

# *Building a Future*

## *Third Edition*

*Strategies on supported housing for adults with intellectual and developmental disabilities*



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## *A Handbook for Families, Third Edition*

*Strategies on supported housing for adults with intellectual and developmental disabilities*

### *The Arc of Massachusetts*

*Edited by Leo V. Sarkissian*

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#### *The mission of The Arc of Massachusetts*

Enhance the lives of individuals with intellectual and developmental disabilities and their families.  
We accomplish this through advocacy of supports and services based in the community.

#### *Mission of the Massachusetts Developmental Disabilities Council*

Provide opportunities for people with developmental disabilities and their families to enhance independence, productivity, and inclusion.

# Acknowledgements

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*Several individuals participated in the editing and preparation of the third edition including John Thomas, Lucie Chansky, Laurie Maranian, Liz Fancher, Cynthia Levine, George Smith, Pat Pakos, Linda Cournoyer, and Carol Daly.*

*We have included the acknowledgements from previous editions. The written work drew on a number of publications, and we have noted any section authors and those who contributed through feedback on drafts of this book. We celebrate the individuals and families who have developed new options for community living in the past decade.*

*Leo V. Sarkissian*

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*What follows are notes from previous editions that are still relevant to this edition.*

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## Notes

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### II. Public and private funding options

1. Further information regarding public support can be obtained by visiting [www.mass.gov](http://www.mass.gov) and selecting options for benefits (MassHealth, Dept. of Mental Retardation, Massachusetts Rehabilitation Commission, etc.). For more on DMR service plans and/or service options, contact a local area office, which can be obtained through the same website or write to: Office of Communications, Department of Mental Retardation, 500 Harrison Ave., Boston, MA 02118.
2. The discussion in "What about family participation" quotes some sections from an article written by Ruth I. Freedman and Donald N. Freedman, "Planning for Now and the Future: Social, Legal, and Financial Concerns," (pp. 167 - 184) in M.M. Seltzer, M.W. Krauss, & M.P. Janicki (Eds.), *Life Course Perspectives on Adulthood and Old Age*. Washington DC: American Association on Mental Retardation, 1994
3. Issues around siblings and parents keeping siblings at a distance in regard to future planning have been written about by Marty Krauss, Ph.D., Heller School at Brandeis University, and also shared in an interview in the *Arc Massachusetts Advocate*, 1996.
4. Statistics regarding sibling interest in supporting siblings with disabilities was cited by Alan Factor, Univ. of Illinois, Chicago, presentation at The Arc, Salt Lake City, Utah, 1997.
5. Most of this material is reprinted from The Arc Q&A, "Friendship between people with and without disabilities." The Arc, a national organization on mental retardation, 1998. Rick Berkobien et al.

### III. Assessments and Agencies

6. Involving the family member with the disability in decision-making is highlighted in "Planning for Now and the Future," by Ruth I. Freedman, Ph.D. and Donald N. Freedman, JD, p. 173; see #3 above.
7. Talking about the process of establishing a home is adapted from "Housing, Residential Supports and Home Ownership" article for Arc resource guide, Catherine White, 1996.
8. Self-determination was emphasized by Tom Anzer, DMR Human Rights Office, who provided some information regarding human rights.
9. In "Why are assessments important?" we reference, Turnbull III, H. Rutherford et al., "Disability and the Family," Brooks Publishing, Maryland, 1989.

10. "How can I get help with medical and behavioral needs?" was written by Dr. Marc Emmerich, Adria Hodas, RN.C and Janet Roxborough, RN.C.

11. "How to arrange for professional assessments?" cited the following publication: "Whole Life Planning: A guide for organizers and facilitators," John Butterworth, David Hagner et al, Institute for Community Inclusion, a university affiliated program.1993. (617) 355-6506.

### IV. The dream as reality.

12. Bertha Young at the Dept. of Mental Retardation shared the concepts and new definitions to be used by DMR effective in fiscal year 2000. "In-Home" partnerships, an option of the Boulet Settlement (waiting list settlement in federal court which included 2,225 persons in need of residential services), does not formally exist as a "DMR" service category in 2006. However, there are DMR supported arrangements which exist where funding is provided to the family to support the independence of individuals in the community.
13. "Designing flexible supports" was adapted from "Housing Residential Supports and Home Ownership," Catherine White, see note #7.
14. Dafna Krouk-Gordon, TILL Inc., provided material for a large part of "Working on your housing alternative" including "Budget Considerations" through a written communication in 1998.

### V. Housing: Renting or Buying?

15. Lisa Sloane, housing consultant to state and private agencies contributed significant rewriting and editorial assistance. Parts of this section were adapted from an existing article by Theresa Varnet, "Home control through trust and estate planning," 8/96- Other specific options were discussed in "Housing Residential Supports and Home Ownership," by Catherine White, see #8.

### VI. Private side of partnership

16. "Financial Planning" was excerpted and adapted from "A financial and estate planning guide for independent living" by Cynthia R. Haddad, CFP and John W. Nadworny, CFP, ChFC, Bay Financial Associates, Waltham, MA. 1998.
17. Discussion on "Special needs trusts" was reprinted from Theresa Varnet, JD "Special Needs Trust Helps Ensure Support, Care," 1996.
18. "Legal planning" from Theresa Varnet, JD "Guardianship and alternatives to guardianship in Massachusetts," 1996.

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# I. Introduction

The search for supports for individuals seeking a full life in the community can be a daunting task. One of the most difficult tasks may be moving into one's first apartment or home. It is especially difficult if a person's disability requires ongoing support services from paid staff. There are many questions:

- Where do I begin? Do I wait for a public program or do I begin planning on my own?
- Can we go ahead without being sure of what type of assistance we will receive?
- Do we have enough money to pay for the support services if public funds are not available?
- How should we plan so we can identify or choose the housing that is consistent with our needs and desires?
- How do we ensure that the long-term plans worked out with the rest of the family are adhered to?
- What is fair for us and the rest of the members of our family?

This handbook is intended for people with disabilities and families that are grappling with such questions. It also provides a helpful overview on other resources necessary for a successful life in the community, such as health care, employment, transportation. All of these areas of need are addressed in the pages that follow, with data and contact information that was current at the date of publication.

In addition to providing an updated guide to resources, The Arc of Massachusetts and the Massachusetts Developmental Disabilities Council have developed a survey that is being used to generate data on the level of need for individuals seeking new services. The data will be shared with the Governor and members of the Legislature for their consideration in determining funding and policies affecting our community. An interactive version is available online at [www.arcmass.org](http://www.arcmass.org) or you may request to take the survey by telephone or ask that a copy be mailed by U.S. post at (781) 891-6270.

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## **We have written the handbook from a parent or family member perspective.**

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**I**n writing this handbook we presume that the individual in search of housing has some level of intellectual disability. We have written the handbook from a “parent or family” perspective because in many instances the family is involved in the search for services or supports. This handbook will assist:

- individuals with disabilities who are planning their own future independently
- families and individuals who are planning and will not use additional public resources.

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## **This isn't new.**

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Over the last twenty years we have witnessed many families secure housing for a son or daughter who has a disabling condition. These pioneers have identified some steps that have worked. There are agencies, public and private, which hold much information. We can benefit from all of their efforts. We have also adapted resources that will make the journey an easier one.

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## **A. How do I use this handbook?**

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There are four areas that are important to address:

- the practical steps to aid in the search for housing and other supports
- the human services network which most individuals and families need to access
- the social network made up of family, friends and community activities
- long-term planning issues which affect the entire family.

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## **Each of these areas will be addressed in this handbook.**

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Since most families will have to work with the human services network, understanding how “human services” work is critical—whether you’re seeking Social Security benefits, the right medical specialist, or a reliable job coach for a family member.

- An appendix describes four different types of housing partnerships.
- Some discussion of the social network and long term planning helps the reader think about the big picture.
- Talk to other people who have walked this road. You will find that they are interested in sharing their stories.
- As you move further ahead, utilize the expertise of professionals.

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## B. Is there a Waiting List for services?

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It is difficult to identify a waiting list for services as entry points to obtain services differ. For example, families of children who need family support services will apply at a local office of DMR while their health care needs require an application to MassHealth, CommonHealth or through specific Department of Public Health programs. Adults also may be eligible for services from the Massachusetts Rehabilitation Commission (MRC) or the MassHealth Day Habilitation State Program. It is difficult to identify waiting lists as there is no central intake registry.

We do know from the five-year Boulet Settlement (2001) which included services to 2437 individuals, that DMR had a waiting list for residential services and day or employment services. The Boulet settlement provided services to a total of 2,437 individuals. We are unclear how large that list is at the present moment. Anecdotally we are informed that there are limited employment training and support options available for consumers. We also know that the number of students graduating special education (“Turning 22”) who are in need of adult disability supports from DMR has grown from 440 to 580 individuals in the past several years. In July 2007, the Legislature, over a gubernatorial veto, appropriated an additional \$4 million dollars (\$17.6 million total) for a full year to address this increased need.

As this handbook goes to print, the Commonwealth is under no further commitment to provide significant funding to serve people on waiting lists and those entering the system. Federal law provides some provisions to help advocates in their efforts to encourage further funding. However the ability to obtain increased supports for those waiting for services will be directly related to the effectiveness of advocacy for long term care support services in this state.

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## C. What agencies will continue to advocate for new services?

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A broad-based coalition that includes family-related and self-advocate groups has worked to secure new resources and funding. Some of these groups include:

- *The Arc of Massachusetts*
- *Massachusetts Developmental Disabilities Council*
- *Massachusetts Families Organizing for Change*
- *Massachusetts Advocates Standing Strong*

These groups have strengthened the capacity of people with developmental disabilities and parent groups to work with state agencies and the Legislature.



## *II. What are the Public and Private Funding Options?*

Public funding for services from state agencies in Massachusetts, including DMR and others, has not kept pace with need. In addition, approximately 13,000 people receive some type of housing or individual support funded by the DMR. People who are not deemed eligible for services through DMR have much more limited options. Most of the services provided by public funds are delivered through private contracted vendors dispersed across the Commonwealth. As we explain, none of this funding is automatic. It requires the involvement of individuals with disabilities, family members and friends. Even after you receive funding, ongoing advocacy is needed to insure that as expenses rise, increases in support are allocated. Whether you call such funding a “cost of living” increase or “support-staff increases” it’s important for you to know that expenses in the “world of human services” rise as anywhere else and without advocacy, funds are not forthcoming.

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## A. How does funding become available?

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The most direct funding for services for individuals with intellectual disabilities is from DMR. Every year the governor, the house of representatives and the state senate agree on a budget. This budget determines how much new money will be available for services. A second way services are established is through an opening at an existing house or apartment when a resident moves to independent living, moves to a less independent setting, or dies. If new public funds are not appropriated through our state legislature and agreed to by the governor, access to new services will be extremely limited.

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## B. What is our role in obtaining public funding?

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Your active role as a citizen in the political process is necessary to obtain public funding. Contacting your state senator, representative and governor's office is essential. Not only can you help in assuring that funding is established but you can help achieve a higher budget for services for increases in salaries or for supports to those who still need to wait.

*There is a direct relationship between legislative advocacy and the appropriation of new funds.*

Funding for services requires constituents to say they are necessary, so legislators will hear about their importance. You can participate in legislative advocacy simply by being informed of the funding requests that are being made and sharing your support with your state representative and senator.

