

News Letter

THE GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES & THE DEVELOPMENTAL DISABILITIES PLANNING OFFICE OF THE STATE PLANNING AGENCY

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DD AMENDMENTS SIGNED INTO LAW ---New DD Definition Stressed

On November 6, President Carter signed the Rehabilitation Comprehensive Services and Developmental Disabilities Amendments of 1978 (P.L. 95-602). The new law contains a number of important, substantive changes to the Developmental Disabilities Program.

Public Law 95-602 contains a new definition of developmental disability, changes the composition of state planning council membership, defines the goals of University Affiliated Programs and increases authorization levels for the basic formula grant to the states and to state protection and advocacy systems.

The new definition of a developmental disability is based upon an individual's functional impairment(s) and avoids the itemization of categories of disability.

HEW is in the process of developing Regulations for P.L. 95-602 and hopes to have them promulgated by early summer.

The next issue of *DD News Letter* will look at the new amendments in greater depth for both the Developmental Disabilities Program and the Rehabilitation and Comprehensive Services Program.

RESIDENTIAL SERVICES FOR DD REVIEWED

INSIDE STORIES

In this issue the theme is **RESIDENTIAL SERVICES** for persons with developmental disabilities. The articles touch upon the philosophy behind community based services trends, the question of community acceptance, zoning, different approaches in residential services and other aspects.



Orvilla residence roommates Steve Holmay and Dan Bjorklund enjoying their company.

LEGAL ADVOCACY HOTLINE 1-800-292-4150

People living outside of the Twin City area may now call toll-free for legal assistance or information. This free service is being provided by the Minnesota Developmental Disabilities Legal Advocacy Project in Minneapolis. The professional staff are available during normal business hours to provide information and advice in such matters as discrimination, social services, financial assistance and education. The Project does not charge for its services, which include: direct representation of clients, counseling, public information/education and in-service training to community groups. People are eligible for services if they have a developmental disability and if their legal problem is related to their disability. Residents within the metropolitan area may dial 338-0968 or 332-1441.

The hotline is financed by a grant from the Developmental Disabilities Protection and Advocacy System of the State Planning Agency and the Department of Health, Education, and Welfare.

DD News Letter is printed in bold type to make it more legible for the visually handicapped readers in our audience.

Portions of *DD News Letter* are read over the Talking Book Radio Network, which serves Minnesotans who are blind or have multiple handicaps.

RESIDENTIAL SERVICES: (AN OVERVIEW)

Residential services for persons with developmental disabilities is the theme of this edition of *DD News Letter*. Since its inception in 1972, the Governor's Planning Council on Developmental Disabilities has strongly supported efforts to expand and/or improve residential services (whether in state institutions or in the community) for persons with developmental disabilities. A basic tenet in the Planning Council's statement of *Philosophy and Mission*, declares that:

"All persons have the right to function in a setting which provides for development of independence, is as similar to the norms of society, and provides an opportunity for participation in meaningful activity and assumption of personal responsibility in the life of that community."

I. PHILOSOPHIES AND TRENDS

Philosophies of care for developmentally disabled persons have shifted drastically from the "custodial care" concept to the realization that "people who are retarded are people." Nowhere is this more evident than in residential care. Historically,

public attitudes toward mentally retarded persons, based on ignorance and fear, dictated that such persons be separated from the rest of society. Large public institutions, tucked away in the country, were considered to be the best alternative for the family of the mentally retarded individual, the state and for the individual.

But starting in the 1960 s, concerned persons began rethinking the theories that had supported massive state institutions. Two key concepts - normalization and the least restrictive alternative -began to shape the attitudes of government agencies and consumer groups.

Parents, educators and others pushed for opportunities for persons with developmental disabilities to have the patterns and conditions of everyday life which are available to the majority of society (normalization). At the same time, legal decisions established the principle that if and when, for the individual's welfare, the state must deprive him of some part of his basic right to independent participation in

Trends to p. 3



Ariel view of traditional institutional setting.

Trends from p. 2

society, the state should choose the alternative which least restricts the individual's freedom.

These concepts fostered the development of small community-based residential facilities, or group homes, because "people live in houses." Realizing both the individual and the community lose when a person's potential as a person is not achieved, the state of Minnesota adopted a goal to shift from state institutions to small residential facilities. The process is called deinstitutionalization and it involves more than merely moving residents of state hospitals to group homes. It encompasses prevention of inappropriate placements in institutions by developing alternatives and maintaining a residential environment that protects human and civil rights. The state attempts to provide a continuum of services which meets the needs of mentally retarded persons.

