Health Care In Impacted Adult Homes: A Survey

New York State Commission on Quality of Care and Advocacy for Persons with Disabilities

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Study Methodology and Purpose

In 2003 the Commission undertook a study of the health care provided to a selected sample of 69 residents of 13 impacted adult homes. On site at the adult home, the study included a review of the resident's adult home record (including ER and hospital discharge papers), an interview with the selected resident, and an interview with the person at the adult home who was responsible for securing medical services for residents, usually the case manager (sometimes a specialized medical case manager) or the administrator. In addition, with the written permission of the individual, Commission staff reviewed the medical record maintained by the individual's primary care practitioner (PCP), whether maintained at the home by physicians who practiced there or at the physician's office or clinic.

Because sample residents were selected to represent genders equally, and a mix of ages and geographic locations, the Commission believes a description of this small but diverse sample, focused on their health issues, would be helpful in understanding some health issues common among persons living in adult homes. The study was guided by several additional specific objectives as well:

- assess the effectiveness of the DSS 3122 form in providing an accurate picture of the individual's health status;
- determine whether residents were receiving medical screenings appropriate to age and gender, such as mammograms and colon cancer screenings;
- determine whether residents were receiving on-going care for chronic conditions;
- determine the frequency of ER usage and hospital stays over a 12 month period;
- assess the quality of health care coordination;
- report the degree of satisfaction expressed by residents regarding their medical care.

Description of the Sample

The sample of 69 individuals was composed of 35 males and 34 females, ranging in age from 35 to 88. The age mix is described in the table below.

Age Range	#Males	#Females
35-49	15	11
50-64	6	8
65-79	10	9
80+	4	6

The individuals in the sample lived in homes that varied greatly in size—from homes serving as few as 24 residents to large homes with 200 or more residents. These homes were located in both rural and urban areas in nine counties across the state.

Adult Home	County	Census	Sample size
Abbey Island	Nassau	99	6
Barton's Rest Home	Chemung	26	4
Bayview Manor	Kings	229	6
Garden of Eden	Kings	202	6
Golden Age	Oneida	42	4
Heritage Manor of Ransomville	Genesee	93	6
Kalet's Adult Home	Onondaga	45	4
Lincoln Elms II	Onondaga	24	4
New Rochelle	Westchester	250	5
Riverdale Manor	Bronx	256	6
South Country	Suffolk	172	6
Surf Manor	Kings	200	6
Woodhaven	Suffolk	181	6

Study Findings

1. **The medical and adult home records of the sample individuals revealed that in several disease categories, the incidence among adult home residents far exceeded the incidence in the general population. All persons in the sample carried multiple diagnoses. Twenty percent of the sample carried between two and four diagnoses, while the remainder carried more. Over one-third of the sample (36%) carried more than eight diagnoses**.

2. **Of the 58 persons carrying a diagnosis of schizophrenia, two-thirds were receiving one of the newer anti-psychotic medications, either singly or in combination with an anti-depressant, anti-anxiety drug or other newer anti-psychotic medication. Over 80 percent were treated with multiple medications.**

Through a review of a variety of records, including the DSS 3122 and the PCP's medical records, we were able to identify the predominant medical diagnoses of the sampled persons. The most prevalent diagnoses related to cardiac conditions, pulmonary disease and digestive problems, including reflux disorders. Each of the diagnoses listed in the chart below was ascribed to 20 percent or more of the sample. Fifty percent or more of the sampled individuals carried one or more of these diagnoses.

A review of incidence data for several of the disorders studied indicated that the disorders were far more common among our sample than in the general American population. This finding is not unexpected, since the vast majority of the CQC sample were persons with serious psychiatric disorders, which may predispose them to certain health risks and which are often associated with lifestyle choices that endanger health, (e.g. smoking, lack of exercise, poor diet). Additionally, the use of psychotropic medications, which may be

associated with diabetes[1], and the fact that all of the persons in the sample had very limited incomes combined to exert a negative impact on health.

