The Quality of Health Care for Adults with Developmental Disabilities

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SYNOPSIS

Objective. The purpose of this study was to determine the health status of adults with developmental disabilities residing in community settings and the quality of the preventive, medical, dental, and psychiatric services they receive.

Methods. Data were collected on a sample of 353 adults residing in Los Angeles, California, in 1997. Historical data were obtained from study subjects or caregivers, physical and dental examinations were performed, blood was drawn for analysis, and a psychiatrist reviewed medical records for reports of psychiatric diagnoses and consultations.

Results. Health markers, such as rates of obesity, and laboratory test results of routine screening panels including blood cell counts, hemoglobin, and hematocrits; blood concentrations of liver enzymes and other enzymes, cholesterol, and tryglycerides; and urinalyses were within normal limits for an adult population. However, preventive services were notably lacking, especially for individuals living at home. Fewer than half of the study subjects had received influenza vaccine; only a third of those living alone or with family or friends had received this vaccination. Chart audits revealed that about a third received psychotropic medications, but only 24% of these individuals had psychiatric consultations noted in their record. Further, 36% of this medicated group received psychotropic drugs without any identifiable diagnosis, and simultaneous receipt of two or more antipsychotics was not uncommon.

Conclusions. Given that the U.S. health care system fails to ensure the provision of preventive services for all people, including the developmentally disabled, a systematic overhaul is necessary to establish an effective quality assurance program that will provide preventive medical, dental, and psychiatric services for people with developmental disabilities.

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Access to quality health care for people with developmental disabilities has been a public health concern since the deinstitutionalization of this population in the 1970s.[1–3] Some studies have reported lower rates of tetanus vaccination and mammography, lower height and weight measurement,[4] the need for health screening,[5] the need to promote exercise to reduce cardiovascular risks,[6] as well as the need for evidence-based research on which to base the delivery of appropriate health care services.[7] Other studies have reported errors in medications administered to adults with mental retardation residing in community facilities,[8] the prevalence of polypharmacy for individuals with developmental disabilities who also had epilepsy,[9] and poor quality of dental care for individuals with developmental disabilities, including mental retardation.[10,11] However, there have been no comprehensive evaluations of the quality of care for developmentally disabled individuals who receive care from community physicians and reside alone, with family members/friends, or in group facilities in the community. To fill this gap and identify needed services, we evaluated a group of adults with developmental disabilities residing in Los Angeles, either in private homes or in group residential facilities, by conducting a comprehensive examination of their physical health, dental health, and the scope and nature of preventive and psychiatric services provided to them.

Given concerns raised about the provision of primary care services in the community for people with developmental disabilities,[3,4,12–14] this study sought to address quality of care issues by asking two questions: (*a*) What is the health status and what are the health habits of individuals with developmental disabilities who reside in community care facilities or in homes in the community (either in their own home with or without assistance or in the homes of family members or friends)? and (*b*) What is the quality of care provided to this population, particularly with regard to preventive health and dental services and the use of medications in managing psychiatric and seizure disorders?

METHODS

In 1997, we conducted a study of a group of 353 adults 18 years of age and older with developmental disabilities who received services from the Lanterman Regional Center in Los Angeles and who volunteered or whose guardians gave consent for a comprehensive health assessment. By definition, individuals with developmental disabilities include those with severe and chronic conditions that occur prior to 22 years of age; result from mental or physical disorders; and require interdisciplinary care. The developmentally disabled population includes not only the mentally retarded, but also those with cerebral palsy (who may or may not have cognitive deficits), autism, epilepsy, and a range of genetic syndromes.[15,16] The sample in this study represented 91% of 390 adults selected on a proportional sampling basis designed to include 50% women and to include approximately 15% living at home with or without assistance, 45% living at home with family or friends, and 40% living in group care facilities in the community. These living arrangements reflected those of the Lanterman population. Of the 37 adults who were selected but who did not participate in the study, 35 refused and records were unavailable for two. Of the 135 developmentally disabled adults living in community care facilities, 104 (77%) lived in small facilities (1–15 beds).

