NEW HOUSING OPTIONS

FOR PEOPLE WITH MENTAL RETARDATION

OR RELATED CONDITIONS:

A GUIDE BOOK

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PREFACE

The topic of this guide book, consumer-owned housing, is a relatively new area of endeavor in human services. Little has been written about it, and the information that exists is fragmented. This book attempts to organize and summarize some of the current information on the topic.

This guide book is directed primarily to parents and has been written with their needs and concerns in mind. Professionals in the fields of law, real estate, and human services may also find it useful as an introduction. For those interested in learning more about the concept, this book provides basic information. For those who have made the decision to make alternative housing arrangements for their sons and daughters, this book is intended as a guide to the appropriate resources and sources of additional information.

The information presented has been gathered from parents and professionals who have been involved in developing these housing options both within and outside the state. Other information has been gathered from a group of volunteers who are professionally involved in law, human service provision, real estate, case management and advocacy. The information is not exhaustive; the reader is encouraged to build his/her own base of information, using this book as a starting point.

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NEW HOUSING OPTIONS FOR PEOPLE WITH MENTAL RETARDATION OR RELATED CONDITIONS: A GUIDE BOOK

INTRODUCTION

In the past two decades, people with mental retardation or related conditions have made great strides in fuller participation in our society. They have been making a place for themselves in the community, after being largely confined to large, isolated institutions. This confinement resulted in part from funding policies which tied the receipt of services to residence in an institutional setting.

Lately, through the ardent efforts of parents and advocates, changes have been made in funding policy which allow persons with mental retardation or related conditions to receive services in the community in smaller, more natural settings. The recently implemented Title XIX Home and Community Based Waiver program now allows states to purchase community services with a portion of their Medicaid funds, which formerly all went to institutional-based service. In Minnesota, the Semi-Independent Living Skills (SILS) program is directed toward enabling persons with mental retardation and related conditions to leave more restrictive settings and receive services in their own apartments or homes, in familial homes or in small group settings. Both the waiver and SILS represent attempts to break the traditional bond between services and place of residence which has kept many persons with mental retardation or related conditions from living more meaningful and productive lives in the community.

The evolution of funding policy has greatly broadened the range of housing options available to people who are mentally retarded or have related con-

ditions. In many places in the nation, "creative" packaging of program services and housing funding has made the dream of typical community living a reality. Parents, case managers and others have combined existing services and funding strategies in non-traditional ways to create stable living situations in settings more closely resembling those of other people, where the resident receives an effective complement of services individualized to his or her needs.

The potential range of housing ownership options available to persons who are mentally retarded or have related conditions is as wide as the range available to anyone else. It includes single-family houses, duplexes, condominiums and housing cooperatives. In some cases, individuals with mental retardation live with others with mental retardation; in others, they live in mixed, integrated households. Some live alone, others receive supervision from licensed foster care providers, mental retardation professionals or other qualified persons.

Some advantages experienced by those who now live in housing arranged for through these non-traditional arrangements include:

Least-restrictive living environment: Home ownership options allow persons with mental retardation and their parents/guardian greater choice in selecting the living arrangement which is most appropriate to their needs, yet least restrictive to increased self-reliance.

Permanency: The risk of being "placed" by an agency, or otherwise forced to change residences, is reduced. Those who live in their own homes have greater freedom to choose their service providers, unlike persons living in residences owned by service providers.

Integration: Persons with mental retardation and related conditions who control their own housing have greater choice in whom they live with and near.

Location: People who purchase their own homes can choose where they live, and not have their service provider choose

for them. They can live where it is most convenient to their jobs, families, friends, services, etc.

- Freedom: People who live in homes they own can make their own rules. The basic privacy needs shared by all human beings are more easily met in one's own home.

- Normalization: Home ownership is a desired objective for many Americans. Home ownership for persons with mental retardation or related conditions extends the principal of normalization from the social environment to the economic environment.

- Equity: While some argue that real estate has lost some of its appeal as an investment in recent years, a careful purchase and long-term monitoring can still yield an equity build up, increasing the owner's financial resources.

Philosophy.

The consumer-owned housing movement in general, and this guidebook in particular, have at their roots a particular philosophy that is shared by many persons with mental retardation or related conditions, parents, advocates and professionals. This philosophy has been well-articulated by Syracuse University's Center on Human Policy in the following excerpt:

> When we examine what we have learned from the field and try to identify the crucial elements in community services for people with the most severe disabilities, the only "model" which makes any sense is one which rejects the logic of adopting a model. The only approach that really seems to work is one which truly focuses on the individual and not on the facility or a predetermined model. For want of a better term, we are calling this a nonfacility-based approach to services, simply because we consistently found that the best community services are trying to get out of the real estate business and concentrate their energies on supporting individuals.
>
> Life in the community for people with disabilities is often built around places designed especially for them, around group homes and other residences, around sheltered workshops and day activity centers. Throughout this country, we often build the places, design the programs, and then try to fit the people into the services. We then help people to overcome the barriers imposed by the segregated settings.
>
> At more and more places throughout the country, people are using a different approach to supporting people with disabi-

lities in the community. This approach is designed around people, not around buildings or places. In a nonfacility-based approach, you start first with the person, their strengths, and their needs. Then you look, with the person and/or their family, at where and with whom they would like to live. Then you build in the other supports that the person with a disability and/or their family may need. These include a job, education, or medical and behavioral supports. Instead of fitting people into programs, the supports are developed around the needs of the individuals wherever they may live or work. Instead of designing segregated places and then helping people to integrate into the community, we start with the person in typical homes and regular workplaces and build in the supports that they need.

This type of approach does not assume that one "prepares" to live in the community; you start in the community and build in the supports. One does not get ready for living one's life; one simply lives it. As the needs of the person change, the amount and type of supports they receive change. The person does not need to move to a new setting to obtain more supports; the supports are added to their home. A person does not need to move to a new place because they learned to do more things; the support in their current home can be adjusted. In a nonfacility-based approach to services, we move our funds from supporting buildings to supporting the services that people need, wherever they may need them.

Of course, people with severe disabilities have some "special" needs. For example, a family with a child who is labeled "medically fragile," or an adult who presents a lot of challenging behaviors, need some additional supports. But, first and foremost, people with disabilities have the same needs as other people: for a home, for warm relationships with other people, and for a chance to give as well as receive. Often, in our attempts to meet the "special" needs of people, we have forgotten their basic human needs.

So, the nonfacility-based approach calls for looking first at the basic demands of life in the community, and then adding in the supports. We need to stop building special places for people with disabilities, and start instead with families and homes, existing industries and businesses, and with the recreational, educational, and other services we all use.

J. Racino and J. Knoll, "Life in the Community: Developing Non-facility Based Services," from TASH Newsletter, September 1986, page 6.

How to Use This Guide Book

The purpose of this guide book is to outline some of the options available to those interested in designing a less restrictive living environment for someone who has mental retardation or a related condition. The major considerations are outlined, as well as some of the program and funding options. Examples of actual cases are presented to illustrate how these packages can be created.