A community-based residential facility is an option which many developmentally disabled persons find to be suitable for their needs. By May of 1976, 121 community residential facilities for mentally retarded children or adults with a total capacity of 2,873 beds had been established in Minnesota. About 65 of those homes had opened in the previous four and one-half years. The occupancy rate of the homes averaged 95.6%, and though originally state hospitals and natural homes provided nearly equal numbers of referrals, by 1976 state hospitals were sending twice as many clients to group homes.

While some facilities for persons with mental retardation provide services to persons with seizures, autistic-like behavior, or to those who are non-ambulatory, no similar projects were estab-

lished specifically for these persons. A few residences have been built for persons who are physically handicapped. Some are structurally adapted to enable independent living, while others are structurally adapted and are staffed to provide assistance with personal care.

Issues such as zoning, concentration of group homes, and provision of support services like transportation make establishment of community-based residential facilities difficult. Group homes may not be the best alternative for all persons with developmental disabilities because of specific individual physical or mental needs and abilities. However, as an exciting and potentially rewarding trend, community-based residential facilities are definitely worth considering.

II. NATIONAL SURVEY COMPLETED

The first phase of the Developmental Disabilities project on Residential Services and Community Adjustment was completed recently. The project was initiated to provide state and federal policy makers with information needed to improve planning, management, and evaluation of residential and community services for mentally retarded persons. Directed by Dr. Robert H. Bruininks, Department of Psychoeducational Studies, University of Minnesota, the project is funded through a three-year Developmental Disabilities project of National Significance grant.

The project conducted a nationwide mail survey designed to obtain current information about the kinds of residential services available to mentally retarded persons. The survey included all facilities and homes which met

the definition of a Community Residential Facility (CRF): Any community-based living quarter(s) which provides 24-hour, seven days-a-week responsibility for room, board, and supervision of mentally retarded persons as of June 30, 1977, with the exceptions of single family homes providing services to a relative, nursing homes, boarding and foster homes that are not formally state licensed or contracted with as mental retardation service provider, and independent living programs which have no staff residing in the same facility. (It also does not include public residential facilities, such as state institutions.)

In an attempt to develop a complete mailing list of all eligible facilities serving persons with mental retardation, a variety of sources were contacted including all the State Mental Retardation Coordinators, State Developmental Disabilities Councils, State Associations for Retarded Citizens, administrators of public and private residential facilities, the National Association of Private Residential Facilities, licensing agencies, contacts listed in past reports of Developmental Disabilities Office Annual Survey of Institutions, and the 1973 National Center for Health Statistics Master Facility Inventory of Inpatient Facilities for Mentally Retarded and the 1977 update.

The initial mailing to 10,271 facilities was launched on August 19, 1977. Three mail inquiries and a telephone follow-up were conducted. Due to the large number of multiple systems (a single ownership operating more than one facility), additions were made to the mailing list throughout the survey. The survey was completed April 28, 1978 with a total of 11,351 facilities and homes. Of the total number surveyed, 5,038

Survey to p. 4

Survey from p. 3

met the definition of a Community Residential Facility.

The 1977 National Survey of Residential Facilities asked, "When did your facility accept its first mentally retarded resident at its current address?" Over one-half (2,140) of those facilities responding to this question opened between 1973 and June 30, 1977. When asked about admission requirements, over 55% stated that their minimum age for acceptance was 18 years or older, while over 72% of the facilities stated they had no maximum age to which a person could remain in their facility. Over half of the community residential facilities (2,424) stated they would accept severely or profoundly mentally retarded residents.

The survey determined for each state the number of Community Residential Facilities, the number of mentally retarded residents housed by them and the average daily reimbursement rate. For example, in Minnesota there were 176 CRF's housing 3,140 persons. The average daily reimbursement rate was \$22.82.

Respondents were also asked to classify their mentally retarded residents into age categories and level of retardation. Over 75% of the mentally retarded residents living in CRF's were over 14 years old. Approximately 65% were

classified as borderline, mildly or moderately retarded while 32% were severely or profoundly retarded. Two percent could not be classified into one of the levels of retardation by the respondents.