During the time of the study, the Lanterman Center oversaw the delivery of services to 2,032 adults with developmental disabilities. The Lanterman Center was one of 21 Regional Centers in California that coordinated services for approximately 62,603 developmentally disabled adults residing in communities during the study period. To determine the representativeness of the sample, we contrasted the demographic characteristics, location of residence (home or community care facility), and level of mental retardation of participants with those of the total Lanterman population of adults with developmental disabilities and the state population of adults with developmental disabilities. Statewide data were provided by the California Department of Developmental Services.

According to the Institutional Review Board for Human Subjects of the University of California, Los Angeles (UCLA), guardians had to provide consent and the study subjects also had to assent to participate.

Measures

Three family nurse practitioners obtained health histories from medical records, supplemented by information from study participants or caregivers, and performed complete physical examinations. Racial/ethnic information was obtained from the participants and the Lanterman records because of the known relationship between ethnicity and living arrangements.[17] Whenever possible, the health history included health habits related to exercise, smoking, any use of alcohol (beer, wine, or liquor and number of glasses in one usual sitting), and drug use. Questions regarding activities of daily living were asked to determine functional status. Sample questions addressed issues ranging from eating independently to being fed, walking alone to being bed/chair confined, and bowel and

bladder continence. Information was also elicited about sexual history, vaccination history, frequency of self-breast exam, and receipt of Pap tests. Information on cognitive status, including level of mental retardation; on receipt of vaccines; on preventive screening tests; and on medical conditions including seizure disorders, cerebral palsy, muscular dystrophy, spina bifida with paralysis, and autism was obtained from the Lanterman records.

Seventy-seven individuals who were not mentally retarded or those who were mildly retarded (I.Q. 70–90 according to Lanterman records) completed their own history forms, while history forms were completed by caregivers for 276 participants. The name of the personal physician, if applicable, was obtained from the individual or his/her caregiver. For each physician, information about graduation from a U.S. or foreign medical school was obtained from the directory of the American Medical Association.[18] We hypothesized that there would be no differences in the quality of care rendered to clients by physicians who were graduates of U.S. medical schools vs. by those who were graduates of foreign medical schools (international medical graduates), as measured by the receipt of preventive services.[19,20]

The comprehensive physical examination, including neurological assessment, required from one and a half to two hours. A vaginal examination and Pap test were performed on those women who agreed to these procedures. Blood for laboratory studies—i.e., blood cell counts, glucose, hemoglobin, hematocrits, urinalyses, and blood concentrations of liver enzymes and other enzymes, cholesterol, and triglycerides—was drawn by the study phlebotomist from 222 individuals who agreed to this procedure, either at the time of the physical examination or in the subject's home or community care facility. Participants' personal physicians were notified of acute or chronic problems that were identified and required attention. Those lacking personal physicians were referred to staff physicians at the UCLA Medical Center for medical care.

The Body Mass Index (BMI), a standard method of assessing ideal body weight, was used to determine the prevalence of weight problems in the study sample. The BMI is calculated as weight in kilograms divided by height in meters squared. According to the World Health Organization, the normal range for body weight is a BMI from 18.5 to 24.9.[21] A value in the 25–29.9 range is classified as overweight. BMIs of 30–39.9 and greater than 40 indicate the most severe health risk. The latter two categories were pooled for our analyses.

A dentist conducted examinations either in the individual's residence or at the Lanterman Center. Information was also collected about who was responsible for brushing the subject's teeth and whether the subject had a personal dentist. The dental assessment included standardized notations regarding the presence/absence of all 32 teeth; whether, if missing, they had been replaced by prostheses; the crown status of each tooth (sound, carious, restored, or restored and carious); tooth mobility; and the presence of abscesses, candidiasis (visual assessment), hyperplasia, or leukoplakia. The examiner also made subjective ratings of the appearance of the teeth, the client's overall dental health status (citing reasons for fair and poor ratings), and the urgency of need for dental care. After the examination, clients and caregivers were advised if treatment was needed.

