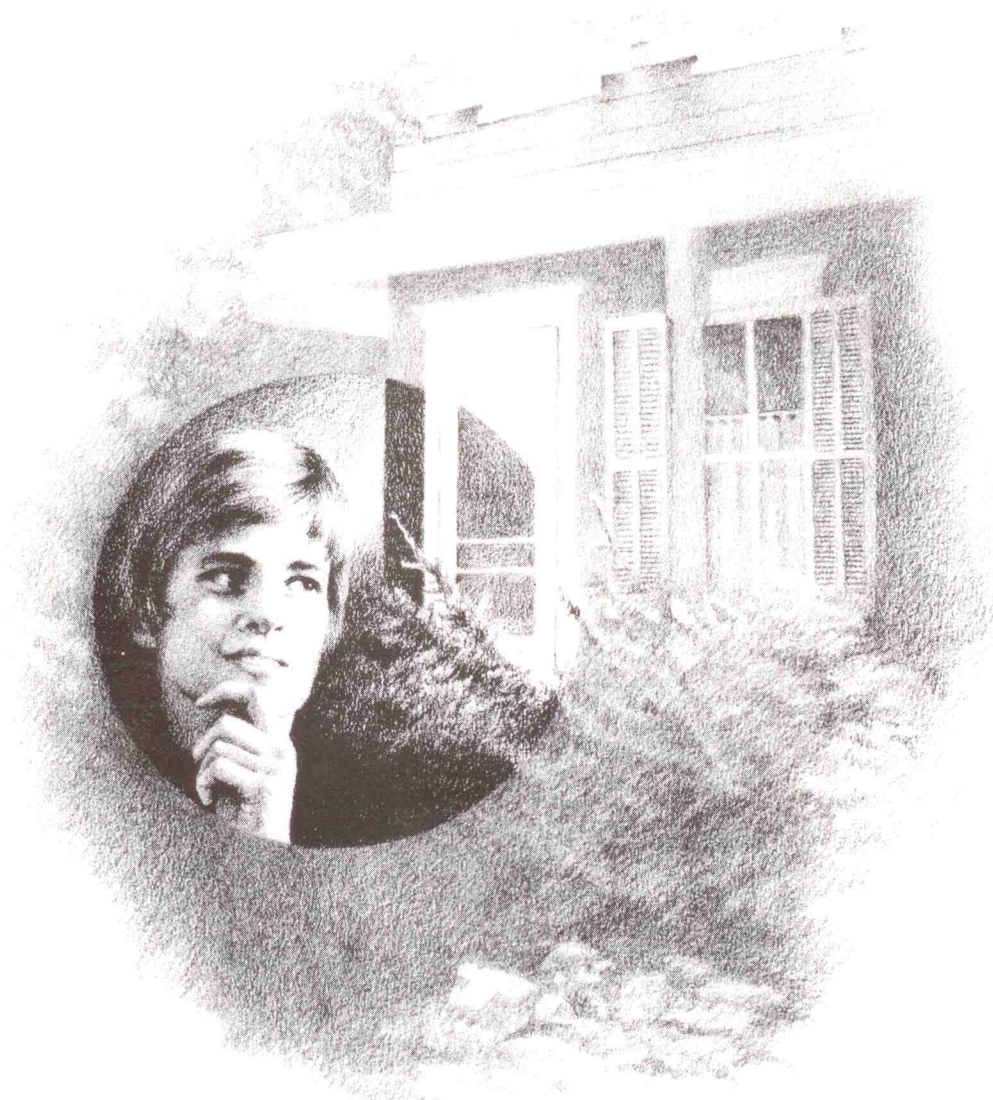


A Home of My Own



A Planning Guide for Individuals, Parents and Agencies in the Community



Association for Community Living - Manitoba

Foreword

Nicola Schaefer

"I couldn't find my wallet this morning so I missed my bus, and then people at work were angry with me because I was late, and then something I ate in the cafeteria gave me a stomach ache. It's been a horrible day and I just can't wait to get home!"

"We've been all over Mexico in the last two weeks, not to mention we drove all the way there and back. It's been a great holiday but now I just can't wait to get home!"

Whether we've been having a wonderful or a rotten time, the place where we want to end up is at home - the familiar, comfortable, safe retreat where we can relax, recover and rejuvenate ourselves.

Most of us at some point in our lives go through the trauma of "moving house" as part of creating either a first home of our own or one of several. We are beset by the dual emotions of excitement and anxiety. We are excited at the prospect of a new house or apartment, maybe new furniture (or at least a rearrangement of the old), new areas nearby to explore, new neighbours and so on. We're anxious because we can't be sure we're making the right move. We wonder how long it will take before we feel a sense of familiarity and belonging in our new place.

The secret to creating a new home with a minimum amount of anxiety is through maximum planning. That's what this book is all about. Just where do we want to live, with whom, etc.? In the pages ahead we are invited and encouraged to consider these and other vital questions before plunging into a new housing arrangement - or helping friends to do so. We are also encouraged to look into the kinds of supports we'll need and how easy or difficult it will be to acquire them.

This is both a thoughtful and thought provoking book and should prove extremely useful to anyone planning a home of his or her own. In fact, my advice would be: don't begin a home without it!

Acknowledgement

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Introduction

Introduction

We all search for a home of our own where we are safe and warm. This book has been developed to give some concrete steps to think about when planning for yourself, your son or daughter, a friend, a sister or brother, or a person served by your agency.

Chapter 1 tries to give a sense of what a home means to each individual and the principles that govern being in a home;

Community presence
Making Choices
Being Respected
Developing and Contributing
Growing in Relationships.

Chapter 2 looks at how we can plan for individuals seeking a place they can call home. Not only is important to look at the immediate needs of an individual, but it is also important to discover the options that will make that person feel at home.

Chapter 3 uncovers some of the housing options available, as well as, anticipates some of the problems which may be encountered. These options range anywhere from either renting an apartment to owning a home.

Chapter 4 looks at support options as another consideration when seeking a home. It discusses the different types of supports, trends in support, choices which need to be made concerning supports, as well as provide worksheet style questions which will raise the issues that need to be addressed when making these kinds of decisions.

Chapter 5 shows us how to organize the supports we need to work with in order to pull everything together. These supports can include volunteers and board members or more informal supports such as family.

As you read through this book you may find yourself feeling confused. The process of finding a home for yourself or someone you love will be confusing, enlightening and maybe even fun. Capture everything, and remember - It is a process we all go through in our lives - formally on behalf of someone else - or informally and gradually for ourselves. Take it slow - get what you want - and most of all when you need it - **ASK FOR HELP**. Some have been there and would be glad to share their experiences. Still others would see this as an exciting venture and an opportunity for learning. Good luck.

