

A Guidebook on

***Consumer Controlled
Housing***
*For Minnesotans with
Developmental Disabilities*

2000 Edition

A joint publication of

ARC MINNESOTA

and the

RESEARCH AND TRAINING CENTER
ON COMMUNITY LIVING

*Institute on Community Integration (UAP)
University of Minnesota*

Arc Minnesota



The College of Education
& Human Development

UNIVERSITY OF MINNESOTA

First edition published September, 1995.
Second edition published June, 2000.

Printing of this guidebook was donated by ReliaStar Financial Corporation. The development and dissemination of this publication was partially supported by a cooperative agreement with the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education (H133B90047). The contents and opinions expressed in this document do not necessarily reflect those of the ReliaStar Financial Corporation or the National Institute on Disability and Rehabilitation Research, and no official endorsement should be inferred.

The University of Minnesota is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.

To obtain additional copies of this publication, contact:

Arc Minnesota
770 Transfer Road, Suite 26
St. Paul, MN 55114
651/523-0823 OR 800/582-5256

or

Institute on Community Integration
University of Minnesota
109 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
612/624-4512

This publication is available in alternative formats upon request.

Cover photograph courtesy of the National Center for Youth with Disability.

Contents

- **FOREWORD**
How to Use This Guidebook

- **ACKNOWLEDGMENTS**

- **CHAPTER 1**
Why People Should Control
Their Own Homes
 - 1 *An Introduction to Consumer Controlled Housing*
 - 2 *Philosophy*

- **CHAPTER 2**
Making the Right Housing Choices
 - 5 *Introduction*
 - 5 *General Considerations*
 - 8 *A Dozen Questions About Housemate Compatibility*
 - 9 *To Own or Rent: Relative Benefits*
 - 10 *Housing and Lifestyle Planning*
 - 15 *Thinking About Affordability*

- **CHAPTER 3**
Ownership as a Means of Consumer Control
 - 19 *Introduction*
 - 19 *Deciding About Home Ownership*
 - 21 *Home-Buyer, Home-Ownership Education*
 - 25 *Deciding About Housing Structures*
 - 26 *Who Shall Live in the Dwelling?*
 - 27 *Nonconventional Approaches to Housing That Build and Support a Community*
 - 31 *How Will the Housing Be Financed?*
 - 32 *Minnesota's HomeChoice Mortgage Program for Persons with Disabilities*
 - 34 *The Minnesota Homestead Law*

- **CHAPTER 4**
Consumer Control Through
Rental Arrangements
 - 35 *Introduction*
 - 35 *Choosing a Rental Home*
 - 37 *Things to Know About Renting*
 - 38 *Getting Help to Find a Place*
 - 39 *The Fair Housing Act*

- **CHAPTER 5**
Making Sure Needed Supports Are in Place
 - 41 *Introduction*
 - 41 *Identifying Service Options*
 - 49 *Finding an Agency to Provide What You Want*
 - 50 *Working Cooperatively: A Service Provider's Perspective*
 - 51 *Informal Supports: Opportunities and Challenges*

- **CHAPTER 6**
Assessing Need & Getting Help
for Home Modifications or Equipment
 - 53 *Introduction*
 - 53 *Thinking About Needed Modifications*
 - 56 *Sources of Financial Support*
 - 58 *Working with the System*

- **CHAPTER 7**
Planning for Long-Term Security
 - 59 *Introduction*
 - 59 *Comprehensive Life Planning*
 - 63 *Guardianship vs. Conservatorship*
 - 64 *Setting Up Trusts*
 - 66 *The Supplemental Needs Trust in Minnesota*

[Continued]

■ **CHAPTER 8**
Toward a More Friendly Environment
for Consumer Controlled Housing

- 67 *Introduction*
- 67 *Recent Moves Toward Consumer Control*
- 69 *Creative Approaches in Other Places*

■ **CHAPTER 9**
Available Help on Housing & Related Issues

- 73 *For Information and Assistance with Housing*
- 75 *For Information on Supporting Desired Lifestyles*
- 76 *For Information and Assistance on Technology
and Home Modifications*
- 77 *For Information and Assistance on
Long-Term Planning*

■ **APPENDIX A**
Worksheets on Consumer Controlled Housing

- 79 *The Costs of Home Ownership*
- 80 *Worksheet One: Monthly Income and Expenses*
- 82 *Worksheet Two: Your Available Cash and Assets*
- 83 *Worksheet Three: Housing Considerations*
- 85 *Worksheet Four: Accessibility Features*
- 87 *Worksheet Five: Home Inspection*
- 88 *Worksheet Six: Choosing a Service Provider*
- 90 *Worksheet Seven: Summary Housing Checklist*

■ **APPENDIX B**

- 93 **Example Lease Agreement**

■ **APPENDIX C**

- 99 **Social Service Acronyms**

■ **APPENDIX D**

- 107 **Real Estate Terms**

Foreword: How to Use This Guidebook

This guidebook has been developed to advance the consideration of consumer controlled housing options by people with developmental disabilities, their families, and others who help them. Consumer controlled housing – housing arranged with the needs and preferences of the consumer in the forefront, rather than the needs and preferences of the service provider or service funder – clearly contributes to the well-being of people with developmental disabilities. The guidebook outlines some of the options available to people interested in creating consumer controlled housing arrangements. It describes major planning considerations, housing options, supportive services and their funding, and available resources. It also includes a number of stories shared by people with developmental disabilities and their families that illustrate how they created housing arrangements and supports that allow them to control their own housing.

The information presented here is an overview of current knowledge, but new developments are occurring every day. For this reason, and in recognition that each person's needs are unique, this guide isn't a "cookbook" with explicit models and instructions. It's intended to help readers consider options and to stimulate the creative thinking required to determine the most beneficial housing arrangements for each person.

It's important to note that housing alone is insufficient to support most persons with develop-

mental disabilities in the community – supports and services are also crucial elements. For this reason the authors hope this material will be reviewed not only by people seeking greater control over their housing, but also by those who are in positions at many levels to provide those supports and services. These include advocacy groups serving people with disabilities, county and state elected officials and administrators, case managers, mortgage bankers, real estate professionals, housing developers, service providers and other members of the community in which people with disabilities live. To support the development of consumer controlled housing in Minnesota, Arc Minnesota has on staff a full-time housing consultant. You can contact the housing consultant for more information about the Fannie Mae mortgage demonstration program and other information about helping persons with disabilities and their families to become homeowners. Arc Minnesota and other agencies plan to stage workshops for families, consumers, and others. The worksheets found in Appendix A have been designed for these workshops, as well as to assist the readers of this book.

The authors hope this guide will serve as a catalyst for people to work together to fulfill the promises of inclusion, self-determination, independence, and choice that are so frequently voiced but less frequently delivered to persons with developmental disabilities.

Acknowledgments

Many people with a variety of expertise and perspectives have helped to produce this book. Their contributions have facilitated what is intended to be a useful, comprehensive, and accurate resource.

We would like to thank the following people who contributed written materials, provided feedback, or reviewed the materials for the first edition of this guidebook: Alex Bartolic, Bob Brick, Richard Bunin, Milt Conrath, Vivian Erickson, Cathy Ficker-Terrell, Tom Fitzpatrick, Arnie Gruetzmacher, Karen Grykiewicz, John Hastings, Kay Henderickson, Deb Holtz, Gene Martinez, Al Mattson, Marijo McBride, Theresa Mustonen, Bob Prouty, Gary Smith, Diane Sprague, and Deb Verdi.

We are grateful to Cheryl Morgan, Laura Lafrenz, Jennifer Sandlin, Charles Gibbons, Mike Vosika, and Vicki Gaylord for their assistance in preparing text and design for this guidebook.

We would especially like to thank the individuals and families – many of whom have chosen to remain anonymous – who shared housing stories with us. We are grateful to them for giving us their stories and even more so for their leadership in pioneering the way to consumer controlled housing.

Finally, we would like to thank ReliaStar Financial Corporation and the National Institute on Disability and Rehabilitation Research (U.S. De-

partment of Education) for the financial support they provided to Arc Minnesota and the Research and Training Center on Community Living at the Institute on Community Integration for the development, production, and dissemination of this guidebook.

The following individuals were involved in the compilation, writing, and editing of this guidebook:

First Edition

Tom Fields

Charlie Lakin

Bud Seltzer

Rachel Wobschall

Second Edition

Tom Fields

Charlie Lakin

Bud Seltzer

Grace Backman

Diane Sprague

Mary Hinze

Dennis Collins

Arnold Gruetzmacher

Lynne Megan

Bob Brick

Barbara Polster

Kathy Luebke

1

Why Should People Control Their Own Homes?

An Introduction to Consumer Controlled Housing

In the past quarter century, people with developmental disabilities have made great strides toward attaining a fuller measure of citizenship in their communities. After being housed primarily in large, isolated institutions, most persons with developmental disabilities who live outside their family homes today enjoy some form of community living. In the early years, residences were primarily group homes that were owned or rented by the agencies providing services to the people living in them. Indeed, even today this remains the most common model of community residential services. But all across the United States, the pattern is slowly but steadily changing.

■ An Increased Range of Housing Options

In Minnesota, two programs in particular have been instrumental in assisting individuals to live in community settings. The approval of the Medicaid Home and Community Based Services (HCBS) waiver program in 1984 allowed the purchase of individual community services with federal and state Medicaid funds, which were previously limited to a package of housing, care, and training in congregate care settings. The Semi-Independent Living Services (SILS) program uses state and county funds to enable persons with developmental disabilities to receive services while living on their own. Both programs broke the link which forced many persons to trade homes and communities for services.

The evolution of service delivery and funding policies has greatly increased the range of housing options for people with developmental disabilities. In many places, separating service financing from housing selection has helped thousands of persons with disabilities realize desired lifestyles. In Minne-

sota and across the nation, persons with developmental disabilities, their parents, service coordinators, housing authority personnel, and others have been acquiring experience, sharing expertise, and developing programs to assist persons with developmental disabilities to live where they want, as they want, in homes that are truly their own, and to still receive the basic services they need.

The range of housing ownership and rental options available to and used by persons with developmental disabilities is as great as that available to everyone else. People with disabilities may live in and purchase or lease single-family houses, duplexes, condos, and units in housing cooperatives. They may live alone or with others who may or may not have disabilities. The common thread here is that people have homes they want with services and supports they need and are able to live on their own terms – rather than feeling like guests in places that are owned or rented and controlled by the agencies that provide services.

■ The Advantages

Some of the numerous advantages of consumer controlled housing include:

- **Permanency:** The risk is reduced that other people will decide one must move from one's own home. People who live in their own homes are free to choose new service providers or even to reject service providers without also losing their homes.
- **Community Inclusion:** People who control their own housing have greater choice in living near people and places that support their participation in the community.

- **Freedom:** People who live in homes they control make their own rules. The basic right to privacy desired by all human beings is more easily met in one's own home. The place where one can "be oneself" is more easily achieved in one's own home.
- **Respect:** A home of one's own is a typical and important achievement of American adults. It gives the owner or leaseholder a valued social role. Obtaining a home of one's own is a natural extension of normalization.
- **Responsibility:** A home of one's own makes an individual responsible for a number of economic and domestic activities. Responding to these responsibilities helps people grow in social competence, both in actual terms and as they are perceived by others in their community.
- **Economic Gain:** People who own homes have found that careful purchase and long-term residence can increase an owner's financial resources. Those who rent can often choose housing and housing arrangements at costs that free funds for other economic decisions. Both owners and renters contribute to the local economy.
- **Location:** People who choose their own homes can live where it's most convenient to their jobs, families, friends, stores, or transportation. Living close to places they enjoy allows more frequent participation with less dependence on others.
- **Choice:** Most people don't want to live with others whom they have had no voice in selecting. Yet this is typical for persons with developmental disabilities. Controlling one's home includes controlling not only where but also with whom one lives.
- **Self-determination:** People should have a right to control as much of their lives as possible. Few areas are more basic and unambiguous in self-determination than selecting the housing one wants within one's resource limits.
- **Independence:** People who live in their own home can exercise independence in seeking a service provider. In contrast, people who reside in buildings owned by a service-provider agency must weigh the potential loss of choice regarding home, neighborhood, and proximity to friends against the need to seek services from another individual or agency.

Philosophy

The consumer controlled housing movement in general, and this guidebook in particular, are rooted in a philosophy shared by a growing number of persons with developmental disabilities, their families, advocates, and professionals. This philosophy is called "supported community living."

Basically, supported community living accepts and embraces each person as an individual with his or her own likes and dislikes, aspirations, abilities, needs, relationships, and ways of contributing to the community. Supported living is described as an entirely new way of conceptualizing the purpose of services for persons with developmental disabilities. Minimally, it's a notable stage in the evolution of their citizenship.

The movement from institutional care to housing in community residential settings is critical in

recognizing each person's uniqueness. But it also shows that planning and structuring the lives of four, five, or six people at a time places some of the same limitations on their lives as does institutional care. The supported community living concept is built around identifying, valuing, and supporting the uniqueness of each individual. The recognition and expression of individual uniqueness through housing is just one crucial aspect of the concept. It has at least six major components:

- **Living in a home of one's own:** People should be able to live in homes they choose, with or without people they choose, and in a place where they can exert appropriate measures of personal control.

- **Receiving appropriate amounts and types of assistance:** People should receive services from providers who can recognize and respond to their abilities as well as impairments, and who have adequate financial and personal resources to meet those needs, and be provided with choice and flexibility in services and providers.
- **Controlling the basic personal decisions that affect one's life:** People should be allowed to make decisions about their lives, or should be assisted in learning to make such decisions.
- **Receiving support in setting and realizing personal goals and aspirations:** Planning processes should identify people's long-range goals and provide the assistance needed to develop means and steps toward achieving them.
- **Enjoying relationships with others of one's own choosing:** People should be supported in maintaining valued relationships with friends and family, and in developing desired new relationships in the neighborhood, community, and work.
- **Participating as a full and valued citizen in one's community:** People should have support to involve themselves in activities and to fulfill valued roles in the community (worker, consumer of housing or goods, user of public transportation, etc.).

Michael Kennedy's story on the next page captures the spirit of supported community living and the role of one's home in it.

Out of My Old Life and Into My New One

By Michael J. Kennedy

I grew up in three New York institutions. In 1982, when I was twenty-one, I moved into a group living situation in the community called a supportive apartment. I lived with three other men with cerebral palsy, and we were supervised by staff whenever we were home. The supported apartment was much better than the institution, but in the six years I lived there I learned everything I could and was ready to be on my own. Also, the program was funded by Medicaid and had too many rules and regulations, like having to have goals and a service plan.

I knew what I wanted, but I needed help to get it. So I started talking to the director of the program about being on my own. I was listened to in one way, but not in another because nothing was happening. What I had to do to get my point across was to threaten to move back into the institution near my family in the Adirondack Mountains area. The director got wind that I was actually going to do it, and the agency staff didn't want that. I know it would have been a mistake, and I didn't want to quit my job at the Center on Human Policy, but I felt my back was against the wall. That was the beginning of my getting my own home.

The agency told me about a new program they had just received funding for. It was called a Family Care program, but what it does is match a person with roommates and the other supports he or she needs. One of the staff at the supported apartment, John, called me into the office one day and asked me if I would consider setting up a home with him and his roommate Gordy. I agreed, with the understanding that I didn't have to follow Medicaid rules or have a service plan. I wanted to make my own decisions. I made it very clear that when it was time to leave the program, I could just go, no strings attached or questions asked.

As time went on, the coordinator of the Family Care program met with John and me. I told her what I wanted in terms of supports and a home. Part of her job is to help us find a place. The exciting part is that we have a friend who used to work for the agency who is into buying real estate. One day I was kidding with her and said, "Why don't you buy a house that would be easily accessible and I would rent it from you?" About a week later she told me she had bought a house! At first I thought she was kidding, but then when she took me and John over to see it I knew she was serious. We called the coordinator on the phone.

John and I then started meeting with her on a regular basis. It was actually pretty easy to set up the supports I would need, like physical therapy and my orthopedic doctor, because I could just take what I had from the apartment and transfer them to my new house. The supports I didn't have at the apartment were just added on. For example, I had to arrange attendant care with one of the agencies in town. Medicaid would pay for all of this when I was on my own because I kept my Medicaid eligibility.

Always keep in mind that it may not be as easy for someone else as it was for me to set it up. The important thing you have to remember is that you should be involved in every aspect from start to finish. You, the individual, must have the supports built around you, and not be made to fit into a program that wasn't designed just for you. This is true regardless of how severe your disabilities are. It's very important that you have a say about how your wants and needs are dealt with.

If you work at an agency, I would hope that you would go along with the individual on how he or she wants to live. You don't have to agree, but they have the right to live like anyone else.

I've lived on my own for the last two years. Through this period John and I have talked about moving down south. We both like the South for a number of reasons. One is that we both have family down there, and they have been asking us to move down there for quite a while. The most important reason is that both John and I felt we needed a change in our lives, we needed something new, and we needed to move on. So, we are moving to a town near Atlanta, Georgia. I am very excited about this move.

2

Making the Right Housing Choices

Introduction

Choosing a home is among the most important decisions a person ever makes. Where a person lives often affects his or her relationships with others, involvement in the community, and overall satisfaction with life. It also has an effect on personal finances.

Because housing decisions are extremely important, most people spend a considerable amount of time narrowing down their selection of a home. They may talk to others about the safety of various locations and evaluate potential neighborhoods in terms of proximity to schools, grocery stores, shopping centers, theaters, parks, and places of worship, as well as availability of public transportation. Some people make lists of "must haves" they use when evaluating places to live. For many people, the number of bedrooms and bathrooms, a yard or a driveway, and storage space are most essential.

Others may evaluate a potential home in terms of its accessibility for someone who has a disability. Some people prefer small yards (less lawn to mow) and short sidewalks (less snow to shovel).

Advocates of consumer controlled housing recognize that the decision about where a person with a developmental disability will live is very important to that person's quality of life. That decision should not be based on availability of openings in residential facilities or a service provider's determination that a particular location will be convenient. Individuals may need different levels of support and assistance in securing and living in their own homes; however, people with developmental disabilities and their families are usually the best qualified to make decisions about where and in what kind of home they will live.

General Considerations

Most people must consider a number of interacting elements in choosing the house they want to live in. For example, location, economics, structure, size, design, and other factors usually play a role. Of course, each element operates differently. Economic factors impose budgetary limits. Physical needs demand accessibility. The varying availability of publicly financed supports may limit choices to certain localities. Certain imposed limitations exist for everyone but within them people with developmental disabilities should enjoy many possibilities for homes of their own. In weighing the possibilities people may want to think about some of the factors outlined below.

■ Location

- **General Location:** In many instances the factors related to the service system that one depends on for support (e.g., residing in a specific county) may affect the choice of location. Some people choose to live relatively close to family and friends because of their important supports. Having the support of a single preferred agency or individual often requires general considerations concerning location. Of course, preferences for urban, suburban, or rural living are important for many individuals. Other considerations are supportive communities, public

transportation, available conveniences, etc.

- **Neighborhood:** People tend to choose neighborhoods that offer specific features of importance to a preferred lifestyle. Many features define neighborhoods, such as community "personalities," inclusiveness/isolation, political and social tolerance/intolerance of diversity, or community activism/conservatism. Neighborhood considerations are also important in different ways to different people; many people are interested in what communities have to offer in the ways of parks and recreation programs, churches, schools, libraries, and so forth. Neighborhood commercial resources, such as stores and restaurants are often important, particularly for persons for whom transportation outside the neighborhood may be difficult and time consuming. So is the neighborhood physical environment important to many people; some want features like lakes, trees, spaces, and quiet whereas others prefer the activity of an urban environment.
- **Important Specific Proximities:** Many individuals must attend to important specific proximities within a neighborhood. For example, people without personal transportation may wish to be close to grocery stores, community resources that are used on a frequent basis (e.g., a YMCA/YWCA), a preferred café, or to have easy access to public transportation. For persons with physical disabilities or persons who may become disoriented and for those for whom traffic may pose a threat, specific paths of community access may need to be assessed.

■ Housing Features

- **Accessibility:** It's obviously important to ensure that the housing and its spaces and appliances are accessible to the users. Physical spaces and appliances need to be easily assessed by the individual with developmental disabilities, family members and others. It's also important to recognize that assistance is often available for accommodations that would make otherwise desirable housing accessible (see Chapter 5).
- **Safety:** Depending on the individual, within the context of the type of housing and neighbor-

hood selected, the available support, and other factors, attention must be given to whether the housing affords reasonable safety. If there are doubts, modifications (e.g., deadbolts, emergency alert systems), protective arrangements (e.g., a neighbor who is willing to act as a monitor), or other accommodations may be made. However, for most persons with developmental disabilities a relatively conservative perspective on safety is just common sense and may be required by the programs that finance the supportive services.

- **Attractiveness:** People with developmental disabilities also should be able to live in housing that meets their standards for attractiveness and cleanliness. Much of what is regarded as attractiveness or cleanliness is too individualistic to define specifically, but for most people it means a pleasing physical layout that is freshly painted in preferred colors and is reasonably clean and tidy. One should always carefully assess what it will take to reach and remain at the desired level of attractiveness and cleanliness and who will be responsible for that work. When looking at apartments, inspect the premises for upkeep and talk to other tenants about maintenance; the latter is usually a good indicator of the landlord's likely contribution to maintaining an apartment. When a home is being considered for purchase it's important to carefully assess the work needed to bring and maintain the residence to the desired condition of attractiveness and cleanliness.
- **Desired Amenities:** People desire different amenities in their housing. Often the absence of a single highly desired feature can substantially lower one's satisfaction. Among the features that have such weight for many people are showers, air conditioning, microwave ovens, washers and dryers, gardens, porches, decks, and balconies. In planning housing, it's important to learn from the person which amenities are important to him or her.
- **Single or Multiple Housing Units:** Some people view a single detached housing unit as important; for others there are clearly recognized (and sometimes unrecognized) advantages in multiple unit housing. The advantages of each are relatively obvious in dimensions such as pri-

vacy, shared space, noise, social contacts and informal monitoring, as well as in the factors of location, neighborhood, and proximity (see above). The availability of single vs. multiple unit housing also varies greatly from place to place, as do housing costs, the possible need for roommates/housemates, a choice between renting or buying, and other such factors.

■ Social and Personal Considerations

- **Roommates/Housemates:** Living with other people can sometimes be difficult and stressful as well as immensely rewarding. A basic principle of consumer controlled housing is that a person should live with whomever he or she wishes. The decision often requires substantial attention and discussion to determine which, how many, and under what conditions, people will share living space. Ideally, when people consider living together they have interpersonal experiences or other indicators of compatibility. It's important that all parties who consider sharing a housing unit become equally involved in considerations of their ability to enjoy and benefit from the experience. It's also important to understand the conditions under which roommates enter an arrangement, how it can be dissolved, and what happens to the housing if it is. Housemates have certain rights in law, as well as the property owner. (See page 8 for more details.)
 - **Permissibility of Desired Lifestyle:** It's important to make sure that reasonable freedom is afforded to individuals to live their desired lifestyles. Often, maintaining this freedom requires planning the future with the prospective house/apartment mate. For example, a person may not currently have a pet but might have a strong desire for one in the new home. In this case, buildings not allowing pets should be avoided. Similarly, persons with developmental disabilities who are younger, have active social lives, and enjoy loud music often do not enjoy living in housing primarily designed and administered for elderly people, even though the costs, accessibility, and support features may be desirable.
- ### ■ Housing Expenditures and Benefits
- **Affordability:** A major factor in any housing decision is the maximum amount of disposable income that is available for housing, and the relative trade-offs of spending at or below that maximum amount. When housing costs and the resources available for housing are separated from service costs, people with developmental disabilities enjoy the dignity of considering options and making choices (e.g., if relatively expensive housing is chosen, relatively less is available for discretionary expenditures or vice versa; if more people live together relatively more housing can be afforded or more resources can be spent on such items as cable TV and furniture). It's important that people receive whatever help they need to understand these options and the many other expenses that are associated with different housing decisions, such as taxes, transportation, utilities, insurance, repairs, likely rental increases, and the like. One option is to meet with a home-ownership counselor. For more information about home-ownership counselors, call Arc Minnesota or the Home Ownership Center (see Chapter 9 for contact information.)
 - **Stability/Flexibility:** A primary decision in housing selection is whether to rent or buy. In addition to the obvious financial considerations, the relative desire and/or need for stability or flexibility is of primary importance. If one or more persons commit themselves to a long-term stay in a home, purchasing that home may be a wise decision. On the other hand, if there is uncertainty about the likely length of stay, then the flexibility of renting has distinct advantages. For persons who do not have access to personal transportation, purchasing a home can tie one to a particular neighborhood and may limit access to new job opportunities and social involvements. As a rule, stability is relatively more important if a person has a well-developed social network in a neighborhood.
 - **Investment/Risk Taking:** In addition to providing shelter, home ownership is also an investment. Just how good an investment a given house is will vary with time and location. Some houses may appreciate in value much faster than

the inflation rate, only to slow down when the area economy stabilizes or declines. Other houses located in a declining neighborhood may actually lose value. Still, most carefully purchased homes do appreciate and build equity for their owners. Assuming that real estate prices will not deflate and that housing upkeep is not a significant additional cost, housing purchases tend to develop enough equity over a five-year period or longer to cover the purchasing or selling costs of the house. But it's important to keep in mind that home ownership also involves risks (deflation, repair expenses, tax increases, negative changes in neighborhood security, etc.). If the decision is made to exert more housing con-

trol by purchasing a property, who will ultimately be responsible for those risks? The answer is important.

- **Financial History:** Many people with developmental disabilities are limited in the housing market as either renters or owners by the absence of a solid financial history. One's credit history is a significant consideration in decisions by a landlord about a person's desirability as a tenant or by a bank about one's dependability as a mortgage borrower. It's often very helpful in renting or buying a first home if persons with developmental disabilities have been assisted and supported in establishing a financial and credit history. This can be done through checking ac-

A Dozen Questions About Housemate Compatibility

A house doesn't feel like home unless people are comfortable. Bob and Cynthia Laux, authors of *Your Place or Mine: A Handbook for Home Ownership*, have developed a dozen questions that housemates ought to answer to get a better sense of whether they'd be comfortable together.

- What do you have in common – music, sports, foods, etc.? In what ways do you differ – smoking, drinking, sleeping habits?
- Have you talked about your differences and how you'll deal with them?
- Have you spent enough time together doing a variety of things – trips, movies, concerts, etc. – to know each other?
- Have you discussed meals and meal planning, especially if you have different tastes in food or dietary needs?
- Do you trust each other? Do you feel you and your possessions will be safe?
- Have you talked about sharing responsibilities – who cleans the bathroom, cooks, does dishes or laundry?
- Did you talk about visitors? What happens when one of you wants to invite others over?
- Have you talked about the potential need or desire for other housemates? How will differences be resolved? What happens when one of you wants to move?
- Have you worked out an arrangement about furnishings? Who owns the furniture? Will you buy or own some things together?
- Have you discussed sexual issues? Will there be potential problems with companions?
- How will you deal with privacy? Will you have private as well as common spaces?
- Have you talked about how potential conflicts will be resolved? Do you know someone who can help to resolve differences when they arise?

counts, secured credit cards, and other recorded financial activities. It's also important that negative financial or credit flags be identified, addressed, and, if possible, removed from a person's financial records. If there are concerns, a

credit reporting agency can provide such a history. Such agencies can be found under "credit reporting agencies" in the yellow pages of the telephone book or on the Internet.

To Own or Rent: Relative Benefits

Deciding between home ownership or rental is a major financial decision in which many of the factors above are relevant. Some of the benefits that should be considered about either owning or renting a home are summarized in the following sections.

Control of Exterior and Interior Design

Owners have total control over the exterior and interior design of homes. However, in condominiums and town houses, the governing associations may have certain policies relating to decorations (e.g., no flamingos in yards), paint jobs (no purple houses), use of balconies (no laundry lines), to which owners must abide.

For renters, changes in exterior and interior design are controlled by a landlord. The landlord imposes limits on changes and a renter is ill-advised to invest his or her resources in improvements that he or she cannot move at the end of a lease and readily adapt to a new home.

Control of Activities

Owners generally have control over activities in their homes within limits of the law and the rules of any cooperative, condominium, or similar housing collective.

Renters may enjoy more freedom in their activities than in other residential settings – but landlords typically list rules in their contracts (e.g., no pets or waterbeds) that should be monitored carefully. It's recommend that specific questions be asked about any such rules and their interpretations.

Stability of Residence

Owners have a home for as long as they choose to remain in it and are able to maintain mortgage and tax payments.

Renters' assurance of stability is usually dictated by a contract that permits the landlord to terminate the housing at the contract's completion or for contract violations. In practice, however, landlords value the stability of "good" renters.

Stability of Payments

Owners have relatively stable long-term housing costs that vary primarily with changes in the costs of mortgages, taxes, insurance, utilities, and repairs.

Renters generally can expect housing costs to go up steadily with rental increases compounding the tax, insurance, and utility increases faced by owners.