A central record is maintained on each of the clients of the Lanterman Center. As medical services are not directly provided by the Center, medical records are collected over time through requests from the Center to primary care and specialist physicians, clinics, and hospitals. An individual client's case manager reviews and updates records at least annually, specifically noting prescribed medications and the treatment of medical conditions that are ongoing or that emerged over the preceding year. The study psychiatrist (BHK) reviewed these records specifically for any report of psychiatric consultation, either evidenced by a psychiatrist's note or a reference in any other medical note. Any psychiatric diagnosis was recorded, whether or not there was evidence that it had originated from a mental health clinician's evaluation. A psychiatric diagnosis was considered present when a recognizable *Diagnostic and Statistical Manual of Medical Disorders (DSM)* term was used, independent of whether criteria were evident to support that diagnosis. Thus, "depression" would have been counted as a diagnosis, but "aggression" would not. In some cases, the diagnosis or consultation may have been rendered several years earlier. The study psychiatrist also recorded all mentions of psychotropic and anticonvulsant medications.

Data analysis

Chi-square tests were used to assess differences in BMI and other categorical variables between adults with developmental disabilities who lived in their homes with or without assistance, those who lived at home with parents or other family members or friends, and those who resided in community care facilities. Differences in continuous variables for participants in the three groups were examined using analysis of variance.

A preventive services index defined by receipt of a flu shot within the past year, a TB skin test within the past 10 years, hepatitis B vaccine, and a tetanus booster

within the past 10 years was calculated for male study participants. The preventive services index calculated for women included a Pap smear within the past three years. Differences in these preventive service indices in relation to the physician status of each study participant as a graduate of either a U.S. or international medical school were assessed with *t*-tests. Logistic regression analysis was conducted to examine the effects of living arrangements on receipt of important preventive services (flu shots, TB tests, hepatitis B vaccination, tetanus shots, if needed, HIV tests, and Pap tests within the past three years for women) by individuals in the sample who had personal physicians to control for potential confounders including the effect of having a physician who was an international medical graduate. Since some patients shared a common personal physician, Huber corrections were applied to adjust for this clustering (Stata, Version 6).[22] In the multivariate analyses we wanted to control for ethnicity to isolate the effects of living arrangements on use of preventive services, given the observed association between living situation and ethnicity.

RESULTS

Results of the physical examination (n = 353) indicated that fewer than 5% of participants had elevated systolic (>140 mm hg) or diastolic (>90 mm hg) blood pressures. Of the 222 individuals with laboratory studies, 10% tested positive for hypercholesterolemia, i.e., had values in excess of 240 mg/dL, and 5% had hemoglobin levels lower than 12 g/mdL. About a quarter of these 222 individuals showed evidence of leukopenia, i.e., low white blood count (<5), and 2% had high blood sugar levels (>120 mg).

According to records, more than a quarter of the total sample of 353 had epilepsy. About a tenth of the sample had a diagnosis of Down syndrome, a tenth had a diagnosis of cerebral palsy, and another tenth had a diagnosis of autism.

One record was not available for the medication review. According to the review, about half of the study participants (172/352 = 49%) were receiving psychotropic medication, defined to include anticonvulsants. Considering only the classes of psychotropic drugs that would be prescribed almost exclusively for behavioral health and not for other medical conditions (i.e., antipsychotics, antidepressants, lithium, stimulants, and anxiolytics), nearly a third (110/352 = 31%) were medicated. Only a quarter (27/110; 24%) of those medicated with psychotropics had evidence of a psychiatric consultation in their record, and slightly over a third (40/110; 36%) of the medicated population was receiving at least one of the above types of psychotropic medications without any identifiable psychiatric diagnosis. Among those receiving antipsychotic drugs, 31% (25/80) had no identifiable psychiatric diagnosis in their records. In contrast, 80/92 (87%) of subjects receiving anticonvulsant medication had a diagnosis of a seizure disorder according to their medical records.

Examination of the relationship between the presence of mental retardation (as determined from medical records) and psychiatric consultation revealed that clients without mental retardation (12/56; 21%) were nearly twice as likely to have psychiatric consultations available in their records as were those with mental retardation (34/296; 11%; $p<0.05$, chi-square test). In contrast, among subjects who were receiving a psychotropic medication, the likelihood that it was an antipsychotic medication was much greater in the presence of mental retardation (78/98 [80%] of those with retardation vs. 4/12 [33%] of those without; $p<0.01$; Fisher's exact test).

