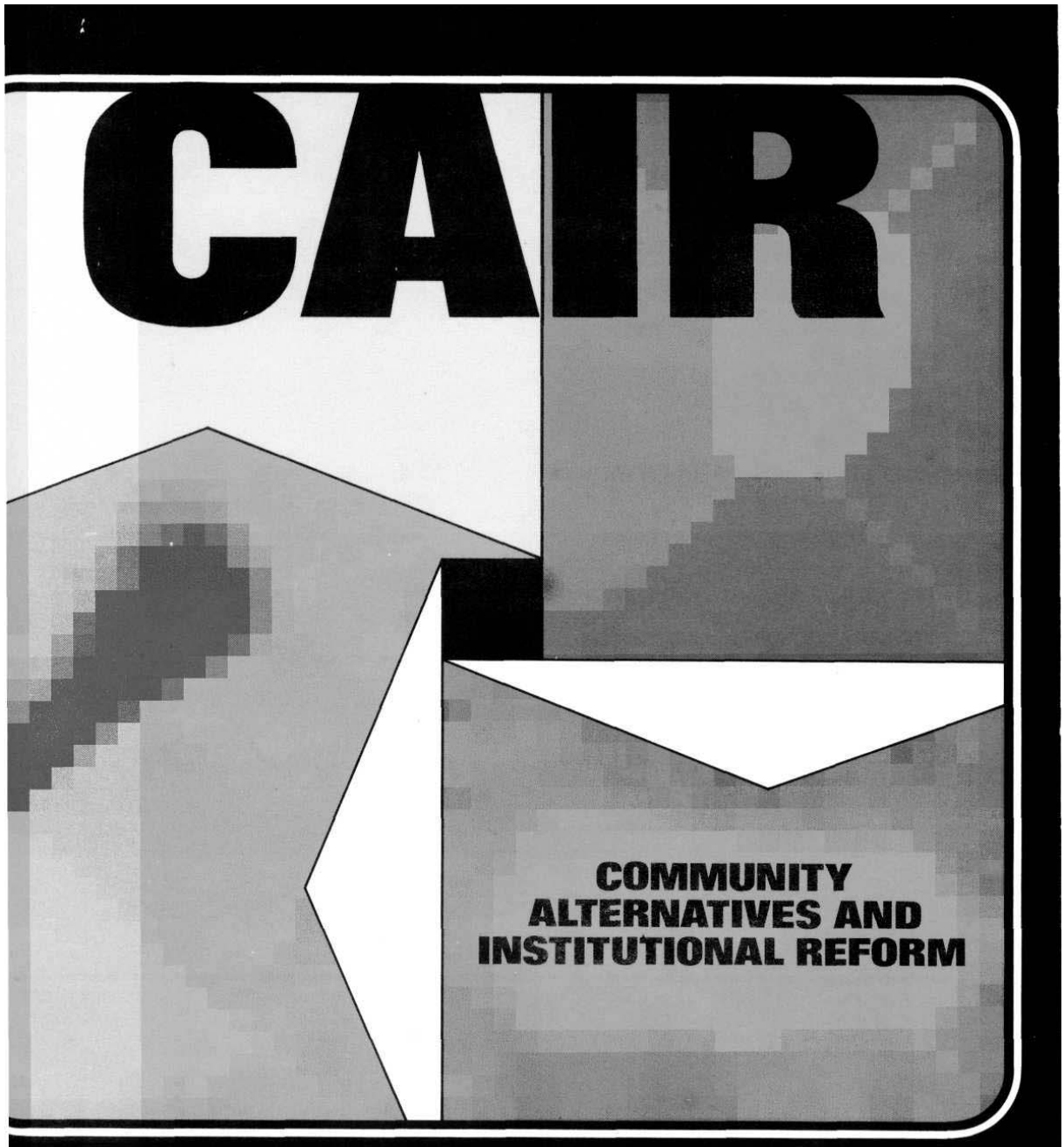

PLANNING ALTERNATIVES FOR THE DEVELOPMENTALLY DISABLED INDIVIDUAL

INNESOTA STATE PLANNING AGENCY ■ DEVELOPMENTAL DISABILITIES PROGRAM

CAIR

COMMUNITY ALTERNATIVES

AND

INSTITUTIONAL REFORM

Minnesota State Planning Agency
Developmental Disabilities Program
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CONTENTS

PREFACE

Following the Presidential mandate for deinstitutionalization and in keeping with the National Developmental Disabilities Advisory Council priority, the Minnesota Developmental Disabilities Program received a grant under Public Law 91-517 (DHEW54-P-2539I/5-0I) to create a process for establishing community alternatives for developmentally disabled individuals.

The primary objectives of the Community Alternatives and Institutional Reform (CAIR) Project were to:

- Integrate the viewpoints of financial/program decisionmakers with those of the groups responsible for the implementation of programs.
- Develop a systematic plan for returning developmentally disabled persons in state facilities to community settings based on their individual needs.

Rather than focus on meeting the needs of a precise number of individuals, the CAIR Project focused on developing an individual-centered process for determining the needs of all developmentally disabled residents of state-operated facilities and planning from those needs. While many residents of state facilities are cerebral palsied or have seizures, the primary disability is mental retardation. Consequently, the CAIR Report centers on the needs of mentally retarded persons with the expectation that many identified needs, rights, and programming requirements can be applied in planning for all developmentally disabled individuals.

The project report represents the joint contribution of many professionals and consumers (pp 40-45) who voluntarily committed their time to reviewing programs, evaluating and discussing alternatives, and creating recommendations for effective planning. Their extensive contributions are gratefully acknowledged.

INTRODUCTION

The trend toward the development of community-based residential programs for developmentally disabled individuals clearly emerged in recent years: O'Connor and Justice (1973) found that over 75% of 300 facilities sampled were opened in the last five years. Since then, the merits of small, community-based residences vs. those of large, institutional residences have been debated in nearly every state.

Systematic evaluations have shown numerous developmental advantages to living in small group homes within communities (Tizard, 1970):

- Free, unregimented activities rather than drab, uninteresting existence
- Living in family-type situations rather than living with a large group
- Direct contact rather than limited exposure to the local community
- Direct involvement of local community resources rather than limited use of community resources.

While some large institutions have created unique and exemplary programs, the historical emphasis has been on maintenance rather than client development. Large institutions have one uniform quality: nearly all services are provided in the same place and under a single budget. Unfortunately, emphasis on the presumed benefits of economic efficiency fostered the development of large, multi-purpose institutions and prevented development of similar services in communities (White and Wolfensberger, 1969).

As a consequence, community residential services have not developed rapidly in the United States. With the growing acceptance of the principle of normalization in the planning and development of human services, there has been increased recognition among consumers and professionals of the need to develop effective residential programs in community settings.

The development of community-based programs must begin with a thorough analysis of service requirements based on the needs of clients who will ultimately reside in the community.

The CAIR Project considered the major steps and decision points in the process of deinstitutionalization (see Figure I) and then created guidelines by which they might be accomplished.

The first step toward deinstitutionalization is identifying the basic residential needs of developmentally disabled individuals throughout the state either by individual assessment with present instruments or through available data defining the general skills and physical characteristics of each client (GLOBAL ASSESSMENT). Using these data as a reference, the type of residence which would most effectively meet each client's needs can be specified (RESIDENTIAL NEEDS).

Once the required residential programs are identified, the availability of such programs must be determined. If the residential program is not available for a particular client, the institutional program should be modified (institutional reform) to approximate the required residence while community-based alternatives are being developed.

Clients will thrive in community residences only if the services they need are available. Before clients move to a community residential program, a more precise assessment of their skills should be completed to determine the exact services which each will need (PROGRAM NEEDS ASSESSMENT). The resulting description of program needs, e.g., transportation, health care (PROGRAM PLAN), will provide the criteria for evaluating the suitability of possible residences for each client.

Each community should be evaluated for service availability to meet potential clients' needs indicating the suitability of locating a small-group residence in a particular community. If the required services are not available, the decision should be made to develop them or to arrange an alternative location for the residential program.

The availability of programs based on individual needs should help assure the success of deinstitutionalization programs. The success of these programs can also be fostered by establishing public information systems and service evaluation procedures prior to transferring individuals to the community. It is imperative, however, that clients be involved in decisions related to their future and that the client data required for effective decision-making be confidential.

Deinstitutionalization, usually considered a group process, can be accomplished through decision-making based on individual needs. It is this conceptualization which served as a basis for planning and the recommendations which follow.

At the outset of the CAIR Project, it was assumed that individual behavioral and physical data defining client needs were available. However, at the time the report was prepared, only global statements, e.g., scores on standardized measures, for a limited sample of institutionalized retarded persons, could be obtained. Consequently, while implementation of many of the recommendations is under way, others must await more detailed individualized client assessment.

Since the Developmental Disabilities Program has no direct responsibility for implementing programs with clients, planning for deinstitutionalization as well as the recommendations which follow are intended to serve as guidelines for those agencies which do have the responsibility; emphasis has been placed on the use and modification of existing structures as contrasted to the creation of new ones. For example, many recommendations in this report apply directly to the Minnesota Department of Public Welfare which has the primary responsibility for providing institutional and community residential services for developmentally disabled individuals; other recommendations are related to services provided by the Minnesota Department of Health, the Division of Vocational Rehabilitation, the Department of Special Education, etc.

Because the recommendations encompass many aspects of program development, all recommendations are presented on pages 4-8 to provide a comprehensive overview of the task force reports. For convenient reference, each recommendation is accompanied by the pages in the report which support it.

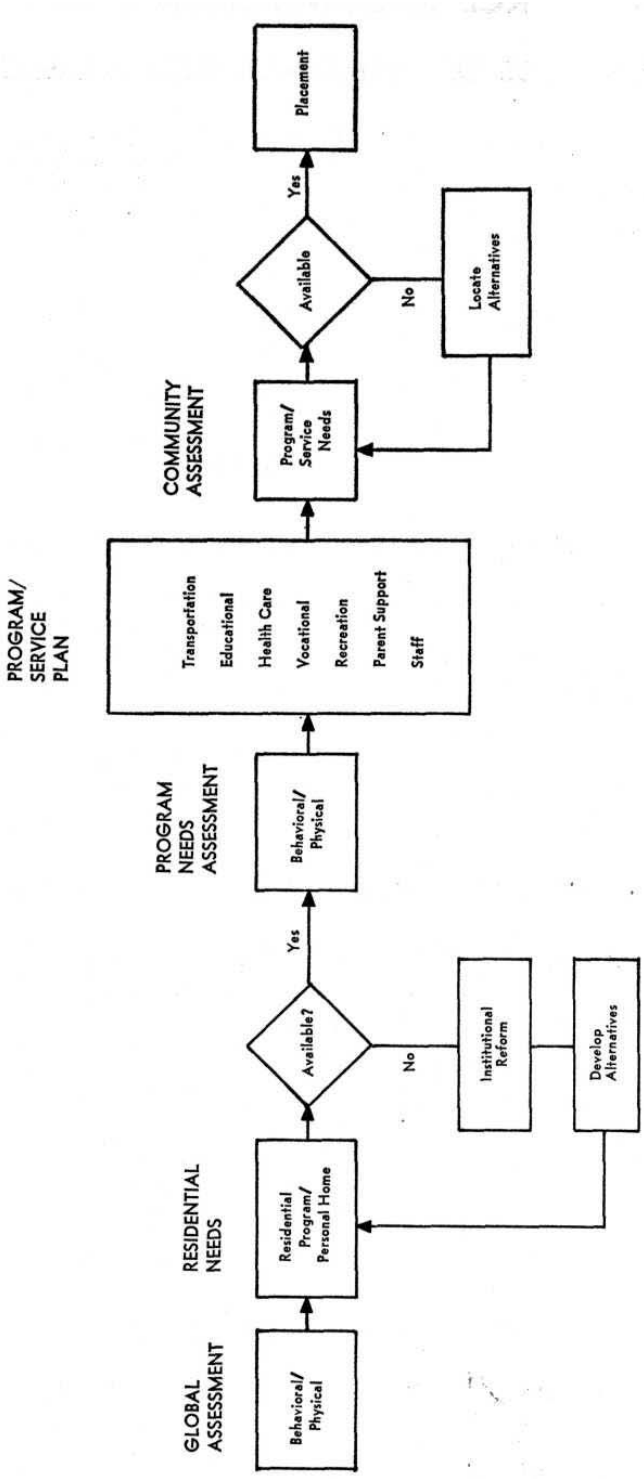


FIG. 1.· Sequence and decisions for deinstitutionalization.

TASK FORCE RECOMMENDATIONS

ON DETERMINING THE NEEDS OF DEVELOPMENTALLY DISABLED INDIVIDUALS

Periodically assess clients at two levels. The first, more global level of assessment should be administered annually for screening and for making placements in programs described in this report. A second, more specific assessment device should be administered quarterly to monitor the development of specific skills around which programs can be developed (p 13).

Precisely state the objectives of individualized training programs. Each objective would include the level of independence, the support needed, and the graduated criteria for success. The statement should be clearly readable and understandable by parents, advocates, and, where possible, the individual client (pp 13, 46-50).

Complete a comprehensive physical assessment of each developmentally disabled individual prior to movement to a community-based alternative and, when indicated, have consultants complete more specific diagnoses based on individual needs. The individual report should include recommendations for:

- Health maintenance
- Medical treatment
- Prosthetic devices
- Medications regimen
- Environmental modification
- Therapeutic programming
- Programming limitations
- Staff and schedule for review of program effects (p. 14).

ON PLANNING AND EVALUATING INDIVIDUALIZED PROGRAMS

Develop a plan with the client on placement in a community-based residence which includes:

- The specific behavioral skills around which the individual's program should be developed and the individual's current level of functioning in each area
- The changes in behavior which are anticipated during the reporting period
- The number of hours per week of structured program services which will be provided to the individual
- The staff who will provide these services and the amount of expected change in behavior over a three-month period of time
- The activities or methods which will be used to accomplish those changes
- The reporting of a monthly staff review of the individual's progress (initially)
- The opportunity for parents' or residents' signatures on a quarterly progress report (p 16).

ON PROVIDING COORDINATED PROGRAM PLANNING

Establish program planning units operating cooperatively with the Area Boards, County Welfare Departments, or Human Service Boards and operate these units in conjunction with a community-based health unit. Initially, such units should be established at each state-operated facility as a primary resource unit for the transition of developmentally disabled people to community settings. Include in the program planning unit a training team for identifying needs and arranging instruction for parents, facility operators, teachers, county welfare placement staff, and other individuals who provide direct services to developmentally disabled people (p 35).

Develop diagnostic and program planning units for the developmentally disabled. The unit should prescribe individualized behavioral and medical treatment programs for clients and demonstrate that these programs effectively remediate skill deficits or reduce inappropriate behavior (p 14).

Each unit should plan for and assist institutionalized clients return to their home communities following the diagnostic and program planning period. Following clients' return to the community, personnel from the planning units should evaluate clients' behavioral progress and program provision. If initial treatment programs prove ineffective in the community, clients should be returned to an area program for an additional program planning period or the community staff should be retrained in the skills necessary to implement the program (p 32).

ON DETERMINING LOCAL NEEDS

Complete a census of developmentally disabled individuals currently housed in state facilities, in community-based facilities, in foster homes, and in private homes (p 18).

Assess individual needs based on existing data (behavioral and physiological) (p 18).

Specify alternative residential programs (types and numbers) which will be required (pp 16-18). Identify licensed residential alternatives (types and numbers) presently in each region (p 18).

ON DEVELOPING RESIDENTIAL PROGRAMS

Develop a continuum of residential programs to accommodate developmentally disabled persons currently in state-operated facilities and other persons with similar characteristics in need but not being served in community facilities (p 16).

Develop respite care services in each county for parents who elect to provide for a developmentally disabled individual in their home (p 17).

Develop residential alternatives as small units rather than clusters of the various residential units representing "mini-institutions." While a precise ratio of homes per community cannot be defined, residences for the developmentally disabled should be structured like "normal" community homes (p 17).

Establish through the Department of Public Welfare facilitators for community alternatives. Such individuals should be responsible for:

Disseminating information about community alternatives such as licensing requirements, funding mechanisms, etc.

Serving as a resource to potential community alternative groups in:

- Obtaining information
- Arranging contact with appropriate officials
- Arranging licensing and funding
- Trouble-shooting problems of new and existing community alternative programs

Collecting data about community alternatives in Minnesota and their problems for use in state-wide planning

Making recommendations in procedures to facilitate community-based programs (p 27).

Publish through cooperation between the Department of Public Welfare, the Department of Health, the Department of Education, and the Department of Corrections, a single package containing:

Step-by-step instructions on how to establish community alternatives

A directory of contact persons in state and local government to arrange licensing and operational funding

Copies of all pertinent rules, regulations, standards, application forms, zoning requirements, etc.

Guidelines for developing budgets

Approved sample floor plans for various sizes and types of facilities

Guidelines for accounting procedures

Guidelines for site selection, zoning evaluation, and public-information activities

A directory of potential sources of start-up money including application forms and guidelines (p 27).

ON LICENSING RESIDENTIAL PROGRAMS

Include requirements for individualized programming in the licensing of facilities. Initial and continuing financial support for a given program should be dependent on these provisions:

The specific opportunities provided by which behavioral development can occur

The means by which behavioral development will be accomplished

The evaluation of the behavioral development of clients.

Review facilities for licensing as a joint venture by teams representing the licensing agencies, e.g., Department of Health, Department of Public Welfare, on an unannounced basis and establish an interagency coordinating office to facilitate and monitor the reviews (p 27).

ON FUNDING THE DEVELOPMENT OF COMMUNITY RESIDENTIAL ALTERNATIVES AND INSTITUTIONAL REFORM

Assure sufficient state support for community residential and treatment programs. The return of developmentally disabled persons to community settings should not be viewed as a means of reducing public expenditures for residential and training programs. Most persons currently residing in institutions and many developmentally disabled persons in communities will need a range of residential and training programs to achieve optimal development (pp 16-17, 51-54).

Assemble a special task force to study available funding sources and needs of community-based residential programs for developmentally disabled individuals (p 35).

Appropriate operating funds in a manner which reduces or eliminates the county's share of support for community alternatives (p 28).

Take the following legislative or administrative action:

Legislation should be adopted to facilitate the development of community alternatives through modification of zoning laws

Construction and operating funds should be appropriated and made available for establishing community alternatives

The procedures for establishing a community alternative should be streamlined

The reimbursement system should be modified so providers need not wait unduly long for payment (p 25).

Establish appropriate levels of dual funding to maintain or reach standards at state-operated facilities and to assure the development of quality community-based residential programs (p 32).

ON DETERMINING SERVICE AVAILABILITY IN THE COMMUNITY

Evaluate all community alternatives to determine whether transportation, educational programs, health-care staff and facilities, recreational programs and facilities, vocational opportunities, support staff, consultants, and program staff are available prior to the transition of the individual to those settings. Each developer of a community-based facility should be required to provide evidence of the current or future availability and coordination of such services (pp 24-25).

Analyze service-delivery potential based on client needs in communities prior to the development or funding of a residential program in that location (pp 24-25). Analyze the responsibility for providing services across private and public agencies at the state and regional levels (pp 24-25).

Develop a continuum of educational programs to accommodate the changing needs of developmentally disabled persons in both community and state-operated programs (pp 17-18, 55).

Demonstrate prior to closing of any state-operated unit that appropriate on-going residential and service programs based on. the affected individual's needs will be available (pp 24-25).

Develop a state-wide inventory of services which can be used by developmentally disabled consumers and provider agencies to secure information on and referral to needed services (p 21).

ON EVALUATING SERVICES AND CLIENT PROGRESS

Provide funds to establish a system for evaluating client services and client progress which insures the confidentiality of individual client data by limiting access to agencies agreed upon by clients, parents, and advocates (pp 32-33).

Develop a form for indicating service delivered and outcomes common to all agencies dealing with developmentally disabled individuals (pp 32-33).

Develop a regional and state-wide information storage and client referral system through which vacancies in existing residences and programs can be identified and selected to meet the needs of individual clients and their parents. The process could be computerized to insure rapid access by decision-makers across the state (pp 32-33).

ON TRAINING PARENTS, STAFFS, DEVELOPMENTALLY DISABLED INDIVIDUALS

Train staffs and parents on educational strategies which can be applied to promote the development of developmentally disabled persons in all behavioral areas (p 22). Training staff should have demonstrated competence in educational and behavioral programming, data collection and analysis, and design and implementation of individualized program plans (p 22).

Establish a state-wide training program to develop the skills of state employees who are currently working in institutional environments so that these individuals assume roles in community alternatives (p 22). Delegate to a state-wide agency the responsibility and funding to develop an on-going inventory of instructional programs for the developmentally disabled (pp 21-22, 58).

ON MEETING PARENT NEEDS

Establish a comprehensive support program for parents who elect to raise a developmentally disabled individual in their home, providing all service options required to meet the program needs of the individual developmentally disabled client and his family. There should be no fixed financial amount specified for all clients, and reimbursement to parents should be based on use of prescribed services (pp 22, 28-30, 33).

Develop program planning units in conjunction with community-based health services to provide evaluative and referral services to parents (pp 29-30).

ON MODIFYING STATE-OPERATED FACILITIES FOR THE DEVELOPMENTALLY DISABLED

Reorganize the present state-operated facilities into small units which include residents and a multi-disciplinary staff (pp 30-31).

Reorganize state-operated facilities to provide a continuum of residential programs and assign residents to residential programs which meet their needs (pp 30-31, 51-54).

Create, as nearly as possible, a developmental training environment in large state-operated and private facilities for the developmentally disabled, including small groupings responsible to identifiable staff person(s), daily opportunities for organized leisure-time activity, specific instruction in self-help skills, and provision for daily structured programming for each individual resident (pp 30-31).

ON PROTECTING THE RIGHTS OF DEVELOPMENTALLY DISABLED INDIVIDUALS

take measures to protect the resident's rights both prior to and on completion of the transition from institutions to community settings. Each transition should be characterzed by a formal report including:

A definitive statement as to why a particular residential alternative and/or educational program was selected based on the behavioral, emotional, and physical needs of the individual.

