual. The department says the death review process should be delayed by a pending investigation.
- DMR is continuing to work on developing standardized nutritional guidelines, as recommended by the state mortality review board.

Demographics

Age: **49** MR Level: **Severe** # Meds: **11** # Diagnoses: **9** Public/Private Home: **Private**

Cause of Death: *Cardiopulmonary Arrest, Secondary to Pneumothorax*

Events Leading to Death

- Client was taken to emergency room with gastric problems (had history of increasing gastric ailments)
- Surgery was performed; client said to be uncooperative in terms of pulling out IV lines, including antibiotics
- Provider hired private “home health agency” to monitor client while in hospital (i.e., making sure IV lines are not removed) – later determined by the state mortality review board, through DPH, the agency was not licensed by DPH as home health care agency
- Client pulled out IV lines apparently and missed antibiotics over the course of approximately 12 hours, developed high fever day before death; two hours before death IV line removed; central line put in, client’s health deteriorated, CPR performed, but client died of cardiac arrest and pneumothorax

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation	X	

Post Death Actions: Results/Outcomes

- Regional mortality review committee said client safety while in hospital could have been better protected by hospital; hospital has historically had health care problems; DPH investigation warranted, but pneumothorax probably could not have been prevented
- DPH investigation confirmed several deficiencies on part of hospital – allegation that patient did not receive IV fluids/antibiotics for 12 hours was partially substantiated
- Hospital submitted plan of correction to DPH
- State mortality review board accepted regional committee’s findings/recommendations, and inquired from DPH whether private monitoring agency was licensed as home health care agency.
- OPA agreed with DPH investigation findings of “partial substantiation” of hospital neglect in that client did not receive the appropriate intervals of antibiotics.

Program Review Committee Staff Comments

- Private hospital monitoring agency must be required by MD order, but no such order in file or found during DPH investigation
- Unclear why client’s removal of IV line was not acknowledged by hospital for an extended period of time
- Surgical procedure performed without first receiving guardian consent
- Although it is a hospital’s responsibility to define the role of a “monitoring agency,” unclear why DMR did not send out any guidelines re: private monitoring services specifically after agency called itself a home health care agency although not licensed as such by DPH
- Hospital did not seem to fully know DMR procedures re: guardian consent

Demographics

Age: **24** MR level: **Moderate** # Meds: **4** # Diagnoses: **3** Public/Private Home: **Private**

Cause of Death: *Suicide by hanging*

Events Leading to Death:

- Client had been living in the home for 12 years
- During evening prior to death -- client had pizza with housemates and staff, and talked on the phone to family and friend.
- Not seen by staff preparing for bed or in bed.
- Client found about 6:00 am fully dressed, hanging from closet rod by bathrobe belt. The staff person on overnight shift indicated he had “checked” on client several times by listening at the bedroom door.
- The staff person had worked regular shift – 2 p.m. Thursday to Friday 6 a.m., then part of the 1st shift on Friday morning (because someone called in absent) then came back for 2 p.m. shift on Friday until Saturday a.m.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- No charges filed as a result of the local police investigation.
- The A/N investigation was conducted by the private provider. It did not substantiate neglect.
- Office of Protection and Advocacy monitored provider and local police investigations, and mortality reviews. OPA asked for further information -- bed check policy, legible staff log on night of incident, and when client was last bathed -- and made 3 recommendations, including implementation of mortality review findings.
- Regional Mortality Review made 7 findings or issue areas including: - the autopsy did not indicate a time of death, and – policy on staff hours allowed to be worked and made three recommendations: 1) in-service staff on warning signs of depression and/or suicidal intent; 2) better documentation on clients’ daily activities; and 3) close case.
- State Mortality Review also question the number of hours staff can work per day; the fact that post mortem does not cite a time of death, although the police report indicates a conversation with Medical Examiner indicating it was soon after dinner, no one able to determine why staff gave conflicting information.
- Same recommendations as RMRC plus check with OPA on status of A/N report; check on status of staff person involved; and staff training on better record keeping (Region to follow up).

Program Review Committee Staff Comments

- Private provider “investigation” consisted of interviewing 2 staff persons.
- The agency investigation does not appear to have considered the autopsy report, the police report, nor does it appear the staff was questioned on the staff log w/scratched-out entry indicating client was fine in the am, (several hours after the death occurred) nor questioned as to whether he had fallen asleep.
- Discussion w/provider indicates they have not changed staff work policy – always had a prohibition against working more than a straight double shift; and had instituted a policy on overnight check-ins by staff that was in place at the time of client’s death. This type of scheduling could still happen and yet comply with policy of no more than a straight double.
- No disciplinary action was taken against staff.

Demographics

Age: **49** MR Level: **Severe** # Meds: **DK** # Diagnoses: **DK** Public/Private Home: **Private**

Cause of Death: *Foreign body in larynx*

Events Leading to Death

- Client had lived in home for 10 months
- Client choked at dinner while staff was serving other clients their plates
- Staff performed Heimlich – no response; Called 9-1-1. Conflicting information about whether staff started CPR. EMTs arrived with tool – removed piece of food, transported to hospital ER. Could not be revived.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- RMRC conducted initial review – found that there were no eating guidelines in place for the client, even though family indicated food needed to be cut up.
- RMRC recommended reopening case once DMR investigation completed. DMR issued report 18 months after death. Findings substantiated program neglect – no plan for cutting food size open to staff interpretation—and even though staff running notes indicate food stealing behavior, no plan for this; failure to report incidents; found neglect on part of staff nurse and falsifying records on part of house manager.
- Investigation makes 8 recommendations -- provider review findings to see if personnel actions are warranted; better training on responsibilities, better training of CPR; better intake process; referral of neglect findings to regional community training home coordinator (2 staff also provide services) there. Regional contract managers to follow-up.
- Regional Committee at 2nd review – after DMR investigation completed – found that the medical and personal care was not timely or appropriate, and supported the recommendations of the investigation.
- State Mortality Review agreed with local findings (essentially the investigation findings) and recommended regional follow-up with provider to ensure recommendations implemented.

Program Review Committee Staff Comments

- Provider had been cited in previous licensing inspection (a year before client death) that documentation was lacking to show the process for updating staff on client-specific info (like eating guidelines).
- Apparently the correction plan from provider was filed. Client had been in home less than one year – client specific information very important until staff becomes familiar with client.
- Psychiatric evaluation does not mention food-stealing behaviors, not clear if rest of IDT knew about these behaviors.
- Does not appear medical examiner was contacted to do autopsy as should be done for sudden, unexpected death. Police not called.
- Staffing in home was minimal at time of incident – one staff for 6 clients – but not clear whether the staffing patterns were looked at to see if this was the usual staffing ratio, and if so, whether adequate given need for eating monitoring.
- Not clear from file documentation if and how the recommendations were implemented. Took 4 months after death for A/N report to be filed. Not clear if OPA agreed with DMR investigation findings.

Demographics

Age: 21 MR Level: **Profound** # Meds: 4 # Diagnoses: 3 Public/Private Home: **DMR Respite**

Cause of death: *Cardiopulmonary arrest*

Events Leading to Death

- Client lived at home but was in DMR respite care for a few days. Client had been this respite before.
- Client had a seizure disorder and was on medications Client had some medications at the respite from previous stay.
- Mother sent additional meds. Staff added the newly sent meds from envelopes to the bottles of meds on-hand, without counting.
- About 5:30 am client found unresponsive in bed. Client had discharge from mouth.
- CPR started 9-1-1 called. EMTs and State police responded. Client pronounced dead by EMTs at the respite.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended	X	
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed*	X	
						DPH Investigation		X

*DMR settled- Paid \$875,000

Post Death Actions: Results/Outcomes

- Almost immediately after client's death father claims that client not given all medications at the appropriate times during stay at respite. State police took all remaining medications with them for their investigation.
- No criminal charges filed by State police. DMR investigation delayed 2 months until State Police ok'd to proceed.
- Regional mortality review could not adequately interpret autopsy results because apparently not enough blood was taken to adequately screen for client's med levels; RMRC also found other problems with autopsy report.
- DMR investigated for A/N. Did not substantiate. OPA disagreed and found neglect.
- Even though neglect was not found by DMR, nursing staff was "counseled" on accepting medications

Program Review Committee Staff Comments

- Autopsy was conducted by a pathologist at the UConn Health Center, not OCME. It is unclear whether DMR contacted the Office of Chief Medical Examiner about conducting the autopsy.
- DMR staff contacted a local medical examiner who did not accept jurisdiction. He did not come to the scene, but based on DMR staff description and client's medical history, ruled the death natural.
- On the day of the death, the State Police contacted the OCME and was told that, based on information from local ME, there would be no autopsy.
- Program review could find no documentation as to which DMR staff had called the ME, and what information had been conveyed. Further the state police report does not indicate that the OCME was informed of the medication issue when SP made contact, thus there is no clear indication that the OCME knew about the medication an issue when autopsy decision was made.
- Both DMR staff and state police knew very soon after client's death that med. administration was an issue, since the client's father was very agitated/upset about the medicines at the respite center, and the state police had seized the medicine bottles as evidence.
- Nothing in documentation indicates what the pathologist at UCHC was told regarding the medication issue and why not enough blood was taken for adequate medication screenings. Autopsy was reviewed by OCME for state police; determined no criminal aspects to the death.
- OPA found problems with autopsy including wrong dates, no clear time or cause of death.
- State Police report apparently not reviewed as part of the Mortality Review process, was not in file and DMR initially stated that a SP investigation had not been done. Program review pursued getting the state police investigation report through the Director of Investigations.
- Even though DMR did not find neglect, the region developed a Quality Improvement Plan for the respite Center making specific people responsible for particular tasks for correction/improvement. One LPN eventually terminated for continuing med errors.
- Program review found client profile sheet used by respite center not thorough, that one of client's medical diagnosis (asthma) was not on the sheet, and food consistency guidelines were contradictory.

Demographics

Age: **28** MR Level: **Profound** # Meds: **14** # Diagnoses: **16** Public/Private Home: **Public**

Cause of death: 1) Respiratory failure; 2) Recurrent aspiration pneumonia

Events Leading to Death

- Client had lived in this CLA for almost 2 years
- Over 6-month period prior to death, client had recurrent aspiration pneumonia.
- Increasing episodes of gastrointestinal problems – reflux, abdominal distention, and vomiting. Hospitalized for a diverting colostomy. Surgery performed; ok for 48 hours.
- Then found unresponsive on 3rd day post-surgery. Full ACLS initiated; transferred to ICU. DNR put in place –died following day.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review found care appropriate and timely. Stated he was a medically involved client; cause of cardiac arrest in hospital could not be determined.
- DNR properly documented.
- OCME did not accept jurisdiction -- no autopsy. No hospital autopsy. RMRC recommended to close case.
- State mortality review examined case (even though not referred by region) agreed with regional findings.