At the time of this writing, the concept of consumer-owned housing is relatively new in the field of mental retardation, and has only recently begun to be explored and developed in the state of Minnesota. In other states and in Canada, consumer-owned housing is more common and new ground is broken daily. The information contained in this guide book is an overview of the current knowledge available, but the reader is encouraged to keep abreast of new developments. For this reason, and in recognition of the fact that each person's needs are unique, this guide book has not been designed as a "cookbook" with explicit models and instructions. Instead, it is hoped that the reader will be inspired to do some creative thinking in designing the most effective program for the individual involved.

CREATING A PLAN

The success of consumer-owned housing arrangements rests heavily on good planning. There is no substitute for it. Parents who wish to develop these arrangements should identify and consider all of the options available, using this guide book as a start. Further identification of options should be made by consulting local experts, officials, and agencies in the areas concerned. Parents are encouraged to work closely with their case managers in developing plans. Approval of the county is crucial to receiving many of the supportive services and programs necessary for adults with mental retardation to live in their own homes.

Because the concept is new, parents should not expect everyone whom they consult, including their case manager, to be knowledgeable, or even supportive of consumer-owned housing. Parents must have a clear vision of what they want and be prepared to educate the experts to help them make their vision a reality.

Elements of an Effective Plan

Effective plans for persons with mental retardation or related conditions to live successfully in their own homes contain the following elements:

> The plan is built solely around the needs and desires of the person(s) who will reside in the home. All supports needed are provided for, including program services and those related to the upkeep of a residence. The person who will benefit from the plan is involved in its development to the greatest extent possible, and his/her choices of location, structure, housemates (if any) are honored.
>
> The plan is based on a realistic assessment of current and potential resources available to the person, including income, support systems (formal and informal) and program services and their funding streams.

- The plan has been developed with the involvement of experts in all of the areas encompassed by the plan, including mental retardation professionals, real estate brokers, lawyers, parents, siblings, other relatives, friends and county case managers.

- The elements of the plan are coordinated: the programmatic aspects are integrated and the effects of resources on program eligibility are taken into account.

- The plan is flexible, to meet the changing needs of the resident. In addition to service provision and housing payments, day-to-day living expenses and responsibilities are also planned for, such as payment of bills, tax liability, insurance coverage, building upkeep, unexpected losses, etc.

- The plan has long-term durability: crystal balls aren't available, but attempts should be made to foresee the basic needs of the person for the remainder of his/her life.

- Opportunities for community integration are provided. Placing persons with mental retardation outside the institutional walls does not automatically guarantee opportunities for contacts with non-handicapped peers. In some communities, large scale housing developments designed solely for persons with mental retardation function as ghettos, confining people as effectively as walls. In planning for consumer-owned housing arrangements, efforts should be made to assure integration opportunities through such elements as location, choice of housemates and neighbors and access to integrated work, recreational and other programs.

Those who plan consumer-owned housing arrangements are likely to find that one or more of the components necessary to achieve the desired results are unavailable, or do not mesh with the other components of the plan. It is in these instances where creativity, ingenuity and persistence are called for. In many situations, the "system" isn't ready to accommodate the need, whether it is an affordable mortgage, an appropriate service program, or ineligibility for a funding stream. Achieving systems change is most effectively done through group effort. Parents developing plans are

encouraged to form networks with parents with similar interests, and work with established advocacy groups, such as the Association for Retarded Citizens, in changing the system to meet the needs of their sons and daughters.

As emphasized above, the residential and program service needs of persons with mental retardation or related conditions vary widely. There is no one approach which could or should be employed for all individuals. However, there are some considerations common to all situations which need to be addressed in planning strategies. Here are some of the basic considerations, with the major options discussed.

Who should own the home?

The choice of legal owner(s) of the dwelling may have considerable implications for the person with mental retardation or a related condition's eligibility for needed funding. Careful consideration should be given in selecting the appropriate party to purchase and own the dwelling after reviewing the eligibility requirements of the programs and services which the resident will use to support him/herself.

a. Tenant-owned.

Advantages: *Normalized lifestyle *Pride of ownership *Control over living environment *Equity

Disadvantages: *Possible difficulty in coming up with down-payment.

*Potential for becoming overwhelmed with responsibilities of home ownership.

b. Parent-owned.

Advantages: *Promotes parents taking a more active role in the care of their son or daughter with mental retardation .

*Parents have greater potential for making a down-payment.

*The new tax law may provide tax credits to parents who invest in real estate to benefit their sons or daughters with mental retardation.

Disadvantages: *Potential tax liability in the future.

*Less control by the consumer.

*Extra work for the parents.

Trust-owned. (Ownership is assigned to a "living trust," set up by the parents.)

Advantages: *Parents can set aside and protect a portion of their assets for the benefit of their son or daughter who has mental retardation or a related condition, while maintaining their eligibility for governmental programs.

Disadvantages: *Laws affecting trusts may change over time.

*Legal expenses of setting up and maintaining the trust.

Corporation-owned (Parents and others, including other parents, set up a corporation to purchase, own and maintain the housing.)

Advantages: *Potentially the most durable instrument.

*The owners can limit their liability.

Disadvantages: *Loss of parent control to board of directors.

*Red tape and legal expenses of setting up the corporation-Partnerships (Parents combine resources with other parents to purchase the dwelling.)

Advantages: *Combined resources yield greater purchasing power.

Disadvantages: *Upon the exit of a partner, the remaining partners may be left with a substantially increased financial burden.

Shared equity (the tenant makes purchase with another party [e.g., parent, friend, housemate, investor], and gradually buys out the other party over time.)

Advantages: *Combined resources yields greater purchasing power.

*Allows full responsibility of ownership to be achieved gradually.

Disadvantages: *Control of property by resident is somewhat diminished .

Which type of physical structure of the housing will best meet the individual's needs?

Consideration of physical structure is largely a matter of preference and availability of financial resources. For persons who are mentally retarded though, other factors are also important, such as opportunities for integration with non-handicapped persons, proximity to services and accessibility for those who also have physical disabilities.

a. Housing Cooperatives: A housing cooperative is a group of people organized for the purpose of owning, building, or rehabilitating housing for its members. The group legally incorporates itself and all property is owned by the coop, as provided for in its articles of incorporation and bylaws. A member (shareholder) does not own his/her own dwelling unit; he/she owns a membership certificate which entitles him/her to occupy a dwelling unit and to have a vote in the operation of the corporation. All decisions affecting the coop are made in a democratic manner. (For further information, see Appendix A.)

Advantages:

*Opportunity for ownership with little money down.

*Opportunities for social interaction and integration can be provided by reserving one portion of shares to be sold only to persons with mental retardation or related conditions and another portion to be sold only to non-disabled persons.

*Costs of upkeep are shared.

Disadvantages:

*Less individual control over property.

*Tax advantage of home ownership is lost, since a coop share is classified for tax purposes as personal property, rather than real property. (However, for Medical Assistance eligibility purposes, a share of a co-op in which an applicant lives would probably be considered exempt personal property.)

