In this edition of *reSearch*, we explore the topic of community-based services for persons with psychiatric and intellectual disabilities before and after the Olmstead decision of 1999 by the U.S. Supreme Court.

The Olmstead decision helped to change the rehabilitation paradigm from medical/institutional model to a consumer-based model of care. Community-based services enforce the idea of consumer choice. The consumer must want community-based services and the treatment team must deem what services are appropriate based on the person's disability and personal preferences. Personal choice and equal opportunity is an extremely important part of community-based services. Community integration is directly tied to the need for independent living centers and personal assistance services to assist persons with disabilities. The idea is to provide persons with all types of disabilities the opportunity for community integration.

*Olmstead v L.C.* (1999), “...involved two women, Lois Curtis and Elaine Wilson, with psychiatric and developmental disabilities, both of whom were living in a state-run hospital in Georgia.” While doctors agreed that both women could benefit from living in the community, the services they needed were not available in the community. The landmark decision, “...rest[ing] on the Americans with Disabilities Act (ADA), a 1990 law that prohibits discrimination against people with disabilities; [the court found] that inappropriate institutionalization is a form of discrimination.” “... (1) institutionalization reinforces stereotypes about people with disabilities, and (2) it denies people important life opportunities such as school, work, friendship, and cultural enrichment.”

The Olmstead decision was influential for the community/consumer-based services movement. While the decision was based on persons with psychiatric and intellectual disabilities, it offered persons with other disabilities, such as brain injury and spinal cord injury, an opportunity for full participation with services provided in a community setting. Previously, persons who had suffered a traumatic brain injury or spinal cord injury were often placed in nursing homes and general hospital facilities because there were no specialty and/or community options available to them.

The main search terms for this issue of *reSearch* were consumer-based services, community-based services, Olmstead, psychosocial, psychiatric disabilities, psychiatric services, intellectual disabilities and mental health. Researching “community-based services” resulted in over 50,000 citations between the NARIC, ERIC, and PubMed databases alone! We narrowed down the scope to provide readers with a “snapshot” of rehabilitation services for persons with psychiatric and intellectual disabilities before and after the Olmstead decision. A sample of approximately 50 descriptor terms between the NARIC, ERIC and PubMed databases can be found at the end of this document.

The REHABDATA search resulted in 30 documents ranging from 2007-1980. PubMed’s database search resulted in five documents ranging from 2005-1989. After reviewing the ERIC thesaurus and searching the database, we identified 11 documents ranging from 1992-1977. The complete citations are included at the end of this research brief.

In addition to document searches, NARIC searched its Program Database of the National Institute on Disability and Rehabilitation Research (NIDRR) projects to locate grantees/projects related to the topic of the community-based services and psychiatric disabilities. NIDRR-funded projects and their publications are offered as additional resources for our patrons.

Footnote:


2 Ibid.

3 Ibid.
Documents from NARIC’s REHABDATA search listed are listed below:

2007


NARIC Accession Number: J52191

ABSTRACT: Study evaluated the outcomes for 25 individuals with severe psychiatric disabilities 1 year after discharge from a community-based residential treatment and rehabilitation program. Results indicated that the following the program, participants lived for significantly longer periods in the community in more independent settings and functioned at higher levels than in the six years prior to participation in the program.

2006


NARIC Accession Number: J51560

ABSTRACT: Study examined the extent to which state psychiatric hospital census changed following the Olmstead decision, in which the Supreme Court ruled in 1999 that it is a violation of the Americans with Disabilities Act to provide services to individuals with disabilities only in institutions. National state hospital data from 1984 to 2003, organized into five 4-year periods, were analyzed to identify trends from pre- to post-Olmstead periods. Results showed steady declines in the hospital census across all periods, with especially large decreases in the 1990s. However, the decline slowed significantly in the post-Olmstead period, compared with the rates in the 1980s.


NARIC Accession Number: O16815

ABSTRACT: Report provides state-by-state information on two major outcomes of the Supreme Court’s 1999 decision in the case of Olmstead v. L.C., which
promotes community integration by requiring states to provide services to people with disabilities in the community rather than in institutions whenever possible. The report contains two tables and a brief outline of the nature and significance of the Olmstead decision. The first table provides information on the formal strategies (Olmstead Plans) that states developed in response to the Olmstead ruling. The second table presents a summary of community integration lawsuits related to Olmstead.

