### **Literature Search: Risk Factors for Institutionalization**

Prepared by Sarah Steenhausen

The purpose of this literature search was to identify the research that has been conducted on the factors leading to institutionalization, for all populations impacted by Olmstead. The below articles represent what was identified through this search process, but is not likely representative of all the research on this subject matter. The committee may wish to identify new areas to pursue or consider new ways to focus the literature search.

### **Article Abstracts**

The Prevalence and Consequences of Unmet Need: Contrasts Between Older and Younger Adults with Disability.

Medical Care. 35(11):1132-1148, November 1997. Allen, Susan M. PhD; Mor, Vincent PhD

#### Abstract:

OBJECTIVES. This article investigates the prevalence, determinants, and consequences of unmet need for assistance with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and transportation in a randomly selected sample of adults with disability residing in Springfield, Massachusetts.

METHODS. Respondents were contacted through random digit dialing, and eligibility was determined through a disability screen. Eligible individuals were stratified by age; 632 people were interviewed (78% of contacted eligibles). The prevalence of need and unmet need for ADLs, IADLs, and transportation assistance was calculated separately by age strata, as was the prevalence of selected negative consequences attributed to inadequate help with specific activities. The determinants of unmet need were modeled using logistic regression.

RESULTS. The prevalence of unmet need for assistance with individual ADLs ranged from 4.1% (eating) to 22.6% (transferring) of the full sample. Unmet need for IADLs assistance was higher, ranging from 15.9% (cooking) to 34.6% (heavy housekeeping). Respondents younger than age 65 reported higher levels of unmet need for IADLs and transportation help than respondents age 65 or older; members of the younger group also were more likely to report five of the seven negative consequences attributed to inadequate help with IADLs and transportation (eg, missing medical appointments). Regression results revealed inability to meet

expenses, having few or no reliable helpers, and impairment severity to be key determinants of unmet need.

CONCLUSIONS. Financial problems, and not age per se, placed working age adults at elevated risk of unmet need in this study. The consequences of inadequate help can impede management of chronic health conditions, and may compromise individuals' ability to maintain a safe and reasonable quality of community living.

Predicting Elderly People's Risk for Nursing Home Placement, Hospitalization, Functional Impairment, and Mortality: A Synthesis Edward Alan Miller, William G. Weissert, University of Michigan Medical Care Research and Review, Vol. 57 No. 3, (September 2000) 259-297

Long-term care resources would be allocated more cost-effectively if care planning and medical/functional eligibility decisions were grounded more firmly in extant evidence regarding the risk of nursing home placement, hospitalization, functional impairment, and mortality. This article synthesizes the studies that longitudinally assess the predictors of each of these outcomes for the 65 and older population in the United States. A database was assembled containing 167 multivariate analyses abstracted from 78 journal articles published between 1985 and 1998. Findings show that 22 risk factors consistently predict two or more outcomes, including three that predict all four: worse performance on physical function measures not based on activities of daily living, greater illness severity, and prior hospital use. Findings should help prioritize variable selection choices of those setting eligibility criteria, allocating care resources, and doing descriptive studies. Gaps are shown to exist in the understanding of outcome effects of facility, market, policy, and other system attributes.

The Vulnerable Elders Survey: A Tool for Identifying Vulnerable Older People in the Community

Journal of the American Geriatrics Society

Volume 49 Issue 12 Page 1691 - December 2001 doi:10.1046/j.1532-5415.2001.49281.x

**OBJECTIVES:** To develop a simple method for identifying community-dwelling vulnerable older people, defined as persons age 65 and older at increased risk of death or functional decline. To assess whether self-reported diagnoses and conditions add predictive ability to a function-based survey.

**DESIGN:** Analysis of longitudinal survey data.

**SETTING:** A nationally representative community-based survey.

**PARTICIPANTS:** Six thousand two hundred five Medicare beneficiaries age 65 and older.

**MEASUREMENTS:** Bivariate and multivariate analyses of the Medicare Current Beneficiary Survey; development and comparison of scoring systems that use age, function, and self-reported diagnoses to predict future death and functional decline.