Equity

Over time, owners establish cash value in their homes which can be used as collateral to borrow money for other items, realized at the sale of the house, used as an income stream through a reverse mortgage, or transferred tax-free to the purchase of a new home.

Renters acquire no equity but do not face the cash loss of an owner if a home is sold before sufficient equity has been built up to cover the costs of buying and selling.

Unexpected Costs

Owners must be ready to face unexpected, significant, and unavoidable expenditures for the repair or replacement of major appliances; internal heating, cooling and plumbing systems; and structural aspects of the property (roof, sidewalk, etc.).

Renters are generally removed from major unexpected costs for repairs and replacements; such costs usually are pro-rated among the tenants and added as part of the individual's rent.

Entry Costs for Housing

Owners often face significant costs in securing a home loan. These include down payment, loan origination fees, and other costs; they generally represent two to ten percent or more of the price of the house.

Renters face costs of entry into a property but generally they are far less than those of home buyers. Frequently, landlords require first and last months' rent and a deposit equal to one month's rent before an individual moves into an apartment.

Flexibility to Move

Owners should be aware that entering a contract to buy substantially limits their flexibility. Generally, home buyers are forewarned against buying homes they will live in for less than four or five years unless they can afford to accept a significant financial loss in the total cost of buying and selling the property.

Renters have much greater flexibility than owners. The degree of flexibility is stipulated by the rental contract. While most contracts are annual, shorter contracts and breaking a contract often can be negotiated at a premium.

Property Upkeep

Owners generally are responsible for maintaining the exterior of the house and the land around it (notably the lawn and sidewalks). This responsibility can represent significant work for individuals and families or significant costs if the work is done by others.

Renters are usually not responsible for maintaining the exterior of a house and its surrounding property, except for yard care and snow removal. Generally, when they do such maintenance, the materials and equipment are provided by the landlord and some form of discount on rent is arranged in return.

Housing and Lifestyle Planning

The success of consumer controlled housing arrangements rests heavily on good planning of both housing and lifestyle. There is no substitute. As noted earlier, people who wish to develop optimal housing arrangements must consider many factors and options. This guidebook provides a start; further consultation with consumers, family members, local housing experts, county officials, service providers, and Arc chapters add to the possibilities. The involvement of local officials – especially the person's case manager – is essential to assure the availability of the supportive services and programs necessary for the person to live in his or her own home.

Because of multi-agency involvement, and the complexity and uniqueness of each person's desired housing and lifestyle, careful person-centered planning is absolutely essential. Certain features of successful housing and lifestyle plans are described in this section, but much more detail is available on specific planning approaches from the resources identified in Chapter 9. Given that the concepts of person-centered planning and consumer controlled

housing are fairly new, neither the person with a developmental disability nor his or her parents or advocates should expect everyone whom they consult, including the case manager and county board, to be knowledgeable or even supportive of the ideas. Those who plan must have a clear vision of what they want and be prepared to educate "experts" to help them to make the housing vision a reality.

■ Elements of Effective Plans

Effective housing and lifestyle plans for consumer controlled housing contain certain essential elements:

- The plan is built around the needs and desires of the person who will reside in the home. All needed supports are provided, including program services and services related to the upkeep of the residence. The person who will benefit from the plan is involved in its development to the greatest extent possible, and his or her choices of location, structure, housemates, etc.,

are honored or renegotiated, based on specifically identified constraints.

- The plan is based on a realistic assessment of the current and potential resources available to the person, including income, support systems (formal and informal), specialized and generic services, and available resources for financing what the person needs and wants in life.
- The plan has been developed with the involvement of all the people whose commitments are essential to carrying out the plan. The people include parents, siblings, other relatives, friends, neighbors, case managers, service providers, real estate professionals, etc., as well as the person with a developmental disability.
- 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 kept flexible to meet the changing needs and desires of the consumer. In addition to service provision and housing payments, day-to-day expenses and responsibilities are also planned for, such as payment of bills, tax liability, insurance coverage, building upkeep, unexpected losses, etc.
- The plan has a long-term focus – not in terms of locking the person into a single view of the future but in terms of attending to the long-range aspirations and basic needs of the consumer.
- Lifestyle considerations are the primary focus of attention. The focus of consumer controlled housing should always be the ability to contribute to a desired lifestyle; the housing is not an end in itself. Controlling one's own housing does not automatically guarantee opportunities for enjoyable social contacts and community participation. For example, large-scale housing developments designed solely for persons with developmental disabilities may hinder residents from being active in the larger community. 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 community work as well as to recreational and other programs.

■ Person-Centered Lifestyle Planning Approaches

People who plan consumer controlled housing arrangements are likely to find that certain desired results are often difficult to attain or even may conflict with the plan (e.g., in areas of safety and independence, affordability, and personal preference). Such instances call for creativity, ingenuity, persistence, and compromise. In many situations, the “system” isn't ready to accommodate the need, whether it's an affordable mortgage, an appropriate service program, or eligibility for a funding stream. Achieving workable solutions is done most effectively through group effort. People seeking to develop and implement consumer controlled housing and lifestyle plans should initiate contact with their case manager early and be prepared to educate members of the service system at all levels. Networking with families, consumers and other individuals with similar interests, and working with established advocacy groups (e.g., Arc Minnesota and local Arc chapters), are ways to shape the system and to increase its capacity to assist people in securing homes of their own.

Before people begin to think about where they want to live, they should think carefully about *how* they want to live.

There are no magical approaches to doing person-centered planning right. That ultimately depends on the care, commitment and creativity of those involved. But for people seeking a structure for person-centered planning, well-developed, successfully tested methods do exist.

Over the past few years, a number of person-centered planning processes have been developed and used successfully to assist people to define and realize the lifestyles they want for themselves. But for many people it's only after the elements of the desired lifestyle have been defined that it makes sense to think about how housing might contribute to that desired lifestyle.

The *McGill Action Planning System* (MAPS), *Personal Futures Planning* (PFP), *Life-Style Planning* (LSP), and *Essential Lifestyle Planning* (ELP) structure the processes of information gathering, brainstorming, and consumer-centered group processes which are used to identify and plan lifestyles and to enhance the quality of life for individuals with developmental disabilities. The MAPS, PFP, LSP,

and ELP processes all begin with the recruitment and preparation of a small group of family members, friends, and significant staff people to work together with the person with a developmental disability to develop the vision and means of enhancing the individual's lifestyle in ways that are pleasing to him or her. Typically, the initial phases of person-centered planning involve the contributions of each participant to define his or her special knowledge and understanding of the focus individual. These contributions may occur as part of a review of the individual's "life history" through the eyes of the group members and those of the individual, or it may involve other strategies to identify what is important to a high-quality lifestyle for the individual (e.g., gathering information about the individual's current relationships, where the individual likes to spend time, the individual's preferences and interests, the individual's abilities and positive characteristics, and so forth). Participants also concentrate on how the individual can contribute to others, and on the assistance and/or accommodations the individual may need from others.

Creating a "vision" or "dream" is often the next step. This must be accomplished before people can determine how to create opportunities for the desired lifestyle. This vision is a highly personalized view of what the individual and committed family and friends want for him or her. At times, these visions are comprehensive and encompass almost every aspect of the person's life. In other cases, they are quite simple and may consist of nothing more than the individual's desire to have a home of his or her own and/or to establish one close friendship.

During this phase of person-centered planning, some facilitators also encourage planning groups to initiate discussion of the "worst nightmares" that might occur to the individual. This process deals directly with the anxieties that many participants may have regarding the future of the person with developmental disabilities if he or she has an opportunity to live out the dream of a consumer controlled home. Housing issues often come up in this stage because home is such a central part of one's lifestyle. Identifying worst-case scenarios often helps participants to think through economic, social, and safety issues associated with different residential situations (e.g., an individual may move to a safe neighborhood but be relatively isolated from

old and valued friends and/or have little money left for favorite activities). It often results in the group being able to focus planning to minimize the chance of this "worst-case scenario" happening.

The initial phases of person-centered planning are often done in sessions that last three hours or longer. Upon completion, the facilitator, the subject of the planning, and members of the planning group should have an in-depth knowledge of the subject, including his or her personal goals and vision for a community lifestyle. They should also have an understanding of the essential aspects of the person's lifestyle (called "non-negotiables" in ELP). The task then shifts to engaging the group in the development of a plan of action that will make the focus person's vision a reality. Developing an "action plan" is the beginning of the intervention phase of person-centered inclusion planning; it involves the group in deciding what can be done to support the person's lifestyle through housing, relationships, work, community participation, formal and informal supports, and other means.

Throughout the planning and implementation process, the group facilitator and other participants continue to meet, though not necessarily as a complete group, to insure that the lifestyle plan developed is effectively carried out and that changes are made when necessary. (Changes are always needed.) Sometimes "subgroups" are formed to take responsibility for overseeing the implementation of particular aspects of the more comprehensive intervention plan (e.g., locating, financing, and maintaining the individual's home). These persons communicate with each other on a regular basis to flesh out the various aspects of the intervention plan. The intervention phase of person-centered planning continues until the individual and the group decide that the vision of the lifestyle, which was created at initial meetings, has been achieved and can be sustained.

By its very nature, the process of person-centered planning is flexible. The person-centered planning group may vary in size and membership in accordance with current needs and goals. New people may be recruited and invited in as they or the group express an interest in participating. The goals and needs of the individual may change as goals are attained and skills, experience, and a sense of empowerment grow. The group may formally dissolve

after a period of time although participants may continue independent involvement in the individual's life. Nevertheless, groups often re-form to assist the focus person when problems, new aspirations for the future, or periods of transition arise.

Person-centered planning has been a valuable tool for defining the essential aspects of a satisfying lifestyle for an individual and for planning the means to achieve that lifestyle. Because a home is such a basic part of one's lifestyle, person-centered planning for an adolescent or adult should not fail to attend to the questions of how, where, and with whom the person will live. Person-centered planning is an excellent process for addressing such questions within the broader context of all the many things the individual wants and needs in life. Chapter 9 lists some excellent resources on the different models of person-centered planning (especially *Personal Futures Planning* developed and published by the Metropolitan Council).

■ Circles of Support

In viewing a home of one's own as a means to realize one's desired lifestyle, lifestyle and associated housing plans are extremely important in identifying and putting in place the key elements for an individual's desired home and life in a community. But few people's lives ever stick to a plan. Often, people change their minds about how they want to live, requiring changes in the best of plans. Because change and new challenges are predictable among people who are gaining control of their homes and lifestyles, it's important that they be surrounded by others who will monitor and support them on an ongoing basis.

Such people are sometimes referred to as "circles of support," and typically include family members and friends, volunteer advocates, staff members who are particularly close to the individual, supportive case managers, and others. A circle of support is defined less by role than by a common commitment to assist a person to live life on his or her own terms.

Circles of support may be formalized. They may be defined as a group of people come together at set periods of time to develop and monitor an individual's service plan (e.g., as in California's Community Supported Living Arrangements program); or they may be less formally defined, that is,

they may include all the people who contribute to the individual's achievement of a desired lifestyle. Most circles of support fall somewhere between formal official roles and loose collections of the individual's allies. In general, circles of support are groups of people who work together to support a person in defining and achieving the lifestyle he or she desires. People in the circle share "knowledge" (often different) of the individual, a deep concern for him or her, a strong desire to support the individual in realizing his or her dreams, and a willingness to commit personal time and energy to help.

It's often through the interaction of the person with disabilities and the circle of support in the planning processes just described that these dreams of a compatible lifestyle are defined and plans for achieving them are developed. Unlike the members of traditional interdisciplinary assessment teams, members of the circle of support see their role as ongoing, not periodic, and as participatory, not advisory. Members of the individual's circle gather regularly around the person with disabilities with the explicit and singular purpose of playing a significant role in assisting the person to achieve his or her dreams. Usually, circles of support employ skilled facilitators to assist circle members in solving the inevitable problems.

Keys to Circles of Support

According to Pat Beeman and George Ducharme (1988), there are a number of keys to developing circles of support:

- **The focus person and family must want change.** Developing a futures plan and forming a network of support is not for everyone. The focus person and the family must want to be part of this process. They must want changes to occur and be willing to help make those changes happen.
- **Focus on an individual to generate a vision.** A vision of what the individual desires will help to determine the structure and strategies of the plan. Knowing the person's vision will help to keep everyone in the network on track when barriers get in the way. When creating a vision, listen to the desires and goals of the focus person and build on what the person says.

- **Plan for success.** Start small; don't take on too much at any one time. This rule should ensure some early successes and movement toward the more difficult steps that may be encountered along the way to the comprehensive vision. The quality of the achievement is more important than the quality of the goal. Don't expect things to happen overnight. Good things take time to develop.
- **Empower people to develop their own visions.** Promote confidence and support achievement. Avoid telling the focus person what is "right" or what is "wrong" about the vision. Everyone has a right to make choices about his or her life and to make mistakes. "Mistakes" are not failures but opportunities to build on valuable experience. Help the individual to focus on his or her strengths and abilities, and on how they can contribute to making his or her vision become a reality. Describe barriers realistically; don't exaggerate them because this might discourage group members. Consider ways the community can help remove those barriers and bring the vision to life. Remember that empowerment starts from the inside out not from the outside in. Short circuiting the empowerment process for the focus person may be counterproductive.
- **Be inclusive and supportive of interested friends, family, and others who care about the person.** Encourage the focus person or the family to invite family members, friends, and neighbors to become part of the support network. Look for the abilities, energies, and resources of group members. View different ideas as ways to discover new things and to see new solutions.
- **Identify members of the group who are active in community life to help make connections within the community.** Seek out group members who are actively engaged with various associations in the community and consider how those associations can help to remove barriers to realization of the focus person's vision.

- **Look outside for connections to increase community involvement.** Some connections may be made through relatives and friends. Where do they work? What clubs do they belong to? What churches do they go to? How might these friends and relatives help the individual to begin to get involved? Find out who are other members of these clubs and associations. Do they or their families have needs or interests that could be matched with the focus person's?

Beeman, P. & Ducharme, G. (1988). *One candle power: Building bridges into community life.* Available from Northspring Consulting, Box 93, North Granby, CT 06060.

Beth Mount, an author of the booklet *It's Never Too Early, It's Never Too Late*, has also summarized some features of circles of support which make them better able to contribute to people who are trying to realize their dreams:

- A skilled facilitator is available to the circle.
- All the circle members, including the focus person, attend to capacities and opportunities rather than disabilities, deficiencies, and barriers.
- Circle members are in position to find out about new possibilities and new ways to organize the assistance the focus person needs.
- At least one circle member has a strong commitment to act vigorously on the focus person's behalf.
- Some circle of support members are active in organizations and coalitions that are focused on changing unjust or ineffective policies.
- Some circle of support members develop influence with people who make policy and administer human service programs that affect the quality of the focus person's life.
- At least one human-service program relied upon by the focus person has an explicit commitment to improving its ability to support people's full participation in community life.

Mount, B. and Zwerink, K. *It's Never Too Early, It's Never Too Late: A Booklet About Personal Futures Planning.* Available from the Metropolitan Council, St. Paul, 651-602-1000.

Thinking About Affordability

The housing options available to people in the United States are largely a function their of relative wealth. For people with substantial incomes, few financial considerations prevent them from making housing decisions on a straight-forward assessment of how the housing meets their needs and preferences. For people with limited incomes, just the opposite is true. Housing decisions must be based on simultaneous assessment of financial considerations and personal preferences and needs. There are a number of areas people should explore in weighing affordability and achieving one's dream home; remember, however, that few people are able to obtain everything they desire in housing.

■ The Basic Budget: How Much is Available for Housing?

A basic budget is an important foundation for considering how much money one can spend for housing. A budget helps to identify all the essential things in one's life that cost money. It helps one to understand how spending more or less for some things may make more or less money available for others. Because housing takes so much of a person's total budget and because there are so many ways to spend and save on housing, housing is a very important and often the largest part of a person's budget. How much one decides to spend on housing, consequently, has a major influence on the other things one can do.

The basic budget begins with the present monthly resources and the detailing of one's essentials in housing and lifestyle. Then one can determine how much money one has for housing and the minimum amount of the remaining money that can be spent on the remaining essentials. Things to consider include:

- What is the individual's total current income that is available for housing (e.g., SSI/SSDI/MSA, work income, family contributions, etc.)?
- What are the supplements for utilities, food, transportation, etc. that the person now has or

has guaranteed access to (e.g., food stamps, low-income heat share, reduced rate bus passes, etc.)?

- What does the person's credit history and/or rental history look like? How will the strengths and weaknesses of these affect rental or mortgage limits?
- What are the individual's support needs and how will they be provided by the services system (e.g., personal assistance, medical services)? What parts of an individual's life needs can be provided or supplemented by family and friends to save resources for other uses (e.g., family-provided transportation, personal assistance on weekends)?

■ Living With Other People

Living with other people is one of the most sensitive issues in housing for persons with disabilities. Part of the reason is that the goal is often to create opportunities that are different from the dominant congregate care models. Housing is such a substantial cost to people with limited incomes, however, it's hard to avoid considering the economic benefits of house sharing. Indeed, house sharing is evident all through our society as single persons and small households with low (and often middle) incomes join each other to afford to live in the neighborhoods they want.

Compatibility among roommates was discussed earlier. In thinking about roommates as an aspect of affordability, finding ways to live with other people is often as much an issue of household and support design as it is of compatibility. It often requires considerable exploration of individual perspectives. Some people who say they do not want to live with other people mean that they do not want to live with other people who have developmental disabilities, but a non-disabled roommate would be acceptable, even enjoyable. Creativity in exploring ways to share housing costs without violating an individual's essential requirements for

housing is often a major factor in helping a consumer to realize his or her preferred lifestyle within the resources available.

Things to consider include:

- What primary considerations underlie the person's expressed desires for housing arrangements and the possibilities for living with others (e.g., avoiding group home regimentation, not being identified as having mental retardation, being able to choose and cook one's own food)? What alternatives can be shown to the person with developmental disabilities that address these considerations?
- What are some of the ways that can be used to keep both the housing and support needs of the individual within affordable ranges (e.g., live-in roommates who provide some supports and/or emergency assistance, shared housing to which the person with developmental disabilities makes specifically defined, necessary contributions)?

■ Resources and Available Assistance

Many people have access to resources that are not part of their basic budget. Indeed many people need access to resources beyond their basic budget to realize the lifestyle they want to live. Basic entitlements (SSI /Medicaid) or disability insurance benefits (SSDI/Medicare) are usually accessed by eligible people, but not always. Section 8 and state and local rental assistance programs typically have long waiting lists that discourage many people from applying, but even if there is a two to three year wait for a benefit it's still worth tens of thousands of dollars over one's lifetime. Food stamps are another benefit that is often not obtained even though worth thousands of dollars. Other public benefits like subsidized public transportation and public food shelves also are available for many communities. The potential for increased income through work for many people is substantial if they are properly supported.

Public benefits are often added to by many families, friends, and civic organizations. Some families and friends may prefer to subsidize people's lives in specific ways, such as paying for cable television for Christmas, buying clothing to free more

money for housing, and so forth. Civic and advocacy organizations often identify specific needs of people which are related to their homes and desired lifestyles and then help to locate benefactors (known or unknown) to fulfill to the person's need.

Things to consider include:

- What opportunities can be developed or expanded to increase the individual's earned income?
- What assistance and resources, available from the individual's family and friends, can help to obtain essential and desired services or items? Can available assistance free resources for other essentials or desirables?
- What civic and advocacy organizations can offer assistance, resources, or goods (e.g., food or furniture) to individuals with developmental disabilities to help them live the lifestyle they desire?
- What primary public income, medical assistance, other programs, cash and service resources, and subsidies are available to the person? How well have they been identified and used to maximize the individual's resources?

■ Living Within a Budget

One of the major challenges to having a home of one's own is staying on a budget after the home is established. There are always new goods and services to buy. Getting to know one's neighborhood may mean finding new ways to spend money in it. Yet living on a budget is also an experience that exemplifies control over one's life and resources. With that control comes the responsibility to manage one's own resources. For people to live on a budget they must know as much as they can understand about where their money comes from and where it goes. They need to have a sense of stable income and core expenditures to provide the basis for making financial decisions. The decisions may range from whether to save or spend money that's left over to deciding what spending to reduce to balance a budget or increase savings.

Things to consider include:

- What are the monthly sources of income: a) Social Security Benefits/Minnesota supplement; b) wages earned; c) rent and other subsidies (Section 8, food stamps); d) other income, including set monthly (budgetable) gifts; e) payments, from housemates, for garage rental, etc.?
- What are the basic monthly expenses: a) rent/mortgage (including taxes); b) utilities (gas, electricity, water, sewer); c) telephone (basic, long distance); d) insurance; e) repairs, replacements and maintenance; f) other home-related "essentials" such as cable TV, transportation to work, etc.?
- What is the difference between the monthly sources of income and the basic monthly expenses? Include the needed set-aside amounts for maintenance, repairs, and equipment.
- Is the difference enough for satisfactory involvement in all other desired activities?
- Are strategies used to increase the resources for other desired involvements (e.g., clipping advertising coupons, buying monthly bus passes)?

■ Meeting Day-to-Day Living Expenses

Whether they own or rent, people need a dependable source of income to meet mortgage, taxes, insurance, upkeep, co-op dues, rent, food, clothing, and other such living expenses. Some of the major funding sources used by adults who have developmental disabilities and are living in their own homes follow:

Supplemental Security Income (SSI), Minnesota Supplemental Aid (MSA), and Group Residential Housing (GRH)

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 recipients whose SSI grant is below state standards. On January 1, 2000, \$512 was the maximum monthly SSI grant award and \$621 was the maximum monthly MSA grant. (Cost-of-living adjustments are added annually for inflation.) The amount of the grant is determined by

the county of residence. SSI/MSA are applied for at the county social services office.

It's 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 programs (see Chapter 4).

If you choose to have the home operate as a licensed program, the people living there may be eligible to receive a Group Residential Housing (GRH) supplemental room and board rate. This rate is in addition to the MSA rate, but is paid directly to the provider of the support services. The GRH rate is negotiated between the county and provider. GRH can only be used for living expenses. Rates will vary by county.

Social Security Disability Insurance (SSDI)

SSDI is a social *insurance* program (in contrast to SSI, which is a social *entitlement* program) administered by the Social Security Administration. It provides assistance to eligible persons who are disabled.

Persons with severe disabilities may qualify for "childhood disability benefits" under this program after they reach their eighteenth birthdays, if they are the sons or daughters of workers entitled to Social Security retirement benefits or disability benefits, or of insured workers who have 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 federal 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 twelve 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 twenty-two years.

Benefits are paid monthly directly to the beneficiary, by direct deposit to a financial organization (e.g., bank, credit union, or trust) or to a representative payee. The benefit amount is determined by the amount of Social Security taxes paid in by the insured worker. Application is made through local Social Security Administration offices.

Food Stamps

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

Earned Income

Of course, income derived from employment is an important source of funds for the living expenses of many, if not most, persons with developmental disabilities who live in their own homes. Arguably, living in a home purchased, at least in part, with income earned through employment increases the owners' pride and satisfaction in having homes of their own. Recent changes in state and federal laws make it easier for persons with developmental disabilities to keep earned income while remaining eligible for long-term support services.

Trust Funds

Persons with developmental disabilities who live in their own homes may be helped to meet living expenses through trust funds set aside by their parents or other family members. 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 or after the parents' death. (For further information on trusts, see Chapter 7.)

■ *Worksheets for Choosing a Home*

When a person is choosing a home, a specific checklist of what is important to the individual is very helpful. Appendix A contains a number of worksheets that can help people choose homes they will like. But these are just examples of lists that can be used to help people decide on a neighborhood and home. It's important to make sure each individual has a personalized "checklist" that truly reflects his or her specific needs and desires in housing.

The Keys are Mine!

By Kevin Otley

When I lived at the Lake Owasso county institution in Minnesota, you had to ask for everything: "Can you let me out?," "Can I have a can of pop?," "Can I stay up a little bit longer?"

When I moved into a group home, I had to follow all the rules. I had to go to bed at a certain time, and when I was in bed, I had to be asleep: that was that. I lived with two other guys. We were being watched all the time, twenty-four hours a day, seven days a week.

Seven years ago I got married. My wife and I moved into our own apartment. Now that I have my own place, I make the decisions. I have my own keys. I can let myself out and let myself back in.

Now I can come and go when I want. I can make my own food, and I decide whether I want to have breakfast or lunch, or when I'm ready for a snack. We can invite friends to stay over. My wife and I decide when the staff come over. They help us with some things, but we make our own decisions.

Reprinted with permission from Voiceprint, a publication of Advocating Change Together, St. Paul, Minnesota.

3

Ownership as a Means of Consumer Control

Introduction

Home ownership is a dream for many people, but of little interest or even a nightmare to others. Before committing to home ownership, it's important to make sure that ownership contributes to the person's desired lifestyle (e.g., it's usually a poor option for people who like to try new surroundings and have more flexibility). Even when personal preferences and desired lifestyle support a person's goal of pur-

chasing a home, some considerations should be addressed in the planning strategies. But before getting to the "heavy" considerations and the major housing options, it's good to reflect on why people go to all that trouble. Mike Hansen's comments on the following page are very helpful in that regard. Mike lived in apartments for many years but in late November 1993 he moved into his own house.

Deciding About Home Ownership

Deciding who will be the legal owner(s) of a house being purchased by and/or for a person with developmental disabilities sometimes requires consideration of many possibilities. The factors may have significant implications concerning obtaining necessary financing, fulfilling individual desires, securing the support of family and friends, and other issues that vary for different people and situations. After reviewing the eligibility requirements of the various programs and services that the individual may need to support him- or herself, consideration can be given to selecting the appropriate party and approach to purchasing and owning the dwelling.

The following considerations may prove useful.

■ **Advantages & Disadvantages of Certain Types of Ownership**

Owner-Occupant

Advantages

- Pride of ownership – it's *really* the person's house.

- Control over the living environment.
- Equity build up.

Disadvantages

- Possible difficulty in coming up with down payment, as well as monthly mortgage payments.
- Potential for needing a great deal of support with the responsibilities of home ownership and home maintenance.

Parent- or Relative-Owned

Advantages

- Promotes relatives' taking a more active role in the support of a loved one.
- Parents may have greater potential for making a down payment.
- Minnesota law allows for homestead classification for property taxes when property is occupied by an immediate family member. (See page 34.)

Disadvantages

- Potential for increased tax liabilities for families if property increases in value or if there are increased assessments.
- Less control by the consumer.
- Extra work for parents due to the responsibility of property ownership.

Trust-Owned

Ownership is assigned to a "living trust" set up by parents (see Chapter 7 for more details).

Advantages

- Parents can set aside and protect a portion of their assets for the benefit of their son or daughter who has developmental disabilities, while maintaining their eligibility for governmental programs.

Disadvantages

- Laws affecting trusts may change over time.
- Legal expenses are incurred in setting up and maintaining a trust.
- Tax consequences require advice and planning.

Corporation-Owned

Family members and others, including family members of other tenants, set up a corporation to purchase, own, and maintain the housing.

Advantages

- Potentially the most durable instrument.
- The owners can limit their liability.
- Combined resources can yield greater purchasing power.

Disadvantages

- Loss of consumer or family control to a board of directors.
- Red tape and legal expenses are involved in setting up the corporation.
- Less consumer control.

Partnerships

Consumers and/or parents combine resources with others to purchase the dwelling.

Advantages

- Combined resources yield greater purchasing power.

Being a Home Owner

By Mike Hansen

Being a home owner means I'm no longer paying rent and getting nothing in return. I finally have a place that holds all my belongings.

I feel a part of the community. I know my neighbors and they know me. We help each other. A few weeks ago during a storm, strong winds blew down a tree in my front yard. A neighbor saw me having a hard time sawing the tree with a bow saw, so he got his chainsaw out and sawed the tree into pieces in no time. Then I gave him all the wood to use in his fireplace.

I feel more of an equal with my family and people in the community. Most people are home owners – I am too. I feel that I have more to talk about with them. We share the same experiences – the good and the bad.

Being a home owner makes me feel proud. My family helped me paint. My house looks great. Every time I fix something I feel proud. Owning my own home hasn't been all glory. Snow removal can be a back breaker. Also, there's a lot to do. Sometimes the inside repairs are tough, but I can usually find someone for help or advice. Sometimes I worry how to pay for repairs. Most people are OK with payments – otherwise I save up.

But one thing is for sure: I never want to go back to not being a home owner.

Reprinted with permission from Voiceprint, a publication of Advocating Change Together, St. Paul, MN.

Disadvantages

- Upon the exit of a partner, the remaining partners may be left to support a substantially increased financial burden.
- Loss of consumer and/or family control to other partner(s).

Shared Equity

The individual makes the purchase with another party – e.g., parent, friend, housemate, investor – and gradually buys out the other party over time.

Advantages

- Combined resources yield greater purchasing power.
- Allows the financial obligations of ownership to be achieved gradually.
- Allows the individual to get into a home with less initial expense.

Disadvantages

- Control of property by resident may be diminished by the relatively lower equity.

