

NATIONAL  
HOME OF YOUR OWN  
ALLIANCE

**Toward a Home of One's Own:  
A Workshop for  
Families on the Journey**

**LEADER'S GUIDE**

April 1995

*Prepared on behalf of:*

National Home of Your Own Alliance  
Institute on Disability University of  
New Hampshire

**by**

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## Alliance Members

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## The Focus Group

In writing this guide, it was essential to consult with people who know what it means to achieve, or let someone you love achieve, a home of one's own. A focus group consisting of parents, adults with disabilities, and professionals from Connecticut and Massachusetts met several times to brainstorm and review the materials. The insights shared by the following people were a major contribution to this guide.

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7

Why Is This Workshop Necessary	5
Introduction	7
Who Should Attend This Workshop	7
How To Use This Guide	7
Accessibility Issues	8
Just Barely Hanging On	8
Who Should Be Involved Behind the Scenes	8
A Word About Words	9
Getting People's Attention	9
Next Steps	10
Definitions	11
Agendas	
Full-Day Agenda	13
Half-Day Agenda	15
Workshop Segments	
Introduction: We've Been There Ourselves	17
Sharing Our Fears: Work Groups	18
Here's What We Found: Work Groups Report Back	18
Maybe It's Not Possible, But Here We Are	18
People And Places That Can Help	19
Supporting Greater Independence And Community Connectedness	20
Handout: Preparing For The Future Today	21
Where Do We Go From Here	23
Resources	25



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# *Why Is This Workshop Necessary*

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There's no doubt about it, people with disabilities are gaining control over their own lives. Legislation such as the Americans with Disabilities Act, innovative ways of arranging support, and higher expectations are making it possible for increasing numbers of people to choose their own lifestyles. More than ever before, people with disabilities are going to work, moving out on their own, and establishing social networks of their own choosing. It is also becoming easier for people who require intensive support to have more typical lives by having their own homes.

Change does not come easily, however; it is often difficult for family members to allow their adult children or siblings to explore the uncertain world beyond their home. It is hard enough for parents to let their non-disabled children venture out on their own; but when they have always been keenly aware of their son's or daughter's vulnerabilities and are concerned about the reliability of support services, it can be even harder. In the same way, adults with disabilities who have always depended on their parents may feel secure in this role and not want more responsibility. They need to build confidence, self-esteem, and assertiveness before they can make the decision to move on.

But what about the vulnerability of people who may not be able to speak, balance a checkbook, or get out of bed without help? If we concentrate too much on independence, we miss the point. Who among us can truly function without the input and support of others? We must develop an interdependent support network consisting of family members, friends, neighbors, and personal assistants. Instead of links in a chain, a vulnerable person needs strands in a net, so that if any strand breaks the whole structure does not collapse.

Gradually the pieces are coming together which will allow every person to exercise his or her right to a life of interdependence and choice. As this happens, families are learning to think in new ways. They are transforming their protection into support, their skepticism into optimism, and their wisdom into a willingness to let their family members make their own decisions.

This workshop is designed to assist in that process.



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# Introduction

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*Toward a Home of One's Own: A Workshop for Families on the journey*<sup>1</sup> was developed by people with disabilities, parents, and members of the National Home of Your Own Alliance. The Alliance, created through a cooperative agreement with the Federal Administration on Developmental Disabilities, is working across the United States to assist people in obtaining homes that they own or control. We are making this workshop available nationally to help ease the transition for families and adults who are in the process of getting out on their own.

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## Who Should Attend This Workshop

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The workshop is designed for parents, siblings, and individuals with disabilities. Examining the interaction between family members and people with disabilities will help everyone see the issues from a number of angles.

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## How to Use This Guide

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The workshop is designed to be led by parents and adults with disabilities. As partners, you will be able to share your own insights with fellow travelers on the same journey. The workshop is intended to challenge conventional notions about who should have his or her own home, and to introduce the participants to new possibilities. With this guide for leaders, we hope that anyone having the time and interest will feel comfortable facilitating the workshop.

Although the guide contains descriptions of five major -workshop segments, there should be an emphasis throughout the day on role models of both parents and people with disabilities. Allow time to share stories, either formally in panels or informally in discussion groups. Many

people say that the most helpful workshops they've ever been to have been the ones in which people told their own stories.

Similarly, networking is very important. You may want to hold the workshop on a Saturday surrounded by a weekend retreat for families or to hold two half-day sessions a week apart, so that families will have time to connect with one another in the afternoon. Sometimes a vital piece of information is discovered while sharing coffee in the hall.