Demonstrable evidence or recorded judgments with support to show the program to which the individual is to be transferred equals or surpasses his present program.

Admission data which includes the objectives (purpose for entry into the program), the dates for re-evaluation, and the actions which will be directed toward meeting the program objectives. A semi-annual program review for individuals who have not been transferred to community alternatives with support indicating why they cannot be placed or why the current placement is considered most appropriate based on the needs of the individual. Specifically, the report should include comparisons between the present program and alternative programs for meeting the individual's needs, the availability of specific alternatives for the individual, the changes in client behavior which would make alternative placements effective, the anticipated time required for the client to acquire these skills, and the program which will be provided to insure client change.

Planned involvement by the parent and/or legal guardian, the County Welfare Department, the staff, and the individual or legal independent advocate in planning possible changes in the individual's current program with provision for appeal of transfer/nontransfer decisions by parents, residents, or legal advocates through Review Boards, the Commissioner of Welfare, or Human Service Boards (pp 16-17, 28-29).

ON DEVELOPING PUBLIC INFORMATION SYSTEMS

Develop public information materials for doctors, social workers, county welfare staffs, religious leaders, teachers, and elected officials—including information related to normalization, human potential, and the advantages of community-based residences. This material should be cast in two forms: for the professional in practice (inservice) and for the curriculum of those preparing to enter the field (preservice). Further, certification requirements should be altered to include a knowledge base in these areas (p 28).

Develop public information materials to prepare communities for the development of residences for developmentally disabled persons. The materials should include basic information about community need for the residential facility coveying the normalcy of the developmentally disabled in terms of behavior and the low probability of property value loss (p 24).

Prepare specific informational materials for realtors (pp. 24-35).

Require realtors to document verbal and written statements related to the negative impact of community-based facilities (p 35).

Develop public information materials for parents and developmentally disabled individuals including basic information about community alternatives and why they are being developed, assurances that their major fears about these alternatives need not be realized, and demonstrations of the continuity and progression of community-based programs (pp 28-29).

Establish a formalized process for analyzing parent and community attitudes toward community-based programs (pp 28-29).

ON REDUCING THE INCIDENCE AND IMPLICATIONS OF DEVELOPMENTAL DISABILITIES

Develop educational programs on prenatal care, parenting behavior, and specific risk factors, e.g., use of drugs, adequate nutrition, and incorporate them in public school programs (p 33).

Designate to a specific public agency the responsibility for state-wide dissemination of these educational programs and provide funding to support the activity (p 33).

Implement state-wide high-risk pregnancy screening (p 33).

Incorporate a comprehensive and consistent set of assessment areas in all early and periodic screening programs to detect serious developmental handicaps in children (pp 33-34).

Assign responsibility for coordination and funding of early and periodic screening programs to a central public agency to which screening and follow-up activities can be reported for systematic retrieval (pp 33-34).

Develop a unified approach to the use of the birth registry including:

Programs for physicians on benefits accrued through Early and Periodic Screening and its value to their ongoing practice

The use of a consistent reporting format Training of health personnel in personal-interaction skills related to acquiring information, service delivery, and the impact of a developmental disability on the family and child (p 34).

Develop programs to meet the diagnostic and treatment needs of developmentally disabled individuals ages 0-21 as a follow-up service for early and periodic screening programs, e.g., educational programming or surgery (p 34).

Develop a standard interagency reporting form for reporting and retrieving information (pp 33-34).

ON PLANNING RESEARCH, DEVELOPMENT, AND DEMONSTRATION PROJECTS

Establish an interagency committee to review research and development proposals and activities in human services, abstract them, and provide a summary for public dissemination (p 34).

Submit the criteria incorporated in this report to a research committee for review, modification, and adoption (pp 34, 59-60).

Establish a state plan outlining priorities for research and development in human services related to the developmentally disabled and solicit proposals on an interagency basis to meet specific components of that plan (p 34).

TOWARD AN INDIVIDUALIZED APPROACH TO PROGRAM PLANNING

Ideology guides programs for disadvantaged members of society and is one of the most frequently overlooked influences on human services (Sarason and Doris, 1969; Wolfensberger, 1972). Over the last one hundred years, changes in social thought greatly influenced residential services for the mentally retarded. When the prevailing philosophy was positive, reflecting an optimistic view of the developmental potential of disabled persons, programs actively promoted the development of individual potential rather than mere maintenance of people under a regimen of passive care.

From 1840 to 1880 institutional programs emphasized educating and training the developmentally disabled with the goal of returning them to productive lives in community settings. Ideology's negative influence on programs for developmentally disabled persons rose in the eugenics period from 1880 to 1930. Then genetic discoveries and social Darwinism led to a spate of studies linking retarded development to crime and other undesirable social qualities, and professionals and laymen argued that retarded individuals were a major social menace. This ideology reversed the philosophy of the residential services, which abandoned habilitation and emphasized economization and sought to protect society from presumably "deviant" persons (White and Wolfensberger, 1969). During the last fifty years, programs for the developmentally disabled rapidly expanded, unfortunately often without the influence of a positive philosophical ideology (White and Wolfensberger, 1969).

Presently, the **normalization** principle directs planning for developmentally disabled persons. If applied as a total concept, this principle has considerable potential for the development of effective programs. Normalization, as defined by Nirje (1969), means making patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society available to the developmentally disabled (p. 182). This definition was recently reformulated by Wolfensberger (1972) who described normalization as ".... utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible (p. 28)." Expanding on the above definition, Nirje (1969) delineated a number of conditions and prerequisites of the normalization principle:

> Normalization means a normal rhythm of the day . . . getting out of bed, getting dressed ... (p. 182). Normalization . . . implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure-time activities in a variety of places. Consequently, it is wrong when a retarded person . . . has his training classes, his structured therapies, and his recreational activities in the same building that serves as his home . . . (p. 182). Normalization means to experience the normal rhythm of the year, with holidays and family days of personal significance . . . (p. 82).
>
> Normalization also means an opportunity to undergo the normal developmental experiences of the life cycle . . . children, youths of school age, adolescents, and adults should have activities and experiences which are age appropriate, including contacts with persons of similar ages and interests (p. 182-183).
>
> The normalization principle also means that the choices, wishes, and desires of the mentally retarded . . . have to be taken into consideration as nearly as possible, and respected (p. 184).
>
> Normalization . . . means living in a bi-sexual world (p. 184).
>
> Normalization implies letting developmentally disabled persons exist as close to normal as possible in economic standards. This implies giving the retarded basic financial privileges available to others ... (p. 185). The normalization principle implies that the standards of physical facilities . . . (the sizes of the facilities) should conform to what is normal and human in society.... They should never be placed in isolated settings merely because they are intended for the mentally retarded (p. 185).

Applying the normalization principle to planning human services does not imply that the nature and severity of the person's handicap should be ignored. It suggests that residential and training programs be structured to reflect culturally normative characteristics as nearly as possible. It is assumed that programs exemplifying such characteristics will more successfully establish and maintain the personal-social behaviors necessary for increased independence and productive living in settings common to the mainstream of society.

The Planning Strategy

Normalization for developmentally disabled persons led to the assumption that living in a community setting more closely approximates a normal life style than does living in a large, multipurpose, state-operated residential facility. On this assumption, several states initiated massive transfer programs. However, unless community support and coordination were developed in advance, the small, community-based residences often provided neither the quality staff nor the quality programs available in state-operated facilities, and many developmentally disabled individuals went to smaller and inferior institutional environments in a community where few of their needs could be met (Edgerton, 1967; **Time,** December, 1973).

To insure both a more normalized living environment and the opportunity to acquire as many life-skills as possible, the CAIR Project aimed at identifying alternative residential facilities and accompanying community programs to meet the varying behavioral needs of developmentally disabled individuals. It was anticipated that most of the information needed for this task was currently available but not consolidated. Therefore, a major aspect of planning was bringing together the resources and expertise of several state and community agencies to examine the problems in establishing community alternatives and to suggest solutions.

The CAIR Steering Committee

Development of an effective plan which could be incorporated in the recommendations of the major state agencies required the involvement of public and private agencies in the initial decision-making. Thus, the Steering Committee comprised representatives of the major organizations and agencies dealing with developmentally dis-

abled individuals. Consumer representatives and service providers serving on the committee insured that the specific needs of developmentally disabled people were considered from the onset.

Development and Review Process

The first step toward a comprehensive work plan was specification of the major areas to be analyzed. Three major task forces set out to identify the basic issues in providing community alternatives. Task force decisions grew from the contrast between expected needs of individual clients and the currently available resources.

The CAIR Task Forces sought a state-wide plan consistent with the normalization principle and its corollaries for developmentally disabled people residing both in institutions and in communities. **The resulting recommendations assume that effective services begin with a thorough study of the characteristics of developmentally disabled individuals, and that programs are most likely to be successful in promoting development if they are consistent with the philosophy of normalization.** More specifically, the assumptions underlying the reports and recommendations are: Programs for developmentally disabled persons should be formulated and operated in a manner consistent with the concept of normalization, i.e., environments should make provision for the maximum feasible participation of the developmentally disabled in normal time schedules, work experiences, leisure activities, training in normal settings, and living in environments which embody physical qualities associated with normal living.

Developmentally disabled persons have an inherent constitutional right to appropriate education, treatment and residential living facilities. This principle has been affirmed repeatedly by Federal courts in class action suits brought on behalf of developmentally disabled people (Abeson, 1973; Welsch v. Likins, 1974); for example, educational services for severely handicapped people have been mandated through court judgments and legislation. Residential and training programs should be formulated consistent with a developmental model. This assumption suggests that the point of origin for planning is the identified needs of the developmentally disabled and should not be dictated by a prior administrative or medical model or by the nature of existing physical facilities. Thus a strong emphasis is placed on program planning based on a detailed analysis of the individual's behavioral and physical capabilities and limitations. Frequent evaluation of individual progress is also stressed to insure program effectiveness as well as public accountability.

Models for residential and training programs should provide a continuum of services to permit the individual to progress toward the development of maximum independent-living skills.

Participation of the developmentally disabled and their parents, guardians, or advocates should be solicited and guaranteed in major decisions regarding placement in residential and training programs. .

Task Force I: What Do Developmentally Disabled Individuals Need?

Since effective planning for normalization must be based on the needs of individual developmentally disabled persons, an assessment process should be designed to facilitate their upward mobility. Assessment should include behavior most relevant to a normalized life style and the physiological limitations which might interfere with its achievement. The needs and characteristics identified by individualized assessment will provide the information for decisions on programs, facilities, and support mechanisms.

The basic questions Task Force I addressed were: Which behaviors should be included in a comprehensive individualized assessment?

What skills must an individual have to live independently?

Which existing assessment devices could evaluate functioning in each behavioral area? Which physiological characteristics should be evaluated in a comprehensive, individualized assessment? What educational and residential environments would be required to meet the needs of individuals demonstrating varying levels of skill development? What behavioral/physical assessment should be completed prior to and after the transition of developmentally disabled individuals to the community-based residences?

Task Force II: What Is Available vs. What Is Needed?

Program support should be available to meet the potential needs identified by Task Force I. Training and support programs required for normalization were determined by evaluating existing agencies, personnel, and materials in terms of probable behavioral needs and physical limitations of developmentally disabled individuals. The results of the evaluation suggested recommendations for staff, agency, and program development.

The basic questions Task Force II addressed were:

What would represent an optimal support program, in terms of personnel, for meeting the needs of the developmentally disabled? Which agencies currently provide such support? What types of residential, vocational, and social settings are available in Minnesota communities? Are any of the potential behaviors or physical limitations not being considered under current support programs?

What would be the optimal environment for training based on specific behaviors and physical limitations?

What materials are available for instructing the developmentally disabled individual in each behavioral area?

Are instructional programs available for personnel who will deliver the instruction (parents and staff)?

Task Force III: How Can the Program Be Implemented?

Success in implementing individualized programming depends on support from parents, from the staff of facilities, and from the communities at large as well as on the availability of services. Though individualized planning may not require their direct involvement, each group must be involved in establishing community alternatives. Thus, the third task force considered strategies for implementing the recommendations of Task Forces I and II.

The basic questions Task Force III addressed were:

What community, staff, and parental attitudes must be dealt with in the process of deinstitutionalization?

What procedures have been successful in dealing with these attitudes?

What criteria could be used to evaluate the suitability of community environments for the developmentally disabled?

What programs should be developed for parents who elect to retain a developmentally disabled individual in their home?

How can existing institutional facilities be used for purposes involving the developmentally disabled and/or for purposes not involving the developmentally disabled?

Which educational programs can provide instruction for parents and support personnel?

What would be an optimal instructional model?

What provisions must be made for the staff at existing facilities?

Task Force Operating Procedures

Each task force, composed of ten to fifteen individuals, followed three basic steps:

Identify individuals, projects, committees, and other data/information sources relevant to the topics being considered and solicit specific information.

Consolidate available information into a consistent format, evaluate it for deficiencies, and make recommendations based on it.

Forward the completed document to the contributors and other relevant agencies for feedback.

Review Panels

To provide expertise, as well as to control potential bias, a review panel was assembled for each task force. The three review panels, composed often to fifteen individuals, evaluated and modified the task force findings. Each task force, working with its review panel, was responsible for the content and recommendations in its report.

The Reactor Panel

A second review body was assembled for the task forces —a reactor panel—which provided the task forces with content during development of the reports and constructive feedback on the completed material. The reactor panel comprised more than fifty participants including the developmental disabilities planners, directors of the county welfare boards, administrators of state hospitals, special education regional consultants, representatives of the county health boards, and a large number of individuals in on-line positions. Review by this group assured the feasibility of the recommendations.

The final reports and recommendations of the task forces were forwarded to the CAIR Steering Committee which then recommended action in five areas:

- Evaluation of the total program for the developmentally disabled
- Monitoring procedures which insure the rights of the developmentally disabled while providing data on all phases of the program plan
- Implementation of the task forces' recommendations and a time schedule for completing them
- Costs for implementing individualized programming with suggested sources of funding
- Application of the existing data to the development of screening and programs for "high-risk" individuals and their families.

DETERMINING INDIVIDUAL NEEDS AND PLANNING PROGRAMS

Moving developmentally disabled people from large institutions to community alternatives which incorporate the concept of normalization requires careful assessment of each person in order to prescribe a residential program and a developmental program tailored to the individual's needs. This assessment, the task force concluded, must include both physical and behavioral measures to assure that residential programs are appropriately selected. In attempting to identify the needs of developmentally disabled persons, the task force discovered that none of the available assessment instruments gauges independent-living skills and other adaptive behaviors precisely enough to serve as a base for prescribing programs.

Since the diversity of needs in the developmentally disabled population rules out fostering growth with a handful of standardized programs, the task force concluded that a number of different types of residential programs would be needed and that each community alternative must be prepared to offer a broad range of services to its clients, e.g., educational programs should be expanded to assure services to children, adolescents and adults. And, the task force said, services should be within reasonable traveling time from the client's place of residence.

Finally, the task force concluded that the services which any region in Minnesota should be prepared to offer can be determined only after the needs of clients moving into community alternatives have been identified within that region.

Developmental Assessment

The development of community-based alternatives to large institutions requires an assessment program which not only specifies the most appropriate environment for the development of social, emotional, and educational skills, but also insures programs based on client's needs.

Since behavior, in conjunction with the physical characteristics of the individual, defines an optimal environment and program, an attempt was made to specify those behaviors most important to achieving independence, i.e., living a more normal life style, and to relate behavioral and physiological variables to residential and program alternatives.

Assessment, in this report, refers to a survey rather than a diagnostic tool. A survey instrument lists general categories of behavior which would indicate a need for environmental changes based on the physical and/or behavioral characteristics of individuals. In contrast, a diagnostic tool based on the survey instrument would deal with specific areas of skill development (observable behavior) in order to individualize programs after an appropriate residential program had been identified.

Behavioral Assessment

Evaluation of current behavioral assessment devices indicated they were unsuitable for defining programs based on client needs because of one or more of the following limitations:

- Multiple behaviors are assessed in single items
- Multiple scoring methods are used both between and within tests
- The tests yield a global score which cannot be used for planning individual programs
- The items are not arranged on a developmental con tinuum
- Recording is based chiefly on hindsight and recall rather than direct observation
- Many items are cast in the form of "not" or negative behavior rather than on-going, positive performance, yielding problems of reliability and validity
- Most items are not evaluative, for they do not include the conditions under which the behavior occurs or the criteria to be used in evaluation.

Because of these limitations and the absence of significant behaviors in all assessment devices reviewed, no currently available assessment device could be recommended.

Behavioral Description

To avoid reliance on a single measurement instrument and creation of a new instrument, the task force specified the broad behavioral categories significant to an individual's approximating a normalized life-style. While insufficiently inclusive, parts of current measures are directed toward independent living. Consequently, existing instruments were analyzed, and the broad categories of behavior specified. These categories were then enlarged using:

- Normal developmental patterns established by authorities in child development
- Characteristics of the institutionalized, developmentally disabled population in Minnesota.

The broad categories of behavior requiring assessment for appropriate individual placement include the following skill areas:

- Personal-hygiene skills
- Eating skills
- Dressing skills
- Communication skills
- Quantitative skills
- Social-interaction skills
- Independent-living skills
- Vocational skills.

Where possible, each category was converted to a hierarchy of descriptive behaviors, for example, eating skills: feeding self, selecting and using correct utensils, displaying appropriate manners, and eating in **a** variety of locations.

As a step toward development of **a** comprehensive diagnostic evaluation, each descriptive behavior was divided into specific behaviors which, if cast in the form of objectives, could be used in measurement (see **Skill Areas and Behavioral Descriptors,** pp 46-50). While the behavioral listings remain incomplete and developmentally unsequenced, they could lead to an interim tool for individualized programming after community placement was arranged.

The broad categories of behavior and the listing of the specific behaviors which they represent provide a base for developing assessment procedures to meet two distinct needs: determining the type of residential programs most suitable for individual clients and preparing programs to meet individual needs. For example, the absence of global skills such as independent eating and dressing would not define the exact instructional program for an individual, but would indicate that the person should reside in an environment where developing self-care skills is emphasized. A more specific assessment of the client's status using the behavioral listings in the areas of eating and dressing skills, e.g., can eat with a fork or cannot use a knife, would indicate a precise point of departure for programming.

It is envisioned that such behavioral listings would become part of each person's record, thereby making assessment an on-going and informative process to direct programming while individuals progress from one program to another or as personnel changes are made within a specific program.

Physical Assessment

Behavioral needs of developmentally disabled individuals partially define the residential programs and services which must be developed. **The physical status of individuals also affects their opportunity to engage in normal experiences and, therefore, must be considered in designing residential programs, setting program goals, determining required services, designing training programs, and developing client-based environments.** Specifically, physical assessment should consider the individual's motor development and functioning, visual abilities, communicative skills, and freedom from seizures.

Ames and Atha (1971) assessed the physical disabilities present among mentally retarded residents in state-operated facilities in Minnesota. They found that visual handicaps limited 8% to 10% of the individuals, and hearing problems limited 4% to 6%. A recent study of the 1,297 residents of Faribault State Hospital (Libby, 1974) con-

firmed these results. Libby's findings indicated that nearly 10% of the residents had moderate to severe visual handicaps, nearly 6% had moderate to severe hearing handicaps, approximately 30% of the residents were subject to seizures, and that approximately 20% of the residents were nonambulatory. These data indicate that physical characteristics must be part of the individualized assessment which precedes transition to community-based programs and that residential programs must be developed and structured to meet a variety of physiological needs.

Assessment has historically developed around a medical model, focusing simply on the degree of disability rather than the level of functioning and its implications for program decisions. For example, motor functioning has been measured in terms of ambulation, extremity use, and level of activity; seizure activity has been described in terms of frequency, intensity, and type of seizure. While providing a physical picture of the individual, these categories provide only limited information on which to base program decisions.

Physical assessment leads to three alternatives: correct the condition, control the condition at varying levels, or accommodate the condition. Correction or control should specify medical treatment, prosthetic devices, or therapeutic program. Accommodation should define the environmental and program alterations to be completed for the individual.

Beyond medical description, effective program design requires that physical characteristics be described in terms of their impact on the individual's behavior and development. Further, the assessment should define the impact of the physical characteristics collectively rather than independently. In other words, a total perspective for each individual should outline an interrelated, comprehensive program rather than several isolated programs based on separate physical characteristics.

Program plans based on physical characteristics should include more than a medical treatment plan. They should include the required phosthetics; specialists; modifications in the living, working, educational, and recreational environments and programs; and a schedule for follow-up evaluations. Descriptions of programming alternatives should be prepared for each area of physical disability, and for specific levels of functioning within each area. For example, the programming model for seizures (pp 56-67) indicates the impact of the limitation on behavior, the required modifications of the residential and educational environments, the specifications for transportation for several levels of functioning. Similar behavioral descriptions should be completed for other physical limitations which will affect program decisions for developmentally disabled individuals.

Health Care

Normalization requires that individuals be physically able to take advantage of their environment. **An individualized health-care program should be specified for each resident of state-operated and community-based residential programs.**

Three levels of health care have been identified in the **Report of the Right to a Developmental Program Committee** (1974): **primary** (preventative/educational), **secondary** (early identification/intervention), and **tertiary** (restorative/rehabilitative). Primary and secondary health care needs are reflected in the recommendations for reducing the incidence and implications of developmental disabilities (p 7). The adequacy of tertiary health services relates directly to the effectiveness of the physical assessment program which provides the basis for restorative/rehabilitative decisions.

Physical data should be collected systematically over time, goals for physical change should be stated in advance, and efforts toward meeting those goals should be monitored. Just as expertise is required to bring behavioral change, specialists must be incorporated in programs for physical change.

The primary question, however, is how to implement such programs on a cost-effective basis for individuals in state-operated and community residential programs. A model for successful implementation is provided by the Comprehensive Health Care Project (1973) which outlined five basic steps: registration, assessment, preparation of a care plan, treatment/implementation, and monitoring/reassessment.

Registration. All developmentally disabled individuals in state-operated and community-based facilities could register on a form common to all agencies concerned with physical assessment and health care. The registration would include basic demographic information as well as a comprehensive medical/physical status and treatment history.