2005

(2005). What is “Olmstead” and how does it affect me?
NARIC Accession Number: O15975
ABSTRACT: Fact sheet discusses the Supreme Court’s 1999 decision in the case of Olmstead v. L.C, and how it affects the rights of people with psychiatric disabilities. The Olmstead decision promotes community integration by requiring states to provide services to people with disabilities in the community rather than in institutions.

This document is available at www.naric.com.

2003

NARIC Accession Number: O15048
ABSTRACT: Paper summarizes survey findings regarding activities conducted in individual states in response 1999 U.S. Supreme Court decision in the case of Olmstead v. L.C. and E.W. The ruling requires states to provide community-based services for people with disabilities whenever possible. Survey results provide an overview of Olmstead activities, consumer involvement, implementation deadlines, major recommendations and strategies for implementing the recommendation, costs, and funding. Implications for future research, training, and policy strategies are discussed. This paper was presented at the State of the Science Conference and Policy Forum 2003.

NARIC Accession Number: J46315
ABSTRACT: Article examines the progress that states have made in implementing the principles of the Supreme Court decision in the case of Olmstead v. L.C. and E.W. The 1999 Olmstead decision requires states to provide appropriate, community-based services for people with disabilities rather than institutional services. Since that time, the progress that states have made in implementing and enforcing the decision has been slow. The reasons for the lag and federal efforts to assist are discussed.

NARIC Accession Number: J45134
ABSTRACT: Article describes specific problems related to providing services to individuals with a dual diagnosis of mental retardation and mental illness. Service issues include inaccessible services, discontinuity of patient care, separate systems for mental health and mental retardation, barriers to multi-system services, primary versus secondary disorder, lack of professional training, and financial responsibility. Author provides recommendations for designing treatment programs to overcome service barriers and describes several effective community-based service programs.

2002

NARIC Accession Number: J44491
ABSTRACT: Article presents a history and overview of psychiatric rehabilitation in the United States. Discusses the impact of deinstitutionalization and antipsychotic medications on psychiatric rehabilitation philosophy, goals, and practices. Describes models for providing rehabilitation services including the community support system, clubhouses, supported employment, and supported education.

2001

NARIC Accession Number: J42691
ABSTRACT: Article summarizing two reports on state responses two years after the U.S. Supreme Court decision in L.C. & E.W. vs. Olmstead, which required
states to provide community-based long term care for persons with disabilities in preference to institutional care. One report, by the National Conference of State Legislatures (NCSL), focused on state policy responses. The other, by the National Association of Protection and Advocacy Services (NAPAS), focuses on the role of consumer advocates in pushing states to comply voluntarily with the Olmstead decision.

NARIC Accession Number: J42247
ABSTRACT: Article on implications of the 1999 U.S. Supreme Court decision in the case of Olmstead v. L.C. and E.W., holding that the Americans with Disabilities Act (ADA) applies to state Medicaid programs and requires that persons with disabilities who do not require institutionalization must be provided with home or community-based care. The article discusses the meaning of the decision, how states must respond, and how the decision can be enforced under the ADA.

Priaulx, E. (2001). *Two-year Olmstead progress report: Disability advocates assess state implementation of mandate to provide community-based services to people with disabilities.* NARIC Accession Number: O14282
ABSTRACT: Report compiles data received from disability rights advocates throughout the United States assessing state efforts to comply with the Supreme Court decision in Olmstead v. L. C. The Olmstead decision requires states to provide community-based services for people with disabilities rather than institutional services. Report describes implementation trends, highlights effective strategies some states are using, and outlines the next steps for advocates and people with disabilities.

2000

NARIC Accession Number: J39856
ABSTRACT: Article discussing the cultural relevance of community support programs (community-based psychosocial interventions), i.e., how they address clients’ cultural orientations. Based on the mental health and practice literature, relevant cultural orientations of different ethnic groups are described, along with implications for practice.

