

**A proposed Programmatic Analysis
of Long-Term Care for the
Developmentally Disabled in Minnesota**

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**Governor's Planning Council
on Developmental Disabilities**

**Minnesota State Planning Agency
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Purpose and Need

The purpose of this research is to re-evaluate the policies of the State of Minnesota for the long-term care of its developmentally disabled populations. The State's policies may have gravitated toward an overemphasis of the institutional and residential forms of care and a possibly resultant lag in developing home-based and Independent living alternatives. The research has two parts, and funding will be sought separately for each:

1. Create the researchable data base needed for a programmatic analysis of the State's Medicaid-supported long-term care system. This is Tasks 1 and 2 of the *Work Plan*, below, and in essence consists of adding some finishing touches to an almost completed four-year longitudinal file of the State's Quality Assurance and Review (QAR) data.
2. Examine this longitudinal file: (a) to identify patient movement into, within, and out of the State's Medicaid-supported long-term care system; (b) to assess Improvement or other changes in patient condition associated with such movements; and (c) to determine whether and to what extent patient movement to more normalized living arrangements can be accelerated. This is Tasks 3 and 4 of the *Work Plan*, below.

Modern program theory, influenced by normalization principles, continuum-of-care philosophies, and court decisions encouraging "most appropriate and least restrictive" placement practices, has failed to produce the expected groundswell of action away from an institutionally dominated approach to long-term care. There is thus a need for an objective look at long-term care policies, but research in this area has been thwarted by inadequate data.

Longitudinal data bases are rare in the human services, virtually non-existent in the long-term care area, and totally unknown in support of programmatic and fiscal policy analysis. The proposed research is therefore believed to be unique.

Approach

The Minnesota Department of Health MDH), in its annual QAR surveys, collects a broad array of data documenting patient condition, quality of placement, and treatment provided. Among the data elements are:

- . Diagnoses - a maximum of six, coded HICDA (1976-1976) or ICD-9(CM) (1979-1982).
- . Self-care ratings - locomotion, transfers, funding, bathing, and other activities of dally living.
- . Ratings on other dimensions of human functioning- hearing, communication, and behavior.
- . Ratings of severity, appropriateness of placement, and potential for improvement.
- . Treatment parameters -- medications (type and dosage), nursing care, physical and occupational therapy, and other modalities.
- . Other characteristics - age, sex, date of onset, date of admission, Institutionalization history, and referral source.

The surveys are cross-sectional in the sense that each record is a once-per-year "snapshot" of the Medicaid patient whose record is reviewed.

Work Completed on Data Base

Staff of the University of Minnesota's Humphrey Institute, in an Informal survey of state data systems under DHHS/OHDS Special Projects Grant #54-P-71407/5, were unable to locate any that supported a longitudinal data base capable of tracking DD patients through the years spent in the state's long-term care facilities. However, they recognized in Minnesota's QAR data the makings of just such a data base and proceeded then to construct what is apparently the nation's only multi-year (1976-1979) longitudinal data base for long-term care.

With the assistance of the systems staff of the Diehl Bio-Medical Library, the QAR data for the years 1976 through 1979 were converted to a " four-year longitudinal file. The number of Medicaid patients accounted for in the QAR surveys averaged 29,000 during the four years, and their survey records were matched on name, Medicaid number, and year

of birth, sex, and county of responsibility to form a longitudinal multi-year record of each of the approximately 45,000 patients whose stays in nursing homes, ICF/MRs, and state hospitals spanned one or more of the four surveys.

Work Remaining on Data Base

The DO population accounts for about twenty percent of the QAR records — 6,000 per year, for a total of 24,000. An estimated 7,000 patients are included in the four-year file.

Extracting the OD population from the main QAR file should pose little problem. If any annual survey record for any client contains a 00 diagnosis, an MR onset date, an MR severity indicator, or an ICF/MR facility number, then all records for that client will be moved.

Problems with "psuedo-movement" are expected. Facility numbering was changed in 1977 from the DPW system to that employed by MDH. Also, some facilities merged, others separated and became two facilities, and yet others experienced a change in ownership. Tracing patient movement by changes in facility numbers is thus prone to considerable error.

