Quarterly Report to the Court
In the Matter of
Evans et al. v. Fenty et al.

Civil Action 76-293 (ESH)

Submitted by: Elizabeth Jones
Court Monitor
May 8, 2008

SUMMARY

Provision of Adequate Health Care

The Court Monitor's attention and resources continue to be concentrated heavily on oversight of health care provided to class members. There continue to be serious deficits in this system.

This Quarter, seventy-two reviews in total were conducted by the Court Monitor's office. Forty-seven class members were selected by the Court Monitor's office. Twenty-five class members were selected jointly by the District and the Court Monitor as part of the required actions mandated by the September 12, 2007 Order of this Court.

It is important to note that each group of reviews, whether conducted this Quarter or in past Quarters, provides a separate "snapshot" of the care, treatment, and services provided to the class members in the sample at the time of the reviews. The findings are not based on statistically significant samples. Any differences across points in time are provided for reference. Data are not analyzed to identify trends.

These reviews are conducted to inform the Court and the parties of the health care issues being experienced by the class. It is hoped that they will continue to serve as a catalyst for change and that the necessary safeguards will be implemented.

The findings from the reviews are graphed for the Court's convenience. All supporting documentation has been provided to the parties. The District disagrees with some of my findings. We have agreed to review each of the individual cases where there is a difference of opinion.

Although the findings from my reviews indicate, in ten cases, more effective monitoring by the DDA nurses and some improvement in the implementation of positioning plans, the findings overall are very troubling. Our monitoring concludes that the health care provided to the majority of the class members reviewed fails to meet minimally acceptable standards of care. These class members remain at very serious risk.

One of the most serious areas of concern is the failure to ensure competent and consistent monitoring of psychotropic drugs and their side effects. An analysis prepared by the DC Health Resources Partnership, a requirement of the September 12, 2007 Order, confirms that "there is a critical need to build capacity in this specialty area." Other deficiencies cited in my report include the failure to implement dining plans; the failure to implement recommendations by clinical therapists; and the lack of comprehensive nursing assessments.

In addition to the more effective monitoring by DDA and the improved implementation of positioning plans, positive findings include clean and safe environments; adequate clothing; and positive staff to client interactions.

My report includes information about actions taken, or planned to be taken, by DDA to address documented concerns. These actions include strengthened quality assurance; enhanced cooperation with the Court Monitor's Office; restructuring service coordination (case management); and development of provider capacity through technical assistance and recruitment.

Provider Capacity

Since the last status conference, one provider, Resources for Human Development, has left the District; two others, Human Resources Development Institute and PSI Services, have given notice of their intent to discontinue residential services within the next two months. Approximately one hundred clients (both class and non-class members) are affected by these changes.

The changes resulting from the departure of Resources for Human Development were stressful and required extensive cooperation between the various stakeholders. Although many of the changes were implemented smoothly, there were instances of concern regarding individual placements. As a result, among other initiatives, DDA has revised its protocols regarding transitions from one provider to another and the Quality Trust is hosting roundtable discussions for self advocates, and for the family members and the attorneys/guardians of the clients affected by the departure of the other two providers.

At the May 15, 2008 status conference, an update will be provided to the Court on the status of the current transitions.

Investigation of Serious Reportable Incidents

The District has kept its commitment to the independent investigation of deaths. The Columbus investigation reports continue to raise significant concerns about the quality and timeliness of health care provided to class members. DDA is continuing to review the effectiveness of its own Mortality Review Committee. Several important changes are being made to ensure that the recommendations from the Columbus reports are, in fact, implemented.

The Court Monitor continues to identify problems with the IMEU's investigations of incidents other than deaths. Discussions are underway with DDA as to corrective actions.

The Medicaid Fraud Control Unit from the Office of the Inspector General continues its effective and thorough investigations into allegations of abuse, neglect, serious injury and theft. It continues to be successful in its prosecution of staff persons who have been charged with abuse and/or neglect of vulnerable adults.

Service Coordination (Case Management)

There is strengthened supervision of the Service Planning and Coordination Unit. The requisite number of site visits and monitoring reports were completed in seventy-three percent of the individual cases reviewed by the Court Monitor's staff during this Quarter. However, legitimate questions remain about the thoroughness of this work.

In response to my report and its documented concerns about health care, DDA has indicated that it is reorganizing Service Coordination; revising position descriptions; and expanding training requirements. It is also purchasing lap tops for field use so that documentation can be timelier.

Home and Community-Based Waiver

The District reports that 302 class members are now enrolled in the waiver. This represents an increase of eighty-two individuals since April 2007.

The expansion of the waiver has been a significant accomplishment of this administration.

Transportation

Complaints continue to be documented regarding the brokered transportation system implemented by the Medical Assistance Administration. As a result, the transportation broker contract is to be modified to address the needs of DDA clients. The modification will be processed by August 8, 2008.

Guardianship

There have been positive policy changes that now promote limited rather than full guardianship of an individual. The Probate Court has expedited the scheduling of petitions for guardianship.

As of March 31, 2008, there are eight individuals awaiting guardianship decisions. Delays in the processing of guardianship requests have been documented. DDA attributes these delays to a lack of timeliness in obtaining medical and psychological affidavits; extended searches for family members; and poor transfers of caseloads between Service Coordinators.

Respectfully Submitted,

/ s /
Elizabeth Jones, Court Monitor
May 8, 2008

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Protection from Harm

Provision of Adequate Health Care

The attention and resources of the Court Monitor's office continue to be concentrated heavily on oversight of the health care provided to class members. The issue of health care remains paramount both because of its importance and because there continue to be serious deficits in this system.

Since September 2006, my reports have graphed the findings of the health reviews conducted by registered nurses, expert in the field of developmental disabilities, who consult to the Court Monitor's office. These reviews are conducted at the residential setting and require a minimum of four hours of observation and record review. Any available documentation is examined. Interviews are held as needed with staff persons who are present and with the class members, if they are at home. Generally, reviews are announced in advance. This Quarter, seven reviews were conducted in unannounced site visits. All findings are shared with the parties and with the providers. Moreover, incident reports are filed if necessary to alert the District of unsafe or unsatisfactory circumstances. (Four incident reports were filed after this Quarter's reviews.)

These reviews are intended to present the Court and the parties with a current snapshot of health care services being provided to class members, of whom most have been identified as "at risk" for serious health and/or behavioral concerns. It is important to note that each group of reviews provides a separate "snapshot" of the care, treatment, and services provided to the individuals in the sample at the time of the reviews. The findings are not based on statistically significant samples. Any differences across points in time are provided for reference. Data are not analyzed to identify trends.

Additionally, the reviews are meant to be helpful to the Department on Disability Services (DDS) as it evaluates compliance with its own set of expectations for health care and the management of psychotropic medications. These expectations are outlined in policies issued in December 2007 and January 2008.

This Quarter, seventy-two reviews in total were conducted by the Court Monitor's office. Forty-seven class members were selected by the Court Monitor's office as described below. Twenty-five class members were selected jointly by the District and the Court Monitor as part of the required actions mandated by the September 12, 2007 Order.

The findings from these reviews are presented separately because the twenty-five class members were reviewed by the DC Health Resources Partnership (DCHRP) prior to the review by the Court Monitor's office. Thus, these class members received heightened attention prior to the reviews reported here.

A. Forty-seven class members reviewed:

These class members are supported by twenty-one provider agencies. They live in Intermediate Care Facilities (22), supported apartments (8), waiver-funded homes (13), and community residential facilities (3). One class member is hospitalized in the forensic section of St. Elizabeths Hospital.

The class members were selected for review as follows: transitioned from residences operated by Resources for Human Development (RHD) to other providers (8); excluded from the new at risk list issued by DDS on November 28, 2007 (16); included on the most recent at risk list (29), of these, sixteen individuals had never been reviewed by this office; and, recommended because they had not been reviewed before and concerns were reported (2). Additionally, seven class members were reviewed as part of a comprehensive evaluation of a single agency.

For this section of the report, I have compared the findings documented one year ago, in my April 2007 report, with those that were compiled as a result of reviews conducted this Quarter. The leadership of the Developmental Disabilities Administration (DDA) has conducted its own review of my findings and has expressed its disagreement. DDA and the Court Monitor have agreed to discuss the individual reviews and to attempt to reconcile/explain any differences.