NARIC Accession Number: J40187
ABSTRACT: Article on the 1999 decision of the U.S. Supreme Court in Olmstead v. L.C., which interpreted the anti-discrimination provisions of the Americans with Disabilities Act (ADA) as they apply to publicly-funded health services. The majority of the court held that the ADA required provision of services for persons with mental disabilities in community-based settings rather than institutions. Implications for state policy and program design, including whether Olmstead will require states to spend more money, what populations are covered by the decision, and what level of planning effort will be needed.

1999

NARIC Accession Number: J37603
ABSTRACT: Article reviewing the history of legal decisions concerning the right of involuntary psychiatric patients to treatment in the least restrictive alternative setting that meets their needs. Changes in the doctrine from the 1970’s through the U.S. Supreme Court decision in Olmstead v. L.C. (1999) are examined.

NARIC Accession Number: J37302
ABSTRACT: Article presents current needs and trends in mental health care, including long-term care, in older persons with severe and persistent mental illness. Emerging models of long-term care are described. While they hold promise for integrated services they do not address the specialized mental health care needs of this population. Issues for financing mental health care needs are reviewed including controversies over fee-for-service and carve-out and carve-in arrangements. Without mechanisms to adequately finance ser-
vices, adjust for risk, and measure outcomes, it is concluded that managed care arrangements will be in conflict with the goal of high-quality care for older persons with severe and persistent mental illness. Proposed directions for future models of care for this population include integration of mental health and medical services, integration of specialized gero-psychiatric services with developing community-based long-term care systems blending financing under shared risk arrangements, and assurance of accountability and outcomes under managed care.

Full-text copies of these documents may be available through NARIC’s document delivery service. To order any of the documents listed above, note the accession number and call an information specialist at 800/346-2742. Or you can order online at www.naric.com/services/requestform.cfm. There is a charge of five cents for copying and shipping with a $5 minimum on all orders. International shipping fees may apply.

Documents from the Education Resource Information Center (ERIC) search at www.eric.ed.gov are listed below:

1992

Abstract: Discusses issues of concern for severely mentally ill people (homelessness, family burden, quality of life, deinstitutionalization, community-based services). Considers how response to severe mental illness has over-relied on pathology-based models of helping. Offers strengths perspective as alternative that sees mentally challenged individuals having strengths and abilities that can be tapped to foster their continued integration in community settings.

1990


ERIC #:ED328023
ABSTRACT: This special journal “Theme” issue presents a collection of papers reflecting the psychiatric practices and community treatment for persons with severe psychiatric disabilities in Asia, Africa, Australia, and India. Some of the papers were presented at the 1988 meeting of the World Association of Psychosocial Rehabilitation (WAPR) in Lyons, France. Compared to technologically advanced nations of the West, the developing nations’ approach is characterized by more efficient utilization of scarce resources, culturally synchronous diagnostic and treatment procedures that merge indigenous healing systems with scientific modalities, and the inclination of most third world practitioners to integrate the patients’ families into the healing process. Papers include: “Rehabilitation in Mental Illness: Insights from Other Cultures” (Harriet P. Lefley); “Report of a World Health Organization (WHO) Meeting on Consumer Involvement in Mental Health Services”; “Psychosocial Rehabilitation in the Developing World: Progress and Problems” (M. Parameshvara Deva); “An Example of a Community Based Mental Health/Home-Care Programme: Haidian District in the Suburbs of Beijing, China” (Shen Yucun and others); “Nigeria: Report on the Care, Treatment and Rehabilitation of People with Mental Illness” (Tolani Asuni); “A Model for the Care of People with Psychosocial Disabilities in Sri Lanka” (Nalaka Mendis); “Integration of Psychosocial Rehabilitation in National Health Care Programmes” (Vijay Nagaswami); and “Rural Psychiatric Rehabilitation and the Interface of Community Development and Rehabilitation Services” (Douglas A. Dunlap.)

ABSTRACT: In 1969, the Joint Commission on the Mental Health of Children made several recommendations based on the conclusions in their report entitled “Crisis in Child Mental Health: Challenge for the 1970’s.” These recommendations included formation of a child advocacy system at every level of society; the development of supportive, preventive, and remedial services within communities for any and all who needed them; increased support for research initiatives in children’s mental health and related fields; and innovative manpower recruitment systems to alleviate shortages at all levels of the child service system. This document reviews the history of legislation affecting community based mental health treatment for children,
both prior to and after the Joint Commission’s study. Specific programs and legislation discussed include the Juvenile Justice and Delinquency Prevention Act of 1974 (P.L. 93-415); the Education for All Handicapped Children Act (P.L. 94-142); the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272); and the Child and Adolescent Service System Program (CASSP) of 1984.