Among study participants receiving antipsychotic drugs (n = 82), 10 (12%) were taking more than one, and one individual was taking three different antipsychotics. Among those receiving anticonvulsants (n = 92), 36 (39%) were taking two different medications, another seven were taking three different medications, and two individuals were taking four different medications (not including benzodiazepines). Just over half of the study participants on anticonvulsants were taking phenobarbital and/or phenytoin (48/92; 52%).

Table 1 shows the age, gender, location of residence, ethnicity, and level of mentalretardation of the 353 participants in this study compared with those of the entire population ofadults 18 years and older served by the Lanterman Center and the state population of adults withdevelopmental disabilities. As shown, there were moderate differences between the study sample and the state population. As expected, there was a lower percentage of individuals identified as white in our Los Angeles area sample than in the other populations; it is estimated that more than a third of the Los Angeles population is Hispanic.[23] The study participants were somewhat less likely to have moderate mental retardation than the adult developmentally disabled population of the state or the total Lanterman adult population ($p<0.05$). They were also about twice as likely as the members of these comparison groups to have no mental retardation ($p<0.001$).

Table 2 shows demographic information, level of mental retardation, BMI, and functional status based on site of residence, i.e., living at home independently or with assistance, at home with family/friends, or residing in a group facility. Three individuals changed

Table 1. Comparison of characteristics of developmentally disabled adults in state of California, 1997 (*N* = 76,755), adult clients of Lanterman Center (*N* = 2,457), and the study sample (*N* = 353)

Characteristic	*State developmentally disabled adult population (N = 76,755)*		*Lanterman adult population (N = 2,457)*		*Study sample (N = 353)*	
Mean age (years)	34.5		35.4		35.8	
	Number	*Percent*	*Number*	*Percent*	*Number*	*Percent*
Gender						
Female	34,622	45.1	1,083	44.1	177	50.1
Male	42,133	54.9	1,374	55.9	176	49.9
Residence[a,b]						
At home with or without assistance	11,774	17.9	208	10.1	56	15.9
With family/friends	35,003	53.3	1,103	53.3	161	45.6
Community care facilities	18,863	28.7	757	36.6	136	38.5
Ethnicity						
African American	7,783	10.1	263	10.7	50	14.2
Hispanic	15,238	19.9	641	26.1	104	29.5
White	45,012	58.6	1,120	45.6	151	42.8
Other	8,722	11.4	433	17.6	48	13.6
Level of mental retardation						
None	8,048	10.5	180	7.3	56	15.9
Mild	30,274	39.4	933	38.0	131	37.1
Moderate	18,011	23.5	517	21.0	58	16.4
Severe	9,876	12.9	347	14.1	52	14.7
Profound	9,524	12.4	423	17.2	54	15.3
Unspecified/missing	1,022	1.3	57	2.3	2	0.6

[a]Excluding state developmental centers, intermediate care facilities, and skilled nursing homes

[b]For state developmentally disabled adult population, *n* = 65,640; for Lanterman adult population, *n* = 2068

their living arrangement during the study period and were not included in these totals. In addition, the *n*'s for some questions varied slightly from the *n*'s shown in Table 2 because of missing data.

Half of the 350 participants were women. More participants lived at home than in community care facilities. The vast majority (93%) of the sample had never been married. Compared to their overall representation in the sample, Hispanic clients were found to have disproportionate numbers living at home, either independently or with assistance, or with parents, other family members or friends, whereas white clients were disproportionately living in community care facilities (62% in facilities vs. 43% in homes). Of the 350 participants, 16% were not mentally retarded; almost half of those who lived in their own homes were not mentally retarded (49%). More than a third (130/350) were classified as having mild mental retardation. Almost a third of participants residing in community facilities had profound mental retardation, and about a quarter were incontinent of bowel. Those individuals without mental retardation had conditions requiring services similar to those with mental retardation; these included seizure disorders, cerebral palsy, muscular dystrophy, spina bifida with paralysis, and autism (not shown).