Housing Cooperatives

A housing cooperative – a *coop* – is a group of people organized for the purpose of owning, building, or rehabilitating housing for its members. The group legally incorporates itself and owns all property, as provided in its articles of incorporation and

bylaws. A member (shareholder) does not own his or her own dwelling unit; he or she owns a membership certificate that entitles him or 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.

See the section “Nonconventional Approaches to Housing” later in this chapter for more details.

Advantages

- Opportunity for ownership could occur with less money for a down payment.
- Opportunities for social interaction and integration can be structured based on how the coop is established.
- 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 rather than real property. (However, for Medical Assistance eligibility purposes, a share of a coop in which an applicant lives would be considered exempt personal property like a home.)
- A shareholder can be “voted out” of a coop by his or her fellow shareholders.
- In “limited equity” coops (see description in this chapter) members do not realize benefits from any increase in the property’s value.

Home-Buyer, Home-Ownership Education

Deciding to buy a house can be a complicated decision. The process can be confusing. Other people want to give advice and tell stories about their experience buying a house or working with a lender. Not understanding the home-buying process can prevent many people from even thinking that they can buy their own home.

Home-buyer training is available throughout Minnesota. Through training, people are provided with the information that they need to make sound decisions about their home purchase, as well as to

remain successful homeowners. Home-buyer training includes two parts. Education is the part offered by a set of housing professionals in a workshop setting. A group of people interested in learning about home ownership come together for a class. Topics included in the class are: basic “how-to’s” of budgeting, saving for the home purchase and after home ownership, shopping for a house, working with different housing professionals, the mortgage application process, different mortgage products, and expectations of home ownership.

From Family Home to Home of Their Own: Stacy and Druanne Lockwood's Story

By Christine Stehly

All good parents have a vision of their children's future that includes the eventual building of a life of their own as independent adults. That vision sometimes has to be modified if a son or daughter has severe disabilities. In 1980, Audrey and Bob Lockwood of Minneapolis latched onto the idea that their two daughters could live in a home of their own, independent of their parents, even though both women have severe cognitive and physical disabilities. The process of making that idea a reality took the next five years.

Stacy and Druanne Lockwood once shared a five-bedroom home with their parents. As the women entered their early twenties, Audrey and Bob thought the house would be a perfect place for their daughters to live with other women their own age. In 1984, after encountering difficulty in implementing the plan owing to changes in the law governing group homes, the Lockwoods were ready to give up on the idea. Their housing concept was categorized as a group home by the state, and a hold on funds to create such housing was in effect.

Then in 1984, the Medicaid HCBS program entered the picture in Minnesota. Waiver services permitted the plan to be put into action by making funding available for a staff to come into private homes to assist families. Interviews were conducted with various management companies, and one was selected. The director of the management company became a "foster parent" to the women to fulfill requirements for the home's licensing to receive additional funding. Roommates were found among Stacy and Druanne's coworkers at a developmental achievement center. Thus, in the fall of 1985, Audrey and Bob moved out of their home and turned it over to their daughters, two roommates, support providers, and the management company.

During the first two years of the arrangement it was difficult to stabilize the household because of support provider turnover. That has since changed; the newest staff member was hired almost three years ago. Of the three female staff members who live at the house, two are present whenever the four women residents are home. When the Lockwoods and their roommates are at work, the staff are at other jobs.

Just like any other home, each person has responsibilities and interests. Each housemate, with assistance from staff, contributes to cleaning duties, meal preparation, and grocery shopping. Currently, all four women work at a developmental achievement center; Audrey and Bob are in the process of helping Stacy and Druanne find other work, however, because they would like their daughters to be able to interact more with people other than their roommates. Out-of-the-home leisure activities include attending a weekly club at church. Other leisure activities are in-home with roommates or alone; Audrey and Bob are exploring ways for their daughters to increase their social involvements through community group activities at least three times a month.

The Lockwoods' arrangement hasn't been without problems. The parents haven't always been satisfied with the management company. They feel there have been breakdowns in communication, leaving Audrey and Bob uninformed about changes they consider important. There have been disputes about whether home maintenance is being adequately handled by the company. Other management firms have been approached, but they share one problem: They all want the Lockwoods to hire a live-in husband and wife couple as a solution to the maintenance problem. Audrey and Bob don't want a live-in couple because they would take on the role of parent figures. They want Stacy and Druanne to continue to live on their own with female peers, not second parents. If a satisfactory arrangement with a management company can't be made, Audrey and Bob will consider moving back into the home. This, however, would reduce their daughters' independence and is seen as a last resort.

[Continued on next page]

Despite all the challenges, Bob and Audrey remain committed to their daughters' having a home of their own and living their lives in the community and recognize that their own role needs to remain an active one.

Note: Since the above article was written in 1990, several changes have taken place. The original staff model was a three-staff "live-in" model. There were problems with staff turnover and coordination. This led to a change in selection of the management team. The second management team operated with a "live-in House Mother" model. This led to the type of concerns mentioned in the above article about whose home was it and whose values and morals were being followed. The second management team suddenly left and took Stacy's and Druanne's roommates with them. Audrey and Bob (the parents) were forced to move back into the home for a year to care for their daughters.

Since 1994, the home has been running smoothly. A third management team that uses a "shift staff" model with a coordinator in charge is now in place. This seems to be the best option based on the family's experience. The relationship between the Lockwoods and the service provider's management team and staff has been very workable.

Adapted with permission from Impact 3(1), 1990, published by the Institute on Community Integration, University of Minnesota.

The second part of home-buyer training is counseling. Counseling offers the chance for potential home buyers to meet with and work individually with a mortgage loan counselor to determine when they might be ready for home ownership. The counselors help to prepare people for the mortgage loan application by looking at income, credit, debt, savings, and all the necessary documents needed. Counselors will work with people to identify barriers to home ownership and to assist in discovering solutions to overcoming those barriers. Counselors are available to help with credit decision making and procedures to developing a corrective action plan.

Why is home-buyer training an important part of the home-buying process? The housing marketplace is changing rapidly. Mortgage loan counselors and educators keep up to date with the latest information. The classes and counseling can help to demystify the process by teaching the facts of mortgage lending and real estate. A potential home buyer gains the confidence to evaluate "how much house" is affordable, so as to be successful in the long term and to go about finding the best house.

When consumers are informed and knowledgeable about an investment, they are less likely to walk away from that investment or to be taken advantage of by others.

Home-buyer training provides a path and the opportunity for successful home ownership for potential home buyers throughout Minnesota. Potential buyers increase their knowledge of the home-buying process and the responsibilities of home ownership through education and counseling that is of a consistent quality. Potential home buyers that complete the education will receive a certificate of completion. Many of the quality, preferred mortgage products require the education and the certificate. In addition, to receive many of the down-payment, closing-cost, or entry-cost assistance products, the certificate is required. For a potential home buyer, it is best to take the class before looking at houses or beginning to work with a real estate professional. With the knowledge gained in a class, an informed decision can be made if home ownership is best at this time, some time in the future, or not at all.

Jim Benson's Journey from Family Home to a Home of His Own

By His Father

Our son Jim lived in our St. Paul, Minnesota, home for twenty-five years. As we grew older and Jim became an adult, it became apparent that we should seek a stable residence he could call home and that would remain his home after we are gone. In our first attempt to meet these goals, Jim moved into a small community group home. He lived there for four years. During the fourth year, he experienced severe injuries that forced him to undergo several operations on his hip; subsequently he spent three years in a nursing home. We searched for a new home for Jim during his stay in the nursing home but the search was made difficult because the state of Minnesota had declared a moratorium on building new group homes. Existing group homes had waiting lists that stretched out to years. In reality, it was because there were no other options that we began working closely with advocacy organizations and our local government to find a path enabling Jim to live in a home of his own.

Each step of the process was filled with uncertainties. The process was not only new to us, but, also, to almost everyone else. Funding had to be found for support services, household expenses, and real estate costs. There were complex questions about possible roommates and about their opportunities for control over their home if, in fact, Jim was the landlord. Related issues that were new to us put us on hold until the county reached a decision. Finally, with county approvals, we looked at over fifty properties before finding Jim's new house.

At this point, we naively thought our problems were behind us. Our first disillusionment appeared when it became apparent that the organization that provided staff for the home viewed it as just another group home in which where they made the decisions and didn't share information with us as a family – we were an integral part of Jim's life and support team. We felt that they considered their staff's stability more important than Jim's welfare or quality of life. In time, we concluded that the agency or its staff was incompetent and, with the county's approval, severed relations with this agency. Looking back, we see the delicate relationship and demanding expectations one holds for an agency when you expect assistance in making a house a home.

The second organization we selected improved the care and support given and was more open to sharing information with us as a family and members of the team. Things went well for a year. This organization experienced substantial growth, which resulted in layers of supervisory administration. Along with this we felt that the understanding of Jim's needs as well as those of the "home" were so filtered that support, care, and mutual understanding suffered greatly. And so two years after starting with the second provider, we changed to a third, the current provider of staff. This time we chose a much smaller organization. Right from the start, they showed competence and real understanding of the young people residing in the home. More than three years have passed and we are very grateful each day for the association that we've established and fostered with this organization.

Five years later, a well-coordinated team of parents, provider staff, doctors, dentists, day-activity staff, and social workers has closely monitored Jim's life. His progress has been made possible by the stability and close-working harmony of Jim's team. For instance, Jim's neurologist left the St. Paul area and relocated to Minneapolis. Provider staff were about to accept the next available St. Paul neurologist, but we, as his parents, had a long working relationship with the departing neurologist and felt that his credentials as an internationally respected leader in his work, plus his intimate knowledge of Jim, warranted the special effort needed to maintain his ties with Jim. The result was that Jim continued to make progress with increasing momentum.

Another example of the quality of the relationship was when Jim's feet were not getting enough blood circulation. The issue was brought to the attention of the team by us, and innovative solutions were put into practice by the provider staff, day-activity staff, and Jim's doctors.

Jim has learned to relax and enjoy a sense of joy and serenity in his own home. He needs and enjoys his space and has it now. The lawns give him a view from the living-room window. The roomy backyard offers peace with the beauty of flowers, trees, and bushes. Staff initiative has created activities of interest and "therapy" by building a walking platform, a trampoline routine, arm pulleys, even a floor-crawling exercise.

[Continued on next page]

There are close human working relationships among all members of the team, including his doctors, staff at Jim's home, staff at the developmental activity center, the county social worker, and his family. Jim has grown through interactions with peers in the community, working in a supported workshop, and going to the circus, musicals, and dances. Above all, he has close ties with his family; he visits at our house every weekend, and we feel welcome to visit him at his house. The care of his neighbors, family, provider agency, and dedicated staff give us reason to believe that Jim will grow socially and achieve his full potential as a community member in the years to come.

For family members who wish to sustain an active commitment and contribution to the lives of their adult children after they leave home, helping them secure homes of their own not only permits but *demand*s it. The energy and dedication this requires shouldn't be underestimated, but neither should the rewards.

Deciding About Housing Structures

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

■ Types of Physical Structures in Owned Housing

Duplexes and Other Multiple Dwellings

Advantages

- Other unit(s) in the structure can be rented to someone responsible for supporting the person with developmental disability.
- Rental income from other units offset some costs of ownership.

Disadvantages

- Responsibility for upkeep of both owner's and other tenants' units.
- Relatively high costs of purchase and upkeep.
- Usually, all units must be occupied to meet mortgage payments.
- Rental income may cause problems with income limits for certain social service benefits (SSI, MA, etc.)

Single-Family Dwellings

Advantages

- A wide range of locations, styles, and structures is available.
- Privacy is maximized, depending on how many people live in the home.

Disadvantages

- Greater responsibility for upkeep.
- Distance between homes may reduce natural encounters with neighbors.
- Often have higher "front end" purchase costs than condominiums.

Condominiums

Condominiums are ownership arrangements in which several households occupy one property (as is the case most commonly associated with rental units) with each dweller owning a housing unit and having an equity in the common areas. Each housing unit is owned solely by its occupant (or by its owner/landlord). Condominiums are built on land that is either owned by the tenants' association, an outside corporation, or is leased to the condo by the land owner. Upkeep on condominiums' building exteriors and grounds is paid for and arranged by an organization of individual owners.

Advantages

- Condominium owners have more individual control over their dwellings than do coop members.
- Opportunities for social integration may be increased through proximity to neighbors and participation in the owner's association.
- Purchase can be made with less money down than most single-family dwellings.

- Owner does not have the personal responsibility for yard work, snow removal, etc.

Disadvantages

- Opportunities for privacy are lessened compared to single family dwellings.
- Owner is responsible for interior upkeep and a share of the costs for upkeep of common areas and exterior.

Who Shall Live in the Dwelling?

Persons with developmental disabilities are living successfully in their own homes in a variety of ways. Some live alone; some live with housemates – who may or may not have disabilities. Sometimes the housemate is paid to provide support to the consumer. However, many persons with disabilities have needs that must be met with live-in assistance. Such assistance is currently being provided to Minnesotans in ways such as:

- A man disabled by a closed-head injury shares a house with a non-disabled man. Each has his own room while the rest of the house is shared equally. The non-disabled man assists his housemate with daily living skills but they are also friends.
- Four men share a two-story house. Two men with developmental disabilities share the first floor while the second floor is occupied by a man with developmental disabilities and a non-disabled man. The latter provides needed support by being in the house overnight and occasionally at other times.
- A young woman with developmental disabilities has gotten the assistance she needs by moving into an apartment with two non-disabled women. The woman with disabilities has developed a peer relationship with her roommates and has been included in activities with their families and friends.
- Two women who have been friends for many years recently purchased a condominium to-

gether. One woman has physical disabilities and the other 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 the location of the residence. John O'Brien, in his book *The Principle of Normalization: A Foundation for Effective Services*, outlines different ways in which programs can be structured for people to overcome physical and social isolation.

O'Brien observed that full community membership requires people to be active participants in a variety of individual and group relationships. Persons whose capacities for communication and mobility are limited can and need to be part of a network of relationships with valued people. Some guidelines that promote full community membership include:

- Individual support should allow opportunities for participation in community events and activities, such as entertainment, recreation religious services, and so forth.
- People shouldn't spend their days in the same area they call home. Except when individual needs or choice dictate otherwise, work or school should take place outside the home in community settings.

- People should use generic health care and other services. Only the minimum amount of services consistent with individual needs should be provided within the walls of the home.
- Individual supports make social participation a reality, regardless of ability. Inclusion should never be made available to only those who earn it.

Nonconventional Approaches to Housing That Build and Support a Community

Not all approaches to consumer ownership involve the direct purchase of a typical housing unit. Some very beneficial approaches may involve the individual as part of community ownership. Such approaches provide not only personal and economic benefits of ownership but also the social benefits of community memberships. *Cooperative housing* and *co-housing* are two models of community ownership.

■ Cooperative Housing

Cooperative housing is based on a simple set of principles: ownership and control by members, democratic control (one member, one vote), limited equity (individuals cannot take control by purchasing more shares), and limited liability. Cooperative traditions encourage mutual assistance and individual growth. As such, cooperative housing can help to overcome the lack of consumer control in most residential services. It also can help break the patterns of isolation experienced by many people with developmental disabilities who may live in community housing but remain estranged from their neighbors. Cooperative housing has the potential to provide security of tenure, to separate services and housing, and to involve community members with and without disabilities in shared efforts that contribute to friendship.

The people who develop housing cooperatives form a special type of corporation (the "cooperative" or "co-op"). Each member owns one share and has one vote at general membership meetings. The members elect a board of directors from among themselves. In turn, the board may hire a property manager or may contract for the needed services, or the members may manage the property themselves on a volunteer basis.

The cooperative (as a corporation) develops or purchases housing, often with financial assistance or low-cost loans from the government. Nonprofit housing co-ops are often eligible for public assistance with financing provided under municipal, regional, state, or federal housing programs. Members occupy individual housing units based on an occupancy agreement but don't "own" their individual units; rather, they own a share in the cooperative and when they move out they sell the share back.

Housing cooperatives provide important opportunities for members to get to know each other intimately, to work collaboratively on complex projects, to gain an understanding of each others' strengths and gifts, and to decide what kind of a community they want to create. Every inclusive cooperative (i.e., one that has purposely included persons with disabilities) is an experiment in community building and the possibilities for enduring friendship and mutual support among people with disabilities and their neighbors.

In order for inclusive cooperatives to work, several things must be "true":

- There must be a high ratio of people without disabilities to people with disabilities, because it's important for the community to maintain a balance of skills, connections, capacities, and income.
- All members must be people who are willing to share activities, interests, and connections, and to help out in practical ways.
- The cooperative must "take care of business" in terms of finances and cooperative management, and the housing association must provide education and support in these areas.

A Success Story: The Creation and Growth of the Monterey Co-Housing Community

By Bud Seltzer

Nine years ago, in 1991, five independent groups of people in the Upper Midwest started working on plans to create co-housing communities. Only one group succeeded, the Monterey Co-Housing Community (MOCOCO). It stands alone as a unique community of fifteen households.

MOCOCO started when an ad appeared in a St. Louis Park, Minnesota, paper offering for sale a three-story Georgian brick building. This 14,000 square foot structure was originally constructed in 1924 as a retirement residence and contained 26 bedrooms and 14 bathrooms. In 1992, 12 households started out to create a new community there. They were caught up in a whirl of activities, creating a legal structure, selling their individual homes, buying the mansion, moving in, and then starting the process of rehabilitation that eventually turned the building into eight independent apartments with 6,000 square feet of common space on two and a half acres of property. Four households left the project. However, plans were later made to construct a number of townhouses on the remainder of the two and a half acres of property. As is typical of co-housing, each unit is individually owned with each unit owning a share of the common space.

The MOCOCO residential units created in the original mansion range from small two-room units of less than 500 square feet each to a three-bedroom unit of over 1500 square feet. The mansion also includes an elegant formal living room, a cherry-paneled library, three fireplaces, an existing institutional kitchen, a TV family room, a childcare room, a laundry, and shop facilities. The community kitchen serves all households and each unit also has a kitchen of its own. It is amazing to think of the countless hours of meetings, and then the hard work tearing down walls and working as a team to create the individual units and common spaces. This common effort has served to build a sense of community with plans for the future.

One of the pioneer MOCOCO households is Dorthea Moga and her then 33-year-old son, Nick. Nick has been diagnosed as having autism. He has three siblings, two sisters and a brother, all of whom are married and live in their own homes. There is a family closeness that brings them all together to celebrate special holidays.

It has been almost five years since I visited MOCOCO. My first impression upon returning was how majestic the mansion appeared with its three-story-high Greek columns. Seven new and separate townhomes have been constructed and occupied since I was here last. A lighted and heated tunnel connects all the buildings together, both the new and the old. Each unit now has its own kitchen and the old institutional kitchen has been remodeled with much shiny new stainless steel equipment. The shop facilities have grown and the childcare area shows active use. A bulletin board clearly displays the weekly division of responsibilities for each aspect of management and maintenance of the property. Regular board meetings are held to maintain progress.

My return visit ended with the impression of serenity and beauty of this vital community. Some incisive observations will now come from Dorthea Moga herself:

The interview for information for this article provided me with an opportunity for deeper assessment of our/my co-housing experience. In reviewing my son Nick's and my six-plus years of residency in our Monterey Co-Housing Community, I can clearly state that it has brought a sense of physical safety-in-living to us, which had been missing for 20 years or more. Since finding that safety had been a major goal, I consider us successful in this.

Another goal has been to find a way to expand our intimate, two-person living arena. As our lives progressed through Nick's adolescent years, I knew that when his siblings were on their own, we would need to do this to prevent becoming isolated. In the past two years, I began to realize that my intimate living arena has expanded and is intertwined with those of our 14 other Monterey households. Nick's is only minimally so intertwined. Together, our experience of autism-living is much the same that we've known for most of Nick's 37 years.

My general inclusion in and Nick's general acceptance by this solid community of people – along with our safety – make this unmet goal less difficult to shoulder. Persons on a journey like ours would do well to spend some part of their trip in a co-housing community like Monterey.

- Building supportive friendships in an inclusive community must be a conscious effort. Because this is something new, people actually must sit down together and talk about things, make commitments, follow through on those commitments, and stay accountable to each other; and they must celebrate the small victories, the growth of community, and the deepening of friendship.
- It's crucial to remember that communities are built on capacities and gifts, not on limitations, so that effective inclusive cooperatives recognize that everyone has a gift, and they talk about, think about, and celebrate the gifts of the members, especially those who have disabilities.

The cooperative community must develop a sense of shared leadership and shared responsibility if it will meet the inevitable challenges involved in such an enterprise. The organizational and personal tasks that face the community are challenging; and members must face those experiences with a conviction of shared responsibility. Cooperative housing is not a "solution" for the housing and community needs of people with developmental disabilities; it's a means of creating a community that chooses to include them.

■ Co-Housing

The shape of American society is changing. Extended families with multiple generations living within a few blocks of each other, children spending their entire childhoods in a single house, and neighbors who know and actually look out for each other are increasingly rare. Co-housing focuses on recreating some of the positive aspects of traditional community life within modern communities. Typically, a co-housing community includes a number of individual units (apartments, townhouses, or single family homes) clustered around a common space. The common space usually includes a kitchen and a dining room and other leisure areas and is large enough to accommodate all the community members. It's around this space that community life revolves.

Co-housing communities are not communes. Individual units are complete residences, often smaller than average, with the saved space included in the common area. Privacy and individual autonomy are thus preserved. Co-housing is usually a special form of cooperative housing.

Most co-housing communities have several common characteristics: decision-making by consensus using a process designed to involve all participants, intentional design of a positive and livable neighborhood, and focus on community living centered on the extensive common facilities. Management of the co-housing facility involves all the residents.

Each co-housing community approaches community issues differently. Some plan dinners together five days a week, some only two. People can always have dinner in their own homes if they choose. There are no hard-and-fast rules.

Co-housing communities present unique challenges. For one thing, the individuality of each community means the "blueprints" of existing communities may not be of great help to new communities. Creating a model and sorting out the particulars can take years. Group members must find a common vision for how they want to live together and a way of maintaining the vision through the practicalities of designing, building, and financing the project.

Financing is often a problem. Communities in Europe often receive government support, whereas co-housing projects in the U.S. must often struggle to find even private financing. Because it's a new concept without a "track record," it's often difficult to find ways of financing a large capital investment that will be co-owned by many households. Another complicating factor is the estimated ten percent that must be added to the cost of each individual unit to finance the common area. Although still a new movement, co-housing seems to offer much potential for the recreation of communities. When these communities include persons with developmental disabilities, the potential to improve their inclusion and empowerment seems enormous.

Mike's House

By Mark and LaVerne Czichotzki

After attending the 1991 State Arc Conference in Rochester and the Housing Options for Persons with Disabilities, we got actively involved in a search for the best housing option for our son Mike. As parents, we talked with all the members of Mike's interdisciplinary team who were concerned with him and the development of services that would meet his needs as best they could be, with Mike having a place to live that would be a true home in home living options. After input and discussions with everyone we decided to purchase a home for Mike.

We set as a goal to have Mike move into a new home before his graduation from high school in 1993. That way Mike's move to the new home would occur before his school routine would be changing too. We thought having all his routines changing at once would be hard for Mike, just as it would be for anyone else. In 1991, we started looking for affordable housing and in August of 1992 we were able to purchase a two-bedroom home in our community for Mike. Mike moved into "Mike's House" in September of 1992 just in time to start his last year at the local high school!

We made a decision to purchase the home and rent to Mike. This arrangement allows our family to have involvement and more control in Mike's living arrangement, since we are his landlords.

Mike receives his support through twenty-four-hour "Adult Foster Care", a program funded through Medicaid waiver services. Because the services were to be provided under an Adult Foster Care license, before we could actually use the home as a "service site" there were a couple of inspections and regulations that were required by the county and state: one by the fire marshal and another by the County Adult Foster Care Coordinator to inspect the house and okay it for adult foster care.

Because of Minnesota law, we were able to qualify for second homestead credit for Mike's house which dramatically saves on property taxes. Because he is low-income, Mike receives phone assistance, fuel assistance, and energy modifications on his house. But, most importantly, Mike's services have a "person-first" philosophy that really supports people living in homes that are their own. Because of this and Mike's hard work, "Mike's House" has been a success.

Mike continues to be successful while living in his own home. This is not to say there haven't been those moments, but overall it continues to be a positive experience for Mike and he continues to meet many challenges throughout his life with the support of *all* community members.

In the past eight years of living in his own home, Mike has become a true community/neighborhood member. As his parents, we felt it was important to have the neighbors include Mike in their activities and consider him a "real" neighbor. We did this in a couple of ways. First, we had an open house in honor of Mike's 21st birthday and his moving into his new home . . . we invited the neighbors! Mike is also a member of the neighborhood watch program that was started about three years ago in his area. They hold neighborhood picnics and safety events, put up street and security lights, and have other events to make the neighborhood a safe place to live and raise families. We made sure Mike contributed toward and participated in the events that the neighborhood watch sponsored. It has been a positive experience for everyone on 12th Street North in Moorhead!

Mike has also had the opportunity to host college students at an event at his home in Moorhead. The college students had a project called "Helping Hands" and they chose Mike and his house as the location to do the project. They met Mike and learned about his challenges in living with many different disabilities, and then they assisted Mike in chores around the house. One student said it best, "We learned a little about autism, but a lot about the importance of helping others."

As Mike's family, we continue to support and work toward upgrading the direct care staff positions that are so important to Mike and his success in living in his own home. This has probably been the most frustrating issue that we have to deal with concerning "Mike's House." We continue to work with Arc Minnesota in the legislation area, and we try to connect with our local legislators concerning these two important issues: 1) obtaining good quality direct care staff, and 2) keeping good, qualified direct care staff! It's important for all of us to advocate for programs that continue to assist Mike in being a community member.

How Will the Housing Be Financed?

Home ownership almost always involves securing a mortgage. Good sources of information on financing options are Arc Minnesota's Housing Consultant, mortgage bankers, licensed real estate brokers, and attorneys who specialize in real estate. For beginners, many publications are available in bookstores and libraries. Several free publications are available from Housing and Urban Development, Rural Development, Fannie Mae, and the Minnesota Housing Finance Agency (see contact information in Chapter 9). They are excellent sources of information on the mortgage market and how to obtain access to it. The brief descriptions here only suggest what housing consumers and families should know about financing options.

Traditional mortgages from a local lender are the common mortgage options that most people explore first. These include Conventional, FHA, and VA type loans. A mortgage lender's willingness to loan funds, of course, is dependent on its internal lending policies. In Minnesota, some banks have specific mortgage products which can be of benefit for individuals with disabilities and their families. These "products" may include below-market mortgage rates and/or special terms or financing assistance. Check with major mortgage lenders in your area, such as Firststar, Wells Fargo, Marquette, and US Bank. Also check with your local Housing and Redevelopment Authority (HRA). Block grant funds, such as "Home" or "Community Development Block Grant" (CBDG), may be available through your HRA. Information is available from them on request.

In addition to a bank's internal lending policies, certain external standards also may have a definite effect on the mortgages a bank will approve. These external standards come from three basic sources:

- National programs that insure loans against default, e.g., the Federal Housing Administration.
- National agencies, such as Fannie Mae and Freddie Mac, that purchase mortgages from lenders (to enable banks to loan out the recycled funds) and then pool these mortgages for sale as a type of investment security.

- The U.S. Department of Agriculture (USDA), which serves rural areas or a community with a population of 25,000 or less with a home-loan program. The program often is the most affordable, with terms up to 38 years. Loans can be made with participation from local lenders. Applications are filed with participating local lenders or with Rural Development Area Offices. More details can be obtained by contacting Arc Minnesota's Housing Consultant.

If a lender participates in any of these programs, mortgage lending activities may be predominantly tailored to serve applicants who readily meet the lender's external criteria.

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

Since these agencies are, in essence, a type of bank, their internal lending policies also affect the mortgages they write. Additionally, tax reform, coupled with the congressional and Internal Revenue Service actions of the last few years, have greatly restricted the total amount of public bonds that can be raised within each state, as well as the borrowers and properties that may qualify for a mortgage. All these factors definitely limit the ready availability of the funds for innovative housing options. Consumers and families should keep current on the mortgage market and on the availability of special housing grants and subsidized mortgages for individuals with disabilities. To stay current with this information, maintain contacts with Arc Minnesota, the Department of Human Services Community Supports for Minnesotans with Disabilities Division, or local social service agency per-

sonnel. One such program is called "HomeChoice," discussed below.

Many individuals with developmental disabilities do not have the financial resources for a down payment on a house. Indeed, federal laws (SSI, Medicaid) governing income and medical assistance entitlements present major obstacles to consumer controlled housing by limiting (to less than \$2,000) the financial assets which can be accumulated by people enrolled in those programs. Proposals have been made to permit individuals with disabilities to set aside financial assets above the current limits into funds that are specifically earmarked for housing. As of this writing, no congressional action has been taken on these proposals. Of course, even if

the rules eventually permit setting aside assets specifically for housing, individuals with developmental disabilities who have low incomes will still be challenged to accumulate sufficient resources for down payments. For this reason, families often play a significant role.