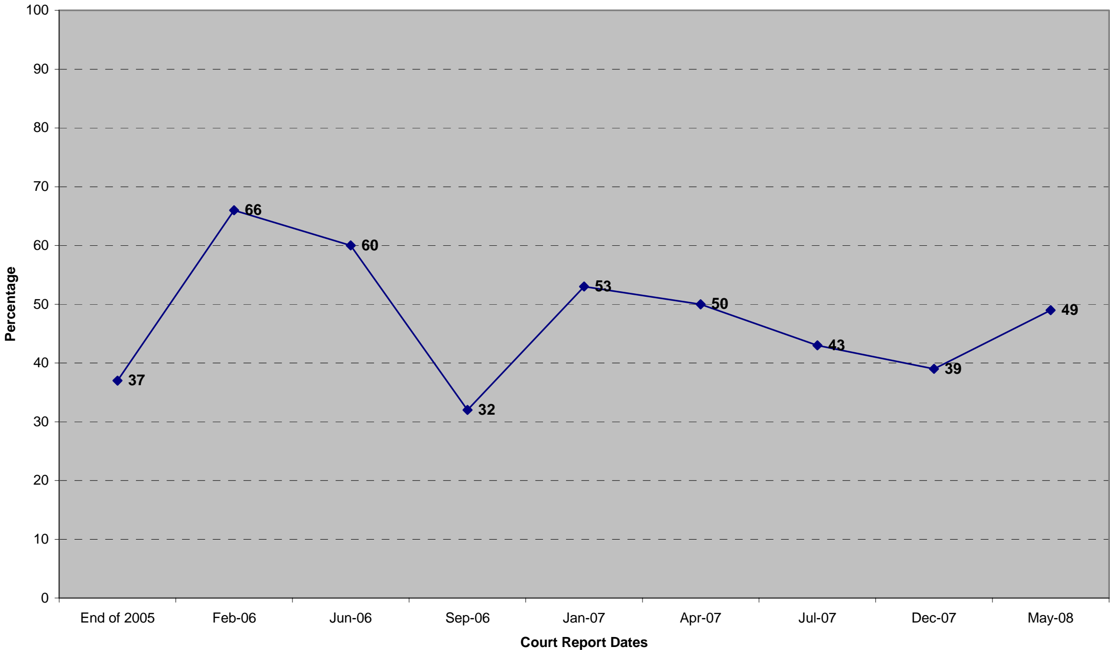
In my opinion, although the monitoring of ten individuals by DDS nurses is documented as more effective and the implementation of positioning plans improved, the findings overall are very troubling. Our monitoring concludes that the health care provided to the majority of the class members reviewed this Quarter fails to meet minimally acceptable standards of care. These class members remain at very serious risk.

Comparison of Health Care Indicators

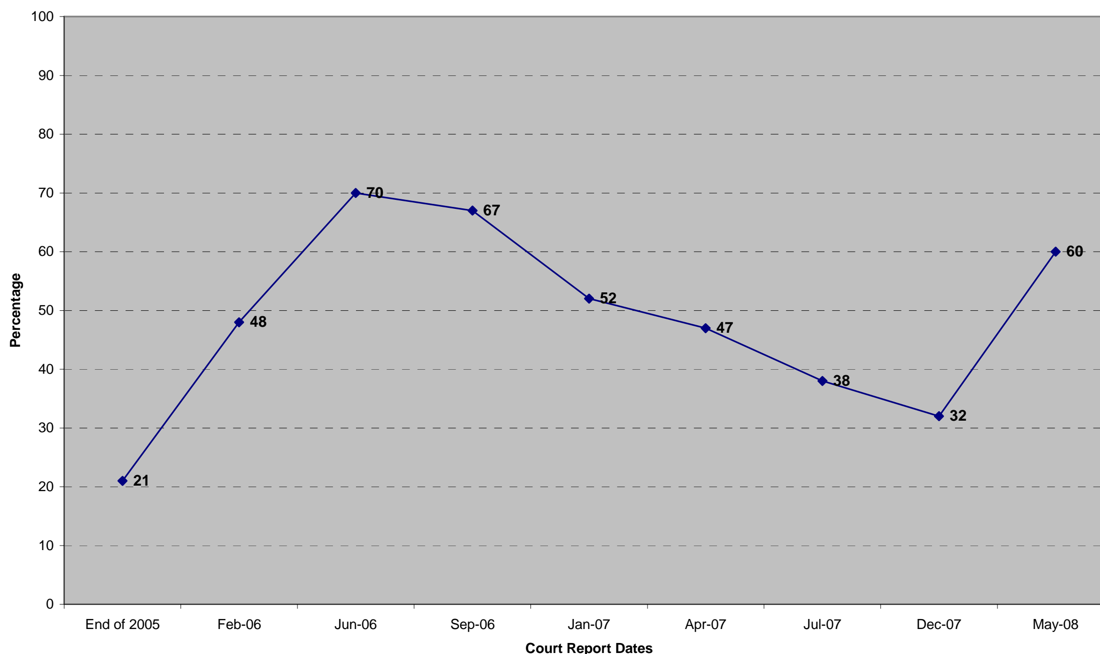
Issues Reviewed	April 2007 N=36	May 2008 N=47
1. HRMP References Current and Significant Health Problems.	50%	49%
2. DDS Quarterly Monitoring Identified Major Problems.	47%	60%
3. DDS Recommendations are Implemented by Facility.	50%	60%
4. HRMP is Monitored by Provider Nurse.	53%	28%
5. Primary Physicians and/or Medical Consultants' Recommendations are Completed in a Timely Manner.	67%	49%
6. Lab Work and Physician Ordered Diagnostic Tests and Consults are Completed as Ordered.	72%	57%
7. Effective Systems for Tracking Food, Fluids, Bowel Movements, etc. are in Place.	67%	32%
8. Competent and Consistent Monitoring of Psychotropic Drug Side Effects is Evident.	38%	17%

9. Clinical Therapy Recommendations are Implemented.	47%	26%
10. Nursing Assessments are Comprehensive and Address Health Risk Issues.	44%	13%
11. Dining Plans are Followed.	96%	69%
12. Positioning Plans are Followed	40%	63%
13. Behavioral Plans are Followed.	75%	48%

The findings summarized above are based on the information reported in the graphs below:

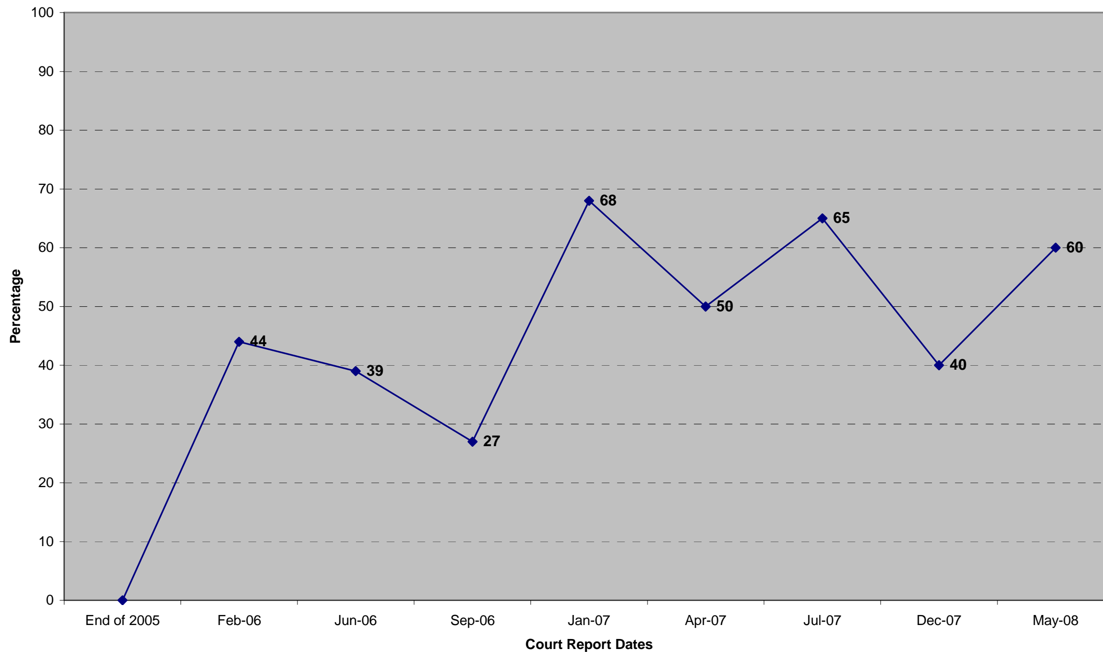


This indicator is affected positively by the attention being paid to the development of the Health Risk Management Plans (now referred to as the Health Care Management Plans). These Plans continue to be scrutinized by DDA and by the DCHRP. Nonetheless, the overall performance in this area is similar to performance measured in April 2007.