Each segment description consists of a brief summary, a statement of purpose, and suggested topic ideas which can be used by the workshop leader. Two suggested agendas are included, one for a full-day workshop and the other for a half-day workshop. Segments may be omitted or added according to the time available and the needs of the audience.

At the end of the guide is a resource list -which may be distributed to program attendees. A follow-up questionnaire asking -whether people made use of these resources will help facilitators measure the success of the workshop.



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## Accessibility Issues

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Be sure to ask participants ahead of time about accessibility accommodations they will need at the workshop. You may need sign language interpreters, readers, and scribes to write for people. In addition to donuts and Danish at the registration table, you should provide fruit, bagels, hard rolls, or bread products for people who cannot eat sugar. People "will need accessible transportation, and, of course, the workshop site must be accessible. Handouts and other materials should be provided, not only in standard print, but in large print, cassette tape, and computer disk (both IBM and Mac). This guide is also available in alternative formats.

In addition, be aware that you will need to accommodate people during the - workshop segments. For instance, there are several segments in which ideas may be recorded on big paper and hung on the wall. The facilitator should read aloud anything that is written, as there may be people in the audience "who don't read print. Some people may require that things be repeated. People with hearing loss may be particularly sensitive to discussions in which several people are talking at once.

These are only a few examples of the accommodations that may be required. It would be impossible to list them all here. The important thing is to ask the participants to join you in developing creative solutions which "will assure their participation.

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## Just Barely Hanging On

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*"Sometimes it's all we can do just to keep going, never mind working on getting somewhere else."*

— A Parent from Connecticut

It is ironic that the people who may need this workshop the most face the greatest obstacles to getting there. For example, parents of younger children with disabilities are often kept running back and forth between doctors, therapy appointments, and meetings at school. Working parents also need exposure to adults with disabilities and to other parents, but simply may not have the time. Parents whose children present special challenges may not feel able to get away for the day. Workshop organizers need to be sensitive to the concerns of these already-stretched parents.

You can help people participate by holding the workshop on a weekend, by providing respite services, by videotaping the sessions, and by making tapes and handouts available to people who would not otherwise be able to benefit from this experience.

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## Who Should Be Involved Behind the Scenes

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As you prepare for this workshop, look to parent groups, independent living centers, and people involved in the disability rights movement for assistance. Their involvement in planning the workshop and in serving as speakers or facilitators will bring the necessary variety of perspectives. You might also ask the director of an innovative supported living agency in the area to be a presenter.

A Word About Words	Getting People's Attention
<p>Certain assumptions went into the writing of this guide for leaders. These involve concepts about the family, independence, interdependence, risk, and supports. "Independence," particularly, has come to be a controversial word, and it is important that everyone participating in this workshop speak the same language. Likewise, people may not be familiar with some essential terms, such as "personal assistance" and "the disability rights movement.'</p> <p>To clarify these concepts, a page of definitions is included at the start. Leaders may use this page in several ways to set the tone of the workshop. For example, it can be used in planning the workshop to insure that everyone is approaching the issues from a similar direction. It can be included in a packet of ideas and issues, and sent in advance to people who have pre-registered. Another approach would be for each member of the opening panel to choose one term and talk about some experiences which illustrate it. The definition page may also be included in the packet given to all attendees, provided a facilitator walks them through it briefly at the beginning of the day. Otherwise, the definitions probably won't be read until later, and the real meaning of the workshop will be lost.</p>	<p>As you prepare the workshop, keep in mind that most parents have already been inundated with information they consider to be boring and useless.</p> <p>Past workshops may have been ineffective because the speakers were "experts in the field," when the true experts are family members and people with disabilities themselves. Parents may have been given the same bleak reports (or the same rosy unrealistic solutions) that they have heard for years. Too often, the "experts" tend to describe real-life problems in neat, pre-packaged ways, when these problems are, by nature, messy and constantly changing.</p> <p>The information may have been considered not helpful because parents could see no similarity between the examples of the "experts" and their lives, or between the people being described and their own children.</p> <p><i>Do everything you can to show them that this workshop is different!</i></p> <p style="text-align: center;">You have experiences . . .</p> <p style="text-align: right;">You have stories . . .</p> <p>Use them creatively and people will come away energized.</p>