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## C. The Department of Mental Retardation (DMR)

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The Department of Mental Retardation (DMR) is the primary state agency identified for adults with a diagnosis of mental retardation. A new Division of Autism was created in 2005, but funding and services through this program are limited mainly to education and outreach at this time. People with other types of developmental disabilities may find services through other state agencies such as the Massachusetts Rehabilitation Commission (MRC), although for many who are deemed NOT eligible for DMR, funding and services are sparse. Families with children (under age 18 years) with a diagnosis of mental retardation and developmental disabilities are eligible for Family Support Services. In the case of children under the age of 22 years, the school district is regarded as the primary provider of service through Chapter 766, the special education law (a state law). It is critical to make sure that your family member is enrolled with the local DMR area office. The DMR toll-free telephone number is (888) 367-4435. DMR local offices are also listed on the web at [www.mass.gov/dmr](http://www.mass.gov/dmr). You should receive a letter of determination at the end of the eligibility process. If you apply for services and are not deemed eligible, you have the right to appeal. If you need help, contact one of the legal services organizations listed in the handbook at the end of Chapter VII.

### *What is the role of a DMR Service Coordinator?*

Each DMR area has a certain number of service coordinators or case managers assigned to the office. Each coordinator has a caseload. Their primary obligation is to review the ongoing services of individuals in work or residential programs. As a result, people waiting for

services may not have the availability of a service coordinator to the extent that they would like since they have not yet had access to these services and programs.

### *What are Home and Community Based Waiver Services?*

Home and community services through public funding have been available in limited form throughout Massachusetts since the 1970s. In 1980, Massachusetts applied for a Federal Waiver so that it could receive federal funds to reimburse the state partially for community services. Waiver services are flexible and may include family support or staff support in a range of employment and residential services. Individuals are listed through identification numbers on the waiver so that the state can receive reimbursement. The state can expand the waiver by adding individuals, but when it does, it makes a commitment to provide all the waiver services that an individual is determined to need. At the present time, Massachusetts must fund 50% of the cost of waiver services. This means advocacy is still required to expand the number of individuals who can receive waiver services.

Individuals can also receive home or community services through the Medicaid State Plan. This funding is not based on the DMR budget and it is an entitlement. If an individual is eligible for the service, he or she can receive it regardless of funding through the MassHealth Budget. However, consumers sometimes face other barriers for these services:

- Finding qualified service providers or clinicians (if it's a medical service)
- Waiting long periods through the application process
- Receiving redeterminations of their eligible hours on an annual basis and having to appeal such reviews.

The Personal Care Attendant (PCA) Program, home health services and day habilitation are examples of state plan services. In addition, individuals may apply for employment services through the vocational rehabilitation program of MRC.

The handbook lists the way to apply for these services under "Resources."

### *What are family support programs?*

DMR contracts with providers to develop family support services. Examples of such services include respite care, information-referral, vouchers, transportation, and after-school programs. If you are waiting for residential services, family support can be an essential alternative to help the individual and family. You can ask for this assistance from your area office. If you don't have a service coordinator, you can request to speak to a supervisor of service coordinators in your particular area office. Your local Arc also should be able to assist you in exploring alternatives. They are listed in the back of the handbook. DMR staff can assist you to identify other public resources that may be available, such as vocational or work support services that are provided through the Massachusetts Rehabilitation Commission (MRC) as well as through DMR. Other state agencies and specific services that are available and their respective phone numbers are listed in the Housing and Other Resources sections. Each state agency has its own rules for eligibility for their services.

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### **D. How do I find out about our status at DMR?**

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The DMR area office maintains DMR client status, use of the Individual Support Plan (ISP), and the appeal of DMR decisions. *Keep in mind that the process at DMR can be revised at any time through regulation and procedure changes.*

**After being determined “eligible” for services,** you need to request the development of an ISP if you are interested in further services. Many readers will have an ISP in place which documents the services to be provided.

Work and Day Supports as well as some Family Support are expected to be provided to those Turning 22. The goal of such funding is to help individuals get the adult support they need within the context of the family home as long as possible.

*Remember: although you may follow the steps outlined here, you may not be able to receive funding.*

## *Individual Support Plans*

DMR identifies the ISP as “the foundation for the development of supports and services.” The ISP identifies desired plans and goals as well as necessary services. Families are an important part of this process and their participation is critical.

### *Who’s eligible for a plan?*

Individuals will receive an ISP automatically if they receive residential, day or employment supports provided or purchased by DMR, or if they receive day habilitation services and have been referred for such services by DMR. Other individuals can receive an ISP if they request one, as long as they are receiving services through another state agency. Others who are eligible for DMR services may request an ISP, but the area director must determine if the individual would benefit from it. The ISP does not automatically result in services but does involve DMR as a partner in your situation.

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## **E. You have the right to appeal.**

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If DMR cannot provide the services you seek, or if you disagree with the ISP, you have the right to appeal. You can appeal the substance;

for example, the residential supports identified (supported living vs. staffed apartment) or the timeline offered, or both. Does the ISP identify housing or residential and/or any other service that is needed? If the ISP does not identify services that are needed, call the DMR area office and request an immediate ISP modification or appeal. Any documentation that you sign approving services or related to the ISP should include an asterisk (\*) that you initial, with a statement that indicates you are waiting for a service for yourself or a family member. Involve your family member in this process as much as possible.

Before your appeal deadline is up (usually 30 days from a decision, meeting or report), contact the director of your DMR area office. In some cases there may be misunderstandings or simple corrections.

- 1.** The first level of appeal should be to the regional office. These offices are located across the state and the area office staff or letter should inform you where to direct the appeal letter.
- 2.** If you lose the appeal at the regional level, you can ask for a “fair hearing” or administrative appeal. The commissioner designates a hearing officer to review the case.
- 3.** The final step of the appeal is the Superior Court of Massachusetts. You would need an attorney at this stage of the process.

### *What do we do when we receive funding?*

Although we hope individuals will have plenty of notice to plan, there is a likelihood that an opportunity for new services may become available within the DMR area in which you live. In such cases, you may be asked whether you would like to begin receiving services. This is why you should be doing some exploring regardless of your status. If you receive a call it’s due to one of the reasons we’ve noted:

- The Massachusetts Legislature appropriated new monies for Turning 22, transportation, vocational or other state-funded programs.
- A change in the status of someone in a house provides an “opening” in an existing residential option.
- You have been working on a plan with others using a combination of program options, and DMR has identified some available funds to complete the plan.
- You received funding through Turning 22 for day/work and family support services.

Most funding from DMR is distributed to provider agencies on behalf of the individuals being served through “contracts.” This is similar to contracts that are used when people hire builders or other business representatives. In the future, it is expected that families and individuals will have more control over the funding allocations received. At the present time, you can request that DMR work with you to develop a consumer directed RFR (CD-RFR) instead of a contract, which may cover the provision of housing for people as a group. The advantage of that approach is that you can better tailor the service to the needs of the individual. This proposal can then be reviewed by a number of agencies. You will want to get two agencies to review it at a draft stage to see if you are being realistic with the dollars projected and services requested.

The other option the individual will have is moving into an existing service funded by the Department. Although most homes are staffed by agencies that contract with DMR, there are some that are staffed by state employees. In each of those cases the individual will be entering an existing home as a new housemate. The recommendations in a following section entitled “Which agency to choose” may be applicable. Also review Chapter VIII, “Specific Housing and Partnership Models.”

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## F. What about family participation?

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Families that plan have better chances of being served than those who don’t plan. In addition, utilizing family resources increases the level of control over a plan. The lack of planning can cause many complications:

- confusion for the individual or family about future living arrangements
- lack of financial preparation— for example, the loss of assets such as money gained from selling a house that is in the name of someone who receives public benefits
- no agency or support system being aware of potential service needs.

What is fair when a family utilizes its resources on behalf of an adult child? Should that family or individual be treated differently than families who don’t have personal resources or choose not to use them? What should you expect to put aside for your family member? This is a personal decision that depends upon a number of factors, including financial capacity. For many families, their biggest investment is their family home. They choose to utilize part or all of it in a family trust. Others may consider certain types of insurance policies as a way to fund a partnership.

One reason to participate in a partnership is that the shared vision for the individual with a disability may have aspects that will never be funded by state or federal sources. Certain quality-of-life goals may require additional support that would not be possible through the use of public funds. Consequently, the more a family can plan and prepare, the better the chances of finding a solution that fits an individual’s goals. It is not realistic for many people to begin this planning process on his or her own. In this handbook, we suggest whom you can contact to provide assistance. It’s never too early for

a family to begin long-term planning. Studies have shown that caregivers struggle with these issues, sometimes for decades.

For those readers with the resources to fund a residential option privately: by all means do so. As we will discuss later, the big variable in cost is the staff support needs of the individual. The staff support can cost more than the annual cost of a private college education. These costs would have to be shouldered for a lifetime instead of four years. The control and security for those who can fund the options independently are significant.

It is important to seek information. Arcs and other groups often host seminars on these topics. It is helpful to attend to get some background on these issues. It is also critical to consult with an attorney who is knowledgeable in this area as well as a financial planner who is not selling a particular product. Estate planning is a popular name for educational sessions that review financial and legal considerations. Balancing between the individual's needs is critical when you decide how to divide the family resources. On the one hand, parents most frequently wish to make equal gifts to their children, to avoid apparent favoritism and jealousies that might make it less likely that the siblings will help the disabled child in the future. On the other hand, making equal gifts just to be "fair" may leave the child with special needs at risk and may result in windfall inheritances to other children who do not need them. What's fair is a personal decision. It may be a clearer decision once you:

- learn about realistic service options and costs
- understand the perspective of other children in the family and their potential roles in the future
- share your possible options separately or in a group with your family.

Keep in mind three important points:

- Your status with any particular agency should not prevent you from beginning personal or family planning: financial, legal and exploration of type of housing and support needed.
- If you don't require state funding support, agencies will still work with you and arrangements can be made with providers.
- If you require state funding, keep informed and help in the global advocacy effort. Otherwise, even if you receive support for your loved one, you are assuming that the funding for services will always be there. This is dangerous since there are few entitlements for adult services and funding can be cut depending on factors beyond your control such as the political or economic climate.

## *Siblings*

We already know that families are the biggest source of support for people with developmental disabilities. This is true of our society as a whole. Individuals who have limitations in making judgments or understanding how to navigate certain routines in our society especially need someone to help them. The role of siblings is critical in this process. Parents often don't involve their other children in talking about present and future needs of the offspring who is disabled. As a result, the siblings can be abruptly confronted with decisions that they have never considered. There are several positive outcomes that can take place by involving adult siblings early on:

- Siblings understand why family decisions were made in the past.
- Their personal concern about their sibling is recognized and can be utilized.
- They may have higher expectations for their siblings and can nudge parents to foster more independence.
- They may be more willing to play a role in the future and they have time to think about various ways in which they can be supportive of their sibling.

Of course what's not apparent is the positive impact the closer relationship with a sibling who is disabled can have on all siblings. The presence of a disability does not mean that the relationship is "one-way" in terms of giving. Fostering family relationships will motivate individuals with and without disabilities.