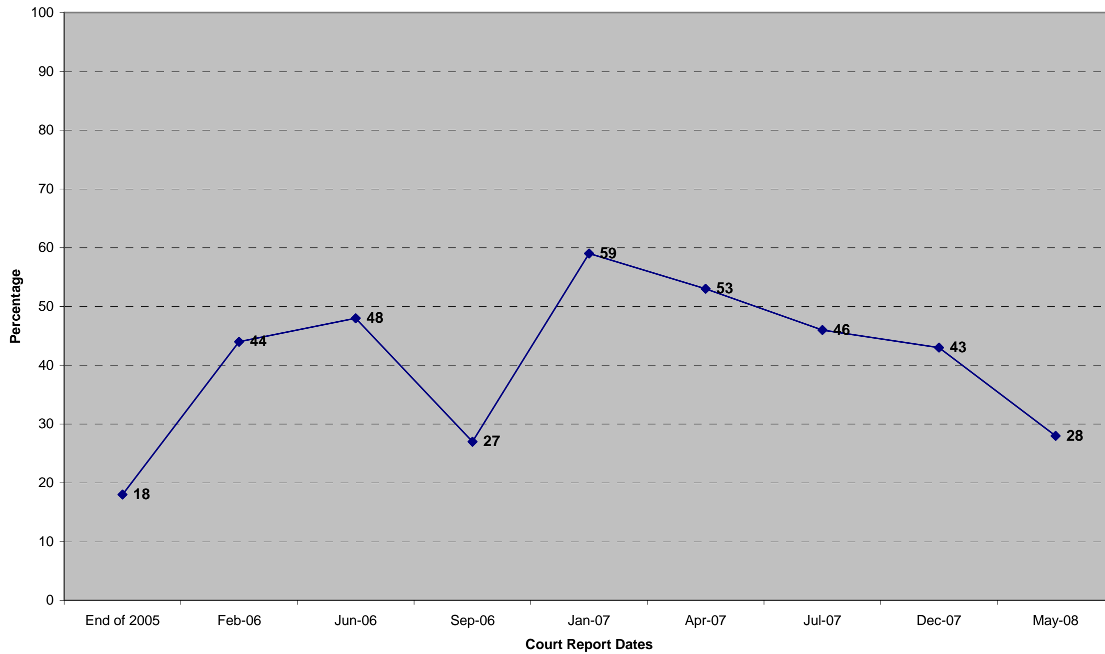


Ten of the Court Monitor's reviews, where there were problems with the Plans, found that monitoring by DDA nurses noted the problems; e.g., DDA nurses identified such issues as the need for vaccinations, the lack of a behavioral support plan, problems with obtaining dental care, missing AIMS tests, as well as outdated nursing assessments and evaluations. As indicated below, corrective action was taken in six of the ten cases.

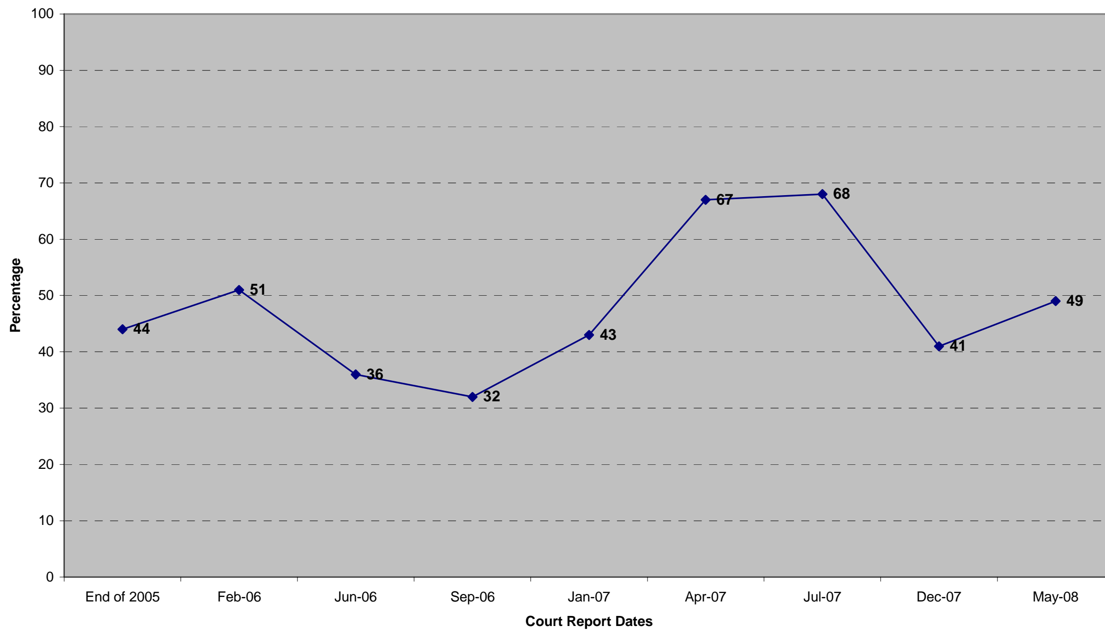
There was no evidence of similar monitoring in the reviews of the remaining thirty-seven class members. In its April 21, 2008 report, the District stated that it is monitoring individuals on the at-risk lists. Completion rates for monitoring were cited as eighty-six percent for those on the prior list and seventy-six percent for those on the new list. (The at-risk lists are discussed further below.)



It is evident that direct intervention can make a difference in the quality of health care. In these ten cases, six of the providers were responsive to the suggestions made by the DDA nurses. Generally, providers have informed the Court Monitor's office of their need for additional support and guidance. Accordingly, on March 12, 2008, the Court Monitor and her nurse consultants met with over seventy provider staff to explain her monitoring process for the review of health care. A protocol was distributed at this meeting so that there would be no uncertainty about the structure of or expectation for the nurse consultants' visits. As a result of this meeting, DDA convened a task force comprised of DDA staff, providers and DCHRP representatives and the Court Monitor to review health care documentation in order to clarify expectations, avoid unnecessary duplication and increase compliance with reporting and treatment requirements. The first meeting of this task force was held on April 29, 2008.



Our reviews again document the failure of provider nurses to monitor health care plans on at least a quarterly basis. This level of performance is unacceptable. Furthermore, our current reviews indicate that more than a quarter (26%) of the direct care staff is not familiar with the health care needs of the class members for whom they are responsible.

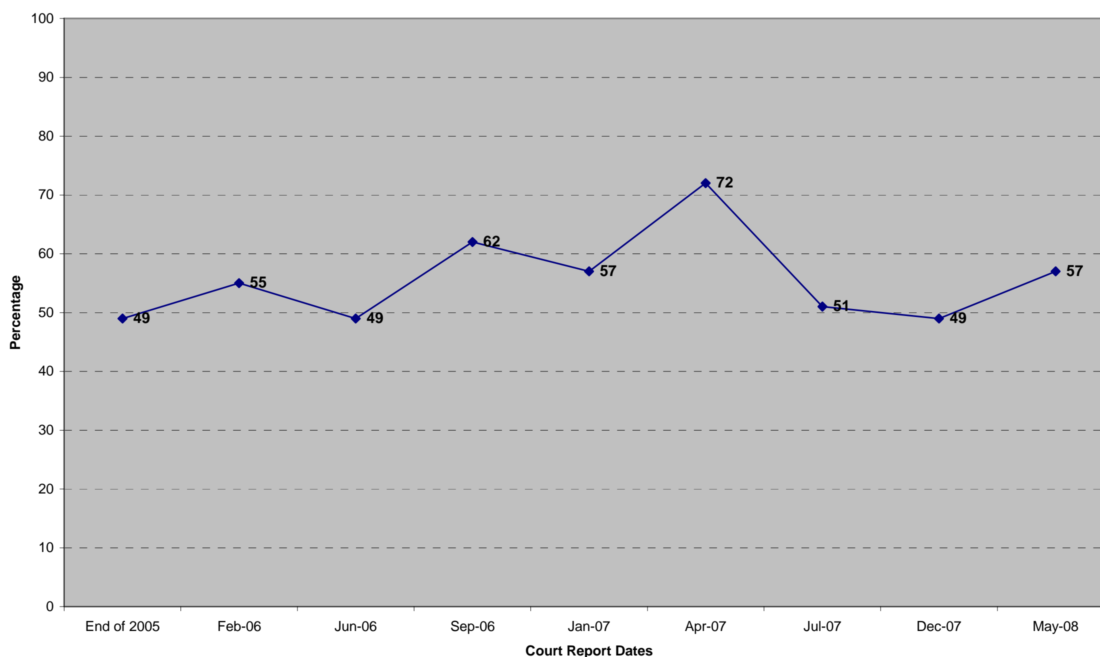


The failure to implement clinical recommendations by the physician and other medical consultants' raises critical concerns in cases reviewed this Quarter. For example:

- Mr. H. was reviewed on February 8, 2008. According to a January 2008 monthly nursing note, he has a history of rectal bleeding and requires a colonoscopy. A guardian is needed to provide consent. The guardianship application was delayed due to difficulties in obtaining the medical affidavit from the physician. The affidavit was obtained on April 29, 2008 and the guardianship application is being processed.

- Mr. F. was reviewed on April 13, 2008. He suffered a contusion to his forehead in March 2008. The consultation required that a nurse complete neurological checks every eight hours for twenty-four hours. There was no documentation in the records (e.g., nursing progress notes) that this was completed.