**RESULTS:** A multivariate model using function, self-rated health, and age to predict death or functional decline was only slightly improved when self-reported diagnoses and conditions were included as predictors and was significantly better than a model using age plus self-reported diagnoses alone. These analyses provide the basis for a 13-item function-based scoring system that considers age, self-rated health, limitation in physical function, and functional disabilities. A score of ≥3 targeted 32% of this nationally representative sample as vulnerable. This targeted group had 4.2 times the risk of death or functional decline over a 2-year period compared with those with scores <3. The receiver operating characteristics curve had an area of .78. An alternative scoring system that included self-reported diagnoses did not substantially improve predictive ability when compared with a function-based scoring system.

**CONCLUSIONS:** A function-based targeting system effectively and efficiently identifies older people at risk of functional decline and death. Self-reported diagnoses and conditions, when added to the system, do not enhance predictive ability. The function-based targeting system relies on self-report and is easily transported across care settings.

#### Can obesity be a risk factor in elderly people?

E. M. Inelmen, G. Sergi, A. Coin, F. Miotto, S. Peruzza and G. Enzi Obesity Reviews

Volume 4 Issue 3 Page 147 - August 2003 doi:10.1046/j.1467-789X.2003.00107.x

Obesity is increasing in middle-aged adults and in elderly subjects (over 65 years), owing to the concurrence of different factors: inactivity, wrong nutritional habits, and basal metabolism and nutritional need reduction. This condition is becoming a serious problem because of the increasing numbers of the aged population all over the world. In the past, obesity was considered as a 'secondary' pathology of no medical importance in old age; but nowadays, obesity is increasingly being studied in Geriatrics too, because it causes disability

and because of its quality-of-life impairment consequences. The Euronut-Seneca study has confirmed the presence of obesity in both men and women in Europe. The definition of obesity, the reference values of body mass index and obesity as a mortality factor in elderly persons are still under discussion. Even when overweight does not represent a serious problem in old age, obese elderly people are certainly at risk of disability, morbidity and mortality. This review focuses on the potential risks of overweight and obesity in the aged population.

# Improving the United States' System of Care for Older Adults With Mental Illness

Findings and Recommendations for The President's New Freedom Commission on Mental Health Stephen J. Bartels, M.D., M.S.

#### **ABSTRACT**

The President's New Freedom Commission on Mental Health was created to evaluate the quality and effectiveness of the nation's mental health service delivery system, to identify unmet needs and barriers to services, and to provide recommendations on methods for improving the mental health system. A health policy analysis was prepared for the Commission examining the organization, delivery, and financing of mental health services for older Americans. The author identified three healthcare themes, including 1) access and continuity of services; 2) quality; and 3) workforce and caregiver capacity. From among these areas, 10 policy issues and recommendations were proposed.

#### **RESULTS**

Ten major policy issues were identified and grouped under three overarching themes: 1) access and continuity of services, 2) quality, and 3) workforce and caregiver capacity. Following an overview of each identified issue, policy recommendations were developed, based on a review of possible actions, with members of the Commission's Subcommittee on Older Adults.

#### CONCLUSIONS

A critical assessment of the service delivery system for older adults identifies substantial shortcomings across key domains, including access to services, quality of care, and the adequacy of the current and future workforce. The current system of care is fragmented and generally fails to correspond to the preferences, needs, and goals of many older adult consumers. Other major barriers to appropriate care include inadequate financing and reimbursement of services for providers, as well as barriers for consumers that include discriminatory co-payments for psychological services and a lack of prescription

drug benefits under Medicare. Public funding of services is also being eroded for the most disabled and financially challenged patients under current plans to cut Medicaid expenditures because of unprecedented deficit budgets in the majority of states. Quality of mental health services for older persons lags behind services for younger adults, despite a growing evidence-base supporting the effectiveness of a variety of interventions and services for late-life mental disorders. Finally, the research and service infrastructure is woefully inadequate to meet the projected demand for interventions, services, and trained providers needed to address the growing number of older adults with mental disorders.