One of the biggest decisions a family needs to discuss is the future role of siblings. Studies have reflected that between 12% and 20% of siblings state that they are willing to have their brother or sister live with them. We recently talked to two men whose mother and brother were moving to Massachusetts. They had decided among themselves that one of them would invite their brother to live with him. The brother who had a disability was looking forward to this eventuality although he was concerned about no longer living with his mother. Obviously this had a major impact on the planning process.

Given their family plan, there were certain services that were critical:

- a job for the brother
- transportation
- respite care sufficient for the "support" brother to maintain aspects of his lifestyle.

The cost of these services is far less than a residential option. This decision made a final plan more affordable for the family and it increased the possibility of public funds for certain services. Advocating by the family for public funding of these services still is necessary.

Other examples of family roles:

- Advocate—be knowledgeable about siblings' service needs; write letters, make calls and go to meetings to arrange for services and/or to ensure services are matching siblings' needs and desires
- Trustee or Representative Payee—a financial role (being listed for bank account, Social Security or both, etc.). It could be done in

conjunction with an organization or someone knowledgeable in the service system. The estate planning section describes various decision-making roles that may be necessary

- Visitor—maintaining ties by visiting sibling's house and also getting to know others in the housing situation
- Friend—when possible, siblings can play a great role not only in their personal relationships, but also in helping a sibling connect with extended family and others in his/her community.

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## G. What about friends and groups?

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Family ties are the most important friendships we have. All of us thrive when we have meaningful relationships with our immediate and extended family members.

But individuals need other relationships. People feel appreciated emotionally when others are involved in their lives. Friends also provide assistance and feedback when needed. Friends choose each other and remain close through good times and times of crisis. They provide companionship for community activities.

We often find that individuals with disabilities such as mental retardation don't have friends that are available to them. It is never too late to support the process of developing friendships. Family members can help involve their sons and daughters, brothers or sisters in various activities. This sometimes means figuring out transportation and schedules.

There are different ways that personal relationships between people with and without disabilities may be encouraged. Perhaps more important than the specific method is the supporting, connecting role of one or more people (family members, staff members, friends, neighbors, etc.) who can spend time and energy for this purpose.

Families can encourage social participation. There are clubs or civic activities that take place in the community. If this is a new step, involvement in a time-limited project such as a “Fourth of July” volunteer activity may be the way to start.

Organizations have staff that can facilitate the development of such relationships. In some parts of the state, grants are available that families can apply for to pay for such “facilitators” or “bridge builders.” DMR has funds that may be used for such a purpose. To explore these suggestions further, contact your local Arc.

# III. Assessments and Agencies

*Beginnings: "Whose life is it anyway?"*

That's a popular line that you may have seen before. Whether you are at the beginning of this journey or in the middle, keep in mind that the future is that of the individual with the disability. As one plans, it is critical to involve the family member with a disability to the maximum extent of his or her capacity in the planning effort. We are talking about adult lives regardless of the level of intellectual disability. Where there are choices to be made, let him or her direct them or, at the least, express a preference. We all want to have control over our lives. For some families this will require the aid of a facilitator or professional.

The process of establishing a home of your own involves self-reflection, asking yourself questions like:

- Who am I?
- What do I enjoy?
- Do I prefer quiet or busy areas?
- Are there places that I want to live near because I enjoy doing certain things?

As the home is being developed and imagined, keep in mind:

- The person who will live in the home must have as much control over his or her life decisions as possible
- The supports or services for the individual should help him or her to live connected to families, friends and communities.

If the person with the disability is unable to verbally express preferences about his or her living situation, use the non-verbal signs that you observe every day to aid in planning for the future. Even after the hard work is done, it will always be important for family, staff and others to have ways to know preferences as situations change. If you have questions on how to do this, the developmental disabilities professionals we refer to in this handbook will be able to make suggestions on some approaches to gather this information.

Self-determination is a basic human right and one of many rights that we have as citizens. Families can help their family member understand his or her rights as they will be working with many people throughout their life. Every agency in the state has a human rights officer who can be a resource on this issue. They can make available to you human rights information as well as explain anything that is unclear. If you aren't connected with an agency and want some help in this area, the DMR Office for Human Rights can help. Call Tom Anzer at (617) 624-7738. (If you want to avoid a toll call, call DMR's toll free number: (888) 367-4435.)

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## A. Why are assessments important?

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Before you embark on the “housing journey” you need to have a basis from which to plan. Some families choose to go immediately to the house-finding stage. We know “Bill” needs a home, so let's just identify the best one—type of home, access to transportation, etc., and then figure everything out around it. In fact, it's important to first make sure that we understand Bill's strengths, needs, and preferences. Let's look at two imaginary vignettes about Bill:

1. Bill has to have his meals prepared. However, over the years, Bill has learned to make parts of certain meals and especially enjoys making peanut butter sandwiches.
2. For years, we thought Bill didn't like crowds. He would get very upset in certain situations and no one could figure out why. But Bill has been going to a local restaurant now for weeks. He enjoys waving to people as they come by and appears to know the way to get there.

These two activities provide us with a partial picture of strengths, needs, and preferences.

**Strengths:** - some food preparation skills  
- outgoing in certain social situations  
- able to learn directions to some destinations

**Needs:** - aid in preparing dinner and breakfast  
- transportation to social and other activities

**Preferences:** - wants to participate as much as possible in meal preparation  
- enjoys public restaurants when he goes with one or two companions but doesn't enjoy them with a large group

These are but two examples which help us see Bill's needs, strengths and preferences. They can affect not only where he lives but how he lives. We know that Bill needs more than drop-in staff for his future home. The largest share of the cost of community living is one's staff support needs. An assessment allows for the development of a realistic budget. Needs will determine the cost of services.

There are several areas that should be explored before you can identify staffing and housing needs. Let's look at the most common areas:

1. Activities of daily living (ADL)—this is a common term that is used in the “disability services” world to identify concrete personal care tasks that all people have: toileting, bathing, dressing, eating, preparing food, cleaning the house, etc.
2. Instrumental activities—these activities are important, but not as personal, such as transportation, money management, food shopping, social activities, etc.
3. Social relationships—how are friends, family and others going to stay in touch? What are their roles? To what extent can the individual with the disability initiate his/her relationships? This is a critical area and can mean the difference between a life that's full or one that is lonely.
4. Work life or daytime activities—though not the focus of this handbook, it's important to have this general area covered. For many people, a job provides an essential source of income to pay for living expenses. There are volunteer jobs that can provide social opportunities. In addition, there is work that can be supported through the Massachusetts Rehabilitation Commission (MRC) or the Department of Mental Retardation, and there are other day options that are discussed in a later section of this handbook.

5. Health and other related issues—are there any specific medical conditions, e.g., seizures, or any behavioral needs (e.g., screaming when frustrated), that need to be taken into account? Are the professionals being utilized adequately and what are the recommendations regarding daily support?
6. Financial assessment—how is all this going to be funded? Take an inventory of public benefits that are presently received or available, e.g. SSI, paycheck, etc. Review your financial situation with a financial counselor and an attorney knowledgeable in special needs estate planning. Although the final decisions won't be made until you have a general idea of what the housing solution will look like, it is possible and desirable to make some decisions in regard to trusts.

There are some great resources on the topic of assessment. The Arc has a future planning book; there are web sites with different organizations; and there are several authors who have written on this topic. Massachusetts has a wealth of agencies, attorneys, and others who can provide professional expertise. One helpful book in regard to assessment is “Disability and the Family: A Guide to Decisions for Adulthood,” edited by H. Rutherford Turnbull. It includes a lengthy and useful inventory of resources.

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## **B. How can I get help with medical and behavioral needs?**

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Adults with developmental disabilities often have complex medical, psychiatric and/or behavioral issues that have not been optimally addressed by generic community providers. An individual's limited ability to communicate about physical discomfort, frustration or anxiety may complicate the assessment of a problem and/or may result in problematic behaviors. Such behavior may limit the housing options available or may affect the level of funding.

Addressing the behavior will allow for more opportunities in housing and in community activities. Furthermore, some providers in typical medical office settings have limited ability to accommodate an individual's special needs. Dental care also often requires distinct techniques, time allotments, and an open attitude.

Families should be aware that many agencies in Massachusetts employ or contract with a variety of health professionals who specialize in the care of adults with developmental disabilities. Psychologists, social workers, nurses, nurse practitioners, physicians and dentists are affiliated with agencies such as private providers of mental retardation services, DMR area and regional offices and facilities, and two University Centers for Excellence in Developmental Disabilities (UCEDD). Families can utilize these developmental disability specialists to help educate and consult with community clinicians with whom the individual already has a relationship. In some cases, however, it may be preferable to establish a more comprehensive relationship with a clinician who specializes in the care of individuals with developmental disabilities.

If there are questions regarding an individual's preventative health care or management of specific medical or behavioral issues, then that individual should be assessed by a health professional experienced in the care of adults with developmental disabilities. The individual's DMR service coordinator or other area office staff can provide referral information or assist in accessing such services.

Families can contact any of the following for assistance:

- DMR area and regional offices, which can access nurses and behavior specialists who can facilitate an initial evaluation and assist in obtaining further evaluations and services
- University Centers for Excellence in Developmental Disabilities:

- The Institute for Community Inclusion in Boston
- The Shriver Center in Waltham
- New England Index (at The Shriver Center in Waltham), has a directory of community-based providers who care for individuals with developmental disabilities
- Local Arc offices.

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## C. How to arrange for professional assessments

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Think about the support that an individual receives now from family, friends and others. The individual with the disabling condition should be part of this review as he or she may have definite ideas about what help is needed and how it should be given. Approximately 70% of the cost of any residential option is the cost of paid staff, when such staff is necessary for support throughout the day.

After you have worked together to define some of the supports needed as well as the strengths and preferences, it is time to bring in a professional. There are many ways to engage in this process. You can initiate a person-centered planning process. Person-centered planning is a way of assisting people with disabilities with planning for their future. Person-centered planning helps clarify and organize personal interests and choices. It also encourages the participation of family and friends in establishing and achieving personal goals. There are several resources to help you if you choose this route. The Institute for Community Inclusion in Boston has published a booklet on this topic. In addition, person-centered planning tools such as Essential Lifestyle Planning, Whole Life Planning, Path and Circles of Support, and other tools can be found on the internet.

You can contract with a provider that provides assessments in your area. Often, the assessments are geared to their specific programs or alternatives. You should arrange an assessment that can be utilized to review various living options, and you should walk away with a copy that can be shared with various organizations that you are considering in the planning process. These assessments may have to be paid for and can cost anywhere from \$300 to \$800, depending on the time invested. You can request flexible funds from DMR to partially subsidize an assessment; agencies may offer free or discounted assessments. In some cases, agencies that you are considering for housing alternatives will conduct “whole life planning” or other assessment procedures that are subsidized as discussed in Section D, which follows. If you don’t know where to start, you can contact a local Arc or your DMR Service Coordinator.

### *Why have a professional assessment?*

1. You or the individual with a disability may not be certain of his/her safety skills, especially in areas such as transportation, home emergencies, financial details, etc.
2. You may be underestimating your family member’s abilities.
3. You can better target what supports are needed in the future home; e.g., a family member agrees to provide assistance for an activity that everyone thinks is twice weekly but turns out to be a daily responsibility. Mistakes like this can result in a failed attempt or long-term frustration about the living situation.
4. The most expensive and recurring cost can be staffing; having a good handle on the scope of staffing is just smart planning. Budgets can be meaningless if the expected staff costs are unrealistic.