Some people may have parents or other family members who can provide funds for a down payment and closing costs (which together are called entry costs and can run ten percent of the sale price of a home). Parents who do not have the cash on hand but whose own homes have market values substantially above what they presently owe on them may consider a home equity loan to raise the down payment. In a home equity loan, the home

Minnesota HomeChoice Mortgage Program for Persons with Disabilities

Minnesota has been selected to participate in a unique mortgage program called HomeChoice. HomeChoice contains lending policies that are structured to increase the home-buying opportunities for people with disabilities (mental or physical impairments). The program offers:

- Low down payment *As little as 5%*
- Down payment and closing cost assistance .. *Loans to cover down-payment and closing costs may be available to eligible home buyers. These loans are interest-free and no payments are made on them; they may even be forgiven after a period of time.*
- Larger mortgage potential *To produce greater mortgage potential for the size of a household's income, all social service incomes are recognized, as well as the use of larger income-to-debt ratios.*
- Non-traditional approach to credit requirements *Alternate payment histories can be considered for credit establishment.*
- Support services *To help assure home-ownership success, home-buyer education, counseling, and support teams prepare the buyer for home ownership.*

HomeChoice is a demonstration program sponsored by Fannie Mae (the Federal National Mortgage Association). The program was designed to be a three-year program but has been extended two additional years and now is available through 2002.

For more details regarding this program and your eligibility, contact Arc Minnesota at 800/582-5256 or visit <http://www.arcmn.com> and click on HomeChoice.

owner's house is the collateral.

Another source of down payment is gifts from relatives or other benefactors such as the family's church or synagogue. Groups of parents in the same community who are interested in securing housing for their sons and daughters sometimes have successfully approached churches, service clubs, and charitable organizations with the idea of creating

funding pools to make down payments available. Such pools also may be created by grants from corporate and community foundations. Local advocacy organizations can provide guidance and assistance in approaching foundations. Again, individuals and families should keep informed about the availability of special grant funds to support down payments.

A Home of Their Own

By Arc Anoka, Ramsey, and Suburban

Mary and her son Tony recently moved into their own townhome purchased through the HomeChoice mortgage program and the assistance of Arc of Minnesota and Arc Anoka, Ramsey, and Suburban.

As Mary said, "The driving force for me to purchase a home was so that some time down the road, Tony would have a house. As a single mom, it's important to know that he will have familiar surroundings and an established place to live."

Mary heard about the HomeChoice program when talking with an Arc advocate. She was connected with Arc Minnesota's HomeChoice Consultant and the process soon began. Mary set up a support team of family members including her sisters and brother-in-law. She attended home-ownership classes with her sister and found them very helpful. The classes covered all the details of home ownership.

Then she began looking at houses. What started out as fun quickly turned into work. With market prices high, she looked at many houses before she found one she liked. When she found the right one she said, "I loved it from the first day – it just felt like home to me."

The work was just beginning, however. She worked closely with the HomeChoice Consultant and her bank to keep on top of all the paperwork that had to be completed by closing. To help keep her monthly cost down, she applied to Arc Anoka, Ramsey, and Suburban, Inc. for additional down payment assistance made available through grants from US Bank and Edina Realty.

After some very close calls, they were able to close and move into their home at the end of August 1999, just in time for Tony to start school in his new neighborhood. Tony has made some new friends to bike with, and they enjoy walks on the wooded trails that lead to the Coon Rapids dam and park.

Mary's advice to others is "Be determined and don't give up. Keep after people if you need to – it's wonderful in the end to have your own home!"

The Minnesota Homestead Law

Minnesota has amended its Homestead Law by enacting Minnesota Statute 273.124, subdivision (c), to allow parents to homestead the home in which they live as the primary residence, and also to homestead a second home that is the primary residence of a qualifying relative. The latter may be their child, stepchild, daughter-in-law, son-in-law, parent, stepparent, brother, brother-in-law, sister, sister-in-law, grandchild, grandparent, aunt, uncle, husband, or wife. To obtain a homestead exemption for the home of a qualifying relative, contact the Assessor's Office and request a "Relative Occupant Form" for Homestead.

Another possible homestead benefit comes from the Special Homestead Classification Program. This program operates within Minnesota Statute 273.13, subdivision 22. The program offers \$150.00 of real estate tax reduction to qualifying households of homeowners with a disability. To determine if you are eligible for this program, you can obtain an application by calling the State Homestead Disability Program at 651/296-0204.

4

Consumer Control Through Rental Arrangements

Introduction

Owning one's home is often called the "American Dream," but some people's dreams lie elsewhere. Whether one owns or rents, the most important consideration in housing is how the choice of housing contributes to the life the individual chooses to live. When people evaluate housing for its contribution to a desired lifestyle, some may well find that renting is more desirable. Renting may present a variety of advantages, including:

- **Greater Mobility:** If you leave a home you have purchased within a few years of buying it, you're likely to lose money. Not so with renting, although there may be penalties for breaking the lease.
- **Less Financial Responsibility:** If equipment or utilities break or are damaged in a rental home, the landlord is usually responsible for the repairs; in an owned home, the owner is responsible. People who are able to do repairs themselves may keep costs manageable, but for people who depend on others for repairs, the costs can be substantial.
- **More Free Time:** Taking care of a house and its yard can take a lot of time for painting, mowing, raking, etc. Many people prefer to spend their time doing other things they enjoy more.
- **Predictable Living Expenses:** When one rents a home, expenses such as rent, electricity, and the telephone are usually predictable and can be planned for easily in a budget; in owning a home, major repairs, tax increases, special assessments, and additional expenses like heating costs during cold winters can cause wider fluctuations in the household budget.
- **Less Money is Tied Up:** Although there are times when special programs make it relatively easier to buy a home without substantial cash down payments, there are also closing costs, insurance, etc., which must be met. Renting a home usually takes less cash in hand. Although considerable cash is sometimes required to move into a rental property (often, first and last months' rent plus a damage deposit usually equal to a month's rent), these monies are recoverable and the damage deposit is returned if the home is left in good repair.
- **Access to Rental Subsidies:** Subsidized rental housing is available to low-income people with disabilities from a number of sources. These subsidies typically limit the amount of one's total income that can be paid for housing (including utilities) to thirty percent.

Choosing a Rental Home

One of the benefits of renting a home is the broad range of available choices. If the place that is rented proves to be inadequate or unpleasant, one can move out at the end of the lease (usually one year) or even sooner. Renting is also good preparation for owning a home.

Still, finding a place, renting it, and moving in involves both financial and time investments as well as a lot of physical work, so it's best to consider carefully what will make a new home enjoyable and livable (at least for a while).

Here are some of the things to plan around in renting (or buying) a place to live:

- **Affordability:** Obviously, people need enough money to be able to afford the place they live in. Affordability, however, is more than just having enough money for rent. A person needs enough money left over after paying rent to enjoy the other things that are important to him or her. (Some things to think about in budgeting for affordable housing are described later.) It's enough to say here that one needs to think about places to live and ways to share or reduce expenses that will permit one to live within his or her available resources.
- **Community Resource and Special Interest Access:** One of the best things about renting is the greater mobility it gives renters. They can live near things they enjoy. This is especially impor-

tant for people who don't have personal transportation. Before signing leases, people should ask themselves what kinds of places and activities are important to them. Some people enjoy easy access to churches, clubs, or centers (e.g., the YMCA or YWCA) they use on a frequent (and often loosely scheduled) basis. Many people want to live near parks or other areas of special interest, whereas others prefer business districts where they can be near stores and sources of entertainment. People need to determine their own priorities when they consider all the possibilities. They need not worry if those priorities change; when they rent they can always move to a new place next year.

- **Jobs and Job Opportunities:** Some people find it especially useful to live near existing jobs or in areas where a number of job opportunities exist.

Tom's and Ron's Names on Their Lease Was No Token Thing

Tom's and Ron's parents had always been actively involved in their sons' lives. When an opportunity for them to move into the community materialized, they quickly snapped up a chance to rent a house for three months until other housing would be available – along with the funding and staffing that would be needed by the agency that provides supports to their sons. Later, Ron's mother heard about another house that would better suit their needs. This information was passed along to the provider agency and the young men moved into their house.

The new house was great, but services for Ron and Tom proved to be unsatisfactory. After many unsuccessful attempts to rectify the situation, the parents asked for a change of providers. To their amazement, the young men and their parents were informed by their county case manager and the provider agency that because they wished to change providers, Ron and Tom would need to vacate their house. The provider agency claimed that it found and licensed the house and had paid the rent. Therefore, the agency claimed the house for as long as it needed it. Even though the lease had been signed in the consumers' names, and their money had paid the rent, purchased furniture, made payments on a car, and contributed to a household account of \$2000, the provider claimed it all. The parents couldn't believe how an agency selected only to provide services could claim control of everything acquired by the people they were hired to serve. They soon learned that in Minnesota the agency could not only make such a claim, but could prevail – with one happy exception.

Ron and Tom lost their furniture, car, and household account to the provider. But because the landlord rented the house to Tom and Ron and not the provider, the young men were not deprived of their home in order to be able to select an agency that could adequately meet their needs and desires. The lesson of the importance of consumer controlled housing was well-learned. The parents are exploring ways of supporting their sons' ownership of property to avoid ever having to go through the stress of those few months. Equally important, these parents don't plan to ever allow another provider to control the resources and decisions in their sons' lives.

Increasing work opportunities are available to people with developmental disabilities in different areas of the community (e.g., shopping centers). Finding a home near where one's job or near where there are good possibilities of finding jobs often allows people to reduce the use of public or other forms of transportation, thus saving money – which can be spent on better housing or other benefits – and reducing dependence on other people.

- **Family and Friends:** Many people look for housing that makes it reasonably easy to spend time with family members and special friends. Of course, many young (and older) adults prefer a certain amount of “space” between them and their families. The important consideration is that the location of one's home may have a dramatic effect on one's interactions with friends and family.
- **Transportation:** For individuals who don't have personal transportation, finding housing on public transportation lines may substantially increase community access. In thinking about transportation, it often pays long-term dividends to lay out the specific places the individual will

want to go and the frequency and complexity associated with the trips. Then one can better assess the extent to which a specific location will contribute to or impede access to the places the individual needs and wants to go.

- **Access to Needed Supports:** Access to needed supports is often a consideration in selecting housing for many reasons. Obviously, for people with significant medical needs, relatively quick access to hospitals and clinics may range from being important to being a medical necessity. But for other people, selecting homes near specific resources and supports may be a factor to weigh against other factors like the desire to live in the country. Frequently, housing is selected in areas where housemates who can provide support can be recruited and retained. The reality of the “system's” ability to deliver needed supports is that resources are limited, and efforts to obtain needed supports within a home of one's own sometimes require a lot of creativity as well as certain compromises to keep total service cost and availability within the limits of one's established resources.

Things to Know About Renting

When people rent an apartment or house, they almost always sign an agreement with the person who owns the property (the *landlord*). They become tenants. The agreement between landlord and tenants (the *lease*) is very important in that it describes what each party can expect of the other. Therefore, it's important to read, understand, and be willing to accept everything in a lease before signing it. Three especially important provisions are found in the lease:

- **Rent, Form of Payment, and Length of Occupancy:** The lease specifies that the tenant will pay a certain amount of money (rent) each month (sometimes each week) to stay in the home. Usually, the lease also shows that the tenant agrees to this arrangement for a certain length of time (often one year). The lease also

gives the tenant certain important information about the date on which rent is due, what happens if the tenant is late with the payment (sometimes a penalty must be paid), where the rent check is to be sent or taken, and so forth. It usually indicates that the tenant must pay a deposit for damages that may happen to the home, how the landlord determines the damage and how the money will be returned (Minnesota law requires landlords to pay interest on deposits held).

The tenant always should make sure he or she has maintained a record of his or her payments. A checking account is one way of keeping a record of payment. If the rent is paid in cash, a receipt should be obtained from the landlord.

(Most landlords, however, prefer or even insist that rent be paid by check.)

- **Responsibility for Utilities:** Utilities, such as gas for heating and cooking, electricity, water, garbage collection, and cable TV, are an important consideration. Before moving in, it's especially important to understand which utilities are the tenant's responsibility. There are two reasons for this: 1) utilities can cost a lot of money and should be considered an addition to the rent – that is, a cost of living in an apartment; and 2) if a tenant is responsible for paying for certain utilities, he or she usually is also responsible for having the service put in his or her name, paying an installation cost and deposit, and arranging for the responsible person and place of billing.
- **Rules and Responsibilities for Living in the Home:** Landlords can make certain rules about their buildings in order to protect their property

and/or the basic safety and comfort of all residents. Landlords can establish rules regarding how many people can live in the place, noises that may disturb other people, pets, and maintaining the cleanliness and appearance of the place. Additional rules should be known and considered carefully before renting a house or apartment. If an individual questions any rule or its interpretation, it's always better to ask before any conflict develops with the landlord. However, it's also important to remember that tenants too have rights.

There are some rules and conditions regarding housing that landlords cannot set. Landlords cannot make rules that discriminate against people because of race or a disability. The Fair Housing Act protects tenants against discrimination in a number of areas; a summary of the Act's contents are listed on the next page.

Getting Help to Find a Place

Some of the ways to get help in finding a place to rent include the following:

- **Family, Friends, and Neighbors:** Frequently, these are the best sources for help in finding affordable rental housing. Aware of the person's preferences and knowing the neighborhood (if staying there is desired), they have the patience and understanding to help the person through the difficulties of this important and difficult decision. They may be valued "counselors" for the individual.
- **Support Providers and Case Managers:** Many support providers and case managers are actually committed to an individual and to that person's having the place he or she wants. Such committed persons willingly share personal and "company" time to pursue desired housing because they value its importance to the person. When these people are involved, they bring a wealth of information because of their involvement with many people. Of course, caution must always be exercised that the decisions are being made to

benefit the individual and not the service or government agencies.

- **Housing Services:** In Minnesota, Medicaid Home and Community Based Service (HCBS) recipients have access to Housing Services on a limited basis for help in locating appropriate housing. A county case manager or social service agency can assist HCBS recipients to gain access to that service (see Chapter 5). For people who are not HCBS recipients, access to these Housing Services is available for a fee or through county support.

■ **The Section 8 Program: A Valuable Resource for Renters**

Many adults with developmental disabilities have found the Section 8 rental assistance program to be a valuable resource in acquiring affordable, decent housing in the community. Section 8 is a federal program in which the government pays a portion of an eligible person's rent. There are two types of as-

sistance available: project-based and tenant-based.

Project-based assistance is found only in apartment buildings that have been financed in part with certain federal funds. These buildings are primarily privately owned. To apply for an apartment at one of these buildings, contact the building's management office directly. For a list of project based Section 8 buildings in your community, contact your local public housing agency. Individuals who don't know the name of their local agency or how to contact it can ask their case managers, who should be able to establish contact.

Tenant-based assistance is provided through "vouchers" issued by the local public housing agency. These can be used to obtain a subsidy to the regular, market-based rent of privately constructed and owned apartment buildings. A voucher can be used anywhere in the community in which it was issued, provided the landlord accepts it. Renters who have vouchers may pay more than the maximum allowable rent. To apply for tenant-based Section 8 assistance, individuals should contact their local public housing agency. To be eligible for Section 8 rental assistance, the prospective renter

The Fair Housing Act

Who is Protected?

The Fair Housing Act prohibits discrimination in housing because of: race or color; national origin; religion; sex; familial status (including children under the age of 18 living with parents or legal custodians, pregnant women and people securing custody of children under 18); sexual orientation; or disability.

What Housing is Covered?

The Fair Housing Act covers most housing. In some circumstances, the Act exempts owner-occupied buildings with no more than four units, single-family housing sold or rented without the use of a broker, and housing operated by organizations and private clubs that limit occupancy to members.

What is Prohibited?

In the sale and rental of housing, no one may take any of the following actions if they are based on race, color, national origin, religion, sex, familial status, sexual orientation, or disability.

- Refusal to rent or sell housing.
- Refusal to negotiate for housing.
- Making housing unavailable.
- Denying a dwelling.
- Setting different terms, conditions, or privileges for sale or rental of a dwelling.
- Providing different housing services or facilities.
- Falsely denying that housing is available for inspection, sale, or rental.
- Persuading owners to sell or rent (blockbusting).
- Denying anyone access to or membership in a facility or service (such as a multiple listing service) related to the sale or rental of housing.

People who feel they have been discriminated against should call the Minnesota Disability Law Center at 612/332-1441.

must have a low or moderate income.

Prospective renters should be aware that the supply of Section 8 vouchers varies widely both among localities and over time. It's common for new applicants to be placed on a waiting list. Those who receive assistance should also be aware that Minnesota law prohibits discrimination against renters receiving Section 8 assistance.

In addition to the project-based Section 8 housing, other governmental and non-governmental organizations sometimes control low-income hous-

ing units. Unfortunately, there is no central consolidation source for information about these low-income public housing locations and the controlling agencies. Individuals interested in low-income housing need to research the housing agencies in their local area. Some agencies to check for are the Minnesota Housing Finance Agency (MHFA), your local Public Housing Authorities (PHA), Housing and Urban Development (HUD), Rural Development (RD), Community Action Programs (CAP), and others.

5

Making Sure Needed Supports Are in Place

Introduction

While finding a desirable place to live that meets one's needs is important, it's only a part of what is necessary to live a life of self-determination. The other part is getting the services and supports needed to stay in the home and become an active community member. Understanding which services and supports are available and how they are accessed is crucial. This chapter presents an overview of Minnesota's service system.

Minnesotans with disabilities find and receive the services they need through a process called "case management." State law requires each county to provide case management to all persons who have, or might have, "mental retardation or a related condition" that need available services. Case man-

agement is defined 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." Some families know their case manager by the term "county social worker."

Through case management the county establishes eligibility, assesses service needs, and develops an individual service plan (ISP) for the consumer. The ISP is developed with the consumer and his or her parents, and outlines the type of services and supports the consumer needs, based on his or her needs and desires. An ISP must be developed for each person with disabilities who requests and needs services.

Identifying Service Options

The array of services available can be confusing, especially when distinguishing the services a person receives from how they are funded. The table on the next page outlines community services and funding

sources related to consumer controlled housing. Descriptions of the services and funding sources follow on the next page.

Service	Funding Source	Key to Abbreviations (also see Appendix C)	
Adult Foster Care	SSI/MSA; CSSA	CHS	Community Health Services Program
Assistive Technology	HCBS	CSSA	Community Social Services Act
Caregiver Living Expenses	HCBS	HCBS	Home and Community-Based Services
Caregiver Training & Education	HCBS	MA	Medical Assistance
Chore Services	CSSA	MHFA	MHFA Accessibility Housing Loan
Consumer-Directed Support Services	HCBS	MSA	Minnesota Supplemental Assistance
Environmental Modifications	HCBS; MHFA	SILS	State SILS Grant Program
Homemaker	MA; HCBS; CSSA; CHS		
Home Health Care	MA; CHS		
Housing Access Coordination	HCBS		
Housing Service	CSSA; HCBS		
In-Home Family Support	HCBS		
Money Management	CSSA		
Personal Care Assistance	MA		
Personal Support	HCBS		
Semi-Independent Living Services	SILS; CSSA; HCBS		
Specialist Services	HCBS		
Supportive Living Services	HCBS		
Transportation Services	HCBS		
24-Hour Emergency Assistance	HCBS		

Note
CSSA includes services which a county may fund with CSSA monies; however, not all counties include all the listed services in their CSSA plans.

■ Descriptions of the Services

A number of services are available in Minnesota to support people with developmental disabilities who live in their own homes. These services are presented here without regard to funding sources. It should be noted that certain means-test and disability-related eligibility standards may determine whether any specific service is available to a particular individual.

Adult Foster Care

This provides a living arrangement for persons with developmental disabilities over 18 years of age who are unable to live independently. The purpose of the program is to help 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 protection.

Adult foster care in Minnesota has traditionally been provided in the home of the foster care provider and the adult in need is included in the family. However, an adult with developmental disabili-

ties who has purchased his or her own home may be able to receive needed supports by renting all or a portion of the dwelling to an adult who can move into the home and become licensed as a foster care provider. In other instances, parents have purchased homes for their sons or daughters and have leased them to service providers who hold adult foster care licenses.

Assistive Technology

This includes devices, equipment, or combinations of methods which improve a person's ability to perform the activities of daily living, personal control of or access to the person's environment, or his or her communication in the community. This service also pays maintenance, repair, and rental during repair of these types of devices.

Caregiver Living Expenses

The room and board costs of a caretaker to live with a person who has a disability may be eligible for payment under certain circumstances.

Caregiver Training and Education

Costs of this training can be reimbursed for primary caregivers who provide supervision and care and are not employed by a corporation.

Chore Services

These services include routine housekeeping tasks, minor household repairs, shopping, lawn care, and snow shoveling provided by county personnel or someone who has a contract with the county.

Consumer-Directed Community Supports

Consumers using this option under the Developmental Disabilities Waiver Program have the ability to design individualized services, including housing, based on their needs, interests, and desires. Consumers and families have more control over the funds used to purchase services on their behalf.

Consumer Support Grant

This is a cash program designed to give adults with disabilities or families who have children with disabilities more control, flexibility, and responsibility in arranging for needed support services. Examples of services are personal care assistance and in-home supports. Participants hire, train, and supervise the person providing the support services. Grant awards are based on the state share of the costs for long-term support services that would have been used by the person with a disability.

Environmental Modifications

These are structural changes to the residence of a person with a developmental disability to increase accessibility or mobility or to provide protection from injury. Such aids include wheelchair ramps, elevated bathtubs, widened doorways, shatterproof windows, lowered kitchen work surfaces, shower and bathtub seats, etc. Some adaptations to vehicles and adaptive equipment also may be eligible expenses.

Home Health Care Services

These include intermittent or part-time nursing services furnished by a home health agency or a registered or licensed practical nurse under the direction of a physician when home health agency services aren't available. These also include medical supplies and necessary equipment and appliances

that are prescribed by a physician for the care of the individual and are suitable for use in the home. Services of a home health aide are provided under the supervision of a professional nurse who is assigned by a home health agency.

Homemaker Services

These include general household activities and ongoing monitoring of a person's well-being. They are provided by a trained person when the person regularly responsible for these activities is temporarily absent or unable to manage the home and care for him- or herself or others in the home. Services include meal preparation, cleaning, repairs, laundry, shopping for food and supplies, and other routine household care.

Housing Access Coordination

This provides assistance to persons attempting to acquire housing in the community. It includes counseling and assistance in identifying options and making choices about location, type of housing, roommate selection (if any); identifying accessibility requirements (including the need for modifications); and planning for ongoing maintenance and repair (if this will be the person's responsibility), financial resources, and eligibility for housing subsidies and other assistance. A purpose of this service is the assurance of separation of housing from service provision.

Housing Service

This helps individuals to obtain, maintain, and improve housing and to modify existing housing.

In-Home Family Support Services

These are home-based services designed to enable the family to care for and maintain the family member with developmental disabilities in the home and may include training and counseling for the family member and his or her family.

Money Management

This 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. The service includes consumer education, debt adjustment, financial counseling, and direct vendor payment.

Personal Care Assistance (PCA)

Personal care assistance services are designed to support the individual with activities of daily living that he or she is unable to perform because of a disability. The services require supervision by a qualified person and are usually provided by a private vendor. People wishing to hire and train their own PCAs without using a traditional vendor may be eligible to use a fiscal agent option.

Personal Support

This is non-medical care, supervision, and assistance provided in the person's home or in the community to achieve increased independence, productivity, and inclusion.

Private Duty Nursing Services

These services are provided by a registered nurse or licensed practical nurse under the general direction of the individual's physician in his or her own home. The services are provided only when the person requires individual and continued care beyond that available from a visiting nurse or home health care agency.

Semi-Independent Living Services (SILS)

SILS is a system of support that enables persons who otherwise would have to reside in more restrictive settings to live in the community. SILS include training, counseling, instruction, supervision, and assistance; they are provided in accordance with a person's individual program plan for fewer than twenty-four hours per day. A friend or family member may provide SILS under certain circumstances if he or she is approved by the county. The 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 the telephone
- Personal appearance and hygiene
- Obtaining and maintaining housing

SILS are provided in the home of the person with developmental disabilities.

Specialist Services

These provide assessments, program development, training and supervision of staff and caregivers, monitoring of program implementation, and evaluation of service outcomes to assure the competency of staff and caregivers. This service is for persons with needs in the areas of behavior management, augmentative communication, personal health, functional motor skills, social skills, leisure/recreational skills, or independent living skills.

Supportive Living Services (SLS)

These are home-based support and training services provided daily in a place where no more than six adults or three children with developmental disabilities reside.

Transportation Services

Transportation is often available through day training and habilitation services or employment programs. The Developmental Disabilities Waiver Program also allows payment to friends, relatives, or others who provide transportation services to the person with a disability.

Twenty-four Hour Emergency Assistance

This is ready access to a qualified provider for on-call counseling and problem solving and/or immediate response for assistance at a person's home due to a health or personal emergency. It can include electronic personal emergency response systems.

■ Funding Sources

This section describes some of the primary sources of funding for the services discussed above.

Medical Assistance (Medicaid)

This pays for a range of health services for eligible individuals. The program is operated by the state with federal and state funds. To be eligible for Medicaid funding because of disability, persons must meet the same disability criteria as those used for the Social Security Disability Income (SSDI) program. In general, there are income and asset

eligibility standards. However, the Social Security Administration has work incentive options called 1619 (A) and (B), which allow people to keep more of their earnings without being penalized. Income and asset eligibility standards must be met. Medicaid is applied for through the county social services office.

Medicare

Medicare is a federal program that pays for services for people who have disabilities and are drawing funds from Social Security Disability benefits. Minnesotans with disabilities who are on Medicare may be eligible to participate in the Medical Assistance for Employed Persons with Disabilities (MA-EPD) program. This enables them to work and save earnings without losing access to health care and long-term support services.

Medicaid Home and Community-Based Services (HCBS)

This is a federal program allowing Medicaid funding of certain services to people living in the community (including with their own families) who, without those services, would be at risk of living in state institutions or specialized group homes. Both adults and children with mental retardation and related conditions are eligible to receive HCBS if:

- 1 They need the level of care provided in intermediate care facilities for persons with mental retardation (ICF/MR) (i.e., Medicaid certified state institutions and specialized group homes);
- 2 They are eligible for Medicaid; *and*
- 3 They actually live in an ICF/MR at the time or are considered "at risk" of being placed in one.

The risk status is determined through a screening process in which the case manager, the person requesting services, the person's legal representative, and a Qualified Mental Retardation Specialist (the case manager often serves in this role) review the assessment information about the person's strengths, and need for support, supervision, assistance, and training, and make a determination of the level of care (the risk status) the person requires. The person and his or her legal representative, if one has been court appointed, make an informed choice from feasible alternatives of the type and

amount of services, including the choice between ICF/MR and HCBS (waivered services), and among the waived services available.

The HCBS has been an extremely significant development in the provision and funding of services to Minnesotans with developmental disabilities. Because it funds services that are delivered on an individual basis to the place where the individual resides, it breaks the historical bond between place of residence and receipt of service. When the person changes providers and/or residence, the funding is now able to follow. For this reason, HCBS is one of the most important programs in the service system that enables the development of consumer controlled housing.

Home and Community-Based Services are applied for through the county social services office. The county case manager establishes eligibility, assesses service needs, facilitates the screening process, and develops an Individual Service Plan (ISP) in coordination with the person and his or her legal representative, if one has been court appointed. The Department of Human Services reviews the screening team's decisions. Based upon this review, Medical Assistance payments for waived services can be authorized.

Services funded by a waiver can be provided in a home that is owned or rented by an adult with developmental disabilities 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 the supportive living services are delivered is certified as an adult foster care home.

Minnesota receives a specific number of allocations from the federal government to serve persons eligible for waived services. In the summer of 2000, there were about 7,900 persons approved to receive waived services. A portion of these resources is reserved for persons currently living in ICFs/MR (conversions) and the remainder is available to persons currently living in the community but have been determined to be at risk of ICF/MR placement (diversions). The number of people each county is able to serve through HCBS is determined by allocation by the State Department of Human Services, upon review of requests submitted by the counties. Although many counties have wait-

ing lists for HCBS allocations, the law requires them to screen each person who requests HCBS in a timely manner.

Community Social Services Act (CSSA)

CSSA funding is a combination of state, federal, and local moneys which counties have available to fund a variety of community 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 submitted annually to the State Human Services Commissioner for approval. By law, all county residents must be allowed input into their county plan.

County Funds

Minnesota counties fund certain human services with monies that have been raised by county tax levies. These types of funds are frequently used to match the state and federal funding sources listed in this section, but in some cases services which can't be funded by other sources are paid for with these county funds. The services and the amounts expended for them can vary widely among the counties.

■ Minnesota Housing Finance Agency (MHFA) Loan Programs

The following loan products are operated by MHFA. For brochures and a listing of participating lenders or local administrators, contact MHFA. (See Chapter 9 for contact information.)

Fix-up Fund Accessibility Loans

This program provides below-market interest rate loans to homeowners to make accessibility improvements to their home. There is no limit on household income.

