

Index

- Abt Associates, Inc.*, 355, 356
ACCESS, 160
Accreditation Council for Graduate Medical Education (ACGME), 348, 349
ACTION, 29
Activities of daily living (ADLs), 70-72, 71, 211, 227, 292-294, 301, 378-379, 499
 reliability and validity of instruments, 294-299, 317
Acute brain syndrome. See Delirium
Adjudication, competence, 172-173
Administration on Aging (AOA), 42, 262, 350
 education and training by, 357-359
 Long-Term Care Gerontology Centers of, 2.5
 research funding by, 47, 50
 subsidies to private charities by, 455
Adult day care, 228-230, 248-252
Advance Directive Principle, 183
Adverse selection, 452, 453, 454
Ageism
 diagnostic error and, 88
 physicians and, 345
Aging and Health Policy Center (AHPC), 375, 388
Agnosia, 69-70
Aid to Families with Dependent Children (AFDC), maximum benefit and need standards of, 422
Aid to the Aged, Blind, and Disabled (AABD), 422
AIDS dementia, 16, 33, 116
Alzheimer, Alois, 97, 98
Alzheimer's disease
 characteristics of, 97-100
 clearinghouse for, 50-51
 diagnosis of, 91-93, 94, 95-96
 diagnostic tests for, 480, 481
 Down's syndrome relationship with, 117-118
 duration of, 14
 familial, 101-102, 103, 116
 funding delay for, 488
 heterogeneity of, 100
 informed consent and, 186-188
 MAD scale and, 308
 Pick's disease relationship with, 117, 118
 possible causes of, 100-106
 postulated causes of, 481-482
 prevalence of, 7, 9, 11, 16, 61, 62-63, 80
 public awareness of, 3
 registry for, 8
 special entitlements for, 38
 specialized care for, 243
 specialized program for, 254
 stages of, 63-67
 Symptoms of, 10-11, 61-62
 treatment issues of, 106-111
 See also Disorders, dementing
Alzheimer's Disease and Related Disorders Association (ADRDA), 3, 7, 48, 148, 491, 493
adult day care centers and, 229
alternative services used by, 247, 248, 2.53
Atlanta area chapter of, 249, 250
behavioral problems and, 72
caregiver survey of, 17-18, 20, 23-25, 32, 70-71, 72, 135-136, 137, 139-143, 14.5-149, 151, 159, 210, 218, 222, 232, 245, 245, 247, 247, 248, 251, 252, 255
caregiver training and, 41, 42, 253
"diagnostic approach" conference by, 96
diagnostic criteria of, 39, 60
family support by, 30, 32
Medicaid biases and, 145
multidisciplinary training by, 331
referrals to long-term care services by, 233
research funding by, 4, 47, 50, 490, 491
service coordination by, 22
specialized care cost estimate by, 251
support groups of, 454
Alzheimer's and Related Diseases Task Force, Kansas, 227
Alzheimer's Disease and Associated Disorders, 4
Alzheimer Disease and Related Dementias Services Research Act, 50
Alzheimer's Disease Assessment Scale, 302
Alzheimer's Disease Research Centers, 8, 487
Alzheimer's Family Center, Inc. (California), 251
Alzheimer's Resource Center of New York City, 42
American Association of Homes for the Aged (AAHA), 45, 256
American Association of Retired Persons (AARP), 28, 154
 long-term care insurance by, 4.52
 Medicare survey by, 451
 respite care programs of, 154
American Board of Family Practice, 348-349
American Board of Internal Medicine, 349
American Board of Urologic Allied Health Professionals, 340
American College of Health Care Administrators (ACHCA), 353
American Express, 251
American Federation for Aging Research (AFAR), 4, 47, 491
American Geriatrics Society (AGS), 349
American Health Care Association, 41, 4.5, 46
 multidisciplinary training by, 331
 peer review by, 394
American Journal of Alzheimer's Care, 4
American Medical Association (AMA)
 certification by, 334
 diagnostic review by, 96
 surrogate decision respect and, 185
American Nurses Association (ANA)
 nurse specialist certification by, 339-340
 professional reviews by, 395
American Psychiatric Association, 7, 12, 39, 60

NOTE: Page numbers appearing in italics are referring to information mentioned in the tables or figures.