About a tenth of the 350 clients were underweight, with BMIs of less than 18.5. A third were within the normal weight range (BMI 18.5–24.9), with individuals living in facilities most likely to fall into this category. A quarter of the sample was overweight (BMI 25–30). Moreover, almost 40% of those individuals living at home with or without assistance were identified as obese, and more than a third of those living with family or friends were found to be obese. Individuals with a profound level of mental retardation had the lowest BMIs (not shown). There was no difference in BMIs by place of residence among those who had mild or moderate mental retardation.

Health habit information is presented in Table 3 for the 325 clients who had stable living arrangements. Information provided by individuals or their caregivers indicated that 40% of developmentally disabled individuals who lived independently said they wanted to

Table 2. Characteristics of clients living at home, living with family/friends, and living in community care facilities (n = 350 clients)

Characteristic	*Living at home with or without assistance (n = 55)*	*Living with family/friends (n = 160)*	*Living in community care facilities (n = 135)*	*Total (n = 350)*
Mean age (years)[a]	41.0	28.7	42.1	35.8
	Percent	*Percent*	*Percent*	*Percent*
Female	47.3	49.4	54.6	51.0
Never married[a]	68.5	96.9	97.8	92.8
Ethnicity[a]				
African American	9.3	19.6	10.5	14.5
Hispanic	35.2	38.0	16.5	29.3
White	42.6	27.2	61.7	42.9
Other	13.0	15.2	11.3	13.3
Education				
No formal education[a]	9.1	7.6	22.0	13.3
Completed high school[a]	41.8	49.7	15.9	35.6
Mental retardation[a]				
None	49.1	14.5	3.7	15.8
Mild	41.8	45.9	24.6	37.1
Moderate	5.5	18.9	18.7	16.7
Severe	1.8	14.5	20.9	14.9
Profound	1.8	6.3	32.1	15.5
Body Mass Index[c]				
Underweight (<18.5)	3.7	12.5	12.0	10.8
Normal (18.5–24.9)	29.6	30.6	41.0	34.3
Overweight (25–29.9)	27.8	22.2	29.1	25.7
Obese (≥30.0)	38.9	34.7	18.0	29.2
Functional status				
Walks without help[a]	88.7	87.3	71.9	81.5
Continent of bladder[a]	90.9	82.4	64.4	76.8
Continent of bowel[b]	90.9	88.1	74.1	83.1

[a]Group differences significant at $p<0.001$

[b]Group differences significant at $p<0.01$

[c]Group differences significant at $p<0.05$

lose weight, compared with one-quarter of those living with family or friends and fewer than one-fifth of those living in community care facilities. There were no differences in patterns of regular exercise among the three groups, but smoking and drinking alcohol were mainly concentrated among those living by themselves.

Data on preventive services (Table 3) show that the vast majority (96%) of individuals living in community care facilities had received a TB skin test within the past 10 years, compared with about three-quarters (78%) of those living with family/friends and about two-thirds (69%) of those living in their own homes. Almost three-quarters (71%) of the community care facility residents had received the flu vaccine in the past year, while approximately one-third (34%) of those living independently and about a quarter of those living with family/friends had received the vaccine in that time frame. Fewer than half (47%) of study subjects residing in community care facilities had received hepatitis B vaccine, and only about a fifth of those living independently or with family/friends had been vaccinated for hepatitis B. About a quarter (24%) of those living alone had been tested for HIV, compared with 3% of those living with family/friends and 4% of those living in community care facilities.

Table 3 shows that, among 169 women, fewer than half (39%) had received a Pap smear within the past three years. Among those living at home with or without assistance, almost two-thirds had received a Pap smear during that time period, compared with just a

quarter of those living with family/friends. Fewer than half of the women living in community care facilities had been screened for cervical cancer.

Among 28 women who were sexually active, according to self- or caregiver report, cervical cancer screening rates ranged from 100% for those living in community care facilities to 86% for those living with family/friends (not shown). Of women whose caregivers provided relevant information, 7% (9/130) were reported to perform breast self-examinations, while 29% of women who self-reported (10/34) said they did breast self-examinations. Among the 66 women 40 years and older, 23% had reportedly had a mammogram within the past year.