The borrower or a resident of the borrower's household must have a permanent physical or mental condition that substantially limits one or more major life activities. Eligible improvements are those that will allow the resident with a disability to reside in the home.

The homeowner provides bids and estimates for the proposed improvements at the time of loan application and arranges for the completion of the improvements after loan closing. The loans are provided by participating banks, credit unions, and housing agencies.

The Great Minnesota Fix-up Fund

This program provides below-market interest rate loans to homeowners to make all types of permanent improvements to their home, including accessibility improvements. The interest rate is based on household income. Borrowers must have a gross annual income of \$55,000 or less.

The homeowner provides bids and estimates for the proposed improvements at the time of loan application and arranges for the completion of the improvements after loan closing.

The loans are provided by participating banks, credit unions, and housing agencies.

Rehabilitation Loans and Revolving Loans

These programs provide loans to homeowners for basic permanent repairs and to make basic permanent improvements to help a resident with a disability to live more independently and safely at home. Homeowners must have an annual adjusted gross income of \$18,000 or less and meet an asset limitation. (Adjusted gross income means income from all sources, including those that are not taxable. A deduction of \$1,000 per household resident will be subtracted from gross income to determine adjusted gross income. There is also a special deduction for extraordinary medical costs, which is determined by a local administrator.)

- *Rehabilitation Loan Program:* This type of loan must be repaid only if the home is sold, transferred, or is no longer owner-occupied within ten years of receiving the loan. Funding is limited and may be allocated according to local priorities.
- *Revolving Loan Program:* This loan is at a below-market interest rate and is made to homeowners who are not eligible for other home improvement programs.

A New Home for Mark and Mary

By Their Parents

Mary and Mark Schlosser are now home owners, or to put it more accurately, like most of us they now own the mortgage on a home of their own. This happy event for our family members emerged as an answer to Mark and Mary's need for stability, for control of their lives, and for quality, affordable housing. It happened because we have a trusted provider (among other things, they've invested in values-based training) who supported our decision; a good friend, Darlene, who knew what questions to ask; a professional, Jan, from Farmers Home Administration who was positively oriented and who saw barriers as something to be overcome; and because members of the family were not willing to accept solutions that were less than Mark and Mary deserved.

But to backtrack a bit: Mary and Mark, ages thirty-one and twenty-six, are sister and brother. They have developmental disabilities and hearing loss. We, their parents, are the guardians. Their adult journey toward independence began with much letter writing and many phone calls so they might receive daily supports through the Medicaid waiver. Mark was on a waiting list for five years and their first services were in the family home.

The next issue we addressed was Mary's and Mark's interest in community employment. Like most advocates, we were learning that because someone says no is not a good reason to retreat. Mary and Mark needed the Client Assistance Project to achieve their goal. During this time the need for quality case management and comprehensive ISPs also became apparent. The resulting ISPs are supportive in tone. They articulate well a design for positive environments for Mark and Mary. The ISPs are central – and the person-centered values base is crucial – to their work and home.

Three years ago Mary moved from the family home. But at the same time our search for good housemates for Mark, young men with waiver allocations, was proving fruitless. We had often spoken of Mary and Mark living together some day. They get along well. They liked this prospect. So we all decided now was the time. And so we needed a house. We found one we liked. Would our provider buy it? We didn't feel we could afford it. Mary and Mark would buy it!

The decision to buy was a good one. Among other positive themes are these. The house is good quality. Mary and Mark have more stability. There is more "family ownership" in the best sense of the words. There was no down payment. Payments are less than rent. It's a win-win situation for the government. When Mary and Mark are no longer here, the house will certainly revert to the government. At our meeting with Jan at Farmers Home Administration the room was full – a provider representative, real estate agent, our friend Darlene, the case manager, Mark and Mary, and parents. Very simply, Mark and Mary qualified for the loan because they are low income but have a stable financial support. The guideline that states incompetence as a reason for refusal was disregarded because of the Americans with Disability Act.

This journey was not without stress and tears. The negotiation with our county concerning the room and board budget (using Supplemental Security Income and Minnesota Supplemental Assistance) was difficult. In the end, however, the budget was substantially lower because of these efforts – house payments were lower than rent. Medicaid waiver services provide daily support staff. Although an attorney was needed for a court hearing to allow us to enter into a real estate agreement for Mark and Mary as their guardians, it proved to be a nonthreatening, positive experience.

The house is a three-bedroom rambler in the center of town with a finished basement. It has a large yard, a garden, a basketball hoop in the driveway, and a welcome mat for Mary's cat, Sassy. An agreement to manage the house was signed with our provider. There is a basic budget for furnishing. Decorating was a family effort: an older brother came forward with some tables, grandmother with a mirror, the parents did some painting. A month after moving into their home, Mary and Mark hosted a housewarming for their friends and relatives. They have pride in their home, a real sense of ownership. We are grateful. After six years, Mary's and Mark's purchase of this home continues to be a good decision.

Community Health Services Program

This program, administered by the Minnesota Department of Health, provides funding to counties for health-related home care programs. Each county in the state submits biannual community health plans outlining services it intends to fund.

■ **Future Developments in Services and Funding**

Support services for persons with developmental disabilities are very comprehensive due to the efforts of Arc Minnesota and other advocacy organizations. However, as you can see, the system has become complicated due to the variety of services, funding streams, and rules.

Because of the large amount of public funding invested in these services, there are often efforts to change the system. Services currently available may change in the future. When going ahead with consumer controlled housing options, it is important for people to be aware of possible changes that may affect them.

The current trend in the service system involves giving consumers and their families a stronger voice in selecting services and providers. In these models, consumers and their families have more control over the funding used to purchase support services and assume more responsibility in ensuring that the services are delivered. This can involve using informal support services such as relatives, friends, neighbors, and general community resources.

These models are based on the success of the Family Support and Consumer Support Grant Programs, and various voucher programs operated by counties. These models often result in consumers and their families spending less money while obtaining more services and being more satisfied. This is due in large part to their ability to use informal support services that aren't typically available to traditional service providers.

These models have different names. They are referred to as "self-determination," "consumer directed community supports," "PCA Choice," "Consumer Directed Home Care," and "Fiscal Agents." Consumers and families wishing to participate in these models should be prepared to take a more active role in dealing with service providers, budgets, contracts, and payments. They should also commit to learning more about potential issues dealing with employees and taxes.

Following the trend to give consumers and families more control over services is a trend to develop managed care options for persons with disabilities. The traditional managed care model involves a buyer contracting with an organization to provide an array of services for a set fee. The managed care organization accepts some financial risks if it doesn't receive enough money to pay for the services it actually delivered. Because of this risk, managed care organizations frequently develop a long list of procedures designed to control costs and limit access to services.

Managed care models are very common in providing acute health care services to people who don't have disabilities. Experiments in several states to serve persons with disabilities through managed care have not been successful. However, there are likely to be continued efforts in Minnesota to create a managed care model specifically for persons with disabilities. Consumers and their families should monitor these initiatives, since the traditional managed care model conflicts with the trend to give consumers and their families more control over services.

Finding an Agency to Provide What You Want

Consumer controlled housing is about much more than whose name is on the lease or mortgage. It's about people having homes of their own – homes where they control what happens, who comes and goes, and whose needs and pleasures come first. Finding a service-providing agency that is willing and able to balance the desires of the consumer with its “administrative efficiencies” and usual ways of operating is a serious undertaking. Such agencies are often difficult to find, but finding them makes immeasurable difference in the benefits, stability, and stresses of consumer controlled housing.

Because people differ, no one set of criteria can be written to determine which agency will best satisfy which people. Questions like the following, however, are worth asking all potential service providers when people are attracted to the idea of consumer controlled housing.

- **Does the service provider accept me as having a right to control my own life?** There is an often quoted business credo: Rule 1 – the customer is always right. Rule 2 – if the customer is ever wrong, refer to Rule 1. It may be too much to expect a service provider to operate entirely from that perspective, but how committed is the provider to trying? How will you deal with those situations in which the provider feels it can't follow these rules? You should expect some disagreements and feel comfortable with what must be done to resolve them.
- **Is the service provider committed to consumer controlled housing and able to understand how I want to live?** Consumer controlled housing depends on serious and effective efforts to respect how the consumer wants to live. It's important to know how the service provider goes about gaining such knowledge. What kinds of planning practices are used? What kinds of experience does the agency have with such practices? What other methods are used to figure out how people want to live? How often and with whom are service support plans reviewed? Are mechanisms in place to attend to changes in people's interests, desires, and needs?
- **Does the service provider respect my house?** Delivering services in someone else's home and respecting entry into their home is a new proposition for many service providers. It's extremely important that certain things are clarified about the resident-service provider relationship. What can you expect when staff arrive? Will they knock and wait or will they enter? Where will they park? Will they have breaks? When and where? Will they have access to the phone, TV, etc., and how will permission be granted – once or each time?
- **Are other people happy with the agency in the areas that are important to me?** Often, the best way to get an idea if an agency will be a good match is first to list characteristics you see as most important (e.g., responsive; flexible; respectful; dependable; supportive) and then to ask other people who receive services from the agency about those characteristics. Not all agencies are alike! Case managers and local advocacy groups can often help identify the characteristics that are most important to you, and can answer questions about the presence of the characteristics in different agencies.
- **Will the people who provide services to me be well-trained, well-supported, and well-treated by the agency?** The quality of life for people living in their own homes is very much affected by the attitudes, skills, and spirit of support staff. Agencies that treat their staff well, provide the supports they need to do their job, and give their staff the compensation (pay and benefits) and respect they deserve for the job they do are more likely to have staff who are effective, respectful, and stable. Ask about how agencies treat their employees.
- **Do the staff members of the agency who will work with me have the initiative, knowledge, commitment and creativity to meet my needs?** People with disabilities face many challenges in their lives. For some, medical challenges and emergencies are to be expected and staff must know what to do. For others, the primary chal-

allenges are social, and effective support staff need to show initiative, commitment, and creativity to help people become included in the community in which they live. It's important to talk to the staff who will be providing supports to make sure that the challenges and issues that are most important to you are ones that staff show sufficient initiative, knowledge, commitment, and creativity to satisfy your expectations. If they don't, talk to the agency management about needed training or different personnel. If you aren't satisfied, talk to another agency.

Unless they're involved in assisting and supporting people they serve to live in their own homes, service providers and case managers can't be considered to be at the leading edge of the evolving services system. Service users have a right to have their interest in controlling their housing taken seriously. When people feel providers don't support their desire to have their own homes, they should feel empowered to find new ones that do. Lists of agencies that provide support services in your area may be obtained from your county social services agency. Other assistance may be obtained from organizations listed in Chapter 9.

Working Cooperatively: A Service Provider's Perspective

Since the mid-1980s, when the first few families began working with the first few service providers to develop consumer controlled housing arrangements, many of the state's service provider agencies have come to view consumer controlled housing as an acceptable, workable setting in which to provide residential services to the people they serve. In fact, the Association for Residential Resources of Minnesota (ARRM), the state's largest association of residential service providers serving persons with developmental disabilities, now has an organizational policy statement which reads, "ARRM supports initiatives that support enhanced consumer choice of providers and services." This would include the owner's control of their residence.

In working with families over the past two decades, provider agencies have experienced their own challenges in developing consumer controlled housing arrangements. Arc Minnesota Board Member Lynne Megan, an administrator for REM Minnesota, Inc., the state's largest residential services provider agency, shares some of her agency's experience with consumer controlled housing, and offers persons with developmental disabilities and their families advice on how to work with the provider agency to assure that the person who controls the housing receives the maximum benefit from the arrangements.

Lynne's primary message is to assure that communication between the family and the provider is open and clear. She says it is essential that the expectations of everyone who is involved in maintaining the housing and service arrangements are made explicit from day one. To illustrate the importance of this, she tells of a family whose son her agency served in a trust-owned home. After the first year of providing services, the management was surprised when the family presented her with a long list of unmet expectations. Upon reviewing the list, the program director realized that most of the expectations on it had not been met, not because her staff could not or would not meet them, but because her agency wasn't even aware of them! Both the agency and the provider learned an important lesson in the importance of communication during this first year of the new housing arrangements.

Running a household is a complicated process that most of us take for granted. Responsibilities, relationships, preferences, rules, rights, and privileges all pose challenges to the general order, but are worked out effectively in well-run households. Who does the cooking, who pays the bills, who decides what color to paint the living room, who fixes the roof, and who makes the rules of the home are usually known to and accepted by all members of the household. But overlay on the operation of a typical

household the unique aspects of a consumer controlled home for one or more person with developmental disabilities, and the challenges increase. The family(ies) and providers, one or more roommates (each with their own individual service plan), the live-in staff, PCAs, and program managers must work in concert to assure that minor "growing pains" don't mushroom into major problems that threaten the living arrangements.

To avoid the kind of conflicts that can arise, Lynne's experience has shown her the importance of all parties understanding one another's roles and duties, responsibilities and rights. Staff need to respect that they are working in the home of the people for whom they are providing services and often times the house is the property of one or more of their parents. Parents need to understand which staff are responsible for which duties. (Expecting the personal care attendant to do something about unplowed snow in the driveway is not realistic) In the case of a home where one family owns the premises and members of other families live there, the family who owns must understand that all of the people who reside in the home have equal

rights in regard to services received, and they must respect the roommates' needs, preferences, and privacy. The families who don't own the home and their sons or daughters shouldn't be expected to play second fiddle.

A clearly written lease is not only essential to convey the legal obligations of the property owner and the service provider, but is also a useful vehicle for recording the expectations of the family. In the Appendix, there is a copy of an actual lease agreement that one Minnesota family has signed with their provider agency. This lease agreement covers not only such standard lease provisions as rent payments and maintenance responsibilities, but it also includes a list of "Rules and Regulations" that covers such issues as the home's policy on pets and expectations on the care of the plumbing fixtures. This list can easily be amended by the family without having to renegotiate the lease. One section of the lease allows the family to "inquire" about any proposed new housemate or staff person. The lease and its list of rules provide the family and the staff an effective means of "staying on the same page" with regard to expectations and responsibilities.

Informal Supports: Opportunities and Challenges

Many of the services and supports necessary for persons with developmental disabilities to live happily and successfully in their own homes can be, and are, provided not through government-funded programs but by family members, friends, neighbors, volunteers, roommates, and others at no charge. As more persons with developmental disabilities take up residence in their own homes in the community and become more fully socially integrated, the possibilities for identifying and using informal supports increase. Such arrangements can be highly satisfying for both the person providing and the person receiving the support. But when developing service plans, it's important to use caution not to become overly dependent or demanding of people who provide informal supports. People

who willingly provide friendship and assistance can easily come to feel – and *be* – taken for granted or burdened beyond what they expected. When no contract is involved in the provision of services, problems with short-term reliability and long-term continuity can arise. In short, informal supports should be cherished and protected as the delicate gift they are.

Because of concerns about the shrinking availability of paid direct care staff, a number of initiatives have begun which will allow payment of family and friends who provide informal support services. The availability of these programs varies across the state. To learn more, contact your local Arc chapter or Arc Minnesota.

6

Assessing Need & Getting Help for Home Modifications or Equipment

Introduction

In recent years, people with disabilities and their friends, families, and service providers have helped communities realize that home is usually the best place for their citizens with disabilities to live. In the process, they have learned that home living can be much less expensive than institutional care. But most importantly, they have learned that living in one's own home increases the quality of one's life.

The federal government has passed legislation to help ensure affordable, accessible, community housing for people with disabilities, as well as the accessibility of public buildings. The National Affordable Housing Act of 1990 (PL 101-625) provides for subsidized housing programs for people with disabilities. The Fair Housing Amendments Act of 1988 (24 CFR Part 100) includes guidelines for accessible restrooms, parking, entryways, and more, and the Architectural and Transportation Barriers Compliance Board publication (36 CFR 1191) contains data on barrier-free environments.

In many cases, homes need to be modified to allow people with disabilities to live independently, safely, and with dignity. Independence and safety are crucial – but dignity is equally important. For

instance, taking a door off its hinges to make a bathroom or bedroom wheelchair-accessible quickly solves the immediate problem, but ignores the dignity of the person. For almost every situation exists a cost-effective solution available that provides both accessibility and dignity.

Solutions to problems of accessibility and safety need not be very expensive and the ideas presented here are generally low-cost. As a rule, it costs more to modify an existing home than to include modifications in the building process of a new home. But, whether one is buying an existing home, building a new home, or modifying a rental property, modifications and assistive devices can be purchased outright through Medicaid programs or through deferred, interest-free loans for home modifications.

This chapter discusses strategies for consumers and families to use in assessing and modifying homes to meet their needs. People who live in public or private rental housing should, of course, contact the property manager to determine whether and under what conditions modifications can be made. If the public housing is federally subsidized, an individual has certain rights under the Fair Housing Act.

Thinking About Needed Modifications

The following considerations are important in thinking about and choosing housing for persons with physical disabilities. One should carefully examine the issues and problems that will need to be taken care of in any home one is looking at. Unresolved issues and problems often lead to regrets about the housing chosen and/or future expense. If

there are important problems that need to be addressed in the home being considered, it's important to make sure there is a plan to make and pay for the needed modifications before committing to a lease or mortgage. Some of the areas of the home and related issues/potential problems that might be particularly important to persons with disabili-

ties are identified in the following pages. Of course, these considerations aren't exhaustive nor does every consideration apply in every situation.

Outdoors

- Make sure walkways are clear and wide enough to accommodate wheelchairs, walkers or other mobility aids that may be used or needed.
- Make sure any needed ramp is at a manageable angle.
- Doors should be at least 32 inches wide (for wheelchair users).
- Check to see if sliding glass doors have thresholds that are low enough for easy and safe crossing.
- Make sure railings are installed on both sides of the front steps.
- If needed or helpful have a lever door handle rather than a doorknob on the entry doors.
- It may be important to have a single-action deadbolt lock on the inside of the front door.
- Examine the walkway/porch front entryway area to see if it's well lighted.
- Make sure that the mailbox is in a location that makes it easy to retrieve mail or that an agreement is made to move it.

Garage and Parking

- Find out if the garage is wide enough to accommodate a wheelchair exiting from a van, or if the person will have to get out of the van outdoors.
- Make sure the garage entrance is high enough for a van.
- Check to see if there is an automatic garage door opener.
- Garage lights, hangers for gardening and other tools, and other things to which an individual needs access should be hung in such a way that they are easily reachable.
- Determine whether the parking lot has convenient handicapped spaces.

Indoors – General

- Make sure that switches and thermostats are located so that they can be easily accessed (usually within 44 inches of the floor).

- Make sure electrical outlets can be reached (preferably placed at least 27 inches from the floor to minimize bending).
- Make sure that carpeting allows easy navigation with a wheelchair or walker. It should be securely fastened to the floor. (People may want to determine whether these are hardwood floors so that carpets might be removed.)
- Examine the stairs to see that both the rail and bannister have a sturdy hand grip and that the carpeting on steps is in good repair and tightly secured to the steps.
- It's recommended that ceiling lights be replaced with wall lights to make it easier to replace light bulbs. Find out if ceiling lights can be changed with a light-bulb changer (available at most hardware stores).
- Make sure any doors to stairs close completely.
- Make sure that light bulbs been replaced with long-life bulbs.
- Check if floor and table lamps have switches that are activated by touch or sound.
- Smoke detectors should be installed low enough to allow ease in changing batteries. Ideally they should be electric or arrangements should be made to insure active smoke detectors.
- Locate an acceptable location to mount a rechargeable flashlight in case of a power failure.
- Check to see if doors have lever handles instead of round doorknobs.
- Interior doorways should be at least 32 inches wide. If not, see if doors can be mounted with swing-clear hinges. This will eliminate the need to tear out doorjamb to widen the doorways.
- For many people personal security devices are advisable for each room of the house. Such devices alert help if someone falls or needs emergency assistance. There are a number of these devices on the market and they often are reimbursable under the funding sources described on page 56 and in Chapter 5. (They can save government agencies a lot of money if they reduce the amount of direct supervision needed by an individual.) Some of these devices, when activated, make a phone call to a central location that can dispatch help. Others are programmed to ring the home phone at prearranged times during the day; if the phone is

not answered, emergency personnel are sent to the house. It's also possible to establish alerting systems directed to apartment staff, neighbors, and others.

Kitchen

The kitchen is usually one of the most "lived-in" rooms in a house. Cooking, eating, cleaning, and entertaining can be made easier by housing modifications and assistive devices. Safety is also an issue in the kitchen because of the potential for burns, spills, and fires. For these reasons, it's important to inspect several features in the kitchen, including:

- Check whether shelves roll out to minimize bending and providing access to the items in the rear.
- Check that there is adequate storage space, given one's likely schedule of shopping.
- It's often helpful to have a shelf with cutouts that can hold bowls securely for one-handed stirring or that is placed at a level convenient to a person who is seated.
- Lighting should be adequate and directed over any modified work areas.
- Make sure that can openers, vegetable peelers, and other kitchen utensils have easy-grip handles. Find out if they can be purchased and mounted.
- The sink should be easily accessible. Some sinks have sloped fronts so that dishes can be slid into them. In addition, long-handled lever faucets and spray nozzles simplify dishwashing.
- The refrigerator is often more convenient if it has a side-by-side refrigerator-freezer setup or a freezer on the bottom for easy access.
- Make sure burner controls are mounted on the front of the stove, to eliminate the risk of burns from reaching over a heating element.
- Check to see that fire extinguishers are easily reached, lightweight and easy to use.
- Find out if dishwashers, microwaves, washers and driers have or require modifications (e.g., Braille or tactile labels, or customized knob turners, special on/off switches).

Besides these fairly major modifications, there are many inexpensive "tricks of the trade" that allow easier maneuvering in the kitchen:

- A small mirror mounted over the range allows seated cooks to see into the pans on back burners.
- Unbreakable glass pots let seated cooks see how the food is cooking.
- Clamps (like clothespins) can be attached to burner knobs, making turning easier, or used to secure pots on a range to help with one-handed stirring.
- An old-fashioned potato masher or slotted spoon can be used to turn knobs on a clothes dryer.
- Tongs can help get cans or boxes off cabinet and refrigerator shelves.
- Oven rack push-pulls can help cooks in wheelchairs or who have limited reach.
- A cart can be used to minimize carrying.

Bathroom

The bathroom often presents some of the greatest challenges for people with physical disabilities. These challenges include preventing falls and eliminating the hazards of using electrical appliances around water, maintaining privacy and dignity while attending to problems of accessibility and safety, and making necessary modifications in efficient and cost-effective ways. Among the areas that should be checked in the bathroom are:

- Make sure the bathroom is located in an easily accessible area of the home.
- Check if the entry door is adequate. If the doorway is too narrow, sliding doors may have to be added to provide needed space or the wall of the adjoining closet may have to be knocked out to create a new doorway. Find out who must approve this, what it costs and who would pay.
- Examine the shower to see if a commode or shower chair will fit.
- Make sure a sturdy seat is installed in the shower.
- Grab bars should be installed around the toilet and tub and should be well positioned.
- Try out the faucet hardware to see if it's easy to operate, with easy to-turn knobs or levers.
- Check the wet surfaces to find out if they have anti-slip material.
- Make sure that a wheelchair can pull up to the sink.

- Take a look at the location of mirrors and outlets to see if they are at usable levels and positions.
- Inspect the linen closet or cabinet for accessible and adequate storage space. (You may want to consider installing extra shelves or organizers.)
- Make sure the electrical outlets are located away from the sink and bathtub, to minimize the risk of electric shock.
- Find out if there is either a telephone or emergency alert device in the bathroom or whether one can be installed.
- Inspect the placement of phone jacks and phones to confirm that they are installed throughout the house for safety and security.
- Remote control devices to allow control of appliances and lights from another room are often desirable. (For instance, these devices can be used to turn lights on before entering a room.)
- Find out if there is an intercom at the front door. Another useful device is a wireless doorbell, which can be carried from room to room to ensure that ringing is heard.
- Make sure that the switches on lights are easy to find, reach, and control.

Living Rooms and Bedrooms

Living rooms, bedrooms, and other rooms without plumbing are fairly easy to make accessible. Some of the major considerations have already been mentioned: wall switches, thermostats, electrical outlets, carpeting, and so forth. Many considerations regarding the adequacy of living and sleeping environments have to do with devices more than specific modifications. Many of the devices that can greatly increase a person's independence in their own homes are ones that are readily available on the open market. Among the issues to consider are:

Living Rooms

- Check the windows to see if they are easy to open. (Windows that tilt out at the base make opening easy, and help keep out rain.)
- It's helpful to have remote controls on the TV, VCR, radio, CD, etc.
- Make sure there is a cordless phone or a speaker phone installed. (This can be an important safety as well as communications device for people with mobility impairments.)

Bedrooms

- Check the height of the bed to see if it's the right height for a minimally assisted wheelchair-to-bed transfer.
- Make sure that lamps near the bed can be turned on by touching the lamp base or another easy way.
- Open the closet door and see if lights turn on automatically when the door is opened.
- Clothing rod heights should be easily adjustable.
- It's helpful to have curtains of the easy gliding type, rather than curtain rods and drawstrings.
- Make sure there is a phone next to the bed.

There are many commercially available products designed to aid people with disabilities in the routines of daily living. The STAR Program in Minnesota was developed to help Minnesotans identify such products that meet their specific needs. The Metropolitan Center on Independent Living (MCIL) can also provide assistance in suggesting devices that can meet individual needs. (See Chapter 9 for contact information for these agencies.)

Sources of Financial Support

Minnesota has a number of programs that can assist people with developmental disabilities to obtain the home modifications and assistive devices they need to live in their own homes. These include the following programs:

Home and Community-Based Services (HCBS) Waiver

This program was described in Chapter 5. It should be noted here that home modifications and assistive technologies may be purchased through the pro-

gram, including architectural items, communication aids/ emergency warning devices, and mobility aids.

Community Alternative Care (CAC) Waiver

This program is available to people under age sixty-five who are eligible for Medical Assistance, regardless of parental or spousal income. They also must be residents of inpatient hospitals or at risk of such placement, but would prefer community-based care. Medical Assistance will provide services to support the person's preference.

Besides regular Medical Assistance services, the services available under this waiver include case management, respite care, minor home adaptations, family counseling and training, extended foster care services, home-maker services and extended coverage for health services, medical supplies and equipment, prescribed drugs, and transportation.

The types of assistive technology that can be funded under this waiver include:

- Ambulation aids
- Seating/ positioning aids
- Prosthetics and orthotics
- Sensory aids
- Communication aids
- Architectural items
- Environmental controls
- Bed aids
- Aids for daily living
- Mobility aids

Community Alternatives for Disabled Individuals (CADI) Waiver

This program provides medical and related services – which can include assistive technology – to children and adults with disabilities who reside in their homes but require the level of care provided in a nursing home. To be eligible, a person must be under age sixty-five and must prefer home or community care. Besides regular Medical Assistance services, this program provides case management, home and vehicle adaptations, adaptive equipment, homemaker services, respite services, family counseling and training and adult day care. The types of assistive technology that can be funded under this

waiver include:

- Ambulation aids
- Seating/ positioning aids
- Prosthetics and orthotics
- Sensory aids
- Communication aids
- Architectural items
- Environmental controls
- Bed aids
- Aids for daily living
- Transportation aids
- Mobility aids

Traumatic Brain Injury (TBI) Waiver

Since November 1998, local agencies may review and authorize home and vehicle adaptations and modification requests for TBI waiver recipients, as well as for HCBS, CADI, and CAC waiver recipients.

Family Support Grant Program

The Family Support Grant Program provides cash grants (maximum \$250 per month) to eligible families for the purchase of services and items, which can include assistive technology, necessary to maintain children (0–22 years) with developmental disabilities in the family home. In 2000, families with annual incomes below \$73,446 were eligible for this program. This is a state-funded program administered at the county level.

Medical Assistance for Assistive Technology

Medical Assistance (MA) funding is available for both assistive technology devices and assistive technology services. Basically, MA funds equipment, devices, and other health services that are “medically necessary.” Examples include:

- Augmentative communication devices.
- Assessment for augmentative communication.
- Bath lifts, bath tub chairs and seats.
- Canes, crutches, and walkers.
- Oxygen and oxygen supplies.
- Seating and positioning devices.
- Wheelchairs, both manual and motorized.

MA also covers medical equipment rental and maintenance/repair of recipient-owned equipment.

Assistive technology devices and services must receive prior authorization by MA before they are provided. In Minnesota, the request for prior authorization must show that the device or service meets all six of the following criteria:

- 1 Must be medically necessary as determined by prevailing medical community standards;
- 2 Must be appropriate and effective to the medical needs of the recipient;
- 3 Must be timely, considering the nature and state of the recipient's medical condition;

- 4 Must be furnished by a provider with appropriate credentials;
- 5 Must be the least expensive, appropriate alternative health services available; and
- 6 Must represent an effective and appropriate use of program funds.

The MHFA Rehabilitation Loan, Fix-Up Fund (Accessibility) Loan, and Access Home Fund Programs

These programs, administered by the Minnesota Housing Finance Agency, are described in Chapter 5.