Assessment. Using the registration information as a guide, a pediatric or adult nurse could highlight significant variables for the physician who would complete a preliminary screening for physical limitations. The physician would then prepare a care plan.

Preparation of a care plan. Using preliminary screening, the physician and other health personnel would prepare a final care plan if the individual required no specialist attention, or an interim care plan if specialists are to make a final care plan. In an interim care plan, the physician would specify the specialists required; assessment by those specialists would follow.

Treatment and implementation. If possible, medical treatment should be provided by community resources, i.e., hospitals and clinics. Changes in client programs should come through the community-based residential and educational facilities wherever possible.

Monitoring and reassessment. The individual's progress should be evaluated, along with other services provided and their effects, at intervals defined in the health-care plan. To assure general health care and systematic monitoring of the care plan, diagnostic teams could be available locally. While these teams would not be responsible for treatment, they would help to assure the availability of specialists when their services were required.

Summary

A normalized existence is contingent on both the physical characteristics and the behavioral status of the individual. To insure that both factors affect the design of programs, the individuals' specific needs must determine the goals in their programs. Such an approach requires three steps:

- Assess the behavioral and physical characteristics of each client
- Set individualized program goals
- Evaluate the service delivery and the effect on the client.

Status of Individuals in State-Operated Facilities

A report by the Minnesota Department of Public Welfare (Bock, 1973) described the basic skills of individuals residing in state hospitals: 50% could not toilet without assistance; 53% had no effective speech; 58% could not dress without help; and 62% became lost if they were more than a few blocks from their residence.

These data and data on the adaptive and maladaptive behavior of the residents provide the direction for planning community alternatives: **residential and training environments must meet a broad spectrum of individual behavioral needs.**

Adaptive Behavior

While development of optimal community alternative programs requires individual data, residential needs can be projected from global measures. Since the only available data on mentally retarded residents of state-operated facilities in Minnesota is based on the **Adaptive behavior Scale** (Libby, 1972), group performance on **Adaptive Behavior Scale (ABS)** items matched to the survey behaviors summarized in Skill Areas and Behavioral Descriptors (pp 46-50) provides a description of the status of nearly 4,000 mentally retarded residents of state facilities in mid-1972.

Table I indicates the number of the ABS item (Part I) judged to be most similar in content to the survey behavior. Where the similarity between the listed behavior and the ABS item is questionable, a question mark follows the item number which is labeled "perhaps." In some cases, appropriate item content could not be found because of the generality of the listed behavior; in other cases the behavior was not included in the ABS scale. The percentage of the population found at various functional levels is presented with the item scores used to define each level. The population data are not currently available for some items either because of the data storage format or because of errors in the retrieval and tabulating process.

These data Indicate that developmentally disabled persons **in** state-operated facilities **will** require community residential **programs which emphasize development of self-**care skills. However, it is significant that a number of in-

TABLE I

An ABS-Based Description of Residents Residing in State Hospitals in 1972

Survey Behavior	ABS Item	Percentage (Item Score) Independent	With Help	No Skills
Eating Skills				
Eating in a variety of locations	2	6% (3)	28% (2)	65% (0-1)
Displaying appropriate manners	4	28% (9)	70% (2-8)	2% (0-1)
Selecting and using correct utensils / Feeding self	1	20% (6)	31% (3-5)	49% (0-2)
Dressing Skills				
Selecting clothes	13	22% (8)	61% (1-7)	17% (0)
Completing basic motor tasks	16	47% (6)	45% (1-5)	8% (0)
Personal-Hygiene Skills				
Caring for health needs	22e, f, & g	- - - - Not available - - - -		
Grooming	14	21% (5)	74% (1-4)	5% (0)
Washing and bathing	8	23% (7)	57% (1-6)	20% (0)
Toileting	5	49% (4)	34% (1-3)	17% (0)
Communication Skills				
Reading for independent living	38(?)	- - - - (4-5)	Not available - - - - (1-3)	(0)
Writing for independent living	33	- - - - (4-5)	Not available - - - - (1-3)	(0)
Responding verbally	36	20% (3)	26% (1-2)	54% (0)
Responding non-verbally	34	57% (6)	33% (1-5)	10% (0)
Quantitative Skills				
Managing currency	29, 30	- - - - (5)	Not available - - - - (2-4)	(0-1)
Managing time	43	10% (6)	65% (1-5)	25% (0)
Applying units of measurement / Applying number concepts	42(?)	12% (5)	33% (1-4)	55% (0)
Social-Interaction Skills				
Caring for and sharing property / Following rules	(11:2-4, 10, 18) / (11:12)	See maladaptive behavior section		
Cooperating	63	- - - - Not available - - - -		
Displaying appropriate social behavior	None	See maladaptive behavior section		
Independent Living Skills				
Avoiding danger situations	None	—	—	—
Using public transportation	20	- - - - (5)	Not available - - - - (1-4)	(0)
Travelling within the community	19	17% (3)	48% (1-2)	35% (0)
Travelling within the neighborhood	19	17% (3)	45% (1-2)	35% (0)
Selecting and purchasing items	32	- - - - (4-5)	Not available - - - - (1-3)	(0)
Telephoning	21	- - - - (6)	Not available - - - - (1-5)	(0)
Selecting and initiating leisure activities	59	- - - - (4)	Not available - - - - (1-3)	(0)
Maintaining clothing	15	14% (6)	67% (1-5)	19% (0)
Managing a residence	22	- - - -	Not available - - - -	
Cleaning a household	45	13% (2)	19% (1)	68% (0)
Preparing and serving meals	47	13% (3)	23% (1-2)	64% (0)
Managing finances	None	—	—	—

dividuals have mastered specific independent-living skills. Unfortunately, this table can only define the status of the total population in each skill area; the status of individuals across skill areas should not be inferred. For example, it is possible that a given individual who succeeds on the independent-living skills of cleaning a household or preparing a meal may perform only "with help" on the personal-hygiene skills.

Maladaptive Behavior

Developmentally disabled individuals frequently exhibit behaviors which decrease acceptance by the community, reduce the chance of acquiring new skills, and ultimately interfere with achievement of a normal life-style. Therefore, the mental health of the developmentally disabled individual must be considered in selecting residential programs. Since a person's attitudes about self and others will, in part, be reflected by behavior, specific social behaviors must be assessed.

Recent experience with Part II of the ABS has demonstrated that it, or a similar checklist of behaviors, describes the frequency of maladaptive behaviors in a group of individuals. Nevertheless, a report which describes specific incidents should be used when planning individual programs. The basis for this recommendation becomes apparent on review of the scoring procedures used on the ABS and the results of its application in Minnesota.

Whether a behavior is maladaptive often depends on the context in which it occurs, not solely on its occurrence. For example, screaming may be quite appropriate for one situation, but extremely maladaptive in another. The frequency and intensity of a behavior may also be related to a judgment as to whether it is maladaptive. Behavior checklists call for rater judgments about the seriousness of the behavior. Thus, whether in present-absent or scale format, the results may vary significantly from rater to rater.

The use of a comprehensive checklist is a time-consuming process which would be warranted where the frequency of maladaptive behavior is extremely high. Table 2 describes the frequency of behaviors in domains sampled by the ABS, Part II, among residents in state-operated facilities in Minnesota in 1972. The data indicate the number and percentage of residents with a score of zero in each category of maladaptive behavior and the percent of scores (maximum = 100) equivalent to the 50tn and 90th percentiles of the sample of institutional residents on which the ABS was standardized. The **Score of Zero** column reflects the percentage of persons who do not show frequent evidence of each particular behavior. The figures show, under **Percent of Scores Equivalent to** the 50th and 90th percentiles, the proportion of residents who also have achieved scores equivalent to the average scores of the upper 10 percent of persons with the most extreme scores of the standardization sample.

TABLE 2

Maladaptive Behaviors: Part II

Domain	Score of Zero		Percent of Scores Equivalent to:	
	Frequency	Percent of Population	50%ile	90%ile
Violent and Destructive	1409	36	3	20
Antisocial	1376	35	3	21
Rebellious	1485	38	3	25
Untrustworthy	2653	67	0	19
Withdrawal	1411	36	7	35
Stereotyped Behavior	1782	45	3	21
Inappropriate Vocal Habits	2659	67	0	20
Inappropriate/Interpersonal	1890	48	5	26
Eccentric Habits	1270	32	3	16
Self-abusive	2563	65	1	20
Hyperactive	2533	64	1	40
Sexually Aberrant	2415	61	1	11
Disturbances	1109	28	4	17

The data suggests that occurrences of maladaptive behaviors are too infrequent to warrant development of a comprehensive checklist. Further, since maladaptive behavior is both defined by its context and at the same time created by that context, direct observation seems the optimal procedure for assessment in the community-based facility and in the educational program. Where behaviors are found to be so extreme as to prevent individuals from living in small group homes or from participating in educational programs, short-term residential programs with emphasis on developing more adaptive behavior should be arranged.

Alternative Residential Programs

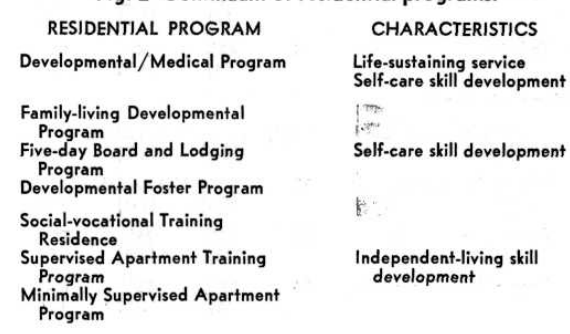
Developmentally disabled individuals do not comprise a homogeneous population for whom a single residential program can be described. While developmentally disabled people are variously retarded in basic developmental processes, each program must reflect the individual's unique behavioral and physical limitations. This diversity calls for a range of residential programs for maximum development and assimilation of the individual into more normalized settings. Also needed are appropriate support services: educational and rehabilitative support, health services, counseling, recreational alternatives, and financial programming.

Residential programs for the developmentally disabled in other states have incorporated service delivery models based on developmental theories and the principles of normalization, for example, the ENCOR program in Nebraska (Proceedings of the CAIR Institute, 1973). Using successful models as a guide, the task force delineated a continuum of residential programming alternatives which would meet the needs of developmentally disabled individuals in Minnesota.

A Continuum of Residential Programs

The proposed model for a continuum of residential programs would accommodate individual needs ranging from extreme dependency to virtual self-reliance. Since the emphasis has been deliberately placed on the anticipated impact on the behavioral development of the individual from each alternative, the suggested continuum can be programmatically divided into three categories: life-sustaining, self-care, and independent-living programs (Figure 2).

Fig. 2 Continuum of residential programs.



A fourth residential program category, the **short-term Behavioral Training Developmental Program,** would modify specific maladaptive behavior of individuals so they could benefit from other residential programs. This program has not been included in the continuum because it is designed to meet the needs of individuals from **all** residential programs.

Each of the other residential programs is designed to serve a specific population under varying circumstances. The **Developmental/Medical Program** which emphasizes life support would also be directed toward developing self-care and social skills. Three separate programs are required for individuals whose primary need is self-care skill development: the **Family-Living Developmental Program** which would serve individuals who could profit through a group living arrangement, the **Developmental Foster Program** which would accommodate the individuals who require a smaller living unit, and the **Five-day Board and Lodging Program** which would serve individuals who wish to remain at home while receiving the benefits of available programs in other communities.

More advanced programs are required for individuals who have acquired the basic self-care skills. The **Social-vocational Training Program** is designed to provide a transition from a highly supervised program to a more independent program. The acquisition of independent-living skills in this program should enable individuals to progress to **Supervised Apartment Training Programs,** where on-site supervision is provided in an essentially independent-living facility. Finally, the **Minimally Supervised Apartment Program** would assure a normalized life-style with easy access to assistance should the need arise.

The Personal Family Home

The individual's family home has been deliberately excluded from the continuum of residential programs because it is a basic unit requiring specific program and support consideration. Support service provided parents who elect home maintenance should be equivalent to that provided community-based or state-operated facilities. Specific recommendations for developing such support services are presented on page 6 of this report.

Since the primary alternative to the family residence has been institutional placement, the continuum of community-based residential programs is proposed as an alternative for developmentally disabled individuals currently residing either in personal family homes or within state-operated facilities.

Program Characteristics Orientation

The continuum of residential alternatives proceeds from programs in which the individual is extremely dependent on others for support to programs in which the individual assumes a nearly independent life-style.

The descriptions of the eight residential programs (see **Continuum of Residential Programs,** pp 51-54) define the populations they serve, the necessary location, the program characteristics, the applicable licensing standards, the required educational programs, and support services. They include residential staff and consultants needed for individuals in each residential program and suggestions for the number of residents and **the** duration of residence.

The progressive sequence reflects the optimism of normalization: developmentally disabled individuals can progress toward independent living. Such progress can only occur if residential programs capitalize on individual developmental advances. **Therefore, placement in any given residential program should be viewed** not as **a final location but rather as a start toward programs reflecting increasing independence.** The overlapping goals (program characteristics) within the residential programs should ease transition between the programs.

Respite and Crisis Care

Provision for respite and crisis assistance easily accessible to parents in any region of the state should be incorporated into proposed residential programs, particularly for short-term care and supervision of individuals who generally live in their personal family homes. Designated residential programs should be prepared to provide:

Residential services to relieve family stress, e.g., money, vacation, moving
Residential services to assist families during major crises, e.g., death, divorce, emotional problems
Supervision for portions of days or evenings, e.g., parent stress periods, personal or recreational needs, and business affairs.

Since only limited data are available related to the effects of age or sex groupings on developmentally disabled individuals, the residential programs do not include precise recommendations in these areas.

Location and Development of Programs

While the locations and types of programs needed may vary from community to community, the report recommends that the continuum of residential programs be available in each region in Minnesota. The number of specific programs of any given type should be determined from the projected needs of the developmentally disabled within that region. As noted by O'Connor and Justice (1973), four serious problems affect operating residential alternatives and, therefore, must be considered during systematic planning: inadequate funding, locating qualified staff, developing individualized client programming, and inadequate community support services.

Educational Programs

Goffman (1961) suggested that a basic social arrangement in our society is one in which people sleep, work, and play in different places. While each residential program is oriented toward the development of specific skills, it is imperative that more extensive educational programs directed toward similar skill acquisition be located in the community. Two basic educational sequences are required for developmentally disabled individuals: those for children and young adults and those for adults.

Each alternative need not be housed in **a** separate plant, that is, a given educational facility might include both **a** work activity center and a sheltered workshop. Minimum distances between residential programs and educational programs cannot be specified; however, little educational value accrues from long hours spent commuting daily between a residence and an educational program.

It would be unrealistic to expect that each community develop a complete set of educational alternatives; cooperative planning among communities or counties may be

required. However, planning and development which insure the availability of educational programs for individuals in a residential program should be completed prior to licensing of the residential program or surely before individuals enter it.

Educational Programs for Children and Young Adults

Normalization implies that programs for the developmentally disabled should parallel, wherever possible, programs for nonhandicapped individuals regardless of the ages of the individuals being served.

A continuum of direct educational programming for developmentally disabled individuals between the ages of 0-21 would include home-based instruction, day care, special schools, special classes within a regular school, and regular class placement with appropriate supplemental instruction through resource rooms and consultative services (see **Continuum of Educational Programs for Children and Young Adults,** p 55).

Educational Programs for Adults

Normalization for the developmentally disabled adult necessitates a continuum of services for the development of independent-living skills among which vocational training assumes primary importance. Every effort should be made to increase the person's employability to assure increasingly independent vocational roles.

Vocational training programs would include residence-based instruction, pre-vocational activity centers, sheltered workshops, comprehensive rehabilitation facilities, vocational-technical schools, and on-the-job training (see **Continuum of Training Programs for Adults,** p 55).

Summary

The combination of a residential program and an educational program directed toward shared objectives based on individual needs will aid goal attainment. Since the two programs are interrelated, it is essential that a common reporting system be established between the programs so individual problems or advances alter both programs for the individual. Also, since the residential/educational programs represent the basic programs, effective planning for the developmentally disabled must directly relate them to many other services, e.g., medical or transportation.

Program Selection and Projection of Needs

The development of programs for the developmentally disabled requires determination of individual needs followed by projection of residential, educational **and** service requirements **based on those needs.** The best indicator of present program and service requirements is the behavioral and physical status of each developmentally disabled individual in Minnesota. Unfortunately, precise individual data are not currently available. However, individual performance on specific items of the **Adaptive Behavior Scale** (ABS) can provide a base for individualized residential and educational program selection. Individual programming requirements could, in turn, be collectively analyzed by the region, county, or community to specify local program needs.

Selection and projection follow four basic steps: item analysis of individual test results, individual program prediction, regional/county population analysis, and cost projection.

STEP 1: Item Analysis for Individuals

Item scores on the ABS can be analyzed to determine the individual's performance in specific areas and physiological limitations which must be considered in program selection. For example, the following analysis could be completed:

SKILL AREA	ABS ITEMS
Eating Skills	1, 2, 4
Dressing Skills	13, 16, 17, 18
Personal-Hygiene Skills	5, 6, 7, 8, 9, 10, 14, 22
Communication Skills	33, 34, 36, 38
Independent-Living Skills	15, 19, 20, 22, 30, 31, 32, 45, 47, 59

PHYSICAL CHARACTERISTICS	DATA SOURCE
Physical Limitations	Medical Record and ABS
Motor	Physical Assessment
Hearing	
Visual	
Speech	
Seizures	
Chronic Medical Conditions	Medical Record

STEP 2: Individual Program Prediction

An effective program for meeting individual needs could be identified by matching individual characteristics with the specific residential/training program characteristics. For example, a guide similar to the following could be used for comparison:

SKILL AREA / PHYSICAL CHARACTERISTICS	LEVEL	PROGRAMS
Severe medical condition	Chronic	Developmental Medical Program
Eating, dressing, personal hygiene, and communication skills	All "none" or "with help"	Family-Living Developmental Program Five-Day Board and Lodging Program Developmental Foster Program
Eating, dressing, personal hygiene, and communication skills	50% "independent" Age: 13 +	Social-Vocational Training Program
Eating, dressing, personal hygiene, and communication skills	All "independent" Age: 16+	Supervised Apartment Training Program
Independent-living skills	100% "independent" or corrected for Age: 18 +	Minimally Supervised Apartment Program

Since behavior training developmental programs would be a resource for all other residential programs, programs of this type should be available to clients in each area of the state. Also, it should be noted that two of the residential programs, the **Supervised Apartment Training Program** and the **Minimally Supervised Apartment Program,** do not require regional construction or development because individuals with specific, independent-living skills could select from existing apartment complexes. Where an individual's physical limitations prevent fully independent living, service programs should be provided, e.g., meal-on-wheels, shopper's service, homemaker services, transportation.

STEP 3: Regional/County Population Analysis

The types and number of residential facilities required can be estimated by identifying the developmentally disabled individuals in each county and region and summarizing their residential needs. The term **estimated** contains a clear caution: individuals may have much greater skill than is indicated in their current situation. Consequently, provision must be made for changing environments based on specific, individual needs.

STEP 4: Cost Projection

Existing programs in Minnesota and similar residential programs in other states offer a base for cost estimates. Data from programs such as ENCOR in Nebraska, weighted by current development and operating costs in Minnesota, can project rough estimates for each type of residential program on the continuum. These costs can then be applied to the number of specific types of residential programs required on a regional basis.

While the procedures cannot be cast as a precise formula for projection, they do estimate regional needs and costs based on the needs of the developmentally disabled in Minnesota.

LOCATING PROGRAMS FOR INDIVIDUALS

Prior to placing a developmentally disabled person in a community alternative, it is imperative to know which of the services a client needs are already available and which services must be established or improved. In attempting to make a comprehensive inventory of services available in each region of Minnesota, the task force found such an inventory beyond its scope and concluded that a systematic and efficient state-wide service information retrieval system is necessary.

Additionally, the task force found few learning programs which help the developmentally disabled acquire independent-living skills. The task force concluded that learning programs which help service staff and parents of the developmentally disabled acquire strategies for behavioral change must be developed.

Availability of Client Services

The skills and, consequently, the needs of developmentally disabled individuals in state-operated facilities vary a great deal**. If these individuals are to reside successfully in communities, it is necessary to determine the availability of services and personnel prior to arranging for community placement and, where needed, increase or improve them.** A comprehensive inventory of services which can be used by both consumers and professionals is not available.

One objective of the CAIR project was to compile a state-wide inventory of services and personnel available to developmentally disabled residents of Minnesota and to determine what additional services and personnel would be needed to bring community services up to the level of services received in state-operated facilities.

The inventory started with a pooling of the regional inventories compiled by the eight regional developmental disabilities planners whose catchment areas cover the entire state. In many regions the inventories were not complete; parts of inventories were outdated, and all were currently being revised. The list of available services was also built from state-wide and local directories, from data requested from state agencies, and from individual or agency information requests.

While existing lists offered a starting point for a comprehensive inventory, their accuracy, the availability of new services, and the relocation of existing agencies needed verification. Umbrella agencies, when identified, often provided inadequate data. Considering these limitations, available service listings were compiled into a single document which represents the first step toward a state-wide service directory (copies of this draft, The Minnesota Inventory of Resources for the Developmentally Disabled, can be obtained from the State Planning Agency, Developmental Disabilities Program).

The identification of services followed the categories established by the Regional Developmental Disabilities Planners. The categories were then expanded to include additional services suggested by the federal guidelines of the Developmental Disabilities Act of 1970 (P. L 91-517):

- Advocacy
- Area Programs
- Day Programs
- Diagnostic Services
- Education Services
- Employment Services
- Health Services
- Planning Services
- Recreational and Social Services
- Rehabilitation Services
- Religious Education Services
- Transportation Services

Manual, one-time compilation cannot accurately inventory available services and personnel. The present compilation of available services and personnel is limited by inaccuracy, incompleteness, and dated information. A systematic, efficient information retrieval system would correct these deficiencies. The system should have the following characteristics:

Development and updating of the inventory should be a major responsibility of a state agency. The designated agency should be allotted sufficient support to produce a comprehensive guide to community services in each region of Minnesota. The listing of the services should include not only name and location of the agencies providing developmental disabilities services, but also the full range and types of services within each program, the specific disabilities served, eligibility requirements, intake procedures, and fees.

