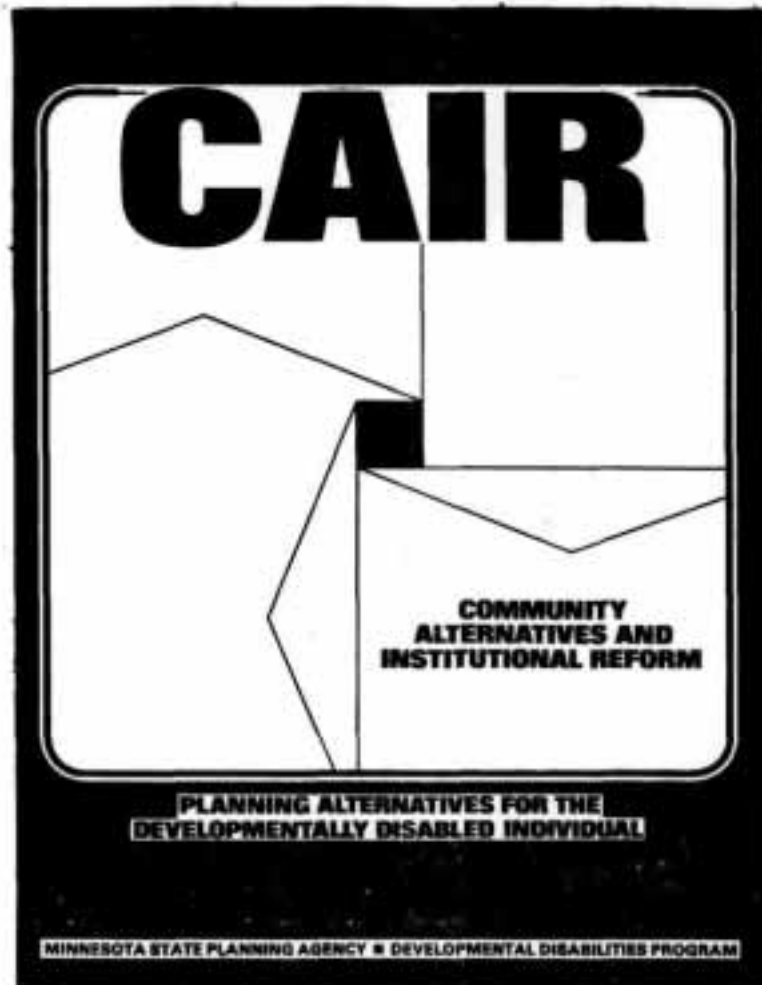


COMMUNITY ALTERNATIVES AND INSTITUTIONAL REFORM
AN ANNOTATED PROJECT SUMMARY



Developmental Disabilities Program Office
Minnesota State Planning Agency 550 Cedar
Street, Room 110 St. Paul, Minnesota
55101

Following the Presidential mandate for deinstitutionalization of developmentally disabled individuals and in keeping with the priority of the National Advisory Council on Developmental Disabilities, the Minnesota Governor's Planning and Advisory Council on Developmental Disabilities of the State Planning Agency received a grant in 1974 to create a comprehensive plan for establishing community alternatives for developmentally disabled persons.

The Community Alternatives and Institutional Reform Project was directed toward two major objectives:

To integrate the viewpoints of financial and program decision-makers with the perspective of individuals responsible for implementing programs.

To develop a systematic plan for returning developmentally disabled persons in state facilities to community settings based on their individual needs.

COMMUNITY ALTERNATIVES AND INSTITUTIONAL REFORM

PROJECT: AN ANNOTATED PROJECT SUMMARY

The movement toward arranging home-like residences in the community rather than placement in large institutions for developmentally disabled persons rests on two beliefs: that each developmentally disabled person has a right to treatment which encourages self-sufficiency, maximum development, and contribution to society consistent with the limits of the disability; and that each person develops best in a situation which is as normal as possible. The latter principle, normalization, underlies each aspect of community-based programs for developmentally disabled individuals.