Policy reforms are indicated that respond to each of these crucial areas. Some of the recommendations identified in this analysis consist of reorganization and restructuring of existing services or shifting of current priorities and resources. Such efforts include regulatory reforms that promote integrated services, public education campaigns aimed at eradicating stigma, and initiatives that support the implementation of evidence-based practices. Other policy reforms are unlikely to occur in the absence of dedicated financial reforms and appropriations, including Medicare and Medicaid reforms, and development of an adequate research and service infrastructure dedicated to older adults with mental disorders. Despite current pressures on legislative budgets to limit growth in healthcare expenditures, the anticipated "graying of America" will inevitably incur substantial acute and long-term costs. Without targeted policy reforms, future generation of young and old Americans will tragically bear the economic and social costs of excess disability, diminished quality of life, and a healthcare system overwhelmed by an epidemic of mental disorders of aging.

Traumatic Brain Injury in the United States: A Public Health Perspective.

Journal of Head Trauma Rehabilitation. 14(6):602-615, December 1999.

Thurman, David J. MD, MPH \*; Alverson, Clinton MS +; Dunn, Kathleen A. MD, MSPH \*; Guerrero, Janet MS ++; Sniezek, Joseph E. MD, MPH \*

#### Abstract:

Traumatic brain injury (TBI) is a leading cause of death and disability among persons in the United States. Each year, an estimated 1.5 million Americans sustain a TBI. As a result of these injuries, 50,000 people die, 230,000 people are hospitalized and survive, and an estimated 80,000-90,000 people experience the onset of long-term disability. Rates of TBI-related hospitalization have declined nearly 50% since 1980, a phenomenon that may be attributed, in part, to successes in injury prevention and also to changes in hospital admission practices that shift the care of persons with less severe TBI from inpatient to outpatient settings. The magnitude of TBI in the United States requires public health measures to prevent these injuries and to improve their consequences. State surveillance systems can provide reliable data on injury causes and

risk factors, identify trends in TBI incidence, enable the development of cause-specific prevention strategies focused on populations at greatest risk, and monitor the effectiveness of such programs. State follow-up registries, built on surveillance systems, can provide more information regarding the frequency and nature of disabilities associated with TBI. This information can help states and communities to design, implement, and evaluate cost-effective programs for people living with TBI and for their families, addressing acute care, rehabilitation, and vocational, school, and community support.

#### Variations in characteristics and service needs of persons with autism

Matthew P. Janicki<sup>1</sup> Robert A. Lubin and Erwin Friedman Journal of Autism and Developmental Disorders (Historical Archive) Publisher: Springer Science+Business Media B.V., Formerly Kluwer Academic

Publishers B.V.

Issue: Volume 13, Number 1

Date: March 1983 Pages: 73 – 85

Abstract Information concerning socio-demographics, disability characteristics, and services received and needed became available on approximately 900 autistic children and adults as a result of a statewide needs assessment and casefinding collection project conducted in New York. Analyses of the results confirmed other findings as to the predominance of males to females and a high concomitant occurrence of mental retardation. Results also showed a population having few problems with mobility, hearing or vision, but moderate deficits in most skills related to activities of daily living, and significant deficits in communication and basic independent functioning skills. Differences were observed between institutionalized and noninstitutionalized autistic persons in terms of level of retardation, functional skills, age, and use of medications. Implications of the findings are drawn for clinicians, administrators, and public policy makers. An earlier version of this paper was presented at the 1981 International Conference on Autism in Boston, Massachusetts, July 1981.