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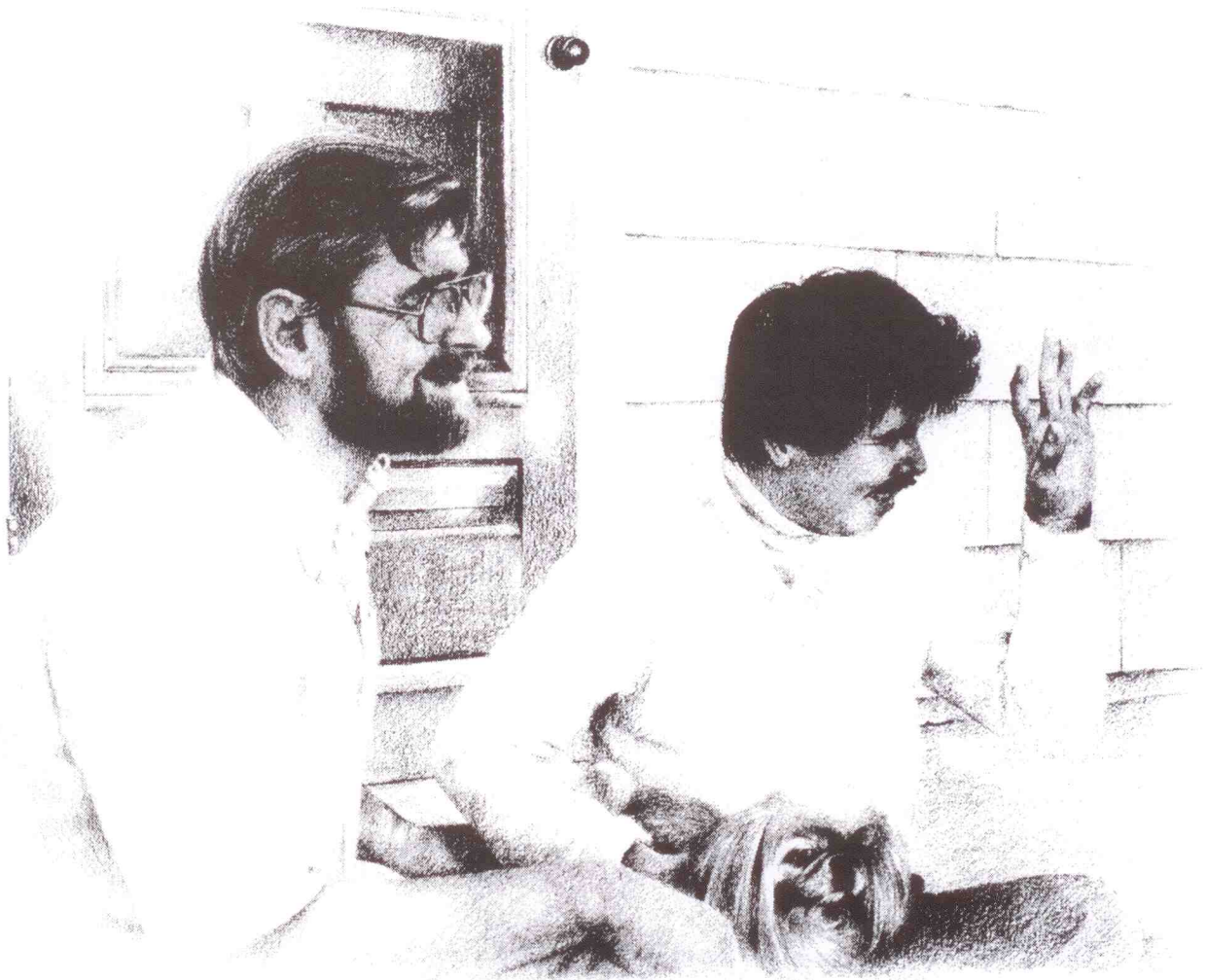
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A Home of My Own

A Home of My Own

The traditional approach in the human services field to providing housing for people with disabilities has been to develop a segregated, congregated setting where all the individual's needs can be met under one roof. In effect, the living arrangements have conveniently served the agencies and caregivers, not the individuals who seek support.

Although this type of living arrangement provided basic needs to its residents, it lacked the essentials necessary to create a home in the true sense. Aside from a physical site, a home must be comprised of a personal and social dimension, as well as a dimension of control.

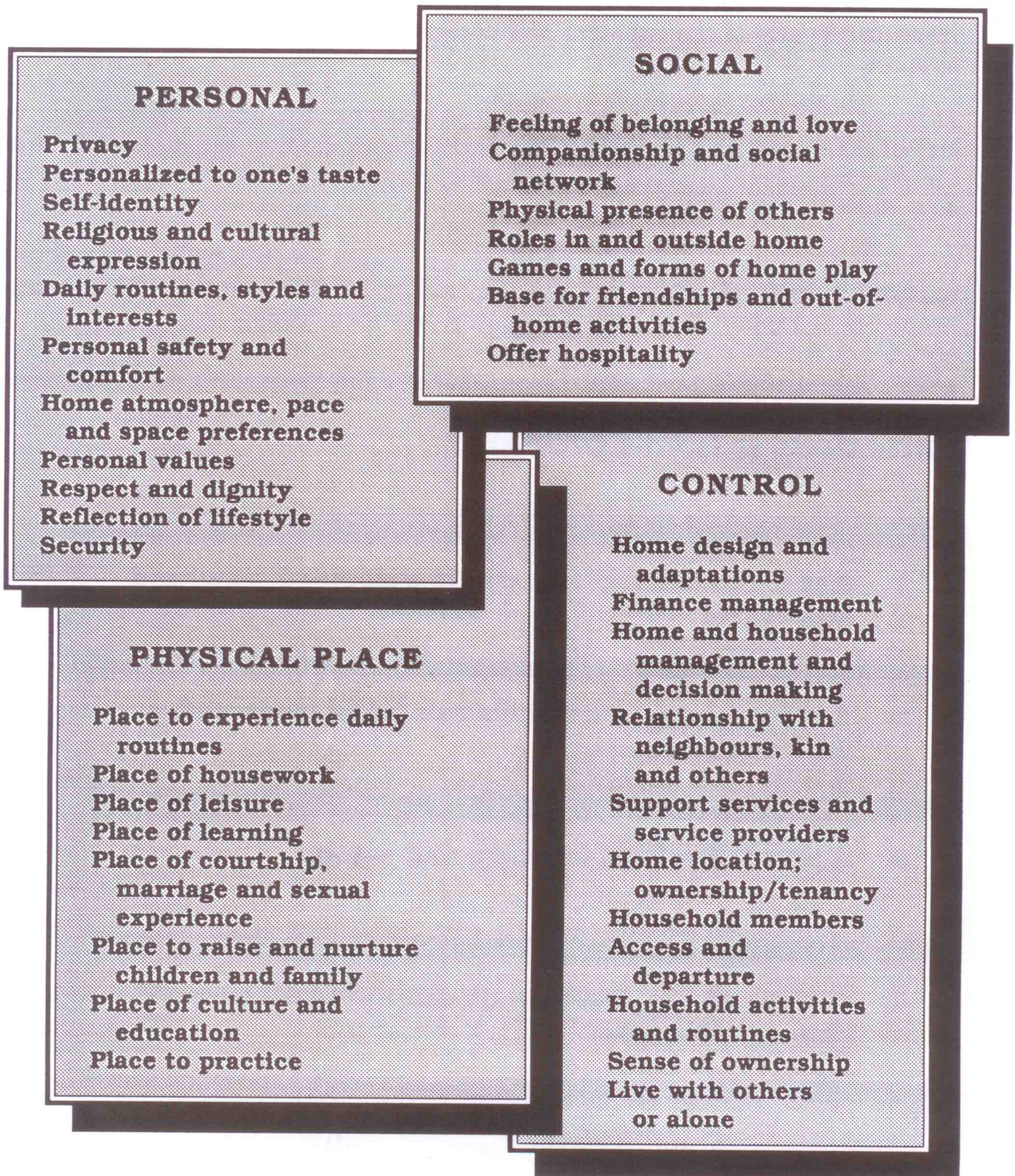
In recent years the challenge has become to provide people with disabilities the opportunity to decide where and how they will live, and to have access to existing resources to support more personal control over their home.

What does a home provide?

- 1. A place where individuals are welcomed, liked and respected.**
- 2. A place where individuals can fulfill their wishes, desires and needs.**
- 3. A place of refuge, security and safety.**
- 4. A place where individuals can live until they choose otherwise.**

Home

Each of us has grown to expect some basic needs to be met in our own home. The following diagram illustrates a few needs common to all of us.



Principles

☞ **Everyone needs and deserves a home.**

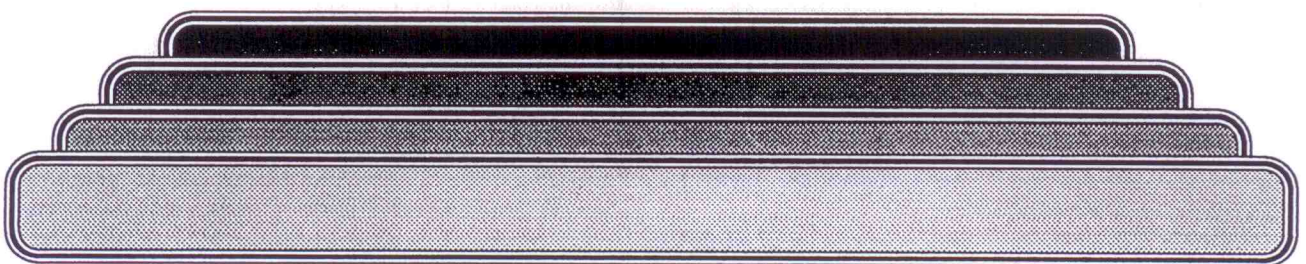
☞ **Planning for a home should be based on achieving five outcomes:**

- ✓ **Community presence** - Sharing ordinary places in the community on a regular basis.
- ✓ **Making Choices** - Having control over large and small decisions that affect one's life.
- ✓ **Being Respected** - Having valued roles in community and being treated in a manner that enhances one's dignity.
- ✓ **Developing and Contributing** - Having opportunities to discover, cultivate and share one's interests, gifts and capacities.
- ✓ **Growing in Relationships** - Having opportunities and supports to develop a variety of friendships in one's community.