*A shareholder can be "voted out" of his/her co-op by his/her fellow shareholders.

*A certain amount of privacy is foregone.

*In "limited equity" coops (see Appendix A.) members do not realize benefits from any increase in the property's value.

b. Condominiums. Condominiums are similar to housing coops in that several households occupy one property, and each dweller owns equity in the property. They differ in that each housing unit is owned solely by its occupant (or his/her landlord), and units can be bought and sold with fewer restrictions. The land under condominiums is generally owned by someone other than the residents, whereas most coops are on land owned by the shareholders. Upkeep on condominiums' building exteriors and grounds is paid for and arranged by an organization of the developments' individual owners.

Advantages:

*Owners have more individual control over their dwellings than do coop members.

^Opportunities for social integration are increased through closer proximity of neighbors and participation in the owner's association.

*Purchase can be made with less money down than most single family dwellings.

Disadvantages:

*Opportunities for privacy are lessened, compared to single family dwellings.

*Owner faces greater responsibility for interior upkeep, compared to coops.

*"Blanket mortgages" are used in financing condominiums: if a lien is brought against the property, all owners in the development share the burden.

Single-family dwellings.

Advantages:

*Wide range of locations, styles and structures is available.

*Privacy is maximized.

Disadvantages:

*Greater responsibility for upkeep.

*Easier to become socially isolated.

*Higher purchase and upkeep costs.

d. Duplexes and other multiple dwellings.

Advantages: *Other unit in structure can be rented to a person responsible for providing support to the person with mental retardation or a related condition.

*Rental income from other units will offset some costs of ownership.

Disadvantages: *Responsibility for upkeep, both owner's and other tenants' units, must be provided for.

*Relatively high costs of purchase and upkeep.

*Usually, all units must be occupied to make mortgage payments.

Who shall live in the dwelling?

Persons who have mental retardation or related conditions are living successfully in their own homes alone, with non-handicapped housemates, with handicapped housemates, and with paid persons who provide various levels of support. Personal preference is again an important factor in making a choice, but many persons who have mental retardation or related conditions have special needs which must be met with live—in assistance. Such assistance is being provided currently to several Minnesotans in a variety of ways. Some examples include:

° A man handicapped by a closed-head injury shares a house with a non-handicapped man. Each has his own room, while the rest of the house is shared equally. The non-handicapped man assists his housemate with daily living skills, and their relationship could be described as friendly.

° Four men share a two story house. Two men having mental retardation and mental illness share the first floor, while the second floor is shared by a man with mental retardation and a non-handicapped man. The non-handicapped man provides the support needed by his housemates by being in the house overnight, and occasional other times.

° A young women with mental retardation has gotten the assistance she needs by moving in an apartment with two non-handicapped

women. The woman with mental retardation has developed a peer relationship with her roommates, and has been included in family activities as well as activities with other friends.

- Two women who have been friends for many years recently purchased a condominum together. One woman has physical disabilities, and the other woman has epilepsy. They provide each other with the assistance they need to live independently.

How can integration be achieved?

Integration is an important consideration in the selection of housemates, as well as in the selection of the location of the residence. John O'Brien, in his monograph "The Principle of Normalization: A Foundation for Effective Services" (Georgia Advocacy Office: Atlanta, 1980), outlines ways programs can be structured for persons with mental retardation to overcome physical and social isolation. He states that people should be served "in a place which makes it easy for people to get to and use a variety of valued resources (and) to maintain contact with his/her family and home community."

Furthermore, O'Brien asserts that full community membership requires that people be active participants in a variety of individual and group relationships. Persons whose capacity for communication and mobility is limited, he adds, can and need to be part of a network of relationships with valued people. Some guidelines which promote full community membership include:

- Program time should allow opportunities for individual and small group participation in community events and activities such as entertainment, religious services, etc.
- People should not spend their days in the same area they calL home: except when individual needs dictate otherwise, work or school should take place in community settings.
- People should learn to use generic health care and other services. The minimum amount of services consistent with individual needs should be provided within the walls of the home.

° The program makes some social participation a reality, regardless of the person's current ability. Social participation is not an all or none possibility, available only to those who "earn" it.

How will the housing be financed?

For some housing choices, this is not an issue: buying into an existing housing cooperative doesn't require getting a mortgage. The prospective resident pays an initial fee to join the coop, then makes monthly payments as long as he/she is a member. With other ownership alternatives though, securing a mortgage is almost a certainty. Good sources of information on financing options are mortgage bankers, licensed real estate brokers and attorneys who specialize in real estate.

Conventional mortgages available through a local lender are probably the first option to consider. A bank's willingness to loan funds if, of course, dependent on its internal lending policies. It's important to note, however, that certain external standards may also have a definite impact on the mortgages a bank will approve. These external standards come from two basic sources:

- national programs that insure loans against default—the Federal Housing Administration (FHA) program is a good example;

- national programs that actually purchase mortgage from lenders (so the banks can loan out these recycled funds again), then pool these mortgages for sale as a type of investment security.

If a lender participates in either or both these types of programs, mortgage lending activities may be predominantly tailored to serve applicants who readily meet these external criteria.

A second funding option to consider are resources available through state and local public agencies, such as the Minnesota Housing Finance Agency and local housing and redevelopment authorities. These public agencies secure funding for various types of housing programs by selling bonds in the national investment market. The standards of what investors will conventionally buy in this market sets certain limits on the funds these agencies can raise, which ultimately affects the types of mortgages they can make available.

Since these agencies are, in effect, a type of bank, their internal lending policies also have an impact on the mortgages they will accept. Additionally, the recent tax reform, coupled with Congressional and IRS actions in the last few years, have greatly restricted the total amount of public bonds that can be raised within each state, and greatly restricted the borrowers and properties that may qualify for a mortgage. All of these factors definitely limit the ready availability of these funds for innovative housing options.

Where will the down payment come from?

Many persons with mental retardation do not have the personal financial resources necessary to make a down payment to obtain their own housing. Some may have parents or other family members who are able to provide the funds. Parents who do not have the cash on hand whose own homes are paid for may wish to consider a home equity loan as a means of raising the down payment. A home equity loan is secured through the use of the homeowner's house as collateral.

Another source of downpayment is gifts from relatives or other benefactors

such as the family's church or synagogue. Groups of parents in the same community interested in securing housing for their sons and daughters with mental retardation or related conditions may wish to consider approaching churches, service clubs and benevolent and charitable organizations with the idea of creating funding pools to make downpayments available. Such pools could also be created by grants from corporate and community foundations. Local advocacy organizations can provide guidance and assistance in approaching foundations.

How will day-to-day living expenses be met?