The inventory should be cross-indexed by service, agency, and region for easy access.

A simple, effective procedure for the quarterly updating of information should be developed and included with the initial request for information from providers.

A standard vocabulary should be used for defining services in the inventory.

Access to the inventory should be made available without charge to all individuals requesting information.

Instructional Programs for Staffs Parents, and Clients

The movement away from institutions to community-based residences and family homes requires alternative models for client instruction, for staff development, and for parent training. It also requires identification of materials meeting the needs of the developmentally disabled and of programs preparing individuals to administer these programs.

Instructional Programs for Clients

Instructional programs for developmentally disabled individuals can be classified as one of two types: published programs which can be completed by the client if he has mastered the set of prerequisite skills to use and understand the materials and prescriptive programs which require direction from another individual if a new skill is to be acquired. Most available programs fall into the latter category. Programs should be further classified in terms of the content, i.e., the skills needed for progress toward independent living.

Correspondence with public and nonpublic service providers cited a larger number of programs available for teaching basic self-care skills than for teaching independent-living and vocational skills (see **Available Programs for Client Instruction,** (p 58).

The duration and scope of the project prevented the task force from comprehensive analysis of instructional programs for clients. However, the results clearly indicated that **if clients are to acquire skills for community living, increased efforts must be directed toward programming for acquisition of independent-living skill.**

Many staff members at state-operated facilities have developed unique programs for instructing the developmentally disabled. These materials, as well as those developed commercially, should be made available for review at an easily accessible site in Minnesota. Further, the responsibility for updating existing materials and obtaining samples of new materials should be delegated to a specific group or agency.

The collection of materials at a common site and classification by skill area would increase both the efficiency and effectiveness of decision-making. If a program is not available for instructing clients in a specific skill area, the decision can be made to develop or encourage develop-

ment of the program. This would eliminate unnecessary development and foster program development in deficient areas.

Programs to be implemented should first be tested to determine their effectiveness. Untested programs should be evaluated by potential users.

Demonstrably ineffective programs should be modified and evidence of their effectiveness be provided before use. Conversely, if programs prove effective, a decision can be made as to how and where to disseminate them.

Instructional Programs for Staffs and Parents

The analysis of instructional programs for parents and staffs indicated that most training is completed through traditional textbook approaches or inservice training programs. Further, little definition of required skills has been provided.

General skill areas can be identified from the results parents and professionals hope to achieve. Basically, parents and staffs assist clients in changing existing behaviors or acquiring new behaviors. Instructional programming, therefore, should be directed toward mastery of those competencies which would most effectively lead to mastery of skills for changing behavior.

Use of behavior modification techniques for the treatment and rehabilitation of developmentally disabled persons has grown rapidly and steadily in recent years. In many institutions and treatment centers for the developmentally disabled in Minnesota and throughout the United States, behavior modification is the major treatment. A review of available information on this subject revealed that in Minnesota several state-operated programs for the developmentally disabled employ behavior modification skills. In fact, one major child treatment program serving state-wide admissions, the Minnesota Learning Center, has a program completely based on behavioral technology. A current issue of a National Institute of Mental Health publication reports that in the United States 76.3% of residential treatment centers having specific mental health services routinely available, as of August 1972, were providing behavior modification therapy.

The potential of behavior modification techniques requires that staffs and parents receive special training and that certification of persons applying these techniques be based not on completion of a degree, but rather on demonstrated ability to apply these techniques in a professionally supervised setting. Consideration of client rights and protection of individuals should be included in any behavior modification program.

The Minnesota Department of Public Welfare, for example, has included the following cautions in the draft guidelines for behavior modification programs:

> The client (or relative or guardian) must give informed consent, and Department of Public Welfare clearance must be obtained for aversive procedures or for unusual withdrawal or delay of positive reinforcement (delay of food, for example).
>
> Goods and services to which the client is ordinarily entitled or which belong to him should not be taken away in order to be bought back by tokens, except as cleared by the Department of Public Welfare.
>
> Time-out rooms should be used only as part of a planned program (not on momentary judgment of an employee).
>
> Local disagreements over possible infringement on client's rights, dignity or comfort should be referred to the Department of Public Welfare.

Specifically, training staffs should demonstrate competency in the following areas:

- Planning the design of a behavioral change program for an individual or for a group of clients
- Behavioral observation, recording, and contingency statement
- Measurement of client behavior and progress towards goals through observational recording and use of measurement software and apparatus
- Use of behavioral procedures such as reinforcement and shaping, and punishment
- Communication of client needs and progress to staff, parents, and others by both oral and written means
- Training others in the use of behavioral analysis techniques
- Administration of one or more program units
- Familiarity with the ethics, laws, and philosophy affecting the practice of behavior modification techniques.

Each of these skill areas can be subdivided into precise tasks which can be translated into specific training activities.

Development and dissemination of effective programs for the developmentally disabled and encouragement of requisite competencies in parents and staffs who implement the programs can maximize the behavioral development of disabled individuals.

IMPLEMENTING INDIVIDUALIZED PROGRAMS

Creating alternatives to large institutions and basing treatment programs on the concept of normalization are complicated by the number of groups affected and the need for accountability in human services. Because more than 75 services could be required for clients moving into community residences, not all communities can support an alternative program.

The task force studying implementation felt that a strong and positive public information campaign could reduce prejudiced resistance to community residences. They also found that many parents of developmentally disabled children and those who advise parents about placing the child are unaware of the advantages of community-based residences. Surveys used by the task force suggest that parents are most concerned that community programs provide for continuity, security, and progressive development. To protect the clients, the task force concluded, the state should assure continuity of programs as a prerequisite to licensing.

Development of effective community residential services in Minnesota should not result in the precipitous closing of state institutions. Complete closure of all institutions would probably be detrimental to the developmentally disabled population in that sufficient community programs are not presently available, and it would eliminate back-up support for unsuccessful alternative programs. During the transition from state institutions to community alternatives, funds must be available for both programs, and provisions should be made to transfer trained staff in institutions to capitalize on skilled resources. Through individualized program planning and adequate financial support, programs can be provided in the community which are consistent with the tenets of normalization.

Assuring quality programs requires that a systematic evaluation program be developed to assure client progress, to provide appropriate residential and individual programming for clients and to establish cost effectiveness.

Finally, the task force decided that measures such as early screening programs which can reduce the incidence and seriousness of developmental disabilities in young children presently lack the consistency and organization needed to cope with the problem. Through uniform reporting and periodic follow-up, the impact of many developmental handicaps in children can be reduced or eliminated.

Establishing Community Alternatives

Developing community alternatives for developmentally disabled individuals will create problems for four major groups: the communities into which residents will move; those who would develop and operate the residential programs; the parents of the developmentally disabled; and the staffs currently working in the institutions. It also raises questions about uses for state-operated residential facilities.

The Community

Some communities may welcome the development of local residential programs for the disabled, but recent zoning conflicts suggest that this will not be the universal response. The attitudes of residents in prospective sites must be recognized and dealt with before a facility can be built. To identify the common problems community facilities face and to seek successful strategies for dealing with them, the Association of Residences for the Retarded in Minnesota sampled fourteen operators of community-based residences.

The survey results indicated that few serious attitude problems exist in communities. Nonetheless, citizens expressed two prejudices against facilities for the disabled: fear that property value would decrease and the belief that the retarded are sexually or emotionally aberrant. Although unfortunate, such, prejudices cannot be ignored.

Facility development is a complex process which can become even more difficult without active community support. Such support comes from an informed and involved public. The primary methods for change will rest on education, re-education, and participation.

Community information projects should present accurate information. Further, realtors should be given data which directly refute existing misconceptions about property value.

While the timing of facility start-up, as long as twenty years ago, may have directly influenced their success, most facilities made special efforts to directly involve the community opinion leaders through one or more of the following strategies:

- Encourage local churches and community organizations to take the residence as a project
- Provide specific services to the community
- Speak to local groups
- Complete a door-to-door visitation of the neighbors
- Prepare newspaper and television coverage
- Encourage community and organizational visits
- Actively involve the residents in community activities
- Invite neighbors for coffee
- Solicit community assistance on trips, for sporting events, etc.
- Petition neighbors before expanding.

Specific community organizations provided the communication line to develop support for community residences. The following list comprises the groups identified in the survey sample:

American Legion 1	Day activity center 2
Associations for Retarded Children 4	4-H 2
	Garden club 1
Chambers of Commerce 3	Homemaker's group 1
Church group 10	Lion's Club 1
County Commissioners 1	Local citizen's board 1
County Welfare Department ... 1	Local hospital staff 2
MI/MR Board 2	Sportsmen's club 1
Private foundation 1	Teen club 1
Rehabilitation center 1	University students 1
Scouting group 4	Veterans of Foreign Wars 1
Senior citizens 2	Women's club 1

Almost any community action group with adequate preparation can catalyze development, and all groups should be considered potential disseminators of information and program advocates.

Required Support Services

Not every community which would be hospitable to a facility can or should have one. While open-mindedness would be one criterion, the community must be able to provide other services required by the developmentally disabled individual who might reside in it.

Service needs will vary with the behavioral and physical characteristics and the number of developmentally disabled individuals to be located in the community. Each community, therefore, must be separately evaluated after the potential population has been identified. Because the service needs may be extensive, those services provided by private and public agencies on a regional and county basis must be identified as the first step. An evaluation of service availability and funding sources on the state and regional basis would provide the following information:

- Areas of service overlap between public and private agencies, indicating the need for alternative role definitions
- Areas of service absence within the state, indicating the need for agency consideration
- Areas of service which because of multiple agency involvement should be approached by an interagency board.

Next, the remaining variables should be analyzed in terms of the needs of the developmentally disabled population to be placed in the community. For example, individuals residing in a **developmental/medical program** would require a different educational program than would individuals residing in a **supervised apartment program.** Services evaluated might include:

I. Advocacy
- **A. Architectural barrier removal**
- **B. Employment advocates**
- **C. Legal advocates**
  1. **Child abuse**
  2. **Civil rights**
  3. **Confidentiality (maintaining privacy)**
  4. **Guardianship**
  5. **Marriage**
  6. **Police protection**
  7. **Prison reform for developmentally disabled**
  8. **Service receipt on follow-up**
  9. **Treatment vs. nontreatment**
  10. **Wills and trusts**
- **D. Legislative advocates**

II. Community Education About Developmental Disabilities
- **A. Clergy**
- **B. General public**
- **C. Law enforcement officers**
- **D. Medical personnel**
- **E. Peer group education**
- **P. Residential program providers G.**

Social workers H. Teachers

III. Education of Developmentally Disabled Individuals
- A. Behavior modification therapy
- B. Driver's training
- C. Health
- D. Homebound
- E. Infant stimulation
- F. Referral
- G. Special class programs
- H. Special school programs
- I. Vocational

IV. Health of Developmentally Disabled Individuals
- A. Dental care
- B. Drug counseling
- C. Family planning
- D. Genetic counseling
- E. Health screening
- F. Hearing prosthetics
- G. Hospital care
- H. Immunization
- I. Medical care
- J. Medications
- K. Motor prosthetics (braces, etc.) L. Nutritional counseling M. Optical prosthetics N. Physical therapy
- O. Psychiatric care
- P. Psychological testing
- Q. Routine physical examinations
- R. Specialized equipment
- S. Speech and hearing therapy

V. Parent Support
- A. Crises assistance
- B. Family planning
- C. Genetic counseling
- D. Homemaker services
- E. Medical support
- F. Parent education programs
- G. Respite care (short-term)
  1. Weekend and vacation relief
  2. Crises relief
- H. Sibling counseling
- I. Special funding
  1. Home care
  2. Transportation
  3. Special diets
  4. Babysitting and day nurseries

VI. Recreation
- A. Friendship enabling services
- B. Programs for young adult developmentally disabled individuals
- C. Programs for individuals having severe physical disabilities

VII. Religious Programs
- A. Parent counseling
- B. Religious classes

VIII. Residential Program Support
- A. Construction
- B. Consultants/specialists
- C. Licensing
- D. Monitoring
- E. Operating costs
- F. Special diets
- G. Special meal programs, e.g., meal-on-wheels
- H. Staff training

IX. Transportation
- A. For appointments
- B. For emergency care
- C. For recreation
- D. To activities
- E. To jobs
- F. To schools

X. Vocational
- A. Job counseling and placement
- B. Occupational therapy
- C. Retirement counseling
- D. Sheltered employment
- E. Skills assessment
- F. Work evaluation
- G. Work training

Each service area required for the developmentally disabled who are to reside in the community should serve as a guide for community development which will coincide with facility development. Through the analysis of service availability, preparations for meeting the needs of the developmentally disabled can be completed prior to their arrival in the community.

Facility Developers and Operators

Facility developers and operators are the second group for whom deinstitutionalization creates problems.

The Association of Residences for the Retarded in Minnesota survey of fourteen community facility operators cited earlier indicated that while community attitude is a problem, it is far from the most serious one facing those who would establish a facility. The survey identified nine specific problems which occur between the operator and the state:

- Lack of criteria for establishing new residences
- Lack of assistance in developing programs
- Licensing and relicensing procedures
- Lack of specific, identified agency/individual responsibility
- Lack of accurate and reliable information
- Volume of paperwork
- Delays in collection of fees
- Problems in setting rates
- Rate interpretation and applicability.

In addition to these problems, the elaborate process needed to develop a facility once a community is chosen can discourage the most highly motivated developers and operators. Since community residences must be developed if deinstitutionalization is to succeed, the following material (adapted from M. W. Reagan) summarizes the steps to be taken in establishing a community-based alternative in Minnesota. The process is broken down into eight categories for convenience and planning:

1. Development of an accountable community agency
2. Development of a service-program
3. Generation of community support for the program
4. Procurement of start-up money
5. Obtaining a mortgage should other start-up monies be insufficient
6. Selection and purchase of a site with the subsequent construction or remodeling of a facility
7. Licensing the facility
8. Staffing the facility.

While each area is relatively distinct, progress toward an operational program is impossible without a great deal of coordination.

The basic steps and their relationship to each other have been illustrated in a flow diagram (see **Steps in Developing a Residential Program,** p. 61). While the flow chart and the narrative which follows provide a generalized overview, the actual implementation would be affected by combinations of the use of an existing facility vs. the building of a new one and development by a proprietary agency vs. by **a** nonprofit agency.

Procedures Toward an Alternative

The first step toward program development is to determine what an effective program should include. Using this as a base, successive efforts can bring the plan into reality.

STEP I: Identify the population to be served

Since funding depends on categorical labels for the population, the clients must be carefully defined. Currently each type of funding is contingent on meeting specific requirements which are often conflicting or unrelated to the best programming for an individual client.

STEP 2: Assess the needs of the population

Assessment must determine the needs of individuals who fall into the category being served and the existing services. In other words, the potential provider must document the need for the program.

STEP 3: Set objectives for the program

Specification of objectives is useful: objectives justify goal-directed programs, direct the development of procedures to achieve individual client objectives, and set a base for evaluating the program.

STEP 4: Design an individualized program

The program description should specify the following requirements:

- Procedures to be used
- Number and type of staff
- Physical plant for the program
- Annual budget.

STEP 5: Design an evaluation system

The evaluation system should answer several broad questions: whom did the program serve; when did it operate; what did it cost; what services were provided; what client objectives were met; were clients and others satisfied with the program; and is the program cost-effective? The design would include the collection procedures and the data to be gathered.

STEP 6: Write a program description

The data gathered in steps one through five comprise a program description which would be part of funding applications and public relations materials.

STEP 7: Incorporate

Needs-determined services require that a community agency be accountable. The most probable agency is a private proprietary or nonprofit corporation. Individuals who wish to incorporate must contact an attorney who drafts the Articles of Incorporation and petitions the Secretary of State of Minnesota for approval of the corporate name.

STEP 8: Write the bylaws

After approval, the corporation may adopt bylaws, elect officers, and, if appropriate, apply to the Internal Revenue Service for certification of tax-exempt status as a nonprofit corporation.

STEP 9: Obtain contract authorization

The officers, board of directors, or other authority provided under the bylaws authorizes the corporation's entry into all contracts.

STEP 10: Identify financial sources

Alternative funding sources include the sale of stock, bonds, debentures, or other instruments; private foundations; charitable organizations; government agencies; and individual philanthropists or investors.

STEP 11: Develop contacts

The agency first compiles a list of contacts and then conducts inquiries to determine the interest of the contact agencies in a community alternative project.

STEP 12: Document long-range funds

Whether proprietary or nonprofit, the agency must find a source of operating funds to sustain the program. The availability of operating capital must be established to show that the program, once set up, will continue. Presently, no known central source of information contains a single, comprehensive description of all funding mechanisms available to community alternative agencies. Therefore, the agency must search out the appropriate contact person in the appropriate agency, present a program description and projected budget, and request conditional approval of the program and the proposed per diem rate.

STEP 13: Develop a preliminary budget

A request for capital must include a preliminary budget. However, a final budget cannot be established without knowledge of specific costs. Consequently, this step depends on the identification of a site (STEP 28), the development of buildings or remodeling plans (STEP 38), preliminary approval of the plans by licensing or certifying authorities (STEP 37), and obtaining bids on the construction or modification of the facility (STEP 39). The budget should also include the cost of equipment for the facility. If capital is being sought as a down payment on the facility, a preliminary mortgage commitment with an accompanying statement of the required down payment may be required.

STEPS 14, 15, 16: Develop proposal

Once the necessary documentation is compiled, a final proposal can be drawn up and submitted simultaneously to many sources.

STEPS 17, 18, 19, 20: Select and purchase equipment

While actual delivery of equipment should be delayed until the completion of the facility, an application for funds should include costs for equipment.

STEP 21: Obtain additional capital

Since a start-up grant may be too small to pay for the entire facility, additional capital may be obtained through a mortgage.

STEPS 22, 23, 24: Apply for a mortgage

Once all the information has been collected it must be compiled into a package for the mortgage application.

STEPS 25, 26, 27, 28, 29: Obtain a mortgage

The information in the application package should be summarized and presented to several potential lending institutions. Once the facility is built and it passes inspection for conformity to standards, the institution must refinance on a long-term basis.

STEPS 30, 31, 32, 33: Select a site

Several factors must be considered when searching for a site: the educational programs, training opportunities, community services, businesses, recreational opportunities, access to utilities, price, local building codes and zoning ordinances, community support, title to the property, proximity to clients' homes, transportation to work sites, and the physical plant.

Should data suggest rejecting a particular site, steps thirty to thirty-three may need to be repeated.

STEPS 34, 35, 36, 37, 38, 39, 40: Develop building plans

Development of the building or remodeling plans must consider: normalized living; building costs; local, state, and federal health codes; building and fire codes; programmatic regulations; floor space; maintenance; heating and

cooling; durability of building materials; storage space; and resale potential.

Local licensing authorities, the fire marshal, and other regulatory agencies should be consulted in revising the plans. The agency should revise the plan, then submit it to contractors for bids.

STEPS 41, 42: Apply for building permits

Once the site is selected, the agency may apply for a building permit. Should the necessary permits and waivers not be received, it is necessary to return to step thirty.

STEP 43: Purchase property

After the permits and waivers are received, the agency may purchase the property.

STEP 44: Construct facility

Once the interim financing is approved (STEP 27) and the land is purchased (STEP 43), a contract can be signed with a builder or remodeler.

STEPS 45, 46, 47: Obtain building inspection

At various stages in the construction or remodeling, components such as the wiring and plumbing should be inspected.

STEPS 48, 49, 50, 51: License facility

The completion of the facility allows the agency to obtain the licenses needed to operate (STEP 12) and apply for a long-term mortgage. The application is an indicator for the various licensing agencies, the fire marshal, and the building inspectors to evaluate the premises. After inspection, the required licenses can be obtained if the facility has met the agencies' specifications. If not, changes must be made until the facility conforms to standards.

STEPS 52, 53: Seek agency agreements

Once licensed, the agency may apply to the Department of Public Welfare for a contract to provide services.

STEPS 54, 55, 56, 57: Solicit agency support

Successful continuation of the project will require a broad public relations effort.

STEPS 58, 59, 60: Solicit community support

Through the contacts made in steps 54 through 57, assistance can be obtained in meeting with potential neighbors. The program should be discussed; neighborhood support should be solicited.

STEPS 61, 62, 63, 64: Keep records

A procedural manual for the staff and forms for keeping records of program data should be developed.

STEP 65: Assess services

Appropriate contacts and arrangements for services should be made when the land is purchased so they will be available when the clients arrive.

STEPS 66, 67, 68: Identify clients

Affected county welfare departments must be informed of the program and encouraged to make referrals.

STEP 69: Select staff

Position descriptions must be written to guide the staff in their activities and to provide a tool for evaluating individual staff effectiveness.

STEPS 70, 71: Arrange staff benefits

The agency must arrange staff benefits: retirement plan, health and hospitalization insurance, etc. At the same time, the agency should arrange its own insurance.

STEPS 72, 73, 74: Hire staff

Staff cannot be salaried until the agency has generated income. Since the staff must be prepared in advance to work in the facility, funds for staff salaries should be obtained prior to resident entry.

Advance Capital

Funds must be available before the agency receives a grant or other type of income as many fees and costs are paid before a grant application can be made:

- Attorney's fees
- Filing fees
- Architect's fees
- Permit and license fees
- Stationery and postage
- Salary, fringe benefits, and travel expenses of a coordinator to establish the program
- Title search fees.

Further, the facility must locate start-up monies to maintain its operation until capacity is reached.

Problems in Establishing Community Alternatives in Minnesota

Access to information and coordination of agencies. People who wish to establish a community alternative need information for several critical decisions: licenses to obtain, standards for licensing, waivers to the regulations, contacts for approval or waivers, type of license to fit a program, appropriate sources of operating funds, contacts for operating funds, budget items and allowances, procedures for requesting funds, sources of start-up money, information required to request start-up money, available services in the area, local regulations, county welfare department contacts for referrals, and equipment which meets regulations.