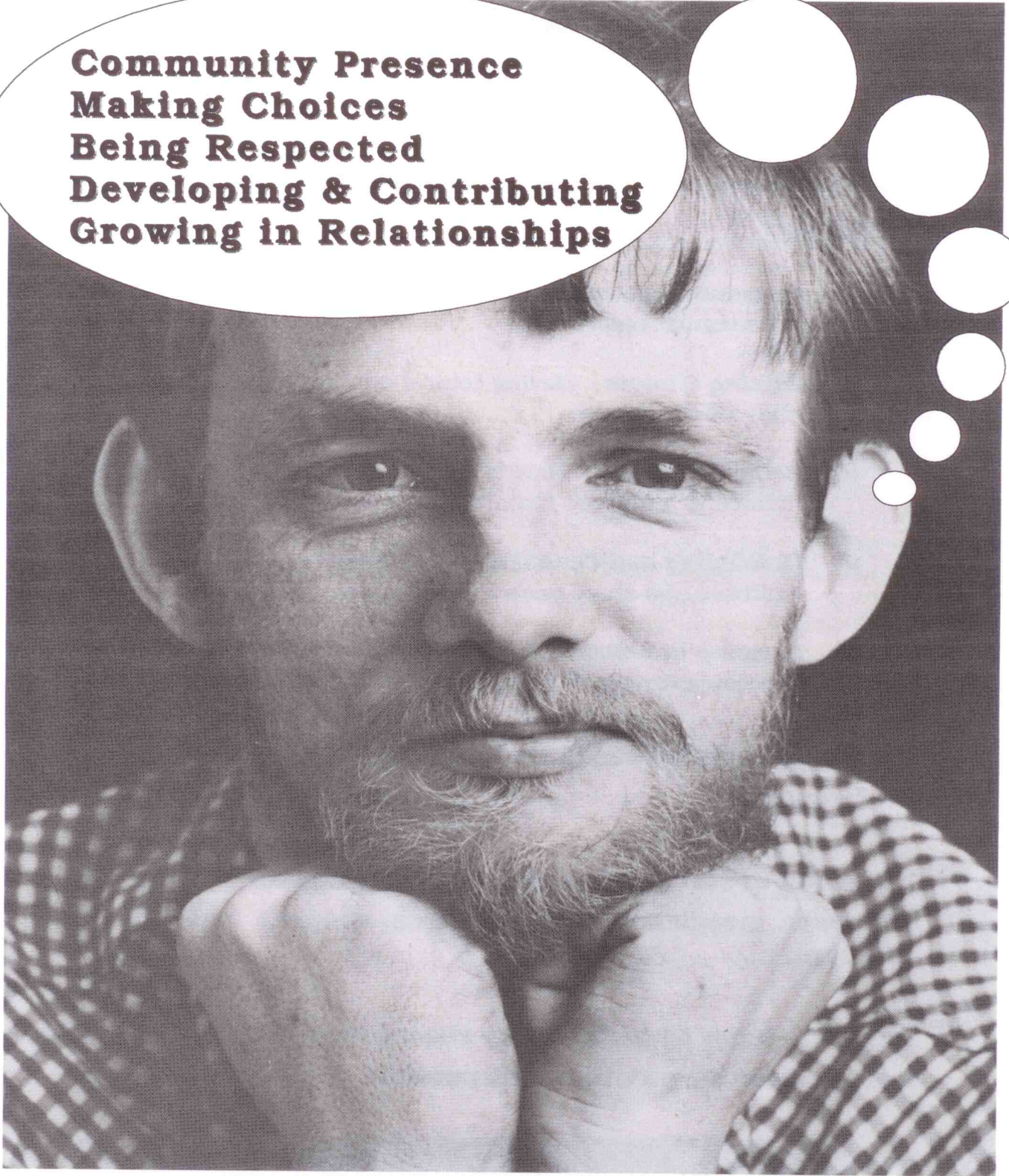
☞ **Housing should be based on individual choice and preferences.**

☞ **Provision of services should be dictated by an individual's own interests, needs and circumstances, not by a facility or program.**

☞ **Supports must be available to allow individuals to live in the least restrictive environment possible.**



**Community Presence
Making Choices
Being Respected
Developing & Contributing
Growing in Relationships**



Individual Planning

Individual Planning

Introduction

The person and his/her needs must come before the system and its needs. In the past we planned services or group homes and expected people to fit in. The person was placed at their current level of functioning and was expected to graduate from one level of service to the next in the movement towards greater independence.

We now know that the results are much better if we do not place any emphasis on readiness or try to change the person to fit in. Instead, we support the person to lead a life that is meaningful with the fullest possible participation and involvement in the community.

Traits of Good Planning

As opportunities increase for people to be more involved in their community more holistic approaches to planning are necessary - approaches that encompass all aspects of a person's life. Program plans should not concentrate solely on paid services such as workshops or group homes. Good planning is centered on the person and is directed by the person. It focuses on the person's skills, talents, capacities and interests. Planning must be flexible to reflect people's growth and reviewed regularly to ensure it meets the need.

Who Should Be Involved?

Planning well is dependent on the involvement of "significant others" or those people who are involved with and care about the person. The person receiving support must be at the center of the entire plan. They must be a part of the group and involved in the decision making, planning and sharing of responsibility for action. The person should be asked "Who would I like to have involved?" Significant others could include family, friends, advocates, acquaintances and paid staff.

Values and Attitudes

Beliefs concerning people's choices, dignity, community participation, opportunities to learn and contribute are the basis for good planning and should be recognized as important to all of us in our lives. The outcome of all holistic planning can be summed up in five areas.

Five Areas of Planning

Community Presence: *sharing ordinary places in the community on a regular basis.*

Making Choices: *having control over small and large decisions that affect one's life.*

Being Respected: *having valued roles in community and being treated in a manner that enhances one's dignity.*

Developing & Contributing: *having opportunities to discover, cultivate and share one's interests, gifts and capacities.*

Growing in Relationships: *having opportunities and supports to develop a variety of friendships in one's community.*

How to Proceed in Planning

It is helpful to begin by finding out a bit about the person's background which can provide clues to planning for the future.

What has life been like?

How has the disability complicated his/her life?

How has the person been involved with the service system?

What is the person's history with parents and other family members?

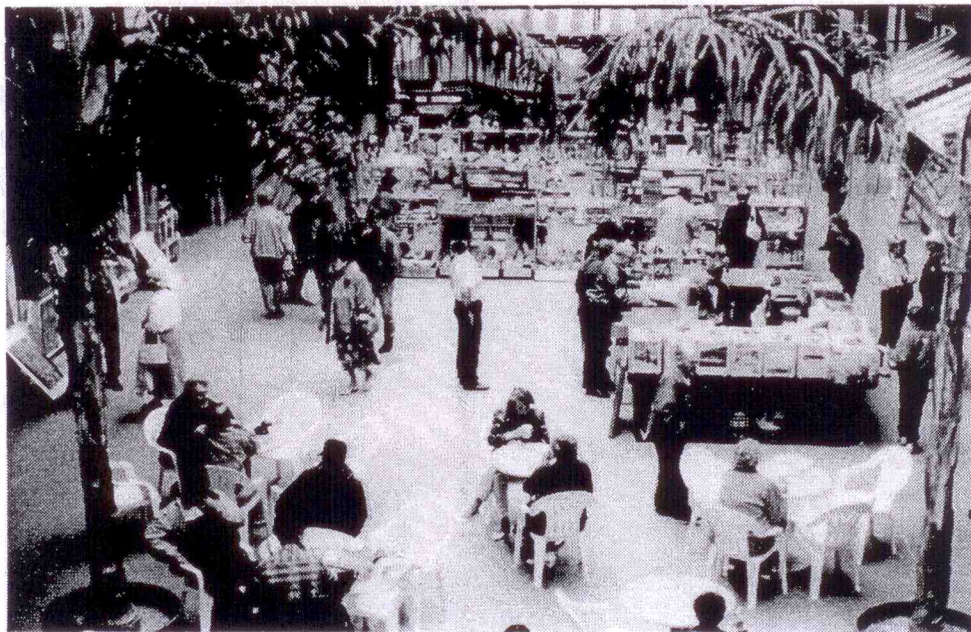
In fact, if we don't base planning on a person's background we are building a recipe for failure, as was the case in **Joe's story**.