Working with the System

People who plan to apply for Medical Assistance to acquire assistive technology devices and services or home modifications should be well informed about Medical Assistance's policies and procedures. By law each state agency that applies for Medical Assistance funds must keep copies of its policies and guidelines in every agency office, and these policies must be available to read or copy during office hours. One should bear in mind that physical modifications to homes are available through the waiver programs, but not the general Medical Assistance program.

If possible, one should meet with a representative from the county agency in which he or she applies for Medical Assistance. It's a good idea to establish a personal rapport with the people who make assessments and decisions about funding. Knowing the specific assistance individuals need (e.g., a modification such as a ramp or widened door; a service such as evaluation; or equipment such as a wheelchair or an augmentative communication device) will also be helpful.

If your doctor recommends a particular service or piece of equipment, he or she will then refer you to an approved provider. The provider contacts Medical Assistance for authorization to purchase the modification, equipment or service. This prior authorization must be received before the recipient

gets most devices and services.

It's important to remember that Medical Assistance requires devices and services that are "necessary." Because medical necessity can be open to interpretation – especially when it comes to assistive technology devices and services – you should be prepared to pursue your case for some time. Obtaining prior approval can take months and can sometimes be a difficult process.

If Medical Assistance denies a request for assistive technology, the denial shouldn't be considered an end to the search for funding. Individuals who want to appeal a denial should contact the state Department of Human Services in writing to schedule an appeal. For further assistance, disability legal services offices can help; the phone number of the state office appears in Chapter 9. An important tool in an appeal will be a complete set of records including all correspondence and phone conversations.

People are their own strongest advocates in an appeals process because they know better than anyone else what their needs and resources are. Federal law supports the individual's right to achieve his or her maximum potential through increased independence, productivity, and integration into the community.

7

Planning for Long-Term Security

Introduction

Many parents, siblings, and guardians of persons with developmental disabilities face some very important questions: "What will happen after I'm gone?" "How will the needs of my child/brother/sister/legal ward be met?" "Who will look after this person's interests?" Indeed, parents who have assisted sons or daughters to secure and maintain homes of their own are often rightfully concerned whether these children will be able to keep their homes for as long as they want or need them, and whether necessary supports will always be available to them.

Many family members and guardians would like to help persons with developmental disabilities to obtain their own housing, but they feel that the persons lack the capability and resources to make current and future personal and economic deci-

sions, including those that relate to housing. They wonder if they can take any action to ensure that the decisions facing the persons with developmental disabilities will be made with appropriate levels of assistance. The worries of family members are often addressed through the formal planning and legal processes that result in formal estate plans.

Minnesota families and guardians have a range of options from which to carefully make selections according to the needs and capabilities of the persons whose interests need protection. This chapter examines some approaches to long-term planning for persons with developmental disabilities and introduces concepts of and processes in long-term planning.

Comprehensive Life Planning

People who care about individuals with developmental disabilities often experience anxious moments wondering what will happen when they are no longer able to attend to a child's or ward's best interests and desires. Questions like the following are brought up:

- How can we make sure that the person's personal priorities and interests will remain a top priority in decisions about his or her lifestyle?
- How can we make sure that governmental assistance such as SSI, SSDI, Medicaid, Medicare, etc., will be continued?
- How can we provide the needed supplemental supports and activities which are not covered by governmental benefits? How will the funds we designate for such efforts be managed?

- How can we provide for a smooth transition in resource management and individual advocacy if a primary care provider and/or guardian is incapacitated or dies?
- How can we integrate a life plan for a family member with developmental disabilities into a total family estate plan?
- How can we provide final arrangements for our family member?

One approach taken by family members to assure that these questions are adequately answered is to develop a comprehensive life plan. Such a plan generally has four major components: the life plan, the financial plan, the legal plan, and plan management.

■ Four Common Components of a Comprehensive Life Plan

Part 1: The Life Plan Component

The life plan component of comprehensive life planning generally includes a written plan that describes a family's hopes and dreams for the family member. It includes information about all areas of the person's life: medical needs and medical care, education, housing, employment, social aspirations, and all other aspects of the person's life. The life plan helps successors to know as much as possible about the individual in order to support the best possible transition when the family member or guardian is no longer able to provide care, support, and advocacy. This information should be written in a letter of intent. The letter of intent should contain information relating to the person with a developmental disability in the following areas, as well as in other areas that are important to the person:

- Residence
- Behavioral needs
- Education
- Social activities
- Employment
- Religious activities
- Medical care
- Final arrangements

A letter of intent worksheet should be developed by listing available options in the preceding categories and in any other important categories. Under each category one should list four or five options and identify their order of preference. As much as possible, the information in the letter of intent should be the result of discussions among the person developing the plan, the person with a developmental disability, and others who know the individual well.

After identifying preferences, the family member or guardian actually should write the letter of intent (without worrying about "legalese"). The letter of intent should be addressed "To whom it may concern" and should give the name, relationship to the person with a disability, and address of the caregivers who are writing the letter. It should contain a life history of the person with a developmen-

tal disability. In this letter, the writer should go into as much detail as possible; he or she should be sure to also indicate what has not worked in the past as well as the important non-negotiables that are most important to the individual's quality of life (e.g., needs own space, is allergic to smoke, hates loud noises). It's important to be as specific as possible. The sole purpose of this letter is to assist one's successors to know all there is to know regarding the individual. In this way the concerned family member can provide for his or her "presence" at future person-centered planning meetings. The letter of intent should be dated and signed by the person(s) responsible for writing it. Even though the letter of intent is not a legal document, it's meant to guide the courts and successors regarding hopes and desires for the family member with the disability.

Part 2: The Legal Component

The legal component requires an attorney who is familiar with this special type of planning. This component should include wills written by the parents (or spouse) of the person(s) with disabilities. In addition to the usual disposition of the estate, the wills often exclude the person with a developmental disability by name and indicate that his or her portion of the estate goes to a supplemental needs trust. The supplemental needs trust is also then included, assuring that all indicated assets are held and protected for the person with a disability as desired. At this time, the advisability of adding Power of Attorney and Health Care Directive should be discussed.

In most situations, a person's basic living needs will be provided by programs such as SSI, SSDI, and Medicaid. But what about those supplemental needs that add to the quality of life for the individual? What about needed items like a new winter coat, extra clothes? What about a new TV? What about other preferences – such as eating out or engaging in a special activity the individual has always enjoyed? What happens to some of the favorite activities in the accustomed life style when the primary caregivers are gone?

Most families know that if they leave a direct inheritance to the family member with a developmental disability, governmental benefits will be reduced or eliminated because the individual's inheritance will exceed the maximum limit of assets allowed. To avoid this problem, some families have

left the person's share of the inheritance to another family member. But this move does not guarantee that the person with a disability will receive the money needed to maintain a quality of life. Even if the relative has the best intentions, problems may arise with creditors, a lawsuit, a marriage or divorce, and so forth. Such occurrences can eat up the money that was intended for the person with a developmental disability.

To solve these problems, it's often suggested that the person with a developmental disability be excluded by name from family wills; any amount intended for him or her should, instead, be placed in a supplemental needs trust. The initial trustee of the trust usually is a parent or the primary caregiver, but several successor trustees should be named. In addition, nominations for successor conservators, if needed, also should be named in the trust.

It's often recommended that the supplemental needs trust be a "living trust" as opposed to a testamentary trust. A testamentary trust only takes effect when the caregiver dies, but in a living trust, gifts and other assets can be placed into the trust while the care provider is alive and it can be used on a regular basis to meet some of the current needs of the person with a disability. The money from the trust is disbursed to the person with a disability at the sole discretion of the trustee, according to the guidelines which are set forth and which provide direction for the successor trustees on how the money may be used.

When determining what assets should be placed into the living trust, caution and financial advice are often recommended. The trust is irrevocable. The money in the trust can be used only for the supplemental needs of the family member with a disability.

A trust is a separate entity. This means the assets owned by the trust *do not* count as assets for the person with a disability, a provision assuring the assets *will not* disqualify the person from receiving governmental benefits, provided that the trust is properly worded.

It should be noted that living trusts are a specialized area of law and the legal documents pertaining to them must be carefully drawn up according to state statutes. When speaking with an attorney about establishing a trust, a caregiver may want to ask for

references – the families with whom the attorney has worked – and/or to find out how many living trusts the attorney actually has completed.

Part 3: The Financial Component

The financial component must address how much it will cost to make certain the family member with a developmental disability will have the quality of life described for him or her in the letter of intent and where the money will come from.

To answer the first question, it's necessary to determine how much money is now spent for items not provided through governmental programs; this includes items such as a new television and/or cable service, an annual vacation, birthday and Christmas presents, new clothes, and other special items that contribute to the person's enjoyment of life.

It's often suggested that the family members establishing a trust keep a record of all the money they currently spend for supplemental items which contribute to the individual's quality of life over a period of time. Doing so will give them a good idea of the amount being spent. An average monthly amount can then be determined and then be used to ascertain the amount needed to fund the supplemental needs trust. To assure a supplemental income for life, a trust usually includes an amount of money or other assets that can provide the desired monthly amount from interest alone. For example, if the average supplemental income needed per month ranges from \$100 to \$200, the total amount needed for the trust would be about \$50,000 to \$150,000. Of course, any remaining funds, when the beneficiary of the trust dies, go to the individuals designated by the trust writer.

The next issue for persons establishing a trust is where this money comes from. The answer will vary from family to family. For some, alternative methods such as life insurance should be explored. Keep in mind that the total amount need not be placed in the trust all at once. It must be there only when the caregivers are no longer able to provide for the supplemental needs of their family member. For this reason, only a small amount of money is usually placed in the trust initially and then it's built up by regular deposits. More information about trusts can be found later in this chapter.

Part 4: Plan Management

Plan management involves three parts: a) preparing a life plan portfolio, b) meeting with one's successors, and c) participating in periodic reviews.

The objective of the life plan portfolio is to put all important information and documents regarding the family member with a disability and the person(s) establishing the plan in one location (e.g., a three-ring binder). The following items typically are included for the person with a developmental disability:

- Letter of intent
- Social Security card
- Guardianship papers
- Medicaid application
- Case manager's card
- A picture of the person
- Birth certificate
- Health card
- Conservatorship papers
- Information on government agencies
- Name and phone number of contacts at agencies
- Admission papers for schools and camps
- Individual Education Plan/Individual Service Plan
- Other evaluations and plans

The family caretaker's items typically include:

- Copies of the caretakers' wills
- Assets in the trust
- Social Security card(s)
- Copies of supplemental needs trust
- Copies of most recent tax return
- Birth, marriage, and divorce documents

It's important to meet with one's successors before and then as soon as possible after completing the planning. These meetings give the writer an opportunity to consider alternatives in the life plan and the roles of successors, and to explain the comprehensive life plan to the successors and hold a detailed discussion. This is critically important with the writer's proposed duties and expectations for others. Any expectation the writer may have for the exercise of guardianship should be understood and agreed to by the designated individual prior to developing the life plan portfolio and be clearly outlined in the documents. Successors and a designated guardian or conservator should know where the life plan portfolio will be kept and other pertinent information. The writer will want to notify friends and relatives of any supplemental needs trust; thus any gift or inheritance to the family member with a disability can be willed to the trust.

The parties should review the plan annually or, if circumstances change, to make sure that all of the objectives are being met. At times it may be necessary to update the letter of intent and to reevaluate successors. If some of the people become unable or less able to carry out a designated role, or move a distance away that would make them less effective or indicate a lack of interest, then one must review the funding goals to assure that they are still realistic and change necessary legal documents to show the change in successors.

With such planning completed, family members can feel comfortable, knowing that they have done what they can to be sure that their family member will be supported in maintaining his or her quality of life even when they are no longer around.

Organizations and individuals engaged in life planning often offer free seminars (see Chapter 9).

Guardianship vs. Conservatorship

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 civil rights, such as the right to vote. Guardianship should be considered only for people who cannot make *any* legal decisions for themselves.

There are two primary types of adult 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 or her son or daughter can choose him- or 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 relative, and must make annual reports to the court describing the services the person under guardianship receives.

Most attorneys recommend naming co-guardians, in the event something happens to the first guardian. While the guardian may make 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 assumes decision-making responsibility. It's 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 authority. Two major disadvantages to state guardianship are that the case manager, who is responsible for meeting the needs of many persons, may not be able to develop as close a personal relationship as a private guardian. Also, the case manager, as an employee of the county responsible for funding services, is faced with a potential conflict of interest.

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 developmental disabilities 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 or her life may find a conservatorship arrangement more suitable. The explicit stipulation of the areas of control and protection allow conservatorship to more 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 can assume decision-making capacity under conservatorship.

■ Other Options

Options that do not require legal procedures and are less intrusive than guardianship and conservatorship include:

- **Appointment of a representative payee**, whereby another person is designated as payee for the son 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 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 guardianship and conservatorship is available from Arc Minnesota.

Setting Up Trusts

A trust is a legal arrangement whereby one party (the grantor) transfers assets to a second party (the trustee), who agrees to invest and use the assets for the benefit of a third party (the beneficiary). The beneficiary of a trust may be a single individual or a group of people. A trust may have more than one grantor; for example, a husband and a wife may together be the grantors of a trust. Almost anything can be put into the trust: bank accounts, stocks, real estate, business interests, or contributions from fourth parties.

The trustee manages the assets of the trust and follows the instructions given by the grantor on how the assets may be used for the trust beneficiary. Sometimes the trustee is granted very broad or more limited discretionary powers. The trustee may be one or more individuals (e.g., siblings) or a corporate officer, such as the trust department of a bank or investment firm. Trusts may provide for successor trustees in the event that a named trustee is unable or no longer chooses to serve. Trustees are entitled to "reasonable compensation" for the services they provide and they may hire other professionals, such as accountants and investment advisors, out of the trust assets.

Parents and family members commonly use trusts to set aside and to protect financial resources for persons with developmental disabilities. Parents who use trusts in this way must be careful in setting them up. In some cases, persons who inherit property or money may lose their eligibility for the government-funded programs that provide services and income support or they may be forced to pay for their own care after it has been determined they have assets.

In setting up a trust, family members may wish the help of a lawyer who has set up trusts for others and is knowledgeable about state and federal regulations. The individual, his or her circle of support, and other persons, including the case manager, may be involved in identifying future needs and incorporating them into the design of the trust instrument.

While well-to-do 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 the assets may not be considered in the determination of eligibility for governmental programs.

■ **How Is a Trust Set Up?**

A trust can be established in either of two ways: by will or by a trust agreement. The first is called a *testamentary trust*. In as much as a will does not actually become effective until after the grantor's death, a testamentary trust also becomes effective only upon the grantor's death.

The trust agreement, or declaration of trust, is a document that is normally prepared by an attorney and is signed by both the grantor and the trustee. Such a trust becomes effective when it's executed and assets are transferred to the trust. This type of trust – a *living trust* (or an *intervivos trust*) – takes effect while the grantor is still living. Assets that are held in living trusts normally avoid probate upon the death of the grantor. Furthermore, living trusts may be either revocable or irrevocable. A *revocable living trust* is one that can be changed by the grantor or even revoked in its entirety. On the other hand, an *irrevocable trust* is one that cannot be changed or revoked once it has been established.

Assets are transferred to a trust in one of two ways. Assets that pass into a testamentary trust go through probate and are directed into the trust through the grantor's will. Assets that pass into a living trust are retitled to that trust. The assets do not have to be moved, sold, or changed in any way except that the name on the asset must be changed.

For example, a grantor can transfer real estate into a living trust by signing a deed that transfers the title into the name of the trustee on behalf of the trust. Different methods exist for transferring different types of assets.

Trusts do not last forever. They end when the purposes for which they were set up have been achieved (e.g., the beneficiary's death).

■ How Does a Trust Work?

A revocable living trust is controlled by the grantor during the grantor's lifetime. The grantor usually acts as trustee in addition to having authority to change the terms of the trust at any time. The grantor can continue to use the assets for any purpose, without limitation, and without the need to report to any other party. The grantor uses his or her own social security number as the tax identification number for the trust. It's not necessary for the grantor to file a special trust tax return. All income from the trust is reported directly on the grantor's personal income tax return.

When the grantor dies or becomes mentally incompetent, the successor named in the trust agreement takes over as trustee. In order to act as trustee, the successor normally needs some evidence of the grantor's inability to act, such as a letter from the grantor's physician asserting the grantor has become incompetent or a copy of the grantor's death certificate. It may also be necessary to produce a copy of the trust agreement or some portion of the agreement. The successor trustee can then proceed with handling the assets in accordance with the terms of the trust. After the death of the grantor, it's necessary for the trustee to obtain a separate tax identification number for the trust and to begin filing a separate trust tax return. It's unnecessary for the trustee to probate any of the assets, to be appointed by a court, or to account to a court. The trustee, however, owes a fiduciary duty to the trust beneficiary and must account to him or her or to the beneficiary's guardian or conservator.

A testamentary trust is, by definition, an irrevocable trust because it becomes effective only upon the death of the grantor. The terms of the trust are spelled out in the will. Unlike the living trust, the will does need to be probated. However, once probate has been accomplished, it may not be necessary for the trustee of the testamentary trust to continue to account to the court. The trustee must obtain a separate tax identification number for the trust and must file separate trust tax returns.

■ Advantages of Trusts

All trusts are somewhat different. Trusts can be established to accomplish different purposes, although not all trusts can accomplish all the benefits listed here. Some reasons for establishing a trust include:

- Protection of a beneficiary with limited capacity to manage assets.
- Protection of assets from means test services which the beneficiary needs.
- Money or property management.
- Operation of a business or handling of real estate.
- Protection of beneficiaries from creditors.
- Avoidance of guardianship or conservatorship of an estate.
- Avoidance of probate.
- Protection of privacy.
- Simplification of transfers between generations.
- Tax savings.
- Protection of the desires of a grantor who may become incapacitated.

Revocable living trusts have gained in popularity in recent years. Among their advantages are:

- Allows the grantor to retain control while alive and competent.
- Effective both while the grantor is living and after death, making transition somewhat easier.
- Assets held in such a trust will avoid probate after the grantor's death.
- Since the trust agreement may be amended it offers flexibility.
- Offers some protection in case of the incapacity of the grantor.
- Grantor may direct management of the trust assets.
- Trust may include almost any type of asset (also true in testamentary trusts).
- May provide for more convenient management of assets by trustee (also true in testamentary trusts).
- Allows the grantor and beneficiaries to become familiar with the trustees while the trust is still revocable.

- Provides privacy for grantor and beneficiaries since it need not be filed anywhere.
- Parents can set aside and protect a portion of their assets for the benefit of a son or daughter while maintaining his or her eligibility for governmental programs (also true in testamentary trusts).

■ Trust Ownership of Real Estate

When real estate is deeded to a trustee on behalf of a trust, the trust becomes the owner of the real estate. The trustee has the legal authority to enter

into all transactions on behalf of the trust. The trustee may be given the flexibility to sell a particular house and purchase another, or to lease a house to a care provider, with a stipulation that the grantor's son or daughter reside in the house. In this latter case there should be a formal written lease agreement with the care provider which can be renewed by agreement between the parties. Lease payments, of course, are income to the trust which can be offset against expenses, such as maintenance, real estate taxes, and the like.

The Supplemental Needs Trust in Minnesota

In 1993 the Minnesota State Legislature passed Section 501b.89, Subdivision 2 of Minnesota Statutes which formally recognizes the use of a supplemental needs trust. This is a trust that a parent or other individual can create for a son or daughter who has a disability to provide for some of their supplemental needs while maintaining his or her eligibility for governmental benefits. As such, the trust is not normally designed to provide for basic health, support, and maintenance. Specific guidelines are laid out in the statute allowing funds to be used for living expenses that supplement the funds provided by public benefits. The rules in the statute provide a "safe harbor" in which a supplemental needs trust will not affect eligibility for publicly funded benefits. In fact, the statute specifically provides that such a trust must state that assets should not be used to replace, reduce, or substitute publicly funded benefits. There can be some limitations after attaining age 64. Consult with competent legal counsel for further information. When the person with a disability dies (beneficiary), any remaining assets of the trust will pass to those designated by the founder of the trust. It's important to understand this statute in order to draft a trust properly. Even older trusts should be reviewed and amended where necessary to accord with this statute.

In 1995, legislation was passed that provided for an *additional* type of supplemental needs trust to be used by a person with a disability to protect assets they may have received from an inheritance, Social Security back payment, or settlement from a lawsuit. These assets would *not* be counted as assets of the individual so they could remain qualified for SSI and Medical Assistance. This second type of trust has the following two differences from the original trust. They are as follows:

- Assets are limited to those of the person with a disability.
- At the death of the person with a disability, any remaining assets of the trust would be repaid to the State of Minnesota up to the amount of benefits received.

It should be noted that these provisions only relate to the second type of trust and the original supplemental needs trust has not changed.

8

Toward a More Friendly Environment for Consumer Controlled Housing

Introduction

This chapter is about environmental change. Not about the natural environment, but about the political, attitudinal, financial, and regulatory environments that must continuously be shaped to support the rights of people with developmental disabilities to have the opportunities they want and to live as fully as other citizens of the community. The people who have told their stories in this book have successfully gained control over their housing and have realized their visions in spite of an environment that has often been unsupportive at best. But if consumer controlled housing continues to require the savvy, determination, personal and family resources, or – often – the luck that was involved in these achievements, people controlling their own homes will remain all too rare an occurrence. In 1998,

Minnesota's state information system indicated that there was a total of about 6,800 people who received long-term care under that state's Medicaid Intermediate Care Facility and Home and Community-Based Services Programs. Of these individuals, only 4.9% were in their own homes (places that they themselves rented or owned). So even as individuals, their families and friends and case managers, service providers, housing specialists, bankers, and others undertake individual efforts to arrange for consumer controlled housing situations, it's important that an environment in which control of the housing by the consumer is the expected outcome for those who want it, with few barriers and much support. There is still much to accomplish.

Recent Moves Toward Consumer Control

The good news is that the environment that has long discouraged people's opportunities for personal housing is changing – at the national and state levels, among the county human services agencies, in the banking industry, and in the advocacy community. In Minnesota, advocates have successfully sought a legislative change in the Homestead exemption statute that fosters greater control of housing by persons with developmental disabilities. Others have created homes for people in rehabilitated foreclosed houses owned by the U.S. Department of Housing and Urban Development (HUD) through the innovative use of a federal and a state program. Lending institutions in Minnesota have been working with advocates, state and local housing officials, and state and local social service agen-

cies and housing centers to make obtaining mortgages easier for those who promote consumer controlled housing. Dozens of county case managers have attended training sessions on consumer controlled housing.

At the Department of Human Services (DHS), based on the findings of an internal study committee which estimated that DHS controls over \$300 million in funding to purchase housing for its clientele – including persons with developmental disabilities – the commissioner set a housing initiative for the department in 1994. This represented DHS's first significant effort to look at the needs of the people it serves from a housing perspective. In addition, DHS successfully sought permission from the federal government in 1994 to include a new service

under its developmental disabilities waiver that provides assistance to persons wanting to establish their own homes in the community. That was the good news. The bad news was that four years later the service went unused. Also in 1994, the Minnesota Housing Finance Agency adopted for its "permanent housing" programs the policy of giving priority to projects where the owner of the housing is not the provider of services. The significance of this policy is described later in this chapter.

In 1994, the President's Committee on Mental Retardation issued a report featuring significant observations and recommendations concerning consumer controlled housing. The report, entitled *The National Reform Agenda and Citizens with Mental Retardation: A Journey of Renewal for All Americans*, stated that changes in federal policy will be "crucial" to developing consumer controlled housing. Significantly, the committee notes that "the federal government has considerable leverage through its housing programs, income support policies, and public relations efforts. Through modifications in these programs, the federal government can play an affirmative leading role in housing reform for people with mental retardation." The committee also recommended that the government "should affirm the principles of choice and control in housing policy for people with mental retardation."

While developments and recommended future directions are encouraging, much still needs to be done to make an environment in which Minnesotans with disabilities find it easier to control their housing. Here are a few things people and groups can do:

- Create greater access to workshops and counseling services through which persons with disabilities, their family members, service providers, case managers, and others can learn how the funding of services and housing for people with developmental disabilities can be integrated to provide people with homes of their own with the support they need. These workshops and counselors can help people understand where funds come from, how they are spent, and benefits derived from them. Often times, public dollars invested in real estate end up on the balance sheets of large corporations.
- Develop a foundation of knowledge among those who can help, such as attorneys, local social services officials and case managers, mortgage lenders, and real estate brokers. Educate and organize these potential allies by providing information, sharing your vision, and helping them meet and learn from people who now control their own housing.
- Look for creative approaches others have developed. While Minnesotans have much to be proud of in their accomplishments in human services in general, and consumer controlled housing in particular, efforts in several other states surpass Minnesota in preparing a more friendly environment for consumer controlled housing, including innovative financial assistance programs for cash assistance, leases, rent subsidies, and vouchers. Examples of creative programs in other states are described on page 73.
- Work for change – in laws, regulations, lending policies, and attitudes. Educate officials – those in Congress, the state legislature, county board of supervisors, and administrators in public housing authority. Remember that the needs of their constituencies are many. Sometimes their attention to an issue can be short. Getting to know real people with real stories often is more memorable and motivating than a list of policy suggestions. The education needed by most policymakers is not just technical, but philosophical as well.

Increased consumer control of housing can seem like a hard sell, but people's right to have a real home is so intertwined with the perceived quality of life of Americans that the idea is for most people commonsensical. The challenge is to accomplish such an outcome without necessarily costing taxpayers any more money. It is important to help people understand that the amount of public funds granted to an individual to help pay a subsidized low income mortgage or rent is often less than the amount granted to a service provider corporation to pay a commercial rate mortgage of the same amount for an equivalent property. Housing for people with developmental disabilities is subsidized; the issue is to whom the subsidy should go – to people with disabilities or service provider agencies.

■ Separating Housing from Supports

One fundamental environmental change that can foster greater housing control for persons with developmental disabilities is the separation of housing from supports. Remarkably, even today most Minnesotans with developmental disabilities who receive residential services have housing arrangements that are purchased as a package with their support

services. For example, the needs of persons living in ICFs/MR are met through a single rate that includes services, room, and board. Most Minnesotans receiving Medicaid Home and Community-Based Waivered Services live in so-called "corporate" foster care settings, in which service providers typically obtain, and for the most part control, the housing.

This isn't the case in other places. Separation of housing from services in community-based settings has been a formal policy in a number of states. This concept isn't new in Minnesota either: it's been discussed, debated, and lobbied in the developmental disabilities community for years – in rule committee meetings, in advisory reports to state officials, and at the legislature. Nonetheless, services and housing are still bundled for most Minnesota developmental disabilities residential services.

Whenever there is a proposed shift in how public funds are spent, those who stand to lose ground will

lobby against the proposal. But while some Minnesota providers favor the status quo, more progressive service providers have been working for years with persons with developmental disabilities and their families to establish homes that consumers control.

Often the route for people with developmental disabilities wanting to obtain a home of their own has begun with their choosing a service provider who is committed to that end. But government has a role, too. As observed by a housing task force brought together by the President's Committee on Mental Retardation: "People should have stable homes while fully exercising their right to choose the agencies who enter their homes to provide supports. Federal and local policy should affirm the separation of all programs specifically funding services or housing."

Creative Approaches in Other Places

There are places outside Minnesota in which people with developmental disabilities and those who assist them find it much easier to develop individualized housing approaches that they control. Learning about them is a good way for local groups to develop better approaches of their own. Here are a few examples:

Movin' Out

In 1992, "Movin' Out" was the name given to themselves by a group of parents of teenagers with disabilities who were concerned about how their children would transition from their family homes to independent living. Many of these teens were receiving some support from the human services system in Wisconsin, but were faced with long waiting lists for services or assistance, particularly in the area of housing, when they reached adulthood.

Movin' Out grew from this parent group to a viable, non-profit organization. A grant requested by the parent group and received from the Wisconsin Division of Housing allowed the parents to contract with a housing organization in Dane County to provide them with technical assistance and lay the groundwork for what has now become Movin' Out, Inc. In mid-1997, one full-time staff person was

hired to provide housing counseling. Her work was heavily supplemented by an extremely active Board of Directors and significant assistance and training from the state's Housing Specialist, also a parent of a child with developmental disabilities.

Movin' Out helps to create opportunities for people with disabilities and their families to establish and maintain their own homes in housing of their choice – housing that is safe, affordable, accessible and integrated. Movin' Out devotes its energy and resources to development of small-scale, integrated housing arrangements that do not congregate people with disabilities.

In the past two and a half years, Movin' Out has assisted 58 low-income households to purchase or rehabilitate a house or condominium leveraging more than two million dollars in conventional financing. The households represent 78 individuals with disabilities and 134 total family members. Subsidies in the form of low-interest or deferred loans have comprised only 19% of the money used for this purpose. The primary source of funding has been conventional mortgages and the rest of the money has come from buyers and/or their families.