- American Psychological Association (APA), 353
 Amyotrophic lateral sclerosis, 104
 Andrus Foundation, 154
 Aphasia, 69
 Apraxia, 69
 Area Health Education Centers (AHECs), 335
 Arizona, 215, 384, 385
 Arkansas, 384, 385
 Asp, Jan, 85
 Assessment,
 behavioral, 301-304
 caregiver burden, 309-311
 cognitive, 39, 43-44, 63-67, 215-216, 217, 232, 249, 250, 279-292, 461-462
 conduction of, 311-312
 functional, 171-172
 funding of, 314-15
 instruments of, 21, 43-44, 63-67, 279-299, 302-304, 305-309, 461-462
 multidimensional, 305-309, 312-314
 self-care ability, 292-301
 setting for, 312-314
 skills for nurses, 341-342
 uses of, 273-279, 304-305, 311
 Associated Press (AP), 108
 Association of University Programs in Health Administration, 353
 Atlanta Community Services Program, 250
 Autopsy, dementia confirmation through, 15
- Baltimore, Maryland, 19, 231, 282, 291, 305
 Battelle Memorial Institute, 17
 Behavioral and Mood Disturbance Scale, 302, 303
 Behavioral problems, 75-77, 137, 137
 drug treatment of, 14, 74, 110
 instruments to measure, 302-304
 management of, 261-262
 nursing homes and, 216-217, 255, 302, 302
 special care facilities and, 254, 258-259
 Best Interest Principle, 183
 Beverly Enterprises, 394
 Bibliometrics, 486
 Binswanger's disease, 113
 Birren, James, 86
 Blessed assessment test, 317
 Block grants, social services, 18, 24, 204-205, 207, 220, 223, 224, 229, 230, 389, 441, 457
 Bowen, Otis, 8, 46, 473, 477
 Brief Cognitive Rating Scale, 63, 64, 216
 Brief Psychiatric Rating Scale (BPRS), 302
 Brody, Elaine, 1
 Brookings Institution, 46
 Burden Interview, The, 310, 310
 Bureau of Health Professionals (BHP), 330, 341
 geriatric projects of, 358-359
 paraprofessional training by, 343
- California
 adult day care in, 248, 250, 251
 Alzheimer's Disease Diagnostic and Treatment Centers in, 317
 cost study by, 17
 deeming exceptions in, 429
 diagnostic classification in, 12, 13
 DPAHC legislation in, 174
 long-term care enforcement in, 402
 MPTP manufacture in, 114, 488
 multi-service programs in, 252
 nursing home study in, 384, 385
 quality assurance legislation in, 255, 266
 services in, 8, 22, 39
 staffing regulations in, 355
 surrogates and, 176, 179, 185
 California, University of, at San Diego, 251
 California, University of, at San Francisco, 253
 Canada, 472
 Care
 in-home, 3, 15, 20-21, 22, 42-43, 135-152, 222-228, 309-311
 medical model of, 245, 246, 267, 382
 multidisciplinary, 331-333
 nursing model of, 330
 process and structural standards of, 396-399
 quality of, 44-45, 217-218, 221, 226-227, 370-405
 regulating quality of, 381-391, 395-404
 respite, 8, 141, 152-157, 244-262
 social model of, 245, 246, 267
 types of, given, 137-138
 See *also* Long-term care; Special care
 Caregivers
 burden, 138-150, 309-311
 employment status of family, 140
 ethical questions for, 79
 family as, 135-152, 309-311
 family doctor rating by, 148
 financial impact on family, 141-145, 141, 143, 144, 245, 449-455
 medication use by, 139, 155
 OTA survey of, 17-18, 20, 23-25, 32, 70-71, 72, 135-143, 145, 149, 151, 152, 157, 159, 210, 218, 222, 232, 245, 245, 247, 247, 248, 251, 252, 255
 support, 30, 34-35, 43
 training family, 41, 252-253
 Care settings, 15, 211-231, 247-253
 dementia patient, 25
 effect of, on dementia patients, 246, 247
 patient's response to, 72, 75, 81
 surrogate decisionmaking and, 182
 See *also* Living arrangements
 Care, specialized. See Special care
 Case management, 39, 148, 160-161, 342
 assessment and, 274-275
 Case mix formulas, 277-278, 299, 304
 Catastrophic reactions, 73-74
 CBS, 3, 108
 Centers for Disease Control (CDC), 492
 Cerebrospinal fluid (CSF)
 tests, 91-93
 Certified occupational therapist (OT), 351
 Certified occupational therapy assistant (COTA), 351
 Channeling project, 39, 160, 233
 China, 31

- Chronic brain syndrome, 21, 61, 215, 216
- Cleveland, Ohio, 31, 42
- Clinical Dementia Rating (CDR) Scale, 63, 66, 302, 307-308
- Cognitive ability tests. See Assessment, instruments of
- Colorado, 384, 385
- Community Mental Health Centers (CMHCs), 30
- Community Mental Health Services Act, 230
- Competence, 76-77
- determining, 170-173
 - policy concerns involving, 39-40
 - See also Incompetence
- Comprehensive Assessment and Referral Evaluation (CARE), 306, 306, 308
- Comprehensive Services on Aging (COPSA), (New Jersey), 253
- Computerized axial tomographic (CT) scanning, 94, 481
- Congressional Budget Office (CBO), 46
- nurse practitioners and, 340
- Congressional Research Service, 50
- Connecticut
- long-term care enforcement in, 402
 - PaCS in, 383
 - SNFs in, 215
 - surrogates and, 179
- Conservatorship. See Guardianship
- Consolidated omnibus Budget Reconciliation Act of 1985 (COBRA), 431
- Council on Alzheimer's Disease, 50
- Council on Post-Secondary Accreditation, 353
- Council on Social Work Education (CSWE), 350
- Crane, Nancy, 85
- Creutzfeldt-Jakob disease, 103, 115-116, 308
- Dartmouth Medical School, implanted drug pumps by, 107, 108
- Davies, Peter, 477
- Deeming, 427-429, 430, 458
- Deficit Reduction Act (1984), 421, 438
- Deinstitutionalization, 213, 242, 378, 456
- Delaware, 384
- Delirium, 8, 9, 60-61, 78
- Dementia. See Disorders, dementing
- Dementia Rating Scale, 289, 298, 298, 301, 302, 308
- Department for Aging, New York State, 42
- Department of Agriculture, U. S., 378
- Department of Health and Human Services, U.S. (DHHS),
- Alzheimer's disease victims estimate by, 479
 - board and care homes study by, 319
 - health services research sponsored by, 278-279
 - insurance affordability estimate by, 453
 - listing of impairments by, 419-420, 424
 - long-term care and, 8, 150
 - Office for Civil Rights of, 440
 - representative payee accounting and, 179
 - research funding by, 317, 318
 - subsidies to private charities by, 455
 - Task Force on Alzheimer's Disease of, 8, 26, 50, 493
 - trained geriatrics faculty estimate by, 334-335
 - training funding by, 42
- Department of Health, Education, and Welfare, U.S. (DHEW), 377
- Depression, 11, 74
- caregiver, 139
 - cognitive deficits caused by, 285, 286, 287-288, 288
- Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-III), 7, 12, 15, 60, 96
- Diagnostic practices, 7, 11, 13, 39, 43-44, 89-97
- costs of, 17-18
 - criteria, 96-97, 96
 - errors in, 7, 87-89
 - Medicare reimbursement for, 437, 461, 463
 - policy concerns and, 38-39
- Director of Nursing Services (DNS), requirements for, 355, 356
- Disability
- definition of, 419
 - excess, 68, 77-79, 246, 259
- Disorders, dementing
- asset transfer and, 432
 - cases of, in the United States, 3, 3, 16
 - causes of, 288-289
 - classification systems for, 7, 9, 11-12, 165, 43-44, 60-61, 96-97
 - conditions causing, 9-13, **10**
 - conditions simulating, 10, 11, 90, 90
 - coordinating services for, 22-30, 252
 - criteria for identifying, 8-13, 60-61, 96-97, 96
 - deeming and, 427-429, 430, 458
 - economic costs of, 4, 5, 7, 16-22, 27, 28, 28, 45-47, 138, 141-145, 155-156, 447-448, 479
 - experience with, and graduate medical education, 348-349
 - Federal roles in, issues, 37
 - groups of special concern, 30-35
 - management of, 396-399
 - multidisciplinary team and, 330
 - neuroscience and, 484, 489, 491
 - nursing curricula, 341
 - outside factors influencing, 77-79
 - prevalence of, 1, 3, 15-16, 16, 61, 62-63, 80, 486
 - private financing of long-term care for, 449-455
 - public awareness of, 3-4, 5, 79
 - public financing of long-term care for, 455-465
 - public health and, 479-480
 - rating scales for, 63-67
 - recent awareness of, 6-7, 242
 - relationship between, and depression-induced dementia, 288, 288
 - research effort directed at, 47, 486-489, 490
 - resources for teaching about, 334-335
 - special entitlements for, 36-38
 - specialized care for, 242-266
 - stages of, 13-15, 62-67, 78-79
 - total funding for, by agency, 47, 487
 - treatment, 10-11, 14-16, 62, 72, 73, 87, 246-247, 396-399
 - uniqueness of, burdens, 150
 - See *also* individual dementias
- District of Columbia, 214, 384