Community residential facilities were asked to indicate how many mentally retarded residents were admitted, readmitted, discharged or died during July 1, 1976 - June 30, 1977. Over 50% of them reported no movement into or out of their facilities during that time period. There were over 16,000 first admissions reported by CRF's during July 1, 1976 - June 30, 1977. Facilities were asked to indicate the previous placement of first admissions. Institutions and natural homes accounted for 67.4% of previous placements for first admissions during that time period.

The survey asked, "How many mentally retarded residents are male and how many are female?" The nationwide breakdown was 55.3% male and 44.7% female.

For further information on this and other reports issued by the project, write: Dr. Robert H. Bruininks, Project Director, Department of Psychoeducational Studies, College of Education, 112 Pattee Hall, 150 Pillsbury Drive S.E., University of Minnesota, Minneapolis, Minnesota 55455.



St. Paul based group home located in established neighborhood.

III. ZONING

This decade may very well be recorded in Minnesota's history as a time when landmark accomplishments toward the goal of "normalization" of developmentally disabled persons occurred. The passage of laws and a number of court orders relating to zoning of community residential facilities have been important events leading toward the accomplishment of this goal. Zoning is a legal device delegated by enabling legislation and used by a unit of local government to control or regulate the use of private land within its boundaries. As a legitimate exercise of control, zoning is a means of protecting the physical environment and the individual property owner by preventing land use conflicts and stabilizing property values. It has become the most important device in carrying out a community's comprehensive plan for residential, commercial and industrial development.

The promotion of programs and services for developmentally disabled persons in the community setting has not been an easy task because of several zoning issues and barriers. The passage of an amendment to the Minnesota zoning statute in 1975 (Minn. Stat. 462.357, Subd. 7, 8), as drafted by the Developmental Disabilities Legal Advocacy Project, overcame some of the major zoning barriers which were used to exclude group homes and other residential facilities for handicapped persons in the community. This statewide zoning statute supports the location of residential facilities within residential areas and supersedes local zoning discretions and ordinances.

Zoning to p. 5

Zoning from p. 4

State licensed facilities which have six or fewer residents are considered a permitted single family residential use of property for zoning purposes. Homes with seven to sixteen mentally retarded or physically handicapped persons are considered a permitted multi-family residential use of property for zoning purposes. Local zoning authorities may require the larger homes to have a special or conditional use permit to assure proper maintenance and operation of the home, but the conditions must not be any more restrictive than those imposed on other conditional or special uses of residential property in the same zone.

Another amendment was passed in 1975 (Minn. State 1 252.28) which gave the Commissioner of Public Welfare the responsibility of considering population, land use and other factors before granting a license. The intent of this procedure is to prevent an excessive concentration of group homes in any one area. A limitation of 300 feet between facilities is allowed unless a conditional use permit is granted. The Department of Public Welfare has drafted a proposed rule (Rule 40) which will attempt to define the term "excessive concentration," according to population density and location of existing facilities.

— ZONING — COURT CONTESTS

1. St. Louis Park

Two recent court contests illustrate just a few of the many complications that residential operators face in gaining community acceptance. In St. Louis Park, the neighbors of the Minnesota Jewish Group Homes, Inc.

sought to permanently restrain occupancy of the premises as a group home for six unrelated mentally retarded adults. (Covin, et. al. vs. Minnesota Jewish Group Homes, Inc., No. 746834 4th D. Minn., filed July 25, 1978.) They claimed that the current use and operation of the home violated the protective and restrictive covenants contained in the deed, which specified that the property could not be used for any purpose other than a single family dwelling for residential purpose. The plaintiffs contended that the thrust of the home was to provide "treatment" and therefore was not serving a residential purpose. It was also their position that the nature of the home was inherently temporary and transient and a threat to the stability of the neighborhood. Central to the argument was the question of what constituted a "family." In this case, Minn. State, i 462.357 was used by the Court to define a family dwelling, which specifies that a licensed facility for six or fewer mentally retarded or handicapped persons is considered as a permitted single family residential use of property for zoning purposes. Douglas K. Amdahl, District Court Judge, stated in his court order that, "The present use of the premises. . . does not violate any of the provisions of the restrictive covenant as interpreted by this court." He further stated, "The home serves a residential purpose and is being used as a single family dwelling. The residents therein interact and exist as a family in every respect while sharing mutual obligations and responsibilities. The 'treatment' to which plaintiffs refer is of the same quality as all parents would seek to bestow upon their children in preparing them for life's everyday challenges."