Program Review Committee Staff Comments

- RMRC indicates DNR properly documented. DNR was not in file.

Demographics

Age: **65** MR Level: **Moderate** # Meds: **3** # Diagnoses: **3** Public/Private Home: **Private**

Cause of Death: *Subdural hematoma due to fall*

Events Leading to Death

- Client had lived in this home for more than three years
- Client had Down Syndrome with Alzheimer's
- Had a series of incident reports related to falling and increasing behavior issues including disrobing and slapping staff.
- Had a choking incident a year prior to death – had dysphasia evaluation – with recommendation to chop food smaller, use smaller spoon, and limit size of bites.
- Also had a geriatric assessment and several other evaluations – found declining cognitive skills. By days prior to death, could no longer feed himself or perform ADLs.
- Client not well – RN called -- RN advised take client to ER. Admitted to hospital, CT scan showed bilateral chronic subdural hematoma.
- Hospital Intensive Care Unit full; taken to regular floor.
- Surgery performed to relieve bleeding. Did not regain consciousness; CT scan showed large re-bleed.
- Niece/guardian opted for no 2nd surgery.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- RMRC states there was no allegation of neglect or abuse, but “caregivers did not provide a safe environment to protect him from harm”
- RMRC recommends team be convened to review issues in the case
- MQAB states injury of unknown origin; makes A/N allegation on 3/28/02; investigation report pending (10/02)

Program Review Committee Staff Comments

- Provider had taken client for several assessments and evaluations related to his deteriorating cognitive skills and increasing behavioral incidents
- Case Management notes indicate client had cut back on day program – had fallen off chair at Day Program and taken to ER
- IDT continues to “voice concerns” about his sleeplessness at night and increasing falls; Case Manager to look at alternative placements;
- No documentation that IDT requests safety belt approval for chair use to prevent falls
- Program review questions whether this is a case of neglect or one where the client was no longer appropriately placed and IDT did not find another placement. Provider had sought assessments/evaluations for client) and shared results w/ IDT.
- A/N allegation comes up almost two years after death
- Not clear if regional team was ever convened or what it found/recommended

Demographics

Age: 35 MR Level: **Mild/Moderate** # Meds: 5 # Diagnoses: 5 Public/Private Home: **Private**

Cause of Death: 1) Respiratory arrest; 2) Aspiration; 3) Seizure disorder

Events Leading to Death

- Client had lived CLA about 2 years
- About one month before death, client put on new medication to control seizures
- Experienced grand mal seizure 3 weeks before death – had respiratory difficulty
- Had another seizure shortly after and went into cardiac arrest
- 9-1-1 called; taken to ER by EMTs
- Put on ventilator and resuscitated -- admitted to ICU
- Deteriorated over ensuing 2 weeks
- About a week before death – tracheotomy and g-tube put in place and client remained on ventilator
- Diagnosis of systemic inflammatory response syndrome (multi-system failure)
- DNR put in place after following DMR protocols; life support withdrawn; died hours later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X	*Guardian	Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	x		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- RMRC found medical and personal care appropriate, hospital calling on medical specialists to determine cause of deterioration
- Found CLA staff acted appropriately getting client to ER
- Recommends a report of possible drug interaction (with multi-system failure) to FDA. Region to check on clients in that region to assess others on that drug
- State mortality review agreed with local findings – reported to FDA

Program Review Committee Staff Comments

- A/N allegation concerning this client at the CLA after the client went to hospital (not related to death); not substantiated, determined to be related to union and strike issues.
- Another abuse allegation 2 months before death was substantiated
- LPR&IC staff not sure if clients in the region were ever assessed for that particular drug use; or if clients in other regions were assessed
- No FDA response -- DMR FDA does not respond to every report of a possible drug interaction, would send out an advisory if there was concern about the drug

Demographics

Age: *10* MR Level: *P* # Meds: *9* # Diagnoses: *6* Public/Private Home: *Private*

Cause of Death: *asphyxia due to drowning (bathtub)*

Events Leading to Death

- Client in private CLA geared to mentally retarded children, had lived there 7 years
- Late afternoon -- Group of nursing school graduates touring home at the time
- 2 staff started to bathe client; placed client in tub ¾ full of water
- Staff had used bathing chair for client had but did not strap client in
- 1st staff person left bathroom w/dirty laundry and stayed in family room w/other clients
- 2nd staff person left bathroom to get client’s meds (no meds found in bathroom later)
- 2nd staff returns to bathroom -- finds client submersed in tub -- lips blue, not breathing
- 9-1-1 called; EMTs and local police department responded
- Transported to hospital ER. Pronounced dead.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended	X	
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Criminal charges of manslaughter in 2nd degree and risk of injury to minor filed against one staff person. Staff person pleaded guilty to the risk of injury charge. Judge sentenced staff to a 5-year suspended sentence and 5 years of probation, and imposed stipulation that staff not work in health care or childcare in future.
- DCF conducts A/N investigation -- found neglect on part of one staff person (not the 2nd)
- Investigation listed a number of programmatic concerns -- not unusual for staff to leave a client alone in tub to get towels, clothing, or meds; also not unusual for staff to not use straps on the bath chair
- Investigation found no formal training or competency test on use of bath chair to ensure staff know how to use
- Quarterly reviews of the last OPS had not been shared with staff (over 2 months)
- Regional Mortality Review and State Mortality Review stated they had no medical records to review (taken by police and DCF for investigation) so findings or recommendations were limited to the social summary and case management notes
- DMR management staff conducted its own “root cause analysis”
- Private provider subject to intense monitoring by case manager and contract monitors – at least 8 visits in 6 weeks after death
- Bathing procedures are now required to be in place for each client in CLAs and checked at site visits

Program Review Committee Staff Comments

- Program review staff found the DCF investigation very thorough, but was unable to determine why in one version of the DCF report there were two finding areas that were crossed out and in a version of the report issued two days later those findings were not included
- Licensing and Inspection had cited the home in previous year for not having clear updates in the OPS on use of safety equipment; provider filed a correction plan. Provider indicated to program review that deficiencies addressed – doctors’ orders for bathing straps in place and implementation of safety protocols for bathing, eating, ambulating and transportation for all clients.
- No indication that regional or state mortality review considered either the local police report or the DCF investigation in reaching findings about care in the case. State mortality review states just that they did not have medical records to evaluate, and that local PD in charge of the case.
- The private provider submitted its response to the investigation, which included actions the provider planned to take but also discussed where provider took exception or found issue with findings
- Case points to a miscommunication (or misinterpretation) of what actually happened to client when 9-1-1 was called and brought to ER. Only at ER did it become clear that child went underwater in bathtub – EMTs thought he had seizure. 9-1-1 tape not part of the document so not clear what CLA staff told the dispatch.

Demographics

Age: **24** MR Level: **Profound** # Meds: **9** # Diagnoses: **4** Public/Private Home: **Public Regional Center**

Cause of Death: *Aspiration pneumonia*

Events Leading to Death

- Client had lived at regional center for about 20 years
- Client had bouts of respiratory infections and recurring incidents of aspiration pneumonia
- Had a feeding tube inserted year prior to death; client continued to aspire on regurgitated material.
- Client also had chronic urinary tract infections
- Had several hospitalizations— client returned back to regional center; continued antibiotics and suctioning
- Client was changed and turned about 3:30 am. – staff discovered client unresponsive at 4:05

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Autopsy conducted by OCME -- showed therapeutic levels of anticonvulsant drugs
- Autopsy also found cause of death chronic aspiration with early bronchial pneumonia; found previously undiagnosed hydrocephalus but not progressive and not cause of death
- Regional and state mortality reviews found medical care appropriate – involvement with family well-documented and family wishes appropriately considered -- no recommendations

Program Review Committee Staff Comments

- Parents had initially not wanted the g-tube inserted (their belief was that they did not want to prolong client's suffering) eventually agreed.
- Not sure why autopsy was done by OCME in this case, while jurisdiction not taken in earlier case with very similar circumstances

Demographics

Age: **26** MR Level: **Profound** # Meds: **5** # Diagnoses: **3** Public/Private Home: **Public Regional Center**

Cause of death: *Asphyxia due to aspiration of food bolus (choked on food)*

Events Leading to Death

- Client had lived at the Regional center for 14 years
- Client had line-of-sight requirements; when in community 6 feet line-of sight
- Client had history of stealing food and gorging (client at one time had a diagnosis of PICA)
- Client had recent incidents of bolting and stealing food
- Client was on way to day program. At parking lot where clients transferred from DMR van to the day program van, staff were outside the van and client was able to access lunchbox
- Client choked on sandwich. 9-1-1 called. Heimlich maneuver and CPR performed. Transported to hospital by ambulance. Pronounced dead.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed	X*	
						DPH Investigation		X

*Case settled. Private provider paid an undisclosed amount

Post Death Actions: Results/Outcomes

- Police investigation –very brief police report, no criminal charges filed
- DMR conducted A/N investigation—neglect substantiated, and other programmatic concerns were substantiated.
- 9 separate findings including: no clear guidelines about supervision needed by client on van – staff left to interpret
- Staff unaware that client needed food chopped to a certain size
- DMR unable to provide in-service (training) records for the 4 people present during the incident. Day program provided training documentation for its staff
- Client had PICA behaviors but no behavior plan in place – no documentation of PICA no longer an issue
- Other clients at client’s residence also showed PICA and/or food-stealing behavior; not addressed as target behaviors
- Other clients on van had these behaviors, yet investigators found many items in both vans (e.g. in DMR van – hard candy, fish hook, cigarette butt; in private sandwich bag with orange powder from crackers client ate before choking)
- Private provider staff did not use cell phone in van to call 9-1-1 told other people to call. EMTs took “too long” according to staff on scene
- 11 recommendations made by DMR investigators. Regional mortality review states recommendations need to be implemented and residential documentation needs to be more specific and address target behaviors and incidents
- State mortality review sends a memorandum to Regional Directors and Southbury Training school to review procedures for keeping vans cleaned and other safety issues around vans (maintenance and safety belts)