- DNA
 Alzheimer's disease and, 93, 101, 105
 Huntington's disease and, 115
 recombinant technology, 484
 testing of, 93
- Doctors. See Physicians
- Domiciliary board and care facilities, 219-222, 254-255
 aged in, 213
 quality of care in, 377, 378-379
 regulation of, 386-388
 surrogate decisionmaking in, 182
- Domiciliary care facility (DCF). See Domiciliary board and care facilities
- Down's syndrome, 101, 102, 117-118
- Drachman, David, 1
- Drugs See Medication
- Duke University
 AARP project, 249
 Center for the Study of Aging and Human Development, 377
 respite care survey by, 152, 154, 157
- Durable power of attorney (DPA), 39, 148, 173-174
- Durable Power of Attorney for Health Care (DPAHC), 174, 175
- Dworkin, Ronald, 445
- Economics, dementia, 4, 5, 7, 8, 16-22, 27, 28, 28, 45-47, 138, 141-145, 155-156, 447-448, 479
 dementia testing, 95, 96-97
 long-term care, 7, 11, 18-22, 27-28, 28, 45-47, 138, 141-145, 155-156, 203-206, 204, 207, 447-455
 of specialized care facilities, 249, 251, 254, 255, 256, 257
 quality of care and, 379-381
- Education, 5
 abnormal aging, for children, 145
 cognitive test performance and, 285-286
 continuing, 335
 Federal funding of, 335-336, 357-361
 Federal programs for health care, 357-361
 issues in, 333-336
 multidisciplinary team approach to, 330-331
 nursing, 338-341
 policy concerns for, 40-42
- Epidemiologic Catchment Area (ECA) survey, 231, 282, 291, 305
- Europe, 7, 109
- Excess disability, 77-78, 246, 259
- Face-Hand Test (FHT), 281, 285, 306, 308
- Families, behavioral problems cited by, 137, 137
 caregiver, 135-152, 309-311
 caregivers within, 136-137
 help for caregiving, 152-157
 in-home care's effect on, 138-150
 nursing home placement's effect on, 138, 218
 proportion of savings spent for patient care by, **144**
- Family care. See Care, in-home; Long-term care, in-formal
- Family Consent Statutes, 179-180, 180, 181
- Family Respite Center (Virginia), 250
- Family Survival Project (California), 7, 253
 caregiver study by, 140
 caregiver services and, 148, 152, 156, 157, 161
 clients served by, 243
 service coordination by, 22
- Federal Council for Internal Medicine, 349
- Federal Life Safety Code, 378
- Finland, 486
- Fireman's Fund, 453
- Five percent problem, 118
- Florida
 long-term care enforcement in, 402
 nursing home beds in, 215
 surrogates and, 179
- Food and Drug Administration, U.S. (FDA), hydergine approval by, 109-110, 111
- Food Stamp Act, 441
- Friedman v. Berger, 421**
- Friend of the court, 180
- Functional Activities Questionnaire, 298, 298
- Functional Assessment Inventory (FAI), 306
- Functional Life Scale, 295, 296
- Gajdusek, D. Carleton, 103
- Gatekeeper program (Washington), 31
- Gateway 11 program (Maryland), 228
- General Accounting Office (GAO), 223
 care study by, 31, 42
 home health services study by, 376
 nursing home care and, 155, 463
 residents' rights study by, 387
- Georgia, 22, 179, 249, 250
- Geriatric assessment centers (GACs), 313
- Geriatric Education Centers (GECs), 330, 359, 363
- Geriatric nurse practitioners (GNPs), 340
- Geriatric research, education, and clinical care centers (GRECCs), 359
- Geriatrics
 in medical school curricula, 346-347, 347
 number of faculty members needed to teach, 334
 in nursing curricula, 341-342
 post-graduate fellowships for, 349
 skills relevant to, to be mastered by medical students, 347-348, 347
- Gerstmann-Strassler syndrome, 103, 115
- Gilhooly, Mary, 85
- Global Deterioration Scale (GDS), 63, 65, 302, 308
- Government, Federal, dementia-related costs to, 21-22, 23, 27, 34, 203-206, 456-464
 efforts to improve nurses training by, 343-344
 long-term care role of, 203-206, 381-391
 policy priorities of, 5-6
 research funding by, 3, 482-489, 493-494
 services provided by, 23, 24
 staffing requirements of, 354, 355, 356
- Government, State, dementia-related costs to, 21-22, 39, 203-206, 214, 456, 458-462
 efforts to improve nurses training by, 344