2. City of Minneapolis

Another court action over a zoning dispute involved the Northeast House, Inc. vs. the City of Minneapolis (4th D. Minn., filed March 5, 1978). In this case, the operators of this community based group care facility for mentally retarded persons had met all of the licensing requirements and the facility was certified as an intermediate care facility. Their application for a conditional use permit was approved separately by the Hearing Committee of the City Planning Commission and the Standing Committee on Community Development of the City Council. However, when appearing before the City Council itself, their application was rejected. District Judge Susanne C. Sedgewick determined that, "(the) plaintiff had met all of the standards and conditions by the ordinance for the issuance of a conditional use permit," and that the City Council's rejection of the application "made no findings of fact." "The denial of plaintiffs' application for conditional use by defendants' City Council was without sufficient basis in law or fact, and was arbitrary, capricious, unreasonable, and invalid," stated Judge Sedgewick. The City Council was therefore ordered to issue the conditional use permit.

To learn more about zoning in Minnesota, a free publication is available to the public: *City Zoning Administration; A Procedural Guide*, Office of Local and Urban Affairs, State Planning Agency, Capitol Square Building, St. Paul, MN. 55101.

IV. COMMUNITY ACCEPTANCE



---Reprinted with permission of J.M. Borgman
Cartoonist, Cincinnati Enquirer

"The mentally retarded are people. People do not live in institutions or facilities. People live in houses." With those words, Danish architect, Jens Mailing Pedersen, captured the essence of residential normalization for retarded and developmentally disabled persons. Although the professional community has wholeheartedly embraced this concept and has urged the migration of developmentally disabled individuals from 64 large institutions to community-based residential facilities, the general public's reaction has often been — "That's a fine idea, but don't put one in *my* neighborhood."

Along with finding suitable housing and funding for 54 establishing such facilities, group homes must often deal with this initial negative reaction from their prospective neighbors.

A 1975 study of community-based facilities in the Twin Cities area was done by Alan Friedlob and Thomas Anding of the Center for Urban and Regional Affairs (CURA) at the University of Minnesota. Friedlob and Anding identified four types of objections that neighbors raised when a group home (not specifically for mentally retarded persons) was proposed for their area.

The study compiled 149 arguments raised against group homes and found that the largest number, 39%, had to do with concerns about safety, parking and property maintenance. 66 neighborhood residents were also worried about adequate programming and supervision for the home's residents. Over concentration of such facilities in a neighborhood was also raised. That is, allowing one such facility to be established might lead to a flood of similar group homes. Ten percent of the arguments against the location of group homes were based on the fear that if such homes were allowed, the property values in the neighborhood would decrease.

These fears and misconceptions plague prospective group homes. P Advocacy Project, affirmed that "the biggest cause of neighborhood opposition is fear that they'll harm kids and the neighborhood."

Outreach Group Homes, Inc. encountered opposition when trying to establish a group home for the mentally retarded in a Minneapolis suburb. "One hundred percent of the neighborhood kept the home out," said Neil Tift, a member of the City Council to testify in behalf of the home. "It wasn't real organized," Tift said,

"The biggest concern was that the children would be different so their children weren't afraid of them. There were also parking problems," Tift said.

"A lot of people thought mentally retarded people were dangerous, but a lot of people also tied it to property values. It's the opposite," Tift said. "Mentally retarded people are the victims of any type of sexual crime. These were not people from institutional settings, these were not people from institutional families, from residences similar to the ones in the neighborhood."

"With property values, it's usually a problem. Because we're so highly regulated, we always keep the grass cut. We can't even have piles of leaves! We're so highly regulated."

"As far as parking goes, that's a problem. We have cars, and the corporation owns cars. The house parents have one; so, at the end of the day, there are a lot of cars."

A study done in Green Bay, Wisconsin, found that a change in property values affected the community. Another study, this time in Minneapolis, found that a group home would alter the character of the neighborhood.