Some individuals in the field stress that it’s important to identify the “non-negotiables” in planning for housing. All of us make compromises about things we buy; the home or neighborhood we choose is based on financial and other factors. However, for everyone there are “must-haves” for which there are no substitutes. It’s no different in this planning process.

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## **D. Having a team will make the journey easier.**

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Identify who your team will be to make this a successful journey. Such a team can be formal or informal. The individual for whom the housing is intended should be able to direct the process as much as possible. Sometimes families can be so concerned about solving a problem that they try to “fix” it for the individual involved without his/her participation. Obviously, each member of the team has to determine how much she or he can participate with her/his own time or resources. Parents and siblings should get the chance to do that as they learn more about what is entailed. This is similar in some ways to planning a college education with a young person or planning a wedding with family. Team members, formal or informal, are those who can aid you in meeting your goal. The “whole life planning” approach includes a process of identifying individuals who are needed for their professional help or personal interest. These individuals should be willing to look at the project through the perspective of the person who has a disability.

Think of this team as having two groups of participants: Individuals who are more involved, such as family, neighbors, an employer or fellow worker, and others. They really know you or your family member and see themselves as personally committed. The second group is made up of people who will

have a time-limited role, but also expertise in a particular area, such as housing, medical issues, transportation, etc. Some of these individuals may even collect fees for the time during which they are involved. Be aware that many people with specific expertise have team activities underwritten through grants or the organization (nonprofit, community, provider, state agency, etc.), and commit a certain portion of time to outreach. Once you identify the right person(s), you can find out if this is the case.

No matter which approach you choose, assembling your team will make the journey feel more predictable. After you have looked at the housing options and gained some background, you will be able to identify the individuals who will be the most helpful.

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## E. What are some different professional roles?

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- 1. Developmental Disabilities professionals** assess the right type of supports; they develop a specific program and estimate the cost. These professionals may be social workers, psychologists, or educators in training. Usually you find these professionals working at local private or public agencies. These professionals should be able to help you link up with medical and behavioral specialists, if your son or daughter has needs that require such help.
- 2. Housing professionals** can explain the different rental vouchers or assistance programs, can direct you to nonprofit housing counseling programs across the state, and can give you examples of different possibilities to pursue. DMR and MRC both have housing professionals that can steer you in the right direction; nonprofit entities in your community (public housing, counseling, etc.—see section on housing) can help.

- 3. Family Support staff** can aid you in getting support while you are waiting for services; they usually are great resources for information and referral in general.
- 4. Financial planners** figure out how to fund services, housing, or special expenses that won't be subsidized through public sources; they can show you various products to achieve financial goals.
- 5. Attorneys** help you develop trusts, wills and related planning instruments. You may want to utilize them in setting up trusteeships, guardianships, and other forms of legal support if needed.

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## F. What is the role of community agencies or providers?

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- 1. Why work with an agency on our journey?**  
In many cases, individuals and families choose an agency to help them in the effort to establish housing. An agency may have an ongoing project that you will want to join, or you may want the agency to be the host or sponsor for your home. It is important to be clear about the arrangements in the beginning. There are a number of possible relationships. For example:
  - a.** An agency has a “home of our own” type program and you utilize the existing resources. The individual/family still has a large role in directing the outcomes. If public dollars are involved, there will be some requirements to address.
  - b.** There is an established group that is trying to develop solutions and needs one more individual to make a home become a reality. In such a case, you will be buying into an existing situation. You should be told about the project boundaries and goals up front. You then have to decide if you want to be part of that project.

- c. You alone, or with others, have a goal and want the house to be owned by a trust, for example, which is controlled by those who reside in the home. This has to be reviewed up front with the agency and the agency has to agree. In such a situation the trust or entity has to be set up prior to applying for any public assistance or the receipt of private financing. It is very difficult to change “owners” in the middle of a project.
- d. You have private or state funding and decide to become part of an existing house or apartment that has an opening. This is like moving into an apartment or house that has been vacated by one of the roommates. There will be rules and routines established. While you will have to accept much of the existing routine, there will be areas where the situation should be able to accommodate you as well.

Another way to discuss working with an agency is to compare it to other situations. Perhaps you have lived in a condominium where an organization is the management entity for that condominium. Depending upon the desires of the association, the management entity can make decisions on all the operations or its oversight can be limited. But someone has to hire contractors, the custodian, and the security staff. The association decides on how much responsibility to give the management firm. The same decision is faced by families. The history of services has been typified by control of decisions mainly in the hands of state or private management. Much of this was natural from the perspective of those entrusted to develop services. Families were asking the state and organizations to develop services, and sat on the boards of these organizations to make it happen. Today we are witnessing an evolution in this regard—where families and individuals are interested in shaping the specific services that they receive as well.

## 2. *How do I choose the right agency?*

Agencies have various strengths. In Massachusetts we have over 150 provider agencies with expertise in the developmental disabilities arena. You will find organizations that are limited in their flexibility but have good management. You will find others who are flexible and see themselves as consultants. There are large organizations with budgets in the tens of millions of dollars and others with less than one million dollar operating budgets. Here are three ways to check out the agency:

- a. Make an appointment to visit the agency; ask them questions about their homes, how much they handle housing requests such as yours, and ask if you could see two of their homes at a convenient time. Request names of a few individuals or families who you can contact. Interview the staff at the house when you visit with questions about the routine. Ask about the frequency of staff turnover.
- b. Ask the case management or service coordinator staff with whom you may work about the agencies that you are interviewing.
- c. Review a number of other factors, such as accreditation by the state or private entity, the connections with the existing community, and the amount of family interaction encouraged by the organization.

Take the information that you have gathered and look at it in context. For example, if an agency that you are interested in does not show much interest in working with families, ask them about it. If staff admit this up front and the agency has established a process or program to address this, that is helpful to know. Or you may have gotten great recommendations about an agency and like the house you have visited, yet you have also heard some complaints. You

should look at how serious those complaints are and how well the agency is addressing them.

If you work with an agency, become involved as time permits. In situations where individuals want or need siblings to be involved, this will be a good way to get to know about the services and the field. The Department of Mental Retardation has citizen advisory boards that need community representation. Nonprofits especially need the participation of families and the wider community. They have boards and committees that require volunteer leadership. Such activity can be on a human rights committee or special program committee. Most important is your participation on the team to the extent the individual wants or needs it. The family sometimes is the one link that has been consistent throughout the life of the individual and, as the support staff changes, that consistency is important.

# *IV. The Dream as Reality*

Over the past two decades much has changed in the development of housing options for people with disabilities. Today there are more individualized models and fewer “cookie-cutter” approaches to providing community-based housing.

Currently, the emphasis is on the individual. Housing options for people with disabilities are beginning to resemble existing housing. After all, housing is housing. People with physical disabilities may require some housing accommodations, such as broader hallways and accessible bathrooms. However, people who require staff support for activities of daily living and/or other tasks don't require a different kind of house. What they require is assistance. Over time, it is difficult for this assistance to be provided by family members; however, as we know, many family members have played "support roles" for decades.

Here are some general questions to consider when deciding which housing model works best for you:

- 1. Who controls the home?**  
Is it the individual with the disability, a provider, or someone else?
- 2. Who chooses what type of home?**  
Is it a house or apartment that the person with the disability or surrogate chose, or is it housing that was available?
- 3. Who chooses the people to live with?**  
Have the roommates chosen each other to the extent possible, or has someone else done the choosing?
- 4. How many people live in the home?**  
Does the number of people in the home reflect how most of us live?

The following terms are used by DMR to describe the different types of residential services it typically funds. These terms do NOT represent a comprehensive list of options that you may wish to explore. We share the terms because you may hear them used as you look to develop partnerships or in the event you receive DMR-funded services. Where applicable, we list the current terminology with historic descriptions in parenthesis.

### **1. Placement Services** (*Specialized Home Care*)

Placement Services use residential support agencies to provide placement, guidance and oversight for individuals with 24-hour paid supports and (1) living in the home of a care provider (shared living) or (2) living in their own homes (owned or leased) with a care provider who lives in the home (home sharing). In both instances, the care provider is a family member or a single person who is unrelated to the individual and, also is not an employee of the residential support agency.

### **2. Residential Supports** (*Residential Services*)

Provider (organizations contracted by DMR) operated, extensive on-going services and supports provided to individuals who need daily intervention with care, supervision, and skills training in activities of daily living, home management, and community integration. These individuals live in a certified or licensed home with 24 hour paid support. Types of residential supports are supervised living and supported living. Residential supports are not available to individuals who live with their immediate family (grandparent, parent, sibling, or spouse) unless the immediate family member lives in the licensed or certified home and is also eligible for DMR supports.

### **3. Individual Support**

Individual Support consists of regular or intermittent limited forms of assistance (less than 15 hours per week) to enable individuals to live as independently as possible. These supports are related to health, safety, personal well-being, and stabilization of behaviors or situations. The services enable adults to retain or improve skills related to personal finance, health, shopping, use of community resources, community safety, and other adaptive skills needed to live in the community. Other supports include assistance to manage PCAs, supplements to adult foster care, and financial stipends. This service is not available to adults who live with their immediate family (grandparent, parent, sibling, spouse) unless the immediate family member is eligible for DMR supports.

#### **4. Individual Support and Community Habilitation**

Individual Support consists of limited services and supports (15 or more hours per week, but less than 24 hours per day) that may be provided regularly or intermittently to enable adults to retain or improve skills related to personal finance, health, shopping, use of community resources, community safety and other adaptive skills to live in the community. It is not available to adults who live in the family home with their immediate family (grandparent, parent, sibling, spouse) unless the immediate family member is eligible for DMR supports

#### **5. State Operated Residential**

Extensive on-going services and supports provided by state staff to individuals who need daily intervention with care, supervision, and skills training in activities of daily living, home management, and community integration. These individuals live in a certified home with 24 hour staffing. This service is not available to individuals who live with their immediate family unless the immediate family member (grandparent, parent, sibling, or spouse) lives in the certified home and is also eligible for DMR supports. This service is provided by state employees.

#### **6. Family Partnership**

DMR has participated in 92 non-traditional “Family Partnerships” in the past four years. We include the description in the event you may wish to explore this as an option, although it is unclear whether DMR will continue to fund these types of arrangements.

- A family participates in a tangible manner toward the residential alternative; one example could be to facilitate the purchase of a house or condominium by paying for the down payment and assuring an affordable rent

- A family participates in a tangible manner toward the residential alternative; one example could be to facilitate the purchase of a house or condominium by paying for the down payment and assuring an affordable rent.
- If housemates are needed, other compatible individuals are matched with the individual whose family is initiating this partnership.
- A clear agreement on the long-term use of the property is made through a trust or some other means. Housemates and the family member share the sense of living in their own home.
- Favorable arrangements to sell the property to other household members or a non-profit agency to continue the living situation may be considered.
- The advantage for the family initiating the partnership is to have more control over geography and type of residential setting.