Joe's Story

Joe lived in an institution for 12 of his 40 years. Prior to living in the institution he had lived with his elderly mother in the north part of the city. He knew street names, merchants, transit system numbers and routes in that area of the city. He loved to wander around and speak to the store owners and neighbours. At the institution he was also the official greeter, welcoming all the newcomers.

Joe was placed in a group home in a quiet suburb where he was not allowed to leave the house without a staff member (which was rarely) accompanying him. He was very unhappy and was soon returned to the institution.

Joe should have been provided with support to live in his old neighbourhood where he still had friends or at least people who knew him and where he could wander around without fear or getting lost.



We must also understand the person's current situation. Where do they live, work or learn? Who do they socialize with and where? What are the person's preferences, gifts and talents? Other group members will have information to add to the person's opinions. Then we are truly creating a recipe for success, as in Ron's story.

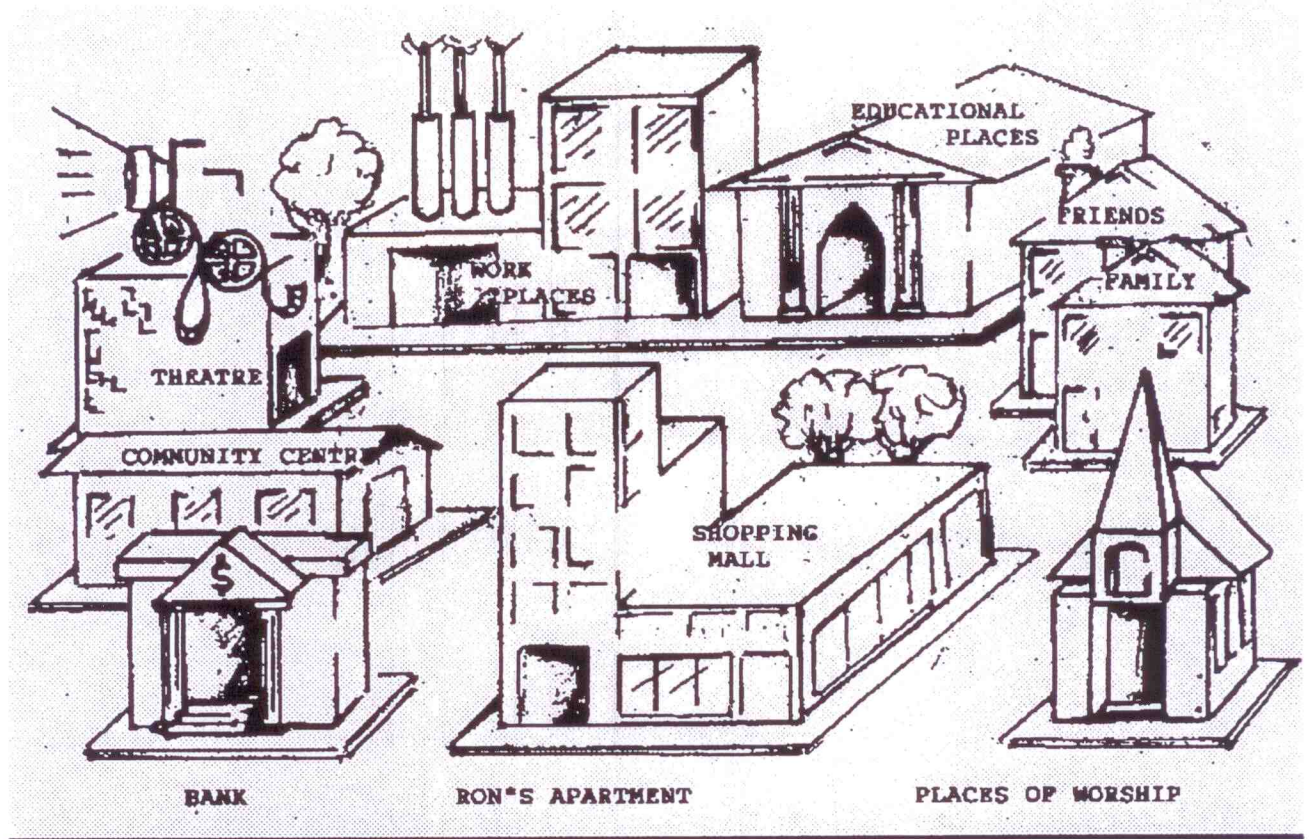


Ron's Story

Ron had lived all his life in a large institution. He had never seen an apartment or spent any time in a family home. He had missed many of the normal life experiences most of us have growing into adulthood. Ron could tell what he liked and didn't like to do. Friends were his biggest need and he clearly indicated he wanted to live with at least one other person and preferably two others. He liked doing "male" activities, like watching sports and hanging out. He seemed to be happiest when he felt like "one of the guys."

Ron's physical disability, which is severe, was the major concern. He is tall and requires a large wheelchair which makes it difficult to manoeuvre around corners and through doorways. Ron likes to go out and be "involved" in the community so access to community resources is important.

Living Arrangement Suited To Ron



Ask the person what they want to have happen for themselves. What do they want to do, to be, to have? Invite others to make suggestions and share their vision. Ideas or visions can be expressed as simple goals, such as, "Ron wants to live in an apartment with a friend downtown where he can go shopping or to a movie without having to arrange transport."

Ron's Story

The vision developed by Ron and his planning/support group is to have him live in a large downtown highrise attached to a shopping complex that is completely accessible to wheelchairs. There are several apartments that are wheelchair accessible and rent subsidy is also a possibility.

We must also deal with the resources and barriers. Resources can include things like family and friends or unpaid supports. Barriers might include availability of funding, transportation, etc. An action plan to make use of the resources and overcome the barriers is the final step. Who will do what by when?

Ron's Story

Who will approach the agency that runs the apartment complex? Who knows someone interested in being a roommate with Ron? Who will find out about rent subsidies and apply with Ron? When will we all get together to share the information we have gathered?



Planning is an ongoing process. It is never finished because we are constantly growing or changing. Most often if we plan well we need to make only minor changes or adjustments. Maybe we need additional supports for the evening or we have to modify the hallway of the apartment. Sometimes we find the situation does not begin to meet the person's needs and we must learn from our mistakes and make a major change like moving from a city apartment to a house with a big yard. Always, our chances for success are much greater if we listen to the person and plan well with him or her.

In summary the essence of good planning includes;

Listening better; In order to react to people with disabilities we must hear what they really want in their lives.

Ask; Although it seems simple, many people with disabilities are seldom asked their opinions, much less have their responses taken seriously.

Spend time together; Some people have more trouble than others when it comes articulating their preferences. Therefore, we may have to learn through observation.

Create opportunity for new experience; Some individuals have never had the choice to live on their own, so they are unable to consider the possibility due to a lack of information or experience.

Create safe environment for speaking; People with disabilities may fear speaking up to avoid being labelled as difficult, uncooperative and exhibiting behavioral problems.

Take initiative; A person with disabilities, or their family and friends, can make their own plans suited to them and then approach agencies to lend support. People with disabilities don't need to wait until others are ready to change. They can take the lead to determine what they need or want and can even pursue choices that do not involve agencies.

Learn together; Staff, parents and other support groups can come together to generate ideas with an individual about where and with whom to live.