<p>The folio-wing suggestions may make your workshop more interesting and relevant to the audience.</p> <p><i>Use humor.</i> Funny stories, cartoons, and comic strips frequently involve themes of success, failure, risk, relationships, and growth. Disability may play a part in the humor, but many situations are universal.</p> <p><i>Use music and food.</i> Singing and eating are great ice-breakers, and will help people to relax and feel at home.</p> <p><i>Photographs or slides</i> can be used to introduce the audience to people unable to attend the workshop, or to give a glimpse of neighborhoods and relationships you would like them to see.</p> <p><i>Mix presenters</i> so people don't say, "This only works for people -with physical disabilities/mental retardation/who are non-verbal/etc." Issues related to growing up affect people of all ages: children, young adults, middle-aged adults, and people who are elderly. Also include people who need various amounts and types of personal assistance. <i>Information on federal, state, and private non-profit programs</i> can be made available, but beware of long, boring presentations. Tables or packets of material tend to work better. If you want to include speakers, make it personal by asking someone to tell his or her own story. With the person's permission, you may invite the residential provider, job coach, and case manager to explain how they worked together to assist the person in moving into his or her own home, going to work, and joining the neighborhood birdwatching association.</p>	<p><i>Information about the disability rights movement</i> may also be made available. You may want to invite your state's independent living centers to provide information booths.</p> <p>Throughout this workshop, stress that this is a <i>team effort</i> between the parents and adults with disabilities who are facilitating and those who are attending. This is not another case of professionals talking at people.</p> <p>Also stress that growing up and moving away from one's parents (whether physically, emotionally, or financially) is a <i>normal developmental process</i>. Everyone experiences it, and having a disability doesn't change its necessity.</p> <p><i>Remember</i>, that ultimately there is nothing you can do to change the minds of people who are determined to have their lives remain the same.</p>
	<p>Next Steps</p> <p>People may get energized at a workshop, only to become overwhelmed again after it is over. At the end of the day, ask people what follow-up activities they would find useful. You may wish to establish an ongoing support group, with a facilitator who understands the issues. Or, you may compile a list of local parents and people with disabilities -who are -willing to act as resources for people to call for any questions they might have following the workshop. Some after-the-workshop ideas are included later in this guide, followed by a list of publications and videos.</p>





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# efinitions

Independence	The opportunity to exercise the maximum amount of control over one's own life. When support is needed to make this happen, it is provided in a way that respects the autonomy of the person.
Interdependence	A network of relationships that allows us to give and to receive help, makes us part of a community, causes us to grow socially, and enhances our gifts while reducing the significance of our weaknesses.
Risk	No human endeavor is completely free of risk. As adults, we have the right to weigh the options and make our own choices. We assume the responsibility for the consequences of our actions.
Personal Assistance	Support services provided by people who are hired, trained, supervised and, when necessary, fired by a person with a disability. Activities a personal assistant performs may include dressing, transferring, driving, running errands, cooking, and balancing a checkbook.
Disability Rights Movement	An informal network promoting the civil rights of people with disabilities. These include the right to choose where one lives, "works, and plays, and with whom one associates. To secure these rights, it is necessary to fight the discrimination that is still prevalent.



# *Toward A Home of One's Own:*

## *A Workshop for Families on the Journey*

### **FULL-DAY AGENDA**

9:00	Registration
9:30	Introduction: We've Been There Ourselves
10:00	Sharing Our Fears: Work Groups
11:00	Here's What We Found: Work Groups Report Back
11:30	Maybe It's Not Possible, But Here We Are: Presentation and discussion with parents and people with disabilities who have done it. They will address fears they had, how they overcame them, and how they've succeeded.
12:30	Lunch
1:30	People and Places that Can Help: Resources Available in the State
2:30	Supporting Greater Independence and Community Connectedness
3:30	Break
3:45	Where Do We Go from Here
4:30	Adjourn





# ***Forward A Home of One's Own:***

## ***A Workshop for Families on the Journey***

### **HALF-DAY AGENDA**

- |       |  |
|-------|--|
| 9:00  | Registration   |
| 9:30  | Introduction: We've Been There Ourselves   |
| 10:00 | Maybe It's Not Possible, But Here We Are:<br>Presentation and discussion with parents and people with disabilities who have done it. They will address fears they had, how they overcame them, and how they've succeeded |
| 11:15 | Break  |
| 11:30 | Supporting Greater Independence and Community Connectedness  |
| 12:30 | Where Do We Go from Here   |
| 1:00  | Adjourn  |



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# Workshop Segments

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## Introduction:

### We've Been There Ourselves

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Workshop leaders introduce themselves and share briefly about their own experiences in letting go of their adult child with a disability or about leaving their parents home.

**Purpose:** This segment establishes the workshop leaders as peers versus experts. Parents have typically had more expert advice than they can use and may avoid situations that offer more of the same.