Program Review Committee Staff Comments

- DMR investigation very thorough.
- Don’t know if recommendations were implemented -- investigation report does not make specific person responsible for follow-up or implementation (mostly DMR central region responsible)
- Don’t know if any personnel actions were taken, those are not part of the investigation report
- The PICA behaviors not addressed in the plan yet no documentation of being discontinued is similar to the circumstances in one of the other cases in this case review (other case happened about 3 years earlier)

Demographics

Age: **37** MR Level: **Profound** # Meds: **5** # Diagnoses: **3** Public/Private Home: **Private**

Cause of Death: *Aspiration of foreign body (choked on a tiny rubber ball)*

Events Leading to Death

- Client lived in a CLA with 4 other people
- Client did have an eating program – cut all food into small pieces to avoid choking only small amount to drink and remind him to drink slowly. Staff must be seated at table with client
- A relative of one of the other residents brought the young woman an Easter basket
- Apparently the client took the small rubber ball (which was attached to a paddle) from the Easter basket, thinking the ball was a candy
- He began choking – staff did not know what he had eaten. According to police report, staff thought it was a marshmallow
- Staff attempted the Heimlich maneuver 9-1-1 was called – Police and EMTs (from fire dept.) responded. He was still breathing when they arrived. Police apparently instructed staff to sit client down and let client relax to get the choking material down
- Client stood up, turned blue, then collapsed. EMTs and police checked client -- no breathing, no pulse.
- CPR started -- transported to hospital ER—client could not be revived

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- There was a police report – no criminal charges filed
- Private provider interviews 3 staff people on duty at the time -- but no investigation was conducted
- Regional mortality review indicates services and care appropriate and that cause of death was not anticipated nor preventable – stated client had no history of PICA.
- Regional mortality review commends staff for excellent care provided to client and for the attempts to provide emergency treatment before client died.
- State mortality review agrees with local findings and made no further recommendations

Program Review Committee Staff Comments

- Program review staff questions why there was no neglect investigation – many questions remain unanswered when no investigation is conducted.
- No documentation in file that client required line-of-sight supervision, but client did have an eating program because there was a concern about choking.
- Regional concern should not have been about PICA -- client had no history of PICA – but about having access to food that was larger than client could eat. (i.e., client may have swallowed rubber ball believing it was edible)
- Issue raised in the Hartford Courant article about the provider’s payment of the client’s life insurance policy to the family with the provision that family not file a lawsuit and whether that was appropriate.

Demographics

Age: 26 MR Level: Severe # Meds: 10 # Diagnoses: 12 Public/Private Home: Private

Cause of death: *Asphyxia due to neck compression (Client was caught between bedrail and mattress)*

Events Leading to Death:

- Client had been in group home for 8 years
- Client had hospital bed with rails; client also needed to be repositioned every two hours.
- According to staff log, client was checked at 1 a.m., 2:30 a.m., and 4:15 a.m.
- Client was found by day shift staff at 7:10 a.m.—client was wedged between bed siderail and mattress with his neck on the bar that attaches the rail to the bed
- Client was not breathing and was cold to touch
- Police and medical examiner called – both responded -- medical examiner came to scene and pronounced the client dead

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended		
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Local police investigated – no criminal charges filed
- A/N investigation conducted by DMR – neglect substantiated

Investigation found:

- There was no provider documentation requiring bed checks;
- Required repositioning required every 2 hours was not done (apparently staff thought other staff had done it);
- LPN recorded repositioning done when it was not
- CPR not started by any of the 5 staff who were there at the time client found -- all thought he had been dead too long
- Staff called Asst. Residential Coordinator before calling 9-1-1

Program Review Committee Staff Comments

- When staff called 9-1-1 told by police not to touch body – don't know if that is why CPR not started
- Provider emergency procedure does not clearly state when to start CPR, nor does DMR policy
- New beds had been delivered in previous few months, but provider did not contract for new side rails
- Provider used the old rails from the old beds, installed by provider
- Case manager indicates there were no issues raised at IDT about client safety and bed rails
- The Food and Drug Administration had issued a bed rail advisory in 1995 (3 years before client's death); it went to DMR but the agency did not distribute it nor alert private agencies
- DMR issued its own bed rail advisory in 1998 (after client death) that went to all regions and providers. Advisory revised in 2000 to address water and air mattress issues.
- Committee staff is not clear what, if any, disciplinary actions were taken against personnel involved.

Demographics

Age: 51 MR Level: **Profound** # Meds: 7 # Diagnoses: 4 Public/Private Home: **Public**

Cause of death: *Acute pulmonary edema due to aspiration of gastric content and small bowel obstruction (Client swallowed a rubber glove)*

Events Leading to Death

- Client was living in a DMR home; had been there 4 years
- When client was placed there it was noted that client had serious PICA behaviors and there was behavioral plan in place for that.
- Staff found client at 4:45 a.m. Client twitching on bathroom floor.
- Staff called “unit” nurse who said to call 9-1-1. 9-1-1 called.
- Taken to hospital. Client admitted to hospital with dehydration and Tegretol (one of client’s meds) toxicity.
- Died a day later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X	Guardian	Police Investigation		X	Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation	X		State Mortality Review	x		Lawsuit Filed		X
						DPH Investigation	X	

Post Death Actions: Results/Outcomes

- Autopsy found client had ingested 2 rubber gloves and other inedible items – clothing tags
- DMR conducted A/N investigation; neglect substantiated
- Investigation found: Client’s PICA condition was not monitored adequately – significant incidents of PICA had occurred and IDT failed to address
- Week before death the day program had written an incident report of PICA
- Regional Mortality Review found that residential unit did not monitor client’s PICA adequately and did not utilize appropriate safeguards in storage and disposal of inedible items.
- RMR found communication between hospital and DMR staff was inadequate
- State mortality review agreed with regional findings; also sent letter to DPH requesting an inquiry into lack of surgical consult while client in hospital.
- DPH conducted inquiry into doctor’s failure to get a surgical consult -- inquiry found no reason for action
- Disciplinary action recommended for group home staff and IDT members who knew (or should have known) about PICA and did not take action

Program Review Committee Staff Comments

- OCME declined jurisdiction -- DMR pursued local hospital pathology dept. to conduct autopsy;
- Not clear what the group home staff told the hospital staff about the client’s PICA condition; May have been only late in the evening (after early morning hospital admission) and upon questioning about client’s abdominal scar that staff conveyed information about previous surgery related to PICA; conflicting statements
- Region issued a rubber glove advisory – cautions people about disposal of rubber gloves and other inedibles-- went out to all regions/providers
- A more comprehensive PICA advisory was sent out to South Central region only; only after OPA questions why the guidance wasn’t sent to all regions/providers is that corrected;
- Probably should have been a reminder about incident reporting. The incident of PICA week before client’s death not reported on CAMRIS; not clear if Day Program wrote the incident to residential program and they did not report

Demographics

Age: **52** MR Level: **Severe** # Meds: **11** # Diagnoses **9** Public/Private Home: **Private**

Cause of Death: *Cardiac arrest after aspiration*

Events Leading to Death

- Hospitalized with pneumonia about 2 weeks before death
- Returned to group home with antibiotic
- A few days before death nursing notes indicate client increasing sleepy; poor facial muscle tone; can't keep eyes open or support head;
- Two days before death client being fed; choked on milk and began to wheeze
- Staff performed Heimlich and CPR; 9-1-1 called; transported to ER
- Revived and put on ventilator; admitted to ICU
- Dopamine started but client essentially brain-dead;
- Discussion between family and MD; Dopamine discontinued but remained on ventilator;
- Died a few hours later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation		X	State Mortality Review	x		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional Mortality Review indicates that because of Alzheimer's and choking, probably should have had an occupational therapist with a special focus on eating (swallowing problems) evaluate client.
- Noted that a habilitation specialist was following client re: mealtime procedures
- State mortality review agreed with local findings

Program Review Committee Staff Comments

- Client's deterioration was noted
- Had a medical consult with a pulmonologist about 18 months prior to death and notes airway disease and recurrent pneumonia but does not recommend a swallowing evaluation
- Had a psychiatric consult a few months before death – about sleeplessness—Melatonin for a while but no help
- Committee staff noted client had eating guidelines in record but they did not indicate who developed them or when developed, and made house manager responsible for implementing them
- About a month before death Day Program indicates client is deteriorating – uncoordinated, agitated; confused, hallucinating and can't eat or drink by himself; but does not appear client's IDT met to address this rapid decline and whether placement remained appropriate
- Committee staff could not locate information on this client in the department's CAMRIS system

Demographics

Age: **62** MR Level: **Moderate** # Meds: **4** # Diagnoses: **8** Public/Private Home: **Private**

Cause of Death: 2nd and 3rd degree burns due to scalding bath water

Events Leading to Death:

- Client had been in the home 9 years
- At the time the home had 13 residents and 2 staff people were on duty
- Clients were quite high-functioning; this client always ran and took her own bath
- The client always took her bath downstairs; this particular day the client ran her bath upstairs
- Another resident went upstairs and called down that client was yelling from the bathroom
- Staff found her in the tub – water still running – client was vocal and breathing
- Staff called for help from others in house; lifted client out of the tub
- 9-1-1 called; Police arrived and instructed staff to apply cold wet towels.
- EMTs arrived and applied gel sheets; transported to local hospital
- After assessment at local hospital, transferred to downstate Hospital burn unit
- Developed hypertension and cardiac status failed
- DNR put in place by sister/guardian; died one day later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional Mortality Review determined the incident “an unfortunate accident”
- Regional mortality review concludes when a licensing waiver is issued should be reviewed annually
- State mortality review agrees with local findings
- Also finds that DMR and group home were not aware of the DNR put in place by sister
- State mortality review sent letter to inform doctor in case of DMR’s policy relative to DNR orders
- Regional DMR staff conducted investigation
- The investigation found no neglect

Program Review Committee Staff Comments

- The police came to the scene but apparently there was no police investigation
- No mention was made in any of the investigation results or mortality review results that the house had 13 residents and 2 staff on duty. This was the staffing pattern in the home’s licensing file at that time with DMR
- Since 1992, the number of residents in this home has gradually decreased (home now licensed for six). Discussion with DMR indicates there was a plan in place to reduce the number of clients in the home even before death,
- From committee staff’s review of the licensing file, it is unclear if all of the residential number reductions were prompted by DMR or by the private provider (at least some of the most recent reductions were required by DMR)
- The licensing waiver – on hot water temp – was first allowed in 1986 by then Director of Quality Assurance
- Reapplied and granted the waiver in 1990 – no date given for expiration. Licensing inspection (6 months before death) cited for temp of 150 (should be 120). No action taken because of waiver.
- State mortality review appears more focused on DNR and not being notified – than cause of the death and prevention
- Some time after death the home was investigated – because of other allegations including sexual activity—and put on more intensive monitoring
- Quality Assurance sent out information on hot water and burn dangers