The degree of disparity between general population norms and people in the Commission sample is startling in some cases. For example, the prevalence of diabetes in the general population is estimated at approximately 6.3 percent[2], while in our sample, one-quarter of the individuals carried this diagnosis. Hypertension was recently cited as afflicting 31.3 percent[3] of the population, while 45 percent of our sample was diagnosed with the disorder. COPD was estimated at between 4 and 8.5 percent[4] of the general population, while it afflicted over half the people in our sample. While 28 percent of the Commission sample had a diagnosis of gastroesophageal reflux disease (GERD), the incidence in the general population is reported to be approximately 21 percent.[5]

Medical Diagnoses	# Persons CQC sample	% of CQC sample
Cardiac Disorders	38	55
Chronic Pulmonary D/Os	37	54
Digestive Disorders	34	49
Hypertension	31	45
Sight or Hearing Disorders	20	29
Nervous System Disorders	19	28
GERD	19	28
Diabetes Mellitus	17	25
Hyperlipidemia	17	25
Acute Respiratory Disorders	17	25
Urological Disorders	16	23

Eighty-four percent (58 individuals) of our sample had a diagnosis of schizophrenia. Of these 58 persons, 19 also carried a mood disorder diagnosis. A review of the medications for this group of 58 persons revealed that two-thirds were receiving one of the newer anti-psychotic medications, either singly or in combination with another drug. (The additional drugs did not include older anti-psychotic medications.) Eighteen individuals (31%) were receiving an older anti-psychotic medication, either singly or in combination with another psychoactive drug(s). Several persons were receiving lithium.

The use of multiple medications for the control of mental health symptoms was common. Over 80 percent of the individuals diagnosed with schizophrenia were receiving multiple medications for this condition. Twenty-four people or 41 percent of the sample received three or more psychotropic medications. Twenty-three people were treated with two

[1] Psychiatric News-July 5, 2002
[2] From the National Diabetes Fact Sheet on the Center for Disease Control (CDC) website.
[3] From 1999-2000 census data and National Health and Nutrition Examination Survey, reported in 2004.
[4] From National Health and Nutrition Surveys III and CDC Morbidity and Mortality Surveillance Summaries 2002.
[5] American College of Gastroenterology website. Common GI Problems: Volume 1. Incidence relates to persons experiencing symptoms at least once a month.

medications. Eleven people in the sample (19%) were treated with monotherapy. (These counts do not include the use of Cogentin and similar medications).

3. **The DSS 3122 form serves a dual purpose for many individuals in adult homes. In addition to asserting that an adult home is an appropriate residential setting, the form also constitutes the individual's annual medical evaluation. In this capacity it is inadequate and fails to capture significant medical information. In addition, many forms examined were incomplete and failed to provide even the minimal information required.**

The 3122 forms reviewed often gave an inaccurate picture of the health status of the individual. In the vast majority of cases significant information was missing, leading a reader to misjudge the current health status of the individual. A review of 3122 forms revealed that 64 of the 69 (93%) did not contain all of the individual's diagnoses. Twenty-three of the 69 forms lacked five or more diagnoses, such as mental health disorders, seizures, arthritis, hypertension, GERD, and cardiac disorders. Many of the individuals were receiving medications for chronic conditions that were not listed on the 3122 form. These medications were often prescribed by the same physician completing the form. For example:

- A history of TB was documented on the 3122 for four individuals. Yet, the PCP records of four additional individuals indicated a history of TB.

- Arthritis was listed on the 3122 for six individuals; for an additional seven individuals this diagnosis appeared in other medical records.

- Diabetes was cited in the medical records of five individuals, but did not appear on the 3122 for these same individuals. One of these individuals was receiving insulin, and two were taking an oral medication for diabetes.

- Reflux disease was listed on the 3122 for nine individuals, while it appeared exclusively in other medical records for an equal number of persons. Three of the people for whom the diagnosis did not appear on the 3122 were taking medication for the condition. Similarly, other digestive ailments appeared as diagnoses in medical records for three times as many individuals than as recorded on the 3122.

- The diagnosis of hypertension did not appear on the 3122 for 6 of the 34 individuals in the sample carrying the diagnosis (18%). Two of the six people were receiving medication for the condition.

- Hyperlipidemia was cited on the 3122 form for nine individuals, but it appeared in other medical records for an additional eight persons. Four of these eight persons were receiving medication for the condition.

Examples of incomplete 3122 forms illustrate the seriousness of the problem and potential for error when assuming the document is an accurate reflection of the individual's health

status. Further, they lay open to question the level of attention paid by the physician in completing the form.

- The form for one woman cited two diagnoses: reflux disease and iron deficiency. Other medical records included diagnoses of schizophrenia, other digestive disorders, urinary tract disorder, and respiratory and skin disorders. This woman was taking seven medications for her medical conditions and Risperdal for schizophrenia.