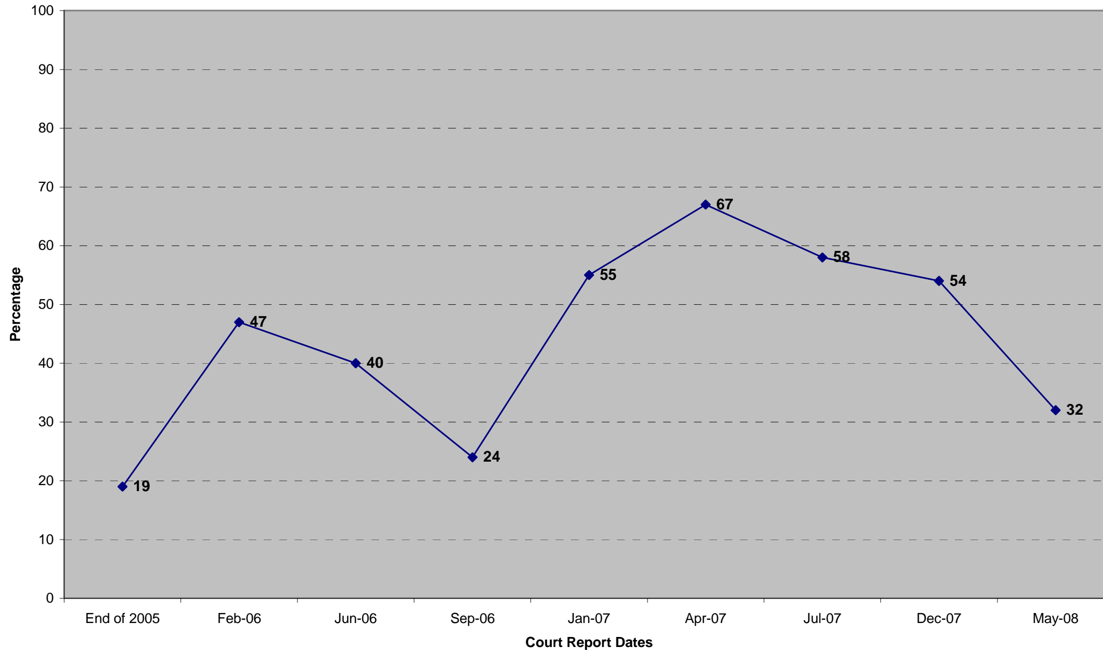
- Mr. L.'s nutritional assessment was completed on March 22, 2008. It was recommended that his diet be changed to a low fat, low cholesterol, high fiber diet with no added salt. His food texture is ordered as bite sized with ground meat. There was no evidence that these recommendations were reviewed or brought forward to Mr. L's physician for consideration. As of April 13, 2008, Mr. L. receives a regular high fiber diet with no salt. The nursing, direct care and administrative staff interviewed at the home were not knowledgeable about these recommendations. Mr. L. is prescribed a gait belt in his annual physical therapy evaluation dated March 26, 2008. The gait belt was not in use during the nurse consultant's visit; reasons for not using the belt were not documented.



Again, a significant number of reviews (43%) found a lack of evidence that diagnostic tests and consults were completed. And, again, the consequences of the failure to implement these physician orders are of serious concern. For example:

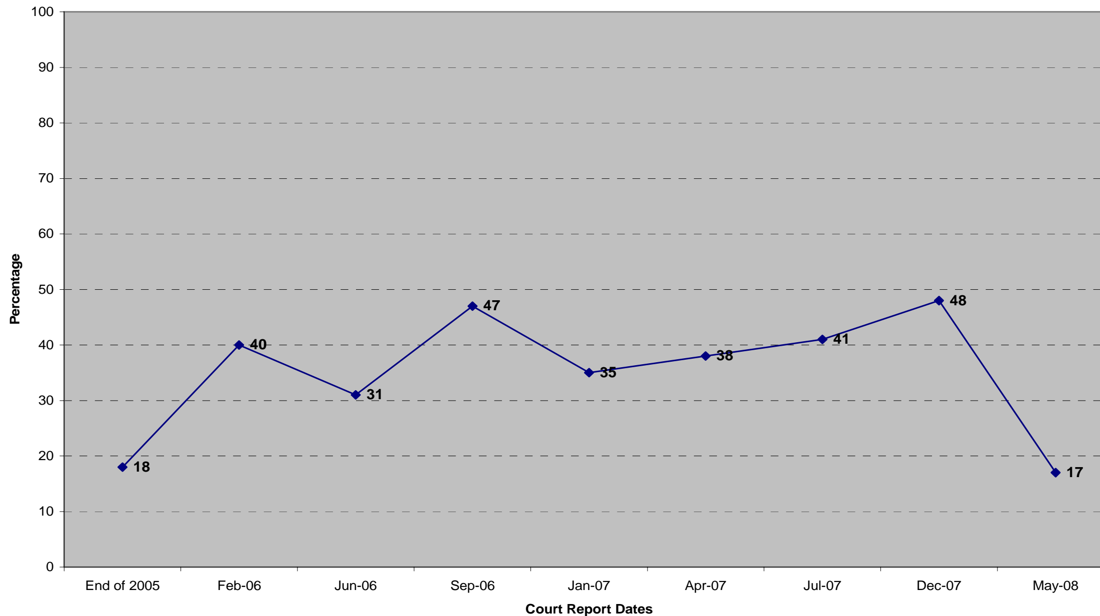
- Mr. F. has prostate cancer. Although the urologist recommended aggressive treatment, and the primary care physician agrees, the client's father has refused. Therefore, the approach ordered by the physician was to observe Mr. F. very closely. In addition to the request for his PSA to be monitored every three months, the urologist requested that the

PSA be completed by his next visit, scheduled for May 2008. The three month repeat of a PSA test was due by mid-March 2008. This test was not completed on April 13, 2008, the date of the nurse consultant's review. (The PSA was completed on April 14, 2008 and the results will be reviewed by the urologist on May 21, 2008.)



The need to establish effective tracking systems has been discussed repeatedly in my reports. After four years, this finding is of utmost concern. The consequences of this ongoing failure to monitor critical information cannot be excused. The nurse consultant reports document that at least seventeen sites managed by fourteen providers are without effective systems. It is urged that action be taken to correct these situations immediately and that penalties be assessed against these providers.

The Court Monitor and her nurse consultants concur that tracking systems may not be appropriate in the smaller, more normative residential settings funded by the Home and Community-Based Waiver. We agree that tracking systems should be based on each individual's known health needs and risks. DDA and the Court Monitor will work together to establish criteria for when these tracking systems are needed and to clarify the expectations for documentation.



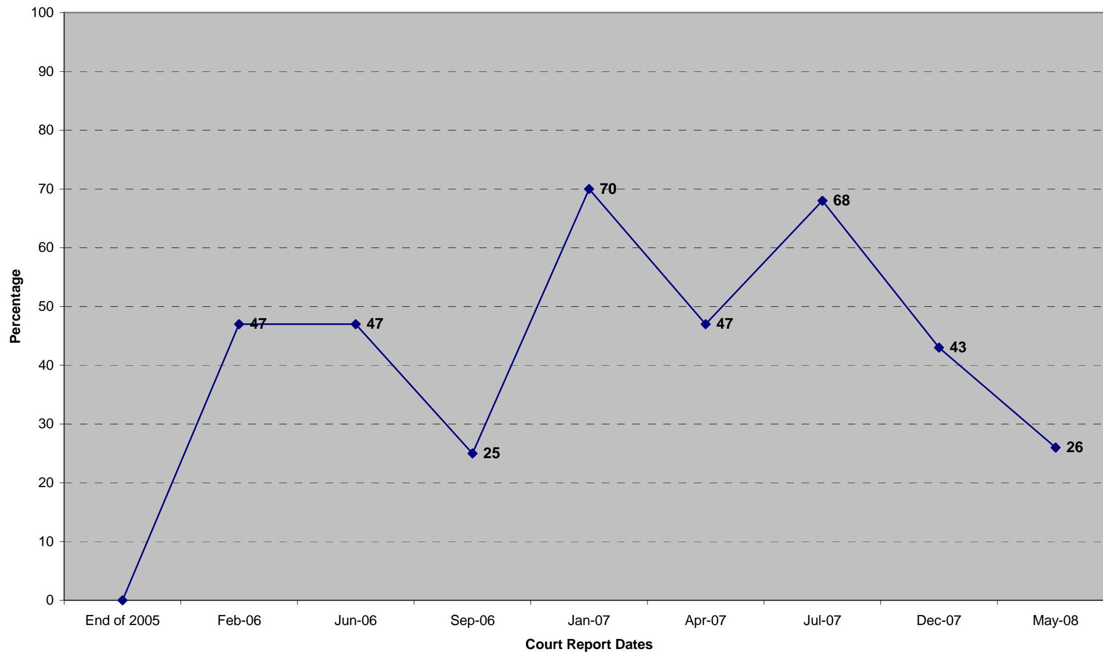
As stated most recently in my January 2008 report, the failure to monitor and appropriately document the monitoring of the side effects of powerful psychotropic medications is substandard professional practice. The documentation of this problem has been consistent.

For example:

- Ms. E's reports state that she has no side effects from her psychotropic medications. However, her AIMS tests repeatedly document minimal to mild abnormal movement of her lips, jaw, tongue and her upper and lower body. None of this information is referenced or addressed by the psychiatrist during his/her monthly reviews. In addition, although Ms. E's primary care physician has noted disruptive and aggressive behavior and her neurologist has documented agitation, screaming and psychotic behavior, there was no evidence of a psychiatric evaluation. (As a result of our review, the provider is being retrained on the DDS psychotropic medications policy.)