A dependable source of income to meet mortgage, upkeep, co-op dues, food, clothing, and other such living expenses is needed to assure the stability of the living environment. Some of the major sources used by adults who have mental retardation and are living in their own homes are:

a. Supplemental Security Income (SSI) and Minnesota Supplemental Aid (MSA). SSI, a federal program of the Social Security Administration, and MSA, a state-funded program, provide monthly payments to qualifying persons for food, shelter, utilities, personal needs and other basic necessities. MSA payments supplement SSI payments for those whose SSI grant is below state standards. Currently, $340 is the maximum SSI grant. The amount of MSA supplement varies by the recipient's circumstances and by county. In "congregate" settings, where two or more recipients live together, "negotiated rate" payments up to $860 per person can be made under certain circumstances. The county of residence determines the actual amount of the grant. SSI/MSA are applied for at the county social services office.

It is important to note that SSI and MSA grants are used for living expenses only, not for program services. Funding for program services is provided through other channels, which are outlined in the next chapter.

b. Social Security Disability Insurance (SSDI). SSDI is a social insurance program (as contrasted to SSI, which is a social entitlement program) administered by the federal Social Security Administration. It provides financial assistance to eligible persons who are disabled.

Persons with severe disabilities may qualify for "childhood disability benefits" under this program after they reach their 18th birthday, if they are the son or daughter of a worker entitled to Social Security retirement benefits or disability benefits, or of an insured worker who has died. In some cases, persons can qualify on the record of a grandparent.

To be eligible for childhood disability benefits, a person must meet the following definition: "'Disability "...(is) the existence of a medically determinable physical or mental impairment or impairments expected to result in death or which have lasted, or can be expected to last for a continuous period of not less than 12 months, and of a level deemed sufficient to prevent an individual from engaging in any gainful activity." This disability must have had its onset before the age of 22 years.

Benefits are paid on a monthly basis to the beneficiary directly, by direct deposit to an organization, such as a bank, credit union or trust, or to a representative payee. The benefit amount is determined

by the amount paid in by the insured worker. Application is made through local Social Security Administration offices.

c. General Assistance (GA). General Assistance is a state-funded program which provides cash aid to all persons not eligible for other federal and state financial assistance programs and who lack the cash needed to secure food, shelter, and other basic necessities. To qualify, a single person must have a monthly cash income of less than $203 (can be higher if some of this income is earned). Personal property and cash assets must be less than $1,000, but the house and its furnishings, as well as clothing, are not counted. At the time of this writing, $203 per month is the maximum payment to a single person, although some counties have a higher maximum. In emergency situations, payments higher than the maximum can be made. General Assistance can be applied for at the county social services office.

d. Food Stamps. The federal food stamp program makes food available to lower income persons at reduced prices. Persons may get food stamps if they: (a) meet program income guidelines, and (b) provide or apply for a Social Security number. Food stamps can be used to purchase basic food items at most grocery stores. Food stamps are applied for at the county social services office.

e. Earned income. Living in a home purchased, at least in part, with income earned through employment, increases the owner's satisfaction and investment in his/her residence.

f. Trust funds. Persons with mental retardation or related conditions who live in their own homes can be helped to meet their living expenses

through trust funds set aside by their parents. These funds provide a regular source of supplemental income for the resident, but are protected as assets in the determination of eligibility for governmental programs. Such trusts can be set up to provide payments prior to and after, the parents' death. Further information about trusts is found in the "Planning for Permanence" section (page 32). .....

IDENTIFYING AND MEETING SERVICE NEEDS

Getting services

The means by which persons with mental retardation or related conditions find and receive the services they need is called case management. State law requires each Minnesota county to provide case management to all persons who have, or might have, mental retardation or a related condition, and are in need of services. Specifically, state law defines case management as "identifying the need for, seeking out, acquiring, authorizing, coordinating, and monitoring the delivery of services to, and protecting the rights of, persons with mental retardation by an individual designated by the county board." Many families know their case manager by the term "county social worker."

By the case managment process, the county establishes eligibility, assesses service needs and develops an individual service plan (ISP). The ISP is developed by the case manager, the person with mental retardation or a related condition and parents, and outlines the general type of services and program required by the client, based on an assessment. An ISP must be developed by the county of financial responsibility for each person with mental retardation or a related condition who requests and is in need of services.

If the assessment indicates that the person requires care 24 hours per day, the case manager convenes a "screening team," which consists of the case manager, client, parents, and a "qualified mental retardation professional" (QMRP). Others may be invited, such as the client's physician, other professionals and his/her advocate. The team reviews the identified needs and develops a program of specific services, including residential, day and sup-

port, as well as service outcomes. The team recommends a service package and payment for services. The person with mental retardation or a related condition has the right to appeal any decision of the screening team.

The wide array of community services available to persons with mental retardation or related conditions in Minnesota is often a source of confusion to parents. A major source of this confusion comes from blurring the distinction between the service program itself, and how it is funded. For better understanding of the service options available and how they are funded, the table on the following page outlines community-based services and their funding sources related to consumer-owned housing. Descriptions of the service programs and funding source listed on the table follow.

Service programs

a. Supportive living services (SLS) are residential-based habilitation services provided on a daily basis at a place where no more than six adults or three children with mental retardation reside.

b. In-home family support services are residential-based habilitation services designed to enable the family to care for and maintain the family member with mental retardation in the home and may include training and counseling for the family member and his/her family.

c. Adaptive aids are structural changes to the person with mental retardation's residence to increase his/her mobility or to provide protection from injury. Such aids include: wheelchair ramps, elevated bathtubs, widened doorways, shatterproof windows, lowered kitchen work

SOME SERVICES WHICH CAN ASSIST PERSONS WITH MENTAL RETARDATION OR RELATED CONDITIONS TO LIVE IN THEIR OWN HOMES

Service	Funding Source*
Supportive Living Services	Waiver
In-home Family Support	Waiver
Adaptive Aids	Waiver; MHFA
Adult Foster Care	SSI/MSA; CSSA
Personal Care Attendant	MA
Homemaker	MA; Waiver; CSSA; CHS
Home Health Care	MA; CHS
Semi-Independent Living Skills	SILS; CSSA
Housing	CSSA
Money Management	CSSA
Chore Services	CSSA

The services and funding sources listed on this table are described in the text. The services listed as funded by CSSA include services which a county may fund with CSSA funding, if they choose to do so. However, not all counties have included all of these services in their CSSA plans, so not all of these services are available in all counties.

County tax levy funding has not been included in the above list, since expenditures from this source vary widely among both services and counties. Generally, county tax levy funds are used at the discretion of the county board of commissioners or human services board, and are expended only after all other sources of funding have been exhausted.

Another source of funding not included above which may be available to some persons for medically-related services is third party payments, such as insurance.

Key to abbreviations:

Waiver - Home and Comirunity-Based Services Waiver
MHFA - MHFA Accessibility Deferred Housing Loan Program
CSSA - Community Social Services Act
MA - Medical Assistance
SILS - State SILS Grant Program
CHS - Community Health Services Program

surfaces, shower and bathtub seats, etc. Some adaptations to vehicles and adaptive equipment may also be eligible expenses.

d. Adult foster care provides a living arrangement for persons with disabilities, including mental retardation and related conditions, who are over 18 and are unable to live independently. The purpose of the program is to assist people to gain or maintain as high a level of independence and community integration as possible. Foster care for adults can provide supervision, personal care, assistance and protec tion, as well as room, board, and laundry services.