Below are ideas which may be used for discussion. Speakers may want to use an overhead projector, slides, or music, or you may even offer a presentation by means of video. The important thing is to offer information and stories which are relevant to your audience. What is relevant may vary according to local conditions and issues. So as you plan this segment, tailor it to the needs of the people in your area.

### **Topic Ideas:**

#### *Moving Out Isn't Easy for Anyone*

1. Most people have a difficult time moving away from home, whether they have a disability or not. Many feel overwhelmed and fear learning "the hard way." Leaders may share how it was when they or their non-disabled siblings or children moved out. Everyone burns food, shrinks clothes, and locks their keys in the house as an example.

2. Obstacles faced by people with disabilities may not be so different from those faced by their non-disabled peers. Finding a place to live, a job, and transportation is challenging for many young people in today's economy, as evidenced by the number of adults without disabilities who have had to return to their parents' homes.

#### *The Double Myth of Readiness*

"But my child isn't ready to move out. There are still so many things she/he cannot do independently." There are two myths behind the idea of readiness.

The first is that there comes a day when someone is fully equipped to take the next big step. If that were true, no one would ever do anything. Is anyone ever really ready... to start college... to move across the country... to get married... to have a baby? Most of us simply take a deep breath, do what we know we must do, and cope with the difficulties as best we can.

The second myth is that a person must achieve total independence before she/he is ready to move out. While it is important for people to master the skills they will need to live on their own, this isn't realistic for everyone. Does it then follow that people shouldn't move out until they have acquired these skills? No, because this would permanently deny the opportunity to anyone who doesn't "measure up." With the right supports, everyone can live in a home of his/her own.

It is frightening to move out knowing one must rely on others for support. But human beings are capable of amazing growth once their capabilities are stretched. Skills people need to participate in the operation and maintenance of their home may well increase once the person is really there.



<b>Sharing Our Fears: Work Groups</b>	
<p>People break up into groups of ten with a facilitator to discuss their concerns about their sons or daughters moving out on their own. Adults with disabilities may also form groups to share their fears about moving into a home of their own.</p> <p><b>Purpose:</b> To give participants a forum in which they can briefly share their concerns and hear that others have similar concerns too.</p> <p>Fears parents have may include - fears about the service system - fears about supports not being there - fears about the competency of their adult child</p> <p>Fears adults have may include - fears about the service system - fears about supports not being there - fear of the unknown - fear of failure</p> <p>One person from each group should be chosen to report back to the larger group.</p>	<p>Ask participants for one word or a few words which describe how it felt to discuss their fears. Be sensitive to the group while making sure the discussion moves along.</p> <p>Ask parents and people with disabilities who have already made the transition to share briefly how they addressed some of the same issues. There won't be time to get into a lot of depth; but people should feel that their concerns are being taken seriously, and they need to hear that problems can be overcome. More answers will be explored in the section entitled, "Maybe It's Not Possible, But Here We Are."</p> <p>Look for common and related themes, and how the fears of parents and people with disabilities compare.</p>
<b>Here's What We Found: Work Groups Report Back</b>	<b>Maybe It's Not Possible, But Here We Are</b>
<p>People reconvene and summarize the comments of the last half hour.</p> <p><b>Purpose:</b> To affirm participants and make their fears more manageable by sharing them with one another.</p> <p>As the issues of each group are summarized, a facilitator records them on big paper on the wall. Take the group's "temperature" by asking for general comments about how people are feeling.</p>	<p>and how they've succeeded.</p> <p><b>Purpose:</b> To establish parents and people with disabilities as role models, and show that creativity, determination, and flexibility are more important than functional level, IQ, or other measurements.</p>

## Guidelines for recruiting speakers

- Limit participation to four people (or teams) on a panel. By the time you get to the fifth and sixth speaker, the audience is no longer listening. You may wish to have more than one panel, but in that case have one in the morning and one in the afternoon.
- Include people with different disabilities and vastly different support needs. Reduce people's tendency to stereotype the speakers as "not like my child."
- Include people of various ages. Your audience may include parents of teens and parents of people in their 50's and 60's.

### Possible Topics

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- What the process of moving out meant to the person and his/her parent
- Creative solutions to problems
- The ability of community members to be there for people

You might consider videotaping this session to share with people who cannot attend, to convince future skeptics, or just to have as a resource.

## People and Places that Can Help

Develop presentations and offer handouts about resources available in the state.

**Purpose:** To increase understanding of the options that are available.

Include independent living centers, People First, grassroots advocacy groups, people already living on their own, innovative service providers, and representatives of state human service agencies. Topics should include both housing options and personal assistance resources.