## Characteristics of people with intellectual disability admitted for psychiatric inpatient treatment

Journal of Intellectual Disability Research

Volume 43 Issue 2 Page 112 - April 1999 doi:10.1046/j.1365-2788.1999.00199.x S. Raitasuo, T. Taiminen & R. K. R. Salokangas

The present prospective study describes the demographic, medical and psychosocial characteristics of 40 people with intellectual disability who were referred for psychiatric inpatient treatment in the special psychiatric unit of the Special Welfare District of South-west Finland. Three different control groups were used to study: (1) demographic variables (n = 122); (2) medical history (n = 39); and (3) psychosocial factors (n = 20). The symptoms leading to an admission to inpatient care and the connections of these clinical signs with the discharge diagnosis were evaluated. The typical inpatients were young males with mild intellectual disability, psychosis and a previous psychiatric diagnosis. They had lived in several places during their lives and their economic situation was poor. Affective and/or disruptive symptoms were the most common causes of an admission to inpatient care. The largest diagnostic group at discharge consisted of patients with psychotic disorders. The people with intellectual disability who were admitted for inpatient care formed a subgroup with certain psychiatric symptoms and social problems. Specialist psychiatric expertise is absolutely necessary for the treatment of this subgroup.

## Institutionalization of Alzheimer's disease patients: reducing precipitating factors through family counseling.

Ferris SH, Steinberg G, Shulman E, Kahn R, Reisberg B.

Although home-care of Alzheimer's disease (AD) patients is more cost-effective than institutionalization, there is limited knowledge concerning the causes and prevention of institutionalization. The goal of this project was to determine the circumstances related to institutionalization of AD patients and to determine if a family counseling program can reduce these precipitating factors. In Study 1, we surveyed 109 family members of institutionalized AD patients. Primary precipitating factors included difficulties with patient behavior, insufficient auxiliary help and respite, financial difficulties, and caregiver emotional and physical complaints. In Study 2 we evaluated the effectiveness of an enhanced counseling program which included specific intervention techniques to cope with precipitating factors. For 41 AD family members who were seriously contemplating institutionalization, the precipitating factors prior to counseling were similar to those found in Study 1. After six months of individual counseling, home visits, and participation in caregiver support groups, there was only one placement, and a consistent reduction in the precipitating factors. These preliminary results suggest that a specially designed counseling program may delay or forestall institutionalization.

### The ventilator-assisted individual: Cost analysis of institutionalization vs. rehabilitation and in-home management

#### JR Bach, P Intintola, AS Alba and IE Holland

New Jersey Medical School-UMDNJ, Newark. Chest, Vol 101, 26-30, Copyright © 1992 by American College of Chest Physicians

The purpose of this article is to present a cost analysis of in-home vs institutionalization for severely physically disabled ventilator- assisted individuals (VAIs). Following rehabilitation and adaptation to noninvasive methods of ventilatory support, 30 VAIs were maintained in the community for 12.9 +/- 1.1 years with personal care attendants organized by a home care vendor reimbursed by New York City Medicaid. The program permitted self-directed severely disabled clients, including these 30 exclusively nontracheostomized VAIs, to live in the community and direct their attendant care and personal affairs. Prior to discharge home, the 30 patients resided in the respiratory unit of a longterm care facility for a mean of 8.9 +/- 10.1 years. The unit is currently reimbursed at a mean rate of \$718.80 per patient per day. The current mean total cost of maintaining these VAIs in the community is \$235.13 +/- 56.73 per patient per day. The conversion to and/or maintenance on 24-h nontracheostomy ventilatory support permitted discharge to the community by allowing the VAI to be attended by trained but uncredentialed home care attendants, thus avoiding prohibitively expensive in-home nursing for tracheostomy care. This created a savings to the public of 77 percent or \$176,137 per year per client. We conclude that conversion to and/or use of noninvasive methods of ventilatory aid can be a reasonable and cost-saving goal. More respiratory rehabilitation centers are needed to free up hospital beds and facilitate discharge of VAIs to the community. There is also evidence that trained attendants should be permitted to suction tracheostomized VAIs in the home.