- Mr. H receives four psychotropic/psychoactive medications. There is no comprehensive psychiatric evaluation in his record. Monthly psychotropic reviews do not address side effects. The exact same statement is reprinted every month regarding the team's opinion that the benefits of medications outweigh the risks. Because recommended labs were not completed, monitoring for metabolic syndrome is incomplete. (As a result of our review, Mr. H's residential provider is changing its documentation process and forms to address, with specificity, the required monitoring of side effects. DDA will monitor compliance with labs.)

  The failure to meet professional standards regarding the use and oversight of psychotropic medication also violates DDA's own policy (6.5) on psychotropic medications. DDA has documented training to DDA staff and providers regarding this policy.



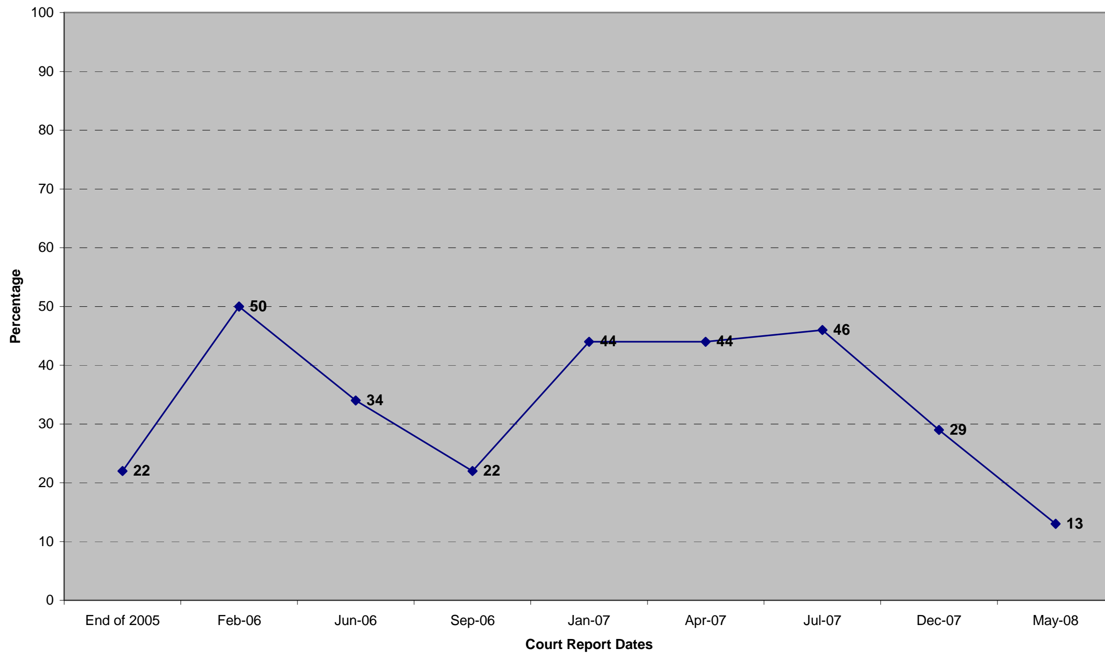
This indicator refers to the provision of such professional supports as physical therapy, occupational therapy, speech, psychology and nutrition. All of these supports are critical for improving or maintaining health and for active treatment/habilitation; they are recommended in the Individual Support Plan.

This indicator documents that such supports are not provided as recommended. Our conclusions are based on information in the record and, where possible, by observation and/or interview. For example:

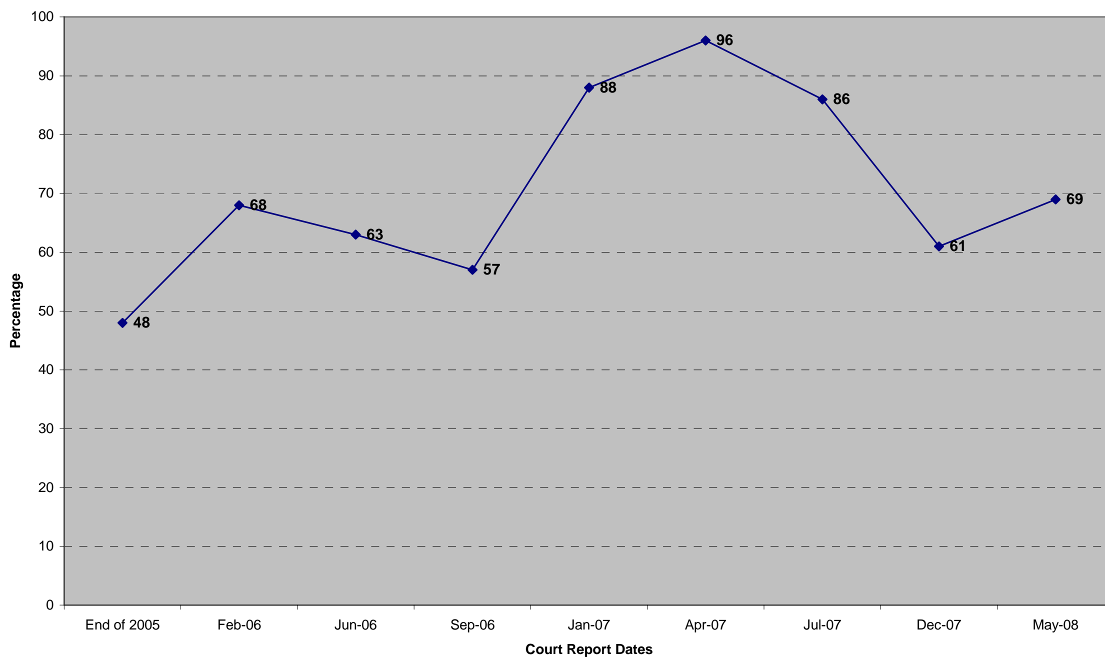
- Ms. E.'s speech/language pathologist and her occupational therapist have requested quarterly monitoring reports. At the time of our review, these were not completed. There was no evidence that the physical therapist's recommendation that she walk more often while at home or at her day program was implemented.

- As of the date of the review, there is no evidence that Mr. C's physical therapist's recommendations that he change his position every hour and walk once around the interior of his home every hour were carried out by staff.

- There was no evidence that Mr. M's dietician's recommendations dated October 10, 2007 have been implemented.

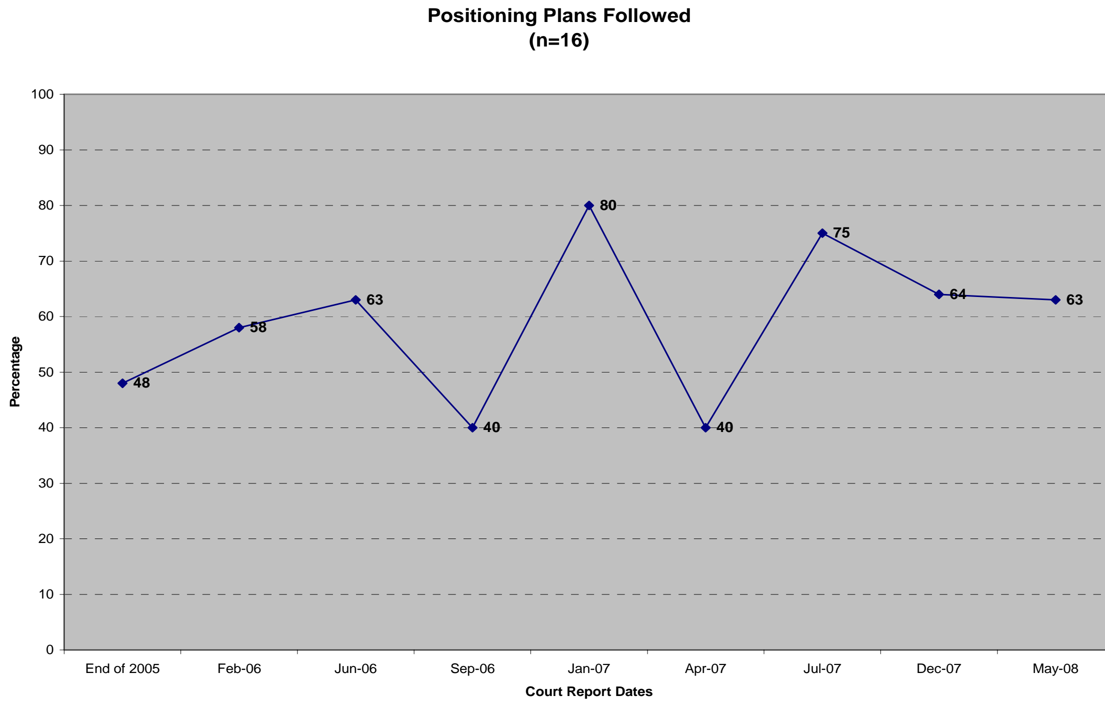


The lack of comprehensive nursing assessments has been of continuous concern. Again, it is imperative that this indicator be improved. The nurse consultant reviews indicate the failure to individualize interventions and the failure to accurately and completely reference appropriate monitoring and oversight of significant health problems.