Slightly more than half of the men (184/353 = 52%) agreed to a rectal examination. Ninety percent had normal exams and 8% had nodules.

The majority (88%) of the 350 study participants with stable living arrangements had personal physicians (Table 3). However, only about three-quarters of those living with family/friends had personal physicians, compared with 99% of those residing in group facilities and 91% of those living independently.

Sub-analyses of data on participants with personal physicians revealed a number of noteworthy findings. Among those with personal physicians, almost half of the residents in community care facilities had physicians who were international medical graduates, com-

Table 3. Health habits, health practices, and dental status of clients living at home, living with family/friends, and living in community care facilities (*n* = 325 clients)

Characteristic	*Living at home with or without assistance (n = 55)* *Percent*	*Living with family/friends (n = 160)* *Percent*	*Living in community care facilities (n = 135)* *Percent*	*Total (n = 325)* *Percent*
Health habits				
Want to lose weight[b]	40.0	25.0	19.3	25.1
Exercise regularly	36.4	43.8	40.0	41.1
Smoke[a]	20.0	3.1	5.2	6.6
Drink alcohol[a]	20.0	9.4	1.5	8.1
Preventive health practices				
Received TB skin test within past 10 years[a]	69.1	78.0	96.3	83.7
Received tetanus booster within past 10 years[c]	47.3	65.0	51.9	57.1
Received influenza vaccine within past year[a]	34.0	27.7	71.1	45.5
Received hepatitis B vaccine[a]	21.8	21.4	46.7	31.2
HIV tested[a]	23.6	3.1	3.7	6.6
	n = *25*	n = *75*	n = *69*	n = *169*
Women who had Pap smear within past 3 years[a]	64.0	25.3	44.9	39.1
Health providers	n = *55*	n = *160*	n = *135*	n = *350*
Had a personal physician[a]	90.9	76.9	99.3	87.7
	n = *48*	n = *144*	n = *129*	n = *321*
Had a personal dentist[a,d]	74.5	68.5	95.3	80.2
Dental health status[c,d]	n = *47*	n = *142*	n = *126*	n = *315*
Good	21.3	19.7	8.7	15.6
Fair	72.3	76.8	81.8	78.1
Poor	6.4	3.5	9.5	6.4

[a]Group differences significant at $p<0.001$

[b]Group differences significant at $p<0.01$

[c]Group differences significant at $p<0.05$

[d]As determined by the study dentist

pared with one-third of those who lived at home with family/friends, and one-fifth of those living by themselves ($p<0.001$). An examination of the relative proportions of U.S. physicians and foreign medical graduates providing care for the individuals with personal physicians revealed that the proportion of physicians certified by one of the American Boards of Medical Specialties was approximately twice as high for U.S. medical graduates (72%) as for those who were foreign medical graduates (39%; $p<0.001$, chi-square test).[18] There were no differences between the preventive services indices of study participants whose physicians were graduates of U.S. medical programs and those whose physicians were international graduates. All of the women received at least one of the preventive services. Of the 16 male participants who received no preventive services, 12 had physicians who were graduates of U.S. medical programs and 4 did not have personal physicians.

As shown in Table 3, among those with dental information, the vast majority (95%) of individuals living in community facilities were reported to have personal dentists. However, only 9% of those who lived in community facilities and were examined by the study dentist, and only 16% of 325 study subjects, had "good" dental health status. Dental health status was rated as "fair" for more than three-quarters of the examined participants. The dental data are presented in more detail elsewhere.[24]

Results of logistic regression analyses of receipt of preventive services among individuals with personal physicians are presented in Table 4. As shown, analyses that were controlled for sex, ethnicity, age, severity of mental retardation, bladder continence, ability to perform basic activities of daily living, and physician's graduate status revealed that individuals living in the community, either alone or with friends and family, were less likely to receive flu shots or to be tested for TB than those living in group facilities. Those living with friends or family were also less likely to receive hepatitis B vaccinations than those living in group facilities. However, those living alone were more likely to have been tested for HIV. Living arrangements were not related to having an updated tetanus booster. Women living with friends or family were less likely than those living in community facilities to have received a Pap smear within the past three years (odds ratio [OR] = 0.18; 95% CI 0.06, 0.58; $p<0.01$). Physician graduate status was not an important predictor in any of these models (not shown).