- Medicaid and, 7
 staffing requirements of, 354, 355, 356
 Governor's Committee on Alzheimer's Disease, Massachusetts, 214, 232
 Governor's Task Force on Alzheimer's Disease, Maryland, 145, 155
 Green Hills Center, 260
 Greene, James A., 85
 Guam, 104, 114
 Guardian ad litem, 178
 Guardianship, 39, 40, 148, 173
 alternatives to, 180-182
 historically, 170
 legal fees associated with, 173-174, 187
- Harbor Area Adult Day Care Program (California), 250
 Haycox Behavioral Scale, 302
 Health care. See Care
 Health Care Financing Administration (HCFA), case mix formulas and, 278
 channeling project of 39, 233
 deeming exceptions and, 429
 geriatric training by, 360-361
 home care/Medicare studies by, 223
 institution for mental disease definition by, 435
 long-term care regulations by, 385, 402
 Medicaid eligibility uncertainty and, 421
 nursing shortage prediction by, 336
 patient care and services (PaCS) system of, 354, 383-384, 399
 reimbursement study by, 49-50
 research funding by, 47, 50, 51
 respite care studies by, 47, 50, 51
 1634 option and, 423
 Social Security disability standards and, 424
 staffing contract by, 355
 Health Interview Study, 225, 226
 Health Maintenance Organization (HMO), 453, 454
 Health Professions Educational Assistance Act (1976), 358
 Hebrew Home for the Aged (New York), 248, 256
 Heckler, Margaret, 8
 long-term care and, 150
 naloxone treatment and, 107
 representative payee accounting and, 179
 Hillhaven Corp., 248, 256, 331
 self-review by, 394
 training and, 41
Hogan v. Heckler, 430
 Home Care Corporations, Massachusetts, 228
 Home equity conversion, 450-451
 Home health agencies, 389
 Hospice, programs for dementia victims, 253
 Hospitals, costs of care in, 27
 State mental, 212-214
 Hospitals, State mental, 212-214
 aged in, 213
 Howard Hughes Medical Institute (HHMI), 489-491
- Huntington's disease
 diagnosis of, 90, 93
 genetics and, 102, 115
 Hydergine, 109
- Idaho, 40
 "relative responsibility" law in, 458
 surrogates and, 176, 179, 185
 Idiopathic dementia, 118
 Illinois, competency in, 170
 Medicaid reimbursement procedure in, 277, 290
 nursing home study in, 384, 385
 services in, 8, 22, 254
 Illness, dementing. See Disorders, dementing
 Income, lost by family caregivers, **141**
 proportion of patient's, used for care, 143
 proportion of spousal, remaining after paying for care, 144
 sources of, used to support dementia patient, 143
 Incompetence, consequences of, 172
 See *also* Competence
 Incontinence, 62, 71, 72, 502, 503
 management of, 262, 373-374
 Index of Independence in Activities of Daily Living. See Katz ADL Scale
 Index of severity, 499, 500
 Indian Health Service, 8
 Individual Retirement Account (IRA), 46, 456
 Information-Memory Concentration Test, 280, 280, 317
 Institute of Medicine, 214
 nursing study by, 336, 338
 quality assurance report by, 393, 394, 398, 403
 Institute on Gerontology, 141
 "Institution for Mental Disease" (IMD), 435
 Institutional ethics committee (IEC), 181-182, 192
 Institutional review boards (IRBs), 187
 Instrumental activities of daily living (IADLs), 70-71, 292, 294, 301
 reliability of instruments, 294-299, 317
 Insurance, availability of, 28
 coverage by, 141-192, 182, 185-186, 450
 long-term care, 45-47, 451-454
 loss of, 32
 "Medigap," 451, 453
 personal payments for health care, 19, 19
 surrogate decisionmaking and, 182, 185-186
 Intermediate care facilities (ICFs), 214-215, 345
 nursing care in, 336, 355
 International Classification of Diseases, 9th revision (ICD-9)
 codes, 12, 12, 499
 Clinical Mod. (ICD-9-CM), 435
 Inventory of Hypothetical Problem Situations, 310
 Invitational Conference on Issues and Strategies in Geriatric Education, 337
- Iowa, 374
 monitoring long-term care providers in, 374, 399
 SNFs in, 214
 Iowa Department of Health, 374, 399

- Japan, 31, 104
- Jewish Chronic Disease Hospital, 186
- Jewish Home and Hospital for the Aged (Florida), 344
- John Douglas French Foundation for Alzheimer's Disease, 7
- research funding by, 4, 47, 491, 492
- Johns Hopkins Hospital (Maryland), 254
- Johns Hopkins Medical School, 17
- Joint Commission on Accreditation of Hospitals (JCAH), 395
- Jordan v. Heckler, 40**
- Kane Group, 374
- Kansas, 8, 22, 227
- "Katie Beckett" waiver, 428
- Katz ADL Scale, 292, 293, 294
- Keiko nursing homes (California), 32
- Kentucky, 174
- Keogh plans, 456
- Kerr-Mills program, 426
- Kuru, 103, 115
- Legal Services Corporation Act, 441
- Legislation, abnormal aging, 145
- certificate-of-need, 28
 - Durable Power of Attorney for Health Care, 174
 - health care training, 335-336
 - long-term care regulatory, 402
 - multidisciplinary assessment, 314
 - quality assurance, 255, 266
 - "relative responsibility," 458
 - service eligibility, 276-277, 286
 - See **also** individual acts
- Licensed practical nurses (LPNs), 214-215, 338-339
- Life, 3**
- Life care community, 453
- Litigation, medical liability, 185-186
- Living arrangements, 136, 140
- changing patterns of, 150-152
 - See **also** Care settings
- London, 306
- Long-term care, access to, 219, 221-222, 227-228, 230
- assessment's application to, 276-278, 289-291, 299
 - defining and measuring quality in, 299, 370-375
 - economic costs of, 5, 7, 11, 18-22, 27-28, 28, 45-47, 138, 141-145, 155-156, 204, 447-455
 - enforcement of providers' standards in, 384-386, 388, 392, 401-404
 - facility administrators, 333, 352-353
 - Federal Government's role in, 203-206
 - funding, 203-206, 204, 207, 447-464
 - health care personnel involved in, 332-333, 336-342, 344-352
 - informal, 20-21, 22, 26-28, 135-152, 204, 222-228, 309-311, 376-377, 388-391, 449-455. See **also** Care, in-home
 - monitoring of, providers, 373-375, 382-384, 387-388, 389-390, 399-401
 - multidimensionality of, 370-371
 - need for, 14-15
 - paraprofessionals in, 342-344
 - policy concerns for, 42-47
 - quality deficiencies in, 375-391
 - reform of quality deficiencies in, 391-405
 - residents rights and, 387, 394
 - salaries and benefits for nurses in, 337-338
 - volunteers and survey staff in, facilities, 353-354
- Long-term Care Gerontology Centers, 358
- Long-term Care surveys, 136, 140, 141, 291, 449
- Los Angeles, California, 286
- Lou Gehrig's disease, 104
- Mace, Nancy, 1
- Magnetic resonance imaging (MRI) scanning, 95, 113, 481
- Maryland, 19, 141, 144, 146, 155, 228, 254, 282
- assessment instrument system in, 299, 304
 - Medicaid reimbursement procedure in, 277
 - nursing home survey in, 216
 - services in, 8, 22
- Maryland State Office on Aging, 144, 344
- Massachusetts, 228
- family caregiver study in, 142
 - nursing home study in, 500
 - services in, 22
 - "spending down" in, 28
 - staffing regulations in, 355
 - surrogates and, 174, 185
- Medicaid
- administrative barriers under, 440-441, 463
 - AFDC linkage with, 421
 - benefits for aged, blind, and disabled persons, 423
 - biases in, 143-145, 156, 210, 276, 436, 439, 440, 461-462
 - care standards of, 44-45
 - coverage, 23, 24, 27, 29, 36, 37, 38, 40, 43-44, 45-47, 141-142, 217, 224-226, 427, 433-437, 450, 459-460, 463
 - reinstitutionalization and, 213
 - eligibility, 216, 276-277, 284, 292, 420-432, 427, 450, 457-459
 - evaluation of, 416-417, 418, 457
 - institutional certification standards of, 214-215, 377
 - regulations, 298, 341, 345, 354, 355, 356
 - reimbursement by, 7, 18, 21, 28, 203-205, 207, 217, 223, 229, 256, 277, 290, 292, 299, 304, 314, 317, 341, 345, 379, 380, 381-386, 460-463
 - SSI linkage with, 421, 422-424
 - 2176 waiver program of, 224, 229, 435-436, 459-460
- Medically needy program, 426-432
- Medicare
- administrative barriers under, 439-440, 463
 - biases in, 143-145, 276
 - care standards of, 44-45
 - coverage, 217, 223-224, 253, 432, 459
 - eligibility, 276-277, 419-420, 457
 - evaluation of, 416-417, 417, 457
 - exclusions under, 432-433
 - ICD-9 and, 12
 - institutional certification standards of, 214-215, 377