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### **A. Funding from State Agencies**

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Many of these program models or housing models are funded through the Department of Mental Retardation. However, funding can come from various sources:

- 1.** Private
- 2.** Partnership
- 3.** Mix of different public agencies
- 4.** DMR only

When state agencies support these services, funding falls into various ranges. These reflect different factors such as the needs of those being served and the number of people supported in the housing model. Section V includes a discussion on costs. For individuals served by DMR it's not unusual to find costs ranging from \$40,000 per person per year to \$90,000 per person per year for 24-hour staffed housing models.

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## B. Designing Flexible Community Supports

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This section reviews various funding options that are available for the staffing component of housing, aside from outright DMR funding for residential services.

Many people served by DMR live alone or with another person with a disability in the community and receive four hours or less of support a week. Usually, a local provider agency will arrange for a person who can assist with banking or grocery shopping and other daily tasks. A staff person can also assist with the responsibilities associated with a living situation. Having a person who acts as a sounding board when problems arise, such as leaky plumbing or finding out where to call when a local service is needed, can lend stability to the living situation, promote relationships, and counteract isolation. In addition to paid support, there are many other forms of support. For example, support can simply be a family member, a friend, or a neighbor that maintains regular contact with the individual. For others it may be a combination of paid staff and close friends or relatives that form a circle of support that allows a person to live independently.

Although the resources for residential services funded through the DMR are limited, there are several ways families can approach the goal of supporting their family member in the community:

- *Flexible Respite Care and Cash Assistance* - Allocations to eligible individuals and families can be used to recruit and hire their own staff. Other needs such as medical, social support, transportation, technological and environmental adaptations and other types of support or equipment can be purchased. Such service is also accompanied by case management and a broker who can assist in locating the appropriate resources.
- *Personal Care Attendant (PCA)* - This is a Medicaid-funded service that reimburses consumers or their surrogates (family or

others) that hire individuals to help with physical and personal care needs. To qualify, an individual needs to require 14 hours of PCA support per week (physical, not verbal assistance) of which 10 hours has to be in daily living activities such as grooming, eating, etc. There are over 11 PCA providers across the state who will work with you.

Ask for references, as reliability of providers differs. The local Arcs listed in the back of the handbook will guide you to your local PCA services program.

- *Adult Foster Care*- This is a Medicaid funded service that provides some limited funding to families who want to provide support in their home. It is a type of “shared living” where Medicaid provides a stipend to the family. The funding from Medicaid can be insufficient for the family caregivers; DMR funding is sometimes combined to make the option work.
- *Partnership or Collaborative Resources* - Some people who choose to live with a friend that may also have a disability combine their flexible respite and family support allocations to purchase needed paid assistance. Other families have saved money over a period of time to add to the combined resources to meet the level of need of their family member. Still other families have planned to use their current home and some assets they put aside to create long-term housing for their child when they are no longer able to live there. Some families choose to develop their own housing cooperatives where each person buys a “share” of the house they choose to live in with several others.

It is important to keep in mind that more than one agency may have to be approached when an individual or family develops a housing alternative independently. Even if DMR is part of supporting the solution, you may still have to access personal care attendant services (personal assistance) through Medicaid (DMA); and obtain housing subsidies from the local housing authority or the Department of Housing and Community Development (DHCD) (housing subsidies are described later in the handbook).

Each of these entities has its own eligibility criteria and application procedures. It is ideal to identify an agency to be a partner with you. The arrangement that you develop with the agency and the cost can be based upon how much work the individuals/ families do in monitoring and developing the project.

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## C. Hiring Staff

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Of course, the most difficult aspect of community housing relates to the staff that may be needed. Agencies have developed procedures for hiring, orientation, staff discipline, payroll, etc. Equally important is the ongoing staff supervision and training that comes with any housing situation. These considerations make it difficult for individuals/ families to develop housing options independently. If you do decide to go this route, you eventually will need a “manager” who oversees the day-to-day operations, or family members will have to play such a role. In any event, you will need to have expectations clearly written to avoid problems after the housing situation is implemented by the agency. You should interview agencies to see how they oversee and provide supervision to managers.

In addition, staff selection and screening is critical. It is important to have certain set procedures for checking references and backgrounds of any staff that are retained. The personal care attendant program is one where consumers or family surrogates are the “employers.” You can contact agencies that administer this program and ask them about their screening and hiring procedures. PCA provider agencies are responsible for training “consumers” or their surrogates in various personnel procedures. The employer also has certain financial responsibilities in regard to employees. If you directly hire staff, you will need to ensure that costs such as taxes, unemployment insurance, disability premiums and Social Security taxes are included and that they are properly deducted. In the PCA program fiscal intermediaries are being organized to serve that purpose (1999).

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## D. Working on your Housing Alternatives

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The models in the Appendix present examples of how a housing situation can work. Of course, those examples are starting points that can be adapted for your particular situation. You can begin this process:

- on your own
- with other families
- with a sponsor agency.

If a group wishes to develop a housing solution together you have to:

- identify the “non-negotiable” needs and wants of each individual early in the planning process
- make sure the individuals are compatible from a personal perspective
- be willing to negotiate and follow certain guidelines in coming to decisions, especially if there is going to be a high level of family involvement
- be willing to accept “mixed” income sources, e.g., all housemates have private funding versus housemates who may have private and public funding.

### Budget Considerations

On the income side there are:

- individual earnings
- SS/SSI/SSDI
- housing subsidies
- state program contribution via DMR funding, PCA program or elsewhere
- family contribution, if any
- special needs trust for restricted items (see Section VII)
- United Way or other charitable support.

The Social Security assistance that is received for a family member will have a significant portion (75%) applied toward any housing option (room and board) even if there is full state funding. This leaves very little to the

individual who has no other income for activities or purchases beyond absolute necessities. Consequently, a minimum consideration for many families is the use of a special needs trust to leave something for those “quality of life” activities that the individual has enjoyed over the years (see financial section below).

The expense side includes the usual basic living expenses plus staff expense:

- mortgage or rent
- utilities including phone, cable TV, etc.
- food
- insurance payments
- clothing
- recreation
- miscellaneous
- staff

One way to develop your budget is to use these examples as a base and make changes as you identify the additional staffing needs or items that your housing will need. For example, none of our models includes a budget for vehicles. If a house is being developed for three or more individuals, then a vehicle may be part of the plan. You would need to add that cost and identify how it would be funded.

Another way to develop a budget and plan is to look at averages that agencies have developed from their experience in providing services. As noted earlier, the cost of staffing is a major portion of any budget. We have adapted one method of determining staffing cost. The following are factors that affect the cost of housing:

- needs of the individual for support services, which affects staffing
- number of people sharing housing
- location of the home or apartment.

The following are examples of average per person per year costs (staffing, housing, food, etc.). These costs are reflective of DMR-funded community programs. Costs do vary, but this provides a picture of average costs across the state:

- 1.** Support staff only where shared living is included with a non-disabled individual; hourly staff who assist or teach 1:1 in areas such as money management, cooking, social-leisure; up to 8 hours per week- *\$20,000 to \$25,000 per year.*
- 2.** Four people who are independent in mobility but require some assistance in cooking, daily living, money management, etc., includes overnight availability (staff ratio of 1 staff to 3 people or 1 staff to 4 people); *\$60,000 to \$70,000 per year.*
- 3.** Four people who require assistance in the community, in food preparation, money management, and require overnight availability. Staff ratio is 2:4; *\$75,000 to \$85,000 per year.*
- 4.** Larger group of eight people with one live-in staff (receives roommate privileges) includes 2 staff to 8 people for 30 hours per week and at all other times 1 staff to 8 people; individuals are capable of being on their own for short periods of time; they are independent for daily living and possess no other disabilities; *\$50,000 to \$55,000 per year.*
- 5.** Six to eight people who have 40 hours of staff per week (1 staff to 6 or 7 people); they are able to be alone for 10-12 hours; no overnight is needed. *\$20,000 to \$25,000 per year.*
- 6.** Four people who have require assistance as per number three above but who also have behavioral and/or medical needs. These costs would reflect nursing and clinical consultation. *\$90,000-110,000 per year.*

# V. *Housing: Renting or Buying?*

There are several strategies that can be utilized to reduce the cost of housing for individuals with disabilities, which may enable them to afford to live independently. These are programs that can help if you are:

- (1) buying or developing housing; or
- (2) renting housing

The programs described below do change, so keep that in mind as you read this section. For an update of purchase programs or subsidies, contact your local housing assistance entity or corporation. We have listed these entities in the resource section. The Citizens' Housing and Planning Association (CHAPA) can direct you to a local housing entity and can be reached for referral information at (617) 742-0820. They conduct an annual seminar on various housing topics. They have a web site ([www.chapa.org](http://www.chapa.org)) that provides the dates of local trainings on home buying and related topics.

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## A. Buying or developing housing

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This section describes the available housing programs and the various steps you have to take as a purchaser. There are two possible approaches you can use in buying housing. Are you going to develop housing as a family, or with a group of families? Or, is a nonprofit agency developing the housing on your behalf? Some housing programs are available to individuals or families, while other programs are applicable to agencies only. At the end of each description we note whether the program is available to families, agencies, or both groups.

1. *Identify affordable properties* Whether affordable properties are available depends on the market.
  - a) The FDIC may have a list of foreclosed properties that are for sale. At the present time there are not many properties, but it may be worth looking into. This list contains the name, address, description, price of the properties, contact person and phone number. The list can be found on the FDIC website, [www.fdic.gov/buying/owned](http://www.fdic.gov/buying/owned). This program is open to families and agencies for application.

- b) Housing and Urban Development (HUD) and the Veterans' Administration (VA) take over properties insured through the Federal Housing Administration (FHA) or VA loans. Since these public entities want to dispose of properties quickly, one can often purchase homes for below market price. The number for HUD in Boston is (617) 994-8200. The number for The VA is (800) 827-1000.
- c) Approach your local bank. Each bank attempts to tally credits for the Community Reinvestment Act (CRA). This is not a specific program; CRA activities reflect the interests of an individual bank. The bank may be able to help in a variety of ways once you explain your goals. It also can provide local phone numbers of HUD, VA or other entities that can help you in the housing search. This program is open to families and agencies for application.

2. *Identify sources of down payment assistance.* You should attempt to get a below-market interest rate. Nonprofit agencies will be interested in grant assistance to support a purchase. Banks may agree to provide 100% loans for families or agencies attempting to develop housing alternatives in order to increase their CRA rating. After you have identified housing, you may want to consider the following possible sources of support for purchase or development:
  - sources that assist in down payment and purchase
  - nonprofits that identify public or private grants for assistance in purchase
  - sources of below-market interest rates
  - rehabilitation or modification grants; no-interest or low-interest loans.

These options also are identified for families or agencies or both.