**Warning:** this segment has the potential to be boring unless handled creatively. Information on programs is important, but don't invite bureaucrats who will simply talk about their services and explain statistics. Instead, make space available for information tables or include materials in participants' conference folders.

If you want to include speakers in this section, have them emphasize real-life examples of how agencies collaborated or staked out new territory to assist people in reaching their goals.



Supporting Greater Independence and Community Connectedness	
<p>Taking control of your own life and/or moving out is a normal part of the developmental process. It is the culmination of many smaller steps taken over a number of years.</p> <p><b>Purpose:</b> To encourage parents and people with disabilities to see the potential for independence, interdependence, and being part of the community as attainable goals, and to give examples of where to begin.</p> <p>Below are some possible topics, which can be presented by an individual speaker, a panel, or in small groups. Again, people may not respond to philosophy, but they will be affected by stories. Keep it personal.</p> <p><i>Messages about the future.</i> Studies have shown that a typical child receives a message about his or her future every</p> <p>you get married you will have to do</p> <p>dishes." or "If you leave your dirty clothes on the floor, you'll never move out/get a job/succeed/marry." But what he or she really means is, "You have a lot of responsibilities ahead. Better start getting ready." Parents are less likely to speak this way to a child with a disability. Therefore, the expectation of a job, home, or relationship may be lacking, along -with the knowledge that it is important to do dishes and pick up clothes. Explore ways that participants can create more future-oriented messages for themselves and others.</p> <p><i>Transitions never stop .</i> First, people are dealing with the big changes that come from having a job. Then they are moving away from home and learning to adjust to life on their own. Next, they</p>	<p>may form a significant relationship and learn how to deal with all the complexities intimacy brings. All these transitions, and many others, form the pattern that makes up LIFE.</p> <p><i>Trying it on for size.</i> Sometimes you don't know what it's like until you get there. People with disabilities, like other people, may need to try out different living situations before they can choose the one that's right for them. People also change their minds about what they want. Discuss the paths people have traveled to arrive at their present situations.</p> <p><i>Community Connectedness.</i> Being connected to one's community occurs when people are present and participate. Bring examples of people being included in schools, neighborhoods, jobs, and associations. Often one opportunity for community participation creates more opportunities, as school leads to 'work, and moving into a neighborhood leads to involvement in local groups.</p>
	<p><b>Handout</b></p> <p>On the next page is a list of things parents can do to promote their child's independence. There are no "right" or "wrong" answers, and no method of scoring is provided. The exercise is included to help parents evaluate their perception of their child's future, and to look at growth as something that can be encouraged or thwarted.</p> <p>The handout is designed both for parents of young children and for parents of adults. You may want to make it available at the end of this segment as a follow-up activity, or to structure some time to work on it together in a group.</p>



## ***Preparing for the Future Today***

No one learns to let go in one day, or even in one year. The gradual process begins in small ways in childhood, as youngsters form relationships with other kids, go to school, pajama parties, and summer camp. When people with disabilities have not had these experiences, the risks seem much greater as they arrive at adulthood.

Below are two lists of statements. Parents of children and teens should answer only the first series, and parents of adults should answer both. Not all questions apply in all situations; and in the case of children, parents of 8-year-olds will answer differently from parents of 13-year-olds.

This exercise is not designed to give you a score at the end. It is intended to help you think about the experiences and social networks which are a natural part of growing up, and how these areas might be enhanced in your child's life.

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### **PAR 1 - For All**

- |     |     |    |  |
|-----|-----|----|--|
| 1.  | Yes | No | My son/daughter has friends, plays (or played) with other kids               |
| 2.  | Yes | No | My son/daughter has been to camp   |
| 3.  | Yes | No | My son/daughter has slept over at a friend's house                           |
| 4.  | Yes | No | My son/daughter has been left with a babysitter or relative while I was out  |
| 5.  | Yes | No | I have left my son/daughter alone for 10 minutes                             |
| 6.  | Yes | No | I have left my son/daughter alone for 1 hour                                 |
| 7.  | Yes | No | I have left my son/daughter alone for 3 hours                                |
| 8.  | Yes | No | My son/daughter does his/her own thing independent of me                     |
| 9.  | Yes | No | My son/daughter develops his/her own schedule to the best of his/her ability |
| 10. |     | No | I encourage my son/daughter to expand his/her interests beyond my own        |
|     | Yes |    | I encourage my son/daughter to select his/her own TV programs                |
|     |     |    | I encourage my son/daughter to try different music                           |
| 11. | Yes | No | I encourage my son/daughter to eat a variety of foods                        |
| 12. | Yes | No | My son/daughter chooses his/her own social and recreational activities       |
| 13. | Yes | No | My son/daughter shops with someone other than me                             |
| 14. | Yes | No | My son/daughter completes simple daily choices                               |
| 15. | Yes | No | My son/daughter asks his/her own questions in all situations                 |
| 16. | Yes | No |  |
| 17. | Yes | No |  |