1988

ABSTRACT: This report recommends a 10-year plan for changes in services to people with intellectual disabilities in Victoria, Australia. Intended key outcomes of the plan include: increases in the numbers of clients receiving direct residential support in community-based accommodations; reductions in numbers of adult clients resident in large scale congregate facilities; more clients in adult day programs; development of the case management system; expansion of local residential service teams; greater numbers of trained staff; and new specialist services. Following an overview of the plan and its principles and philosophies, a framework is given for changes in commonwealth, state, and local government activity. The report makes recommendations regarding residential services; housing; specialist child and family services; education; employment; the justice system; behavior and psychiatric services; other services; prevention of intellectual disability; community education; and human resource development. A plan for implementation as well as costing and financial analysis is provided. Seven appendices are given, including: models for local residential service teams and an equity housing cooperative system, a statement regarding future directions for specialist child and family services, a statement from state trustees, recommendations regarding vocational services, population assumptions and a glossary of terms.

ABSTRACT: This paper describes the development of community-based rehabilitation services for persons with mental illness in Israel. It focuses on occupational, social, and residential community psychiatric rehabilitation services. The paper argues that service development has been slow and out of step with the philosophy and objectives of community psychology.

ABSTRACT: This report highlights the major issues discussed during a 2-day workshop on Medicaid funding for community-based mental health services for children and youth with severe emotional disturbances. The report opens with a brief description of the service needs of children and youth with severe emotional disturbances and the system of care that can meet those needs. It examines the role Medicaid can play in helping to finance services and some of the barriers state mental health planners face in using Medicaid funds. It describes the overall process that states must follow in developing a coordinated network of mental health and other services, with the emphasis on building a close working relationship with Medicaid agency personnel. The report then focuses on specific options states can use to expand the range of Medicaid-funded services available to children with severe emotional disabilities and describes the experiences some states have had using these Medicaid options. Appendixes contain a workshop agenda, a list of participants, and a description of services for children and adolescents from “Operation Help: A Mental Health Advocate’s Guide to Medicaid” (Chris Koyanagi).

1984

ABSTRACT: The move toward deinstitutionalization of chronic psychiatric patients has been hampered by inadequate community-based rehabilitation programs. To investigate whether psychosocial rehabilitation promotes higher levels of functioning in discharged psychiatric patients, assessments of social adjustment, re-
cidivism, and a non-traditional measure of client demoralization were administered to 102 clients in a community psychosocial rehabilitation program. Results confirmed that a comprehensive support system, which assumes primary responsibility for patient mental health care, maintains or enhances the level of functioning in former psychiatric patients. Results showed very low recidivism rates, improved or maintained social adjustment, and a significant decrease in reported demoralization.

1983

ERIC #:EJ288859
ABSTRACT: The shift from institutional to community-based care for the mentally ill failed because communities were not prepared to undertake this responsibility. Suggestions for more humane care are given.

1981

ERIC #:EJ258848
ABSTRACT: Demonstrates that following termination of treatment, there is little difference between psychiatric subjects treated in institutions and those treated in community-based alternatives. Presents a model for assessing psychiatric treatment effectiveness. Concludes that institutional and community-based alternatives should be viewed as complementary rather than mutually exclusive approaches.

1980

ERIC #:EJ236080
ABSTRACT: A community-based program was designed to serve as an alternative to traditional short-term hospital treatment and after-care services for the psychiatrically disabled client. Comparisons revealed significant differences in favor of this approach. A rehabilitation counselor worked half-time and was an invaluable member.