Get involved with a formal planning policy; Ask for assistance to become involved with:

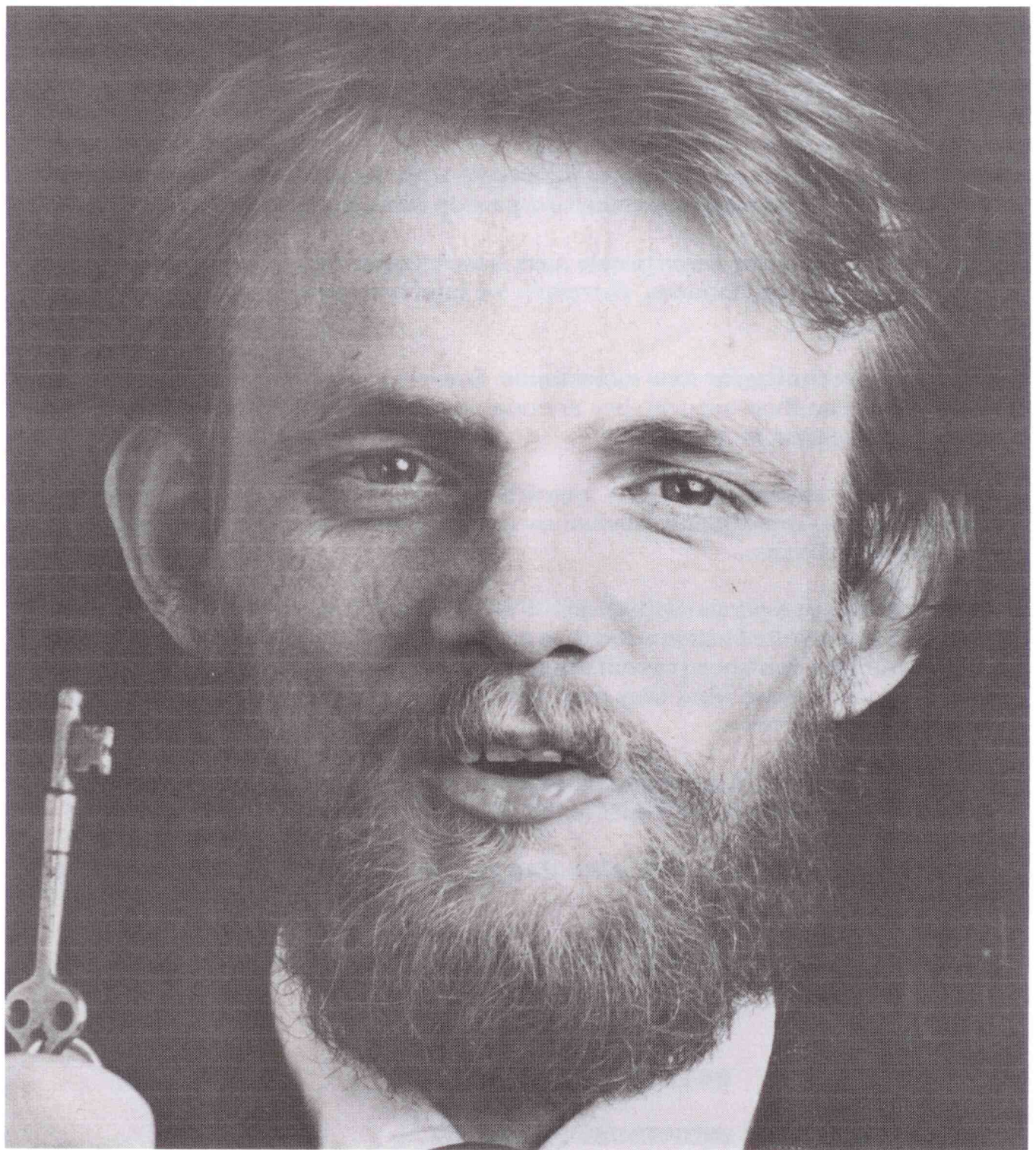
PATH

MAPS

24 HR PLANS

INDIVIDUAL PLANNING

-
-
- **Contact your local Association for Community Living for support to create a plan for the future.**
-
-



**Considering the Options -
Housing**

Types of Housing

A person with a disability is likely to require two basic considerations when planning for his/her home:

Housing Options
Support Options

This chapter will focus on the various housing options that have been developed for people with disabilities. Housing options are the physical settings that become the structure and foundation of a home.

The types of housing available for people with disabilities is as varied as the types of houses available to the general public.

Housing Options

Own Home
Shared Home
Mobile Home
Condominiums
Existing Home & Households
Co-operative Housing/ Apartments
Parents' or Guardian's Home
Corporation Owned or Rented
**Home owned by a Person with a
Disability**
**Home Leased by a Person with a
Disability**
**Home Owned or Leased by a
Parent or Guardian**
Home in Trust

Housing Options

Creating Choices:

Encountering These Problems ...

Consider These Options

**Lack of accessible
community housing**



Funding for home modifications

**Lack of decent,
affordable housing**



**Create trusts, co-ops subsidies,
private sources, tax credits;
federal, provincial and local
funding**

**Lack of choice in
housing**

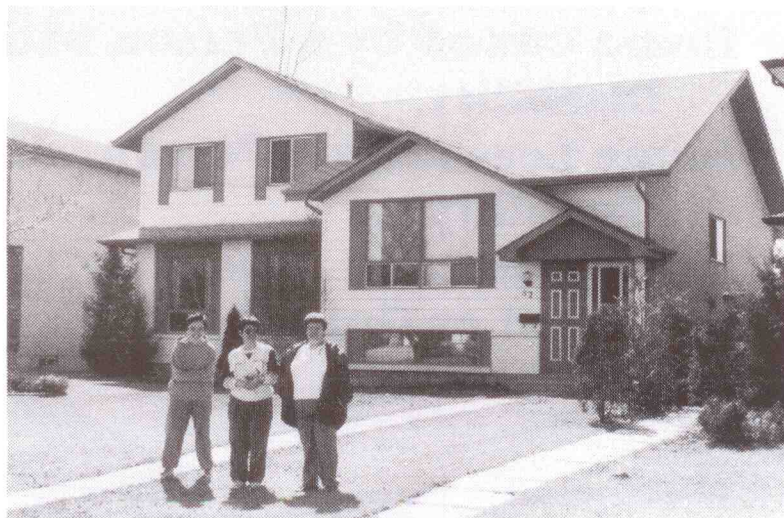


**Create housing ownership, co-op
housing, shared living
arrangements**

Permanency:

Living arrangements are subject to change, just as interests, desires and needs are not static or permanent.

By empowering the individual with real choices we create a sense of security, stability and control in their life which enables them to pursue interests and dreams.



Apartment Options

An apartment can be an ideal living situation when a person does not want the complications or added responsibilities of maintaining a home. A person with a disability may choose the convenience of an apartment or townhouse setting where many of the external expenses are included (utilities, snow removal, lawn care, cable). The level of disability will not be a factor. Individuals requiring more assistance will need to plan ahead as will be discussed in the next chapter. One thing that will need to be considered however, is the landlord's willingness to renovate an existing apartment to accommodate varying levels of physical disabilities.



Clustered apartments are living situations where 8-10 apartments for people with disabilities are scattered throughout a large apartment building (at least 70 suites). In several apartment buildings support is available through "pooled" staffing to respond to individual needs. Mary may need help with meal preparation, while Bob needs support to attend community recreational activities at the YMCA. In this illustration, the type of support required is coordinated and provided by the support service agency. Other options are available to provide needed support.

Housing Co-operatives

Co-operatives are often defined as housing collectively owned and operated by and for the mutual benefit of the people who live there.

Unlike ownership of a single dwelling, co-operatives are owned by a co-operative corporation where all members own a share. The corporation owns and leases the project to the residents, who are joint stockholders in the corporation. The corporation collects monthly payments from the tenants to cover operating costs. Being owners, the residents also carry out maintenance operations.

Besides ownership, co-operatives carry several advantages. Members get to know each other through the shared active participation of maintaining their home; people are part of decision making processes that provide a sense of community; people earn equity through the money they've invested; people obtain affordable long term housing; people have central security and community.



Housing Trusts

One method of promoting home ownership as well as future security for people with disabilities is through the use of trusts. There are various forms trusts can take. Housing trust funds are sources of revenue that are committed to the purpose of providing low and moderate income housing.

The trusts usually come from government in the form of loans or grants. The funds go to non-profit development corporations, private developers, individuals and organizations. The main commitment is to new construction or other housing services, including rental subsidies.

Another type of trust includes private trusts. A family can appoint a trustee who acts for the beneficiary. The family home, for example, can be set aside legally for the person with the disability, although the management is handled by the trustee.

The key to having a trust program work is the assurance that people with disabilities are still able to maintain eligibility for various other assistance programs.