- Similarly, a man was diagnosed with arthritis and mental retardation on the 3122 form. Seven additional diagnoses were cited in other medical records, and he was taking five medications for treatment of these additional health problems.

- One man diagnosed only with schizophrenia on the 3122 was taking six medications for health problems documented in other medical records.

If the 3122 served only as a form to document that the individual is appropriate for an adult home, our finding would not be particularly consequential. But, in fact, for many residents of adult homes, the completion of the 3122 by the physician constitutes the individual's annual physical evaluation and in some cases is the only medical history available to medical personnel in the event of an emergency. In addition, in many adult homes, particularly those who do not have a primary care physician coming on site, this form is the primary source of information about the health of a resident for the case manager. The finding that nearly all of the forms reviewed were inaccurate and /or incomplete points to the need for the Department of Health to reconsider both the purpose and content of the form. "Upgraded" 3122 forms would also facilitate any future assessments of adult home residents the Department of Health might undertake.

4. **Between approximately 50-60 percent of the relevant sampled individuals had received exams/screenings for dental care and eye care and tuberculosis. A similar percentage of women had gynecological exams and mammograms and men, prostate exams or PSA screening. Screening for colon cancer was significantly less frequent. The percentage of the CQC sample having had an annual gyn visit, dental visit and colon cancer screening was considerably less than for the general population. The percentage of persons in the sample reporting mammograms and prostate exams was the same as for the population at large.**

Commission staff examined the provision of commonly accepted health care screenings for the sampled population through review of the medical and adult home records and through interviews with the individuals and the adult home staff members most knowledgeable about these issues. It is important to note that reviewers looked for evidence of these exams/screenings in medical and adult home records. However, if we did not find this information (we did not have access to specialists' records in some cases), but an individual told reviewers he/she had had the exam/screening, we accepted this account. The screenings reviewed included: dental exams, eye care, mammograms, gynecological

exams, prostate exams or PSA readings, TB testing, and colon cancer screening. Standards related to age were taken into account.[6] The review showed fairly similar rates of compliance with the screenings, except for colon cancer screening, which was much lower.

Screening/Test	**# persons screened**	**% eligible persons screened**
Annual dental exam	39	56
Annual TB testing	37	54
Eye exam (q 3 years for persons 31-40)	5	62
Eye care (q 2 years for persons 41-60)	17	61
Eye care annually for persons 61 and older	20	61
Mammogram (q 2 years for women over 40)	18	60
Annual gyn exam	20	59
Colon cancer screening for persons over 49	15	35
Prostate exam /PSA for men over 49.	14	70

More than half of the relevant sample had been screened in eight of the nine areas under consideration. Approximately 60 percent of the relevant sample had received eye exams, mammograms and gyn exams. This latter result is considerably lower than the report from the 2002 Behavioral Risk Factor Surveillance System (BRFSS) data for New York State that reports 71 percent of women over 18 reported having had a Pap smear in the last year. Figures from the CQC sample regarding mammography compare more favorably with 2000 national data reporting that 70 percent of women over 40 having had a mammogram within the last two years.

The most favorable results were related to screening for prostate cancer, where 70 percent of the men in the Commission sample were screened. BRFSS figures for prostate screening cite the same figure for New York residents at large. In contrast, slightly over one third of the relevant sample had been screened for colon cancer (colonoscopy, sigmoidoscopy or occult blood testing). Statewide general population figures from 1999 indicate that between 47-56 percent of residents 50 or older had been screened. The percent of persons reporting dental visits in the CQC sample also lagged behind general NYS population data, with 56 percent of the sample reporting an annual visit as compared to 71 percent of the general population (BRFSS figures). There is no requirement for persons in adult homes to have an annual TB test.

The practice pattern of the primary care physician and the communication between the home and the physician appeared to be critical factors in whether individuals went for screenings. For example, in one home, the physician had not recommended dental, eye care, blood work or a mammogram for a female resident in over two years until the Commission questioned this. The physician responded by ordering the blood work and recommending a mammogram and dental and eye care. Similarly, the physician also ordered blood work for two other residents in the CQC sample, including a PSA level for

[6] Frequency and age standards generally reflect CDC standards or standards of disease-specific interest/research groups, e.g. American Cancer Society.

the male resident. In the same home, a female resident had refused blood work, an EKG, a mammogram and gyn care, but the physician had not advised the home, and hence the case manager was not in a position to encourage the resident to attend to these health care needs. The physician had made no referrals for colon cancer or TB testing for this resident.