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**PART 2 - For Parents of Adults**

18. Yes No Yes My son/daughter has his/her own bank account My
19. No Yes No son/daughter chooses his/her own friends
20. My son/daughter has received assistance from someone  
other than me: a personal assistant, home health aide, traveling
21. Yes No companion, etc.
22. Yes No
23. Yes No My son/daughter knows how to use the stove
24. Yes No My son/daughter knows how to call 911 in an emergency
25. Yes No My son/daughter has friends who will give him/her  
support and advice
26. Yes No My son/daughter gives support and advice to his/her friends I
27. Yes No have left my son/daughter alone overnight My son/daughter  
attends meetings with someone other than me My son/daughter  
has input and control over medical decisions

## Where Do We Go From Here

Some of the following resources may already exist in your community. If they don't, you may want to create them. Make a list of how, when, and where people can access resources in the community.

### *Peer Support/Support Groups*

- Your local independent living center may offer a peer support program, where people dealing with an issue are paired up "with people who have been there"
- Support group for adults with disabilities
- Support group for parents
- Support group of adults and parents together

### *Information/Planning/ Brainstorming*

- Transition plans for both parent and adult child
- A place for parents to hear from other parents and learn about alternatives
- An opportunity for young children to hear from adult role models who have made the transition
- Video of a day in the life of an adult living successfully on his/her own
- Video of a panel of parents and adults with disabilities sharing their stories
- Disability column in "typical" parenting magazine
- Transition column in magazine about parenting children with disabilities
- Series of booklets about all the things to think about while preparing to move out
- Study of how prepared average high school students are to deal with moving out compared with students who have disabilities



In developing this guide for leaders, we contacted our friends and colleagues around the country and asked them to suggest materials which might be helpful. People not only sent us their recommendations, but many sent descriptions of materials they had read. We appreciate their input and their enthusiasm for our project.

Still, it is important to stress that this list is not complete. There are many good resources available, and we do not claim to have found them all. We have done our best to catalog what seemed to be the most relevant information and hope you will find it useful.

Some of the resources that follow may be obtained through your local library. Others, however, may be more challenging to locate. Wherever possible, we have included the addresses and phone numbers of the publishers. The Alliance has recently developed an InfoPak - (lists of resources) around housing - it may be ordered by contacting the Alliance at the phone number and address listed below.

Many of the books are published by Paul H. Brookes, and may be obtained by contacting:

Paul H. Brookes Publishing Co.  
Post Office Box 10624 Baltimore,  
MD 21285-0624 800-638-3775

For information or a publications list from the National Home of Your Own Alliance contact:

National Home of Your Own Alliance  
c/o The Center for Universal Design  
North Carolina State University  
School of Design  
Box 8613  
Raleigh, NC 27695-8613

Toll Free Information Line:  
800-220-8770



## Expanding Choices

Gershe, Leonard (1969). *Butterflies Are Free*, New York: Random House.

This classic play deals humorously with the attempt of a young man to establish a home of his own. Blind since birth, Don struggles to find an identity independent of his overbearing mother. In the process, he and the girl next door teach one another some important lessons about ability, disability, freedom, commitment, and trust. Enjoyable reading punctuated by moments of profound wisdom.

*This book is out of print and may be difficult to find at the local library, but you can probably obtain it through inter-library loan.*

Moore, C. (1993). Letting Go, Moving On. In J. Racino, Walker P., O'Connor, S., & Taylor, S., *Housing, Support and Community: Choices and Strategies for Adults with Disabilities*. Baltimore, MD: Paul H. Brookes.

A powerful chapter written by Cory Moore, one of this nation's leaders in instilling compassion in human services, on her experiences with her daughter Leslie. Cory died in 1993, but left us with the message that "feelings and history cannot be discounted." She paints a vivid picture about the dilemmas one parent experienced in supporting her daughter to live in her own home with people of her choice.

Pendler, Betty (1977). *Children Learn*

*While Parents Squirm*, The Exceptional Parent, February 1977, p. T10.