DISCUSSION

This study found that individuals living independently were more than twice as likely as those in facilities to want to lose weight and more than twice as likely to need to lose weight, which most likely reflects greater (or less restricted) access to food, coupled with failure to exercise on a regular basis. Those individuals with developmental disabilities living alone, or with family/friends, had the highest rates of obesity. Their rates of obesity were similar to those of the general population of adults without developmental disabilities in the nation.[25] For those living at home with or without assistance, the prevalence of smoking was comparable to that of the general adult population of the United

Table 4. Adjusted odds of receiving selected preventive services for clients with personal physicians who lived in their own homes or the homes of family/friends, compared with those who lived in community facilities (*n* = 290 clients)

	Influenza vaccination		*Hepatitis B vaccination*		*TB skin test*		*HIV test*		*Tetanus booster*	
Residence	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
At home with or without assistance	0.15	0.07, 0.35[a]	0.50	0.22, 1.12	0.12	0.02, 0.67[c]	6.24	1.67, 23.3[b]	0.86	0.32, 2.33
With family/friends	0.16	0.08, 0.36[a]	0.22	0.10, 0.47[a]	0.16	0.03, 1.00[c]	1.02	0.23, 4.60	1.70	0.75, 3.84

NOTE: Odds ratios adjusted for the linear effects of sex, ethnicity, age, severity of mental retardation, bladder continence, ability to perform basic activities of daily living, and physician's graduate status

[a]$p<0.001$

[b]$p<0.01$

[c]$p<0.05$

OR = odds ratio

CI = confidence interval

States,[26,27] while the prevalence of drinking alcohol (20%) was lower than that reported for national samples.[28] Thus the health habits and BMIs of the developmentally disabled individuals in this study were no worse than those in the general population of adults without developmental disabilities in the United States.

Slightly more than 10% of the individuals examined had hypercholesterolemia, i.e., cholesterol in excess of 240 mg/dL,[29] which may reflect inactivity, excess weight, and the nutritional content of food consumed. However, this rate is relatively low compared to the 19% prevalence rate found in a national sample.[30]

More than three-quarters of the individuals examined received an assessment of "fair" dental health status—which is associated with inadequate dental care[31]—despite the high proportion of those who lived at home with family or friends. However, the majority of individuals residing in community care facilities had personal dentists, as did three-quarters of those living at home and more than two-thirds of those living with family members or friends. The main reasons for rendering fair or poor assessments were poor oral hygiene and lack of evidence of preventive care.

The results of the record reviews raise concerns about the quality of psychiatric and neurologic care for this population. Slightly more than one in 10 individuals receiving neuroleptics received intraclass polypharmacy, a practice for which specific cautions have been issued.[32,33] Similarly, half of those receiving anticonvulsant medication were taking phenobarbital or phenytoin—drugs for which specific cautions have also been raised for persons with developmental disabilities.[34]

In the absence of a general population control group, it is not possible to comment on whether people with disabilities are more likely to receive substandard psychiatric or neurologic care. It is noteworthy, however, that within our study sample, individuals without mental retardation were more likely to have evidence of psychiatric consultation than were those with cognitive disability.

One of the problems associated with medical record reviews is the possibility that some individuals were receiving undocumented care. Some of the study subjects may have been diagnosed by mental health professionals with conditions for which medication could be indicated without these diagnoses being noted in their files. However, this is unlikely to account for the rate of use of psychotropic medications without accompanying diagnoses for two reasons. First, at annual reviews for all of the Lanterman clients, neurological, psychiatric, and other specialty medical visits and findings are specifically highlighted. Second, if a consultant's diagnosis were driving the prescription of a particular medication, it would seem unlikely that the prescribing physician would fail to document such a diagnosis. Thus, nearly 90% of study subjects who were on anticonvulsants had identifiable references to seizures or epilepsy in their records.