Demographics

Age: 39 MR Level: **Profound** # Meds: 4 # Diagnoses: 8 Public/Private Home: **Public**

Cause of Death: *Respiratory failure due to adult respiratory distress syndrome*

Events Leading to Death

- Client had lived in home for 2 years
- Client had many health problems including cerebral palsy, had had 2 spinal fusions; respiratory problems, spastic bladder; and intermittent pressure sores;
- Requires total nursing care;
- Client had developed headcold symptoms; treated at home
- Sent to ER – temp 101.6
- Client intubated and improved temporarily, but developed septic shock
- DNR order put in place day before he died
- Family did not wish autopsy

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional Mortality Review had no findings but due to high profile of this DMR home – several other deaths occurred there – it was referred to State Mortality Review
- State Mortality Review agreed with local findings

Program Review Committee Staff Comments

- Had been an allegation of physical abuse – related to giving client a cold shower and spraying water in client’s face several months prior to death. Had been a “special concern” but was raised to level of investigation when staff called Office of Protection and Advocacy. Not clear whether DMR intended to handle this internally before OPA was called.
- The allegation of abuse was not substantiated by DMR
- OPA disagreed with DMR’s finding, did its own investigation and stated neglect substantiated
- The staff who made the allegation was later terminated (not clear why).
- The same former staff person, through attorney, made a neglect charge after the client died. It was related to the same cold shower incident, but the charge also stated the incident had contributed to the client’s death. Allegation was investigated by DMR and OPA separately, and not substantiated.
- Neither the regional or state mortality review file documentation mention either A/N allegations or findings. Neither considered, even though both would have been available during the review.
- DMR staff probably should have been reminded how any allegation of neglect/abuse needs to be reported immediately

Demographics

Age: **36** MR Level: **Profound** # Meds:**11** # Diagnoses: **9** Public/Private Home: **Public**

Cause of Death: 1) Septicemia; 2) Small bowel obstruction

Events Leading to Death

- Client lived in this home about 10 months
- Client very medically involved – had a g-tube—and required round the clock nursing services
- Client also had direct and consultative physical therapy services
- Had several prior hospitalizations prior to death, mostly for pneumonia
- Hospitalized for 8 days 1 month prior to death with gram negative pneumonia
- Discharged from hospital – condition had improved – but prognosis guarded
- Developed diarrhea with increasing fever
- Admitted to hospital with hyperthermia; had x-rays of abdomen and surgical consult
- Had exploratory laparoscopic surgery and found bowel obstruction; surgery to remove
- 1st surgery -- abdomen still distended, no bowel sounds --not successful, given morphine for pain
- 2nd surgery—placed on ventilator—condition continued to deteriorate for 4 days
- Doctor speaks w/family and client taken off ventilator
- Client dies hours later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review		X	Other Enforcement Actions Recommended		X
A/N Investigation		x	State Mortality Review	x		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality found overall health care to be excellent
- Communication with guardian a concern – group home did not have an accurate phone number
- Guardian not aware of hospitalization until 2 days after admitted
- Found hospital care to be aggressive and appropriate to DMR
- Regional directive sent to DMR homes to remind staff of responsibilities in calling family/guardian in medical situations

Program Review Committee Staff Comments

- Does not appear there was a DNR in place, even though client taken off ventilator with comfort measures only
- Does not seem to be addressed by either mortality review
- Not sure if notice was sent to private homes as well on the responsibility to call family and guardians

Demographics

Age: **56** MR Level: **Severe** # Meds: **9** # Diagnoses: **16** Public/Private Home: **Public**

Cause of Death: Sepsis; Pneumonia; and Chronic Obstructive Pulmonary Disease

Events Leading to Death

- Client had lived at this home for two years
- Client was very medically involved – had many hospitalizations in two years prior to death for aspiration pneumonia
- Had been on life supports with prior hospitalizations
- At 9:30 a.m. LPN notes facial edema (swelling) and wheezing
- Staff called doctor; said notify if respiratory distress increases
- By evening, doctor called again—doctor told staff to bring to hospital
- Ambulance called – transport to hospital
- Client has high temp – 103 – and is intubated at hospital
- Client has no pulse –atropine administered – pulse not regained. Client pronounced dead

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X	Guardian	Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality finds care appropriate – states client lived beyond life expectancy given medical problems
- Had a DNR one year prior – in hospital and on life support-- but that DNR had been removed
- Region recommends to close case
- State mortality review examines case, despite being closed at region

Program Review Committee Staff Comments

- Not sure why this case was selected for story in Hartford Courant except this client lived at home where a number of the deaths had occurred

Demographics

Age: **65** MR Level: **Mild** # Meds: **1** # Diagnoses: **1** Public/Private Home: **Public**

Cause of death: *Acute subdural hematoma*

Events Leading to Death

- Client lived in group home for six years
- Had Parkinson's disease
- Few months prior to death taken to hospital ER by ambulance; client had slurred speech and confusion
- Client had increasing falls – one fall resulted in fractured ribs
- Many incident reports related to falls
- A few days prior to death fell and had a nosebleed
- Day before death fell away from home but was able to walk back home with assistance
- Day of death staff noticed a facial droop and slurred speech.
- Client taken by ambulance to ER – client admitted
- Client continues to deteriorate – CT scan reveals subdural hemotoma w/pressure on brainstem
- Discussions with family, client “virtually brain dead”; decide on no surgical intervention, put DNR in place
- Died 4 days later

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional Mortality Review finds – given Parkinson's and increasing falls—should have been seen by a neurologist
- Regional mortality recommends better monitoring/tracking of falls for clients in region
- Due to falls 3-4 days before death –should have had an ER/neurological evaluation
- State mortality review agrees that a neuro-evaluation should have been done
- State mortality review states regional Health services director to submit a regional process for risk assessment and tracking of falls

Program Review Committee Staff Comments

- Region states, in response to committee staff inquiry, that the proposal of a tracking system was brought to “treatment team” and it was decided it would not be appropriate for a majority of clients and that it could be addressed on a case-by-case basis in quarterly nursing assessments. (Committee staff thinks that would have been the system that would have been in place at the time of the client's incidents and death – not sure what the change would be)
- Not clear from the file what the client's IDT knew about client's increasing falls and how this was addressed in plan.
- DMR indicates in write-up that only minor injuries were sustained in client's prior falls –yet one resulted in fractured ribs
- DMR has instituted a new risk assessment procedure which will evaluate a client's mobility, this may address issue of clients with increasing falls

Demographics

Age: **42** MR Level: **Severe** # Meds: **6** # Diagnoses: **5** Public/Private Home: **Private**

Cause of Death: 1) Respiratory failure; 2)Aspiration 3) Hypotrenia

Events Leading to Death

- Client had lived in home for 3 years;
- Client very medically involved – blind, seizure disorder, incontinent, chronic edema, and difficulty swallowing
- Client taking a diuretic for edema
- Client had eating guidelines;
- Client had change in mental status following a seizure
- Taken to internists then brought to ER
- Client admitted – with acute renal failure, UTI, hypotrenia
- Endotracheal tube, gastric tube and foley catheter inserted
- Seemed to be doing ok, diet planned and meds changed
- Client began vomiting, deteriorated; client moved at to ICU CPR initiated twice and revived
- Third time unsuccessful – client expired

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X*		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Death report indicates hospital autopsy performed
- Regional mortality review cites should have been better communication between group home staff and hospital especially around choking
- State mortality review indicates might have been good to measure fluid intake and output, but because of client’s incontinence this would have been impossible
- Cites a problem with hospital transcription – one place “hypertrenia” and in another “hypotrenia”

Program Review Committee Staff Comments

- Not clear whether client had a choking episode in hospital
- Not sure where Hartford Courant obtained cause of death –different cause of death than committee staff saw on any document in file
- Communication issue – DMR not notified of hospitalization
- Regional mortality review to send letter to private agency regarding communication—staff to hospital, staff to DMR, saw no letter in file;
- Not clear whether autopsy done – death report indicates yes, RMRC indicates none; none in file

Demographics

Age: **36** MR Level: **Mild** # Meds: **DK** # Diagnoses: **2** Public/Private Home: **Private**

Cause of Death: *Asphyxiation by Submersion*

Events Leading to Death

- Client had lived at CLA for 15 years. The client was taking a bath one afternoon in the attendance of a direct care staff person. The staff person left the client unattended in the bathtub while the staff person went to find a towel. While unattended, the client, who had a known seizure disorder, had a seizure and drowned.
- The client was found submerged by the staff person, who administered CPR and told another resident to call 911. 911 responded
- When the death occurred, there was only the one staff person on duty, with a total of six residents.
- The client's individual plan indicated client was not to be left alone in the bathroom, and the staff person had been trained and was aware of that requirement.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended	X	
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation	X	

Post Death Actions: Results/Outcomes

- Abuse/neglect investigation conducted by provider, found the staff person had committed neglect by leaving the client unattended in the bathtub. Staff acted contrary to training without good cause. Recommended provider decide about continued employment of staff person, and that bathing protocols should be reviewed with all staff.
- Local police investigation led to staff person's arrest for second degree manslaughter, and ultimate conviction.
- DMR Safety Alert issued two days after client's death to all DMR and Private Agency Directors on Bathing and Personal Care (Three weeks before, another person drowned unattended in a bathtub at another CLA). Required immediate review of agency protocols and individual procedures, including staff training, to ensure individual needs/supports during personal care are met, including bathing. Documentation was required to be sent to DMR within nine days.
- OPA agreed with neglect finding; sought evidence of follow-up to safety alert.
- Regional Mortality Review found supervision inappropriate; "found" 1:6 staff/client ratio, and that staff recently decreased to 1 on Sundays; was aware police investigation ongoing.
- State Mortality Review Board agreed with abuse/neglect investigation report recommendations.
- DMR Root Cause Analysis led to many systemic recommendations, including Risk Screening Assessment

Program Review Committee Staff Comments

- Clear staff should not have started bath in first place, but some other emergency could have come up unduly distracting one staff, creating risk for client. Local police report noted client's parents, who were very involved with their child, had an understanding with the provider that at least two staff would be on duty at all times due to their child's medical issues.
- Issue of past staff problems

Demographics

Age: **63** MR Level: **Mild** # Meds: **7** # Diagnoses: **10** Public/Private Home: **Private**

Cause of Death: 1) *Hypoxic encephalopathy with survival in coma*; 2) *airway obstruction*; 3) *aspiration of food*

Events Leading to Death

- Client lived at home for three years
- Client was at day program away from her group home and choked while eating a sandwich for lunch.
- Staff tried Heimlich and called 911.
- Client died next day at hospital.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review concerned that sandwich client was eating not consistent with her mechanically ground diet order; residential notes not comprehensive; day staff responded appropriately, but regional committee not sure Heimlich done correctly; Referred for state level review
- State Mortality Review Board noted diet orders not clear; use by hospital of “mechanical soft” versus “ground” consistency
 - Requested CLA provider to send policies and procedures regarding dysphasia policy and general handling of dietary needs; explain earlier removal of feeding tube a year earlier.
 - Accepted response (see below), but diet consistency definitions remained. Noted DMR Nutrition Workgroup working on diet definitions
- Provider responded to state mortality review board noting client’s diet was consistently ordered as “mechanical soft”, and ham and cheese sandwich could be consistent with “mechanical soft”. Client never diagnosed with dysphagia. A feeding tube had been in for specific period of time after client had stroke, but determination was made client could return to eating on own.