- a)** *Section 8 program*—This program allows eligible individuals and families to convert current Section 8 vouchers from rental supplements to mortgage supplements and allows future eligible individuals and families to choose between mortgage subsidies and rental subsidies. As with the rental program, an individual can get a Section 8 from one local public housing authority and use it to purchase a home in a different community. Three hundred and fifty-two communities have housing authorities; you can get a list by calling the Dept. of Housing and Community Development at (617) 573-1100 or by visiting their website, [www.mass.gov/dhcd](http://www.mass.gov/dhcd) and clicking on “Community Profiles” at the top of the web page. Please note that as this handbook goes to print it is becoming increasingly difficult to obtain Section 8 housing as the Department of Housing and Urban Development (HUD) has proposed cutting program funding.
- b)** *Rural Housing Services (RHS)*, formerly the Farmer’s Home Administration, is a federal program that offers a “First Time Homebuyer Program.” It has a lower down payment requirement and offers a lower interest rate. You can reach the RHS at (413) 253-4300, menu choice #1. This program is open to individuals or families.
- c)** *Community Development Block Grants* are funded by HUD. These grants are administered through local community development offices (planning board offices in some towns). The funds may be used to purchase or to rehabilitate residential properties. They are available only to low and moderate income individuals or families. Check with your local planning or community development office to see if they receive these funds and what may be available. You may need to advocate for funding to be allocated in the disability area. This program is open to families and agencies.
- d)** *The HOME Program* is another HUD program that is extremely flexible. HOME funds can be provided to persons on Waiting Lists for the Section 8 program, be used to rehabilitate rental or homeowner properties, and even to construct new property. Basically, the HOME program bridges the gap between what persons with low income can afford and the market cost of housing in the local community. Again, check with your local planning or community development office to see if they receive HOME funds and what may be available. This program is open to families and agencies for application.
- e)** *The Affordable Housing Program (AHP)*, which can be accessed through various banks in New England that are members of the Federal Home Loan Bank of Boston, provides funds for individuals and families with incomes at or below 80% of the median income for the area in which they live. Financing can be used for the purchase or construction of a home, or the purchase or rehabilitation of rental units that have at least 20% of their apartments rented to people of low income. Interest rates vary as low as zero percent based on income levels. This program is open to agencies for application.

- f) *Soft Second Mortgage*—This is part of the state’s first-time home buyer assistance program facilitated by MassHousing (mentioned above). Not all communities or banks participate. The phone number is (617) 330-9955; they can tell you which area banks offer it. Buyers obtain a bank mortgage for 75% of the purchase price; the Soft Second program provides a second mortgage for 20% of the price. The interest on a second mortgage is subsidized for 10 years. Families can avoid a mortgage insurance charge while providing a lower down payment (5% of which at least 3% must be individual’s own funds). This is open to individuals and families.
- g) *Home Modifications Program*—Loans with no or low interest are available to individuals or families to make their homes accessible. (617) 204-3724 ([www.mass.gov/mrc](http://www.mass.gov/mrc)). Loan payment is deferred until the house is sold.
- h) *MassHousing*—provides a number of programs that support purchase or rehabilitation of housing. The general information phone number is (617) 854-1000. This program is open to agencies for application. Their website is: [www.masshousing.com](http://www.masshousing.com).
- i) Federal or State funded programs offer grants or loans for creation of alternative rental and ownership housing such as the Housing Innovations Fund and Capital Improvement and Preservation Fund. HUD Section 811 programs subsidize much of the costs of building a home. It also subsidizes the mortgage after a certain percentage (30%) of income per individual is allotted. The program now allows flexible, scattered sites. This program is open to agencies for application.

- j) Private and corporate foundations—  
There are specific foundations that focus on individuals with disabilities and housing needs. These can be approached for assistance in purchase, rehabilitation or subsidizing consumer payments. Agencies would have to be the applicants and recipients of these funds. This program is open to agencies for application.

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## B. Renting Housing

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Rental housing programs are a good option for many people with disabilities. The state and federal government fund a number of affordable rental housing programs for low-income people, including people with disabilities. A few of these are specifically targeted to serve people with disabilities. There is the “Massachusetts Access Housing Registry”-a rental voucher program for families with low income administered by CHAPA ([www.massaccesshousingregistry.org](http://www.massaccesshousingregistry.org)) that can assist you in locating affordable, accessible housing. Or you can send an e-mail to [massaccess@chapa.org](mailto:massaccess@chapa.org).

There are a few important things to know about affordable rental housing programs:

**Rent is based on income:** Most affordable rental housing programs charge tenants 30% of their income for rent (minus the cost of tenant-paid utilities). The difference between this amount and the total rent is called a “rent subsidy” and is paid by the state or federal government to the owner of the housing.

**There are two basic types of rental subsidies:**

- 1. Project-Based:** In project-based programs, the rent subsidy is attached to the apartment. When the consumer moves in, they receive subsidized rent; when they move out, they no longer receive a subsidized rent.
- 2. Tenant-Based:** With tenant-based programs, the subsidy stays with the tenant, even if he or she moves. The best known of the tenant-based programs is the “Section 8 program” (see below). As you can imagine, the tenant-based programs are very popular and often have very long waiting lists. Sometimes the list is “closed” because it is so long; no one can sign up for the program until the list opens up again.

### **Public Housing Authorities**

Public housing authorities are quasi-municipal agencies. 352 cities and towns in Massachusetts have housing authorities. At a housing authority, consumers can sign up for several different programs. Most housing authorities have elderly/handicapped housing; this is project-based rental housing. Many, but not all, housing authorities have Section 8 tenant-based programs. In addition, some housing authorities have a state-funded tenant-based program called the Alternative Housing Voucher Program (AHVP). This program is specifically targeted to serve individuals with disabilities. Consumers can sign up for housing with one centralized application and express preference about where they want to live.

You can get a free list of public housing authorities from the Department of Housing and Community Development at (617) 573-1100 or go to <http://www.mass.gov/dhcd> and select “Community Profiles” at the top of the web page.

### **Privately-Owned Subsidized Housing**

Both the state and federal government have funded private developers to develop affordable housing across the state. Unlike housing authorities at which you can sign up for several different programs, you must sign up for each of the private developments individually. Consumers can sign up at as many developments as they want. You can get free lists of these project-based developments by calling the Massachusetts Housing Finance Agency (617) 854-1000 and the U.S. Department of Housing and Urban Development Boston office (617) 994-8200.

### **Regional Nonprofit Section 8 Programs**

Currently, the state provides funds to nine nonprofit Housing Consumer Education Centers across the state for tenant-based Section 8 Programs. For more information call (800) 224-5124 or go to [www.masshousinginfo.org](http://www.masshousinginfo.org).

### **Congregate Housing**

Some of the housing authorities also manage congregate housing. This is a form of shared housing for senior citizens and people with disabilities. Generally, in these developments the tenant has a private room, often a private bath, but shares kitchen and other common areas with 2 to 10 other tenants. Consumers who prefer or need socialization may want to apply for congregate housing.

A list of the congregate housing developments across the state is available from the Executive Office of Elder Affairs at (617) 727-7750.



# VI. *The Private Side of Partnership: Financial and Estate Planning*

Generally, funding for services and/or other needs is derived from three sources: the individual's earnings from work and/or benefits; the "services" or funding provided through governmental entities and funding that the family makes available. Funding from other sources such as foundation or corporate grants and the United Way can be a factor. Usually such funds are time-limited or relate to specific projects.

This section provides a short review of considerations related to the family's financial support of a residential option for the family member with a disability. The general topic of estate planning covers financial and various legal considerations.

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## A. Financial Planning

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What makes planning particularly challenging for a family with a member who has a disability is the need to provide for two generations: the parents' financial security and the child's lifetime needs. If you are going to participate in a partnership or independently attempt to set up an option for your son or daughter, you will have to project your capacity to participate.

Families will want to participate with the following in mind:

- Have I arranged my own personal financial matters to coincide with my future vision of my life?
- Have I maximized my own financial resources to provide for my son or daughter's future as well?
- Have I made every effort to protect his or her eligibility for government benefits?

Proper planning can answer many of these questions and provide you with the peace of mind knowing that you have done all that you can for your family long after you are gone.

The recommended steps to make this decision include:

1. Identify and prioritize your goals and financial needs
2. Identify and list your present resources – private and public
3. Determine your annual or monthly savings available towards your goals

4. Calculate the costs of son's/daughter's housing, services, and lifestyle needs
5. Identify financial shortfalls and gaps
6. Identify planning strategies to fill the gaps
7. Implement a properly coordinated plan of action
8. Periodically review and monitor your plan.

In order to identify how much you can participate you have to make an inventory of your resources similar to any major decision that you have made in your life.

### Identify private resources:

Take an inventory of your private resources, how they are owned, and who is the beneficiary designated upon your death. The easiest way to do this is to gather the most recent statements and/or policies of each item.

- Savings and Checking Accounts
- Certificate of Deposits
- Money Market Accounts
- Treasury Bills or Savings Bonds
- Stocks
- Bonds
- Mutual Funds
- Retirement Plans (IRA, 401(k), 403(b), TSA, Keogh, Pensions, etc.)
- Annuities
- Insurance Policies (life, health, disability, long-term care, auto, home)
- Employer Provided Benefits (stock options, life insurance, disability insurance, etc.)
- Real estate (home, rental property, land, etc.)
- Business interests
- Outstanding debts (mortgage, equity line, credit cards, other loans)
- Personal property (furnishings, automobiles, boats, etc.)
- Any other resources (family members, custodial accounts, etc.)

What are the monthly savings that can be set aside toward the goal that you have in mind? For younger families the advantage of time is a big factor. Families with younger children should try to save as much as possible and as soon as possible. Time provides the ability for your money to compound and earn more. For example, if you start by saving only \$50 per month when your child is 5 years old, earning an estimated 8% rate of return, by the time he or she is age 22, you will have accumulated over \$21,000. This could provide a nice deposit towards the purchase of a condominium or house. Of course you can accumulate a larger sum if you save more, start sooner, or earn a better rate of return. (This hypothetical example is for illustrative purposes only. This is not a prediction or a guarantee of actual results.)

Carefully review your current resources and plans in light of what your goals are. Typical considerations in developing a plan include taxes and inflation. Often wills are outdated (or non-existent), trusts are not properly funded, insurance policies are not adequate, investments are not properly allocated, assets are not properly titled, beneficiary designations are not current, or employer benefits are not properly understood. Different strategies are available for a parent in retirement versus one who has 25 more years to work. This will help you to determine what the picture will look like and how to plan. This process could be aided with the help of a financial planner. These individuals are certified or licensed as a Certified Financial Planner Licensee/CFP Licensee or Chartered Financial Consultant (ChFC). Of course, you should verify that the professional is knowledgeable in special needs planning as well. Your local Arc should be able to refer you to planners that have relevant experience. Be careful not to use professionals selling particular insurance products for the planning process since

their main goal is to demonstrate the benefits of their product. Approach those individuals for descriptions and quotes after you have a plan.

As you walk through your personal inventory you may find that your retirement after your death can be assigned to your son or daughter with a disability. This may mean taking a smaller benefit while you are alive but it can provide regular income if distributed via a special needs trust and still not risk his/her other benefits. Or you may decide to take the higher distribution from your pension but purchase a life insurance policy on yourself or on your spouse with the additional funds. In any case, planning should take place ahead of time so these decisions can be made. If you wait until retirement, you may not have the ability to choose the best option for you.

One of the most frustrating aspects of planning from a personal level is if your goal is to forge a public-private partnership. There are government benefits that you can estimate and be certain of such as Social Security or a housing subsidy if your son or daughter is fortunate enough to receive one. However, you cannot count on public funds for staffing until you have received word that the funds are forthcoming.

Section V of the handbook identifies housing programs that can help to provide subsidies for rentals as well as programs for home purchases. Section IV, "Dream as Reality," reviews various government programs for staffing including the personal care attendant program and adult foster care. See Part C of Section IV- "Designing flexible community supports."