Adult foster care in Minnesota has been traditionally given in the home of the foster care provider, where the adult in need is included in the family. However, an adult with mental retardation who has purchased his/her own home may be able to receive adult foster care by renting a portion of the dwelling to an adult who would move into the home and became licensed as a foster care provider.

e. The personal care attendant program provides personal care services which are prescribed by a physician and supervised by a registered nurse. These services include: bladder care, skin care, range of motion, bathing/grooming/dressing, self-administered medication, trans ferring, turning and positioning and feeding (but not meal preparation). The services are provided by private vendors, arranged for by the family (assistance with making these arrangements is available from the case manager). This service is available only to persons who are capable of directing their own care.

f. Private duty nursing services are nursing services provided by a registered nurse or licensed practical nurse under the general direc-

tion of the patient's physician in the patient's own home. These services are provided only when the person requires individual and continued care beyond that available from a visiting nurse or home health care agency.

g. Homemaker services include general household activities and ongoing monitoring of the client's well-being provided by a trained person when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him/her self or others in the home. Services include meal preparation, cleaning, simple household repairs, laundry, shopping, for food and supplies, and other routine household care.

h. Home health care services include: intermittent or part-time nursing services furnished by a home health agency, or by a registered nurse or licensed practical nurse under the direction of a physician when no home health agency services are available; medical supplies, equipment and appliances prescribed by a physician as necessary for the care of the patient and suitable for use in the home; and services of a home health aide under the supervision of a professional nurse assigned by a home health agency.

i. Semi-independent Living Skills (SILS) services is a system of support which enables persons who would otherwise reside in more restrictive settings to live in the community. SILS services include training, counseling, instruction, supervision and assistance provided in accordance with a person's individual program plan, for fewer than 24 hours per day. Services are directed at maintaining and improving the person's functioning level, and include the following areas:

° meal planning and preparation °

shopping

first-aid training

° money management

administration of medications °

use of telephone

personal appearance and hygiene °

home maintenance and upkeep

SII,S services are provided in the home of the person with mental retardation or a related condition.

j. Housing Service helps individuals obtain, maintain and improve housing, and modify existing housing.

k. Money Management assists eligible individuals in the management of their income so that they are able to obtain a stable level of economic functioning within the limits of their present financial resources; including consumer education, debt adjustment, financial counseling, protective and vendor payment.

1. Chore Services include routine housekeeping tasks, minor household repairs, shopping, lawn care and snow shoveling.

Funding sour ces

a. Medical Assistance (Medicaid) pays for health services for eligible individuals. The program is operated by the state with federal, state and county financial participation.

To be eligible for Medicaid funding on the basis of disability, persons must meet the same disability criteria used for the Social Security Disability Income (SSDI) program, referenced earlier on page 18. There are income and asset eligibility standards that vary by family size and composition. Medicaid is applied for through the county social services office.

b. Medical Assistance Home and Community Based Services ("Waivered Services") is a federal program allowing certain Medicaid funding, which formerly was channelled exciusiveiy to state hospitals and group homes, to be used to provide services in the least restrictive environment. Adults and children with mental retardation and related conditions who need the level of care provided in Intermediate Care Facilities for Persons with Mental Retardation (includes state hospitals and group homes) (ICFs/MR) are eligible to receive Home and Community Based waivers.

These persons do not actually have to be living in an ICF/MR at the time they are considered for a waiver, but may be determined to be "at risk" of being placed in an ICF/MR. The risk status is determined through the case management system by obtaining information about the person with mental retardation in respect to his or her need for support, supervision, assistance and training.

The waiver is a significant development in the provision and funding of services to persons with mental retardation or related conditions. Because it funds services to be delivered on an individual basis where the individual resides, it breaks the bond between place of residence

and receipt of service. When the person changes providers, the funding can follow. For this reason, the waiver is one of the most important recent changes in the service system which enables the development of consumer-owned housing.

The waiver is applied for through the county social services office. The county establishes eligibility, assesses service needs and develops an individual service plan (ISP) through the case management system described earlier. The final recommendations of the screening team are reviewed by the State Department of Human Services. Based on this review, Medical Assistance payments for services can be authorized through the waiver.

If the services recommended by the screening team are not available, the county may issue a "request for proposals" (RFP). An RFP is a written request from a county board to the public, soliciting proposals from potential providers to provide the needed service.

Services funded by a waiver can be provided in a home owned, leased, or rented by an adult with mental retardation or a related condition only when the screening team determines that the home is an appropriate service site. In such instances, the county board may grant a variance from the requirement that the site where supportive living services are delivered must be certified as an adult foster care home.

The number of waivers available ("slots") is limited in Minnesota. By July 1, 1987, 1,000 slots were in use. A portion of these is reserved for persons currently living in ICFs/MR (conversions) and another portion is reserved for persons currently living in the com-

munity, but determined to be at risk of ICF/MR placement (diversions). The number of slots available in each state is determined by the federal government, based on proposals submitted by the states. The number of slots available in each county is allocated by the State Department of Human Services, upon review of proposals submitted by the counties. At the time of this writing, many counties have waiting lists for waiver slots.

c. Community Social Services Act (CSSA) funding is a combination of state, federal and local moneys which counties have available to fund a variety of community-based human services. Within certain guidelines, counties can determine which services they will fund, how much service will be provided in each service area, which groups will be served and to what extent, and financial eligibility guidelines. Counties must fund services in accordance with their annual CSSA plan, which is sub mitted annually to the State Human Services Commissioner for his/her approval. By law, all county residents must be allowed input into their county plan.

d. County funds. Minnesota counties fund certain human services with funding that has been raised by county tax levies. These funds are frequently used to match the state and federal funding sources listed in this section, but in some cases, services which cannot be funded by other sources are funded with these dollars. These services and the amounts expended for them vary widely among the counties.

e. The State Semi-independent Living Skills Grant Program reimburses counties for a major portion of their costs of providing SILS services. In fiscal year 1988, the reimbursement rate is anticipated to be 68

percent. The remainder of the counties' costs are funded with CSSA and other county funds. Annual costs in excess of $9,544 are not reimbursed by the state. In recent years, state SILS grant program funding has been extremely limited. A few counties have chosen to fund SILS services for some persons using no funding from this funding source because of the unavailability of these funds, or because the persons were ineligible for state SILS funds.

Those eligible to receive SILS under this funding source must have mental retardation or a related condition as defined by state statute, must be age 18 or older, and must require less than 24 hours per day supervision. The annual state appropriation is set by the Legislature. County allocations are made by the State Human Services Commissioner based on proposals submitted by the counties.

f. MHFA Accessability Deferred Loan Program. This program, operated by the Minnesota Housing Finance Agency (MHFA), makes up to $10,000 available to homeowners who are disabled. The purpose of the loan is to make modifications to the home to increase the owner's accessibility and safety. To be eligible for this funding, the applicant's household's adjusted gross income must be $24,000 per year or less (obtained by adding total incomes of each individual living in the house, minus $1,000 for each one).