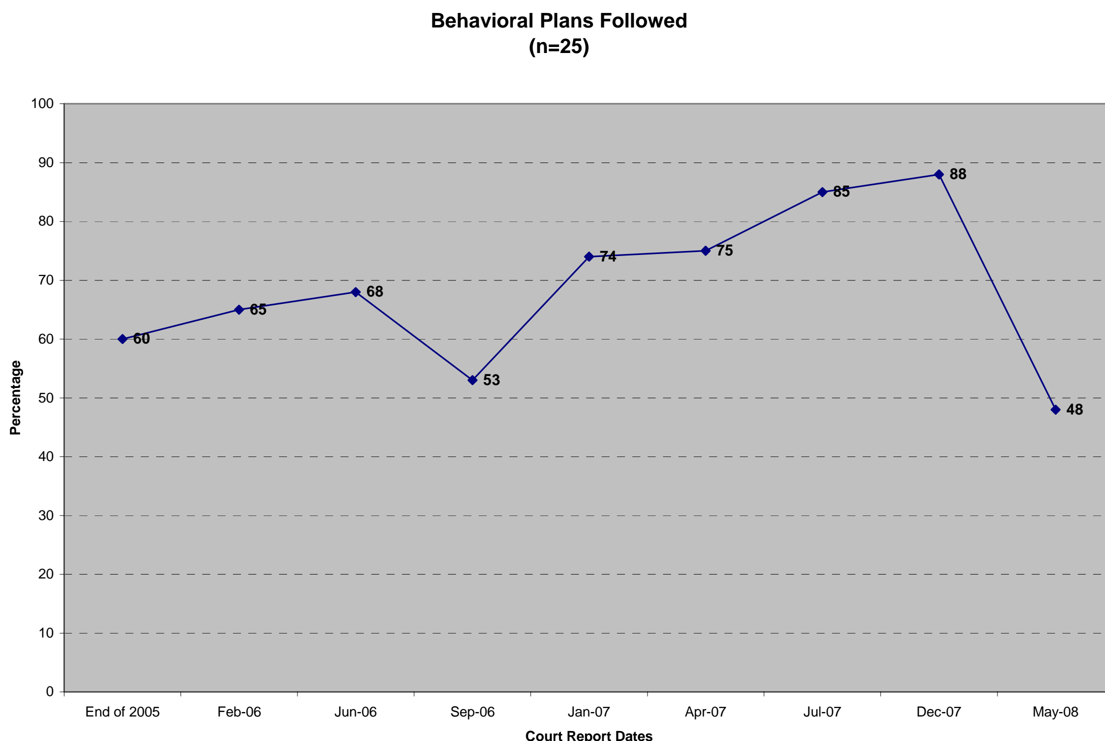


This graph indicates that performance is still unacceptable. There must be full adherence to dining plans to avoid the risk of choking and/or discomfort.

The concern about dining plans is reflected in other actions taken by the Court Monitor's office. For example, this February, after unannounced site visits, the Court Monitor filed two incident reports alleging neglect of class members at mealtime. Dining plans were not implemented, even though the plan was readily available to staff (i.e. placed on the table directly in front of the class member) and reminders were given by the Monitor. DDA has informed the Court Monitor that one incident has been substantiated for neglect. The other incident has not been substantiated for neglect but is substantiated for an agency staffing shortage.



Nearly forty percent of the positioning plans were documented as not implemented during the most recent reviews.



The indicator is even more troubling when linked to the findings about the monitoring of psychotropic medications. The failure to address behavioral issues has serious consequences for the class members including the disruption of social activities and social relationships; possible injury and discomfort; and the loss of activities designed for habilitation.

Finally, the more positive findings in this Quarter's reviews center on non-health related characteristics of the residential setting: eighty-four percent (84%) of the class members reviewed lived in a clean and safe environment; ninety-eight percent (98%) of the class members had adequate clothing; and positive staff to client interactions were noted in eighty-eight percent (88%) of the reviews.

B. Twenty-five class members reviewed:

The twenty-five class members reviewed as part of the September 12, 2007 Court Order were selected because they were known to be at high risk for health or behavioral reasons. The majority of these class members are supported by thirteen provider agencies. They reside in Intermediate Care Facilities (13); supported apartments (5); waiver-funded homes (5); and community residential facilities (1). One class member resides with her family.

The Court Monitor's review of this group of class members was conducted primarily to determine whether any recommendations issued by the DCHRP were implemented prior to December 31, 2007. In order to make this determination, a review of the individual's health status was conducted no earlier than ten days after the recommendations were forwarded to the provider agency.

Findings Regarding Health Reviews Included in September 12, 2007 Order

	"n"	Yes	% yes	Partially	% Partially
HRMP references all current, significant health problems and provides appropriate interventions.	25	12	48	0	0
Primary physicians' and/or medical consultants' recommendations are acted upon in a complete and timely manner.	25	7	28	1	4
Lab work and physician-ordered diagnostic tests and consultations are completed as ordered.	25	14	56	0	0
The home has an effective system for tracking BMs, fluid intake, food intake, urine output, tube feedings, seizures, etc. as required.	24	11	46	0	0
Clinical therapy recommendations are implemented (PT, OT, Speech, Nutrition).	25	6	24	0	0
Nursing Assessments are timely, complete, accurate, and identify and address all of the individual's health needs and risk issues.	25	8	32	0	0
Dining plans are implemented.	16	12	75	0	0
Positioning plans are implemented.	11	8	73	0	0
Behavior support plans are implemented.	17	9	53	1	6
There is evidence of routine monitoring of individuals receiving psychotropic medications, especially after new medications are initiated or dosages are changed.	13	5	38	03	0

On December 30, 2007, the DCHRP issued an analysis of systemic concerns about health care as part of the District's compliance with the September 12, 2007 Court Order. (See Exhibit 8.07—"Report of Clinical Review of 25 Evans' Class Members.") These concerns included:

- In general, the multiple disciplines represented in the care of this sample function in silos; with little documented evidence that the various therapists and licensed personnel are reading each other's reports, or taking into consideration the impact of another's assessment on their recommendations. Even in ICF-MRs, the medical directors are not leading proactive approaches to identifying etiologies or assisting the teams to understand disease processes and proactive measures that can be taken. (p.82)

- (DCHRP's report emphasized that the care of the twenty-five individuals reviewed exceeds the Health Effectiveness Data Information Set (HEDIS) Standards for breast cancer screening, cervical cancer screening, colorectal cancer screening and flu shots.) Medical care is meeting most requirements for preventative screening and commonly accepted community standards. However, there are no incentives, either fiscal or motivational, to encourage practitioners to take a more scholarly and investigative approach…(p.83)

- There is a serious capacity issue in the District of Columbia to provide mental health assessment and treatment services for people with intellectual disabilities…In general, progress is being assessed at regular intervals, and positive behavioral approaches are being recommended, but the foundation of care, i.e. differential diagnosis, consideration of all treatment options and thorough assessment are not in place. In some instances, newer pharmacologic approaches are not being tried. There is a critical need to build capacity in this specialty area. (p.85)

- Medical records do not include sufficient history or rationale for treatment planning. Even when individuals are facing complicated medical procedures or when end-of-life planning may be in order, it is rare to find summaries of the observations of team members, plans of action, and criteria for evaluation. (p.86)

- The overall quality of nursing care is affected by nursing shortages, particularly in those agencies that have not planned for adequate nursing personnel to meet the increasing demands of an aging population. (p.87)

These concerns are very insightful and provide some explanation as to the possible reasons for the continuing deficiencies in the provision of health care for DDA clients. On April 15, 2008, leadership staff from DDA and DCHRP met to discuss this analysis. Recommended actions include developing a rapid response safety net; establishing stronger avenues for communication with local hospitals; developing new sources of primary care; providing more support for current primary care providers; and addressing the nursing shortage.

Since receipt of my draft report (dated April 24, 2008), DDA has informed me that it has taken or is planning to take proactive steps as well as corrective actions to ensure adequate health care for class and non-class members.

Specifically, I have confirmed:

- The new Director of Program Integrity is very responsive to concerns raised by the Court Monitor's office. On May 9, 2008, he will meet with the Court Monitor and the nurse consultants to discuss a more coordinated approach to our respective reviews of health care.

- An aggressive effort was initiated during this Quarter to respond to the nurse consultant reports and to improve remediation of identified deficiencies. DDA Program Integrity and Service Coordination staff are collaborating on responding to the reports, using a template that was designed to chart each item identified by the nurse consultants, verify the finding, insert the provider plan of correction and report needed follow-up activities. Providers have five days to provide DDA with their Plan of Correction ("POC") and POCs will be (and, in fact, already have been) returned if deemed insufficient. DDA will

share all of this documentation with the Court Monitor and it will be used to explore any discrepancies in findings.

- DDA has drafted a revised format for the Individual Support Plan (ISP). The new format includes an expanded section on health care and requires more information about the rationale for and the use of psychotropic medications. The changes will go into effect in October 2008.

- In March 2008, DDA initiated a quality assurance review of services provided under the Waiver. The review includes a sample of at least twenty-five percent of all individuals receiving Waiver services. DDA has agreed to provide documentation from the review of class members to the Court Monitor.