By planning and identifying what you can do, however, other options may arise. Do not allow the questions about public funding to stop you from making the best plan possible for your son or daughter.

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## B. Special Needs Trusts

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There are predictable life events such as death which can cause upheaval if planning has not been done. Upon the death of a parent, it is critical that the proper estate planning documents are in place to help protect any government benefits. Asset ownership and beneficiary designations should be properly coordinated. If a son or daughter is in a housing situation and dependent on family income, cash should be available to allow the child to continue to live in his home without being a financial burden to other siblings and/or housemates.

Estate planning for parents with a dependent who has a disability is a complex process. Most parents find it difficult to even contemplate their death and, as a result, planning can be an upsetting experience for families. It is not unusual for parents to feel either too young to consider estate planning or to feel they have so few assets that this type of planning is not applicable to them.

You need not be wealthy or old to begin seriously considering the need to write a will and a supplemental or “special needs” trust if you have a family member who needs government benefits to ensure that he or she receives the care and support necessary over a lifetime. But in order to do this, you must plan carefully.

For most families, planning means having a legal will drafted to ensure that your assets go to people you designate and to name a guardian for a minor or adult child with a disability who needs guardianship. If you die without a will, the state determines how your assets are distributed and the probate court determines who shall serve as guardian of that child, even when there is one surviving parent. The probate court’s decision on a guardian may not be what you desired.

For most families with a dependent who has mental retardation, *the primary goal of planning is to ensure the dependent receives a lifetime of adequate care and support that eligibility for governmental benefits can offer.* This requires proper handling of family resources. One legal instrument that can be very useful is commonly referred to as a “special needs” trust. A special needs trust remains the only estate planning option that avoids the loss of the trust meant to supplement your son’s or daughter’s life. A special needs trust enables your child to receive ongoing support services from an adequate share of your estate while still preserving the child’s eligibility for government benefits and the care and support these benefits can provide. If properly drafted, it protects the assets of the trust from liability for services which should be provided as a responsibility of the state.

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## C. Legal Planning

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Planning for the future includes consideration of the decision-making capability of an individual with a cognitive disability. This decision has to consider the rights and needs of the individual to control his/her life to the extent possible while protecting him/her from dishonest individuals or decisions that he or she cannot understand. It is important, however, to always consider the individual’s preferences even when he or she cannot make decisions about certain aspects of his/her life. This section provides a brief description of various legal planning tools.

### **Guardianship**

The subject of guardianship for an adult child who is disabled is of concern to most parents. Parents of children with mental retardation often assume that they continue to be their child’s legal guardian during their entire lifetime. Legally, the adult individual is presumed

competent unless otherwise decided through an incompetency proceeding in probate court. In other words, once your child reaches the age of 18, you, the parent, are no longer his/her legal guardian.

Guardianship is an option for persons who are incapable of making decisions about both personal and financial affairs. The probate court requires evidence of incompetence caused by either the person's mental illness, his/her mental retardation, or in some cases, by his/her inability to communicate wishes due to a physical or medical problem.

Guardianship also may be **limited** to certain areas of decision making, (for example, decisions about medical treatment), allowing the individual to continue making his/her own decisions in all other areas. The benefit of limited guardianship is in tailoring guardianship decrees to fit the special needs of the ward in the least restrictive manner.

For highly unusual decisions which were not anticipated at the time of the original guardianship hearing, the guardian may and probably should ask the court for instructions. **Decisions involving intrusive** forms of treatment such as administration of anti-psychotic medication and the withdrawal of life-prolonging treatment, must be made by the court.

As with conservatorship, the guardian must file an annual accounting of the ward's funds with the appointing probate court. The guardian must also be over 18, and if the guardian does not reside in Massachusetts, a local resident must be appointed as agent.

It is important for parents to realize that guardianship should not be applied for automatically when their child turns eighteen years of age. The parent needs to consider their child's strengths and weaknesses before deciding to seek guardianship. Where an individual is capable of making some, but not all, decisions, a parent should consider first one of the alternatives to guardianship discussed in the following paragraphs.

1. *Special bank accounts - Joint bank accounts* can be created to prevent rash expenditures. Arrangements can be made with most banks for a person's benefit check, such as Social Security or SSI, to be sent directly to the bank for deposit. Additionally, a permanent withdrawal order can be arranged authorizing the bank to send certain sums of money on a regular basis to a specified party, such as to a landlord or for pocket money, thus providing structure to allow for budgeting and money management.
2. *Trusts* may be an appropriate alternative to guardianship or conservatorship. A trust is a legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual. A trust will be less expensive in that no bond is required, it will keep the courts out of one's life (permission of a court is not needed to make disbursements from the trust or to make investments), and it protects the individual's assets without him/her having to be declared incompetent.
3. For persons receiving benefit checks from Social Security or Veteran's pensions, consider obtaining a *representative payee* to manage these funds. Benefit checks are sent to the representative payee who manages them and spends them for the benefit of the individual with the mental disability. The person who is disabled would still make personal decisions. Contact your local Social Security office to learn more about this arrangement.
4. A durable *power of attorney for property* is useful where the person is mildly or moderately incapacitated, and is capable of choosing another person to handle his/her money. The power of attorney (POA) is a legal document that grants one person the legal authority to handle the financial affairs of another. A durable POA continues the authority in the event the individual becomes disabled or incapacitated.

5. A *health care proxy* should be considered for individuals who presently are capable of making decisions about their health care and wish to anticipate possible future incompetency. A health care proxy is a legal document that enables a competent individual (the “principal”) to designate a health care agent to make health care decisions should the individual become incompetent to make them. The health care agent is permitted to make all health care decisions, including decisions about life-sustaining treatment, and in many ways eliminates the need for a guardian. Proxy forms are available from hospitals and health care providers.
6. *Conservatorship* should be considered when individuals are too disabled to manage their finances and who have income from sources other than benefit checks. It is not as broad a form of control as guardianship; a conservator handles only the person’s financial affairs, allowing the person to make personal decisions. The court may appoint a conservator if by reason of “mental weakness” the person is “unable to properly care for his/her property.”

All these alternatives should be considered prior to reviewing the option of guardianship.

# VII. *What are Other Resources to Draw Upon?*

This section is a short overview of programs for health care, work, and income. These programs sometimes change and you will need to apply for the specific service needed.

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## A. Income: Social Security and related programs

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Social Security is a program intended to provide income to retirees, people with disabilities and their dependents. The program is the major source of income for people with disabilities who are not employed. To get information about the program you can call a toll-free number, 1-800-772-1213. We have written a short overview of the program. In some cases, families request assistance in filling out the application. A local family support program or DMR area office may be able to assist you. It's also important to remember that Social Security benefits are utilized for room and board costs in public or subsidized housing.

Social Security has four programs related to individuals with developmental disabilities.

1. About 60% of Social Security beneficiaries are retirees who have paid into Social Security. A person eligible for Social Security retirement benefits becomes eligible to start collecting those benefits at age 62, but the benefit will be reduced based upon the number of months prior to age 65 the individual began collecting Social Security retirement benefits. At age 65, a person eligible for Social Security benefits becomes eligible for Medicare.
2. A second program within Social Security and the most utilized by those with disabilities is Supplemental Security Income or SSI. Eligibility for this program is based upon having a disability or being 65 years old or older, and also upon the level of household income and assets. Children who have a disability also qualify for this program if their family's income and assets are beneath

a certain level. When the child reaches the age of 18 years, Social Security will consider him/her independent from his/her parents when the household's income and assets are determined. The individual must undergo a disability determination to be eligible. Eligibility for SSI triggers eligibility for MassHealth (Medicaid) which is the state-funded health insurance program. This is a valuable resource. Eligibility for MassHealth allows you access to long-term support services such as personal care assistance (PCA) as well as health and dental care. Individuals who receive Social Security can also qualify for SSI if their check isn't above a certain maximum income figure.

3. A third program that is available through Social Security is Social Security Disability Income (SSDI) for individuals who become disabled during adulthood, and who have sufficient work history to qualify on their own. Usually the individual suffers a physical or psychological trauma that results in the inability to work. After two years of being eligible for SSDI the individual becomes eligible for Medicare coverage.
4. A dependent of an individual collecting Social Security retirement benefits or Social Security disability benefits, or a survivor of someone who has a sufficient work history to be eligible for those benefits, is also eligible for Social Security benefits. There is a family cap on the amount of benefits that can be paid out on an individual's earnings record. Therefore, a dependent's benefits can change as more people become eligible or lose their eligibility for Social Security based upon the same individual's earnings record. For example, a person with a disability qualifies under his/her father's Social Security benefits. Five years later, his/her

mother retires and collects from his/her father's benefits. Due to a family cap, the amount received from Social Security may be reduced or eliminated. The individual should apply for SSI (see program described in #2) before this change takes place or if receiving SSI as a secondary benefit, inform Social Security of the upcoming change.

- One other category of dependent or survivors' benefits that is very important to people with developmental disabilities is commonly referred to as "adult disabled child benefits." To be eligible for this benefit you must be 18 years of age or older, and show that you were continuously disabled before you turned 22 years of age. You can then collect Social Security benefits from a parent's earning record who is either already receiving Social Security retirement or disability benefits or who is deceased but who had worked enough to qualify for Social Security retirement or disability benefits. A person who receives adult disabled child benefits also obtains Medicare coverage. This benefit is subject to the family cap discussed above.
- If you have difficulty accessing any of the programs described in this section you may be able to receive assistance at your local legal services office (See lists after the appendix.) You can also contact the Disability Law Center at (800) 872-9992 and complete an intake for technical assistance.

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## B. Medical Care and Access to Long Term Care Programs:

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There are a number of healthcare coverage plans available for people with disabilities. The information which follows is meant to help you decide which benefit plan is the best option for you or your family member with a disability.

1. SSI, which stands for Supplemental Security Income, is administered by Social Security. Monthly benefits are distributed to people with limited income and resources who are disabled, blind, or age 65 or older. Blind or disabled children, as well as adults, can get SSI benefits. Unlike Social Security benefits, SSI benefits are not based on an individual's prior work or a family member's prior work. SSI is financed by general funds of the U.S. Treasury--personal income taxes, corporation taxes and other taxes. Social Security taxes withheld under the Federal Insurance Contributions Act (FICA) do not fund the SSI program. In most States, SSI beneficiaries can also get Medicaid (medical assistance) to pay for hospital stays, doctor bills, prescription drugs, and other health costs. ([www.saa.gov](http://www.saa.gov))
2. MassHealth (also referred to as Medicaid) covered services include inpatient hospital services, outpatient services such as home-healthcare and the Personal Care Attendant Program, medical services such as prescription medications, well-child screenings including medical, vision, dental, and hearing tests, shots, prescription and non-prescription drugs, and transportation services.