In addition to the financial eligibility requirement, other criteria apply: (1) applicants must have a minimum one-third ownership interest in the property or a valid life estate, (2) the disabled person must occupy the property or intend to join in the occupancy of the home on a year round basis, and be expected to continue living there for at least

approximately two years, (3) the residence must be in Minnesota, (4) it must be a permanent residence, (5) it must meet zoning and property standard requirements, and (6) it must be structurally viable after completion of the proposed improvements.

This program can be applied for through the local social service agency.

g. Community Health Services Program. This program, administered by the Minnesota Department of Health, provides state funding to counties for the provision of health-related home care programs. Counties submit bi-annual community health plans to the state outlining which services they intend to fund. Currently, all counties in the state participate in this program.

Informal supports and services

Many of the services and supports necessary for persons with mental retardation or related conditions to live successfully in homes they own can be, and are provided not through the government-funded programs listed above, but by family members, friends, neighbors, volunteers, roommates, and others at no charge. As more persons with mental retardation take up residence in the community and become more fully socially integrated, the possibilities for arranging these types of supports increases. While such arrangements can be highly satisfying for both the person providing and the person receiving the support, those developing service plans should use caution in reliance on them. When no contract governs the provision of services, problems with short-term reliability and long-term continuity can arise.

PLANNING FOR PERMANENCE

A big question many parents and guardians of persons who have mental retardation or a related condition face is "What will happen after I'm gone?" How will their son's or daughter's needs be met and who will look after his/her interests? Parents who have assisted their son or daughter to purchase their own housing are concerned whether they will be able to keep this housing as long as they wish, and whether the needed supports will always be there.

Parents who wish to assist their sons or daughters to purchase their own housing, but feel the sons or daughters lack the capability to make some major decisions having an impact on their lives, including decisions necessary to maintain a residence, can take action to ensure the decisions are made for him or her. These actions are affected through the legal process in the form of formalized estate plans. Minnesota parents have a range of options, from which they should carefully select in accordance with the needs and capabilities of their son or daughter.

Guardianship

Guardianship is the most encompassing type of protection a person can have. It also is the most limiting of the person's rights. An individual under guardianship is presumed to be legally incompetent. The individual loses the authority to make decisions, such as where he or she will live, how to spend his or her money, and what kind of program he or she will participate in. A person under guardianship loses his or her civil rights, such as the right to vote or marry. Guardianship should be considered only for people who cannot make any legal decisions for themselves.

There are two types of guardianship: private and state. Private guardianship provides for a private person to act on behalf of the individual. The parent who selects private guardianship for his son or daughter can choose him/herself, a sibling or other relative, friend or any other interested party to assist and make decisions for the son or daughter. The guardian should be willing to assume this responsibility for the lifetime of the son or daughter, and must make annual reports to the court describing the services the son or daughter receives. Most attorneys recommend naming a succession of guardians, in the event something happens to the first one. While the guardian makes payments on behalf of an adult son or daughter, the guardian is not financially responsible.

Private guardianship is obtained through a court process. An attorney is not absolutely necessary, but is recommended.

Under state guardianship, the State of Minnesota assumes decision-making responsibility. It is also obtained through a court process. While the Commissioner of Human Services has the ultimate responsibility, someone in the county social services agency, often a case manager or his or her supervisor is usually delegated the authority. Two major disadvantages to state guardianhip are that the case manager, who is responsible for meeting the needs of many persons on his/her caseload, may not be able to develop as close a personal relationship as a private guardian might. Also, the case manager, as an employee of the county responsible for funding services, is faced with a potential conflict of interest.

Persons who are seeking to make arrangements for a person under state guardianship to own their own home should consult with an attorney and/or the

Minnesota Department of Human Services Guardianship Unit before proceeding. Such arrangements may not, in some cases, be feasible for these persons.

Conservators hip

Conservatorship is a limited form of guardianship. While guardianship is a total limitation of a person's right to make decisions, conservatorship limits only some of those rights. Unlike guardianship, a finding of legal incompetence does not need to be made. The person with mental retardation may be allowed by the court to retain some decision-making powers.

Parents whose son or daughter needs help only in certain areas of his/her life may find a conservatorship arrangement most suitable. The explicit stipulation of the areas of control and protection allow conservatorship to most closely meet the needs of the individual, while allowing him or her maximum freedom. Like guardianship, conservatorship is obtained through the court process, and conservators must submit annual reports to the court. Also, as in guardianship, the State of Minnesota can assume decision-making capacity under conservatorship.

Trusts

A trust is a legal instrument parents have used to set aside and protect financial resources for their children with mental retardation or a related condition. A trustee, designated by the parents, takes care of the money. Parents who use trusts in this way must be extremely careful in setting them up, or they may work against the child. For example, in some cases persons with mental retardation who inherit property or money lose their eligibility for government-funded programs which had been providing services and income support. Also, in some cases persons with disabilities have been forced to pay for their own care once it was determined they had assets.

In setting up a trust, parents should select a lawyer who is sensitive to their and their son's or daughter's needs, preferably one who has set up similar trusts for others. The lawyer must have detailed and current knowledge of state and federal regulations so that court challenges which may arise can be resolved to the advantage of the person being challenged. The case manager and other mental retardation professionals should be involved in determining the beneficiary's future needs and incorporating them into the design of the trust instrument.

While wealthy parents are able to fund trusts with substantial contributions prior to their death, most parents use life insurance plans to fund theirs. The trust instrument must make it clear that their assets may not be considered in the determination of eligibility for governmental programs.

Programs to Insure Future Oversight

Since finding assistance in making and carrying out effective future plans for persons with mental retardation and related conditions has been difficult, several non-profit organizations have recently emerged across the nation. Most have been founded through the efforts of parents of persons who are mentally retarded and their advocates. Approximately 20 programs now exist to provide guardianship and help in obtaining services.

Some experts feel that many of these programs, because they are in the early stages of development, and for other reasons, have potentially serious organizational and financial problems. Parents and guardians are urged to use caution in enrolling in these programs.

Other Options

Options which do not require legal procedures and are less intrusive include:

- Appointment of a representative payee, whereby another person is designated as payee for the son's or daughter's Supplemental Security Income or Social Security Disability Income, can be arranged through the Social Security Administration office.

- Establishment of a joint bank account, enabling a designated person to have equal access to the son's or daughter's bank account, can be used to make sure the son or daughter is not being financially exploited. Under this arrangement, two signatures are required to write a check.

  Informal supervision or protection can be arranged to be provided by a citizen advocate, friend, or relative.

Further information on the topics of this chapter is available from Association for Retarded Citizens/Minnesota.

CASE STUDIES

The following case studies are presented to illustrate the wide spectrum of consumer-owned housing arrangements which are possible. All of these are drawn from actual cases, both in Minnesota and in other places. Some of the names have been changed to protect the confidentiality of the families involved.