A facility register exists that identifies each facility by all of its identifying numbers during the four-year period, and linking this register to the QAR file will resolve the problem. The net result will be equivalent to assigning a unique Identifier to each facility.

Analysis

Of key interest will be DD patients who moved from one type of facility to another (e.g., from a state Institution to a community ICF/HR). What is expected for the developmentally disabled is a demonstration of the value of a treatment philosophy that encourages movement along a continuum of care. Whether movement was precipitated by, is the result of, or is unrelated to Improvement, it is expected that a substantial subset continued to Improve and that there are those who have taken -- or are ready to take -- the next step toward Independent living.

Enough self-care ratings are available to enable the construction of a self-care score reasonably in line with the Kenny Self-Care

Evaluation (an ADL rating system which one of the project's consultants helped develop in the mid-1960's). Coupled with the other QAR measures of patient capability, the improvement (or regression) patterns associated with different types of movements should become visible.

Also of interest will be DD patients who improve (or regress) while a state Institution, community ICF/MRs, or nursing homes during the four-year period. The Minnesota Department of Public Welfare conservatively estimates that at least 500 residents of ICF/MR's (most of whom are former residents of state institutions) will "graduate" during the next seven years. Others have placed this number as high as 1,000. The longitudinal data file should provide some insight into this phenomenon.

Patients who enter the system for the first time or who leave it will also be studied. The latter, however, present a problem since the QAR surveys provide no indication of placement following discharge or reason for discharge. If trends cannot be isolated on a client-by-client basis, an attempt will be made to determine whether the aggregated admissions or discharges in each of the four years reveals a chronological pattern indicative of some "macro" change taking place.

Work Plan

The work plan is directed first to the work that remains in creating a four-year file of the developmentally disabled in the state's long-term care facilities and then to an analysis of the movements and changes that have taken place during the period. The tasks are as follows:

Task 1. Linking the QAR file to a facility register.

The DPW numbering system was used in 1976, the MDH system in the years after that. Mergers, splits, and ownership changes further complicate unique identification. The facility register lists, for each facility, all of the numbers by which the facility was known during the four years. The task here will be to reconcile the numbering systems via a translation table so that each facility will be uniquely identified in the QAR file.

Task 2. Extracting the DD sub-population.

The task here is to extract, from the QAR file, the longitudinal record of every patient whose record for any year carries a diagnosis or other indication of developmental disability.

Task 3. Transformations.

The separately rated activities of daily living will be combined to form a self-care score. Behavioral measures also will be combined, as will the indicators of communication difficulties, to achieve two more composite measures of disability.

Task 4. Analysis.

The analysis will focus primarily on the DD sub-populations: (1) who have four-year data histories; (2) who moved from one type of facility to another; (3) and/or who left the system before the fourth year QAR study.

Tasks 1 and 2 may be reversed if any problems requiring manual intervention are encountered in linking the facility register to the

QAR file. The primary objective of Task 1 is a linkage of the two files for the DD population. The linkage will be extended to the entire QAR file only if this can be accomplished without undue effort.

A part of Task 2 will be creating a protected file that translates personal Identifiers (name and Medicaid number) into unique record identifiers and stripping all personal identifiers from the four-year data base. This ensures client confidentiality.

Resources Needed

Staff: Iver Iversen, Project Director
Eugene Lourey, Consultant
Colleen Meiers Traviss, Consultant

Funding: Part 1 (Tasks 1 and 2) -- \$4,000
Part 2 (Tasks 3 and 4) -- \$16.000

IVER A. IVERSEN

Curriculum Vitae, abbreviated

SENECA CORPORATION
1005 W. Franklin Avenue
Minneapolis, MN 55405

Employment History

Seneca Corporation: 1971-present. Vice-president in charge of operations. Designed and directed all major projects.

University of Minnesota: 1978-1981. Research Associate. Codirector of developmental disabilities technical assistance program.

Sister Kenny Institute, formerly American Rehabilitation Foundation: 1961-1971. Consulting statistician, Statistical Service Department head.

University of Minnesota: 1957-1961. Graduate student with research and teaching responsibilities.

Education

University of Minnesota, Minneapolis, Minnesota. 1958-1961: Pre-doctoral studies in Bio-statistics. MS 1958: Bio-statistics and Mathematics. BA 1954: Physics and Mathematics.