5. At least eighty percent of the relevant persons in the Commission sample were receiving medical attention for chronic medical conditions under review. The care often included the attention of a specialist.

Commission staff used several simple measures to assess whether residents were receiving treatment for chronic medical conditions: review of dietary recommendations, review of medications, referral to specialists, and evidence of monitoring of the condition in the primary physician's notes. For example, staff looked for insulin, an oral hypoglycemic and/or a restricted sweets diet, finger sticks or referral to an endocrinologist for persons with a diagnosis of diabetes. Our findings include the following:

- Of the 17 individuals with a diagnosis of diabetes, 13 were treated with insulin or an oral medication. The remaining four individuals were on a "no concentrated sweets" diet.

- Sixteen of the 19 persons diagnosed with reflux disease (84%) were treated with medication.

- Ninety percent of the 31 people with a diagnosis of hypertension were being treated with medication.

- Medication was used to treat 83 percent of the people who had diagnoses of incontinence or urinary tract disorder.

- Hyperlipidemia was treated with medication for 13 of the 17 residents in the sample (80%). Approximately half of the sample, eight individuals, was prescribed low-fat or low-cholesterol diets.

- All persons diagnosed with schizophrenia were being treated with psychoactive medication.

Our review found numerous instances where individuals were being treated by specialists or in specialized clinics for serious medical conditions. An oncologist was treating each of the four individuals with cancer, for example. A gentleman in the sample was going weekly to an "Anti-coagulation Clinic" where his blood clotting time was monitored because he was taking anti-coagulation medication. Several residents were going regularly to diabetes clinics for diabetic teaching as well as for monitoring. Urologists were treating seven of the ten men diagnosed with urinary tract problems.

In contrast to these positive findings, ten persons in our sample were taking medications for which there was no corresponding diagnosis on the 3122 or in the PCP records. These

included cardiac, hypertension and glaucoma medications, and medications for arthritis, reflux and allergies.

Some primary care physicians and specialists were providing on-site services at the adult home. As identified in the Commission's Layering of Services Study, this sometimes meant that individuals were seen monthly by their primary care physician even when they had no complaints and had made no request to see him/her. It also sometimes meant that individuals were screened by specialists when they had no documented need for such. For example, in one home a dermatologist screened all residents. In other instances, the presence of on-site specialists seemed to encourage residents to take advantage of screenings and regular monitoring. For example, in one adult home, a gynecologist provided services monthly. The three female residents in our sample from this home had each had an annual mammogram and gynecological exam. This level of compliance with gynecological exams was higher than at any other study site.

6. Consistent with our finding that the persons studied had multiple health problems and were taking numerous medications, we found that they used medical services frequently. Specifically, the sampled persons used emergency department services significantly more often than the general population, and they were admitted to hospitals at four times the rate of the general NYS population.

Using 2001 data that reported emergency department (ED) use in the general population as 39 visits for every 100 persons,[7] the Commission study revealed that people in our adult home resident sample used this service 2.8 times the national average. The 69 people in our sample visited the ED 76 times in a one-year period. This count did not include eight visits to CPEPs. Twenty-nine people accounted for the 76 visits, leaving 40 individuals who did not use the ED during the study period. Looking more closely, seven people, each visiting the ED from four to ten times, accounted for 54 percent or 42 of the 76 visits. In short, 10 percent of the Commission sample accounted for over half the visits.

Similarly the adult home residents in the CQC sample were admitted for hospital stays approximately four times more frequently than the average New Yorker. Using 2002 figures, there were approximately 13 hospital admissions for every 100 persons in the general population in the state. In the CQC sample, this figure rose to 54 admissions per 100 persons or slightly more than four times the state general population figure. Thirty-seven people had hospital stays for medical or mental health reasons during the study period; 14 of these individuals experienced mental health admissions only.

Multiple admissions were far less frequent, however. Only seven individuals (10% of the sample) had two or more hospitalizations for medical issues and six individuals (9%) had more than one psychiatric admission.

[7] From website of Center for Studying Health System Change, referencing "National Hospital Ambulatory Medical Care Survey: 2001 Emergency Department Summary."