Case Study A: A Single-Family Home in Minnesota

In a quiet, upper middle class neighborhood in a Twin Cities suburb, four women, ages 27 - 38 are living together in a single family home. Linda has epilepsy. Her sister, Karen, has a severe case of diabetes. Fran has epilepsy, and Becky has cerebral palsy. All test in the range of severe mental retardation, and all are under medical supervision, requiring the regular administration of medicine.

Prior to moving to their current home, Linda, Karen, and Becky had been living in the homes of their parents. Fran lived in an institutional setting in an adjoining county. The women have been living together for over a year, and have been getting along with no major problems. They live as a family, taking meals together and making trips to churches, parks, the library and other community activities. Assistance and supervision are provided by three women shift staff who are employed by a private service provider.

The service provider is paid through the Home and Community Based Service Waiver. Through a provision in the contract with the provider, the parents have the right to interview the staff who work with their daughters and the persons who will live in the home.

The home is currently owned by Linda and Karen's parents. Prior to the current arrangement, it was the parents' family home. When they moved to a smaller home of their own, they set up the current arrangement. The parents still have a conventional mortgage on the home. Payments are made with Linda and Karen's SSI/MSA payments and with rental income from Becky and Fran. Becky and Fran's rental payments are made from their monthly SSI/MSA grants.

Linda and Karen's parents have set up a trust to own the house and administer their daughters' affairs after the parents die. The trust will provide financial support necessary to maintain the house. Fran and Becky's parents who have been friends with Karen and Linda's parents since before their daughters became housemates, currently have no plans to buy into ownership of the house. However, they consider the house Fran's and Becky's permanent home.

The parents reported that the most difficult part of setting up these housing arrangements was getting Home and Community-Based Services Waivers for the four women. They also report that they are actively involved in monitoring the services their daughters receive from their provider.

Case Study B: A Canadian Housing Cooperative

In the Canadian city of Winnipeg, the Prairie Housing Cooperative owns 20 houses in five neighborhoods, in which 60 people live. Among the 60 shareholders, 18 are persons with disabilities. In each of the five neighborhoods, clusters of two to four ordinary three-bedroom homes comprise the co-op. One unit in each house is occupied by someone who needs extra assistance.

The shareholders who need extra assistance receive it from the other members, on a freely-given basis. All relationships are voluntary. In cases where support is unavailable on a voluntary basis, support persons are employed through special project grants or governmental funds. Co-op members who need paid services obtain them on a contract basis through a separate co-op of which they are members. This arrangement assures the important separation of service provision from the housing site.

Prairie Housing Co-op, which was organized in 1982, has purchased all of its properties with the needs and desires of the specific residents of the houses in mind. The members selected their sites to be close to family, friends, jobs, transportation and generic services. All housing expenses are shared equally among the co-op members. Upkeep of the properties is obtained through a contract between the co-op and a property management company.

The co-op purchased its houses with mortgages subsidized by the Canadian government. These mortgages are from a fund created to develop housing cooperatives throughout Canada. The group was assisted in the design of the structure of the co-op by a provincial agency which fosters the development of housing co-ops.

One of the co-op's latest projects is the conversion of a historic commercial building in downtown Winnipeg to housing units for 27 co-op members and their families. Nine of the units are reserved for persons with disabilities. The building is in a desirable location, close to parks, shopping and transportation. The project has received funding

from the provincial government as well as the city redevelopment authority.

The co-op's organizers admit that they have faced "challenges" over the few years of the co-op's existence. Among them have been complex administrative problems in dealing with 20 separate properties; "discontinuity" in households when housemates moved out; and in at least one case, not enough support provided by co-op members.

In spite of the early difficulties, the Prairie Housing Cooperative today is helping 18 persons with disabilities to live in normalized settings while experiencing the rights and obligations of home ownership.

Profiles: Three Prairie Housing Cooperative Members.

Hazel is currently in her twenties. She lived with her family until age ten, when she was placed in a provincial institution for persons with mental retardation. At age 20, Hazel left the institution, moving into a small group home. A few years later, she joined the co-op, and with the assistance of friends and fellow co-op members, moved into a house she shares with two non-handicapped women, also members of the co-op. She now holds a job at a fast-food restaurant, and receives advice and assistance on money management and other personal matters from her housemates and her neighbors. Hazel believes that her involvement with the co-op allows her to be her "own person."

Arnold is 23 and is a former resident of the same institution as Hazel. At the institution, Arnold was described as "violent, destructive,

rebellious, self-abusive, sexually aberrant and anti-social." His brother described Arnold's life there as "doped-up, locked-up, with no freedom or privileges . "

In his first home in the community, Arnold shared a house with his brother. When his brother later married, Arnold joined the co-op. His family and fellow co-op members selected, trained, and supported new roommates to share a house with Arnold, and provide the supports he needs. At one point, when his family decided it was best for him to have new roommates, these arrangements were made again.

Arnold is now described by his fellow co-op members as "affectionate, curious, friendly and generous." Through his co-op involvement, his interaction with his family has increased "by a thousandfold," and he is socializing with women through his new interest in dancing.

Janelle, age six, cannot talk, walk or crawl, but she attends a neighborhood day care center with other neighbor kids. She will soon start attending her neighborhood elementary school. When Janelle was born, her mother rejected professional advice to place her in an institution.

Janelle lives in a three-bedroom house with her mother and sisters which is owned by the Prairie Housing Cooperative. The house was selected by Janelle's mother to meet the family's needs. It is located near the home of an old family friend, who understands Janelle's needs and provides some support, including babysitting. Other supports are provided by co-op members living in two other houses adjacent to Janelle's.

The information used to write this profile was gathered in part from a magazine article, "People Caring About People - the Prairie Housing Cooperative," B. Kappel and D. Wetherow, Entourage (Canada), Vol. 1 number 4, Autumn, 1986, pages 37-42.

Case Study C: A Single Family Home in Minnesota

In early 1987, four men aged 21 to 30, all described as having severe mental retardation, moved into a three bedroom house in a Minnesota city. The services they need are provided by private providers; the house is owned by the parents of one of the men. This arrangement was developed through the joint efforts of the parents, the county human services board and the private provider.

Prior to moving into the home, two of the residents had resided in a group home, one lived with his parents, and the fourth lived in a larger group setting.

The house is an ordinary three-bedroom home in a newer subdivision. It includes an apartment on the lower level for a live-in couple who act as houseparents. The parent who owns the house holds a conventional mortgage. Payments are made through the four residents' SSI and MSA grants. These funds also provide for their other living expenses. The home's appliances were purchased by the owner; other furnishings were purchased by the parents and donated by others. Currently, the residents rent the house from the owner/parents and the county selects and contracts with the service provider.

In addition to the house parents, whom the county has certified as adult foster care providers, the men receive support from shift staff.

During the daytime, they attend a DAC and school. The program services are funded by Home and Community Based Services Waivers.

Case Study D: A Massachusetts Condominium

In 1982, a group of adults with mental retardation and their parents in the Boston area began developing new housing to address what they saw as a lack of options. Specifically, they wanted housing that would free its residents from the whims of landlords, provider agencies or state policymakers, and from the loneliness and isolation which some persons with mental retardation face in living on their own or with their parents. With the help of an architect/developer and an attorney, two large Victorian houses were converted to 22 units of condominium housing.