A parent tells the story of how she taught her daughter to travel independently on the subways of New York City. She shares not only the experiences in the subway, but her own inner conflict between keeping her daughter "safe" and allowing her to grow into a capable young adult.

Pendler, Betty (1979). *My Daughter Is Leaving Home. What Do I Do Now?* The Exceptional Parent, June 1979, p. D14.

Reflections on the importance of moving out and preparing young people with disabilities to take this step. A parent shares the process she experienced with her daughter, as well as her own ambivalence about letting her go out on her own.

Summers, Jean Ann, B.G.S. (1986). *The Right to Grow Up: An Introduction to Adults with Developmental Disabilities*. Baltimore, MD: Paul H. Brookes.

This thoughtful book provides a sensitive appraisal of the changing emotional and physical needs of maturing young adults with developmental disabilities. The information provides consistent strategies that give people the opportunity to choose how they live.

## Natural Supports and Community

Nisbet, J. (1992). *Natural Supports in*

*School, at Work and in the Community for People with Severe Disabilities.*

Baltimore, MD: Paul H. Brookes.

This work supports the position that assistance must be defined by the needs of individuals rather than the requirements of service systems. It combines thoughtful research and provocative first-person accounts to illustrate how natural supports work. Included is a chapter by Jay Klein titled, "Get Me the Hell Out of Here," which discusses natural supports for people living in their own homes.

Racino, J., "walker, P., O'Connor, S., &

Taylor, S. (1993). *Housing, Support, and Community: Choices and Strategies for Adults with Disabilities.* Baltimore, MD: Paul H. Brookes.

From the cover: "New options are emerging for adults to live in their own homes — no matter what their level of ability. [In this book], chapters explore supportive living efforts on the local, state, and federal levels . . . reveal the powerful personal perspectives of people involved in different aspects of housing and support . . . and examine case studies of organizations following new principles of assisting people with disabilities in community life.'

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Taylor, Steven J., Bogdan, R., and Racino J.

(1991) *Life in the Community: Case Studies of Organizations Supporting People with Disabilities.* Baltimore, MD: Paul H. Brookes.

From the cover: "Comprehensive case studies organized around three themes — families and their children; housing, homes, and support for adults with disabilities; and the role of community and society in integration — provide the reader with practical ideas, applications, and strategies to promote successful community integration for people of all abilities."

Wetherow, David & Communitas (1992).

*The Whole Community Catalogue:*

*Welcoming People with Disabilities into the Heart of Community Life.* Winnipeg: Gunnars & Campbell.

A source book for enriching the communities, neighborhoods, schools, workplaces, associations and families through full participation and inclusion of people who have disabilities. A collection of essential articles, ideas, reviews and connections. Includes resources on relationships, education, vocations, training, networks, periodicals, catalogues and housing.

*To order, send \$15plus \$2 shipping and handling to Communitas, Inc., 730 Main Street, Manchester, CT 06040. For more information, call 860-645-6976.*



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## Supported Living

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Davis, Linda (1995). *A Guide to Supported Living in Florida*. Tallahassee, FL: The Supported Living Project.

This book includes sections on the characteristics of supported living, establishing a real home, supporting choice and responsibility, and support services.

*To order, contact the Florida Developmental Disabilities Council, 124 Marriott Drive, Suite 203, Tallahassee, FL 32301-2981. For more information, call 1-800-580-7801.*

Allen, Shea and Associates and Forrest, C. (1993). *Patterns of Supported Living: A Resource Catalogue*. Napa, CA: Allen, Shea and Associates and Forrest, C.

A resource catalog developed for use by the California Department of Developmental Services by a technical assistance working group. Includes values and definitions, patterns of services, community resources, community employment, stories of people's lives, and other resources such as community building.

*To order, contact 1040 Main Street, Suite 200 B, Napa, CA 94559- For more information, call 707-258-1326 (voice) or 707-258-8354 (fax).*

Smith, Gary A. (1990). *Supported Living: New Directions in Services to People with Developmental Disabilities*. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.

From the preface: "The excitement of supported living is that it affirms, not compromises, our beliefs in the values of integration and independence. Supported living makes 'community presence and participation' a reality, not a vague goal for people with disabilities. . . . [This report is intended to assist policymakers, people with disabilities, and their families] to better understand supported living services, particularly in addressing the practical issues involved in implementing and managing this 'new way of doing business.'"

Included in this report are chapters comparing supported living programs in ten states, lessons learned, funding, federal policy, and possibilities for the future. Part of NASMRPD's *Community Management Initiative* series.