Program Review Committee Staff Comments

- In provider’s documentation, “mechanical soft is used for clients who can swallow without difficulty but have problems chewing. All foods must be able to be fork mashed.”
- Case revealed issues with common food consistency definitions.

Demographics

Age: **32** MR Level: **Profound** # Meds: **4** # Diagnoses: **5** Public/Private Home: **Public**

Cause of Death: 1) *Seizure Disorder*; 2) *Obstruction of splenic flexure of colon*

Events Leading to Death

- Client had lived at home for three years before his death; client was in good health, with his biggest concerns being behavioral, including self-injurious behavior.
- In the early morning hours of the day client died, client was awake, hyperactive, and very vocal. Around noon that day, he refused lunch, was thrashing on floor with helmet on, and took Tylenol for discomfort. A nurse was notified
- Later in afternoon client's stomach was very distended; client ate nothing for dinner, and appeared uncomfortable.
- The nurse assigned to the home (CNC) was called, but not at home. CLA staff called DMR nurse at the regional center, who advised over the phone to give client a fleet enema.
- In early evening client went into seizure. Regional center nurse called again, who told staff to call 911. EMTs responded and took client to hospital; all care measures taken, but client died about an hour later.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		?
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review committee found overall health care management excellent; but client's behavior was clearly escalated and signs and symptoms significant, but CLA non-nursing staff not able to link what they saw to emergency situation until seizure, despite training in observational skills and emergency response
- Had systemic concern about nurses providing care instructions over the phone for clients they have not evaluated or do not know
- Recommended training for staff regarding GI implications for clients prone to GI problems; region and DMR central office should develop clear written directions and expectations for nurses who serve as non-nurse staff resources.
- State Mortality Review noted MD should have been called sooner; recommended region should issue advisory to act quicker in emergencies
- Systemic issue of nurses responding to telephone inquiries to be discussed with regional directors of health services

Program Review Committee Staff Comments

- A memo went to regional nursing staff soon after state review instructing nurse to be extremely conservative in their phone directions; if a nurse cannot assess a client, instructions should be limited to seeking evaluations. Non-nurse staff have authority to make necessary decisions.

Demographics

Age: **44** MR Level: **Profound** # Meds: **8** # Diagnoses: **13** Public/Private Home: **Public**

Cause of Death: 1) *Respiratory Failure*; 2) *Aspiration*

Events Leading to Death

- Client had just moved to public CLA five days before death, because it had 24 nursing care. He moved from a private CLA where he had live for 16 months. Before that, client had lived in a nursing home for 14 years.
- For year and half before death client was admitted several times to emergency room for many reasons, including pneumonia and seizures.
 - Client had feeding tube put in five months before death due to a positive test for aspiration.
- Three months before death, client's team discussed client's declining health and need for increased nursing services, which led to the transfer days before client's death.
- Two to three days after client's transfer, client became congested and had respiratory problems.
- 911 was called, client taken to hospital, treated with full code, but client died.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review found private CLA provided excellent care and recognized his need for increased nursing coverage, leading to transfer to public CLA with 24 hour nursing. Staff at that CLA responded quickly and appropriately the day client died.
- State Mortality Review Board accepted local findings; no further recommendations

Program Review Committee Staff Comments

- Unclear why this death was considered questionable by media.

Demographics

Age: **29** MR Level: **Profound** # Meds: **1** # Diagnoses: **6** Public/Private Home: **Public Regional Center**

Cause of Death: *Traumatic asphyxia due to exclusion of air*

Events Leading to Death

- Client had lived at regional center for 18 years.
- One night DMR staff put conditioner on client's hair, covered hair with a plastic bag tied at the back of head and put client to bed
- Client had limited use of arms
- About an hour after going to bed, client was found by staff with the bag over client's face, and was asphyxiated. Staff tried CPR, chest compression and mouth-to-mouth breathing. 911 was called, but client was dead on arrival at hospital.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation	X		Personnel Actions Recommended	X	
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		?
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed	X	
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Abuse/Neglect investigation conducted by DMR staff; found staff neglect was substantiated based on staff putting a plastic bag on client's head for overnight when she was unattended, and another staff for not coming to client's assistance immediately.
- Two persons were terminated, one suspended.
- The regional mortality review committee found problem with personal care leading to accidental death of traumatic asphyxia; found systemic issues: identified improper use of materials (plastic bag) in hair care; failure in supervisory judgment in allowing improper use of material; possible delay in provision of emergency resuscitation. Recommended memo from management to staff on safety/common sense issue of hair care; regional review of all hair care practices in all DMR operated facilities
- State mortality review committee accepted regional findings and investigation findings that substantiated neglect. Recommended DMR should consider sending statewide notification about need for caution when doing using/using head coverings appropriately
- OPA agreed with DMR investigation neglect substantiation
- State and local police investigation did not lead to arrest based on state's attorney determination there was no criminal liability or intent related to the death.
- Jury awarded \$1 million verdict in wrongful death case.

Program Review Committee Staff Comments

- Assigning director of regional center to investigate appears to be a conflict.

Demographics

Age: **49** MR Level: **Mild** # Meds: **5** # Diagnoses: **1** Public/Private Home: **Public**

Cause of Death: *Asphyxia due to airway obstruction*

Events Leading to Death

- Client had lived at his CLA for two years.
- Client was eating a peanut butter sandwich as a late night snack, prepared by a staff person.
- He began to choke on sandwich, staff did Heimlich and called 911.
- EMTs came, made efforts including a tracheotomy, but client died on way to hospital.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		?
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		?
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Injury/Unknown Origin investigation conducted by DMR; found no neglect; noted, though, client's episodes of choking/vomiting while eating not well documented in staff running notes and client's IDT never discussed issue, didn't set up data collection to monitor his aspiration risk with eating special eating program; also noted problems with documentation and staff ability to communicate at home because of separate apartment configuration.
- Recommended any resident determined to be at risk for aspiration be formally evaluated and a clearly defined dietary/feeding program established.
- Regional mortality review committee found medical and personal care prior to death timely and appropriate; but events leading up to death not accurately reflected/documentated in residential records; records indicate client was inappropriately placed in supervised apartment program and he did not have a program.
- State Mortality Board accepted regional findings and recommendations including investigation recommendations.
- OPA disagreed with DMR finding of no neglect and substantiated neglect by DMR for failing to generate feeding guidelines to maintain his health and safety based on evidence in DMR investigation

Program Review Committee Staff Comments

- DMR investigators didn't interview DMR staff until 6 days after incident.
- Question of programmatic neglect: attention to client's eating habits
- When OPA disagrees with DMR conclusion about neglect, unless DMR disputes the finding, OPA assumes its finding is the final disposition. DMR CAMRIS does not report OPA finding.
- Client had mental illness for which client took many medications, and was episodic. When stable, client could provide own basic life skills independently, although he had eating behaviors; when not, he required close supervision.

Demographics

Age: 55 MR Level: **Moderate** # Meds: 4 # Diagnoses: 6

Public/Private Home:
Private/Nursing Home

Cause of Death: 1) *Pneumonia*; 2) *Right Lower Lobe Lung Abscess*; 3) *Inhalation from dementia from Down Syndrome*

Events Leading to Death

- Client had been at nursing home for seven months. Before that, client had lived at a private group home for just three to four months after living at another home for three years.
- In the last 3-4 years, client, who had Down Syndrome, began to show signs of Alzheimer-like dementia. Client also began having significant pulmonary conditions, and there was discussion about surgery.
- Client's guardian did not authorize surgery due to problems with narcotics used for an earlier surgical procedure, which exacerbated her mental confusion. At the same time, a DNR was put in place with the consent of her guardian and after discussion with the DMR director of health services. Client then was moved to the nursing home.
- Seven months later, client was admitted to hospital and died a day later.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- The regional mortality review found death was anticipated; medical and personal care appropriate; no systemic issues identified.
- State Mortality Review Board accepted local findings; no further recommendation (did note that DNR form not included with MQAB packet, but knew that DMR was involved/aware of decision).

Program Review Committee Staff Comments

- Question why regional review done so long after death (2 years).
- Unclear why this would be considered questionable death by media.

Demographics

Age: **48** MR Level: **Severe** # Meds: **4** # Diagnoses: **9** Public/Private Home: **Private**

Cause of Death: *Asphyxia by Food Bolus*

Events Leading to Death

- Client had lived at home for seven years; he had habit of trying to get food he wasn't supposed to have, because of his diabetes. He had no teeth and was on a ground diet.
- One afternoon for about a 15 minute period, while all three staff were attending four other clients/activities in other parts of house, client took a raw pork chop from refrigerator, and attempted to eat it.
- Client choked and fell. Staff heard him fall, attempted the Heimlich maneuver, and called 911. At hospital, client remained unresponsive for three days, family requested DNR, and he died.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy		X	Regional Mortality Review	X		Other Enforcement Actions Recommended		?
A/N Investigation	X		State Mortality Review	X		Lawsuit Filed	X	
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Abuse/Neglect investigation conducted by DMR staff substantiated neglect on the part of the provider; provider failed to provide client with adequate care and supervision to ensure his safety, and direction to staff to provide adequate care and supervise all residents; provider failed to bring staff request to prevent access to food to Human Rights Committee in light of diabetic condition and risk of choking; recommended increased communication about and familiarity with client needs on the part of provider supervisor and staff be aware of their role in care of individual clients.
- Also recommended DMR develop process for case managers and contract monitors to work together in home oversight, more clearly define roles and systems to resolve problems, use a formal programmatic transition process when a home changes providers, give more detail about client needs in profiles in RFPs, and be careful grouping ambulatory persons with those needing greater levels of care.
- Regional Mortality Review found medical care appropriate; personal care was not (cites A/N investigation); recommend review by state mortality board.
- State Mortality Review closed case
- Wrongful death lawsuit filed and settled in 2002 for \$500,000.
- Changes provider made included clarifying procedure for staff to "hand off" client supervision; identify two specific clients for each shift that a staff person is responsible for; and more screening for choking. (Provider had had unwritten protocols for staff to know where client was, keep counters clear, cover things in the refrigerator.)