To establish a community alternative, one may need a license from the department of public welfare, a supervised living facility license, an intermediate care facility certification from the department of health, a fire marshal's endorsement, a city building inspector's endorsement, a title search, a zoning board's endorsement, an area mental health/mental retardation board endorsement, the county welfare department's endorsement, a rule 52 commitment, a vendor's contract, an insurance inspector's endorsement, a bank appraisal, and many other approvals. The red tape involved may frustrate or discourage many capable people who wish to provide a service.

This situation has often been justified as a check-and-balance system. Unfortunately, it prevents action. Wading through red tape may suppress those who would provide a needed and effective service. Thus it is no longer a check-and-balance system but an obstacle course.

Obtaining capital. Obtaining capital is complex. For a proprietary agency, sources can be either investors or creditors. Nonprofit agencies must depend on either philanthropic patrons or a governmental agency. Nonprofit agencies are forced to seek private philanthropy, competing for limited monies with many other worthy causes. Currently, the boards of most foundations do not seem to find community alternatives an overwhelmingly attractive priority. Thus, the chief source of funds must be governmental.

If community alternatives to large institutions are to be developed, adequate funds must be appropriated.

Obtaining sites and community support. The problems of obtaining sites and of obtaining support for programs are inseparable. There are many available sites which are suitable from a technical aspect but are often located in zones which prohibit construction of community alternatives.

Applications for permits are made at public hearings where resistance often emerges even after extensive public-information campaigns in the neighborhood.

County welfare department support. Support from county welfare departments is significant because of the increased financial burden placed on the county by the present funding mechanisms—ultimately a property tax. Currently, county financial support of institutional programs is minimal.

Categorical funding. Clients often do not fit established categories. Yet, these categories are often the basis for funding programs and services for clients possibly causing inadequate programming and exclusion of clients from needed services. Further, such categorization can stigmatize the client and severely limit his opportunities.

Parent Needs

The third group whose attitudes and concerns must be a part of alternative facility planning are the parents of developmentally disabled individuals. While there is little question that raising a developmentally disabled person in the family home may be disruptive and that community residences may provide a more stable environment for some, parents and clients should have a choice. To choose, parents need to know about the advantages and disadvantages of the alternatives. Further, those who help parents must know how they reach such decisions.

Little research has been conducted on parental attitudes before and after placement of the child in a residential facility. Consequently, parental fears and questions about placement which would assist those who work with parents are not well known. At the same time, parents who would prefer to keep the child at home need support services adequate for optimal development of the child. Without support services, there is no real choice. Without knowledge of support systems, the choices are uneven.

Parent Attitudes

It has been frequently assumed that placement of a child in a residential facility resolves the family's dilemma, so parental attitudes toward placement have not greatly concerned researchers. To provide information on parent concerns the following three surveys were conducted:

Concerned Families of Residents of State Hospitals. A questionnaire on parent attitudes was completed by 65 individuals attending the organizational meeting of the Concerned Families of Residents of State Hospitals. Of the 65 respondents, 39 were opposed to moving their relative to community-based facilities; 26 favored it.

Minnesota Department of Public Welfare. An attitudinal questionnaire was sent to over 400 relatives of developmentally disabled individuals currently residing in state-operated facilities. Of the 76 relatives responding to the question, "Are you in favor of your relative living in the community?" 59 said "yes." **Association of Residences for the Retarded in Minnesota.** Twenty relatives of developmentally disabled individuals living in community-based facilities were sampled using the questionnaire forwarded by the Department of Public Welfare. The results favored community placement.

The differences among the questionnaires, the limited return, and the inconsistent completion of items limit the conclusions which can be drawn. However, the survey results discussed in the material which follows indicate directions for program development.

The decision to place a developmentally disabled individual in a state-operated facility is often based solely on the parent's personal conviction about family benefits. However, the decision has often been based on the advice of the professionals who counseled parents. If the movement towards more normalized living in community-based residences is to be realized, both the parents and the professionals who frequently assist parents in these decisions must recognize the advantages.

The Minnesota Department of Public Welfare Survey questioned parents as to who most influenced their decision to place their child in a state-operated residential facility. The results indicated four major groups: doctor (52 , social worker (22), county welfare department staff (18) , and minister, priest, or rabbi (10). These same groups could become the strongest advocates for community-based alternatives. To do this, informational materials related to normalization, human potential, and the advantages of community-based facilities must be systematically provided for those currently in these fields and put into the curricula of individuals preparing to enter them.

Parent Concerns

In his study of the concerns of parents who had placed their child in a community-based facility, Walsh (1973) found that parents were most concerned about health, education, food, recreation, injuries, the effect of other residents, sleep, medications, and homesickness in that order. A wide difference exists between these results and those on a survey conducted by the Minneapolis Association for Retarded Citizens (1973) to determine reasons for parent opposition to placement of their children in community-based facilities. The survey indicated three basic concerns:

> Their retarded son or daughter is severely or profoundly retarded or has complications of severe physical handicaps in many instances, or both. The programs for them in the community are either nonexistent, in the process of development, or poor as existing and certainly not in sufficient numbers.
>
> They fear the possibility that their involvement with their son or daughter and all the frustrations and inability to cope with their problems will once again be shifted to them.
>
> State-run facilities will always be around to care for their offspring even after they die. Thus an assumption of permanency has much to do with their opposition to closing ANY state hospital.

The responses of 56 members of the Concerned Families of Residents of State Hospitals indicated the following concerns related to community-based residences:

Staff/Facility Adequacy		**Program Adequacy**	
Limited staff	7	Inadequate program	7
Inadequate facilities	4	Less quality care	9
Cost/Permanency		Inadequate medical care	4
Expensive	3	Lack of skills of	
Less Permanent	8	retarded people	13

Similar responses were made to the Minnesota Department of Public Welfare Survey where the two primary concerns were the quality of the staff and the quality of the programs in community-based facilities.

In contrast to these surveys, the Association of Residences for the Retarded in Minnesota Survey, reflecting the concerns of parents who had already placed their children in a community-based facility, indicated that the most serious concern was the possible risk to the developmentally disabled individual when living in the community.

The security/permanency needs also were clearly indicated in both the Minnesota Department of Public Welfare and the Association of Residences for the Retarded in Minnesota surveys. Of the 79 family members whose relatives were under the guardianship of the Commissioner of Public Welfare, only seven would prefer an alternative arrangement (Minnesota Department of Public Welfare Survey). Of the 15 parents responding to the same item on the Association of Residences for the Retarded in Minnesota survey, only one indicated the preference that the individual not be under state guardianship.

Implications

Previous studies and the three surveys conducted for the CAIR project indicate that parents have a wide variety of concerns which must be considered in the planning process.

The most significant step to be taken appears to be to inform parents about community-based facilities. On the Minnesota Department of Public Welfare Survey, for example, 75 parents indicated that they were not familiar with any community group homes. One respondent indicated that the question on the form was her first exposure.

Following the introduction of community-based residences, steps should be taken to dispel the basic fears which parents have and to develop an accountability system which will insure that their fears are groundless. This means doing more than extolling community-based residences for their relative.

Residential facilities should demonstrate that: They
build in continuity and systematic progression of the individual.
Community services, e.g., medical, will be equal to those received in state-operated facilities. The staff is both adequate and large enough to meet specific needs.
The developmentally disabled individual will acquire the necessary skills and demonstrate responsibilities before acting independently, e.g., taking medications, moving about in the community.

Parents should be informed about the major advantages which others see in community-based residences. For example, on both the Minnesota Department of Welfare and the Association of Residences for the Retarded in Minnesota surveys, parents indicated the two greatest advantages as a more homelike place to live and a more normal life for the individual. These points should be emphasized in materials designed for parents who may not be well informed.

Finally, parents should be assured of program continuity and security similar to the present guardianship system and assumed to be present in state-operated facilities.

Parent-Support Programs

Several states have already established parent-support programs, specifically Washington D.C. (Dittmann, 1957), Pennsylvania (Davies, 1959), and Wisconsin (Stevens, Townsend, and Caswell, 1972), and local programs have been established in Minnesota at St. Paul Ramsey Hospital. Most of these programs train parents to work with their developmentally disabled child. Some of these programs also provide social casework services, direct counseling, referral to community agencies, and general moral support. Shearer and Shearer (1972) describe a behaviorally-based program in which parents receive in-the-home training and encouragement in using behavioral change procedures with their child. The **Parent to Parent Program** of the Pennsylvania Association for Retarded Children provides a different service to parents. Parents contact each other directly, obtain referrals and service information, receive professional contacts for services, and receive supportive services when ineligible for other programs. Each of these successful programs could serve as a model for developing parent-support services. **However, the development of a comprehensive program requires that all potential service needs be identified and that alternative delivery methods be arranged.**

The first question regarding parent support is: "What types of services would parents need for a developmentally disabled child in their home?" This question was part of the Department of Public Welfare (DPW) parent survey, and the combined results indicated the following priorities (in order):

- Medical (professional availability and funds)
- Supplemental income
- Home assistance
- Special school programs
- Respite care
- Social activities for the child
- Transportation for the child
- Home tutors
- Parent guidance
- Day activity centers.

No single agency could possibly provide these services directly. However, the Minnesota Department of Public Welfare has proposed an alternative delivery system (Restad, 1973). Specifically, the proposal recommends providing parents with a fixed dollar amount with which to procure required services, a voucher plan. This innovation presented as "open to modification," became a base for recommending a comprehensive parent-support program. Since this program is untested, it should be implemented and evaluated on an experimental basis.

The limited information available and the cost variation among the different regions make it impossible to anticipate parent costs for any one child. Therefore, the amount to be provided should be flexible, but limited to those specific services which precisely match the behavioral/physical treatment program for the child. In other words, parents should be able to obtain needed service at minimum personal cost.

Numerious problems accompany reimbursement from agencies which serve many functions. Therefore, a reimbursement program would require that a specific agency be accountable for instructing parents in interpreting the program plan, identifying service providers, rapidly evaluating service claims, and reimbursing parents.

The questions to be answered by such an experimental program are:

Do parents avail themselves of needed services? If not, perhaps this is a directive for social worker guidance, etc.

What are the expected costs for services based on age and specific behavioral/physical limitations in different regions?

How does the cost-per-year for this program compare to costs for care in state-operated or community facilities?

Does the developmentally disabled individual receive greater service provision under this model? Are parents able to maintain a developmentally disabled child without excessively disrupting the home?

The ideal unit for such an activity would be a local planning unit (behavioral) operating in conjunction with a local health-care unit (physical). The two units could monitor programs prescribed for individuals residing in their own homes and in community alternatives.

Through the referral and financial support services, parents could choose the optimal program for their child based on professionally determined needs. Given comprehensive support, parents could arrange effective programs insuring both optimal development and reduced dependency for their child.

The Staff

The fourth group directly affected by deinstitutionalization is the staff in each of the present state-operated residential facilities.

Clearly, the success of deinstitutionalization depends on the availability of a comprehensive array of services in the community. Institutionalization cannot be remedied if community programs are unavailable, nor can returning clients to **the** community succeed without the appropriate community programs for residents who need assistance and training.

Transfer of services to community-based operations can be accomplished in a variety of ways. However, procedures for this transfer must either allow for a temporary duplication of services during the community start-up period or for complete transfer of components of the institutional services program into community-based operations. Community programs will waste human resources if they do not retain the highly skilled personnel from the institutions. Both limited financial resources and a dearth of available skilled personnel prohibit losing those who currently work in the institutions. As services transfer to communities, those who provide them should have the opportunity to move to community programs as well. This is a key issue in institutional reform: institutions should provide services in ways which assist developmentally disabled individuals reach their maximum level of functioning through an organizational structure which can be decentralized without the loss of effectiveness.

The current reorganization of the Department of Public Welfare and the adoption of the Minnesota Management System provides a unique opportunity to accomplish the necessary organizational alterations (state operated facilities for the mentally retarded have been organized around units rather than departments since 1970). Historically, institutions have been organized into service departments. That is, each organizational component of a residential treatment program provided one element of the total array of services. Numerous benefits result from this type of organization, the most obvious being that a very small number of highly skilled professionals provide services to a large number of residents. Further, paraprofessionals and/or line staff can perform their tasks with minimal in-service training because the structure reduces the variety of their tasks.

From the perspective of institutional reform and the development of community alternatives, the most serious problem a departmentalized institutional program creates is in the direct transfer of service program elements to community-based operations which could not otherwise provide these services. Since the services of each department depends on those of other departments for successful treatment, no program stands alone. Consequently, transferring a single department to community-based operations would leave a serious gap in service.

Through a minimal function unit, the Minnesota Management System allows development of local structures unaffected by the weaknesses of departmental structures. Community-based programs must be small to accomplish the normalization of life styles, one of their major service objectives.

The reorganization of the Minnesota Learning Center provides one example of organization around small functional units. Prior to the opening of the center at Brainerd State Hospital in June, 1970, an extensive study identified an optimal staffing pattern for meeting the needs of the residents. A simplified version of that pattern is presented in Figure 3.

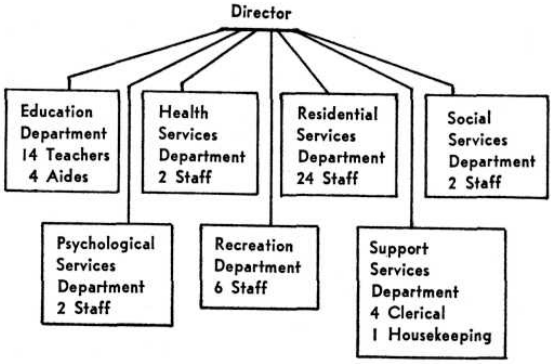


Fig. 3. Staffing Pattern Based on Departments.

This pattern, while functional for institutionalized residents, does little to aid the transfer of institutional services to community-based operations, because, while each department could serve all residents, none of the departments could provide all of the services any given resident requires.

Implementation of a new management system and the legislative mandate to prepare for deinstitutionalization allowed implementation of an organization structure based on the minimal functional unit concept. This concept leads to a basic service unit defined through reviews of job descriptions and analysis of the resources required for client programs (see Figure 4).

While many variations are possible, the basic service unit of the learning center consisted of a small staff responsible for providing individualized treatment services to a specific portion of the client population. This unit, a teaching or treatment team, included a team leader, a certified teacher, a recreation therapist, and five paraprofessional team members. These teams provided programmed recreational and educational services, as well as twenty-four hour residential supervision for up to a dozen clients.

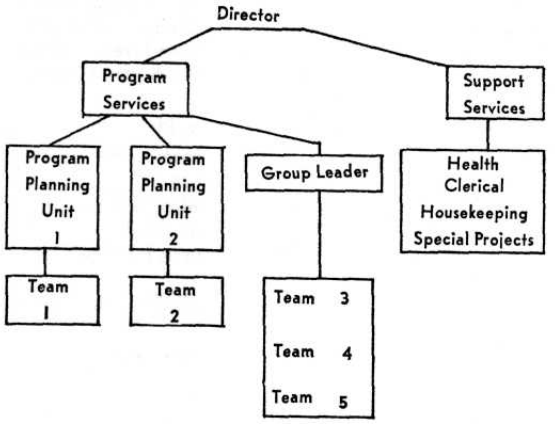


Fig. 4. Basic Service Unit Model.

A second service unit, the program planning unit, was assembled as an interdisciplinary team of professionals who assume responsibility for identifying client problems and constructing individualized, developmental programs. The unit was composed of a psychologist, an educational diagnostician, a speech therapist, a social worker, a parent/teacher trainer, and a secretary. At the state facility, this team was supported by the diagnostic and treatment services of the medical staff. Program services arranged in small interdisciplinary units like this could be transferred to community alternatives without losing the effectiveness of the institutional program.

Implications

Given a physical plant in which to provide services in the community, a teaching team could enter the community and continue to deliver services in an alternative program without interruption and without new staff. Further, if the residents of new community programs can be served by special education programs, day activity centers, work training programs, etc., the staff required to maintain a unit could be reduced. Staffs could be reduced if two of the team members serve as houseparents.

Using a "functional unit" organization, large portions of treatment programs can move into the community while the institution provides individualized client programs which could be then transferred later to the community for long-range implementation.

Summary

One of the issues in the development of community alternatives and institutional reform which must be addressed is institutional organization. Institutional programs which are departmentally organized must attend to the requirements of community-based service programs and reorganize internally to ease the transfer of as many services as can be practically operated in the community.

Uses for Existing Facilities

Implicit in the development of community-based facilities is the systematic decrease in the use of large state-operated residential facilities. Often, this gradual projected decrease in the population of institutions is interpreted as immediate closure. Presently, there are insufficient community residences to accommodate the residents of state facilities, and, where residences do exist, the communities may not be able to provide the other services required to meet client needs.

Dual funding for the development of community-based residences and for the reform of present state-operated facilities will be required for a time. To aid the transition of residents from state-operated facilities when community programs become available, present facilities should be restructured according to the alternative residential programs. Clients can then reside in a program matched to their specific needs and, grouped for their personal ties and county of origin, they can maintain stable relationships when relocation in a community-based facility becomes possible. These procedures would provide:

- Continuity of relationships
- Opportunities for acquisition of community-living skills in an institutional environment
- Staff training opportunity and staff continuity
- Minimal readjustment for the developmentally disabled when transferred to the community
- A structured setting for the evaluation of individuals in terms of the appropriateness of the residential pro gram type.

However, this procedure should not restrict the transfer of individuals for whom an appropriate community-based residence is available.

Closure of State-Operated Facilities and Transfer to Local Administration

The increased number of individuals in community residences will inevitably lead to local or regional administration and closure of state-operated facilities. However, rapid closing would precipitate serious problems:

State-operated residential programs will probably be needed—some individuals may not immediately adjust to the community, and some communities may not be prepared to meet client needs. It may be unreasonable or too expensive to provide for some clients in the community in the near future. For some individuals the most normalized environment might, in fact, be a well-designed, structured, state-operated facility.

Community programs may not be available for some individuals.

Before closing a state-operated facility, the following questions must be addressed:

Have individual program plans been completed for everyone affected by the closure? Have all staff obligations like retirement been considered?

Has the existing staff, where possible, been incorporated into community-based programs?

Have arrangements been made for staff retraining?

Have programs and residential facilities been developed based on individual program plans (client)? Are the required community services available for each individual, e.g., education, medical care? Have community attitudes been dealt with to insure the integration of individuals into the community at large?

How has this been accomplished?

What index indicates success?

Can the developmentally disabled or other groups use present state-operated facilities in other ways?

As they exist?

If they are modified?

Alternative Uses

Gradual phasing out of state-operated facilities should reduce the local impact of closure. Even more important to the communities, however, is a creative approach to the use of existing facilities. Because of their regional location, they can serve several functions.

While it was beyond the scope of the project to recommend which facilities should be closed or how vacant facilities should be used, suggestions were solicited. Each use requires that the environment be modified.

Alternate uses relating to the developmentally disabled:

- Day activity centers, sheltered workshops, demonstration centers
- Parental relief for respite care
- Live-in parent/college student/community training "provider" centers
- Program planning and treatment development centers
- Diagnostic centers
- Short-term training centers
- Community-based programming centers for MI/MR or other disabilities
- Retraining centers for preparing existing staff for new fields if they cannot be incorporated into community-based residences.

Alternate uses unrelated to the developmentally disabled:

- Halfway residences for individuals leaving correctional facilities
- Office complexes for nonstate agencies
- Office complexes for regional-state agencies
- Vocational education and training facilities
- Student housing and classrooms.

Closing state-operated facilities should not be based on expediency nor age of the facility, but rather on the degree to which client/community needs can best be met. It is apparent that gradual closure will require a temporary overlap in services and, consequently, funding to maintain partial operations at the state-operated facility and development of community alternatives. To ease the impact on the community, as well as to defray at least part of the cost of limited maintenance of state facilities, alternative uses should be explored and systematically arranged.

System Evaluation Through Client Assessment

The CAIR Project was directed to create a comprehensive plan for developing community alternatives and initiating reform in institutions for the developmentally disabled. The overall effectiveness of the resulting system has not been established. Effectiveness can be determined only by an on-going analysis of the impact of the system on individual clients. In other words, a monitoring system should be established which uses individual progress data to evaluate the effectiveness of programs and to modify them. Individual data would help the system respond to clients, not make clients respond to the system.

Clearly, client rights need to be protected; systematic follow-up should not invade their privacy nor use them as research subjects. Client data are required, however, if the individual is to receive optimal services and treatment and if a statewide program for meeting individual needs is to be continually improved.

Specifically, a monitoring system would:

- Provide an index of the adjustment of the developmentally disabled to community life
- Provide data for evaluating the effectiveness of programs for the developmentally disabled
- Provide data for modifying programs for the developmentally disabled
- Provide data for insuring accessibility, availability, and delivery of services
- Indicate major problem areas which affect the adjustment of the developmentally disabled to community programs
- Encourage interagency involvement and uniform reporting which would promote comprehensive program planning
- Provide cost data for fiscal planning and population projections.

The danger of not providing systematic follow-up is evident in the ofttimes disastrous effects on the developmentally disabled such as loss of services or maltreatment (Edgerton, 1967).

Several follow-up systems have been developed and are being tested, e.g., the Standard Record System in North Carolina (1973), the Individualized Data Base in California (1974). The Individual Data Base System is of particular interest, for it has been computerized to allow control and analysis of more factors which may affect the progress of the developmentally disabled, a prerequisite for analyzing effectiveness and improving individual progress.

From the perspective of the CAIR Task Forces, follow-up systems generally have several limitations:

The categories for assessment are not tied directly to behavior consistent with normalization and, in general, are based on inadequate assessment instruments for individualized program planning and evaluation. The assessment schema is directed primarily toward the mentally retarded and may not accommodate program planning for other disabilities. The data are often provided on a normative basis rather than in terms of individual progress on precise objectives.

The systems do not have competency-based training programs for reporting agents.

A follow-up system should control the identified deficits. It should provide multiple assessment devices covering all areas (psychological, physical, social) which are directly tied to the need for specific programs, including residen-

tial and educational program requirements, health-care needs, general service requirements (transportation), and specific specialist follow-through. The systematic input of individual progress data and service outcomes would allow evaluation of the program plan and its modification based on areas of inadequacy.

The follow-up system should store data related to all services. For example, listings of all residential and educational programs by region and community maintained through a monthly vacancy report could assure immediate access to available programs. Similar regional and community lists for other service areas could be compiled and provided to help parents or staff select services for meeting individual needs.