1977

ABSTRACT: Reported are the trends in patterns of use of psychiatric facilities in the United States from 1946 to 1973 and the impact such changes have had on the composition of the institutional population. Sections cover the sources of data, changes in locus of delivery of mental health services, changes in composition of other institutional populations, factors responsible for change in composition of institutional population, and implications of expected changes in the composition of the population for the mental health services and the institutional population. Findings are noted to show that as a result of the development of community-based programs for the diagnosis, treatment, and rehabilitation of persons with mental disorders, the locus of care of persons with such disorders has shifted from the large state mental hospitals to community-based facilities, particularly to outpatient psychiatric services and community mental health centers. It is explained that these changes have effected the composition of the institutional population with a shift from greater numbers in mental institutions to greater numbers in homes for the aged. Changes are seen to be caused by a variety of factors which include social legislation, treatment discoveries, and increasing costs of general hospital and domiciliary care for persons with chronic illnesses. Among appendixes are definitions and tables detailing the numbers of persons in specific types of institutions according to age, sex, and race.

Documents from the National Library of Medicine PubMed search at www.pubmed.com are listed below:

2005

ABSTRACT: An institutional-based care system in mental health has been replaced by a network of community-based services with different levels of structure and support. This poses both an opportunity and a challenge to provide appropriate and effective care to persons with serious mental illnesses. This paper describes a simulation-based approach for mental health system planning, focused on hospital and residential service components that can be used as a decision support tool. A key feature of this approach is the ability to represent the current service configuration of psychiatric care and the client flow pattern within that framework. The strength of the simulation model is to help mental health service managers and planners visualize the interconnected nature of client flow in their mental health system and understand possible impacts of changes in arrival rates, service times, and bed capacity on overall system performance. The planning model will assist state mental health agencies to respond to requirements of the Olmstead decision to ensure that individuals with serious mental illness receive care in the least restrictive setting. Future plans for refining the model and its application to other service systems is discussed.


PMID: 14971129
ABSTRACT: BACKGROUND: Deinstitutionalization and community mental health services have become the focus of mental health care in the United States, Italy, and England, and now in Israel. METHODS: Tirat Carmel MHC developed an intervention model of organizational change implemented in a rehabilitation hostel. It is an interim service based on graduated transition from maintenance care to a transitional Half-way House, followed by a Transitional Living Skills Center oriented for independent community living. RESULTS: Of 205 rehabilitees who resided in the hostel since the beginning of the project, 138 were discharged to community residential settings: 67 patients were discharged to reinforced community hostels; 27 to sheltered housing and 23 to independent residential quarters; 7 patients were discharged to comprehensive hostels, 3 to old-age homes, and 11 returned home to their families. In terms of employment, 79 were placed in sheltered employment facilities, 24 work in the open market, and 3 returned to school; 22 work in therapeutic occupational settings and 10 patients discharged to comprehensive hostels and old-age homes are engaged in sheltered employment programs in those settings. CONCLUSION: The system flexibility model and the rehabilitation processes anchored in normalization supported the relocation of hospitalized psychiatric patients to community-based settings and enabled the rehabilitees to cope with readjustment to community life.

PMID: 14687386
ABSTRACT: OBJECTIVES: In response to the recent Olmstead decision, to compare consumer and clinician perspectives on the appropriateness of nursing home settings for older adults with severe mental illness (SMI) in relation to clinical characteristics and care needs. DESIGN: Cross-sectional, descriptive, correlational study. SETTING: Ten community mental health centers and two state-funded nursing homes specializing in long-term care for older persons with SMI. PARTICIPANTS: Consumers of mental health services in the community (n=115) and in nursing homes (n=106), aged 60 and older, with SMI. Sixty-four clinicians (51% registered nurses, 29% masters-level clinicians, and 20% certified social workers) conducted ratings. MEASUREMENTS: Consumers and their clinicians were independently asked to determine the most appropriate care setting for each consumer based on care needs from three alternatives: nursing home, congregate (group) living setting, or individual apartment/home. Clinical characteristics of participants with SMI were rated using the Mini-Mental State Examination, Brief Psychiatric Rating Scale, Specific Level of Function Scale, Cumulative Illness Rating Scale for Geriatrics, a modified memory and orientation subscale from the Clinical Dementia Rating Scale, and an item from the Minimum Data Set related to reasoning. RESULTS: Of nursing home residents with SMI who did not have
severe cognitive impairment, 40% (n=42) and 51% (n=54) were considered by consumers or by their clinician, respectively, to be more appropriate for a community-based setting, but there was a low level of agreement (only 27.6%; no better than chance) between consumers and clinicians on which nursing home residents were most appropriate for living in the community. Determinations by clinicians were associated with clinical need (diagnosis and less-severe behavioral problems), whereas there was no association between clinical needs and level of care determinations by consumers. Finally, clinicians considered a group home necessary for 93.7% of nursing home residents judged to be more appropriate for a community-based setting, whereas 90.5% of consumers stated that an apartment or individual home was indicated. CONCLUSION: State implementation of the Olmstead decision will need to consider major differences in perspectives between clinicians and consumers on the most appropriate long-term care setting for older persons with SMI.