The concept of normalization rests on research, which demonstrates that developmentally disabled persons represent underdeveloped human potential rather than a threat to society as was supposed earlier in this century. For the developmentally disabled, normalization means, in part, living arrangements, which parallel those of non-disabled people. It implies having choices, making decisions, caring for one's self, meeting different people, being part of the ebb and flow of everyday living. Clearly, each person's disability limits the extent of participation in life experiences. This means some people may remain in full-care facilities not altogether unlike the present state facilities because their needs can be best met there; others, needing less continuous care will live in supervised board and lodging homes and take training in sheltered workshops. And some will live in minimally supervised apartments and work in the community. In each case, normalization means that the medical, educational, work and living

prescriptions for the individual must be specifically tailored to meet that individual's needs and abilities. The client's level of disability should determine the treatment program for optimal development (pp. 2-3, 9-11).

The process of moving clients into more normal home-like residences is known as deinstitutionalization. The experience of several states which have deinstitutionalized developmentally disabled people provides ample evidence that inadequate planning, inadequate funding, insufficient services in the community can quickly blunt the thrust of normalization, impeding rather than aiding client development (pp. 2-3, 9-11). The recommendations of the CAIR task forces (pp. 4-8) represent a planning alternative based on the experience of professionals, consumers, and agencies representing every aspect of care for the developmentally disabled in Minnesota (pp. 2, 9-11, 40-45).

ON CLIENT CARE

Planning for individual relocation in a community-based program must begin with an assessment of each developmentally disabled person to determine the present skill level, e.g., social, self-care, and physical status. The results of this assessment should lead to a comprehensive treatment plan for each client, which prescribes programs in several areas: residential arrangements, health-care, training, and work programs. Client development must then be frequently reassessed to assure maximum progress and accountability. Data available on persons in state-operated facilities indicates that self-care skills will be a large part of each program (pp. 12-19).

Because of its size, the large institution offers a wide range of treatments on site. Moving individuals into community settings will require

that the same range of services, including advocacy, health-care, recreation, transportation, and education, be available within a reasonable distance. The selection of sites for residences as well as part of the program prescription should be based on the identification of the services which will be needed and their availability for each client (pp. 17-18, 21, 24-25, 55).

Moving from institution to community will cause stress for the developmentally disabled and their relatives. Clients should be prepared for such moves while in their present institutions and staffs are being reorganized and trained to carry out the move as naturally as possible (pp. 30-31, 51-54). Evidence should be provided to clients and family members demonstrating that new programs are based on the client's needs and represent his best interests.

Handling of all data related to the client must be consistent with the individual's right to privacy. Planning based on individual needs will require considerable assessment and progress review; these should not be opportunities for unauthorized access (pp. 16-17, 28-29, 32-33).

ON COMMUNITY-BASED FACILITIES

Construction and operation of community-based residential facilities should be encouraged under the direction and supervision of public agencies, which should remain ultimately responsible for the treatment received by each client. Construction and operation of community facilities will require: funds for development, assured continuous public support, assured quality of care, accountability for client care, and community acceptance.

Some communities have sought to "zone out" local facilities for the developmentally disabled. The recently passed statewide zoning statute (Chapter 60, Laws of Minnesota, 1975) recommended in the CAIR Report, prohibiting discrimination against mentally retarded persons, will ease the development of residential programs (pp. 25 , 60).

Community-based programs require more than just houses; comprehensive treatment and developmental programs are needed as well. Not every community has the support services necessary to maintain community care facilities thus the amount of assistance for development of services should be adjusted based on the existing capability of a community to provide needed services (pp. 24-25).

Development of community care residences would be greatly aided by uniform, state-wide licensing standards and procedures which eliminate overlap between public agencies. While standards must be maintained in construction of residences to insure fire resistance, sanitation, utility and comfort, development and licensing procedures need streamlining. A comprehensive step-by-step procedure for developers and local officials on licensing standards, funding, trouble-shooting, and other data should be prepared (pp. 16-17, 27).

Without adequate funding for developing services, community-based programs face a grueling and probably stunted growth. Community-care facilities are not so much a way to reduce state expenditures for the developmentally disabled as a way to insure maximum benefit from each dollar spent. Many clients will never cease to need full assistance, but dollars can be accounted for in terms of clients benefits and progress. Responsibility for funding community-based care should not fall unduly heavily on counties or communities; the state should provide incentives for local placement rather than encouraging institutional placement by increasing its financial participation in providing services only when clients are placed in a state-operated facilities (pp. 17, 25, 28, 32, 35, 51-54).

Residential facilities should be dispersed within each community to avoid construction of compounds or clusters of homes for disabled persons which would be inconsistent with the purpose: more normalized living.

The range of residential types and the number of clients should be based on a ratio which enhances normalization (pp. 16-18, 21, 24-25).