Program Review Committee Staff Comments

- It does not appear DMR required provider to respond to how it would address investigation findings.
- Program review staff could not determine how DMR responded to the recommendations directed toward the department.
- Although client had lived in home for several years with the same housemates, when the client died, the provider had run the home for a year and a half. According to the provider, the major concern about the client and his getting at food was because of his diabetic condition; a choking incident that occurred 10 years earlier before the client moved to the home was not mentioned in any material the provider saw prior to taking over the home or after. In the months before client's death, there were episodes of food stealing, although the record as to how client's IDT or the provider was addressing the behavior is unclear, but looks minimal. Also unclear was if and how the possibility of locking the refrigerator was considered as a solution to promote client's safety, given the differences in mobility and need for assistance among house members.

Demographics

Age: **38** MR Level: **Mild** # Meds: **4** # Diagnoses: **2** Public/Private Home: **Private**

Cause of Death: *Cardiac Arrest; Acute haloperidol toxicity*

Events Leading to Death

- Client had lived at CLA for seven years.
- Client had mental illness, took medications for it, and had been hospitalized in past. A couple of weeks before death, client had increased behavioral symptoms and was admitted to a hospital psychiatric unit under client's psychiatrist's direction.
- A few days after admission, client was transferred to another hospital's psychiatric unit. Behaviors did not improve and medications increased and new ones added.
- Eight days later, client was found unresponsive, no pulse and no breathing. Full code was called, but no cardiac activity seen; pronounced dead.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X*		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation	X	

* restricted by family-could not do brain.

Post Death Actions: Results/Outcomes

- Regional Mortality Review found psychiatric care at hospital of concern; numerous changes of medication; use of medications on an as needed basis; concern about unresponsiveness of hospital staff to group home staff's concern about client appearing overmedicated. Sent to state level review
- State Mortality Review concerned about care, especially the use of Haldol on an as-needed basis; questioned hospital use of restraints; sought expert opinion from independent psychiatrist on medication question and then referred question of care to Department of Public Health for its review.
- Expert noted limitations of review due to limited autopsy consent by family; could not examine central nervous system; raised questions about documentation of medication use and its effects, along with levels, but could not clearly read M.D. notes so couldn't make definitive conclusion; client pre-death blood lab report was not available to expert.
- State mortality review referred case to DPH
- DPH found regulatory violations related to documentation of medication use.

Program Review Committee Staff Comments

- Final determination was that level of Haldol in blood was within therapeutic levels, thus no toxicity

Demographics

Age: **68** MR Level: **Moderate** # Meds: **DK** # Diagnoses: **DK** Public/Private Home: **Public**

Cause of Death: *Cardiopulmonary arrest due to subdural hematoma*

Events Leading to Death

- Client had lived at CLA for four years, and was moved to a nursing home less than two weeks before client died
- Move was due to inability to perform self-care skills independently, increased confusion, stubbornness, and forgetfulness, impaired balance and falls, and onset of dementia (possibly Alzheimer's, related to Down Syndrome).
- Admitted to hospital four days before death due to increasing unresponsiveness and congestion requiring suction; CAT scan of head revealed subdural hematoma
- Guardian/family did not consent to proposed surgery.
- Day before death DNR was obtained with consent of family because outlook not good; not responsive; very congested

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		?
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation		X

Post Death Actions: Results/Outcomes

- Regional mortality review answered “unknown” to question of whether medical/personal care was timely and appropriate; questioned if hematoma caused by fall, noting no recent fall recorded in records; noted if had a fall, with a head injury, it should have been evaluated at hospital immediately; outcome might have been different with timely treatment; wondered why CAT scan ordered
- State Mortality Review found care appropriate; case closed

Program Review Committee Staff Comments

- Client was admitted to hospital from group home for evaluation because client's caregivers believed he was no longer safe in a group home, according to hospital discharge summary
 - Cannot tell from state review report what if any discussion there was about issue of possible fall as the cause of the subdural hematoma
- Query if the regional review committee attempted to answer the fall question it raised
- Unclear how state mortality review board addressed hematoma question

Demographics

Age: **33** MR Level: **Profound** # Meds: **DK** # Diagnoses: **10** Public/Private Home: **Public**

Cause of Death: 1) Cardiopulmonary Arrest; 2) Chronic Obstructive Pulmonary Disease; 3) Recurrent aspiration pneumonia

Events Leading to Death

- Client had lived at the group home for six weeks, moving from MTS where he had lived for 27 years. He had used a feeding tube for 11 years for all his nutrition and medication.
- In month before client died, he had increased seizure activities, elevated temperatures, and respiratory problems.
- Client was admitted to the hospital by client’s primary care physician’s order to treat the respiratory ailment that was not responding to outpatient care. Two days after admission, the client had a cardiac arrest, was resuscitated, and sent to intensive care. There he had a multi-system failure, a DNR order was put in place, and he died after four days in hospital.

Post Death Actions

	Yes	No		Yes	No		Yes	No
Family Contacted	X		Police Investigation		X	Personnel Actions Recommended		X
Autopsy	X		Regional Mortality Review	X		Other Enforcement Actions Recommended		X
A/N Investigation		X	State Mortality Review	X		Lawsuit Filed		X
						DPH Investigation	X	

Post Death Actions: Results/Outcomes

- Regional Mortality Review found care was appropriate and nursing care at MTS and at home was loving, supportive, and probably contribute to client living as long as client did; found systemic issue that guardianship should have been pursued several years ago with a client this frail, and funeral planning should occur as part of OPS process
- State Mortality Review Board accepted local findings
- The autopsy found no single cause of death, but pointed to multi-system failure.

Program Review Committee Staff Comments

- Client’s terminal condition was discussed with the Office of Attorney General and OPA. Probate Court appointed guardian while client was in hospital
- Unclear why death would be considered questionable by media

Appendix J: Licensing and Inspections

CLA Licensing Inspection Analysis

- Two automated databases exist in the licensing unit offering comprehensive licensing and inspection information for potential management analysis.
- Information outlining several key dates in the inspection process, however, is not updated on a regular basis in either database. As a result, committee staff was only able to analyze inspection process date information for 125 public home inspections and 592 private homes, occurring in calendar years 2000 and 2001, rather than current information for FY 02. Information about providers' plans of correction for rectifying licensing deficiencies is also scant. Regardless, the data available offer a relatively good point-in-time snapshot of the CLA inspection process.
- A separate licensing database, outlining such areas as inspection citations, is more current and includes fiscal year data through FY 02.

Inspection Process -- Public v. Private

- Table J-1 offers a comparison of licensing inspection information between public and private homes covering calendar years 2000 and 2001. State regulations call for CLA licenses to be renewed every year and inspections to occur every two years based on the license expiration date.
- A full two-thirds of public homes were inspected after the license expiration date; the rate for private homes was almost 40 percent.
 - Inspections for half the public homes analyzed occurred at least 12 days *after* the license expiration date and seven days *after* the same date for private homes.
 - Of the public homes with late inspections, 75 percent occurred within 36 days of the license expiration date, compared with 51 days for private homes. The longest delay for a licensing inspection was just under three months for public homes, and just under four months for private homes.

**Table J-1. Public and Private Community Living Arrangements
Licensing Information -- Calendar Years 2000 and 2001**

	Public CLAs (n=130)	Private CLAs (n=592)
Inspections occurring after due date	66% (n=125)	37% (n=568)
Median time from inspection due date to actual inspection	12 days <i>after</i> inspection due date (n=125)	7 days <i>after</i> inspection due date (n=568)
Median time from inspection conclusion to when Statement of Citations was issued to provider (this process includes report development by the inspector and review by the unit supervisor)	22 Days (n=110)	20 Days (n=525)
Median time from Statement of Citations sent to provider to when Plan of Correction received by DMR licensing unit	50 Days (n=106)	28 Days (n=512)
Initial Plan of Correction accepted by licensing unit following inspection on first review	98% (n=102)	97% (n=525)
Source of Data: LPR&IC Staff Analysis of DMR Licensing Database Information.		

- Once an inspection is concluded a “Statement of Citations” (SOCs) is sent to the provider. This process includes the inspector developing the report, forwarding it to the licensing supervisor for review, and sending the report to the provider. This process was consistent for public and private homes, with half the SOC’s being sent to the provider more than three weeks after the inspection. State regulations call for such reports to be sent within 15 working days of the inspection.
- A key component of the licensing process is a provider completing a “Plan of Correction” (POC) if deficiencies are found during an inspection. Complete POC information is not formally tracked by the DMR licensing unit in its automated database. The database only tracks the date when the POC was returned by the provider to DMR. Providers have 15 working days from receipt of the statement of citations to submit a plan of correction to DMR.

- Analysis shows half of the POCs from public providers were submitted within 50 days of being sent by DMR, which is almost twice as long as private providers at 28 days. State regulations call for the provider to submit its plan of correction within 15 working days after receiving the citation summary. Although the date the provider receives a statement of citations is not formally tracked, it is doubtful the delay in submitting plans of correction to DMR is due to circumstances outside the provider's control.
- Almost all the plans of correction were accepted by the licensing unit on the initial submittal without the provider having to resubmit a modified POC – 98 percent for public homes and 97 percent for private providers. The unit accepts the plans based on the document submitted by the provider. Until recently, very little on-site follow-up by the licensing unit was conducted to ensure the plans were implemented. The committee was told limited personnel resources made it difficult to do on-site follow-up.
- A new process whereby plans of correction are monitored through on-site visits by DMR was implemented this year. The process uses a three-fold approach, including:
 - licensing inspectors now conduct on-site visits for all inspections resulting in immediate health or safety citations as determined by the licensing unit;
 - inspectors conduct two unannounced follow-up visits per month to ensure providers' recently submitted plans of correction are implemented; and
 - contract monitors use their routine site visits (conducted several times a year per provider) to follow-up on providers' plans of correction resulting from a recent licensing inspection – this decentralized approach has coordination and logistic issues given the monitors are regionally-based and not trained on licensing regulations.