Resident Mike Tift
in front of

articulated in 1975, have continued to Suita, an attorney with the DD Legal Services about retarded persons are the position to group homes."

retarded people," Suita said. "They are like that."

entered a similar situation while trying to help mentally retarded adults in Richfield, a city where sixty people had signed a petition to force a referendum. The case was called before the Richfield Citizens' Outreach Group Home Corp. "It was not the fear was real."

mentally retarded people were sexually abused. Other concerns included property damage and fire.

mentally retarded was the same as mentally ill, said Tift. "My reaction was, if anything, that mentally retarded people are more apt to be victims than the perpetrators of one. And the reason — they came from their own families is one."

just the opposite also," Tift said. "Our homes are open constantly to unannounced visitors and house in spotless order. We are often the cleanest and safest because

Very few residents have their own cars, one for each home. Sometimes the maximum there are two cars," he said.

son, found that there was no significant difference when a group home was established in a neighborhood. In San Francisco, refuted the idea of a parking or child safety situation in a



"Our House" staffer Melody Newcomb with Beverly Hovda

Despite these assurances to the contrary, neighborhood residents still remain skeptical of group homes in their areas. The Minnesota State Legislature spoke to this feeling in 1975 when it passed Section 463.357 of the State Zoning Law. This provision states that group homes with six or fewer residents shall be considered single family dwellings for zoning purposes, and larger homes (from 7 to 16 residents) may be required to get special or conditional use permits, but not under any stricter regulations than another applicant.

"It's helped tremendously," said Tift, who has been with Outreach Group Homes, Inc. while it began four more homes. "The only thing I wish is that because rates are so expensive, the number would be raised to eight."

Although small homes do not need to inform the neighbors about their impending entrance into the community, there is some debate as to whether or not they should anyway. Toni Lippert, DD Planner for the Metro area, advises ample notification of the community. "But Tift disagrees.

"It is probably better not to tell anybody," he said. "Number one, with the normalization principle, the mentally retarded have the same rights and responsibilities as other people. And you or I don't send letters out when we move into a community. Also, if you've been there a year and a half and then somebody finds out you're there, you get away from the stigma and you can blend in. Many times telling people ahead of times causes more harm than good."

For those larger group homes that may need special-or conditional-use permits, and would therefore have to participate in a public hearing, Tift recommends a different approach.

"Have a neighborhood meeting," Tift said. "Have some of the residents and some of the staff there and keep it small. Invite individuals by name. Also, invite other people in the field, for moral support if nothing else. It's healthy to have parents of mentally retarded people, not necessarily the residents, there too so when someone says, "pervert" a mother can really put 'em down."

Lippert suggested that prospective applicants for special-and conditional-use permits approach the planning commissions and councils in the neighborhood.



son (our house)
group home

V. Family Subsidy - - - D P W

Preventing inappropriate placements is a vital part of a comprehensive deinstitutionalization plan, and the Minnesota Department of Public Welfare (DPW) has attempted to address this aspect with its Family Subsidy Program.

The pilot program, funded by the 1975 State Legislature, currently serves 50 families with 52 children. Funding for the program is \$250,000 with each family receiving a maximum per family subsidy of \$250 per month. Set up as a pilot project, funds will end June, 1979.

"We support a choice for the family," Boswell said. "If they want to place the child, they have the resources to do that. If they want to keep the child, we give them the resources to do that also. One family told us that the program had helped delay their decision to place their child."

The only one of its kind in the nation, DPW's family subsidy works on a direct-cash basis. If the child is under 18 and a social worker certifies that the child would be eligible for placement in an institution or a community-

providing money for services that school districts or insurance policies do not provide.

Seventy families have taken advantage of the program since its creation, but never more than 50 at one time. The turnover was due to the death of a child, a move out of the state by a family, a child becoming 18 or being placed in an institution.

Twenty-five children have multiple handicaps and five were diagnosed as only mentally retarded. Nine of the children have special learning disabilities

*"--- what has developed --- is the time
it gives parents to make a decision ---"*

The program was originally designed to assist parents in caring for their mentally retarded children at home, who had previously been placed in institutions or nursing homes; however, the program did not develop as planned. Only one of the 70 families who had taken part in the program took their child out of an institution. Instead, what has developed as the program's biggest advantage is the time it gives parents to make a decision on whether or not to institutionalize their child.