Finally, the follow-up system should be developed as an information retrieval system. The data could be drawn for individual case management, for example, program planning units could evaluate the adequacy of a program plan by reviewing the progress of the individual. Or it could be used to evaluate the effectiveness of a specific type of program for individuals having common characteristics. In both cases, if the data indicate program effectiveness, the program could be continued and recommended in the future; if the program is demonstrably ineffective, it could be modified and re-evaluated.

Arranging optimal programs for developmentally disabled individuals requires a systematic interagency follow-up. The system should be designed to provide service in all areas of developmental disability, to prescribe programs for individual clients, to provide sources of required services, and to evaluate the adequacy of programs for individual clients.

Reduction and Prevention of Developmental Disabilities

The task forces of the CAIR Project concentrated on developing treatment and program models to deal with an existing problem—providing comprehensive services to developmentally disabled individuals in community settings. Of equal significance and priority are the steps which can be taken to reduce the incidence and the effects of disabilities: parent education, counseling and treatment, and early and periodic screening programs.

Parent Education, Counseling and Treatment Programs

Research has clearly established that specific characteristics of the mother affect the probability of giving birth to a healthy child. In fact, the Minnesota Department of Health (1971) has described a specific set of conditions which define a high-risk mother, i.e., a mother who has or may have a condition or complication associated with childbearing which increases the hazards to the health of the mother or the infant:

Mother who has had previous reproductive disasters such as an abortion, fetal death, ectopic pregnancy, premature birth, toxemia, hemorrhage complication, dystocia, malpresentation, traumatic or birth-injured infant, and Caesarean section. Mother with concurrent medical problems such as hypertension, diabetes, hyperthyroidism, metabolic disorders, cardiovascular disease, cancer, tuberculosis, anemia, poor nutrition, infections, drug addiction, alcoholism, and toxemia.

Mother whose age is under 16 years or over 40 years.

Mother on certain drugs (at least 40 drugs may affect fetal development).

Mother whose weight is under 100 pounds or over 200 pounds.

Mother of large families (5 or more children).

Mother where cultural factors may affect nutrition and health.

Mother from a low-income family.

A review of these factors clearly indicates that a decrease in infant morbidity and mortality will be contingent in part on the adequacy of parent education programs and on the degree to which prospective high-risk mothers can be screened and given appropriate treatment.

Educational programs directed toward changing the behavior of prospective mothers are almost nonexistent, and, where such programs have been prepared, they are directed toward mothers above the age of 16 and are focused on problems of child rearing as contrasted to prenatal care and appropriate behaviors during pregnancy.

The Child Development Planning Project (1974) identified numerous public and private programs for parent education. However, while the number of parents reached, approximately 63,000, would indicate large coverage, little data exist to document whether those programs are directed toward preparenting behavior, and whether the programs, in fact, lead to changes in the behavior of the parents who participate in it.

Parent education programs should be developed around parent skills which, if practiced, would reduce the risk-factor of developmental disabilities occurring, and a state-wide system for delivering such programs and measuring their effects should be created.

Many high-risk factors cannot be dealt with in the absence of a medical judgment. Since the high-risk factors would not be present in the majority of the population and not all of the factors would be present in a given individual, comprehensive medical evaluation and follow-up on all pregnancies would not be warranted. A screening procedure could be established to identify high-risk pregnancies and to direct medical attention to prenatal and infant care.

A high-risk pregnancy screening system has been developed and demonstrated effective in predicting prenatal morbidity and mortality (Hobel, Hyvarinen, Okada, and Oh, 1973). Adequate prenatal treatment programs would suggest that this system or a similar procedure be initiated on a state-wide basis.

The implementation of a pregnancy screening program would necessitate that the development of prenatal and infant care services be accelerated to correspond with it. At the present time these services are provided only on a limited basis (Child Development Planning Project, 1974).

Through a comprehensive approach including parent education, pregnancy screening, and delivery of prenatal and infant care, many of the high-risk factors can be corrected, leading to a potential decrease in the incidence of developmental disabilities.

Early and Periodic Screening of Children

The development of optimal parent education, pregnancy screening, and treatment programs will reduce, but not prevent, the occurrence of developmental disabilities.

Where developmental disabilities do occur, the child's development can be aided through early intervention which is contingent on early identification. In other words, if a developmental disability is detected early, programs and services can be provided which will help reduce the effects of the disability on the child.

The birth registry represents the first opportunity for early identification. However, several problems currently exist in its use: registry information is not available across the state, physicians are often reluctant to provide precise information, and professionals who could use the information for follow-up and service provision are frequently untrained in basic interaction skills. If these specific limitations could be corrected, the birth registry would provide an early screening tool.

At minimum, the birth registry provides an index of gross disabilities. While many screening programs have evolved to detect disabilities, there are numerous problems associated with them. These are evident in the data reported by the child development planning project which indicated that:

> Early screening programs are not consistent in terms of the areas assessed. For example, some programs concentrate only on vision and hearing while others represent the comprehensive approach required if developmental disabilities are to be detected. Many agencies are involved in early screening with little coordination and/or common reporting being completed.
>
> Only a limited portion of the population between ages 0 and 6 is being reached by any screening program, i.e., approximately 56,000 of an estimated 400,000 children.
>
> Periodic follow-up activities are not incorporated in most programs.

A uniform and coordinated program for early and periodic screening would require specification of a comprehensive, consistent set of areas to be assessed, the development of a universal reporting form, provisions for central retrieval and follow-up on a regional or local basis, the coordination of the efforts of all agencies involved on a regional or local basis by the selected agency, and the development of a program including both primary and secondary screening.

The implementation of a comprehensive early and periodic screening program would lead to earlier detection of developmental disabilities. Due to the failure in early identification or the lack of programs, present programs do not meet the needs of the developmentally disabled under age six (Child Development Planning Project, 1974). While the tentative data reported are not directed exclusively toward the developmentally disabled, inferences can be drawn from them. By a conservative estimate, the handicapped population between the age of 0 and 6 would be 40,000. Yet programs are presently provided for approximately 2,500 individuals or, roughly, 6% of the handicapped population between the ages of 0 and 6 would be state-wide early and periodic screening program can be realized only if increased funding is allocated and services developed for handicapped preschool populations.

Developmental disabilities can be prevented, reduced, or partially compensated for through the development of effective programs including competency-based parent education; state-wide pregnancy screening; comprehensive prenatal and infant care; coordinated, state-wide early and periodic screening; and effective programming for preschool handicapped populations. It would be possible to develop separate programs in each of these areas; however, optimal programming would include a coordinated development and simultaneous implementation of each of these components.

Research, Development, and Demonstration

The complete implementation of the plan prepared by the CAIR Task Forces must be based on systematic research, development, and demonstration efforts. Supporting data for state-wide implementation of some components is unavailable, requiring further evaluation; other components require development of specific materials and/or programs.

Presently, several major problems affect research, development, and demonstration efforts:

> There is duplication of efforts by public and private agencies in both research and implementation activities.
>
> Research and development efforts are often nonsequential and, in some cases, premature from a goal-based planning perspective.
>
> The criteria for research, for the use of existing materials, and for the development of new materials are frequently arbitrary.

The efforts of the agencies involved in planning for developmentally disabled individuals could be better channeled if project applications or descriptions were forwarded to a central advisory board—not as a review or approval process, but rather as an abstracting, feedback, and dissemination mechanism. In other words, the board could provide the preparing agency with descriptions of similar projects and names of persons working on similar projects on the state or national level. Additionally, the board could abstract the proposal or activity for dissemination to individuals working with developmentally disabled clients so they could provide relevant information to the project developers, request participation in the study or evaluation activities, or follow-up on the results.

Establishing Sequence

Plans for research, development, and demonstration efforts should be established on an interagency basis. Once the goals of a program are established, deficits (informational or programmatic) can be identified and assigned priorities. Based on the priorities as well as available and anticipated funding, a sequential research and development program can be drafted which will lead to proposals in specific program areas rather than proposals on general needs or interests.

Establishing Criteria

While various criteria have been established for the evaluation of research and development proposals, they are frequently presented in a form that is difficult for the nonresearcher to clearly understand and apply. The criterion examples presented in **Criteria for Developing and Evaluating Programs (p 59)** and **Criteria for Evaluating Research Proposals** (p 60) are provided not as procedures by which to accept or reject research and development proposals, but rather as guides for proposal preparation and for program review. Their use would provide a procedure to increase the skills of individuals in the field while upgrading the quality of research proposals and instructional programs.

The CAIR Project formulated recommendations for developing community alternatives and reforming institutions to avoid many problems observed in the process of deinstitutionalization in other states. Many of these recommendations have already been acted on or are presently being incorporated into the planning efforts of several state departments, e.g., Technical Assistance Planning Project (DPW), Early and Periodic Screening Program (MDH), and all of the recommendations have been supported by representatives of consumer groups, representatives of state agencies, and by the Governor's Planning and Advisory Council on Developmental Disabilities. However, the implementation of several recommendations will require that new issues be addressed in subsequent studies and planning efforts: the feasibility of the task force recommendations must be systematically evaluated; the strategies, schedules, and responsibilities for implementation of each recommendation must be established; the cost for implementing new programs must be determined; a procedure for coordinating the delivery of the spectrum of needed services at the local level must be developed; and barriers to establishment of community-based residential services must be eliminated. A unique opportunity to reduce the effect of a disability on a large number of citizens and to provide a better life for those who are already disabled presents itself. Through support of early intervention programs and the development of community-based services, the number of individuals residing in institutions can be reduced, and those with disabilities can have new opportunities for participation in society. More extensive analysis of each of these areas will aid development of community-based services as realistic alternatives to institutional programs.

Evaluating the CAIR Recommendations

There is little available data to support any plan for deinstitutionalization. Therefore, it is important that the recommendations for a service model found in the CAIR Report be systematically evaluated prior to or concurrent with statewide implementation. Any service delivery model should:

- Provide services equal to or superior to those present in state hospitals
- Provide services through community-based residences, educational programs, and parents
- Capitalize on locally available services and encourage development where services are not provided
- Assume responsibility for assessing client needs, for evaluating client progress, and for reimbursing ser vice purchasers and providers
- Include interagency and interdisciplinary representation in planning for developmentally disabled individuals.

Establishing Implementation Strategies, Schedules, and Responsibilities

The primary responsibility for providing residential services and income maintenance programs for developmentally disabled individuals in Minnesota is currently vested in the Department of Public Welfare, and, consequently, most of the recommendations in the CAIR Report have been addressed to this agency. In order to insure comprehensive and coordinated programs for clients in commu-

tally disabled individuals, and procedures leading to community acceptance should be identified. Specifically, prohibitive zoning ordinances must be replaced by statutes which insure the rights of developmentally disabled individuals (see Proposed Zoning Statute p. 60). Not only must zoning provisions be altered to insure available residences for developmentally disabled individuals, but they must also promote normalized living through limitations on the number of residences in a given geological area and foster community acceptance, e.g., clustering residences may lead to community rejection.

While this discussion includes the most pressing issues related to the development of community alternatives, several other areas also warrant specific consideration, e.g., locating training personnel for community programs, insuring the continuity of programs for clients. Each of these issues will require strong interagency planning and support in order to insure systematic and effective development of community-based residential, training, and support services for developmentally disabled individuals in Minnesota.

GLOSSARY

ACCOUNTABILITY: Demonstrable evidence that resources are used in the most economical and efficient manner to bring about maximum development of an individual's potential.

AMBULATORY: The ability to walk independently and at least negotiate any barriers such as ramps, doors, stairs, corridors, etc., necessary to get in and out of the facility.

ASSESSMENT: A general inventory or description of individual characteristics.

CEREBRAL PALSY: A condition characterized by paralysis, weakness, incoordination, or any other aberration of motor function due to pathology in the motor control centers of the brain.

CLIENT: Individual served — developmentally disabled person, parent, staff member.

COMMUNITY ALTERNATIVES: Residential service programs in the community provided as an alternative to institutionalization.

DAY CARE: Comprehensive and coordinated sets of activities providing personal care and other services to preschool, school-age, and adult developmentally disabled individuals outside their own homes during a portion of a 24-hour day.

DEINSTITUTIONALIZATION: The acts of preventing new admissions to institutions, returning residents of institutions to appropriate residential programs in the community, and creating an environment at institutions which fosters resident development and insures protection of client rights.

DEVELOPMENTAL DISABILITY (DD): A disability which (1) is attributable to mental retardation, cerebral palsy, epilepsy, or other neurological conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals; (2) originated before the individual attained age 18 and has continued or can be expected to continue indefinitely; and (3) constitutes a substantial handicap to the individual.

EPILEPSY: A chronic symptom of cerebral dysfunction, characterized by recurrent attacks involving changes in the state of consciousness, sudden in onset, and of brief duration. Many attacks are accompanied by a seizure in which the person falls involuntarily.

GOAL: General statement of the overall, final accomplishment toward which activities are directed (purpose).

INDIVIDUALIZED INSTRUCTION: Each learner participates in a program based on his specific needs and existing skills.

INDIVIDUALIZED PROGRAM: A set of progressive goals and objectives with services and activities by which they will be met for a specific individual.

INSTITUTIONAL REFORM: Modification or improvement of the total institutional environment to insure maximum individual development in the least restrictive environment possible.

INTERMEDIATE CARE FACILITY (ICF): Facility for the mentally retarded or persons with related conditions; ICF/MR means an institution (or distinct part thereof) primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions.

INTERMEDIATE PROGRAM: A program in which participation is anticipated for one to three years.

LIFE-SUPPORT SERVICES: Direct, possibly continuous, medical services for maintaining the life of an individual.

LINE STAFF: Persons having direct responsibility for the care, welfare, and/or instruction of clients.

LONG-RANGE PROGRAM: A program in which participation is anticipated for three years or more;

MENTAL RETARDATION: Refers to the subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.

MOBILE: The ability to move from place to place with the use of devices such as walkers, crutches, wheelchairs, wheeled platforms, etc.

NONAMBULATORY: Inability to walk independently.

NONMOBILE: Inability to independently move from place to place.

OBJECTIVE: Specific, measurable step toward reaching a goal (outcome).

PHYSICAL HANDICAPS: Those orthopedic, coordination, sight, and hearing disabilities that culminate in the significant reduction of mobility, flexibility, coordination, or perceptiveness and that, alone or in combination, interfere with the individual's ability to live and function independently; that are not the result of the normal aging process; and that are considered to be chronic conditions.

SHORT-TERM PROGRAM: A program in which participation is anticipated for one year or less.

SUPERVISED LIVING FACILITY (SLF): A facility licensed by the Minnesota State Board of Health to provide a residential, noninstitutional, home-like setting for persons who are mentally retarded.

SUPPORT STAFF: Persons whose skills are required on either a part or full-time basis to provide prescribed program services.

REFERENCES

This section includes documents significant to the topics which were reviewed by the task forces but not cited directly in their reports.

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MODELS AND WORKING MATERIALS
Skill Areas and Behavioral Descriptions

PERSONAL HYGIENE SKILLS

Toileting

Communicates discomfort when wet, soiled
Expresses need to use toilet
Controls bladder (day/night)
Controls bowel (day/night)
Asks to go to toilet or goes without asking
Lowers pants and/or undergarments
Sits on toilet seat
Stands proper distance from bowl while urinating
Remains on toilet until finished
Removes toilet tissue and wipes self
Washes and dries hands
Flushes toilet
Puts on clothing
Adjusts clothing

Grooming

Cooperates with grooming by adult
Changes underwear regularly
Cleans/trims/files nails
Sets hair
Combs or brushes hair
Applies toothpaste to tooth brush
Brushes teeth
Flosses teeth
Shaves face
Shaves underarms and legs
Blows/wipes nose when needed
Applies makeup
Applies deodorant
Cares for self during menstruation
Disposes of sanitary napkins or tampons
Places soiled or dirty clothing in appropriate container

Washing and bathing

Cooperates in washing, bathing, and general grooming
Puts hands under water
Picks up soap and rubs hands
Washes hands and face
Dries hands and face
Prepares bath, selects correct water temperature
Showers/bathes self
Uses soap when washing or bathing
Dries self
Washes/dries hair
Wrings out washcloth
Puts soap on washcloth
Maintains general cleanliness

Caring for health needs

Swallows pills as instructed
Treats minor injuries/illnesses
Meets general health needs
Selects self-medications appropriately
Reports accidents
Reports and seeks assistance when ill and takes preventive measures
Covers mouth and nose when sneezing
Takes and stores medications appropriately
Takes prescribed medications as instructed
Arranges routine medical or dental appointments
Refills own prescription
Seeks help when needed
Allows corrective device to be put on
Wears device where needed
Removes device
Puts on device
Cares for device
Stores device

EATING SKILLS

Feeding self

Displays sucking response
Opens mouth to food stimulus
Uses tongue in moving food to mouth
Swallows soft foods
Makes hand to mouth motions
Sits without restraint at **meal**
Selects edible materials from inedible
Feeds self using fingers
Chews chopped foods
Chews solid foods before swallowing
Eats sandwich without dropping pieces
Eats solids without dropping pieces
Eats soup without spilling
Unwraps food for eating
Prepares his own food on plate
Sips from cup or glass
Picks up glass or cup
Holds glass or cup
Drinks from cup or glass
Drinks without spilling
Drinks using a straw
Drinks from fountain
Obtains water from various sources, e.g., **tap**
Follows diet where prescribed
Eats food and drinks alcohol moderately
Selects seasoning and uses it appropriately

Selecting and using correct utensils

Holds spoon
Feeds self with spoon
Holds fork
Scoops food with a fork
Pierces food with a fork
Feeds self with a fork
Holds knife
Cuts with a table knife
Spreads food with a knife
Peels food with a knife
Cuts with a knife and fork

Displaying appropriate manners

Chews solid food before swallowing
Chews food with mouth closed
Uses napkin correctly
Talks only when mouth is empty
Eats at moderate pace
Eats without playing with food or removing food from others' plates
Requests more food by word or gesture
Requests that food be passed
Serves self appropriate portion
Waits turn to serve self
Passes food to others, e.g., bowls, platters, trays
Serves solid foods
Serves semi-solid foods
Pours from a pitcher to a glass or cup
Serves hot liquids
Cleans up after himself
Carries solid foods
Carries semi-solid foods
Carries pitcher or glass of liquid

Eating in a variety of locations

Selects proper amounts of food
Selects proper types of food Waits in cafeteria line Carries an empty tray Carries a full tray Orders soft drinks at fountain Orders simple foods like hamburgers Orders complete meal in restaurant Pays for meal
Tips waiter/waitress appropriately (in terms of personal finances)

DRESSING SKILLS

Completing basic motor tasks

Cooperates passively
Extends arms and legs
Initiates dressing
Adjusts own clothing
Buttons and unbuttons clothing
Zips and unzips clothing
Snaps and unsnaps clothing
Buckles and unbuckles belts and straps
Fastens ties and other accessories
Puts on and removes underwear
Puts on and removes general items of clothing in correct sequence
Puts on and removes sweater (front opening and pullover)
Puts on and removes coat
Puts paired shoes on correct feet
Puts on and removes rubbers/boots
Puts on and removes socks
Puts on, ties, unties, removes shoes
Puts on and removes brassiere

Selecting clothes

Selects articles of clothing when named Selects clothes which fit appropriately Selects clothes of appropriate combinations. Selects clothing which is clean, pressed, and untorn Selects proper clothing for indoor/outdoor activities Selects proper clothing for present and impending weather conditions Selects clothing for specific circumstances, e.g., time of day, time of year, play Selects protective clothing for work or play activities

COMMUNICATION SKILLS

Comprehending and expressing (non-orally)

Turns head or searches in response to sound
Indicates hunger
Indicates likes and dislikes in an appropriate manner
Establishes eye contact when addressed
Responds to gestures
Gestures with face to communicate feelings
Turns head or comes when name is called
Responds to requests
Gestures/points to communicate a need
Gestures meaningful "no"
Gestures meaningful "yes"
Answers simple question with gestures
Answers simple question with an action

Comprehending and expressing (orally)

Makes oral sounds
Imitates sounds
Indicates wants by vocal sounds
Expresses feelings with vocal sounds
Imitates words
Names body parts
Names common colors
States first and last name intelligibly when asked
Vocalizes "yes" and "no"
Makes eye contact with the speaker
Names familiar objects
Repeats sentences when requested to do so
States a limited number of specific words
Names school personnel, family, peers
Asks for specific objects
Names people or objects in pictures
Describes action in pictures
Names weather conditions
Speaks in short phrases
States address and telephone number
Speaks in short sentences
Answers questions other than "yes"/"no"
Speaks in complex sentences
Asks questions
Engages in conversations
Delivers oral messages
Relates personal experiences
Retells stories
Attends when spoken to
Recognizes his address when spoken
Follows a series of instructions

Writing for independent living

Grasps pencil or crayon and makes strokes
Scribbles spontaneously
Holds pencil or crayon between index finger and thumb
Copies lines; joins dots
Draws with pencil or crayon
Stays within parallel lines when writing
Stays on single line when writing
Copies printed letters
Prints letters when named
Prints own name
Prints common words
Prints numbers
Writes alphabet when letters are named
Writes own name
Writes common words
Writes a simple sentence
Writes or prints name and address
Writes short notes
Writes understandable letters
Answers ads; purchases by mail
Fills out simple application forms

Reading for independent living

Plays with books
Names objects
Names colors
Names objects in pictures
Names actions in pictures
Sorts shapes into various groupings
Identifies letters
Selects books for play
Reads his printed name
Reads functional words
Reads name and address
Reads common phrases
Reads simple messages
Reads stories/comics
Reads primer—1st grade books
Reads 2nd - 3rd grade readers
Reads instructions
Reads 4th grade reader
Reads common signs
Reads for personal enjoyment
Initiates reading activities
Locates specific sections in a newspaper
Reads headlines