- In June 2008, DDA will begin training non-clinical personnel in the ongoing monitoring of health care needs. The training program was obtained from the Philadelphia Coordinated Health Care (PCHC) organization.

Finally, one review (A.C.) out of the forty-seven completed by the nurse consultants received a positive finding for every indicator. This review can be used as a model. Certainly, it should be noted that the Board members of the District's provider coalition, as well as individual executives of certain provider agencies, have expressed genuine concern about the pattern of findings documented in my reports. Several months ago, they convened a standing committee to review health care issues and to suggest improved practices. DDA nursing staff and representatives from DCHRP attend these meetings.

<u>At Risk List</u>

As required by the September 12, 2007 Court Order, the Court Monitor met with DDA to review, and agree upon, the process for developing a revised "at risk" list. This list has been important because it has provided heightened scrutiny of health care.

On November 28, 2007, the District issued a new at risk list. The list is based on findings from the Supports Intensity Scale (SIS), a standardized assessment instrument developed by the American Association on Intellectual Disabilities (AAID) and implemented by the DCHRP as part of the requirements of the September 12, 2007 Order. After analysis of this list, the Court Monitor and the plaintiffs reported their concern that, although some change was expected, seventy-four class members from the previous at risk list were not included. Many of these class members are known to have medical and/or behavioral issues. In fact, seven of the excluded individuals were subjects of the health reviews mandated by the September 12, 2007 Order. Ten of the excluded individuals live in ICF/MRs with twenty-four hour nursing care. The sole class member institutionalized in an out of state placement was omitted from the new list. This man has both medical and behavioral needs.

Although DDA agreed to re-administer the SIS for these individuals, that work is not completed. As a result, the concern about the accuracy of the at risk list has not been resolved.

<u>Nursing Home Placements</u>

As of the date of this report, there is one class member (W.W.) in a District nursing home. This client's whereabouts were unknown until May 2, 2008; she was found after the list of "lost" class

members was compared to the list of residents at a local nursing home. This class member has been referred to DDA for services. One class member (W.B.) was admitted to an out-of state nursing home in order to be closer to his family. On April 28, 2008, a third class member (J.M.) died in a nursing home where she was being weaned from a ventilator and tracheotomy.

Dental Care

On March 4, 2008, the DCHRP issued its *Survey of Oral Health Providers*. Seven private dentists responded to the survey and were responsive to providing dental services to individuals with a developmental disability. This Quarter, the District announced a new Dental Health Line to assist Medicaid recipients in obtaining dental care. Dental coverage under Medicaid has been expanded. On May 7, 2008, a District-wide training session was held for dentists to provide information on the Waiver, including billing.

On April 4, 2008, University Legal Services arranged for representatives from DDA, the Department of Health, the DCHRP, the Quality Trust and the Court Monitor's office to attend a presentation by Dr. Paul Glassman, Associate Dean at the University of the Pacific. Dr. Glassman initiated a highly praised statewide program to provide dental services to California residents with an intellectual disability. The DCHRP and the Quality Trust agreed to coordinate follow-up action to Dr. Glassman's suggestions for strengthening dental care services in the District.

It is undisputed that dental care for class members requires continuing attention. Serious dental problems were noted in at least seven of the health reviews completed this Quarter. For example:

- There were significant problems obtaining dental care for Mr. H. The last dental visit was September 2006 and Mr. H. requires treatment. Staff stated that it is extremely difficult for them to find a dentist who will accept DC Medicaid. (DDA reports that Mr. H. had a dental consultation on February 12, 2008; this was four days after the Court Monitor's review.)

- Ms. M's dental treatment also was delayed. DDA reports that Ms. M's dental appointment is scheduled for May 2008. The significant delay was due to waiting on prior authorizations from the Medical Assistance Administration (MAA), as well as the dentist's schedule. There is a systemic issue for the ICF/MR providers in obtaining prior authorizations from MAA. Reportedly, MAA is working to address this concern.

Provider Capacity

Since the last status conference, one provider has left the District and two others have given notice of their intent to discontinue services within the next two months. Approximately one hundred clients (both class and non class members) are affected by these changes.

The first provider, Resources for Human Development, left the District at the end of January 2008. In an April 14, 2008 interview with the Court Monitor, this agency's administrators acknowledged that they had agreed, in an email dated September 7, 2007, "to contribute 100% positive energy and effort to completing the waiver conversion process." It was hoped by all parties that conversion to the waiver, and other discrete measures, would permit this provider to

remain in the District. Ultimately, however, this provider decided that its ongoing financial losses could not be reversed.

This agency supported fifty-one individuals, including thirty-three class members, in eight residences:

- Site A--three class and three non-class members were moved to apartment settings;
- Site B--four class members and two non-class members were moved to a new and to an existing provider (one class member died prior to the transition);
- Site C--seven non-class members were relocated when the house closed;
- Site D--four class members and three non-class members remain here with a new provider;
- Site E--five class members and one non-class member were separated into two residences. One group remained at the site and the others moved to a new house;
- Site F: the residence was closed and the four class members and one non-class member moved to new provider agencies;
- Site G: the residence was closed and three new providers share responsibility for the six class members (one class member moved to an existing provider prior to transition);
- Site H: the residence remained open and an existing provider assumed responsibility for the six class members.

These changes were stressful and required extensive cooperation between the various stakeholders. DDA experienced a number of difficulties regarding the leases for these properties requiring last minute decisions regarding location.

A series of meetings held after the transition indicated the need for revised policies and protocols regarding changes in placement. These policies were shared with the plaintiffs and the Court Monitor before they were finalized.

Although many of the changes were implemented smoothly, there were instances of concern regarding individual placements. Transition problems were described by the Court Monitor in a letter to the plaintiff-intervenor dated April 8, 2008. The letter cites the failure to consider travel time from the new residence to the day program; location of a residence in a neighborhood with few resources and a history of crime/violence; and difficulties with billing. Additionally, documents were not transferred in a timely manner; there were lapses in coordination between the old and new providers; decisions were made about placements that resulted in some disruption to established routines. In recent interviews conducted with new providers, DDA support was acknowledged and appreciated. However, there was a lack of information about the provider helpline and the availability of start-up funding. Three of the four new providers did not know about the existence of such funding. One provider did apply for the funds and is awaiting payment. One provider was fined ten thousand dollars by the DC Zoning Commission when the surveyor incorrectly insisted that an occupancy permit was required. DDA intervened and the fine was not paid.

A second agency, Human Resources Development Institute, has given notice of its intent to terminate its services at the end of June 2008. It cites financial losses as a result of the rate for ICF/MRs as the primary reason for this decision. This agency currently supports forty-eight individuals; twenty-five of whom are class members. Clients have been notified of the anticipated change and planning efforts are underway now. The Quality Trust is hosting transition roundtables for self advocates, their family members and their attorney/guardians to discuss critical issues that should guide selection of and transition to new residential providers.

The third agency, PSI Services, gave unexpected notice to terminate its residential services. Five class members are supported by this agency.

Investigation of Serious Reportable Incidents

This Quarter, there were 177 serious reportable incidents submitted by providers to DDS.

Fifty-seven investigation reports were due this Quarter; thirty-three were received. Fifteen of the received reports were late.

There were 123 investigation reports overdue from the previous Quarter. Eighty-six have been received; thirty-seven are still outstanding.

Finally, an additional seventeen reports are still due from FY 07.

On March 3, 2008, DDS, the plaintiffs, the Quality Trust and the Court Monitor met to discuss the investigation process and the recurring concerns about the quality of the investigation reports. It was decided that the use of the investigation checklist--an assessment form agreed upon previously--would be re-instituted and that the meeting participants would reconvene to discuss the results of these reviews. The review has been started and will continue through this Quarter.

The Court Monitor's office also has begun the review of incident reports concerning medical emergencies. Nurse consultants to the Court Monitor's office conducted three such reviews in March 2008. These reports have been provided to the parties; they describe both positive aspects of the provider's internal investigations as well as concerns about the thoroughness and timeliness of the investigations.

On April 21, 2008, the Court Monitor met with the Chief of the Office of Incident Management and Enforcement (IMEU) to discuss concerns about the eighty-three reports from this Quarter that she had read thus far. These concerns include late submissions; careless mistakes; incomplete forms; a format that requires restructuring for clarity; failure to consider past incident reports and, most importantly, hesitant or inconclusive analysis. For example, an incident report (08-0022) filed by a DDS service coordinator after she witnessed improper mealtime procedures was marked as substantiated but the conclusion was stated as "…it appears more likely than not that Ms. W. was eating in her room unsupervised."

The Chief of the IMEU has announced his intent to resign. The lack of stability in the investigative unit of DDS is of concern because there are deeply entrenched problems that need to be remedied.

The Office of the Inspector General's Medicaid Fraud Control Unit (MFCU) continues to conduct its thorough and effective investigations into allegations of abuse, neglect, serious injury and theft. It has successfully prosecuted staff persons who have been charged with abuse and/or neglect of vulnerable adults. Its most recent annual report documents the convictions of eight employees who physically assaulted or mistreated DDS clients.