- regulations, 298, 341, 345, 354, 356
 reimbursement by, 17-18, 22, 203-205, 204, 207, 223, 278, 317, 341, 345-346, 360-361, 375, 381-386, 437, 438-439, 460-463
- Medication
 behavioral disorders and, 14, 74, 110, 246, 258
 caregiver use of, 131, 155
 dementia symptoms caused by, 90
 effect of, on cognitive function, 284-285
 implantable, pumps, 107-108, 489
 overuse of, 373, 377
 use of, in nursing homes, 217, 373
- Memory, dementia's effect on, 8, 60-61, 68-69
- Mental health centers, community (CMHCs), 230-231
- Mental retardation, difference between dementia and, 8, 60
- Mental status exam, 279-280
- Mental Status Questionnaire (MSQ), 256, 280, 281, 306, 317
- Michigan
 caregiver burden study in, 310
 nursing home study in, 384, 385
 special care programs in, 254, 256, 257, 260, 261, 262
 surrogates and, 174, 185
- Michigan, University of, special care facility at, 256, 257, 260, 261, 262
- Milbank Memorial Fund, 170
- Mini Mental State Examination (MMSE), 250, 280-281, 281, 291, 300, 306, 307, 317, 500
- Minnesota
 long-term care regulation in, 402
 nursing home study in, 385
 services in, 8, 22
 surrogates and, 174, 185
- Minority groups, 31-32
 cognitive test performance by, 285-286
 dementia prevalence of, 486
 long-term care needs of, 209-210
 Medicaid bias towards, 440, 463
 patterns of elder care among, 138, 146
 residents from, in nursing homes, 217-218
- Missouri, 377
- Model
 Canadian, of long-term care financing, 472
 conceptual, of a regulatory quality assurance system, 395-396
 consultation, for facilities regulation, 385-386
 medical, of care, 24.5, 246, 247, 329-330, 382
 social, of care, 245, 246, 247
- Moreland Act Commission (New York), 382
- Mova-Mova disease, 113
- MPTP, 114, 488
- Multidimensional Assessment for Dementia (MAD) scale, 308, 309
- Multi-infarct dementia (MID), 112-113
 diagnosis of, 90
 duration of, 14
 MAD scale and, 308
 prevalence of, 61, 62-63
- National Aeronautics and Space Administration (NASA), 262
- National Association for Home Care
 peer review by, 394-395
 quality assurance by, 45
- National Association of Boards of Examiners for Nursing Home Administrators, 353
- National Association of State Mental Health Commissioners
 Task Force on Alzheimer's Disease of, 213
- National Cancer Institute, 483
- National Center for Health Services Research (NCHSR), 50, 51
- National Commission for the Protection of Human Subjects of Biomedical & Behavioral Research, 186
- National Committee to Preserve Social Security and Medicare, 493
- National Conference of Commissioners on Uniform State Laws, 175, 180
- National Council on Aging (NCOA), 252
 professional reviews by, 395
 quality assurance by, 45
- National Health Corp., 394
- National Heart, Lung, and Blood Institute (NHLBI)
 funding by, 482, 482
 Systemic Hypertension in the Elderly Project of, 112
- National Institute for Handicapped Research, 262
- National Institute on Adult Daycare (NIAD), 228, 229, 230, 251
- National Institute on Aging (NIA), 3, 111, 262
 Alzheimer's Disease Research Centers of, 8, 487
 appropriations, 486, 486, 493
 cost study by, 17
 creation of, 7
 "diagnostic approach" conference by, 96
 diagnostic criteria, of, 39
 informed consent and, 187, 194
 research by, 47, 50, 51, 313-314, 317
 subsidies to private charities by, 455
 teaching nursing home projects by, 348
 vascular dementia studies by, 112
- National Institute on Mental Health (NIMH), 3, 30
 geriatric training by, 360
 research funding by, 47, 50, 51, 486, 492
 specialized dementia research centers funded by, 313-314
 subsidies to private charities by, 455
- National Institute for Neurological and Communicative Disorders and Stroke (NINCDS)
 "diagnostic approach" conference by, 96
 diagnostic criteria of, 39, 60
 research funding by, 47, 486, 487, 492
- National Institutes of Health (NIH)
 consensus development conference of, 11, 30, 88
 research funding by, 482, 483, 485, 486, 492
 SSI disability policies, 33
- National League for Nursing (NLN), 338, 341
 certification by, 333-334
 professional reviews by, 395