Community acceptance of local residential facilities and individual clients can only be developed with a strong, active, and positive public information campaign. Not only must health-care professionals and politicians be informed about the benefits of such programs, but popular prejudices and stereotypes must be dispelled (pp. 24, 28-29, 35).

ON RELATIVES OF THE DEVELOPMENTALLY DISABLED

Because parents who elect to place their child in a large state-operated facility experience an emotionally draining process, they and those who counsel them need greater assistance in obtaining the best available information regarding community programs (pp. 27-29).

Parents who place their child in state facilities are concerned with the child's care after they are deceased, with having to make such a decision but once, with not having their child "shuffled" from side to side, and with skilled-care for the child in humane settings; parents need assurances that local programs will be as enduring as state-operated programs (pp. 28-29).

For parents who elect to raise a developmentally disabled child in the family home, comprehensive health, educational, and financial support equal to that provided in state-operated facilities should be readily and easily available. While funding should be limited to services which precisely meet client needs based on professional judgment/program planning, parents should incur no extraordinary cost or hardship in fostering their child's physical and behavioral development (pp. 29-30).

FOR ACCOUNTABILITY

A monitoring system independent of local facilities and serving the public interest should evaluate delivery systems in every phase of community-based programs. The criteria for determining the quality of programs would include individual client adjustment and progress, the effectiveness of care programs, the implementation of care programs, the maintenance of quality environments, and the effective use of state support. Data obtained in the monitoring would aid cost projection and program modification, but it should neither invade client privacy nor use clients as research subjects without control (p. 32).

Local facilities should maintain frequent review of client progress to insure program aptness and effectiveness. Local agencies should assist overall care facility reviews (pp. 32-33).

A uniform reporting system used across public agencies in the state would simplify reporting and evaluation, and, through connection with a centralized information source, aid placement of incoming clients in facilities and programs best able to meet the client's needs (pp. 21, 24-25, 32-33).

ON REDUCING THE INCIDENCE OF DEVELOPMENTAL DISABILITIES

The incidence of developmental disabilities could be reduced through a program of education aimed at teen-agers and pregnant women and focusing on specific risk factors, e.g., use of drugs, inadequate nutrition, inconsistent prenatal care. Presently no such program is widely available. Education, to be effective, should be associated with counseling and treatment programs (p. 33).

The impact of developmental disabilities could be reduced through

early intervention and treatment programs. But, such programs will depend on coordinated state-wide early and periodic screening of children and the availability of treatment programs to follow-up on screening results to significantly affect the need for later treatment and care (pp. 33-34).

Research on problems attendant to community-based programs and treatment for developmentally disabled individuals requires a directed rather than a non-focused approach. Such a focus could be maintained through an inter agency research and development group which would establish research priorities and review proposals submitted to the various agencies (p. 34).

ON PRESENT STAFFS AND FACILITIES

The demands which community-based residential facilities place on professional staff will differ significantly from those which the institution places on them. At the same time, trained and skilled professionals are too valuable a resource to be simply lost. As clients move to alternative care facilities, the professional staffs should be encouraged to move also. The reorganization of staffing patterns mandated by community based programs must be part of an overall plan which also includes retraining present staff to meet the needs of clients in smaller living situations and to adapt to entirely different staffing patterns (pp. 30-31).

Precipitous closing of all present state facilities for the developmentally disabled would be ill-advised because a number of individuals would best be served at this time by a full-service, total-care facility. Closing would also eliminate an alternative for those who do not readily adapt to community-care facilities. The present hospital environment should be modified to meet individual client needs until sufficient

community-based residences are developed; some sections might also be remodeled to serve as in-service training centers, diagnostic centers, workshops, or day-care facilities because of their regional location (pp. 31-32).

A CAIR Committee has now been assembled to consider a number of issues related to establishing and maintaining community-based programs;

- a report on the status of CAIR recommendations, priority issues yet to be addressed.
- information dissemination activities.
- study on the status of individuals recently released from state institutions.
- identification and analysis of the "costs" of community-based services and programs.
- analysis of staffing qualifications for a range of community-based programs

Additional information related to the CAIR Report and follow-up efforts can be obtained by writing:

Developmental Disabilities Planning Office
Minnesota State Planning Agency
Room 110 Capitol Square Building
550 Cedar Street
St. Paul, Minnesota 55101