In any case, the diagnostic justification for the administration of a psychotropic medication should not be a mystery, and the lack of such justification raises concerns about poor clinical care. As noted earlier, in the absence of a control group, we cannot conclude that the care for people with disabilities is worse than that for the general population. However, treatment guidelines for people with mental retardation are clear with respect to the need for psychopharmacological interventions to be diagnosis-driven.[32,35,36]

Virtually all of the individuals living in community care facilities had personal physicians, yet only half of those with personal physicians were protected against tetanus, fewer than half were protected against hepatitis B, and fewer than three-quarters had received influenza vaccine during the previous year. Moreover, for the women in the study, including those in group facilities, cervical cancer screening rates were inadequate. These findings suggest that the provision of preventive services was not a high priority for physicians caring for these individuals. A variety of factors may be contributory. Most people with developmental disabilities require more than the usual time allotted for a provider encounter.[37] People with developmental disabilities may have difficulties communicating, and thus may be viewed as less desirable patients,[38,39] which reduces their chances of receiving recommended preventive services. It is reassuring that of 28 sexually active women, only one had not received a Pap smear within three years. However, in general, it is apparent that guidelines governing the provision of preventive services for this vulnerable population must include both specific recommendations and an effective monitoring system that ensures the provision of adequate reimbursement for appropriate preventive services.

The preventive services provided were generally even less adequate for those individuals living at home independently or with family/friends. Although the majority of those living alone or with family/friends had personal physicians, they were less likely than those in group facilities to have been skin-tested for TB or to have received the influenza vaccine in analyses adjusted for important demographic characteristics, functional status, level of mental retardation, and physician graduate status. Those living with family/friends were also less likely than those in group facilities to have received the hepatitis B vaccine, and women living with family and friends were less likely than those

in group facilities to have received a Pap smear within the past three years. However, individuals living alone were more likely to have been HIV-tested. Some researchers contend that inferences about quality of care have been based primarily on structural variables, including board certification of physicians.[19,20] They conclude that no definitive answer about quality of care provided by foreign trained physicians is available at this time. However, the data from this report show no evidence that care was less adequate among those being cared for by international medical graduates.

All of the participants who agreed to be in this study were volunteers; thus, there are major limitations to generalizing the results to other populations of developmentally disabled adults. There were moderate differences in ethnicity between the study sample and the state population of developmentally disabled adults, as well as between the study sample and the Lanterman adult population. However, approximately half of the adults in the state and Lanterman populations lived at home with family and friends. Furthermore, 10% to 18% of the adults in the state and Lanterman groups lived in their homes with or without assistance. Thus, our findings related to living situation should be generalizable to these populations.

After the findings of this study were made available to the administrative staff of the Lanterman Center, several health and wellness interventions were initiated to address the problems reported. These interventions focus on the clients, parents/providers, and the health system. Some of the consumer interventions include an annual health status review, along with a review of medication utilization by a pharmacist in each community care facility; a health care passport, which has information to assist physicians in emergency departments and hospitals; and dental assessments/care by a dental hygienist. Some of the parent/provider interventions include review of medication handling in community-based facilities, utilization of a Head-To-Toe Assessment form to identify early signs and symptoms of disease/illness, training caregivers and service coordinators on oral health, and utilization of a set of nursing protocols to prevent complications of health problems. Some of the health system interventions include expansion of physician and dental networks; redesign of the family practice residency curriculum at the UCLA School of Medicine, including clinical experiences with people with developmental disabilities; a training video for medical students on physician attitudes toward patients with developmental disabilities; and the distribution of preventive health guidelines to all physicians caring for Lanterman clients.

Community-based care is the predominant service mode for individuals with developmental disabilities. However, given the reluctance of some physicians to provide care for these patients—due to attitudes related to provision of health promotion services,[38] lack of formal training in caring for these individuals,[17] as well as financial disincentives—system changes will be required in order to improve the quality of care provided. Thus, it will take time before improved outcomes are evident. Similarly, efforts directed toward changing broader health care system reimbursement policies and implementing a quality assurance program are beyond the control of the Lanterman Center and other Regional Centers. It will require the California legislature to appropriate adequate resources, and the Department of Health Services to collaborate with the Regional Centers and the Department of Developmental Services, to improve the delivery of health services for this vulnerable population.

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