- National Master Facility Inventory (NMFI), 214
 National Nursing Home Survey, 19, 21, 214, 215, 225, 291-292
 Nebraska, 174, 185
 Nerve growth factor (NGF), 106
 Neuroscience, 100
Neurosurgery, 108
 New England *Journal of Medicine*, 107, 108-109
 New Guinea, 103
 New Jersey
 board and care regulations in, 388
 nursing home study in, 384, 385
 respite care program in, 50
 surrogates and, 174, 179, 181
 New York City, 42, 306
 New York State, 19, 20, 156, 373, 374, 382
 Board and care regulations in, 388
 long-term care enforcement in, 402, 403
 Medicaid reimbursement procedure in, 277, 290-291
 nursing home study in, 214, 302, 384, 385
 RUG-II project in, 21, 43-44, 216, 461-462, 499
 staffing regulations in, 355
 surrogates and, 174, 179, 181
 New York State Case Mix Reimbursement Project, 21, 43-44, 216, 461-462, 499
 New York State Patient Assessment Instrument, 290-291, 299, 300, 304
 New York State Patient Review Assessment
 ADLs in, 300
 behaviors in, 304
 quality of care in, 317
 Newsweek, 3, 108
 Nongovernment organizations (NGOs)
 public consciousness and, 7
 research funding by, 4, 47, 50, 489-491
 See also individual organizations
 Normal Pressure Hydrocephalus (NPH), 90, 9.5, 117
 North Dakota, 174, 179, 181
 Nurse practitioners (NPs), 340-341
 training, 41
 Nurse specialists, 339-340
 Nurse Training Act (1975), 341, 343, 358
 Nurses' aides, 218, 342-344
 pre-employment requirements for, 343, 343
 specialized care facilities and, 260
 training, 41, 299
 See also Paraprofessionals in long-term care
 Nurses' observation Scale for Inpatient Evaluation (NOSIE), 302
 Nursing, curricula, 341-342
 distribution of, task responsibilities, 338-339, 339
 long-term care, 336-342
 in special care centers, 242, 248, 249, 251, 252, 253, 254
 State boards of, 333
 training for, 41, 299
 See also Professionals, health care
 Nursing homes, 214-219
 bed availability in, 27-28, 215
 behavioral problems in, 216-217, 302, 302, .504, 505
 caregivers' rating of, 148, 155
 characteristics of, residents with dementia, 499-500
 chronic brain syndrome residents in, 215
 costs of care in, 18-20, 18, 27, 204, 254, 256, 450
 custodial care exclusion and, 433
 diagnostic practices in, 7
 drug treatment in, 110
 factors leading to, placement, 156-157
 Medicaid reimbursement of, 439, 461-462
 Medicare reimbursement of, 438-439, 461
 physicians in, 344, 345-346, 345
 policy in, 253
 proportion of residents by bathing ability, 502
 proportion of residents by bladder control, 502
 proportion of residents by bowel control, 502
 proportion of residents by dressing ability, 501
 proportion of residents by eating ability, 501
 proportion of residents by personal hygiene skills, 503
 proportion of residents by toileting ability, 503
 proportion of residents who are verbally abusive, .504
 proportion of residents who exhibit physical aggression, 505
 proportion of residents who exhibit regressive or inappropriate behavior, 505
 proportion of residents who wander, 504
 quality of care in, 262-264, 377-378
 regulatory system for, 381-386
 respite care and, use, 154-155
 specialized units in, 255-262
 SSI income eligibility standards for, 425
 staffing of, 217, 355-356
 State reimbursement rates to, 379, 380
 surrogate decisionmaking in, 182
 Nursing home cap program, 426
 Object Memory Evaluation (OME), 280, 287
 office of Management and Budget, cost-effectiveness interpretation by, 435-436
 Ohio
 long-term care in, 378
 Medicaid reimbursement procedure in, 277
 nursing home study in, 384, 385
 surrogates and, 174, 185
 Ohio Presbyterian Homes, 394
 Oklahoma, 176, 179
 Old Age and Survivors' Disability Insurance (OASDI), 141
 eligibility criteria for, 62, 70
 Older Americans Act (OAA), 24, 357, 358
 Older Americans Act (OAA), 357, 358
 amendments to, 386, 387
 long-term care funding, 18, 204-205, 207, 223, 224, 229, 389, 441, 457
 Older Americans Act (OAA), long-term care funding under, 389
 Older Americans' Research and Service Center Instrument (OARS), 294, 306
 omnibus Budget Reconciliation Act (1981), Federal sanctions authorized under, 385, 402
 Omnibus Budget Reconciliation Act, 421, 435-436, 459-460