(The program review committee recommends several changes in the process – see full report.)

- Although automated licensing information exists, DMR is not consistently using the information for management analysis purposes. No management reports examining the licensing function from a broad perspective are developed on a consistent basis. Any reports using the licensing data are created on an ad-hoc basis.

Regulation Citations

- Committee staff analyzed the automated licensing database to compare the types of regulations cited during licensing inspections between public and private providers. This was done as another way to gauge whether DMR is applying the same oversight standards among public and private homes during its licensing inspection process.
- Table J-2 shows the top five regulatory categories most frequently cited during licensing inspections for public and private homes for FYs 00-02. There were no differences among public and private homes in the top five regulatory categories cited – each sector had the same top five categories cited for the period analyzed. Note: the regulatory categories in the table encompass a broad range of areas where inspectors can cite providers as being deficient. Specific licensing citations (e.g. excessive water temperature) are made within the context of a broader regulatory category.

Table J-2. Top five regulatory categories most frequently cited as deficiencies during licensing inspections of public and private community living arrangements – FYs 00-02.	
Conn. Regs. Sec. 17a-227-11d	Hazard Prevention – the residence and grounds shall be free from unpleasant odors, refuse, and potential safety hazards
11e	Furnishing Good Repair – Furniture and furnishings shall be safe and in good repair
12b	Emergency Response Training/Monthly Fire Drills – the licensee shall provide training for direct contact personnel and individuals being served on how to respond in case of fire and other life threatening situations and shall carry out monthly evacuation drills
17h	Overall Plan of Services Review and Update Timeliness – The overall plan of services, including goals and objectives, shall be reviewed and updated, at a minimum, on a quarterly basis to meet ongoing individual needs
18a(1)	Medication Administration Regulations – Each residence shall comply with C.G.S. Secs. 20-14h to 20-14j and the regulations pertaining to the administration of medication
Source: Program review committee staff analysis of DMR licensing inspection data.	

Service and Systems Enhancement

- The Service and Systems Enhancement unit exists within the Quality Assurance Division “to examine services and systems through outcome-based measurement processes in order to elicit actions that positively affect people with mental retardation.”
- The unit consists of four facilities inspectors (including a nurse), two nurse coordinators, and one supervisor.
- In 1998, DMR required the Quality Assurance Division to replace the previous individual professional review/utilization review process (IPR/UR) with a new process called “quality reviews.” The IPR/UR process was conducted by DMR for Intermediate Care Facilities for Mentally Retarded in response to federal Medicaid requirements. The reviews were used to help ensure clients were properly placed and receiving appropriate services.
- When DMR eliminated its ICFs/MR in the community by changing them to Home and Community Based Waiver sites, the federal requirement for the IPR/UR review was also eliminated. The federal reimbursement for that type of review is no longer available.
- The current quality review process focuses primarily on clients at DMR regional centers. Several reviews of individuals at day programs and respite centers also take place.
- In FY 01, the unit conducted 34 reviews involving 188 clients. Table J-3 shows the distribution of reviews. The reviews covered various areas of a client’s program and residence. The table shows close to 80 percent of all individuals reviewed by the Service and Systems Enhancement unit inspectors resided in DMR’s regional centers, which are designated ICFs/MR.

Table J-3. Service and Systems Enhancement Unit Activity – FY 01.		
Type of Facility Reviewed	Reviews Conducted	Individuals Reviewed
Residential Units at DMR Centers	24	147
Family Respite Centers	5	20
Community Living Arrangements	5	21
Day Service Sites	71	N/A
Source: DMR “Quest for Excellence – Annual Report 2001.”		

- The process uses formalized guidelines to evaluate client safety and health, rights and protections, and individual supports and services. A sample of half the facility's residents is chosen for review. All reviews are announced. The reviews result in a multi-page narrative "on the status and outcomes for individual and service system findings." A voluntary feedback questionnaire is also given to providers.
- The quality review process does not produce a statement of deficiencies following a review, and no corrective action plans are required from providers. The reports are sent to DMR regional managers for "consideration in enhancing quality of services." There is no formal implementation process of the outcomes of the quality reviews conducted by the Service and Systems unit.
- The Department of Public Health currently conducts health and safety inspections of DMR's ICFs/MR facilities, including regional centers. The reviews are conducted by a team of DPH inspectors over the course of several days and follow a scripted process. Inspection reports outlining deficiencies are sent to the provider, with summaries sent to the DMR central office. The provider is required to submit a plan of correction to DPH and is responsible for implementing the corrective actions outlined in the plan.
- The committee believes the "quality review" process duplicates the effort of DPH's formal inspections of ICF residences, namely regional centers and Southbury Training School. The DMR process does not result in concrete, measurable outcomes, given no citations are issued or plans of correction developed.
- The program review committee believes the health and safety of DMR's clients would be better served if the inspectors from the department's SSE unit were integrated with the licensing and inspection unit within the Division of Quality Assurance. More inspectors would then be available to the licensing unit to help ensure the health and safety of clients living in community living arrangements. Making the transfer would provide the necessary staff resources to the licensing unit to conduct on-site follow-up visits to observe whether providers are fully implementing their plans of correction – a process not currently done by the unit for every plan of correction. The transfer would not affect the department's requirement to continuing auditing Southbury Training School as mandated.

Other Considerations

- The program review committee also considered moving the licensing and inspection function to the Department of Public Health with attendant staff. DPH is responsible for inspecting the ICFs/MR for federal certification under Medicare/Medicaid, as described above. Given the enhancements to the licensing and inspection function recommended by the committee in the full report, such a move was not considered necessary at this time.

Appendix K: DMR Caseloads and Comparative Substantiation Rates with Private Provider Investigations

Current Caseloads

Table K-1 below shows the current caseloads for the DMR lead investigators, including the number of pool investigations supervised by the leads. The pool investigations are conducted by DMR employees with full-time responsibilities in other areas of DMR operations.

While some of the cases noted below may involve private providers, the bulk of those investigations are handled by private agencies themselves and are not accounted for in the table. DMR reports that since May 2000, approximately 31 private provider cases have been taken over by DMR.

Table K-1. Current Caseloads for DMR Division of Investigations Lead Investigators (12/9/02)		
Region	Number of Cases Assigned to Lead Investigator	Number of Pool Investigations Supervised by Lead
Eastern	4	17
North Central	4	11
Northwest	2	31
South Central	8	22
Southwest*	1	45
* In the Southwest Region, the lead investigator supervises all cases, both public and private.		

Substantiation Rates

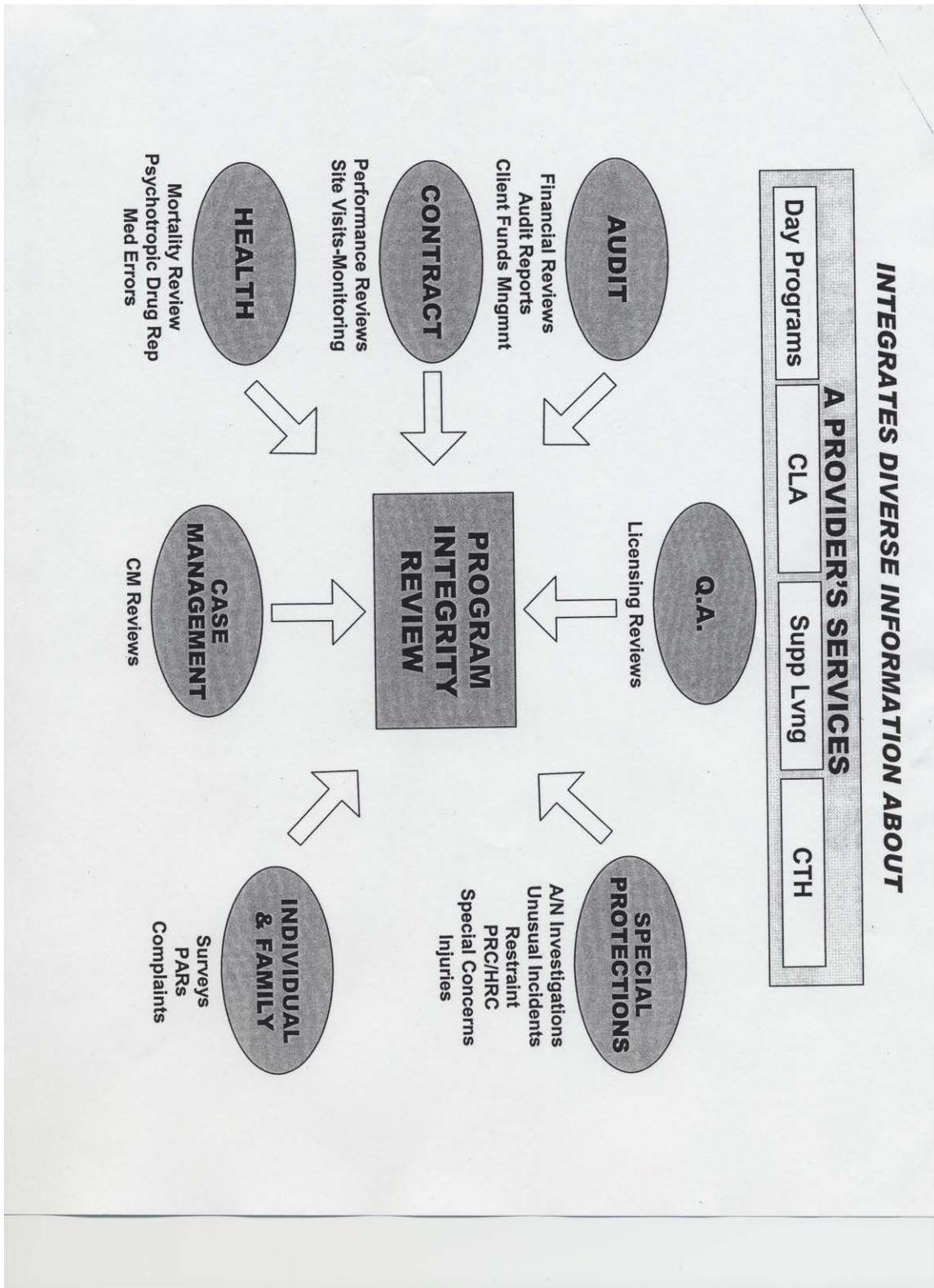
Table K-2 shows, for a three-year period, the substantiation rates for DMR and private providers when they are primary investigators. The differences raise questions about the similarity of the investigations between the private and public investigations, bolstering the concern that DMR client abuse/neglect issues are treated differently solely based on where the clients live. For the years shown in the table, in neglect cases, private provider investigations tend to substantiate neglect more than DMR investigations. For physical abuse cases, in FY 2000, the rates were similar, but not so in 2001, when DMR found physical abuse more often than the private providers.