QUANTITATIVE SKILLS

Managing currency

Identifies money
Selects real from play money
Names specific coins
Names units of paper money
Matches coins with symbols up to $1.00
States value of money
Counts by coins to specified amount
Produces the correct amount of money for purchase
Adds coins up to $1.00
Converts coins/bills to equivalents
Makes change correctly
Fills out deposit and withdrawal slips
Saves money for specific purposes
Sets priorities: Immediate vs. long-term needs
Pays bills
Plans monetary expenditures, e.g., budgets
Shops comparatively
Purchases items, e.g., clothing
Purchases for others
Utilizes coin-operated machines

Managing time

States correct age
Identifies twelve numbers on a clock
Tells time to nearest hour 1 1/2 hour)
Tells time to nearest 5 minutes
Names days of week
Names seasons of year
Names current year
Names months
Names specific holidays
Recognizes time intervals
Recognizes parts of day
Applies clock and calendar to events
Pairs time to specific events
Arrives at events punctually
Plans a schedule

Applying number concepts

Verbally imitates numbers 1I-10
Counts objects to 10
Recites in sequence numbers 1-10
Pairs visual symbol with quantities 1-10
Places numbers 1-10 in sequential order
Matches number symbol with various quantities of objects 1-10
Writes numbers 1-10
Adds numbers with sums to 10
Subtracts quantities to 5
Subtracts quantities to 10
Verbally imitates numbers beyond 10
Recites in sequence numbers beyond 10
Matches visual symbol with quantities beyond 10
Places numbers 10-20 in sequential order
Matches number symbols with various quantities of objects
Writes numbers 10-20
Adds numbers with sum greater than 10
Subtracts quantities beyond 10
Reads numbers 1 **- 100**
Adds two-digit numbers
Subtracts two-digit numbers

Applying units of measurement

Sorts objects based on shapes
Sorts objects based on size
Sorts objects into groups of one or more
Sorts objects into subgroupings based on quantity description
Selects objects based on quantity
Selects objects based on size
Selects objects based on height
Selects objects based on length
Selects objects based on weight
Describes relative weight of objects
Describes relative distances of points
Describes relative size of objects
Measures a cup (liquid/dry)
Measures **a** pint, quart, gallon ,
Measures distance in feet and inches
Measures objects in pounds and ounces

SOCIAL-INTERACTION SKILLS

Displaying appropriate social behavior

Reaches for familiar person
Responds acceptably to strangers
Seeks the company of others
Greets personnel, visitors, and peers
Greets strangers in his own environment with a smile, nod, or handshake
Listens to conversations without inappropriate interruption
Apologizes where appropriate Accepts criticim
Says "please," "thank you," etc. where appropriate
Functions well in unfamiliar situations Introduces self to others Dates acceptably in groups Dates acceptably in couples Defends self where necessary
Sets realistic personal goals, e.g., vocational, recreational
Votes on major issues Seeks help or assistance where needed

Caring for and sharing of property

Identifies personal property
Puts personal property away
Reports damaged property
Cares for personal property
Protects personal property
Shares personal property
Requests permission to borrow materials and returns them Cares for property of other individuals or of agencies, e.g., library

Cooperating

Respects peers physically
Respects peers verbally
Accepts changes without emotional or tantrum behavior
Waits his turn
Takes his turn
Offers assistance where needed
Participates in team activities
Joins in activities with individuals
Joins in small group activities (non-competitive/competitive) Joins in large group activities Initiates group activities Completes simple, supervised tasks Tells the truth Accepts group decisions
Competes in games fairly Accepts losing games Follows instructions Provides direction for activities, e.g., presents rules, instructs others Cleans up after activities

Following rules

Respects persons in authority
Responds to verbal instructions
Participates in required activities
Follows rules and regulations in presence of adult
Follows rules when no one is present

INDEPENDENT-LIVING SKILLS

Preparing and serving meals

Turns faucet on and off
Sets table, (plates, glasses, utensils, etc.)
Assists in food preparation
Prepares simple foods (no mix - no cook)
Prepares simple foods (no cook)
Starts stove, boils water
Mixes and cooks simple food
Cooks two items simultaneously
Cooks a complete meal
Serves a meal
Toasts bread
Opens cans with manual opener
Clears table (breakable dishes, etc.)
Replaces items in the refrigerator and shelves
Scrapes and stacks dishes
Washes and stores dishes
Disposes of garbage
Places food in refrigerator compartments correctly
Identifies and discards spoiled foods

Maintaining clothing

Separates colored clothing from white
Separates dry cleaning from washables
Launders clothing (washer)
Washes small garments (hand)
Dries clothing (dryer or line)
Cuts with scissors
Mends and sews buttons
Presses clothes
Folds laundered items
Cleans laundering facilities
Takes clothes to cleaners
Takes clothes to appropriate repair facility
Stores clothing in neat order
Hangs clothes on hangers and hooks
Cleans and polishes shoes

Managing a residence

Responds to alarm clock
Answers door
Selects radio/TV programs
Adjusts radio/TV
Adjusts shades, blinds, drapes
Adjusts heat
Adjusts windows
Replaces bulbs
Inserts plugs in outlets
Replaces fuses/breakers
Locates and contacts support agencies
Makes and opens bed
Performs bedtime preparations
Secures the environment
Maintains plants and pets
Maintains grass and shrubs
Clears snow and ice
Cares for garden
Cleans car
Maintains appliances and furnitures
Paints large flat surfaces
Paints small units
Uses hand tools appropriately
Listens to and acts on weather reports
Listens to and shares news reports

Telephoning

Answers telephone
Dials numbers accurately
Calls appropriate person
Takes phone messages
Makes telephone call from private phone
Locates pay telephone
Makes telephone call from pay phone
Makes long-distance call
Locates number in directory (white)
Locates number in directory (yellow)
Requests information by phone

Cleaning household

Puts objects away
Picks up rubbish
Vacuums floor
Sweeps floor
Mops and waxes floor
Cleans up liquid/dry spills
Straightens room
Dusts room
Cleans windows, walls, mirrors
Cleans bathroom
Changes bedding
Makes bed correctly
Empties trash
Cleans oven
Cleans and defrosts refrigerator

Traveling within the community

Displays sense of direction
States directions
Obeys traffic signs (non-read)
Obeys traffic signs (read)
Stops at curbs
Steps up or down at curbs
Crosses streets safely
Identifies major public servants
Requests direction as needed
Proceeds to specific shop to make a purchase
Proceeds to familiar location for a purpose
Proceeds to unfamiliar location for a purpose
Locates specific facilities in the community
Locates home from **a** variety of locations
Travels at night

Traveling within the neighborhood

States address and telephone number
Rides a tricycle
Rides a bicycle
Opens and closes doors having a variety of handles
Opens and closes a variety of locks
Locates own room in home or school from a variety of points Moves from place to place within the home or school (or in yard) based on interest or need Moves from place to place outside the home or school purposefully
Drives a car

Avoiding danger situations

Responds to emergency signals
Displays appropriate emergency behavior
Demonstrates awareness of environmental hazards
Lights match safely when needed
Extinguishes small fire
Handles flammable and combustible items and hot appliances safely
Turns in fire alarm under appropriate stimulus situation Handles gas safely
Handles sharp objects safely, e.g., knife, razor Handles poisonous substances safely Stores poisonous substances safely Handles electricity safely Handles breakable objects safely
Locates and contacts the appropriate agency in an emergency Moves up and down stairs safely
Displays water-safety behavior (pool and beach)
Swims safely Boats safely Bathes safely Selects hot and cold taps and adjusts as needed

Managing finances

Deposits money
Records deposits
Writes checks not to exceed account balance
Balances checkbook
Justifies with bank statement

Managing personal/sexual behavior

Demonstrates genital hygiene practices Obtains periodic medical and/or gynecological exams Engages in direct sexual (physical) activities in private Makes appropriate personal/sexual advances toward
persons of similar age
group Discusses sexual topics and/or concerns
in accepting environments
Identifies social situations where direct or
indirect sexual behavior is inappropriate
Demonstrates knowledge of reproduction
Demonstrates use of birth control methods (if appropriate) Identifies symptoms of venereal diseases Engages in sexual activities (technique) Follows prenatal care regimen
Demonstrates procedures for infant/child care

Selecting **and** engaging in leisure activities

Engages toys actively
Organizes leisure at a limited level, e.g., records, TV, radio
Engages in a hobby
Engages in passive games
Engages in active games or activities
Organizes complex leisure activities
Follows news, sports, and general events on TV or in paper
Scores a variety of games
Initiates and directs own activities
Plans activities for leisure
Attends entertainment in the community
Participates in organized **sports**

Using public transportation

Observes safety rules while traveling
Wears seat belt
Locates and rides subway or city bus to familiar locations
Locates and rides subway or city bus to unfamiliar locations
Calls a taxi
Rides taxi
Rides train, long-distance bus, or plane
Travels between cities
Selects and arranges own transportation (local end abroad)
Rides elevators, escalators

VOCATIONAL SKILLS

Locating **and obtaining** work

States personal skills Locates potential jobs in community Uses community resources to locate a job Prepares self for work daily
Participates in a job interview

Performing in a work situation

Arrives for work regularly
Arrives for work punctually
Stays on task
Obtains own materials
Cares for tools
Replaces tools and materials
Speaks positively of work activity
Cleans work space
Demonstrates job-safety skills
Completes tasks accurately
Works productively across time
Works on jobs requiring machinery
Discriminates between "good" and "poor" work
Interacts with fellow employees when appropriate
Requests appropriate relief time, breaks, etc.
Avoids danger in work situations
Completes work-tasks consistently (speed and quality)
Follows verbal instructions related to work-tasks
Remains in assigned work area
Completes work-tasks with time constraints
Completes work-tasks with direct supervision
Completes work-tasks in a large group setting
Completes new work-task based on existing skills
Completes work-tasks for reimbursement
Interacts positively with co-workers and employees

Continuum of Residential Programs

DEVELOPMENTAL/MEDICAL PROGRAM

Definition: Program for individuals having severe, chronic health problems requiring a life support program in conjunction with training in adaptive behaviors. **Location:** In larger communities having comprehensive hospitals and medical personnel.

Population Characteristics: Nonambulatory individuals having severe chronic health problems in conjunction with severe developmental handicaps; individuals who require medical care more than any other specific service.

Program Characteristics: Life support services
Convalescent care
Equipment training for ambulation and mobility
Self-care skills
Physical development
Ambulation
Communication skills
Social-interaction skills

Size: Less than 25

Duration: Intermediate to long term

Staff:

Primary	Consultant
Pediatric Nurse (Age 0-16)	Dentist
Registered Nurse (Age 16 +)	Dietician
Paraprofessional staff	Occupational therapist
Public health nurse	Physical therapist
Social worker	Physician (immediate availability)
Special education/child development specialist	Speech pathologist

Licensing Standards: DPW: Rules 80 and/or 34; MDH: Nursing Home or Hospital

Certification: Federal—Skilled Nursing Home or Hospital

Educational Support Services:

0-21	16+
Infant stimulation centers programs	Adult day activity
Preschool programs	Work activity centers
Special school programs	
Special class programs	

Community Support Services:
Medical — Public or private hospital facilities
Transportation — Private system
Recreation — Individual-centered recreational program

FAMILY-LIVING DEVELOPMENTAL PROGRAM

Definition: Serves individuals without severe, chronic medical problems but generally with more severe developmental handicaps than individuals in developmental foster programs. While the primary sources of education and training would exist outside the residence, a formal training program to accelerate development of adaptive behaviors would be provided. **Location:** Near schools in communities of varying sizes having the required support services.

Population Characteristics: Nonmobile to ambulatory; may not have self-care skills.

Program Characteristics: Stimulation activities
Ambulation or mobility skills
Personal-hygiene skills
Eating skills
Dressing skills
Communication skills
Social-interaction skills
Family-living skills

Size: 6 - 8 individuals

Duration: Short term to long term

Staff:

Primary	Consultant
Trained houseparents	Health personnel
	Occupational therapist
	Physical therapist
	Psychologist
	Public health nurse
	Social worker
	Special education/child development training specialist
	Speech pathologist

Licensing Standards: DPW: Rules 80 and/or 34; MDH: Boarding Care or SLF/B

Certification: Federal—ICF-S or ICF-MR

Educational Support Services:

0-21	16 +
Infant stimulation centers programs	Adult day activity
Preschool programs	Work activity centers
Special school programs	Sheltered workshops
Special class programs	Comprehensive rehabilitation facilities
	Competitive work training programs

Community Support Services:
Medical — Public or private hospital facilities
Transportation — Private and public systems
Recreation — Structured programs

FIVE-DAY BOARD AND LODGING PROGRAM

Definition: Serves individuals from sparsely populated areas attending community training programs and electing to return to a home base on weekends. **Location:** In communities having the required education/ training support services. **Population Characteristics:** Ambulatory or mobile; over 3 years of age. **Program Characteristics:** Stimulation activities
Ambulation or mobility skills Personal-hygiene skills Eating skills Dressing skills Communication skills Social-interaction skills Family-living skills **Size:** 6 - 1 5
Duration: Short term to intermediate

Staff:	**Primary**	**Consultant**
	Trained houseparents	Health personnel Occupational therapist Physical therapist Psychologist Public health nurse Social worker Special education/child development training specialist Speech pathologist

Licensing Standards: DPW: Rules 80 and/or 34; MDH: SLF/A
Certification: Federal—ICF/MR
Educational Support Services:

0-21	**16 +**
Special school programs Special class programs	Work activity centers Comprehensive rehabilitation facilities Competitive work Sheltered workshops Competitive work training programs

Community Support Services:
Medical — Public or private hospital facilities
Transportation — Private and public systems
Recreation — Structured programs

DEVELOPMENTAL FOSTER PROGRAM

Definition: Serves individuals having a wide range of developmental handicaps exclusive of severe or chronic medical problems.
Location: In communities of varying sizes. **Population Characteristics:** Ambulatory or mobile; may not have self-care skills. **Program Characteristics:** Stimulation activities
Ambulation or mobility skills Personal-hygiene skills Eating skills Dressing skills Communication skills Social-interaction skills Family-living skills **Size:** **1** - 3 (Dependent on the number of natural children in the family.)
Duration: Short term to long term

Staff:	**Primary**	**Consultant**
	Licensed, trained foster parents	Developmental psychologist Health personnel Occupational therapist Physical therapist Public health nurse Social worker Special education/child development training specialist Speech pathologist

Licensing **Standard:** Rule 1 **Educational Support Services:**

0-21	**16 +**
Infant stimulation programs Preschool programs Special school programs Special class programs	Adult day activity centers Work activity centers Sheltered workshops Comprehensive rehabilitation facilities Competitive work training programs

Community Support Services:
Medical — Public or private hospital facilities
Transportation — Private and public systems
Recreation — Structured programs

SOCIAL-VOCATIONAL TRAINING PROGRAM

Definition: Serves individuals who have acquired the basic self-care skills but require basic training in independent-living skills and vocational skills in a group environment. **Location:** In community settings close to schools, shopping, transportation. Vocational opportunities should be present or arranged within the community. **Population Characteristics:** Mobile or ambulatory; individuals who have acquired the basic self-care skills, but whose present skills preclude independent living; age 14 or over.
Program Characteristics: Directed toward 24-hour self-sufficiency in the areas of:
Communication skills Social-interaction skills Basic independent-living skills Basic vocational skills **Size: 10**
Duration: Short term to intermediate

Staff:	**Primary**	**Consultant**
	Trained houseparents	Psychologist Social worker Special educator Vocational counselor

Licensing Standards: DPW: Rules 34 and/or 80; MDH: SLF/A
Certification: Federal ICF/MR
Educational Support Services:

0-21	**16 +**
Special school programs Special class programs	Work activity centers Sheltered workshops Comprehensive rehabilitation facilities Competitive work training programs Competitive work

Community Support Services:
Medical — Public or private hospital facilities
Transportatiton — Public and private systems
Recreation — Planned adolescent/adult recreational programs

SUPERVISED APARTMENT TRAINING PROGRAM

Definition: Serves adults attending community vocational training programs, sheltered employment, supervised or independent employment. **Location:** In existing apartment complexes close to shopping, transportation, and vocational opportunities.
Population Characteristics: Ambulatory or mobile; over 18 years of age; having mastered self-care skills and those skills required for semi-independent living.
Size: Less than 10 units; maximum of 2 persons/unit
Duration: Short term to long term

Staff:	**Primary**	**Consultant**
	Live-in counselor	Health educator Psychologist Social worker Special educator

Licensing Standards: Central supervisory agency licensing as contrasted to licensing of individual units. MDH — SLF/A
Certification: Federal — ICF/MR **Educational Support Services:**

0-21	**16 +**
Special school programs Special class programs	Work activity centers Sheltered workshops Area vocational technical schools (large cities only) Comprehensive rehabilitation facilities Competitive work training programs Competitive work

Community Support Services:
Medical — Public or private hospital facilities
Transportation — Public and private systems
Recreation — Planned adolescent/adult recreational programs

MINIMALLY SUPERVISED APARTMENT PROGRAM

Definition: Serves persons who need little outside support to assume independent roles in community settings,i.e., the individual can independently deal with life situations with occasional visits by a counselor.

Location:. In existing apartment complexes close to shopping, transportation, vocational opportunities, banking facilities.

Population Characteristics: Mobile or ambulatory; 18 years or older.

Program Characteristics: Situational counseling for maintenance of independent life.

Size: Individual or family (1-4)

Duration: Intermediate to long-term

Staff: **Consultant**
Social worker Special educator Vocational counselor

Licensing **Standards:** Central supervisory agency licensing as contrasted to licensing of individual units.

Educational Support Services:

16+

Work activity centers Sheltered workshops
Comprehensive rehabilitation facilities
Competitive work training programs
Competitive work

Community Support Services:

Medical— Public or private hospital facilities
Transportation — Public systems Recreation — Variety of adolescent/adult recreation available in the community

BEHAVIOR TRAINING DEVELOPMENTAL PROGRAM

Definition: Serves persons on a short-term basis to eliminate serious maladaptive behaviors and to improve adaptive behaviors to a level appropriate for placement in Developmental Foster Homes, Family Living Developmental Residences, or Five-day Boarding Homes.

Location: In small or large community centers on a regional basis.

Population Characteristics: Ambulatory/mobile. Persons whose behavior and/or social conduct require a highly structured, response-contingent, and restrictive environment, i.e., whose behavior cannot be changed in the present environment. Generally, the population would include individuals who are consistently destructive to themselves, other individuals, or property, or who, because of behavioral characteristics, are rejected by individuals in residential and program alternatives. The individual must be formally located in a specific, on-going residential program and then formally demitted with rights of review prior to placement in the program.

Program Characteristics: Intensive behavior modification program, basic social skills, communication skills, self care skills.

Size: Less than 10

Duration: Short-term

Staff:

Primary	**Consultant**
Psychologist or Special with spe- behavior modification	Physician Educator Social worker cific training in

Licensing Standards:

Educational Support Services:

0-21	**16+**
Special school programs	Work activity centers
Special class programs	Sheltered workshops

Community Support Services:

Medical — Public and private hospital facilities
Transportation — Private and public systems Recreation — Structured and non-structured programs

Continuum of Educational Programs for Children and Young Adults

INFANT STIMULATION PROGRAM (0-3 Years)

In the home with a resource consultant or in a day activity center with professional and paraprofessional support. Orientation:

Gross motor skill development Visual, auditory, and tactile-kinesthetic stimulation Sensory stimulation in modalities other than handicap Prompting in the developmental milestones Physical therapy and use of prosthetic devices , Social stimulation activities

PRESCHOOL PROGRAMS (3 - 7 Years)

Orientation:

Gross motor skill development Self-care skills Preacademic skills Social interaction skills Communication skills

SPECIAL SCHOOL AND HOMEBOUND EDUCATION PROGRAMS (5-21 Years)

Orientation:

Fine and gross motor skill development Self-care skills
Ambulation and locomotor skills
Communication skills
Academic skills
Social-interaction skills
Independent-living skills
Preparatory vocational skills

SPECIAL CLASS AND REGULAR CLASS PROGRAMS (5-21 Years)

Orientation:

Fine and gross motor skill development
Communication skills
Self-care skills
Academic skills with emphasis on functional needs
Social-interaction skills
Independent-living skills

Continuum of Training Programs for Adults

ADULT DAY ACTIVITY CENTERS

Orientation:

Fine and gross motor skills
Self-help skills
Physical activities for body maintenance
Social-interaction skills
Communication skills
Work activity

WORK ACTIVITY CENTER

Work program for individuals who produce at or below 25% normal productivity. Orientation:

Work experience directed toward the value of earning money, feelings of self worth; introduction to work behaviors
Developmental skills including basic education, coordination, exercises, speech; independent living skills based on individual needs
One-half to two-thirds work directed toward progression to sheltered workshop or competitive employment

SHELTERED WORKSHOP

Employment program for individuals not readily placeable in competitive employment. Orientation:

Work experience directed toward speed and ability to learn numerous similar jobs Work habits and appropriate work behavior Work directed toward competitive employment (50% or above of normal productivity; potential for competitive employment)

COMPREHENSIVE REHABILITATION FACILITY

Entry level skill training for specific occupation (should accompany adult day activity centers). Orientation:

Vocational evaluation, vocational training, and sheltered work opportunities Work activity, adult day activity, and skill training for specific occupations
Structured program services: Vocational counseling Social services Placement services

AREA VOCATIONAL TECHNICAL SCHOOL

Extensive skill training.
Orientation:

Vocational evaluation
Skill training in specific occupations
Competitive employment or referral to a specific training center

COMPETITIVE WORK TRAINING

On-the-job training situations.