In 1999, Movin' Out expanded both geographi-

cally and programmatically and hired a second housing counselor and a part-time executive director. It now has both local and statewide roles, but the roles are different. In Madison, it has contracted to loan federal HOME funds to low-income households who have a member with a disability. These properties must then remain as affordable housing for up to 80 years. It is also involved in a mixed-income condominium development to be completed in 2000, with a minimum six of the 23 units guaranteed for low-income households/persons with disabilities. Movin' Out's original parent group

remains active, involved, and committed to a diverse community with affordable housing. Many of the former "teens," now young adults, are in apartments or homes of their own.

MI Home Program

Michigan's State Housing Development Authority is currently operating the MI Home (More Independence through Home) Program to assist non-profit agencies to acquire one to four unit residential properties for rental by persons with disabilities. A goal of the project is to make rental housing affordable to

A Home for Darin

By His Sister

When my brother Darin was born, the experts advised my parents to put him in an institution. They said he'd never walk, talk, or be toilet-trained.

Darin has a large family – seven sisters and one brother. All of us pitched in to help him learn the things they said he'd never learn. Darin learned to do it all, proving a lot of love and hard work pays off. When Darin lived at home he washed dishes, vacuumed, and all the rest. He was never treated any differently from the rest of us kids. After graduating from high school, Darin and Mom decided it was time to move on. Darin had the opportunity to move to Community Involvement Programs' Northern Light Group Home where he worked on improving his community skills. In 1990, the family discussed the next step for Darin. I had been working as Assistant Director at Northern Light and had attended a conference with Darin and Mom on home ownership. After this conference Darin, along with the family, decided he should have a home of his own. So we started to work on getting Darin a home. Darin also needed supports to live in his home. The county said "no problem – we'll find a way to fund staff from CIP to provide support." Darin also needed some companions who, in addition to being friends, could add financial support for the house.

The next step was to purchase property. After an extensive search, I helped Darin and Mom purchase a six acre site on the south end of Sandstone. Darin and Mom own this property jointly. One of Darin's childhood friends wanted to move into Darin's house when completed. Her parents offered to lend Darin the money on a Contract for Deed. I designed the plans for the house with a friend and ground-breaking took place in July of 1992. After a lot of excitement, Darin and his friends moved into the house at the end of that October. Darin was very involved in this process, choosing many items for the house, such as the color of the siding, carpet styles, paint colors, and cabinets.

There were many obstacles to be overcome, like how Darin could get Medical Assistance and still receive rent, wages, and so forth. Darin no longer gets Medical Assistance and if he were to have a medical emergency he would have to pay a large spend-down to have Medical Assistance pay the rest of his medical bills. At times he also finds it difficult to pay all his bills, taxes, and insurance. But the family feels that's all right: those are the struggles any person experiences – and why should Darin's life be any different from the rest of ours?

Five years later, the same people still live in the home. There have been typical housemate struggles: sharing items, getting on each other's nerves, normal day-to-day difficulties. They've learned to work most situations out or accept how it is for the day. Darin now gets Medical Assistance due to new legislation passed in 1999. His property taxes are going up annually. Darin wants to build a new home – he would like this one to be bigger and have a hot tub in it.

persons with modest incomes (participants pay no more than 30% of their income for rent). Prospective tenants are primarily persons with a history of residency in an institutional setting or foster care.

The non-profit sponsors are expected to assume a primary role as owner and landlord, although they may employ professional housing managers to handle day to day operation and leasing. Program requirements state that non-profit board members may not be employees, officials or board members of state or local agencies responsible for funding services which are or could be used by program participants. Sponsors must have a feasible long term support plan for its residents.

The program is funded through federal funds from the HOME Program through the Department of Housing and Urban Development.

Mortgage Program for Persons with Developmental Disabilities

The state of Rhode Island has made \$600,000 available for home ownership for persons with developmental disabilities in a one-year demonstration project called the Mortgage Program for Persons with Developmental Disabilities. New and existing single family homes and condominiums requiring minimal maintenance are eligible for purchase. Staff from the state Housing Mortgage Finance Corporation are available to help consumers in searching for property. Staff from the state Department of Mental Health, Mental Retardation and Hospitals will also evaluate properties relative to needed community services, structural condition and maintenance needs.

A home buyer counseling component has been built into the demonstration. The Housing Mortgage Finance Corporation provides initial counseling to make sure participants consider the various housing options available to them and the responsibilities that home ownership involve. A *Home Ownership Guide* has been prepared for this purpose. After a home is purchased, the corporation provides counseling at both six and twelve months after closing, and then as needed after that.

Funding for this project have been made available through a bond issue approved by the state's voters.

Home of Your Own Project/Alliance

New Hampshire's Home of Your Own Demonstra-

tion was first implemented through the state's Mental Health and Developmental Services Department and the state Housing Finance Agency (HFA) in collaboration with the University of New Hampshire's Institute on Disability, the state Developmental Disabilities Council, and the state Disability Rights Center. From this beginning in the late 1980's, the project grew into a National Home of Your Own Alliance to assist other states in developing home ownership programs. The original New Hampshire program permits purchase of single family homes and condominiums with a maximum purchase price of \$100,000.

The HFA set aside \$1.5 million of its standard first time buyer program especially for persons with developmental disabilities. For down payment and closing costs, the HFA budgeted an additional \$100,000 which was matched with another \$100,000 from the Mental Health and Developmental Services Department. Funds are made available to the participants as grant-like second mortgages. In addition, federal funds from the HOPE program have been used for down-payment and closing costs, necessary general repairs, and accessibility modifications.

The HFA has originated the mortgages, in part to retain control, and in part because community lenders weren't interested in participating due to the extra paperwork involved. From the original New Hampshire project, the National Home of your Own Alliance grew to projects in 23 states. Although considerably curtailed since 1999, technical assistance, information, print materials, and support are still available.

Community Capital Assistance Project

Ohio's Community Capital Assistance Project purchases housing for persons with developmental disabilities who require supportive living services. The consumer takes an active role in selecting the type and location of the housing, who their roommates will be, and how the home is furnished. Existing properties (no new construction is permitted) are acquired with the assistance of local real estate brokers. The consumer is assisted in his or her selections by a local non-profit (such as a community action agency or a local Arc chapter). Each county board of mental retardation that participates in the program (67 out of 88 counties) is responsible to select or set up the non-profit agency that provides the assistance

to the consumers. When properties are sold, the proceeds must be reinvested in other acceptable housing.

By 1998, 585 properties had been acquired, housing 1,465 clients. State funds provided \$23 million for property valued at \$40 million. The state of Ohio has budgeted \$3.9 million for fiscal year 2000 and expects to allocate another \$9.6 million in 2001/2002. The program is operated by the state Department of Mental Retardation/Developmental Disabilities, using funds raised by the Ohio Public Facilities Commission.

Equity Fund for Community Integrated Housing

In Illinois, the Equity Fund for Community Integrated Housing uses federal low-income tax credits to assist local organizations to develop affordable single family homes, condominiums, townhomes and duplexes as homes for three or fewer people with disabilities. To ensure separation of housing and services, properties must be managed by a local development corporation that is not affiliated with the service provider. The program is designed to allow persons with developmental disabilities to buy or otherwise control their housing units.

An example of a development funded by this fund is a program run by a non-profit agency in suburban Chicago which purchased three two bedroom condominium units in one building and three in another building. The agency received equity from a corporate investor and debt financing from the state's Housing Trust Fund. Under the program's guidelines, a newly-created limited partnership will own the property for fifteen years, but will be managed by the non profit agency. During the fifteen-year period, the corporate investor will continue to receive the tax credits. At the end of the fifteen years, the property can be sold to either the non-profit or the consumers who live there.

The Affordable Housing Trust Fund used by this agency for its project's debt financing is run by the Illinois Housing Development Agency, which has adopted housing for people with disabilities as a priority area. Other examples of how the funds can be used include down payment assistance, interest rate markdowns, housing rehabilitation and construction, and other forms of subsidy.

The tax credits, which are a central feature of the Equity Fund's design, are allocated to each state by the federal government, and can be obtained by

private investors in return for developing housing for low income individuals.

■ An Issue of Freedom

Securing attention and support for consumer controlled housing in a time of waiting lists, staff shortages, and budget restrictions can seem like an uphill battle. In the midst of state and national discussions of people's needs for energy assistance, welfare-to-work, job training, medical service access, housing assistance for impoverished families, shelter for homeless persons, and psychiatric services for persons with chronic mental illness, expecting or demanding personalized housing for people with developmental disabilities may seem almost selfish. People with developmental disabilities, their families, and their allies have achieved so much in recent decades; is it fair to seek more? The daily reality of people's lives makes it clear that more must be expected. The significant gains in funding, the growing flexibility in community supports and providers available to people with developmental disabilities, and the changing public attitudes that respect the rights of people with developmental disabilities and their place in the community are hollow advances to those people who do not even enjoy control over their own front door and who do not live where, how, and with whom they choose.

This issue demands the attention of legislators, federal and state officials, county supervisors, housing authorities, service providers, advocates, and others who control decisions about where and how people with developmental disabilities receive services. Changes in policy and expectations can give adults with developmental disabilities a basic freedom and dignity of having a home of their own. The quality of life for persons with developmental disabilities depends on such freedom because, as persons who often require intensive life-long support, without it people too often become economic and social dependents of those who provide both housing and supports. Because of this, it's important that persons with developmental disabilities, their families, advocates, and the human services professionals who would be their allies continue to struggle for the dignity and self-determination that derives from people receiving the support they need in homes that are their own.

9

Available Help on Housing & Related Issues

For Information and Assistance with Housing

The following agencies, individuals, and print and electronic resources may be of assistance for further information on consumer controlled housing.

■ Organizations

Arc Minnesota

Contact our HomeChoice consultant for information on consumer controlled housing, locating and receiving appropriate services, and for advocacy assistance. Contacts can also be made for workshops on consumer controlled housing to be provided in local communities. Visit the Arc Minnesota Website at www.arcminnesota.com.

770 Transfer Road, Suite 26
St. Paul, MN 55114
651/523-0823 or 800/582-5256
e-mail: mail@arcminnesota.com

County Social Services Agencies

For information on eligibility and for making application for services and case management. Expect considerable variability in knowledge about and support of consumer controlled housing. For assistance with advocacy, contact Arc Minnesota or a local Arc.

See your local telephone directory for the name and address of the agency serving your county.

HUD Area Office

For information on accessing any HUD program, including Section 8 certificates and vouchers.

220 South Second Street
Minneapolis, MN 55401
612/370-3000

Minnesota Disability Law Center

For information and assistance in accessing programs and services and in matters related to discrimination on the basis of disability. This is an excellent source of information and assistance related to the Fair Housing Act and on rights of personal choice and control in the use of publicly-funded services.

430 First Avenue North, Suite 300
Minneapolis, MN 55401-1780
612/332-1441 or 800/292-4150
e-mail: lcohen@midmnlegal.org

Minnesota Housing Finance Agency

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

400 Sibley Street
St. Paul, MN 55101
651/296-7608 or 800/710-8871
www.mhfa.state.mn.us

Housing and Redevelopment Authorities

For information on local programs and initiatives specifically serving your community.

See your local telephone directory for the name and address of the agency serving your community.

Minnesota Department of Human Services (DHS)

For information on the state programs, laws, and regulations regarding the provision of services to persons with developmental disabilities, including programs described in Chapter 5.

Community Supports for Minnesotans with Developmental Disabilities
444 Lafayette Road, Second Floor
St. Paul, MN 55155
651/582-1998
www.dhs.state.mn.us

Home Ownership Center

For information assisting families to achieve stable, successful home ownership through education, counseling, and foreclosure prevention.

1885 University Avenue West, Suite 350
St. Paul, MN 55104-3469
651/659-9336
e-mail: hocenter@uswest.net

Rural Development (RD)

(Section 502 Rural Housing, Single Family Housing) Housing loans designed for low-income families. Loans may be used to buy, build, improve, or repair rural homes. Information available from:

RD State Office
375 Jackson Street
410 AgriBank Building
St. Paul, MN 55101
651/602-7800
www.usda.gov

■ Print Resources

Your Place or Mine: A Handbook for Home Ownership

B. Laux and C. Morgan Laux
This handbook provides an overview and basic guidance about the concepts, issues, and decisions involved in persons with developmental disabilities obtaining homes of their own. It's written for the consumer and contains worksheets, checklists, and sets of questions to guide their consideration of factors that must be weighed in housing decisions. Available from:

Illinois Planning Council on
Developmental Disabilities
100 W. Randolph, Suite 10-600
Chicago, IL 60601
312/814-2080

and from:

Creative Management Associates
P.O. Box 5488
Portsmouth, NH 03802-5788

A Home of Your Own Guide

Fannie Mae

This extremely informative and clearly written guide provides general information on a wide range of topics to help potential home buyers obtain affordable housing. It contains worksheets for use by consumers in evaluating available and needed resources, evaluating potential housing, and pulling together needed materials. Available from:

Fannie Mae/Consumer Education Group
3900 Wisconsin Avenue NW
Washington, DC 20016-2899

Impact: Feature Issue on Consumer Controlled Housing

E. Skarnulis and K.C. Lakin, Eds.

This newsletter provides a summary of the key purposes and benefits of the consumer controlled housing movement and issues facing consumers, families, and service providers in the securing and support of homes for people with developmental disabilities; describes some of the major housing programs available to support consumer controlled housing; and identifies resources available to people interested in consumer controlled housing. Available from:

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall / 150 Pillsbury Drive SE
Minneapolis, MN 55455
612/624-4512

Co-Housing: A Contemporary Approach to Housing Ourselves

K. McCamant and C. Durrett: Ten Speed Press
This handbook is an easy-to-read summary of the basic philosophy, development, and operation of co-housing communities. Available from area bookstores and public libraries.

For Information on Supporting Desired Lifestyles

The following agencies and print resources may be useful for further information or assistance on identifying, planning, and providing the supports that people need to live the lifestyles that they desire for themselves.

■ Organizations

Minnesota Governor's Council on Developmental Disabilities

For information on programs, resources and individuals to assist in the development and implementation of person-centered planning and support of individually desired lifestyles.

300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
651/296-4018

Research and Training Center on Community Living

For information and assistance on person-centered planning, support of social inclusion in preferred activities, developing and supporting relationship, and about self-determination and self-advocacy involvements.

Institute on Community Integration
University of Minnesota
212 Pattee Hall/150 Pillsbury Drive SE
Minneapolis, MN 55455
612/624-6328

Human Services Research and Development Center

For information and assistance on person-centered agency planning and development and in the development and support of friendships.

1195 Juno Avenue
St. Paul, MN 55116
651/698-5565
e-mail: amado003@tc.umn.edu

■ Print Resources

A New Way of Thinking

Governor's Council on Developmental Disabilities
An overview of the principles and practices leading people with developmental disabilities to greater control over their own lives, including their homes. Available from the Governor's Council (see above).

Essential Lifestyle Planning for Persons with Severe Reputations

M. Smull and S. Harrison
Provides an excellent overview of how person-centered planning and the supported living model can be used to give greater freedom and choice to all persons with developmental disabilities, including those with long histories of institutionalization and/or challenging behaviors. Available from:
National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, VA 22314
703/684-1395

It's Never Too Early, It's Never Too Late: A Booklet About Personal Futures Planning

B. Mount and K. Zivernik
Provides an introduction to the purpose, principles, and practices in "Personal Futures Planning," for families, consumers, and advocates. Provides some guidance on how person-centered plans and formal Individual Habilitation Plans can be integrated to support people's living in the ways they wish. Available from:

Metropolitan Council
230 East Fifth Street
St. Paul, MN 55101
651/602-1000

Framework for Accomplishment

J. O'Brien and C. Lyle O'Brien

Provides guidelines for a workshop to assist human services agency managers and staff in understanding and evaluating their services from the perspective of the desires, interests, qualities, and experiences of their service recipients, and then to identify and

develop actions around a commitment to the individual as the focus of quality for the agency. Available from:

Responsive Systems Associates
58 Willock Drive
Lithonia, GA 30038
404/987-9785

For Information and Assistance on Technology and Home Modifications

The following organizations and print resources may be useful for further information or assistance on assessing need and alternatives, securing and financing technologies and physical adaptations to permit access to a home of one's own.

■ Organizations

Assistive Technology of Minnesota (ATMN)

An initiative of the STAR Program, ATMN is a nonprofit organization helping people with disabilities acquire the assistive technology they need to reach their full potential. ATMN has a low-interest financial loan program people can use to pay for their assistive technology. Additionally, businesses can get a loan to develop access to employment.

Attn: Low Interest Program
360 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
651/296-2771 or 800/657-3862
e-mail: star.program@state.mn.us

Metropolitan Center for Independent Living

In a cooperative arrangement with MHFA, MCIL maintains for free review a small library of books and other resource materials on building and remodeling homes for persons with a disability. Additionally, free services include site visit, layout and design for the construction of ramps or special steps.
1600 University Avenue West, Suite 16
St. Paul, MN 55104
651/646-8342
email: mcil2@aol.com

The Center for Universal Design

The national resource on accessibility modifications and universal design. The center has many publications available on the subject and provides technical assistance/consulting over the phone.

North Carolina State University
School of Design
Box 8613
Raleigh, NC 27695-8613
800/647-6777

Minnesota Housing Finance Agency

For assistance and information on designing, reviewing and financing plans for home modifications.

400 Sibley Street, Suite 300
St. Paul, MN 55101
651/296-7608 or 800/710-8871

■ Print Resources

Impact: Feature Issue on Assistive Technology

R. Wobschall and K.C. Lakin, Eds.

Provides descriptions of the evolving state of knowledge and best practice regarding applications of assistive technology. Describes programs assisting persons with disabilities of all ages to obtain and use technologies that provide them opportunities for living with greater independence and dignity. Available from:

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall / 150 Pillsbury Drive SE
Minneapolis, MN 55455
612/624-4512

Home Accessibility Information

The Minnesota Housing Finance Agency (MHFA) is distributing the following materials to households interested in building or remodeling a home for accessibility:

Home Accessibility Information Series. A set of 10 bulletins that describe how modifications can be made in various areas of the home.

The Cost of Accessibility in the Construction of New Single-Family Homes. A report analyzing costs involved in building a home with various accessibility features.

MHFA Homes Division
400 Sibley Street, Suite 300
St. Paul, MN 55101
651/296-7608

For Information and Assistance on Long-Term Planning

The following organizations may be useful for further information and assistance on long-term and estate planning.

■ Organizations

Life Planning for Persons with a Disability and Their Families

Provides comprehensive life planning services for families who have loved ones with disabilities. It also provides seminars to organizations who serve people with disabilities and their families.

1609 West Wayzata Boulevard
Long Lake, MN 55356
612/249-9193 or 800/487-5310

Richard D. Bunin Law Offices

Law offices providing services to individuals and families in the areas of estate planning, real estate law, and Medical Assistance and long-term care planning. Richard Bunin speaks regularly to business and civic groups.

Interchange Tower, Suite 1670
600 Highway 169
St. Louis Park, MN 55426
952/544-2345

A

Appendix A: Worksheets on Consumer Controlled Housing

The Costs of Home Ownership

There are many costs when buying a home and as you live in that home over time. Here is an example using some very basic information. This should help you see if homeownership fits your own budget.

■ Cash Expenses Needed When Buying and Operating a Home

Buying a House

- **Down payment.** Usually expressed as a percentage of the value of the home, (i.e., "5% down"). The down payment is meant to be an expression of the buyer's personal stake in the ownership responsibility.
- **Closing costs, escrow, and prepaid fees.** Expenses the lender requires to be paid prior to or at closing. Typically, these costs run 3-5% of the value of the home.
- **Cash reserve.** An amount of money equal to the monthly house payment. The buyer may have to show the lender that the buyer has one or more months of house payment money available.

Ongoing Costs of Owning a Home

- **Monthly house payment.** "PITI" (Principle, Interest, Taxes, Insurance)
- **Monthly utility payments.** Electricity, gas, oil, phone, trash removal, etc.
- **Maintenance, repairs, and replacements.** Lawn mowing, fixing a broken window, replacing a worn-out refrigerator, etc.

Example of Buying Costs

Here is an example of buying a \$100,000 house purchased using the HomeChoice demonstration mortgage program:

- Down Payment (5% as required in the HomeChoice Program) \$5,000
- Closing Costs (estimated at 3%) \$3,000
- Cash Reserve (HomeChoice requires two months of PITI reserve) \$1,700
- Total Cash needed at closing \$9,700

However, with HomeChoice, *if you are eligible*, you can get:

- Entry Cost assistance, up to -\$6,000
- Cash Reserve assistance -\$1,700
- With HomeChoice, the cash you will need at closing is \$2,000

Example of Monthly Payments

Ongoing monthly expenses of this same home with a \$95,000 mortgage:

- Principle and Interest (assume 30 year mortgage at 8.25%) \$710
- Taxes (assume \$1,200/year) \$100
- Insurance (property, liability, mortgage) \$40
- Monthly House Payment \$850
- Add:
- Monthly utility costs (estimated heating, electricity, gas, trash, water/sewer, other) ... \$400
- Maintenance, repairs, replacements \$50
- Monthly Homeownership Costs \$1,300

Worksheet One: Monthly Income and Expenses

This worksheet is to help you figure out how much money you have each month and how much all the things you will need to buy will cost.

■ Monthly Income

List all current, regular monthly income after taxes for yourself and your co-borrower or housemate from all the different sources listed below:

	Average monthly amount
Money from jobs (after-tax)	\$ _____
Supplemental Security Income (SSI)	\$ _____
Minnesota Supplemental Aid (MSA)	\$ _____
Social Security Disability Insurance (SSDI)	\$ _____
General assistance payments	\$ _____
Food stamps (the difference between what you pay and your certificate values)	\$ _____
Trust funds	\$ _____
Dividends or interest earnings from stocks, bank accounts, etc.	\$ _____
Money received regularly from family or friends	\$ _____
Other sources of income, cash or cash equivalents, such as Food Stamps, bus passes, etc. (please list):	
_____	\$ _____
_____	\$ _____
_____	\$ _____
Your total monthly income	\$ _____

■ Monthly Expenses

Estimate your monthly expenses for the housing situation you would like. Then you can see if your income is enough to pay for all the things you need and want. At the bottom of the page you can compare total monthly expenses with total monthly income. If expenses are more than income you may need to think how to reduce expenses (or how to increase income).

	Average monthly payment
Mortgage payment or rent for your home*	\$ _____
Property taxes/condominium or cooperative fees*	\$ _____
Home owner's or renter's insurance	\$ _____
Electricity payment*	\$ _____
Gas payment*	\$ _____

[Continued on next page]

Water, sewer, and garbage charges*	\$ _____
Repairs and maintenance on your home	\$ _____
Food	\$ _____
Clothing	\$ _____
Furniture, appliances, and household items	\$ _____
Telephone	\$ _____
Transportation	\$ _____
Recreation and leisure activities	\$ _____
Cable TV and video rentals	\$ _____
Health care and assistive devices	\$ _____
Debt payments	\$ _____
Other [please list]:	
<u>Repairs and replacement fund</u> _____	\$ _____
_____	\$ _____
 Total monthly expenses	 \$ _____
Total monthly income	\$ _____

* Estimates of these costs should be available from a landlord of a rental property or from a realtor.

Worksheet Two: Your Available Cash and Assets

It often takes 10-20% of your annual rent or mortgage payments to move into a new place. List all your (and your co-borrower's or roommate's) sources of cash and any assets that you can use for the down payment and closing costs for purchasing a home, or for the security deposit and other deposits and fees for renting a home.

Checking account(s)	\$ _____
Savings account(s)	\$ _____
Mutual funds, stocks, and bonds	\$ _____
Cash value of life insurance policy	\$ _____
Cash gifts from family and/or friends	\$ _____
Special grants	\$ _____
Other assets [<i>please list</i>]	
_____	\$ _____
_____	\$ _____
_____	\$ _____
Total cash and assets	\$ _____

Worksheet Three: Housing Considerations

Part A: The following is a list of factors to consider in choosing the location and features of a home that's right for you. You can also use this worksheet to evaluate possible homes based on what's important to you.

	Important			Comments
	Yes	No	Unsure	
<i>Location</i>				
In the city or suburbs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
In the country	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to job or day activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to public transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to businesses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to favorite recreation activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to place of worship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Close to other things:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
[please list] _____				
[please list] _____				
Safety in the neighborhood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Physical accessibility of the neighborhood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Atmosphere/personality of the neighborhood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

Part B: Check the housing features that are important to you.

	Important		Present		Comments
	Y	N	Y	N	
<i>Type of Home</i>					
Apartment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Single detached housing unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Condominium	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Multiple unit housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Doesn't matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Rooms</i>					
Private bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Enough bathrooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Dining room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Den or family room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Basement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

[Continued on next page]

	Important		Present		Comments
	Y	N	Y	N	
<i>Accessibility</i> (see Worksheet 4)					
Outdoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Indoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Extras</i>					
Air conditioning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Fireplace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Garage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Porch/balcony/deck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Washer/dryer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Microwave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Yard/garden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Safety</i>					
Deadbolt locks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Emergency alarm system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Neighborhood watch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Attractiveness</i>					
Indoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Outdoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

Worksheet Four: Accessibility Features

These questions may be important if you, a housemate, or guests have mobility limitations.

	Present		Important		Comments
	Y	N	Y	N	
<i>Outdoors</i>					
Are walkways clear and wide enough to accommodate wheelchairs or walkers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Is there a ramp at a manageable angle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are doors at least thirty-two inches wide (for wheelchair users)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are railings installed on both sides of the front steps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Is the mailbox in a location that makes it easy to retrieve mail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Garage / Parking</i>					
Is the garage wide enough to accommodate a wheelchair exiting from a van, or will the person have to get out of the van outdoors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Is the garage entrance high enough for a van?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Is there an automatic garage door opener?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are handicapped parking spots available and convenient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
<i>Indoors--General</i>					
Are switches and thermostats within forty-four inches of floor for easy access from a wheelchair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are electrical outlets located twenty-seven inches from the floor to minimize bending?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Will carpeting allow easy navigation with a wheelchair or walker? Is it securely fastened to the floor (or are there hardwood floors so that carpets can be removed)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Do stairs have a sturdy hand grip on the rail and banister?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Is carpeting on steps in good repair and tightly secured to the steps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Do doors have lever handles instead of round doorknobs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are doorways at least thirty-two inches wide (or can doors be mounted with swing-clear hinges)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Are windows easy to open? (Windows that tilt out make opening easy and help keep out rain.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

[Continued on next page]

Worksheet Six: Choosing a Service Provider

Finding the service provider agency that is right for you can be difficult (or easy, if you're lucky). The following questions may be helpful in your search.

- Does the service provider accept me as having a right to control my own life?

Y N
Comments:

- Is the service provider committed to spending time to help me and agency staff become better able to understand how I want to live?

Y N
Comments:

- Does the service provider respect my house as my castle (e.g., knocking before entering, asking permission to use my appliances, etc.)?

Y N
Comments:

- Are other people served by the agency happy with it in the areas that are most important to me?

Y N
Comments:

[Continued on next page]

- Does the agency recognize and respect me as the primary decision-maker about who should come into my home to provide support to me?

Y N

Comments:

- Will the people who provide services to me be well-trained, well-supported and well-treated by the agency?

Y N

Comments:

- Are there ways to insure that I will have the opportunity to guide and if I choose replace the staff who will be working with me?

Y N

Comments:

- Do the staff members that the agency nominates to work with me seem to have the initiative, knowledge, commitment, and creativity to meet my needs?

Y N

Comments:

Worksheet Seven: Summary Housing Checklist

This checklist summarizes all the other checklists. You can use this as a final checklist to make sure you have considered the major factors in choosing your home.

Address _____

Issue

• I have enough monthly income to afford living in this home (mortgage, rent, utilities, food transportation, etc.). Y N
Comments:

• I can afford the expenses to be able to move into this home (closing costs, security deposit, utility deposits, moving expenses). Y N
Comments:

• The home is in a neighborhood in which I want to live. Y N
Comments:

• The home is clean and well-kept enough for me inside and outside. Y N
Comments:

[Continued on next page]

- From this home, I can get the transportation that I must have.

Y N
Comments:

- I am close enough to family, friends, recreation, stores, transportation, etc.

Y N
Comments:

- The home's plumbing, heating, electrical system, and appliances are all in good condition.

Y N
Comments:

- My accessibility concerns are properly addressed.

Y N
Comments:

- I will be able to get the support (family, friends, service provider) that I need to live here.

Y N
Comments:

B

Appendix B: Example Lease Agreements

LEASE AGREEMENT

BY THIS LEASE AGREEMENT, made and entered into on _____, _____ between _____ (*home owner*), whose address is _____, (herein referred to as "Lessor") and _____ (*service provider*), whose address is _____, (herein referred to as "Lessee"). Lessor leases and lets to Lessee the premises situated at _____ in the City of _____ and County of _____, State of Minnesota, (herein referred to as the "premises") and more particularly described as follows:

Together with all appurtenances, for a term of one (1) year to commence on _____, 2000, and to end on _____, 2001, at _____ o'clock .m, on the following terms and conditions.