Strategies to Insure Involvement

- ✓ Homes should be located as near as possible to the individual's family, friends and work.. The goal is community participation, so avoid situations that create isolation.
- ✓ Access to homes should be convenient for people who live there; staff, family and friends. Avoid common barriers such as traffic conjection, lack of roads, lack of parking and lack of public transportation options.
- ✓ Homes should be located reasonably close to schools, stores, theatres, libraries and recreation facilities.
- ✓ Planners should avoid selecting areas where there are already services for other people with disabilities. The concentration of too many people with disabilities in one area reduces the ease with which the individual will integrate in the community.
- ✓ Homes should avoid having attention drawn to them as being "different" from other people living in the neighbourhood.
- ✓ The outside of the building should "fit" the area. Buildings, lawns and grounds should be kept neat and free of clutter in order to give the community a positive image of the home. This will also enable people who live there to develop a sense of pride in their home.

Remember the five goals ...

- 1. Community Presence**
- 2. Making Choices**
- 3. Being Respected**
- 4. Developing and Contributing**
- 5. Growing in Relationships**



**Considering the Options -
Supports**

Types of Support

People with disabilities will require varying degrees of support in order to live successfully in their own homes. We have now learned that everyone is able to live in a typical home in the community regardless of their disability. Technology has assisted in providing support solutions for people with the most complex needs. There is no need to exclude any person from fulfilling his/her dream of living in a home of their own.

The supports required will be based on the unique needs of each person. As discussed in the chapter on planning, the first step is to identify what those needs are for each person. John, for example, might need someone to help him budget his money each week and assist in shopping for food. Mary might require assistance in bathing each evening. Kim might require direct medical supervision with her respirator while Joanne might need someone to provide support with all of her basic living skills on a 24 hour basis. None of these supports are unusual or are more challenging than can be provided in a regular home setting.



FORMAL & INFORMAL SUPPORTS

Having a basic understanding of the differences between formal and informal supports becomes critical when dealing with people with disabilities in such matters as relationships, community associations, and neighbourhoods.

Formal supports tend to be more bureaucratic and governed by rules and plans, whereas informal supports are based on personal ties. Typically, formal supports include government, social agencies and professionals such as doctors.

Informal supports can include co-workers, neighbours, friends and family. Sometimes formal and informal supports overlap, as in the case of a paid staff member developing a relationship with an individual with a disability.

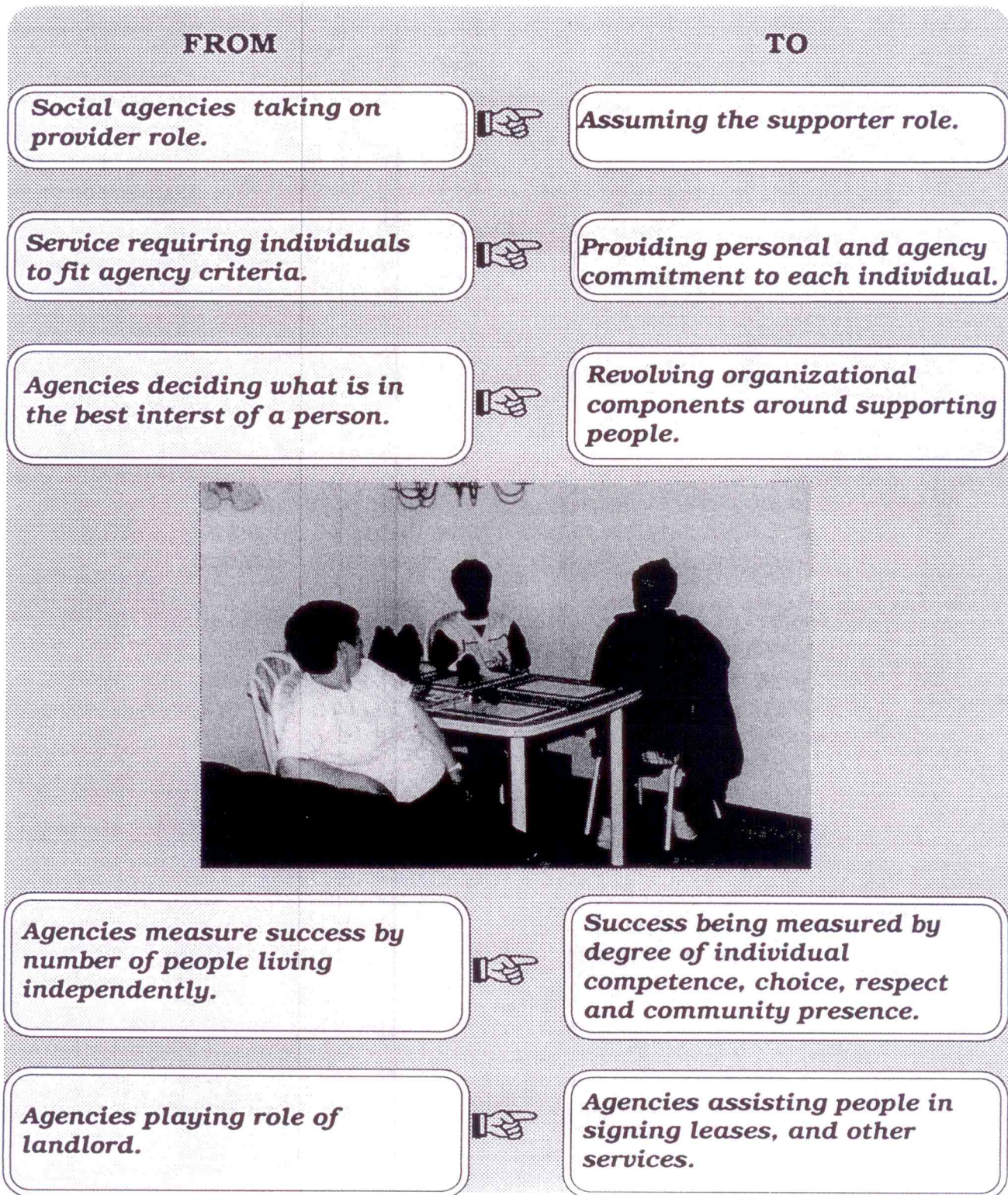
Recognizing these supports will help provide a foundation for people with disabilities in determining where they would like to live. Social agencies have to utilize the opportunities provided by both formal and informal supports and to facilitate decision-making.

There are *five trends* regarding formal and informal supports which are emerging in the field.

1. **Agencies are encouraging approaches less bureaucratic and providing greater spontaneity in the lives of people with disabilities. This also includes developing relationships between people with disabilities and workers.**
2. **Agencies are facilitating relationships between people with disabilities and community members.**
3. **Service agencies are entering into formal relationships with co-workers, neighbours, roommates and others on behalf of people with disabilities; these relationships might involve paid agreements or contracts.**
4. **Community organizations are being approached to develop ways they can be supportive and accepting of people with disabilities.**
5. **"Circles of support" are being created; these are informal networks of people with disabilities, family members or other friends who come together to assist someone in planning and participation in their community.**

Trends - The Shared Vision

Over the years support services have been moving away from directing and controlling individuals and, instead, towards assisting and supporting people as shown in the following diagram:



A Review of the Choices

Ultimately, as we move towards housing and support options, the key ingredient must center around a person's own choice for their own home.



Types of Housing; Decisions can range from houses, apartments and condominiums to cooperatives, housing projects and mobile homes. People with disabilities should have the same range of typical housing options available to them as other community members.



Location of Housing; There are varying rationales for choosing the neighbourhood people want to live in. Some people want to live near family or work while others desire to be near community places or resources. Some individuals might prefer to live in sparsely populated areas where they have plenty of open spaces.



Choices Continued



Living Alone or with Others; There are many factors which must be considered when people decide whether to live alone or with others. People with disabilities, whether single or married, should be supported to live in homes by themselves, with roommates, with spouses, or with paid staff, depending on their interests and values.



Who to Live with; For people with disabilities a roommate will also provide some support. Considerations in selection of a roommate might include: the age of the roommate, if this is important to the person with a disability; personal characteristics, habits and needs of the roommate, and how compatible the people would be with each other; and shared interests, preferences, values and living styles. The planning should remain flexible about possible roommates and should always involve the person with a disability.