Personal Data

Birthdate: March 26, 1923. Birthplace: Minneapolis, Minnesota. Married to Ione Pederson of Courtnay, North Dakota: October 10, 1953. Two children. Home address: 3828 Edgewood Avenue North, Minneapolis, MN 55427. Telephone: (612) 533-6915.

Professional Consulting

Illinois Governor's Planning Council on Developmental Disabilities (1980-present). Development of computer-aided de-institutionalization planning model.

Metropolitan Human Services Commission of Franklin County (1979-1981). Technical assistance in Inter-agency financing of human services.

New York Bureau of the Budget (1972-1978). Design and implementation of a state-wide project to develop and document the Title IV-A/XVI reimbursement claims of eight state agencies. Technical assistance in converting state's adult public assistance programs to SSI; design of an APL recalculation project; and design of quality assurance procedures for monitoring APL recalculations. Design of studies of utilization patterns for the state's non-medical residential care facilities. Design specifications for simulating benefit-program eligibility decisions and effecting integrated referrals to state agencies. Technical assistance in Federal/State funding negotiations.

Also: Cleveland Public Library (1979-1981); Illinois Office of the Governor (1978); Child Welfare League of America and Family Service Association of America (1976-1977); Council on Accreditation of Services for Families and Children (1977-1978); Illinois Department of Public Welfare (1975-1976). New York Department of Mental Hygiene (1974); Florida Department of Social and Rehabilitative Services (1974); Massachusetts Department of Public Welfare (1972-1973); Minnesota Department of Public Welfare (1971-1972); Hennepin County Welfare Department (1972); Hennepin County Alcoholism and Inebriety

Agency (1971-1972); Illinois Bureau of the Budget (1971); DHEW/RSA Task Force on Guidelines for Referral for Vocational Rehabilitation (1969); St. Paul Ramsey Hospital Division of Pulmonary Diseases (1968-1970); Minnesota Division of Vocational Rehabilitation (1968); Department of Physical Medicine and Rehabilitation, College of Medical Sciences, University of Minnesota (1963-1971).

Teaching Experience

Minnesota Department of Public Welfare (1972): Seminars in all sub-state regions on client eligibility and cost accounting. Sister Kenny Institute (1968-1971): Lecturer on measurement theory in educational testing. University of Minnesota (1964-1966): Lecturer in bio-statistics. University of Minnesota (1959-1960): Instructor - graduate courses in bio-statistics.

Research Experience

Co-director, DHEW/OHDS Special Projects Grant #54-P-71407/5: Technical Assistance to States in Developmental Disabilities Planning. Co-director, Minnesota Division of Vocational Rehabilitation Grant (1970): The HELP Campaign Evaluation. Co-director, DHEW Project (1969-1970): A Study to Develop Guidelines for the Referral of AFDC Recipients for Vocational Rehabilitation or other Employment-Related Services. Co-director, American Rehabilitation Foundation Project (1969-1970): A Study of Employment-Related Services for Welfare Recipients. Director, DHEW Project (1965-1967): The Griffis Study -- Decision Models in Disability Determination and Rehabilitation Assessment. Project Director and Research Director, DHEW Grant (1961-1965): Comprehensive Live-Team Evaluation of Applicants for Social Security Disability Insurance Benefits (Project 21). Research Fellow, University of Minnesota (1957-1961): Design and analysis of surveys and experiments in medicine, psychology, and sociology.

Memberships

Institute of Mathematical Statistics, Biometric Society, American Statistical Association, American Accounting Association, Operations Research Society of America, and Institute of Management Sciences.

Publications

Refinancing and Reorganizing Human Services: Interagency Net Budgeting and Other Fiscal Incentives. Project SHARE Monograph Series, Number 20, DHHS/ASPE, 1981 (with W. Copeland).

Roadmap Through Title XX. CWLA Hecht Institute for State Child Welfare Planning, Washington, DC. 1978 (with W. Copeland).

Managing Federal Money for Children. CWLA Hecht Institute for State Child Welfare Planning. Washington, DC. 1978 (with W. Copeland).

The Revised Kenny Self-Care Evaluation; A Numerical Measure of Independence in Activities of Daily Living. Sister Kenny Institute. Minneapolis, MN. 1973 (with N. Silberberg and others).

(Complete list available.)