The people who moved into the units were all over age 18, capable of self care, and able to negotiate the community on their own. Most of them had previously lived with their parents.

The residents of the two buildings received needed support from around-the-clock staff. The staff's function is "to facilitate independent living, not to provide services to dependent adults." Each resident has a say in the hiring of staff.

During the daytime, the residents attend school or work in sheltered and competitive settings. At home, the lifestyle is communal. Each resident owns his own living quarters, but the kitchen, dining, recreation and guest rooms are owned jointly by the residents. The residents attend weekly meetings to make decisions which affect the group as a whole.

A non-profit corporation oversees the operation and maintenance of the buildings and manages the staff. The buildings are owned by a condominium trust. Some of the residents and/or their parents have purchased their condo units outright, others have obtained mortgages. The condo owners pay real estate taxes to the town. Financially and legally, the development is like any other condominium development in the community.

Each resident pays a monthly "operational fee" of $500 - $600 per month. These fees pay for staff, meals, administration, insurance, utilities, taxes and building maintenance. Some residents pay this fee with income from earnings and governmental income assistance programs. Others rely on financial help from their families.

The communal lifestyle represented by this case study is not for everyone. But for those willing to share in property, responsibilities and living space, returns are gained through greater opportunities for deeper social relationships, a sense of being an integral member of a meaningful group and affordable home ownership.

While this development has been deliberately located to maximize integration in the community, one criticism is that the development itself is not integrated. All 22 condo owners have disabilities. A truly integrated condominium could be developed by reserving units for nondisabled residents, similar to the Prairie Housing Cooperative model described in Case Study B.

The information used to write this profile was gathered largely from a magazine article, "Owning Our Own Home: A New Model for Independent

Living," D. Wizansky and M. Wizansky, Exceptional Parent, December 1985, pages 10 - 12.

For further information on the specific areas covered by this handbook, contact the following agencies and organizations.

Association for Retarded Citizens
(Contact ARC/Minnesota for the local chapter nearest you: 1-800-582-5256)

- For information on locating and receiving appropriate services and for advocacy.

County Human Services (Welfare) Agencies
(See local telephone directory for the name and address of the agency serving your county.)

- For funding of services, case management, and provision of service.

Legal Advocacy for Persons with Developmental Disabilities
222 Grain Exchange Building
323-4th Avenue South
Minneapolis, MN 55415
612/338-0968

- For information and advocacy on legal rights to programs and services.

Minnesota Housing Finance Agency
400 Sibley Street St. Paul, MN
55101 612/296-7608

- For information on low and moderate income home loans and related programs.

Minnesota Department of Human Services, Mental Retardation Division
Centennial Building
4th Floor
St. Paul, MN 55155
612/297-1241

- For information on the state laws and regulations mandating and funding the provision of services to persons with mental retardation and related conditions.

Common Space Mutual Housing Association
2550 Pillsbury Avenue South Minneapolis,
MN 55404 612/872-0550

- For information on, sponsorship of, and development of, lower income housing cooperatives.

Creative Management Associates
Robert J. Laux, President P.O.
Box 5488 Portsmouth, NH 03801
603/A36-6308

- Consultant services and workshops on consumer-owned housing.

Twin Cities Society for Children
and Adults with Autism, Inc.
253 East 4th Street St. Paul, MN
55101 612/228-9074

- For information and referral and advocacy services to persons with autism and their families.

Association for Retarded Citizens/Minnesota
3225 Lyndale Avenue South
Minneapolis, MN 55408
612/827-5641
800/582-5256 (toll free)

For additional information on consumer-owned housing.

APPENDIX A. HOUSING COOPERATIVES

A housing cooperative is a group of people organized for the purpose of owning, building or rehabilitating housing for its members and possibly for other people. The coop itself is a corporation which owns the housing in which the resident-members live. Each resident owns one share or membership in the corporation Like other types of coops, housing coops are democratically managed: one member, one vote. Members usually elect a board of directors who manage the cooperatively owned housing

A housing coop is actually a form of consumer coop. Depending on how you view it. the coop is providing a service (housing) or a product (a home) to its members

Housing coops are often eligible for 100% financing. A coop can purchase housing without raising significant capitai from its members. The corporation holds one mortgage for the entire coop, collects the rents, makes the mortgage payments, pays the property taxes, pays the bills, does the bookkeeping and maintains the buildings. The corporation is responsible for major repairs, insurance, replacement of worn out equipment and upkeep of common grounds and facilities Sometimes the corporation hires professional managers and sometimes the members manage the operation themselves. Members are not personally liable for the coop's mortgage.

Federal law and most state laws allow members of housing coops to deduct their share of the mortgage interest and property taxes on their personal tax returns

Some housing coop bylaws specify that when a member moves out, the member's share is repurchased by the corporation for the same amount the member originally paid or possibly for a slightly greater amount to compensate for inflation. This kind of set up is often referred to as a "limited equity coop" The members do not benefit from any increase in the market value of the real estate. In essence, the member is renting housing from the cooperative (except, of course, no landlord can jack up the rent or evict a tenant at will). The member's original "down payment"—the membership fee—is much like a cleaning or security deposit, refunded when the member moves out. This limited equity system creates housing which is affordable by low-income families and keeps it that way There is no incentive for speculators to buy memberships, hoping to resell and make a large profit. To further discourage speculation and profit, the bylaws of many housing coops require that all members be residents of the coop. This way. people are not allowed to buy an inexpensive membership and then sublease the housing to others at high rents

Some housing coops allow departing members to sell a membership for whatever it will fetch on the open market Such coops are called "market rate" or "full equity" coops. As the cost of housing escalates, so does the cost of a membership. Few coops survive under such an arrangement. The value of a membership increases until only wealthy people can afford shares. Speculators buy up memberships in hopes of reselling them at a handsome profit. The drive to make a killing in the housing market destroys the principles and ideals which coops stand for.

Allowing memberships to sell at market value can have disastrous results for the entire coop if prices climb significantly. People, desperate for housing, buy in at prices they can't realistically afford; they are unable to make the steep monthly payments; the other members of the coop are unable to cover the payments, the entire coop faces foreclosure and loss of its housing. A limited equity coop will prevent this scenario

Housing coops are most successful when a few specific procedures are followed:

1. The board of directors keeps members informed of all its actions. A system of regular communications through meetings, newsletters, bulletim boards, etc. is set up and maintained.
2. The coop maintains adequate cash reserves for emergencies, for replacements and for repairs. Reserves reduce the possibility of members having to pay unexpected additional fees.
3. The board has the right to approve new member-residents. Boards often run credit checks on prospective members Boards often meet with prospective members to explain the rights and responsibilities of coop membership
4 Sub-leasing is restricted to a short term or else not allowed at all. Where allowed, the bylaws specify the maximum time and how much rent may he charged.

APPENDIX B. BIBLIOGRAPHY

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