The MFCU and the Court Monitor's office work together closely to ensure complete documentation of serious reportable incidents and to examine patterns of poor care in a provider agency.

Since December 2007, eight class members have died. Their deaths will be investigated by the Columbus Organization. The District has kept its commitment to the independent investigation of deaths.

Eleven Columbus reports were received this Quarter. The Mortality Review Committee has met six times this Quarter and reviewed eight Columbus reports. According to its minutes, the MRC is reconsidering its protocols to ensure follow-up to the recommendations that are offered by Columbus.

And, based on its investigations, Columbus has recommended a number of actions for the provider, DDS and other relevant parties. These recommendations include changes in practice, coordination across relevant parties, improved documentation and increased vigilance in identifying possible risks to the individual.

Upon review, the Columbus reports reflect many of the concerns cited by the Court Monitor's Office in its health reviews. For example:

- It is of major concern that there was no evidence anyone monitored the decedent for symptoms (e.g., appetite, pain/discomfort, bowel movements) and signs (e.g., abdominal distention) during that time and that he became suddenly ill on December 8, 2007, three days after the last dose of Reglan. He died of bowel necrosis the pathologist felt was related to his chronic GI problems. (R.L.)

- It was also unclear whether the decedent was adequately monitored for physiological side effects of his medications and routine monitoring of drug side effects was not consistent with accepted practice standards. There was no clear clinical rationale for maintaining the decedent on six psychotropic medications including two antipsychotic drugs. (A.M.)

- It is not known whether consideration was given to Risperdal as the causative agent for the decedent's dysphagia. This is particularly relevant to the decedent's medical concerns as antipsychotic medications commonly cause or exacerbate dysphagia, and tardive dyskinesia can exacerbate choking and aspiration. The decedent reportedly has abnormal mouth and jaw movements per Neurology exam in 2/07 and AIMS test in 3/06. (J.S.)

- Although the decedent was considered a fall risk and had 1:1 staff to assist with ambulation due to unsteady gait, it did not appear that the decedent received a comprehensive diagnostic workup to determine factors that might contribute to this problem e.g. doing an assessment for orthostatic B/P changes related to his psychotropic medications, obtaining a neurological workup etc. (J.S.)

DDA reports that it is finalizing a revised policy, including new procedures, on the mortality review process. The revised policy will strengthen the Mortality Review Committee ("MRC") membership requirements, including specifying the presence of a legal advocate and a representative of the Quality Trust. It will list explicit instructions to the MRC for the review and follow-up of all deaths of individuals served by DDA. It will focus the MRC on recommendations for discrete and systems improvements and include instructions on enforcement of recommendations. The policy will also detail the role of the Office of Program Integrity regarding its monitoring, follow-up and trend analysis related to the deaths of individuals served by DDA.

Case Management

Using the MCIS (the electronic database used by DDA) and supplemental paper documentation provided by DDA as sources, case manager (now called service coordinator) notes and other pertinent information were reviewed for fifty-six class members.

Forty-one of the class members reviewed (73%) had documentation of at least eight visits by the service coordinator and at least eight completed monitoring tools. These are the minimum annual expectations that have been established.

Fifteen of the class members reviewed (27%) had documentation of at least eight visits but the requisite monitoring tools were not completed.

As reported last Quarter, the number of visits is no longer the issue. The Court Monitor is aware of the strengthened supervision being given to the Service Planning and Coordination Unit. Certainly, there has been improvement in the quality and the timeliness of responses to individual issues raised by the Court Monitor's office. Nonetheless, given the findings of the health reviews described above, legitimate questions still remain as to the focus and depth of this work.

In response to my draft report, DDA has indicated:

- Service Coordination is being reorganized. Disciplinary actions are being taken, as warranted. Seven of the fifteen class members who did not have the requisite monitoring tools on record were supported by service coordinators who are no longer employed as a result of performance issues.

- Position descriptions are being revised for both Service Coordinators and their Supervisors.

- A comprehensive overhaul of the current orientation and training for Service Coordinators is in process.

- Laptops for field use will be purchased for Service Coordinators to expedite timely documentation.

Most Integrated Setting

Home and Community-Based Waiver

The District reports that 302 class members are enrolled in this waiver program. This represents an increase of eighty-two individuals since April 2007.

The expansion of the waiver has been a significant accomplishment of this administration. The workload has been substantial and there have been critical problems, including those related to billing, which have required corrective action.

Overall, the new residences opened under the waiver are of very good physical quality. Privacy and personal comfort have been enhanced for class members--most now have their own bedrooms and have furniture that they chose. With one exception, the neighborhoods are attractive and close to community resources. There is evidence of community support in many of the new neighborhoods.

In some instances, we have documented that the move to smaller, more integrated environments has increased participation in household activities, activities that promote skill development. For example, Mr. F., a class member with complex behavioral and medical needs, is delighted with his home with only two housemates. He has responded by beginning to learn to do more; he is now taking some responsibility for his laundry.

DDA has stated its intent to reduce the use of Intermediate Care Facilities (ICF/MRs)--environments that are based on a medical model of care and that retain many institutional characteristics. Also, DDA has expressed its intent to achieve a more individualized rate setting process so that more flexible supports can be provided. At this time, budget constraints have been created by the transitions to smaller settings.

Although the expansion of the waiver cannot, on its own, eliminate the substandard care we have documented above, it does provide a foundation for reform and for more individualized approaches to habilitation.

Transportation

In October 2007, DDS was informed by the Medical Assistance Administration (MRDD) that the new Medicaid State Plan amendment moving the District into a brokered transportation system would include individuals receiving services through the Home and Community-Based waiver. Until then, it was understood that individuals receiving services from DDA would be exempted.

DDA cannot be blamed for the chaos that followed, and the unpredictability that continues to follow, this decision. At the time of this report, numerous complaints continue to be made about the lack of timely transportation. Medical appointments and other plans for community outings have been missed because the transportation provider was late or failed to show up at all. Providers have been required to expend unbudgeted funds to compensate for this lack of accountability. For example, one new provider has been transporting its client to his day program despite the fact that it must pay staff overtime to take care of this responsibility.

DDA has reported that the transportation broker contract will be modified to address the needs of the provider community. The modification will be processed by August 8, 2008. The following changes will occur:

- Rate changes: MAA has requested a separate rate be established for the DDA population. This capitation rate should factor in the additional resources required to properly care for this more vulnerable population.

- Medical Necessity: DDS will provide an agreed upon medical necessity form that outlines the specific needs of the person and the appropriate mode of transportation. The form shall be good for one year unless the client status changes at which point DDS will submit an updated medical necessity form identifying what has changed.

- Attendants: When scheduling a trip, DDS will identify those individuals who require an attendant. The attendant will be responsible for assisting the person from door to door and no one will be dropped off unattended.

- Dedicated Transportation Providers: Waiver providers will have the opportunity to request dedicated transportation providers to allow for consistency in routine in transportation services.

Supported Employment

This Quarter, four additional class members were placed in supported employment. (According to our information, five of the class members cited by DDA in its report actually were placed last Quarter.)

Three of the class members now work in local grocery stores. Their wages range from $6.15 to $7.25/hr. The fourth class member receives nearly eleven dollars an hour. However, he appears to be included in a group assignment rather than in individualized competitive employment.

Other Issues

Personal Needs Allowance

Recently, the Court Monitor and the parties were informed that the personal needs allowance for Medicaid recipients had been raised from seventy to one hundred dollars/month. This change was promulgated by the Department of Health on October 20, 2006.

The Department of Health did not intend to include the ICF/MR or DDA service recipient in the increase. As such, MRDDA was not notified of the change. The author of the rule made an error and did not place appropriate exclusionary language in the rule. When DDS researched the personal needs allowance process to request an increase, the error was identified. Hence, DDA service recipients were found to be eligible; actions are underway to implement the rule, and increase the allowance amount for DDA clients.

The Office of the Chief Financial Officer has confirmed that personal needs allowance payments of one hundred dollars were effective with disbursements beginning in April 2008. Back payments for the last seventeen months will be identified and paid in incremental amounts.

Guardianship

Advocates involved in the guardianship process affecting DDS clients have commented positively on the policy changes that promote limited rather than full guardianship of an individual. Also, it has been noted that the Probate Court has expedited the scheduling of petitions for guardianship.

As of March 31, 2008, DDS has reported that there are eight individuals awaiting guardianship decisions. One guardian was appointed on April 8, 2008. There continue to be significant periods of time between the notification to the case manager that a guardian is needed and the time that the documentation is submitted to the Office of the Attorney General. DDS notes time lapses of 123, 273, 257, 74, 63, 202, 74, 97 and 3 days respectively for each of the cases. When time is added from the submission of the documentation to the filing of the petition and, further, the time required until the hearing date, the process continues to be very lengthy. The individual recently appointed a limited guardian waited nearly a year (354 days) for that decision. DDA has provided the parties an explanation for the time frames reported above. It concludes that most of the delays can be attributed to providers not obtaining medical and psychological affidavits in a timely fashion; extended searches for family members as the lesser restrictive alternative; and poor transfers of caseloads between Service Coordinators.