COMPETITIVE WORK

On-the-job

Model for Functional Description of Physical Limitations[1]

Level of Functioning	Functional Description	Residential Modification
	Seizures occur infrequently. Does not drive any vehicle. Does not work in high places or close to heavy moving machinery that may be injurious to self or others.	None except general safety measures.
1	Does not swim without supervision. Uses public transportation independently. Can be educated or trained for any type of job provided above restrictions are observed. Can be self-supporting. Can live independently. Can take and self-dispense medication without supervision. May need counseling and/or social services.	
	Limited control of seizures achieved through medications. Seizures interfere with activities. Does not drive any vehicle. Does not work in high places, near open fires or close to heavy machinery that may be injurious to self or others.	Environmental safeguards such as carpeting and railings. Measures to protect the individual from possible injury caused by open fires, heavy moving machinery, appliances, or sharp objects.
2	Uses public transportation independently. Can be trained for low-risk jobs. Can benefit from occupational training center programs and rehabilitation programs. May need individualized attention in school. Can be partially self-supporting. Can participate in gym, shop, swimming, etc., with supervision. May not be capable of taking medication independently.	
	Poor control of seizures with medications. Requires specialized health care. Activities greatly curtailed, e.g., stair climbing, bike riding. Does not drive any vehicle. Does not work in high places, close to heavy machinery, near fires or heated objects. May need supervision in other potentially dangerous conditions, e.g., bathtubs, sharp objects.	Environmental safeguards such as carpeting, railings and ramps (where unavailable, space should be provided on the first floor for daily living and program activities). Measures to protect the individual from possible injury from open fires, heavy moving machinery, appliances, or sharp objects.
3	Does not use public transportation independently. Cannot attend school regularly. Cannot be competitively employed (probably). May be able to contribute to self-support. Cannot live independently. Is unable to take medications independently. Is restricted from household chores such as cooking over open fire, ironing, burning trash.	Other environmental changes may be desirable depending on type of seizures, e.g., absence of flashing neon lights as well as shrill sounds.
	Uncontrollable seizures. Seizures of great severity and frequency. Activities greatly restricted. Requires supervision in potentially dangerous conditions, e.g., bathtubs, sharp objects. Dependent for support and care. Cannot transport self independently. Requires protected environment. Cannot take own medications. Requires frequent hospitalization or nursing care. Unable to perform most household chores.	Preceding modifications. If individuals have a tendency to be bedridden over a long period of time, special efforts should be directed toward ambulation to avoid the complications of prolonged periods of inactivity.

[1] Reuben, S. A programming model for epileptics, St. Paul; Department of Neurology, St. Paul-Ramsey Hospital, Mimeograph, March 1974.

Instructional Needs	Transportation Needs	Modifications to Educational Environment
No special requirements other than the generally accepted program limitations for persons with seizures, e.g., cannot drive; should not work in high places, close to moving machinery, or open fires.	An easily accessible system of public transportation should be provided so individuals can commute with ease to jobs, schools, shopping, recreation areas, doctors, etc. Operators of school buses and other public conveyances should be knowledgeable as to what to do should a seizure occur.	No special changes in classroom and curriculum required. However, teachers and other school personnel should be able to recognize seizures and take appropriate steps. Programs should be developed so individuals can resume activities when post-seizure effects have passed (postictal stage) including tutoring if necessary. Space should be available for the individual to rest after the seizure. Individuals should not be excluded from activities, but safety measures should be taken to enable them to participate, e.g., a buddy system should be enforced for swimming. Physical activities should be curtailed only with physician's recommendation. Classroom driver's training should be available with provision for behind-the-wheel training after the individual has been free of seizures for one year.
Preceding limitations. Occupational rehabilitation training center staff should be aware of the needs of persons with seizures. Personnel should be knowledgeable in what individuals with seizures can and cannot do. Appropriate testing of capabilities should be conducted. Training programs should be based on the results of comprehensive assessment rather than solely on the degree of control over seizures. The Division of Vocational Rehabilitation should be actively involved in developing such testing and training programs. Skills for applying for employment should be an integral part of the program. A program for special employment positions should be developed jointly by DVR, training centers, prospective employers, and others.	As before.	As before, with closer supervision when engaging in high-risk activities. Provisions should be made for the student to catch up on material he missed because of seizures. School personnel should be aware of the student's condition and be prepared to dispense medication. When a student cannot participate in specific activities such as gym or shop, his program should be supplemented with other activities that afford similar experiences. Counseling (including Vocational Rehabilitation counseling) should be provided early so that individuals can be introduced to instruction and training based on their capabilities.
Preceding limitations. When sheltered training is indicated the environment should be conducive to the development of the full potential of people with seizures rather than just keep them occupied. Close supervision of medications and means for observing and monitoring seizures should be provided.	Special means of transportation should be provided for individuals who cannot independently avail themselves of public transportation. Seat belts should be provided to protect individuals against falls that may occur as a result of seizures.	In addition to the preceding, provision should be made for home-bound instruction when the student is unable to attend regular classes.
Instruction should necessarily be directed toward basic self-care skills. Brief, simple chores should be arranged for the individual.	Since they will have to be driven wherever they go and provided with very close supervision, individuals will be dependent to a great extent on others. Special types of transportation should be provided. The preceding precautions should be observed.	Because educational and vocational goals are very limited, most training should be conducted under the auspices of day activity centers or similar programs.

Available Programs for Client Instruction

The following chart is provided as a model for the classification of instructional programs by skill development categories. Providers of the indicated programs can be obtained by requesting **Sources of Instructional Programs for Developmentally Disabled Individuals,** Developmental Disabilities Program, Minnesota State Planning Agency.

SKILL AREA	BEHAVIORAL DESCRIPTIONS	NUMBER OF AVAILABLE PROGRAMS
Personal-Hygiene Skills	Toileting	4
	Washing and bathing	5
	Grooming	5
	Caring for health needs	4
Eating Skills	Feeding self	4
	Selecting and using correct utensils	2
	Displaying appropriate manners	3
	Eating in a variety of locations	1
Dressing Skills	Completing basic motor tasks	7
	Selecting clothes	3
Communication Skills	Responding nonverbally	1
	Responding verbally	4
	Writing for independent living	5
	Reading for independent living	4
Quantitative Skills	Managing currency	3
	Managing time	3
	Applying units of measurement	2
	Applying number concepts	2
Social-Interaction Skills	Displaying appropriate social behavior	4
	Caring for and sharing of property	1
	Following rules	3
	Cooperating	1
Independent-Living Skills	Managing a residence	1
	Cleaning a household	2
	Maintaining clothing	2
	Preparing and serving meals	2
	Avoiding danger situations	1
	Telephoning	1
	Traveling within the community	1
	Traveling within the neighborhood	1
	Using public transportation	1
	Selecting and engaging in leisure activities	2
	Managing finances	
Vocational Skills	Locating and obtaining a job	
	Performing on the job	1

Criteria for Developing and Evaluating Programs[2]

Evaluating and providing feedback on proposals for instructional programs requires that criteria for assuring program quality be developed. The following checklist presents the basic questions to which affirmative responses would be required for effective program development.

Job Description

1. Does it include a general description of what someone does when performing the job?
2. Is the description clear enough to distinguish this job from other, similar jobs?
3. Is a persuasive rationale presented for the need to train personnel for this job?

Task Analysis

4. Has the job been broken down into the various tasks which must be performed?
5. Have the steps involved in performing each task been specified in performance terms?

Target Population

6. Are the present characteristics of the actual (rather than the ideal) population of people to be trained described?
7. Are the present characteristics of the target population measurable?

Course Objectives

8. Are the performances to be demonstrated by the individual upon completion of training clearly stated?
9. Are the performance objectives directly related to the performances specified in the task analysis?

Criterion Examination

10. Are the procedures used to test for mastery of the performance objectives clearly specified?
11. Does the criterion examination closely resemble [approximate) on-the-job performance?

Prerequisites

12. Are the performances (skills) necessary for entering the training program specified?
13. Are the procedures used to test for prerequisite skills specified?

Objective **Sequence**

14. Are the intermediate or enabling objectives through which the individual will progress from prerequisite performance to criterion performance clearly specified?
15. Are progress checks (tests) for determining mastery of each of the intermediate objectives specified?
16. Are the intermediate objectives sequenced?

Mastery **Charting**

'7. Has a system for frequent recording and display of individual progress on the intermediate objectives been clearly specified?
18. Has a time schedule for attainment of mastery been described for the objectives sequence?

Instructional Procedures

19. Are the techniques (materials and procedures) to be used in assisting the individual to achieve mastery on **each** of the intermediate objectives described?
20. Are alternative procedures and formats avail able for individualization and remediation?

Rationale for Procedures

21. Does it indicate why particular instructional procedures were selected for each objective in contrast to other possibilities, and why lectures instead of autoinstructional materials were selected?

Program Evaluation and Improvement

22. Do the program procedures include a regular summary of the proportion of entering individuals who achieve mastery on the criterion test?
23. Is the amount of time it takes individuals to attain mastery on intermediate objectives and to complete the program summarized?
24. Is there provision for systematically revising the program based on progress and outcome data?

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[2] **Deno, S.L Evaluating Training Programs and Program Proposals, Task Force Memorandum.**

Criteria for Evaluating Research Proposals

The following interpretation of basic proposal components as questions should enable both the applicant and evaluator to more easily analyze a specific project proposal.

Problem

Is the research needed?
Does the problem fall into a priority area?
Is the problem of state-wide significance?
Is the problem well defined?
Does the review include references to existing research on the topic?

Objectives

Are the questions to be answered or the objectives to be met stated in measurable terms? Do the objectives, if met, provide a clear response to the problem?

Procedures

Are the steps to be followed clearly defined?
Are the steps to be followed logical?
Do the steps to be followed lead to the project outcome as defined by the objective?
Has a timeline been attached to the specific steps?
Are reporting dates identified in the timeline?
Are the procedures to be followed scientifically sound, e.g., sampling, data gathering, data analysis, validity threats?
Is the dependent variable defined?
Is the independent variable defined?
Are these variables within the control of the researcher?

Outcomes

Will the described outcomes respond to the problem?

Staff and Facilities

Are the roles of project personnel clearly stated? Do each person's skills tie directly to project objectives?
Can the described staff do the job effectively? Are the deficiences covered by specific consultant support?
Are the facilities appropriate for investigating the problem?

Budget

Do the outcomes justify the total expenditure?
Are the costs, e.g., salary, facility, support, reasonable?

Dissemination

How will the results or materials be disseminated—publication, final report, replication, e.g., workshops, production? Who will hold the rights to the materials developed?

Implications

The research and development efforts which are integral to the implementation of the CAIR plan would be strengthened by three major activities:

Establishment of a clearing house for information related to research and development activities
Establishment of a research and development plan and solicitation of fund proposals based on the systematic completion of that plan
Establishment of clear criteria for both research and development activities to increase the skills of preparers as well as to improve the evaluation of proposals and completed projects.

Proposed Zoning Statute[3]

§252.28, subdivision 3

(1) No license shall be granted pursuant to this section when the issuance of such a license would substantially con tribute to the excessive concentration of residential facilities for the mentally retarded within any town, municipality or county of the state.

(2) In determining whether a license shall be issued pursuant to this subdivision, the commissioner of public welfare shall take into account the population, size, availability of community services and the pre-existence of community residential facilities for mentally retarded individuals in the town, municipality or county in which a licensee seeks to operate a residence.

(3) The commissioner of public welfare shall establish uniform rules and regulations to implement the provisions of this subdivision.

Section 462.357

Subdivision 7

(1) It is the policy of this state that mentally retarded and physically handicapped persons are entitled to share with non-handicapped individuals the benefits of normal residential surroundings and should not be excluded therefrom because of their disability.

(2) Pursuant to this policy it is the intent of the Legislature that municipal zoning ordinances and administrative interpretations thereof should not deny the handicapped or retarded person the exercise of this right.

(3) In order to achieve statewide implementation of the policy and legislative intent expressed in this subdivision and notwithstanding any law to the contrary, a state licensed group home, or foster home, serving six or fewer mentally retarded or physically handicapped persons shall be considered a residential use of property for the purposes of zoning and a permitted use in all residential zones.

(4) Notwithstanding any law to the contrary, such group and foster homes shall be a permitted use in all residential zones including, but not limited to, residential zones for single-family dwellings.

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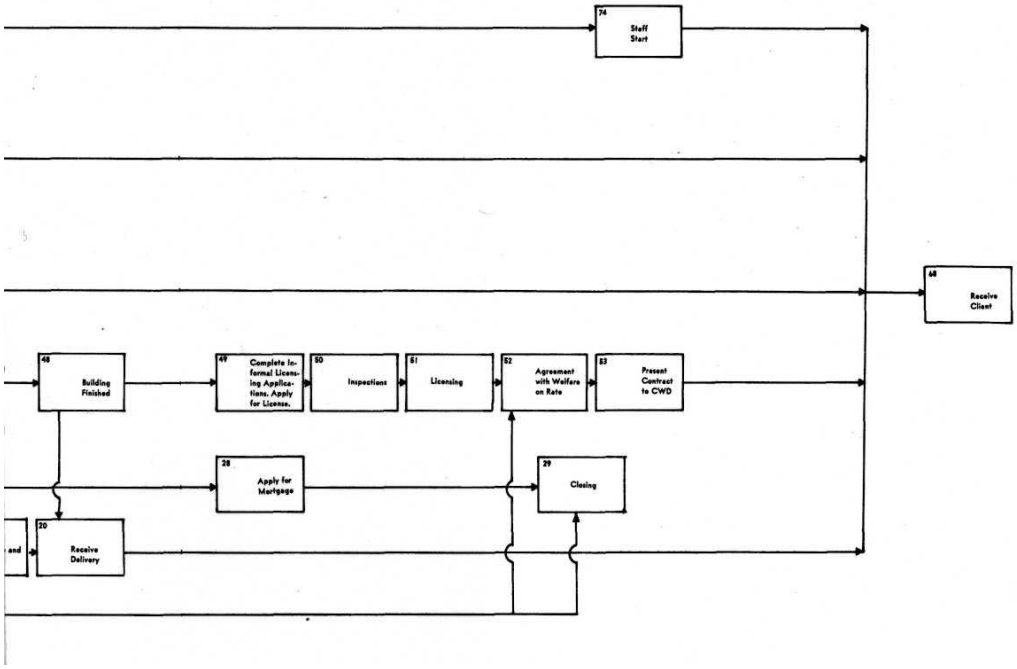
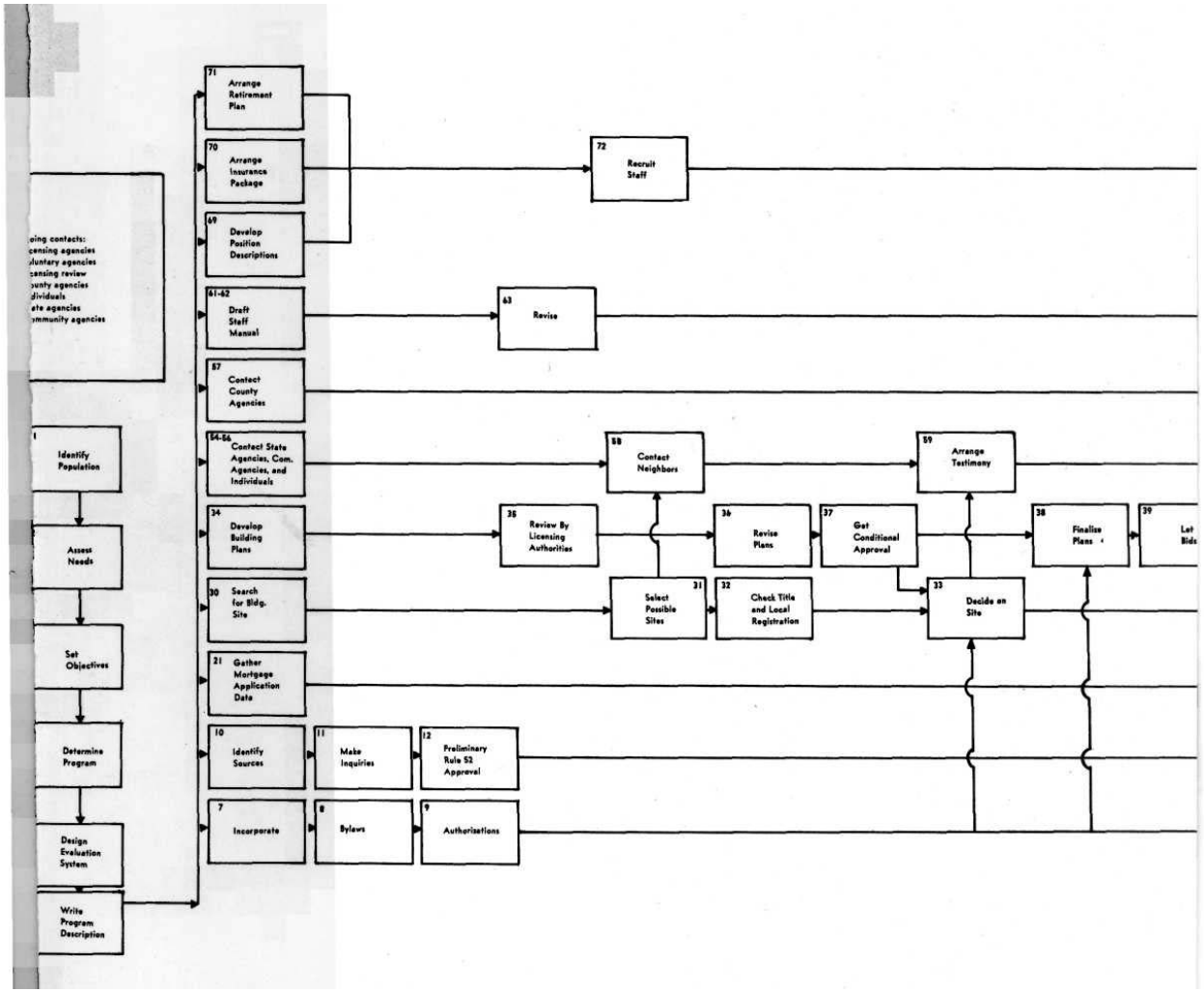
3 Mickenberg, N. Model Zoning Statute: Part 1. Minneapolis Legal Aid Society, August, 1974,


74
Staff Start
68
Receive Client
48
Building Finished
49
Complete Informal Licensing Applications. Apply for License.
50
Inspections
51
Licensing
52
Agreement with Welfare on Rate
53
Present Contract to CWD
28
Apply for Mortgage
29
Closing
20
Receive Delivery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Identify Population
Assess Needs
Set Objectives
Determine Program
Design Evaluation System
Write Program Description
71 Arrange Retirement Plan
70 Arrange Insurance Package
69 Develop Position Descriptions
61-62 Draft Staff Manual
87 Contact County Agencies
54-56 Contact State Agencies, Com. Agencies, and Individuals
34 Develop Building Plans
30 Search for Bldg. Site
21 Gather Mortgage Application Data
10 Identify Sources
7 Incorporate
11 Make Inquiries
8 Bylaws
12 Preliminary Rule 52 Approval
9 Authorizations
72 Recruit Staff
63 Revise
88 Contact Neighbors
89 Arrange Testimony
35 Review By Licensing Authorities
36 Revise Plans
37 Get Conditional Approval
38 Finalize Plans
39 Let Bids
31 Select Possible Sites
32 Check Title and Local Registration
33 Decide on Site

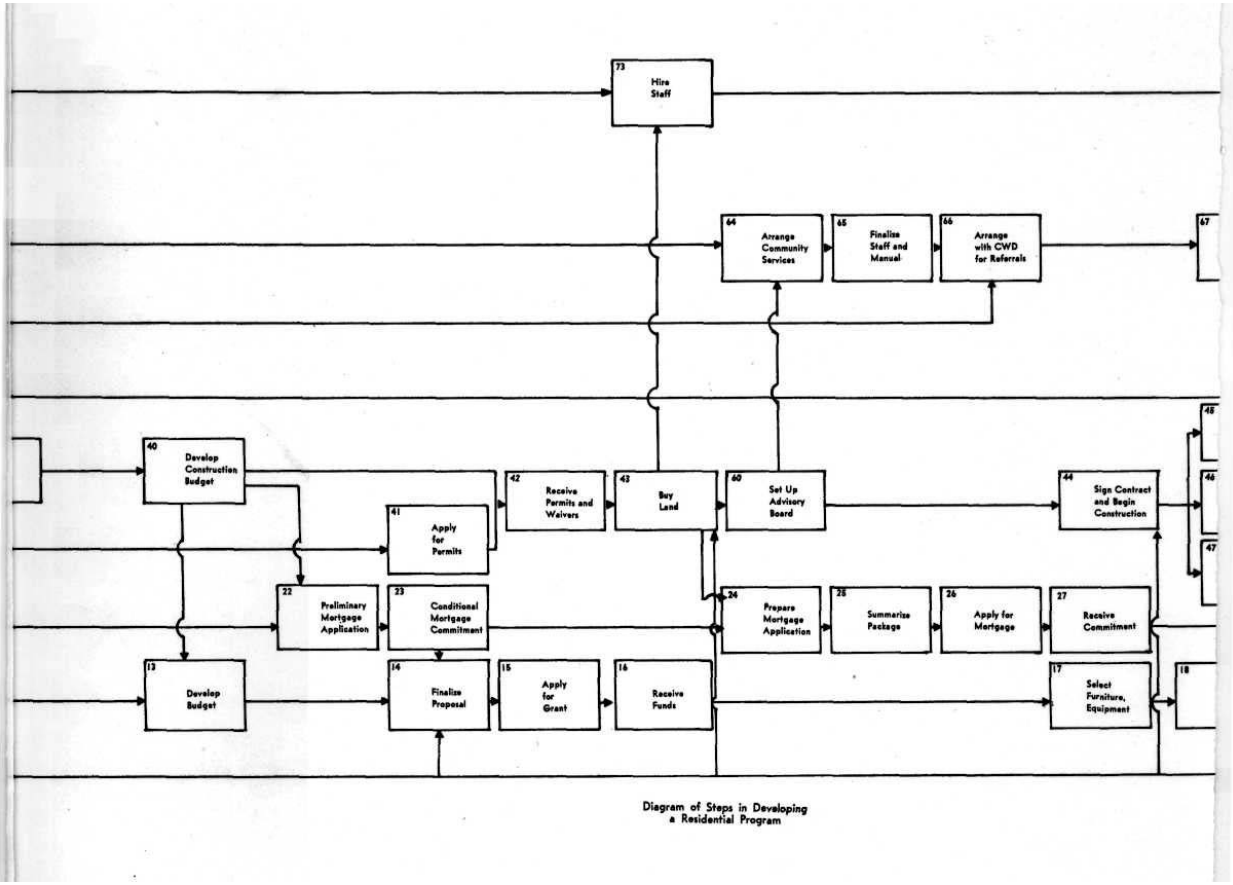

Diagram of Steps in Developing a Residential Program