"It was always billed as a pilot program so families that had gone through the trauma of placing their child didn't want to run the risk of taking the child back for a year," Christine Boswell, DPW project coordinator, stated. "It would have been just too much for them. I don't know if it would have been different if it had been a long-term, permanent program or not."

based facility, the family is eligible for the program. There are no income limits and most of the families on the program have incomes between \$10,000 and \$15,000. Twenty-five families currently are on the waiting list and an additional 87 have expressed interest in the program and would be qualified.

"We do require an annual behavioral assessment of the child, and every six months the parents fill out a prorated plan of their expenses; they have to keep track of what they actually spend," Boswell said.

Parents of the program listed special equipment as their first priority and 35% said they wouldn't have been able to get such equipment had they not been on the program. Babysitting and special therapy were other top considerations, along with respite care and special medical expenses. The program specifically is designed to be supplemental,

in addition to their mental retardation, while eight also have autism and three have epilepsy.

The Department of Public Welfare has recently completed an evaluation of the program and has prepared a report for the legislature regarding the program's operation beyond June, 1979. The Department has recommended making the program permanent and expanding it to more than 50 families.

These and other recommendations are contained in a summary of the Evaluation Report for the MR - Family Subsidy Program available from the Mental Retardation Program Division, Mental Health Bureau, Minnesota Department of Public Welfare, Centennial Building, St. Paul, Minnesota 55155 (612/296-4977).

VI. INDEPENDENT LIVING

Learning to live on one's own is a tough and sometimes frightening experience, particularly for a person with a developmental disability. But several services for easing the transition from state institutions or group homes to independent apartment living are available in Minnesota for persons who are mentally retarded.

CIP

One of the pioneers in this area was Community Involvement Program (CIP), a seven-year-old program in the heart of Minneapolis. CIP has a building with 17 one-bedroom apartments for 34 clients. In these apartments residents work on six basic skill areas: food preparation, money management, apartment maintenance, grooming, social skills and medical concerns. Residents must have a daytime activity; so some attend school, sheltered workshops or are competitively employed. Five counselors, with an average caseload of seven clients, assist the individuals with basic skills and coordinate special workshops on topics such as assertiveness training, sexuality and cooking. CIP does not have a recreational program, although counselors encourage clients to make use of their leisure time. Two live-in counselors are available 24 hours a day.

The clients, whose average age is between 20 and 25, come to CIP from many sources, the most common being their parents' home. A few clients come from state institutions, but other residential facilities do refer some residents. The program has no specific time frame, and though it is not intended to be a permanent arrangement, it is funded for ten

long-term clients. Most graduate to their own private apartments after one and a half years.

HOMES INC.

Homes, Inc. operates a program very similar to CIP. Two large apartment buildings house 20 clients along with other tenants. Homes, Inc. serves "anyone who needs help," said Georgeann Bianchi. That includes persons who are mentally retarded, mentally ill, blind, or who have other disabilities. The program is five years old.

"Our philosophy is to teach our residents responsibility for themselves instead of telling them what to do," Bianchi said. Clients must participate in a day program, whether school or work, to be involved with Homes, Inc. The prospective client spends at least a month in an evaluation apartment where the staff determines what skills the person needs to learn.

After the evaluation period, the resident moves into an apartment with two or three roommates. Skills such as cooking, grocery shopping, cleaning and money management are improved. When the person has developed some confidence and skill, the client moves to the apartment building next door where staff supervision is reduced.

NEKTON, INC.

Instead of training clients within an apartment complex, Nekton, Inc. attempts to achieve that same goal in a slightly different way. Nekton assists clients in finding an apartment in the community and then aids the individual in learning living skills.

A Private agency which operates on a purchase-of-service contract with Ramsey County, Nekton's "Project Self-Dependence" began five years ago, according to project coordinator, Dave Borner. The program



CIP residents Ann Parkin and Pam Cahill assist in pizza preparation

Independent Living

from p. 9

currently is serving 30 clients with four regular staff and one person on-call for emergencies.

"We're not meant to be a long-term program," Borner said, "but some persons will need some supervision in areas they will never master.

Locating apartments within the community that persons with developmental disabilities can afford is more difficult than overcoming any social stigma," Borner said.

"If they (retarded clients) have money, they (landlords) will take them," Borner said. "But most of our clients have low paying jobs and landlords are leery of renting to someone with an unstable income."

The program places persons close to one another occasionally, but Borner said he prefers not "to load up one area. There's support there, but it gets to be a kind of ghettoizing also." Many of the clients are interested in having roommates, which is another problem situation if no other client in the program is available.