*To order, contact the National Association of State Directors of Developmental Services, Inc., 113 Oronoco Street, Alexandria, VA 22314. For more information, call 703-283-4202.*

(1993) *"Supported Community Living"*

O'Brien, J. & O'Brien, C. (1992).

*Remembering the Soul of Our Work.*  
Madison, WI: Options in  
Community Living.

A book of stories composed by staff members of Options in Community Living, a leading supported living agency, as a means of building community and "communicating qualities of thought and action that make their work distinctive and meaningful." These stories are a powerful description of what it takes to "walk with people in the community."

*To order, contact Options in Community Living, 1954 East Washington Street, Madison, WI 53704. The book is \$15, which includes shipping, but payment must accompany the order (no purchase orders or charge accounts). For more information, contact Options at 608-249-1585.*

*Midland at 517-631-4430*



## Changing Systems

Castellani, P., Bird, W., & Manning, B.

(1993). *Supporting Individuals with Developmental Disabilities in the Community*. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities.

Worthwhile for people involved in systems change, this is a New York State research report regarding making individualized services and supports more available and accessible to people with developmental disabilities. The report includes recognition of the challenges faced in states such as the "major discontinuities" between current management structures and the flexible, changing and decentralized characteristics of an individualized support and services approach.

*This report is available free of charge from the Office of Mental Retardation and Developmental Disabilities; Division of Policy, Planning and Service Design; 44 Holland Avenue, Albany, NY 12229, Attn Paul F. Castellani, Ph.D. For more information, contact the Office at 518-473-9689.*

New York State Developmental

Disabilities Planning Council. (1992). *How to make your voices count: Influencing people who are important to your cause*. Albany, NY: Partners in Policymaking Training Project.

This handbook was designed to accompany the NYS Partners in Policymaking Project which educates parents and people with disabilities about state-of-the-art community practices and helps to build leadership and coalition capacities in the area of traumatic brain injury. The work is important because it introduces a critical component in the development of person-responsive systems for people who have sustained a traumatic brain injury.

*The handbook is available free of charge from the Developmental Disabilities Planning Council, 155 Washington Avenue, 2nd Floor, Albany, NY 12210, To order by phone, call 518-432-8233.*



*Discipline*. New York: Doubleday/Currency.

The author is Director of the Systems Thinking and Organizational Learning Program at MIT's Sloan School of Management. He has shared his philosophy of building "learning organizations" with the managers of many large corporations. The book describes the method this way: "Not only is the learning organization a new source of competitive advantage, it also offers a marvelously empowering approach to work, one which promises that, as Archimedes put it, *with a lever long enough . . . single-handed I can move the world.*"

Smith, G. & Gettings, R. (1993).

*Medicaid-Funded Home and Community-based Waiver Services for People with Developmental Disabilities*. Alexandria, VA: National Association of State Mental Retardation Program Directors.

An excellent source of the status of state and federal policy and financing developments, this is a useful update on the home and community-based Medicaid waiver (a primary source of funding for "supported living"). The report, primarily useful for practitioners, administrators, and policymakers, urges that "there should be less discussion of assessment strategies, managed care, and 'care coordination' and more regarding the fundamental changes in public policy that will promote community membership and support people with severe disabilities to live their desired lifestyles."

*To order, contact the National Association of State Directors of Developmental Services, Inc., 113 Oronoco Street, Alexandria, VA 22314. For more information, call 703-283-4202.*

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## People with Disabilities as Parents

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Supported Parenting Project (1990-92).  
*Issues in Supported Parenting.*  
Madison, WI: Wisconsin Council on  
Developmental Disabilities.

Of the practical resources available,  
this is among the best because of its  
positive stance toward parents and its  
willingness to deal with challenging  
issues. Included are pieces on public  
policy around supported parenting,  
discovering the parent's language of  
learning, the children's code, helping  
parents parent, and cultivating  
competence.

*To order, contact the Wisconsin  
Council on Developmental  
Disabilities, 722 Williamson Street,  
Second Floor, P.O. Box 7851,  
Madison, WI 53707-7851, or call  
608-266-7826.*

Peter, D. (1991). "We Began To Listen." In  
S. Taylor, Bogdan, R., & Racino, J., *Life  
In the Community: Case Studies of  
Organizations Supporting People With  
Disabilities In the Community.*  
Baltimore, MD: Paul H. Brookes.

A qualitative research case study of an  
organization that includes in its  
mission supporting parents to  
maintain their children at home. This  
California agency assists parents in  
advocating for their rights, hosts  
parent support groups, and provides  
in-home instruction and support in  
parenting skills.