- omnibus Health Act (1986), 41, 50
 On-Look program (California), 22, 32
- Paraprofessionals in long-term care, 342-344
 training, 41, 342
 See *also* Nurses' aides
- Parkinson's disease, 91, 98, 104, 113-114, 480, 488
- Patient Assessment Instrument (PAI), 499
- Patient care and services (PaCS), 383-384, 399
- Patients, demented
 amount of trouble locating a doctor by, **147**
 benefits of special care facilities to, 258-259
 in board and care facilities, 220-221
 care services for, 25
 case history of, 35
 conceptual issues in long-term care of, 206-211
 conceptual issues raised by characteristics of, 79-81
 coordinating services for, 23-30, 252
 costs of caring for, 4, 143
 experience of, 59
 frequency of visits to physician, **147**
 home care services for, 225-226
 identifying, in health services research, 278-279, 291-292
 impact on children of, behavior, 145-146
 level of satisfaction with physician care, 147
 life expectancy of, 14
 number of physicians seen by, 147
 in nursing homes, 215-217
 relationship between cognitive deficits and self-care abilities of, 299-301
 relationship between cognitive deficits and behavioral problems of, 305
 services needed by, 201-203, 202, 211, 244-245, 245-247
 treatment of, 10-11, 14-15, 62, 72, 73, 87, 246-247
- Pennsylvania, 21
 board and care facilities survey in, 220, 221, 222
 surrogates and, 174
- Performance Activities of Daily Living Scale, 294
- Pfizer pharmaceuticals, 349
- Philadelphia, Pennsylvania, 21, 139
- Philadelphia Geriatric Center, 139, 257, 294
- Physical and Mental Impairment of Function Evaluation (PAMIE), 302
- Physicians
 assessment by, 274-275, 295, 312
 characteristics of, 3-/5
 delegation to GNP's by, 340-341
 diagnosis by, 7, 89
 referrals to long-term care services by, 233
 role of, in long-term care, **344-349**
 surrogate decision respect and, 184-185
 training, 41
 See *also* Professionals, health care
- Pick's disease, 95-96, 118
- Policy
 assessment's application to, 275-279, 289-292, 299, 304-305, 307, 311
 dementia, 6-8
 Federal funding, 246
 goals of dementia, 4-5
 long-term care, 15, 27, 29
 nursing home, 253
 priorities, 5-6, 11-12
- Policy issues, 36-51
 biomedical research, 492-94
 family caregiving, 146-49, 158-162, 311
 financing long-term care for dementia victims, 464-466
 patient assessment, 315-318
 personnel and training, 361-363
 regulatory quality assurance, 396-404
 special care, 264-267
 surrogate decisionmaking, 188-195
- Policy options, 5
 biomedical research, 492-494
 family caregiving, 158-162
 financing long-term care for dementia victims, 466-474, 467
 Medicare and Medicaid reform 441-442
 patient assessment, 315-318
 personnel and training, 361-363
 regulatory quality assurance, 396-404
 special care, 264-267
 surrogate decisionmaking, 188-195
- Positron emission tomography (PET) scanning, 94, 100, 481
- Professionals, health care
 assessment of, role in care (by families), 146-149, 147
 dementia interest by, 3, 4
 family training by, 253
 in long-term care, 260, 336-342, 344-352
 medical management by, 109-111
 needed to care for elderly (by system of delegation), **340**
 training, 41-42
 See *also* Physicians; Nursing curricula; Psychologists; Social workers
- Progressive Supranuclear Palsy (PSP), 114-115
- Prospective payment system (PPS), 233, 284, 314-315
- Prudential, long-term care insurance by, 452
- Psychogeriatric Dependency Rating Scale (PGDRS), 302, 303
- Psychologist, 332, 351-352
 See *also* Professionals, health care
- Public Health Service Act, 335-336
- Pugilistic, dementia, 90, 103
- Pumps, implantable infusion, 107-108, 489
- Quality assurance, 44-45
 assessment use in, programs, 278, 291, 299, 304
 conceptual model of a regulatory system, 395-396
 consumers' role in, 393-394
 market forces for, 392-394
 professional organization review for, 395
 provider self-review for, 394
 regulation and, 381-391, 395-404
 specialized care, 255, 266
 trade association review for, 394-395
 See *also* Care, quality of
- Quinlan, Karen Ann, 181

- Rating scales
 behavioral) 302-304
 dementia, 216, 289, 298, 298, 301, 302, 307-309
- Reality orientation, 261
- Registered nurses (RN)
 education of, 338
 employment profiles of, 338, 338
 role of, in long-term care, 337
- Relatives' Stress Scale, 303
- Rensselaer Polytechnic Institute, 216, 499
- Report on Alzheimer's Disease and Related Disorders, Maryland, 141, 146
- Representative payee, 40, 178-179
- Research Triangle Institute, 75
- Research
 assessment's use in, 274, 275
 basic, 4-5, 480-485
 biomedical, 4, 5, 47-48, 484-485
 cancer, 483-484
 caregiver burden, 145, 153-154, 156
 cognitive assessment, 282, 286, 287, 290-291
 Federal funding for, 482-489, 493-494
 funding, 4, 47, 47, 47, 50, 80-81, 482-489, 493-494
 health services, 5, 7, 12, 30, 48-51, 80-81, 111, 212, 216, 229, 264, 266, 267, 278-279, 201-292, 310-312
 heart disease, 482-483
 investigator-initiated, grants, 488, 489
 long-term care, 404-405
 misleading data from 107-109
 nongovernmental organizations' role in, 489-491
 patients as, subjects, 186-188
 policy concerns for, 38, 47-51
 publications on Alzheimer's disease, 487
 quality assurance and, 404-405
 specialized, 38
- Residency Review Committee (RRC), 348, 349
- Resource Utilization Group (RUG) Survey, 150
 New York State's, 21, 43-44, 216, 461-462, 499
- Respite Demonstration Project, New York State, 156
- Rhode Island, 8, 22
 Legislative Commission on Dementias Related to Aging, 213
 nursing home survey in, 214
 PaCS in, 383
 surrogates and, 174
- RNA, Alzheimer's disease and, 105
- Robert Wood Johnson Foundation, 111
 research funding by, 50
 teaching nursing home program of, 395
 teaching nursing home projects by, 348
- Sandoz Clinical Assessment Geriatric Scale (SCAG), 302
- Schneck, Stuart A., 85
- Scrapie, 103
- Seattle, Washington, 358
- Senior Respite Care Program (Oregon) 248
- Sentinel Health Events (New York), 374
- Services
 access to, 146-149
 assessment of importance of, 149
 availability and use of, 245
 caregiver survey of, 23-26
 coordinating, 252
 delivery systems for, 231-233
 dementia care, 201-203, 202, 211
 eligibility for, 79, 80
 health care, 23-29, 143-145, 146-149
 home care, 136-137, 141, 152-157
 in-home providers of, 248
 policy concerns for, 36, 43-45
 reasons for not using available, 247
 regulation of long-term care, 388-391
 social, 28-29
 specialized for dementia patients, 247-253
- Servidores*, 32
- Shinsetsu sua hito* networks, 32
- Short Portable Mental Status Questionnaire (SPMSQ), 280, 281, 281, 291, 300, 306, 307, 308
- SHORTCARE, 306
- Single photo emission computer tomography (SPECT) scanning, 94-95
- Skilled nursing facilities (SNFs), 214-216, 335, 345, 355
- Smith v. Heckler*, 384, 399
- Social Security Act, 23, 24
 amendments of 1965, 430
 amendments of 1972, 423
 Boren-Long amendments to, 431
 Keys amendment to (1976), 386, 394, 403-404
 Medicaid eligibility and, 421
 Medicare waiting period and, 420, 457-458
- Social Security Administration
 educational programs of, 51
 guardianship and, 40
 representative payee recognition by, 178-179
- Social Security Disability Benefits Reform Act (1974), 40, 179
- Social Security Disability Insurance. See Old Age Survivors' Disability Insurance (OASDI)
- Social workers
 in long-term care settings, 332, 349-351
 masters' concentrations chosen by, 350
 See also Professionals, health care
- Social/Health Maintenance Organizations (S/HMOs), 46, 231-232, 453-454
- South Dakota, 174
- Southern Baptist Hospital (Louisiana), 252
- Special care
 advantages and disadvantages of, 243, 244
 availability of, 256
 behavior management in, facilities, 261-262
 benefits to residents in, facilities, 258-259
 costs of, 249, 251, 254, 255, 256, 267
 criteria for placement in, units, 242-243
 environmental setting in, facilities, 256-258, 259, 261-262, 374
 multi-service programs for, 252
 regulations' effect on, development, 262-264
 residential, 252, 254-262
 staff-to-resident ratio in, facilities, 252, 256, 257, 260-261