"They usually end up with strangers and that just doesn't work out," Borner said. "They don't want to live alone, but they don't have anyone to live with."

A still more puzzling quandry is the rent-assistance program, Section 8 administered by the St. Paul Public Housing Program. Persons pay only 25 percent of their income for rent in certified apartments, but most of the available certified apartments are studios; so many of Nekton's clients end up living alone.

To counteract this isolation, Nekton "plugs into anything in the community," and encourages its clients to participate in the community's social and recreational activities.

VI. INDEPENDENCE FOR IMPAIRED INDIVIDUALS



Triple I live-in aids Phil and Mary Swanson (top center) w/mates (L-R) Kipka, Nielson, Frahm and France - May, 1975

Six years ago, a new idea about independent living for handicapped adults dropped like a rock into the relatively calm waters of popular philosophies concerning nursing home care for handicapped individuals.

Charlie Frahm wanted out of a nursing home in 1972. He belonged to Triple I, Independence for Impaired Individuals, Inc., and, as he put it, "kept heckling them." Triple I began in 1972 as Handi-Registration, an organization primarily devoted to helping handicapped persons vote. It expanded its focus to finding alternative housing for handicapped persons and now consists of twenty-five to thirty members. Its newsletter reaches another one hundred interested individuals.

The ripples that Frahm's idea created spread. Although he and his three apartment-mates have been comfortably settled for three years in their apartment at 1528 Iglehart, a cozy neighborhood tucked just out of hearing from Snelling Avenue in St. Paul,

Frahm and Triple I have already begun work on a second home.

The four men at Iglehart, all with differing degrees of cerebral palsy, live in the remodeled bottom floor of what was originally a fourplex. The top two apartments are rented to able-bodied persons whose rent payments help pay the expenses of maintaining the house, which is owned by the Triple I Corporation.

The bottom two apartments in the fourplex were renovated with volunteer help into one ten-room apartment with special adaptations for two of the residents who use wheelchairs. Volunteers built ramps into the building, widened doorways and set up other adaptations such as bath facilities to make the house accessible.

But the building itself was not the only thing that needed alterations in order for the residents to make a satisfactory adjustment from sheltered living, either in a nursing home or in their parents' home, to the independence of Iglehart. "We had a lot of trouble at

VII. RESPITE

first with the different personalities," Frahm said. "It took time." More troublesome was the search for acceptable aides. The men employ two full-time aides who live-in and two part-time aides who relieve the live-in aides. The workers are responsible for preparing meals, caring for the residents' personal needs, housekeeping and furnishing transportation for the men. After experimenting with different aides for nearly a year, Frahm, who is the resident director of the apartment, settled on a married couple who have been with the house ever since. "I finally got smart and started hiring married couples," Frahm said. "They know they have to work and there isn't any bickering among them."

Despite initial problems with government funding and finding appropriate attendant help, the four men have grown to enjoy their new living arrangement, especially its location.

"I like that the most," Frahm said. "We're right next to shopping areas. The only thing I would like to see is a moviehouse nearby so we could get there on our electric wheelchairs."

The arrangement at Iglehart has turned out not only to be of enormous advantage to the residents in terms of independence — it has proven to be cost saving to the community as well. While costs in long-term care facilities run from \$30 to \$60 per day, the amount paid by an Iglehart resident is much less. Residents pay a monthly \$150 room and board charge, either from personal funds or from social security. This money, along with a county contract of \$16.35 per diem for attendant care, covers their expenses.

An important support service, respite care, is appearing throughout Minnesota, in a number of different forms.

Respite care is short-term temporary care of a person with a developmental disability so the person's family can take a vacation or handle a family crisis.

Respite care services range from the program at Fergus Falls State Hospital to the in-home service which Brown County provided. Other respite care arrangements include the foster care program in Ramsey County and the program at the Home for Creative Living in Windom.

The Mental Retardation Unit at Fergus Falls State Hospital began offering respite care in 1970-71, but the program was not specifically defined until 1975. In the past year, the hospital has had 12 respite clients for an average stay of 10 days. The maximum length of stay in the facility is 90 days. The hospital does not set aside a certain number of beds for respite care, nor has it ever turned an eligible client away.

Medical problems of other members of the developmentally disabled person's family are most often the reason for respite care, although often families will use respite care so that other family members may take a vacation.