Table K-2. Abuse/Neglect Substantiation Rates by Primary Investigating Agency and Type of Allegation: Fys 2000-2002

OUTCOMES	DMR 2000	PRO 2000		DMR 2001	PRO 2001		DMR 2002	PRO 2002
No Neglect	52%	47%		56%	45%		47%	45%
Yes Neglect	46%	51%		42%	54%		40%	44%
No Information	2%	2%		2%	2%		13%	11%
No Physical Abuse	80%	78%		73%	81%		73%	66%
Yes Physical Abuse	20%	20%		25%	17%		9%	23%
No Information	0%	2%		1%	2%		17%	10%
NO Injury of Unknown Origin A/N	93%	86%		93%	82%		84%	80%
YES Injury of Unknown Origin A/N	7%	14%		7%	14%		1%	10%
No Information	0%	0%		0%	3%		15%	10%
NO Sex Abuse	100%	86%		60%	82%		43%	87%
YES Sex Abuse	0%	9%		30%	18%		29%	7%
No Information	0%	5%		10%	0%		28%	7%
NO Verbal Abuse	69%	49%		67%	68%		65%	49%
YES Verbal Abuse	28%	47%		33%	30%		29%	30%
No Information	3%	4%		0%	2%		6%	21%
No Psychological Abuse	43%	78%		78%	100%		100%	60%
Yes Psychological Abuse	57%	20%		22%	0%		0%	40%
No Information	0%	2%		0%	0%		0%	0%

DMR=Department of Mental Retardation
 PRO=Private Provider
 Source: DMR CAMRIS

Appendix L: Program Integrity Format



Source: DMR

Sample Program Integrity Tracking System

Agency	Review Date	Issue Area	Issue	Recommendation	Action	Date Completed
Agency X	8/15/02	Physical Plant	Poor maintenance at selected homes	<ol style="list-style-type: none"> 1. Increased monitoring for CLAs 2. Performance objectives in contract for FY 03 	<p>Monthly Site Visits Scheduled by SC and NW</p> <p>FY 03 Contract Includes Performance Objectives re: Maintenance</p>	<p>9/1/02</p> <p>9/1/02</p>
		Training	No CPR certification at one home	<ol style="list-style-type: none"> 1. Expedite CPR certificate for staff in Daniel CT 	3 staff obtained CPR certification	9/1/02
		Safety	No protocol for bedrail use	<ol style="list-style-type: none"> 1. Immediate development of agency procedure 	Protocol implemented and approved by SC and NW regions	8/15/02
Agency C	9/1/02	Training	<p>Med cert outdated for 4 staff</p> <p>NET not completed for 2 staff</p>	<ol style="list-style-type: none"> 1. Performance objectives for FY03 	Contract monitor	9/15/02
		PRC & HRC	Emergency restraint	Review reporting responsibilities with Ex. Director	Meeting scheduled	
		Health & clinical services	<p>Nurses not supporting G-tube feedings</p> <p>Med error rate high in 3 homes</p>	<p>Review nursing responsibilities w/ Exec. Director</p> <p>Monitor med records on site visits</p>	Monitoring instructions developed	
Source: DMR						

Appendix M: Regulatory Component Benchmarks

Financial/Audits

- Provider has submitted all required audits in a timely fashion
- DMR audit indicates the provider is financially sound
- The provider's administrative and general expense ratio is 15 percent or less
- The provider's audit submissions offer complete disclosure that enable DMR to track where payments are being spent

Staffing

- Provider has no key positions (e.g., house manager, nurse) vacant for unacceptable period of time (e.g., no longer than 60 days)
- That overall turnover is in an acceptable range – (e.g., no more than 10 percent above the median turnover rate for the private providers in the region)
- No significant licensing citations in the area of staff training or background checks, as determined by DMR
- Staff records -- including scheduling and staff hours worked -- are kept and maintained so they may be produced upon advance request by licensing inspectors or for other DMR-related inquiries (e.g., mortality review, abuse or neglect investigations)

Licensing and Inspections

- No significant findings regarding physical plant or environmental concerns
- That the provider is not on a one-year inspection cycle
- That any plans of correction were submitted timely and approved by DMR as addressing the deficiencies
- There were no “urgent” health or safety deficiencies cited in the previous licensing inspection

Client Health and Safety

- Client deaths were expected or full inquiries into sudden and unexpected deaths were conducted
- All death reporting requirements to the appropriate persons/authorities were completed
- All accident reporting was done as required
- Participation in mortality review was forthcoming, and any recommendations resulting from mortality reviews were implemented
- Any DMR health/safety advisories or bulletins have been adopted into the provider procedure (based on most recent licensing inspection)

Client Issues/Satisfaction

- Provider vacancies respond to DMR client referrals in a timely manner
- Provider acts upon client/family survey suggestions and concerns
- Provider responsibilities with OPS are performed, and issues identified for provider follow-up or service are implemented in a timely manner
- Any submissions to program review or human rights committees are timely; client health and safety issues needing human rights committee or program review committee approval are addressed

Abuse and Neglect

- Provider reports all incidents required in the area of abuse and neglect and unusual incidents
- Investigations are conducted on a timely basis
- The number of incidents is within an acceptable range, as determined by DMR
- Providers who terminate employees notify DMR so names can be placed on registry

Appendix N: Deficiencies Noted During Case File Review

How Staff Handled an Emergency	(n=127)
9-1-1 issue	14
CPR issue	17
call police issue	1
Heimlich	1
staff panic	5
Other (broken equipment, etc)	2
Medical Communication Problem	
Information w/client at placement	5
medical information gap following placement	7
nursing assessment issue	8
medical provider information getting to group home	8
problem scheduling/getting to appts	4
provider/hospice communication	5
staff to EMT communication	8
staff to ER/hospital communication	8
staff to SNF	5
other medical communication	13
Delegatable nursing responsibility issue	8
Staffing/Coverage issue	10
Record-Keeping Issue	
nursing	31
case-management	17
staff running log	20
Case/Management Functions	1
contact w/family guardian	4
involvement w/IDT	2
client contact issue	2
case management/legal issue	4
DNRs	
documentation issue	25
staff training/knowledge/ response	6
Other Client Issue(in place but not done -- or not done correctly)	5
food consistency	8
safety equipment	2
bath/shower assistance/monitoring	2
alarms/monitors	1
diet	1

Actions Not Taken/Later Questioned	
safety straps/belts	1
room monitors	1
bed checks	3
house monitor/alarms	
locks on cupboards/fridges	
repositioning	2
OPS/IDT Issue	
Clients issues not addressed	25
OPS not timely	5
Consistency/agreement issue w/OPS	6

Appendix O: DMR Salary Parity Study

Parity Study: Comparing Average Hourly Wages from FY 00 Analytical Report to
 (1) the Highest Paid Private Provider
 (2) MR Workers to all Private Providers

Equity\01JGBudgetOption01[Summary 4a]
 jg\02-26-02

**Comparing the
 Highest Paid
 Private Provider
 to All Other
 Private
 Providers**

				A	B	A + B	
		Difference [highest hourly - all other hourly]	Difference times 2080	# all other staff	Difference times # all other staff	Madated Fringes FY 2K Analytical Report .098637	Increase + Mandated Fringe
A	Managers						
	DAY	\$0.02	\$51.90	149.162	\$7,742.19	\$765.99	\$8,508.18
	CLA	\$3.17	\$6,601.39	323.795	\$2,137,497.29	\$211,478.00	\$2,348,975.29
	SLA	\$5.91	\$12,291.31	51.216	\$629,511.94	\$62,282.15	\$691,794.09
B	Supervisors						
	DAY	\$12.37	\$25,728.86	196.964	\$5,067,658.93	\$501,379.99	\$5,569,038.92
	CLA	\$4.02	\$8,360.19	305.242	\$2,551,880.97	\$252,475.96	\$2,804,356.93
	SLA	\$8.98	\$18,672.44	54.352	\$1,014,884.19	\$100,409.80	\$1,115,293.99
C	Aides						
	DAY	\$4.83	\$10,038.68	1,311.073	\$13,161,438.15	\$1,302,155.85	\$14,463,594.00
	CLA	\$4.81	\$10,006.46	2,345.998	\$23,475,126.15	\$2,322,563.27	\$25,797,689.42
	SLA	\$5.36	\$11,148.40	452.023	\$5,039,335.16	\$498,577.72	\$5,537,912.87
			<u>5,189.83</u>		<u>\$53,085,074.96</u>	<u>\$5,252,088.73</u>	<u>\$58,337,163.69</u>

**Comparing public
 employees to private**

					A	B	A + B
		Difference [State Employees hourly - private provider hourly]	Difference times 2080	# private provider staff	Difference times # private provider staff	Madated Fringes Analytical Report .098637	Increase + Mandated Fringe
Managers	Lead MR Worker						
	DAY	\$7.30	\$15,175.53	163.462	\$2,480,622.94	\$762,774.85	\$3,243,397.79
	CLA	\$9.87	\$20,521.13	375.695	\$7,709,686.99	\$103,035.45	\$7,812,722.44
	SLA	\$9.78	\$20,333.93	51.216	\$1,041,422.70	\$0.00	\$1,041,422.70
Supervisor:	MR Worker II						
	DAY	\$9.22	\$19,186.92	199.964	\$3,836,694.20	\$641,890.09	\$4,478,584.29
	CLA	\$9.81	\$20,414.12	317.812	\$6,487,853.78	\$104,162.45	\$6,592,016.23
	SLA	\$9.23	\$19,207.72	54.812	\$1,052,813.80	\$0.00	\$1,052,813.80
Aides	MR Worker I						
	DAY	\$11.17	\$23,229.17	1,373.733	\$31,910,681.04	\$5,577,943.08	\$37,488,624.12
	CLA	\$9.75	\$20,275.57	2,780.618	\$56,378,622.28	\$983,147.45	\$57,361,769.73
	SLA	\$10.44	\$21,710.77	457.703	\$9,937,085.78	\$11,955,124.51	\$21,892,210.28
			<u>5,775.02</u>		<u>\$120,835,483.51</u>	<u>\$20,128,077.88</u>	<u>\$140,963,561.39</u>

Source: DMR February 2002