7. **Our study revealed evidence of a shift in health care coordination for persons in the adult homes studied. Increasingly, responsibility for coordination of health services had shifted from the case manager at the home to the provider of health services. Health information available to the case manager varied considerably.**

Adult home regulations charge the adult home case manager with responsibility for "establishing linkages with and arranging for services" from health and mental health services. Additionally, the case manager is required to assist adult home residents in making arrangements for "services, examinations and reports needed to maintain . . .the resident's health or mental health…."[8] The Commission's review found that in many adult homes, regardless of whether the primary care physician visited residents on site or individuals visited the practitioner in his/her office or clinic, scheduling appointments and making referrals to specialists and in general coordinating an individual's care was in the hands of the health practitioner.

In some homes, the health practitioner's receptionist/assistant made all necessary appointments for patients and provided the time and date to the adult home as a courtesy and to ensure that the person would be ready when transportation arrived. All information from consultations and screenings and exams went directly to the health care practitioner. Information was shared with the adult home only on a "need to know" basis, which generally meant that information was shared when there was a significant change in the individual's health status, when the individual needed extra care, or when the individual's condition could impact on the health of other residents.

Not surprisingly, the level of communication between the adult homes and the health care practitioners varied. In one home, the administrator/case manager knew very little about the health status of the residents. Most of the residents were admitted to the home from the hospital, which provided minimal information. The newly admitted resident was the sole source of historical health information and psycho-social information. In other homes, communication flowed more freely, and practitioners sent copies of relevant findings from exams/screenings to the adult homes. In homes where physicians practiced on site, the case manager was able to converse with the physician or leave a note alerting him/her to a problem or asking a question, thereby staying current regarding the changing health status of residents. Nonetheless, the effectiveness of communication varied in these situations also.

In contrast to practitioner coordination of health care, some physicians followed the more traditional style of ordering tests and consultations by writing prescriptions for these, with the expectation that the adult home would make the arrangements. In several of these homes, the consultation/exam results were sent to the adult home and the home took responsibility for forwarding them to the attention of the physician.

In no instance did the Commission find that the adult home lacked information such that it prevented the home from providing appropriate care or placed other residents at risk.

[8] 18 NYCRR Part 487 (12)(g)(vi)(viii)

8. A short interview with the persons in the sample indicated general satisfaction with their health care and comfort in reporting symptoms to staff when they were feeling ill. Answers to other questions sometimes resulted in conflicting information.

Commission staff interviewed all of the 69 people in the sample using eight straightforward questions. We believe that 54 of these individuals had a reasonable understanding of the questions we were asking and were able to respond. The remaining 15 individuals either could not focus on the question or were not able to remember the information needed to answer the questions. Thus, the results reported here reflect the answers of 54 individuals. A review of the interview results reveals inconsistent responses to several questions, but overall satisfaction among the respondents with their health care.

In answer to the fundamental question about how they felt most of the time, 45 individuals (83%) answered that they felt well. Eight people said they felt sick most of the time and one person was unable to answer. When asked if they had health problems, 37 people responded affirmatively, but only 31 individuals said they were receiving care for their problem. In apparent contradiction of this finding, fifty (93%) of the respondents said they were satisfied with their medical care. Significantly, 87 percent of the respondents said they felt comfortable relaying symptoms to staff when they felt ill. Only five people said they would not tell staff if they were ill (one person said she would go to the doctor independently) and two people were not sure. The vast majority of the respondents (83%) could provide the interviewer with the name of their primary physician. Many could also identify the specialists they saw.

Recommendations

Acknowledging the limited extent of the study, the Commission believes that our findings offer an opportunity for presenting several recommendations to improve care for adult home residents. Specifically:

- The Commission recommends that the Department review with surveillance staff, as necessary, the de facto changing locus of control for the coordination of mental and physical health treatment observed by the Commission, so that staff will assure that case management documentation clearly states the identity of the party responsible for coordination, particularly if it is not the adult home, and reflects receipt of essential health information necessary for the home to meet its obligation to an individual.

- The 3122 form should be revised to include additional information necessary to present an accurate and complete portrait of the individual's health status. Additionally, the Department should hold homes accountable for ensuring that physicians fill in all required areas on the forms.

- As a protection to adult home residents, the Department should consider requiring TB testing when an individual is admitted to an adult home, as well as when there is a clinical trigger for testing.