A. Rent. Lessee agrees to pay, without demand, to Lessor as rent for the demised premises the sum of _____ Dollars (\$ _____) per month in advance on the first day of each calendar month beginning _____, 2000, at _____, City of _____, State of _____, or at such other place as Lessor may designate. The monthly rent is allocated as follows:

- 1) \$ _____ for the real property; and
- 2) \$ _____ for the furnishings and personal property (see Exhibit B for list of property)

B. Security Deposit. On execution of this Agreement, Lessee deposits with Lessor _____ Dollars (\$ _____), receipt of which is acknowledged by Lessor as security for the faithful performance by Lessee of the terms herein. Said security deposit shall bear simple interest at the rate provided in M.S.A. 504.20 Subd. 2, computed from the first day of the next month following the full payment of such deposit to the last day of the month of termination of the tenancy. In compliance with M.S.A. 504.20, Subd. 3, Lessor shall refund said security deposit or furnish to Lessee vacating the demised premises a statement showing the reason for the withholding of the security deposit or any portion thereof within two weeks after termination of the tenancy and receipt of Lessee's mailing address or delivery instructions.

C. Quiet Enjoyment. Lessor covenants that on paying the rent and performing the covenants herein contained, Lessee shall peacefully and quietly have, hold, and enjoy the demised premises for the agreed term.

D. Use of Premises. The demised premises shall be used and occupied by Lessee exclusively as a residential home for Lessor's two developmentally disabled daughters, _____ and _____ and for such other adults with developmental disabilities as determined by whether the home is operated as a foster home or some other similar entity, the parties agree that the operation of the home shall comply with all reasonable rules imposed by Lessor and all rules, laws, and regulations by federal, state and local

[Continued on next page]

authorities. Neither the premises nor any part thereof shall be used at any time during the term of this Agreement by Lessee for the purpose of carrying on any other business, profession, or trade of any kind. Lessee has read and agrees to abide by the terms of the Rules and Regulations on Exhibit A attached hereto and incorporated herein by this reference, and acknowledges that violation of any provision in said Rules and Regulations shall constitute a default hereunder. Lessee shall not perform or permit any practice that is unlawful or may damage the reputation of, or otherwise be injurious to Lessor, be disturbing to other residents, or be likely to cause an increase in rate or insurance on the premises.

E. Prior Approval of Residents and Staff. Lessor retains right to inquire about any proposed resident of the premises or staff person proposed to work on the premises. Lessee agrees that this right of Lessor is reasonable in that Lessor's daughters will reside on the premises.

F. Alterations and Improvements. Lessee shall make no alterations to the buildings on the demised premises or construct any building or make other improvements on the demised premises without the prior written consent of Lessor. All alterations, changes and improvements built, constructed, or placed on the demised premises by Lessee with the exception of fixtures removable without damage to the premises and movable personal property, shall, unless otherwise provided by written agreement between Lessor and Lessee be the property of Lessor, and remain on the demised premises at the expiration or sooner termination of this Agreement.

G. Maintenance and Repair. Lessor covenants (a) to keep the structural parts of the premises in reasonable repair during the term of the Agreement, and to make major repairs to plumbing, heating and lighting systems, and (b) to maintain the premises in compliance with the applicable health and safety laws of the state and of the local units of government where the demised premises are located during the term of this Agreement. Lessee agrees to immediately notify Lessor of repairs that are the obligation of Lessor. Lessee will, at Lessee's sole expense, make all required repairs of the premises, except those which are landlord's responsibility. Lessee's obligation to repair shall include, but not be limited to the following: (a) repair of all appliances, provided, however, that should any major appliance provided by Lessor fail completely and be deemed unrepairable by a qualified service person, Lessee shall have no obligation to repair such appliance and Lessor shall have no obligation to replace such appliance or compensate Lessee for any proximate damages caused by such failure, and (b) keep all drains and plumbing fixtures open. All yard work (cutting of grass, raking of leaves, snow removal) shall be the responsibility of the Lessee. Lessee shall comply with all the sanitary laws, ordinances, rules and orders of appropriate governmental authorities affecting the cleanliness, occupancy, and preservation of the demised premises during the term of this Agreement, and any renewal thereof, except where such compliance is the duty of the Lessor under M.S.A. 504.18(c) and the covenants contained herein.

H. Signs. Lessee agrees that no signs shall be placed or painting done on or about the demised premises by Lessee or at Lessee's direction without the prior written consent of Lessor.

I. Damage to Premises. If the demised premises, or any part thereof, shall be partially damaged by fire or other casualty not due to Lessee's negligence or willful act or that of Lessee's employee, family, agent or visitor, the premises shall be promptly repaired by Lessor and there shall be an abatement of rent corresponding with the time during which, and the extent to which, the leased premises may have

been untenantable; but, if the leased premises should be damaged other than by Lessee's negligence or willful act or that of Lessee's employee, family, agent, or visitor to the extent that Lessor shall, in good faith, decide not to rebuild or repair, the term of this Agreement shall end and the rent shall be prorated up to the time of the damage.

J. Utilities. Lessee shall be responsible for paying for all utility services required on the premises.

K. Right of Entry. Lessor and Lessor's agents reserve the right to enter the demised premises at all reasonable hours during the term of this Agreement, and any renewal thereof, for the purpose of inspecting the premises and all building improvements thereon, and whenever necessary to make repairs and alterations to the demised premises. This covenant shall in no way restrict Lessor's right to visit Lessor's daughters living in the premises. Lessee hereby grants permission to Lessor to show the demised premises to new rental applicants at reasonable hours of the day, within ninety (90) days of the expiration of the tenancy.

L. Assignment and Subletting. Without prior written consent of Lessor, Lessee shall not assign this Agreement, or sublet or grant any concession or licensure to use the premises or any part thereof. Lessor retains absolute discretion in granting or denying any request to assign or sublet this Agreement. A consent by Lessor to one assignment, subletting, concession, or license shall not be deemed to be a consent to any subsequent assignment, subletting, concession, or license. An assignment, subletting, concession, or license without the prior written consent of Lessor, or an assignment or subletting by operation of law, shall be void and this Agreement and any sublease shall, at Lessor's option, be terminated in compliance with the default provision contained herein.

M. Termination of Agreement. Lessor or Lessee may terminate this Agreement by mailing a written notice of termination to the other party at least ninety (90) days prior to the date of termination.

N. Surrender of Premises. At the expiration of the term of this Agreement or upon earlier termination by Lessor, Lessee shall quit and surrender the premises hereby demised in as good state and condition as they were at the commencement of this Agreement, reasonable use and wear thereof and damages by the elements excepted.

O. Abandonment. If at any time during the term of this Agreement Lessee abandons the demised premises, or any part thereof, Lessor may, at Lessor's option, bring an action to recover possession of the demised premises and such action is equivalent to a demand for the rent and reentry upon the property. Lessor may, at Lessor's option, hold Lessee liable for any differences between the rent that would have been payable under this Agreement during the balance of the unexpired term, if this Agreement had continued in force, and the net rent realized by Lessor by means of reletting the premises. If Lessor recovers possession of the demised premises following abandonment of the premises by Lessee then Lessor may consider any personal property belonging to Lessee and left on the premises to also have been abandoned; in which case Lessor may dispose of all such property in any manner Lessor shall deem proper and Lessee is hereby relieved of all liability for doing so.

P. Default. If any default is made in the payment of rent, or any part thereof, at the times herein before specified, or if any default is made in performance of or compliance with any other term or condition hereof, Lessor may, at its options, terminate this Agreement, and, without process, re-enter immediately into the premises and remove all parties and property therefrom. In case of any such termination, Lessee will be liable for and will indemnify Lessor against all loss of rent and other damage which Lessor may incur by reason of such termination during the remainder of the term of the Agreement, and also against all attorney's fees and expenses incurred in enforcing any of the terms of Agreement.

Q. Indemnification and Hold Harmless. Lessee shall at all times be responsible for the safety of all residents of the premises, all staff persons, workers and all guests and their respective belongings. Lessee agrees to hold Lessor harmless from and indemnify Lessor against any and all liabilities, damages and expenses arising from injury, damage or loss to or cause by Lessee, residents, staff persons, workers, guests, employees, agents, assigns, subtenants, visitors or licensees, or any property of said persons, in or about the premises, buildings or grounds from any cause whatsoever, growing out of or connected with the use and occupancy of or activities in or about the same. This hold harmless and indemnification shall also run in favor of any subsidiaries and employees of Lessor and subsidiaries. LESSEE IS ENCOURAGED TO CARRY TENANT INSURANCE TO PROTECT HIMSELF AGAINST ANY AND ALL SUCH LOSSES. INSURANCE CARRIED BY LESSOR DOES NOT COVER ANY PROPERTY OF LESSEE.

R. Holding Over. In the event Lessee remains in possession of the premises after the expiration of this Agreement and without the execution of a new Agreement, Lessee shall be deemed to be occupying the premises as a Lessee from year to year in accordance with the terms of this Agreement.

S. Miscellaneous. In the event Lessor provides a washer, dryer, stove, dishwasher, refrigerator or other appliance to the premises, it is understood that Lessor has no obligation to repair or replace said appliance or appliances, and Lessor has no liability for any damage caused by the failure of such appliance or appliances.

T. Heirs and Assigns. The covenants and conditions herein contained shall apply to and bind the heirs, legal representatives, and assigns of the parties hereto, and all covenants are to be construed as conditions of this Agreement.

U. Lessor's Personal Belongings. Lessor retains the right to store personal belongings in half of the lowest level floor.

EXHIBIT A

RULES AND REGULATIONS

1. No pets except by written permission of Lessor.
2. All trash and garbage are to be placed inside the proper containers.
3. Lessee shall not alter any lock or install a new lock, knocker, peephole or other attachment on any door of the house without the written consent of Lessor. All permitted alterations, additions and fixtures shall remain as part of the house unless Lessor otherwise elects.
4. No interior alterations, painting, or redecorating of a permanent nature may be done to the house without written approval of Lessor. Lessee may not install or use any additional major appliances such as washers, dryers, freezers, portable dishwashers, etc. Lessor or Agent may agree to a change by approval.
5. Use only small nails for hanging pictures. No adhesive type hangers or tape shall be applied to the walls. No nails or screws shall be driven into the woodwork. No mounting of any kind shall be attached to the ceilings.
6. The water closets, basins and other plumbing fixtures shall not be used for any purpose other than for those for which they were designed. Any damage resulting from misuse of such facilities shall be paid for by Lessee.
7. No water beds or other water filled furniture may be used in any room without specific written approval from Lessor, and evidence of adequate liability insurance.
8. No abrasives shall be used to clean any of the bathroom fixtures.
9. There shall be no more than _____ occupants living on the premises.
10. There shall be no illegal drugs used on the premises.
11. These rules may be added to or amended from time to time by Lessor, and such amendments will become effective immediately upon notification to Lessee.

C

Appendix C: Social Service Acronyms

AMI	Alliance for the Mentally Ill of Minnesota
Arc	Formerly known as the Association of Retarded Citizens, an advocacy organization for persons with developmental disabilities.
BI	Brain Injured – An individual whose deficits in adaptive behavior or substantial functional limitations are caused by injury to the brain resulting in tissue damage and affecting functional abilities.
CAC	Community Alternative Care – CAC is a home and community care program which pays for health care services in the home of an individual who requires the level of care of a hospital. This is a medical assistance program approved by the federal HCFA.
CADI	Community Alternatives for Disabled Individuals – CADI is a home and community care program which pays for health care services in the home of an individual who requires the level of care of a nursing facility. This is a medical assistance program approved by the federal HCFA.
CD	Chemical Dependency
CDCS	Consumer-Directed Community Supports – An approved service under the Developmental Disabilities Waiver Program that gives consumers or their families more control over the funds used to buy various support services.
CHCO	Children Home Care Option
CMV	Current Market Value
CSG	Consumer Support Grant – A program that awards cash grants to adults with disabilities or families who have children with disabilities. Grants may be used to obtain various support services.
CSMD	Community Supports for Minnesotans with Disabilities, MN Department of Human Services.
CSSA	Community Social Services Act (Minnesota Statutes, Section 256B .) – This Act establishes a system of planning for and provision of community and social services administered by boards of county commissioners in each county of the state under the supervision of the Commissioner of Human Services.
DD	Developmental Disability – Persons diagnosed with mental retardation or a related condition who have substantial functional limitations or deficits in adaptive behavior and who manifest these conditions before their 21 st birthday.

DHS	Department of Human Services
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, Third Edition-Revised – American Psychiatrist’s Association official manual of mental disorders. Manual contains glossary of descriptions of the diagnostic categories.
DT & H	Day Training and Habilitation Centers – Nonprofit organizations that provide employment and habilitative services for persons with developmental disabilities.
EGA	Emergency General Assistance
FFP	Federal Financial Participation – Federal monies, matched by state and local monies, which are used to provide for maintenance service needs of eligible individuals. For example, federal monies available through Title XX of the Social Service Act to be used in payment for social services.
FSG	Family Support Grant – A program which awards cash grants to families who have children under 22 who are at risk of out-of-home placement. Grants can be used for a variety of purposes if they are part of an approved plan.
GA	General Assistance – State program which provides financial assistance to eligible people who are unable to provide for themselves and dependents. Individuals must meet established criteria of eligibility.
GA-EA	General Assistance-Emergency Assistance (also know as EGA) – Monies provided to eligible persons in crisis situations which receiving EGA will resolve, provided that the individual is unable to resolve the crisis situation on their own without EGA and that the situation will result in severe hardship for the individual if not solved. Must be a bonafide emergency.
GAMC	General Assistance Medical Care – State-funded health care coverage program for individuals who are either General Assistance recipients or who do not meet the categorical requirements of medical assistance whose financial situation prevents them from affording necessary health care. Typically these are adults under age 65 who are not disabled and are not caring for children.
GRH	Group Residential Housing – A state-funded income supplement program that pays for room and board costs for low income persons who have been placed in a licensed or registered setting with which a county human service agency has negotiated a monthly rate.
HCBW	Home and Community Based Medicaid Waivers – Waivers to regular medical assistance program which are authorized by state law and approved by federal Health Care Financing Administration (HCFA), which allows reimbursement of services not usually covered by Medical Assistance (MA), but will help an individual get the services they need in the community and keep them out of an institution. Includes day program, habilitation services, supported employment program, respite care, SILS, adaptive equipment, and several other services.
ICF/MR	Intermediate Care Facility for the Mentally Retarded – Facility certified by State Department of Health to provide health or rehabilitative services for mentally retarded individuals or persons with related conditions who require active treatment.

IEP	Individual Education Plan
IPP	Individual Program Plan – A detailed plan developed by a county case manager for a person who has mental retardation or a related condition. This includes assessments, diagnosis, needed services, and annual and long-term goals for the client.
MA	Medical Assistance (also known as Medicaid or Title XIX of the Social Security Act)
MA-EPD	Employed Persons with Disabilities – MA buy-in option for people with disabilities who are employed.
MA-ID	Medical Assistance Identification Card – ID card mailed by Department of Human Services to an eligible individual to show health care providers that the individual is a Medical Assistance recipient and to provide billing information to the providers.
MCHA	Minnesota Comprehensive Health Association – A state operated insurance program for people who otherwise are unable to obtain insurance.
MDH	Minnesota Department of Health
MHA	Mental Health Association (of Minnesota)
MNCARE	MinnesotaCare
MR/RC	Mental Retardation or a Related Condition – See DD.
MSA	Minnesota Supplemental Aid – State program which provides financial assistance to elderly, disabled, and blind recipients of Supplemental Security Income (SSI).
NF	Nursing Facility – An institution, certified by the State Department of Health to provide skilled nursing care.
PCA	Personal Care Assistant/Attendant
PDN	Private Duty Nursing
PMAP	Prepaid Medical Assistance Program
QA	Quality Assurance
QI or CQI	Quality Improvement or Continuous Quality Improvement – Service design that uses continuous feedback to improve effectiveness and/or efficiency.
QMB	Qualified Medicare Beneficiary – An individual who is entitled to Medicare Part A, whose income is below 100 % of the federal poverty guideline, and whose assets are below two times the SSI asset limit. This is a medical assistance (MA) category of eligibility which entitles the QMB to MA coverage of Medicare cost-sharing.
RSDI	Retirement, Survivors, Disability Insurance (Social Security or OASDI.)

RSS	Regional Services Specialist – An expert in the area of developmental disabilities, who authorizes home and community-based services under the case managers in-service provision, and acts as a liaison between the county and the state in a given area of the state.
RTC	Regional Treatment Center – A state operated institutional facility providing 24-hour a day care and treatment for persons diagnosed as mentally retarded, mentally ill, or chemically dependent. Formerly known as state hospitals.
SEP	Supported Employment Program – A program to assist a developmentally disabled (DD) person to keep a job with support from a program which includes a job coach, social workers, and staff knowledgeable in working with individuals with DD.
SILS	Semi-Independent Living Services – A residential program for developmentally disabled adults in which they can live semi-independently, such as in an apartment with a roommate, with follow along services to help the client live as independently as possible.
SMRT	State Medical Review Team – Determines disability status using Social Security Administration criteria.
SOCS	State Operated Community Services – Community ICFs/MR facilities with six or fewer beds that are operated by the Department of Human Services.
SSA	Social Security Administration
SSI	Supplemental Security Income – Federal program which provides a monthly grant to qualified aged, blind, and disabled individuals under Title XVI of the Social Security Act to help pay their living expenses.
TBI	Traumatic Brain Injury
TDD	Telephone Device for the Deaf
TEFRA	Tax Equity and Fiscal Responsibility Act of 1962 – Federal Public Law 97-248 . This term is also commonly used to describe the optional medical assistance (MA) category of eligibility enacted under TEFRA Subs. 134 for children with disabilities who require a level of care of an institutional setting and who, if they lived in an institution, would be MA eligible but for whom care at home is less expensive for the MA program.
TITLE XIV	SSI (Supplemental Security Income) – The federal cash program for persons who are aged, blind, or have disabilities.
TITLE XIX	Medicaid
TITLE XX	Federal Social Services Program

Source: Minnesota Department of Human Services, February 2000.

D

Appendix D: Real Estate Terms

Accessibility	The capacity to be approached, entered, or made livable for a person with a physical disability.
Adjustable Rate Mortgage (ARM)	A mortgage that permits the lender to adjust the interest rate periodically on the basis of changes in a specified index.
Annual Percentage Rate (APR)	The total cost of a mortgage stated as a yearly rate; includes the base interest rate, loan origination fee (points), commitment fees, prepaid interest, and credit costs that may be paid by the borrower.
Appraisal	An estimate of the market value of a property (determined by a professional appraiser), based on prices that have been recently paid for similar property in the same area.
Budget	Summary of estimated income and expenses.
Buyer	A person who enters the home buying process.
Capacity	A person's financial ability to make payments.
Capital	Money or property owned by an individual.
Clear title	A title that is free of liens or legal questions as to ownership of property.
Closing	A meeting to finalize the sale of property by delivery of a deed from seller to buyer. The buyer signs the mortgage documents and pays the closing costs. It is also called a "settlement."
Closing costs	The upfront expenses that must be paid at the time of purchase (over and above the price of the property.) These "closing costs" generally range from three to six percent of the total mortgage. For example: to buy a \$60,000 house with a five percent down payment, your closing costs would total between \$1,710 and \$3,420.
Commercial bank	Private, profit-making business that loans money and carries out numerous financial transactions.
Commission	A fee, usually a percentage of the purchase price of the property, charged by a real estate agent to complete a sale.
Condominium	A residential unit that is individually owned, while the facilities and common areas (the surrounding land, the hallways, and elevators, and any recreational facilities) are owned collectively by the owners of each unit.
Conservator	In some states, a conservator is an individual or organization who has been named by a court to exercise some or all powers and rights over a person and/or estate of the person. In other states, a conservator may be described as having control over a person's estate only.

Contractor	A person who contracts to perform work or provide a service, such as repair or construction.
Cooperative	A residential unit, also referred to as a co-op, in which owners own shares in a corporation rather than owning the individual units in which they live.
Counteroffer	Response from a seller to a buyer's offer. A counteroffer is typically higher than the buyer's offer and lower than the original sale price of the house.
Credit counselor	A person who is trained to give advice about how to manage one's money. The counselor may either work for a lender or for an independent credit counseling agency.
Credit report	A report that shows an individual's history as a bill payer, as well as how much money the person owes.
Debt	Money that is owed.
Deed	A legal document that transfers and verifies ownership of (or title to) a property.
Deposit	A "good faith" payment submitted by a buyer along with an offer to purchase a house. Assures the seller that a buyer is serious about purchasing a house.
Discretionary expense	An expense that one has control over, such as entertainment, eating out, and clothing.
Down payment	The portion of the purchase price that the buyer pays in cash and does not finance with a mortgage.
Earnest money (deposit)	A "good faith" payment submitted by a buyer along with an offer to purchase a house. Assures the seller that a buyer is serious about purchasing a house.
Escrow	The holding of documents and/or money by a neutral third party prior to closing; also, an account held by the lender into which a homeowner deposits money for taxes and insurance.
Estimate	A statement of the approximate cost of a service.
Expense	Cost or allotment for an item or a service.
Facilitator	A person who knows a potential home buyer well, believes in his or her dream of owning a home, and is willing and able to assist the person to reach his or her goal of homeownership.
Fair Housing Act	Law which prohibits discrimination on the basis of race, religion, age, national origin, receipt of public assistance funds, sex, marital status, or disability.
Federal Housing Administration (FHA)	The government agency established to improve housing standards and conditions, and provide an adequate home financing system through insurance of mortgages, as well as stabilize the mortgage market.
Financing	Funds or credit provided to a buyer from a bank or other lending source.

Fixed expense	An expense such as a mortgage payment, utilities, and insurance premiums.
Fixed-rate mortgage	A mortgage in which the interest rate does not change during the entire term of the loan.
Foreclosure	Legal action taken by a lender if a borrower fails to pay monthly mortgage payments on time. The bank or lender takes back the property and sells it to try to recover the money it loaned.
Grant	Money that does not need to be repaid. Grants may be obtained from numerous agencies; affordable housing programs; endowments for first-time home buyers; and/or private foundations.
Guardian	An individual or organization who has been named by a court to exercise some or all powers and rights over a person and/or estate of the person.
Hazard insurance	Also called "property insurance," protects a homeowner and the lender from loss in the event the house is destroyed or damaged in any way.
Home improvements	Repairs or renovations that restore or increase the value and may beautify a home.
Home inspection	A property inspection to evaluate the structural and mechanical condition (not the market value) of the property. Performed by a professional inspector, the inspection is based on observable, unconcealed structural conditions.
Housing counselor/ education provider	A person who is trained to assist prospective home buyers throughout the purchase process.
Housing finance agency	State-mandated agency that finances housing for low and moderate income people.
HUD - 1 Settlement Statement	This form is required by federal law. The purpose of the form is to itemize the services provided and list the charges to the buyer and the seller. The form is filled out by the settlement agent who conducts the closing. Both the buyer and seller must sign it.
Inspection	A thorough examination of a property by a professional home inspector.
Insurance	A contract providing protection against loss or harm, in return for a payment of money.
Interest	The fee charged for borrowing money. Interest rates may change from day to day and can vary between different lenders and different types of loans.
Investment	The purchase of an item or piece of property that will hold its value or is likely to increase in value.
Lease-Purchase Mortgage Loan	A mortgage product that allows low and moderate income home buyers to lease a home from a non-profit organization or private seller, with an option to buy. Each month's rent payment consists of PITI payments on the first mortgage, plus an extra amount designated for deposit to a savings account where money for a down payment accumulates.

Lender	A person or institution that provides funds to a borrower.
Lien	A legal claim filed against a property by creditors trying to collect unpaid bills, or by the IRS for nonpayment of taxes. A lien gives creditors the right to collect the money owed them when the owner sells the property.
Loan	A sum of money that is provided with the expectation of repayment.
Loan interview	A meeting between the person applying for a mortgage and an agent from the lending institution (the loan officer or originator).
Loan officer	Agent of the bank or lending institution who collects the data required by the underwriter who determines whether a borrower is granted a loan. Also called an originator.
Loan origination fee	A fee paid by the buyer to cover the administrative costs of processing the loan. The fee may be described as a percentage of the loan (for example, one percent of the mortgage amount).
Loan processing	The steps performed by a loan officer or other lenders to determine whether to grant a loan to a borrower. These include a review of the borrower's financial circumstances, credit history, and appraisal of the property.
Loan servicing	The collection of mortgage payments from borrowers and the related responsibilities of a loan servicer.
Loan term	The length of time you have to pay back the loan. Most mortgages are paid back over 15 to 35 years. First-time home buyers usually request the longest possible mortgage term in order to have the lowest monthly payment.
Loan-to-Value Percentage (LTV)	The relationship between the unpaid principle balance of the mortgage and the appraised value (or sales price if it is lower) of the property. Typically, the difference is expressed as a percentage of the amount the lender is willing to lend.
Maintenance	Ongoing care of a property to keep it in good condition.
Mortgage	A legal document that pledges a property to the lender as security for repayment of a loan.
Mortgage broker	An individual or company that, for a fee, acts as intermediary between borrowers and lenders.
Mortgage company (Lender)	Private, profit-making business that offers mortgage loans.
Mortgage insurance	A contract to protect the lender if the buyer fails to repay the mortgage loan. Loans with private mortgage insurance (or PMI) enable the home buyer to purchase a home with a lower down payment than would otherwise be acceptable to the lender.
Multiple listing service (MLS)	An electronic system used by real estate agents that generates a list of properties for sale.

Negotiate	To deal or bargain with another person.
Net income	The amount of money one has after taxes and any other deductions, such as medical insurance. Also called take-home pay.
Nontraditional credit history	Documentation of monthly payments to previous landlords or property managers; utility companies for electricity, gas, water, and telephone services; cable television companies; and to insurance companies for medical or life insurance. These payments will not appear on a credit report, but canceled checks, receipts, and reference letters from creditors will provide proof that payments were made.
Obligation	A moral or legal responsibility or promise.
Owner financing	A property purchase transaction in which the property seller provides all or part of the financing.
PITI	Stands for principal, interest, taxes, and insurance - the components of a monthly mortgage payment.
Pre-qualification	Process that determines the amount a lender may be willing to lend a borrower to purchase a house.
Premium	The amount paid by a borrower or insurance policy holder.
Principal and interest (P&I)	The portion of a mortgage payment that includes the principal (the amount you actually borrowed) and the interest (a fee for borrowing the lender's funds).
Property insurance	Also called "hazard" insurance, protects a homeowner and the lender from loss in the event the house is destroyed or damaged in any way.
Public benefits	Income from a governmental agency. This includes funds received from the Social Security Administration, Medicaid, and federal and state agencies.
Public Housing Authority	Local housing agencies that administer public housing.
Probate Court	Court that grants and oversees guardianship and conservatorship, as well as, establishes the validity of wills.
Real estate sales professional	A person who is trained and licensed to sell real estate. Also referred to as a realtor, agent or broker.
Reference	A statement regarding a person's character or abilities.
Renovations	Repairs or construction which either restores a house to its original condition or improves its condition.
Representative payee	A person or organization selected by the Social Security Administration (SSA) to manage the benefit payments of an individual receiving cash benefits from the Social Security Administration (i.e., SSI, SSDI) who is unable to do so on their own. The representative payee receives cash benefit payments on the individual's behalf and determines how these funds will be spent.

Resource	A source of financial or other support that can be readily drawn upon.
Rural Housing Service (RHS)	Formerly known as the Farmers Home Administration, this branch of the U.S. Department of Agriculture offers low interest rate home loans with no down payments to persons with low and moderate incomes who live in rural areas.
Savings and loan association	A financial institution that invests primarily in mortgage loans.
Seller	A person or organization who offers a property for sale.
Settlement agent	A lender, title insurance company, escrow company, real estate broker, or attorney who conducts a closing.
Single-family home	A house that usually stands on its own, unattached to another home, and is designed to be occupied by one person or family. In some urban areas single-family homes share a common wall. Generally, the land and the house are owned by the same person.
Tax	A sum of money paid by an individual or organization to the government in return for its services.
Title	A legal document, a claim or right, stating that there are no legal questions as to who owns a property.
Title insurance	A contract providing protection against any problems that may arise with the title.
Townhouse	Type of condominium. These units share common walls and may have two or more stories. Each unit has its own ground space, but as with condos, the common spaces and facilities are collectively owned by all of the unit owners.
Trust	A legal agreement between two or more people where one person places money or property in the name of an individual or a bank (the trustee) for the benefit of another person (the beneficiary). The trustee owns the property but is legally required to use the money or property for the benefit of the beneficiary.
Truth-in-Lending Act (TILA) statement	A document required by the Truth-in-Lending Act that obligates mortgage lenders to explain in writing the terms and conditions of a mortgage. The lender is required to give a copy to the loan applicant within three business days of receiving the initial application.
Veteran's Affairs (VA) loan	A loan that allows qualified veterans to buy a house with no down payment.
Warranty	A legally binding guarantee which covers the cost, or part of the cost, to replace or repair an item.
Wish list	A list or outline of one's desires.

Source: Fannie Mae, *A Home Of Your Own* Guide.