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ABSTRACT

This bibliography cites genetics literature identified during a project to investigate the issue of accessibility to genetics services through the reimbursement process. Citations represent both traditional published literature and such "fugitive literature" as unpublished manuscripts, government documents, service provider protocols, and health policy documents. The entries are organized into 13 categories: accessibility, chronic care (long term care), consumer issues, cost containment and reimbursement, general definitions, ethics, genetics funding, health insurance, health maintenance organizations, international issues, Medicaid/Medicare, new technologies, and quality control. (JDD)

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REIMBURSEMENT FOR MEDICAL GENETICS SERVICES: A Selected Bibliography



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PREFACE

This bibliography evolved as a product of many hours of information acquisition and library research during the first two project years of a three year Maternal and Child Health SPRANS grant, "Assessment of Reimbursement for Genetic Services" (DHHS, BHCDA, MCH Genetics Disease Services Branch, Grant No. MCJ-09100-030). The project has been carried out by staff of the Division of Human Genetics, Department of Pediatrics, University of Connecticut Medical School.

The central mission of this project is to develop a financial demographic data base from 19 genetic centers throughout New England derived from a full year's billing-reimbursement experience from each center and a description of their organizational structure and personnel. In addition to an assessment of direct genetics service billings (professional fees, procedures and laboratory tests), an attempt was made to examine contiguous or collaborative services, such as contributing departments of pathology, radiology and obstetrics-gynecology. The objective of this data collection was to investigate the issue of accessibility to genetics services through the reimbursement process. This permitted us the opportunity to construct a profile of third party payors for each institution (payor mix) and relate this profile to the demographic characteristics of each institution's geographic region.

The project also developed investigations of reimbursement by Medicaid for all 50 states; a survey of HMO's and managed care providers in New England; a description of the satellite programs for each of the genetics centers; an analysis of MSAFP utilization throughout New England from 1983-1985; an international survey of reimbursement practices in 20 countries, and a survey of New England Regional Genetics Group members to develop a working definition of a "comprehensive genetics center".

The traditional genetics literature surveyed during the project revealed relatively few articles that specifically addressed the issues of reimbursement and accessibility. However, the search into related fields of health economics, health care planning, Medicaid/Medicare, health insurance and health care and hospital administration proved fruitful, albeit not focused on genetics services. In addition, our research led us into the "fugitive literature" of unpublished manuscripts, governmental agency documents, service provider protocols and health policy documents.

In order to organize this heterogeneous array of articles, the authors developed a cross-indexed set of 13 literature categories for ease of retrieval. This will be described in the next section.

It should be understood that this is a partial or selected bibliography which reflects the activities of our projects. Inclusion does not imply endorsement of the information therein by NCEMCH, the Genetics Disease Services Branch of MCH or the University of Connecticut Medical School. Readers are invited to expand the contents of the bibliography in any manner they choose. We would appreciate your sharing those references and documents with us in order to continue to expand this bibliography.

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DEFINITION OF CATEGORIES

The authors have organized the bibliographic material into 13 categories which may be cross-indexed by their category codes. Each reference is coded by both a primary and secondary category. The primary code signifies the principal emphasis of the reference. If there was an additional strong emphasis in the reference, a secondary code was also assigned. Therefore, a large proportion of references are found to be cross-indexed against two category codes.

The following is a listing of the categories, each with a brief description of its content.

- AC **Accessibility**—Limiting factors that may affect the availability of health services to any population
- CC **Chronic Care (Long Term Care)**—Studies addressing the unique problems of conditions requiring long term or chronic care
- CN **Consumer Issues**—Articles focusing on the accessibility of medical genetics services from the consumer perspective
- CR **Cost Containment/Reimbursement**—Studies addressing policy issues of cost benefit, cost control, cost sharing, diagnostic related groups (DRGs) and reimbursement
- GD **General Definitions**—Descriptive articles that provide background information on personnel, technologies, and phenomena pertaining to the study of reimbursement for genetic disease
- ET **Ethics**—Articles concerning the promise and perils of new and not so new technologies—how ethics may affect public policy considerations
- GF **Genetics Funding**—Past, present and future methods of funding genetics services including government (i.e., local, state, federal and grants)
- HI **Health Insurance (Commercial)**—Issues involving commercial health insurance reimbursement methods—past, present and future
- HM **Health Maintenance Organizations (HMOs) and Individual Physician Associations (IPAs)**—Historical, current and future commentaries on the evolution of HMOs and IPAs—specifically as it may apply to the offering of and reimbursement for genetics services
- IN **International Issues**—Articles that address international concerns regarding the accessibility and economics of medical genetics
- MM **Medicaid/Medicare**—Medicaid and Medicare policies on, and experiences with, reimbursement for different types of medical services
- NT **New Technologies**—Services not currently used on a routine basis, or not routinely available to the public for more than 10 years—how new technologies become incorporated into general practice
- QC **Quality Control**—Issues affecting the acceptable level of service quality offered to the public including accreditation, licensing and legal ramifications which may, in turn, affect reimbursement

CATEGORY 1—ACCESSIBILITY

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