2002

PMID: 12086010
ABSTRACT: As the disability field moves to the next generation of community life, this article describes the findings of a qualitative state policy research study on deinstitutionalization and community integration. New Hampshire was selected as a leading national example in the United States based, in part, upon the closure of its only public institution showing community leadership in the field of mental retardation and developmental disabilities. Drawing on the disciplines of political science, sociology, psychology and rehabilitation (Majchrzak, 1980), the research design uses a multi-case, multi-site study approach (Yin, 1989), and on-site, semi-structured interviewing of key informants using a research field guide (Taylor & Bogdan, 1984/1998). The qualitative research reflects an indepth version of state formative evaluation research studies on community integration (e.g., Taylor, Racino, & Rothenberg, 1988), and the use of coded data and multiple analytic techniques (e.g., Glaser & Strauss, 1967) congruent with the emerging support and empowerment paradigm (Racino, 1992). The article highlights four sets of research findings (i.e., state characteristics and community integration practices, thematic case studies of change, comparative roles in the change process, and a theoretical framework for understanding change) which form the basis for further statewide study of change toward community life in the United States.

1989

PMID: 2721137
ABSTRACT: “Prior Notification” policies have elicited fears of community opposition from agencies who have adopted a “low profile” approach in locating community-based residential facilities. Nevertheless, data from a survey of New Jersey community care providers indicate that local government officials express less opposition when informed of the proposed location and invited to meet with the provider. Arranging to meet with local officials is most important when neighbors have leadership, since officials express more intense opposition when neighbors invite them to a meeting. The literature has already established the fact that meeting with neighbors can facilitate mobilization and thereby engender more intense opposition, both from neighbors and from local officials. Hence, the available evidence suggests that providers should meet with local officials to discuss the community care program but should attempt to deal with neighbors individually. This strategy is compatible with the policy of “prior notification” adopted in New Jersey.
Search Terms for Olmstead and Community-Based Services for Persons with Psychiatric and Intellectual Disabilities

Assisted Living Facilities
Attitudes
Case Studies
Children
Community-Based
Community Development/Programs/Resources/Services
Community Mental Health Services
Consumer
Consumer-Based Services
Cultural Differences
Deinstitutionalization
Delivery Systems
Disabilities
Early Intervention
Emotional Disturbances
Evaluation Criteria/Methods, Utilization
Family Programs
Government/State/Federal
Group Homes
Health Facility Closure
Health Planning
Health Services Research
Home Programs
Hospitalization
Housing Needs
Housing Needs/Opportunities
Independent Living
Institutionalization
Legislation/State/Federal
Mental Disorders
Mental Health/Programs/Rehabilitation
Mental Retardation
Mentally Disabled Persons
Models
Normalization
Nursing Homes
Olmstead
Organizational Case Studies/Innovation
Program Development/Effectiveness
Psychiatric Disabilities/Hospitals/Services
Psychological Services
Psychosocial
Public Health Administration
Quality of Life

Recidivism
Rehabilitation Counseling/Programs
Research Methodology
Residential Facilities/Treatment
Rural Areas
Severe Disabilities
Severity of Illness Index
Social Adjustment/Change
Trend Analysis

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We search several sources both in-house and online, to fill these requests including:

- REHABDATA and the NIDRR Program database

- Education Resources Information Center

- National Clearinghouse of Rehabilitation Training Materials

- Campbell and Cochrane Collaborations

- PubMed and other National Library of Medicine databases

- Agency for Health Care Policy and Research databases

- Center for International Rehabilitation Research Information and Exchange

and other reputable, scholarly information resources.

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- NARIC Information and Media Team