- transportation to, 251
 Staging, 62-67, 308-309
 Staging, dementia rating scales and, 308-309
 Standards
 competence, 171
 Federal health and safety, 385
 quality assurance, 255, 262-264, 267
 regulatory, 262-324, 266-267, 385
 Stress
 on families, 20, 34-35, 139, 145, 150, 155, 157, 253, 303
 on patients, 20, 77, 78, 257, 263, 285
 Subacute arteriosclerotic encephalopathy, 113
 Substituted Judgment Principle, 183
 Suncoast Institute for Applied Gerontology (California), 254, 255
 Supplemental Security Income (SSI), 23, 24
 caregiver's dependence on, 143, 144
 eligibility, 424-425
 long-term care funding by, 204-205, 209, 220, 223, 255
 Medicaid linkage with, 421, 422-424
 Surrogate
 decisionmaking, 170, 173-188
 de facto, 177-178, 184
 designation of, 170, 173, 178, 182
 informants, 90
 Symptoms
 behavioral, 72-77, 73, 110-111
 cognitive, 68-70
 dementia, 8-9, 13-15, 61-62, 68-79
 neurological. See Symptoms, cognitive
 psychiatric. See Symptoms, behavioral
 Syracuse University, 350-151

 Taiwan, 31
 Takayasu's disease, 113
 Task Force on Alzheimer's Disease, 8, 26, 50
 Tax
 dependent care, credit, 46, 155, 455-456
 medical expense deduction, 455
 subsidies through the, system, 455-456
 Tax Equity and Fiscal Responsibility Act (1982), 421, 430, 431, 433
 Technical Corrections Act (1982), 431
 Technology, application of, to health care, 262
 Tennessee, PaCS in, 383
 Terminal illness, definitions of, 175-177, 190
 Tests
 brain biopsy, 95-96
 brain imaging, 94-95
 cerebrospinal fluid (CSF), 91-93
 choosing, 96-97
 costs of, 95, 96-108
 diagnostic laboratory, 91-93, 92
 neurological, 91
 neuropsychological, 62, 68, 69
 organ system, 90
 psychological, 93
 Tetrahydroaminoacridine (THA), 108-109
 Texas, 19

 nursing home survey in, 214, 385, 500
 reimbursement study in, 49-50
 Services in, 8, 22, 377-378, 403
 Therapists, rehabilitative and recreational, 332, 351
36-hour Day, The, 3, 135, 145
Toxic dementia, 116-117
 prevention of, 11
 Training
 caregiver, 29, 41
 dementia assessment, 312-313
 family caregivers, 252-253
 health care personnel, 260
 health care professionals, 4, 6, 14, 26, 41-42
 interdisciplinary health care delivery, 358-359
 nurses, 299
 of nurses' aides, 343-344
 policy concerns for, 409-442
 related to care of dementia patients, 357-358
 service, 331
 surveyor, 354
 volunteer, 354
 Transmissible dementia, 103, 115-116
 Travelers Insurance Co., 140, 146
 Treatment
 behavioral symptoms, 14, 73, 74, 75, 76
 dementia, 10-11, 14-15, 62, 72, 73, 87, 273, 313
 diagnosis and, 88, 89
 policy concerns and, 38-39, 246-247
 psychological tests and, 93
 TRIAGE, 160

 Uniform Probate Code, 171, 178
 United Equitable, long-term care insurance by, 452-453
 United Kingdom
 Alzheimer's research in, 104
 dementia care in, 45
 geriatric assessment in, 313, 314
 geriatric day hospitals in, 248, 251
 United Seniors Consumer Cooperative (Washington, D.C.), 455
 United States, 7
 dementia prevalence in, 3, 16, 486
 life expectancy at birth in, 484
 mortality from selected causes in, 479
 number and proportion of population 65 or older, 3, 16, 480, 480
 support for research and development, by source, 47, 485, 485
 United Way, 229
 Utah, University of, 34 I

 Valenti Alzheimer Care Centers (Pennsylvania) 254, 255
 Vascular dementia, 112
 prevalence of, 11, 16
 Veterans Administration, 27, 262
 biases in programs of, 210, 276
 continuing education support by, 360
 dementia care by, 8, 18, 33-34, 20.5-206, 208-209, 220, 221, 223, 225, 229, 255, 456-457
 eligibility requirements for, services, 276-277

- geriatric assessment of, 313
- geriatric medicine fellowships by, 349
- guardianship and, 40
- Health Professional Scholarship Program, 360
- Interdisciplinary Team Training in Geriatrics, 330, 359-360
- nursing home affiliation and, 111
- patients' income from, 143
- representative payee recognition by, 178-179
- research sponsored by, .278279, 492
- Residential Respite Programs of, 25.2
- training funding by, 42
- Virginia
 - administrator requirements in, 353
 - geriatric nurse's aide training in, 344
 - long-term care in, 377
 - nursing home study in, 385
- Washington State
 - geriatric training in, 358
 - long-term care enforcement in, 402
- Wechsler Adult Intelligence Scale (WAIS), 280, 281, 287, 289
- Wechsler Memory Scale (WMS), 280, 281, 287
- Wernicke-Korsakoff syndrome, 116-117
- Wesley Hall (Michigan), 256, 247, 260, 261, 262
- West Virginia, 277, 290
- Westbrook College, 343
- White House Conference on Aging, 26, 329
- Willowbrook State Hospital (New York), 186
- Wills, living, 39, 174-177, 176, 177
- Wisconsin
 - long-term care enforcement in, 402
 - nursing home bed availability in, 27, 215
 - staffing regulations in, 355
- Women
 - deeming's effect on, 429
 - return of, to work, 151
- Yau Sum, 32***