Renting and Owning a Place; Having a lease in the person's own name may provide an enriched sense of responsibility. The person renting his/her own home would maintain a sense of control typically held by an agency.

Owning instead of renting may be another option to consider. The same sense of control would likely occur, as well as a sense of roots, pride and continuity.

**Community Presence
Making Choices
Being Respected
Developing and Contributing
Growing in Relationships**

Lack of attention to these five accomplishments can result in others (agencies, staff) controlling decision-making. It is important to ensure that people are receiving assistance in making decisions in their own home rather than others making those decisions for them.

Questions to Think About When Planning for the Home Where You Will Live

-
-
1. What makes your home a warm and welcoming place? _____

2. What must be present in your home that will make it a warm and welcoming home for you? _____

3. Where would you prefer to live when you can no longer care for yourself?
- | | |
|---|---|
| <input type="checkbox"/> Family Home | <input type="checkbox"/> Group Home |
| <input type="checkbox"/> With a Relative or Friend | <input type="checkbox"/> Housing Co-op |
| <input type="checkbox"/> In Own Home (with support) | <input type="checkbox"/> (with support) |
| <input type="checkbox"/> Other _____ | |
4. Is it important where your home is located? If yes, please indicate where.
- | | |
|--|--|
| <input type="checkbox"/> City or Town | <input type="checkbox"/> Close to Work |
| <input type="checkbox"/> Country | <input type="checkbox"/> Close to Other Family |
| <input type="checkbox"/> Same Neighbourhood/Area | <input type="checkbox"/> Members and/or Friends |
| <input type="checkbox"/> You Live in Now | <input type="checkbox"/> Close to Where the |
| | <input type="checkbox"/> Activities You Participate in |
| | <input type="checkbox"/> Take Place |
5. Do you prefer to live alone or with others?
- | | |
|--|--|
| <input type="checkbox"/> Alone | <input type="checkbox"/> With Handicapped People |
| <input type="checkbox"/> With Others: | <input type="checkbox"/> With Non-handicapped |
| <input type="checkbox"/> With a Family Member | <input type="checkbox"/> People |
| <input type="checkbox"/> With Another Family | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> With Someone Close in Age | |
-
-

6. How important is it that you choose with whom you will live?

7. Do you prefer to live in one of these types of homes listed below?

- Apartment Trailer
- Duplex Townhouse
- Single Dwelling House

What are the reasons for this choice? _____

8. a) Is it important that you can remain living in your home for as long as you want to?

Yes No

If yes, how can you be sure this can happen? _____

b) Who should own the home?

- You Should Own the Home
- Another Family Should Own the Home
- Ownership of Home Should be Shared by Several Individuals
- Ownership of Home Should be Shared by Several Families
- You Should Own Shares in a Housing Co-op
- You Have a Lifetime Interest in the Home (the home will go to some other person when you die or decide to live elsewhere)
- Other _____
- _____

9. Can you help in financing the purchase of a home? If so, in what ways?

10. Can you help in financing the maintenance of a home? If so, in what ways?

11. Will you need outside help to finance the purchase of the home? If so, what are some of the resources you can explore? For example, provincial government housing agency, private investors, service clubs, other families who may wish to share a house, other family members. _____

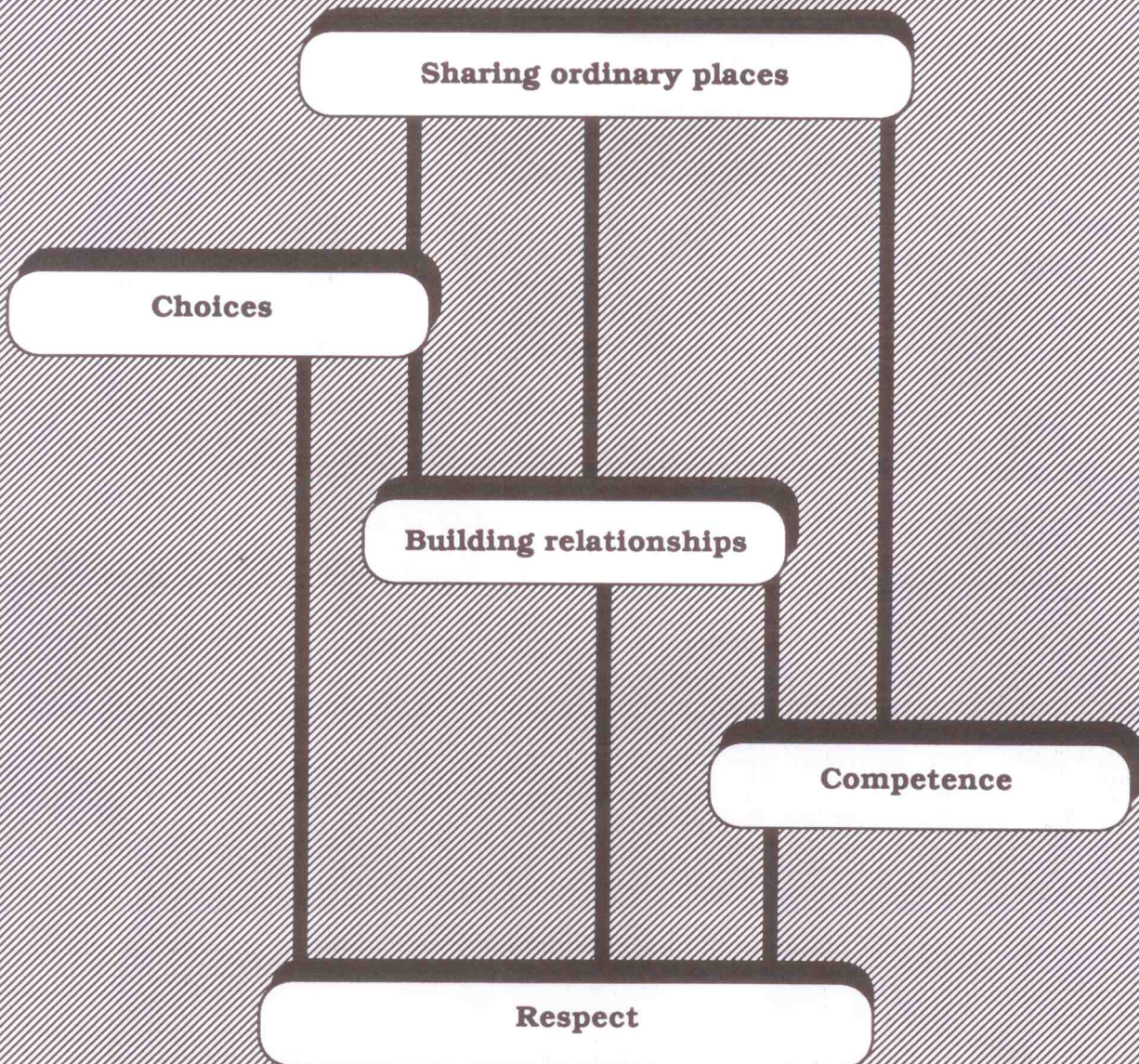
12. The statements listed below characterize the physical nature of the home. Please check the level of importance attached to each for yourself.

	Very Important	Somewhat Important	Not Important
a) The house be usable for someone with a wheelchair	_____	_____	_____
b) You have your own bedroom	_____	_____	_____
c) You use your own furniture, T.V., etc.	_____	_____	_____
d) You have a say in home decoration	_____	_____	_____
e) Outdoor recreation area	_____	_____	_____



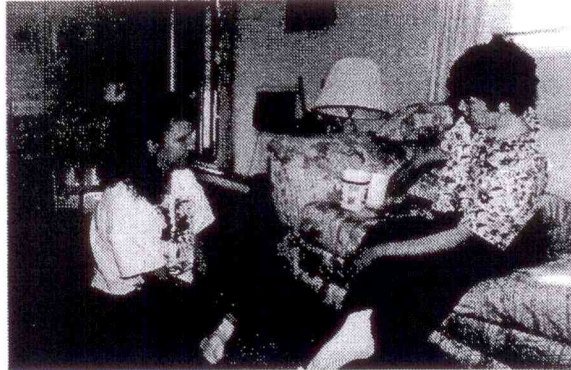
Organizing Supports

REMEMBER ...