Behavioral problems of the developmentally disabled person are another common reason for families to make use of this service. Although the hospital does not "advertise" its program in an attempt to increase the use of it, officials at the hospital are puzzled as to why it is not used more frequently. "It's used so little, it's hard to make generalizations about it," Dave Aanes said. "Geography has something to do with it. It is definitely an advan-

tage to have respite in the counties and if each county had a bed or two, they probably would be utilized more."

All of the state facilities which have units for persons who are mentally retarded, accept clients for respite care, according to Shirley Bengsten, Department of Public Welfare.

With the same purpose but using a slightly different approach, the Home for Creative Living in Windom offers its facility for respite care for multiply handicapped persons up to age 25. The person with the disability may stay for up to two weeks (some exceptions are made).

Opening in September, 1977, the Home for Creative Living has had six different clients use its one respite bed most often for family vacations, but also during times of family crisis, such as a death in the family. The respite service is not being used as frequently as the home's directors would like, however. Only fifteen days of respite had been provided from September, 1977 to May, 1978. The home plans to incorporate the respite option into its programming for another year, but unless used more extensively, the respite bed may have to be converted into a regular placement.

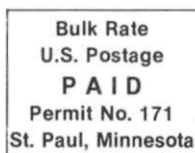
Ramsey County has had a different problem with their respite care program. The county began to develop a system of temporary foster home placements for respite care two years ago. The program can accommodate 12 clients now, but Project Coordinator, Milt Conrath, said that number is too small. "Three or four times as many people could use it if it were available," Conrath said. "There is no question there's a need for it."

General Funds for the program come from the Child Welfare Relief Program, the Cost of Care Legislative Appropriation, or when respite care occurs in an ICF-MR residential facility, medical assistance funds may be used. Funds for doubling the program's size were requested and received from the Ramsey County Welfare Board this fall.

Brown County developed a system of respite care which operated during the summer of 1978 in which a trained CETA employee provided care in the developmentally disabled person's home. After conducting a survey of the needs of the population in Brown County, the Brown County Respite Care Committee learned that both long-term respite care for vacations, serious illnesses, etc. and short-term for grocery shopping or evenings out were needs of the developmentally disabled population. The CETA employee provided long-term care primarily for family vacations. The respite period ranged from two hours to 10 days, although the program planners encouraged families to utilize weekends. Efforts are underway to find resources to reestablish the program in the near future.

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VIII. CAMBRIDGE ENVIRONMENT CHANGES

Cambridge State Hospital will hire new staff, prepare residents for community living, remodel, and make other improvements under terms of a December, 1977 agreement between the State of Minnesota and representatives of institution residents.

The settlement resolved the Cambridge State Hospital portion of *Welsch v. Dirkswager*, a lawsuit brought on behalf of mentally retarded persons committed to Cambridge and four other Minnesota state hospitals.

U.S. District Court Judge Earl Larson first ruled in 1974 that conditions at Cambridge violated residents' constitutional rights to adequate care and treatment, provided in the "least restrictive environment." Larson ordered major improvements in programs at Cambridge, which have not been carried out completely due to insufficient legislative appropriations.

Terms of the December, 1977 settlement incorporate standards of earlier court orders and set some new requirements for Cambridge State Hospital. The consent decree also ordered the state Commissioner of Welfare to re-

quest a legislative appropriation to bring staffing ratios in other state hospitals up to what is agreed upon for Cambridge.

Under the agreement, 202 employees must be added to the Cambridge staff, for a total of 822.

Cambridge must establish an effective system to evaluate the use of major tranquilizers with residents, subject to expert review.

As in the original court order, the consent decree restricts new admissions at Cambridge to severely retarded persons or those who also have behavior problems, and for whom community placements are unavailable in the community.

The legislature has thus far failed to appropriate funds sufficient to bring other state institutions for mentally retarded persons up to the standards contained in the Cambridge consent decree. Unless funds are appropriated, another trial in the case will probably occur in 1979 concerning conditions at state hospitals in Faribault, Brainerd, Fergus Falls, and Moose Lake.

Central Minnesota Legal Services director Luther Granquist told the State DD Council in January, 1979 that his clients are generally satisfied with terms of the Cambridge settlement. Legal Services is counsel for the residents.

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DD Newsletter welcomes reactions from its readers. (612/296-4018)