Organizing Supports

The final step in establishing a home for a person with a disability is the structure that organizes the supports. Most governments require structure to be a registered organization which usually includes a volunteer board of directors. It is highly recommended that board members represent the larger community in which the supports will occur. Additionally, many boards include both families of individuals served, as well as individuals themselves. Most organizations providing human services choose to be non-profit. This added safeguard ensures that any income generated by a surplus budget goes back into the organization to enhance the service.



Functions of a Board

The Board of Directors has the responsibility to ensure that the supports it provides assist the individuals to move towards the five accomplishments as discussed in earlier chapters.

- 1. Community Presence**
- 2. Making Choices**
- 3. Being Respected**
- 4. Developing and Contributing**
- 5. Growing in Relationships**

In order to do this board members must:

Carefully choose staff who will serve each person's best interest with understanding, patience and commitment.

Ensure an open line of communication between themselves, families, staff members, and individuals supported by the agency.

Regularly review programs and supports for quality and accomplishment of goals.

Address and discuss the "people" concerns and formulate policies that will support individuals' own decision-making.

In addition each board of director must maintain the financial stability of the organization and must be accountable to the funder. That will require regular financial statements, yearly budgets and usually a certified audit at the end of each fiscal year. In essence, the "running of the business" must provide the foundation for the individuals dependent on the services and supports.

The above list is not inclusive but a starting point in *organizing the supports*. There are organizations in each community that provide more detailed information to new and existing boards to assist them in their work. Issues such as by-laws, roles of specific board members, letters of incorporation, etc., are some of the many specifics that members of the board of directors may need to know.

Equally or more important is the framework that is required to ensure that each person is supported in his/her own home. How the agency or organization provides this is by far the most challenging role of the board.

The following excerpt from the article, *"Sustaining Roles for the Community Support Circle,"* describes some sustaining roles that board members may wish to adopt. The ten roles are intended to describe community support circles and are equally viable for the informal circle or the more formal board members of human service.

"It is important to remember that these are not 'new' roles. We already know the art of hospitality; we know how to be faithful friends; and we know how to endure through times of confusion and difficulty. We know how to create good conditions for the development of our children, and we also know how and when to 'let go'. But, often we do many of these things automatically without thinking much about them. As well, we are not accustomed to doing these things for young adults and mature citizens, and we sometimes find the issues of disability confusing. The following is a description of roles which may be useful in organizing a sustaining circle of support for a person with significant disabilities.

1. Your first (and continuing) role is to **get to know the person**, to **identify and celebrate the gifts** which he brings to the community, and to **help him find ways of expressing those gifts**.
2. The second role is to **form community** with the person. Rather than depending on an outside 'program' to find friends for her, be her friend. This means spending time with her (as friends spend time with each other), get to know her, and let her take part in your life and in the life of your family. Visit her in her home; invite her to visit your home. Listen to her.
3. The third role is to **recognize and support the caregiving relationship** that is at the heart of the person's household. This means celebrating that relationship and giving the people who live with him some regular opportunities to reflect with you on what they are experiencing. Make sure that they are getting the kind of practical support they need to maintain energy and enthusiasm and a good balance in life.
4. The fourth role is to **be a bridge to other relationships** - to act as a guide to community for the person. This means to announce and introduce her to your own friends and members of your family; inviting her and introducing her to the places where you meet your friends (church, community associations, etc.), and inviting other people to enter into personal relationships with her. **Work with people you trust**. Use your power of introduction in the places where you are a valued member. Ask your friends to accept the person, to spend time with her, and to include her in their lives.
5. The fifth role is to **be a source of continuity** for the person. Make sure that among your friends there is always someone who knows the person well, who

* Wetherow, David "Sustaining Roles for the Community Support Circle"

knows what you are doing, and who would be willing to step in and replace you if you become unable to continue in this relationship. Let people know ahead of time that you might ask them to take your place in the future. Again, work with people whom you know and trust. Recognize also that there could come a time when the person's primary caregiver might not be able to continue in the same way, and make sure that there are other people in the person's life who care deeply about him and who would be willing to live with him on the same heartfelt basis.

6. The sixth role is to **let your relationship act as a safeguard** for the person's comfort, dignity and security. It involves developing a strong sense of 'what's right' in the overall direction, style and ambience of her life (ideally using your own life as a point of reference), and regularly reviewing whether or not those elements are in place in her life. Visit often enough to be sure that things really are going well, and openly and collectively reflect on the 'quality' issues on a regular basis. This also involves giving the person some regular opportunities to reflect with you about what she's experiencing.
7. The seventh role will be to **help the person with personal planning, with arranging for and/or providing direct personal supports, and with the management of financial resources.**
8. The eighth role will be to **provide financial and 'program' accountability to the people who are providing financial resources.**
9. The ninth role will be to pay attention to '**renewal**' of the circle of support. This means spending some regular times reflecting on how well the group is dealing with the inevitable tensions that arise in this work, celebrating successes, and honouring each others contributions.
10. The tenth role is to **make sure that the first nine roles stay in order** and in proper relationship to each other, so that the instrumental roles don't completely override the 'affective' roles. Don't spend so much time in the roles of 'stewardship' and 'accountability' that you forget to form community with the person.

All of these roles can (and should) be elaborated by the group and described more thoroughly: What does it mean *in this particular case* to be a 'bridge-builder' to other relationships? What other roles might be needed?"

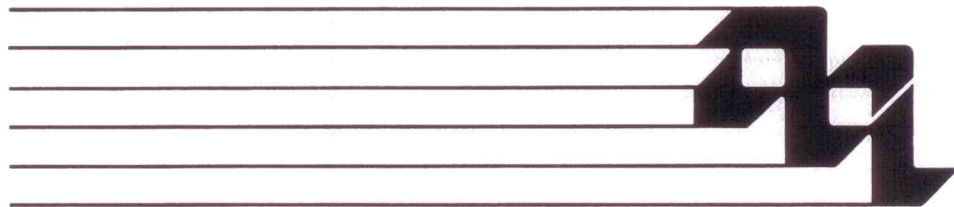
Epilogue

In this book we have turned our attention to people who have traditionally been excluded from enjoying the safety and security of living in "a home of their own." To date, we have done an excellent job of providing individuals with housing, staffing, food, even fine furniture in some cases. We have moved away from separating people in larger settings and developed hundreds of "group homes" for people to move in and out of. Now we must move closer towards supporting people in lifestyles that reflect their own values and the values of their family and friends instead of the agencies that provide the service.

We hope this book raises the questions and issues to think about as you plan for yourself, your son/daughter, your family member or the person who lives within your agency.

The following "workbook style" pages provide a beginning to this planning.

Our association remains committed to assisting you and those working along with you in creating your vision for your home. We hope this book helps you move a step closer to realizing that dream for yourself or someone you care about.



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Questions Regarding Community Participation and Contribution

1. Make a list of what you like to do and have the opportunity to do now. This may include horseback riding, visiting friends, gardening, attending or participating in sporting events, playing cards, bowling, needlepoint, listening to music and anything else you enjoy. _____

2. Make a list of what you like to do but are unable to do now (for any number of reasons). _____

3. Make a list of what you don't like to do or things that really frustrate you.

4. What places in the community do you go to on a daily, weekly, monthly or occasional basis?

Daily _____

Weekly _____

Monthly _____

Occasionally _____

Participation/Contribution Questions Continued

5. Which of these places do you go to alone, with friends, supervised or supported?

Alone _____

With Friends _____

Supervised/Supported _____

6. If you require help to go to a community event or activity, what type of assistance do you require? _____

7. What do other people like about you? What contribution do you make to others? _____

8. What makes it difficult for you to be involved in activities and groups in the community? _____

Setting Goals

1. Is your life significantly different from that of your brothers and sisters or other people of similar age? If so, in what ways? _____

2. Are your desires, goals and hopes for the future significantly different from others of similar age? If so, how? _____

3. What are the gaps between how your life is now and how you think it should be? _____

4. When you think about your future, what do you worry about the most? What problems have you not yet solved? _____

5. What are the goals you have for your life? _____

Setting Goals Continued

6. What are the goals your parents or guardians have for your life?

7. What do you think is required to ensure you have a decent quality of life?
Consider the following areas:

A home and support in the home _____

Employment or something to do during the day _____

Friends and acquaintances with whom to do things _____

Financial security _____

Advocate or someone to speak on your behalf (when needed) _____