You can call the MassHealth Customer Service Center at 1-800-841-2900 (TTY: 1-800-497-4648) to request an application. Eligibility is based upon family income, but adults and children with disabilities are also eligible. ([www.mass.gov/eohhs](http://www.mass.gov/eohhs))

**3.** CommonHealth is a Massachusetts health care program for adults who are disabled and working, and also children who are disabled. Adults with disabilities who are working (at least 40 hours a month or \$510 a month) and people under the age of 18 or over the age of 65 who have a disability are eligible to receive CommonHealth. Benefits include hospital and doctor visits, prescription drugs, eye care, therapy, personal care attendants, and transportation to and from medical appointments. A monthly premium is based on family income and family size. If a family makes less than 114% of the federal poverty level, then they do not have to pay any premiums. There are sliding scale premiums above 114%. ([www.hcfama.org](http://www.hcfama.org))

To apply for CommonHealth, call the MassHealth Enrollment Center nearest you:

<b>Springfield</b>	<b>(413) 785-4100</b> <b>1-800-332-5545</b> <b>TTY: 1-800-596-1276</b>
<b>Taunton</b>	<b>(508) 828-4600</b> <b>1-800-242-1340 x700</b> <b>TTY: 1-800-586-1272</b>
<b>Tewksbury</b>	<b>1-800-408-1253</b> <b>TTY: 1-800-231-5698</b>

**4.** Medicare is a federal health insurance program for seniors and people with disabilities. It does not cover most long-term nursing home care, or full-time home care. It also does not cover certain routine services, including physical exams (except for a one-time only annual physical for new Part B members) and tests for vision and hearing. For more information, call Medicare at 1-800-633-4227 (TTY 1-877-486-2048). ([www.pathwaystocoverage.org](http://www.pathwaystocoverage.org))

**5.** Medigap is a special type of health insurance policy that helps pay for some of the things original Medicare doesn't cover. It fills in some of the "gaps" in Medicare coverage, but doesn't completely cover all costs. There is a monthly charge on top of the Medicare Part B premium to get Medigap.

Medigap policies are offered by private companies, but must follow certain rules set by Medicare. All Massachusetts Medigap policies must include hospital coinsurance coverage, 365 extra days of full hospitalization coverage, the first three pints of blood each year, and payment of the 20% coinsurance costs for medical care. Medigap policies may also offer benefits not included in Medicare, such as routine check-ups or emergency care out of the country. New Medigap plans do not include prescription drug coverage.

Many people with the Original Medicare Plan buy Medigap insurance, but not everyone. For example, some people have health insurance from a former job that offers more coverage than Medigap. You should consider your finances and health care needs before making a decision. If you do not buy Medigap when you are first eligible, you can buy it later during an open enrollment period.

For more information about Medigap call Medicare at 1-800-633-4227 (TTY 1-877-486-2048). ([www.massresources.org](http://www.massresources.org))

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## C. Work or Day Programs

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Social Security isn't enough to support one's needs. Work training is available through DMR or the Massachusetts Rehabilitation Commission (MRC). A central phone number for MRC is (617) 204-3600 or (800) 245-6543 (within Massachusetts). Supported employment or work programs are ideal to prepare for the work force. Furthermore, teenagers should be prepared for the world of work while attending school. If you receive Social Security or SSI, there are work incentive programs that can preserve health benefits or part of the SSI income. Work programs funded by MRC or DMR should be aware of these incentives.

SSI will even allow for benefits to be used for the development of a business or career. These programs have to be reauthorized by Congress from time to time.

If an individual needs services such as occupational or physical therapy he/she can attend a day habilitation program. This is funded by the Division of Medical Assistance (DMA). The DMR area office or local Arc can refer you to a local day habilitation program.

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## D. Elder Services

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There are several programs offered through Elder Services. As a person with a disability ages the elder service program in personal assistance may be more desirable. There are community day programs to be accessed as well. Elder Services also manages the Adult Family and Foster Care programs. (617) 727-7750 is the main number. They can also be reached via the agency hotline number, (800) 882-2003 or Voice/TTY: (800) 872-0166.

People with disabilities can qualify for some volunteer services provided by local elder agencies. One of these programs has a money management service to help people with their bills and checkbooks.

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## E. Transportation

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Transportation services continue to be inadequate for many people with disabilities. Those individuals with funded services are able to access DMR-funded transportation. Anyone attending a licensed employment program also should be able to get transportation services through DMR or another state agency. However, there may be a waiting period involved or long routes to tolerate. Advocacy for better transportation, especially in suburban and rural areas, is needed.

The Massachusetts Bay Transportation Authority (MBTA) provides services for people with disabilities who can't utilize standard public transportation. For information contact The RIDE at (617) 222-5123 or (617) 222-5415 (TTY). The RIDE serves a limited geographic area. Every region also has an RTA-regional transportation authority. Contact your town hall if you are unsure of the name of your authority. They may have limited programs for transportation in your community.

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## F. State agencies and corresponding services

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Type of Service	State or Public Agency other than DMR
Personal Care Services	Division of Medical Assistance (DMA-Medicaid) 1-800-841-2900 <a href="http://www.mass.gov/dma">www.mass.gov/dma</a>
Adult Family or Adult Foster Care	Local Area agency identified through Elder Affairs (617) 727-7750 <a href="http://www.mass.gov/elder">www.mass.gov/elder</a> or (800) 497-4648
Home Health Services	Visiting Nurse or Agency through Elder Affairs
Housing Assistance	Department of Housing and Community Development (DHCD) (617) 573-1100 <a href="http://www.mass.gov/dhcd">www.mass.gov/dhcd</a> Local Housing Authorities
Housing Accommodations	Massachusetts Rehabilitation Commission (MRC) (800) 245-6543 or (800) 204-3600 [ask for regional office nearest you] <a href="http://www.mass.gov/mrc">www.mass.gov/mrc</a>
Independent Living Centers (ILCs) Independent Living Centers are typically non-residential, private, non-profit, consumer- controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. Their goal is to assist individuals with disabilities to achieve their maximum potential within their families and communities.	Go to <a href="http://www.masilc.org">www.masilc.org</a> and look under “Membership” for a list of centers near you.
Employment/Day Support	MRC, Day Habilitation (DMA funded)
Transition Services	Local School or Special Education Director Department of Education (DOE) (781) 338-3000 <a href="http://www.mass.gov/doe">www.mass.gov/doe</a>

The Massachusetts Developmental Disabilities Council (MDDC) is involved in systems advocacy. Staff there can be contacted at (617) 770-7676 (TTY: 617-770-9499) or visit [www.mass.gov/mddc](http://www.mass.gov/mddc). In addition, the Massachusetts Office on Disability (MOD) advances legal rights and promotes opportunities for support services; client services and community services access programs are available through (617) 727-7440 (TTY: 800-322-2020) and [www.mass.gov/mod](http://www.mass.gov/mod).

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## G. Glossary

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This short glossary reviews some terms that were not defined in the handbook. The other terms such as description of supports and estate planning terms have not been repeated in the glossary.

### **Assessment**

Used for understanding the abilities and needs of an individual. The process is performed by a professional in developmental disabilities. It may include verbal and written tests, looking at past reports and history, and observing the individual doing various tasks.

### **Availability**

After individuals are determined eligible for services or supports from DMR or another state agency, the issue of availability of funding or services arises. For PCA services and special education services, availability does not apply as they are “entitlements.” For DMR and other state agencies, availability is based upon the size of the waiting list and the specific funds made available during the that fiscal year.

### **Eligibility**

This is the procedure that persons have to go through to determine whether they qualify for public programs. Each agency has its own guidelines. This process is the first step in obtaining services.

### **Family Support**

This is a “services category” that includes funding for any specific support given to a family that has a member with a disability. This includes items such as respite care, vouchers for after school and camp programs or concrete needs, and case management.

### **Partnership**

Private funds from families and others combined with public funds from DMR or other state/local agencies to develop a housing solution. It helps to increase the availability of limited public funds and also allows individuals/families more control over the solutions utilized.

### **Providers**

The state agencies often “contract” for services through a provider organization. The organization can be “non-profit,” which means its board of directors is made up of volunteers who gain no financial benefit; or, it can be a “for-profit” similar to many businesses where profits are distributed to board members and others.

### **Supports**

This term is used in place of the word “services.” They are provided by any staff person or volunteer in the activities of daily living.

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## H. National, State, and Local ARCs

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### **The Arc of the United States**

1010 Wayne Avenue, Suite 650  
Silver Spring MD 20910  
Ph: (301) 565-3842 Fax: (301) 565-3843  
Email: info@thearc.org  
Web: www.thearc.org

### **Public Policy Collaboration**

1331 H Street, NW, Suite 301  
Washington DC 20005  
Ph: (202) 783-2229 Fax: (202) 783-8250  
Email: gaoinfo@thearc.org

### **Massachusetts State Office:**

#### **The Arc of Massachusetts**

217 South Street, Waltham MA 02453  
Ph: (781) 891-6270 Fax: (781) 891-6271  
Email: arcmass@arcmass.org  
Web: www.arcmass.org  
Mary Ellen May, RN, MS, President  
Leo V. Sarkissian, Executive Director

## **Massachusetts Regional Chapters**

### **ARC COMMUNITY SERVICES**

564 Main Street Terry Kennedy  
Fitchburg MA 01420 Executive Director  
PH: (978)343-6662 info@arccommunityservices.org  
FX: (978)343-8852 www.arccommunityservices.org

### **BERKSHIRE COUNTY ARC**

395 South Street Ken Singer (x239)  
Pittsfield MA 01201 Executive Director  
PH: (413) 499-4241 bcarc@bcarc.org  
ksinger@bcarc.org  
FX: (413) 445-7863 www.bcarc.org

### **BOSTON ARC, GREATER (GBARC)**

221 N. Beacon Street Terri Angelone  
Boston MA 02135 Executive Director  
PH: (617) 783-3900 gbarc1@msn.com  
FX: (617) 783-9190 www.gbarc.org

### **BROCKTON AREA ARC (BAARC)**

1250 W. Chestnut Street Jay Lynch  
Brockton MA 02301 Executive Director  
PH: (508) 583-8030 BAARC@comcast.net  
FX: (508) 583-1739 www.BrocktonAreaArc.org

### **ARC OF CAPE COD,**

P. O. 428 Rob Spongberg  
171 Main Street Executive Director  
Hyannis MA 02601 arcofcapecod@hotmail.com  
PH: (508) 790-3667 www.arcofcapecod.org  
FX: (508) 775-5233

### **CENTRAL MIDDLESEX ARC (CMARC)**

147 New Boston Street Sheri McCann  
Woburn MA 01801 Executive Director  
PH: (781) 935-7057 smccann@cmarc.org  
FX: (781) 935-4227 www.cmarc.org

### **CHARLES RIVER ARC**

59 E. Militia Heights John Grugan  
Needham MA 02492 Pres. (453-9704)  
PH: (781) 444-4347 jgrugan@crarc.org  
FX: (781) 444-5146 www.crarc.org

### **THE ARC OF EAST MIDDLESEX ARC (EMARC)**

20 Gould Street Jo Ann Simons  
Reading MA 01867 Executive Director  
PH: (781) 942-4888 info@theemarc.org  
FX: (781) 942-0820 www.theemarc.org

### **FALL RIVER, ARC OF GREATER**

P. O. Box 1943 Dan Smith  
405 Pleasant Street Executive Director  
Fall River MA 02722 danarc29@msn.com  
PH: (508) 679-0001  
FX: (508) 679-9375

### **GREATER LAWRENCE, The Arc OF (CLASS, INC.)**

One Parker Street Robert Harris x 1202  
Lawrence MA 01843 Executive Director  
PH: (978) 975 8587 bharris@classinc.org  
FX: (978) 975-0498 www.classinc.org

### **GREATER WALTHAM ASSOCIATION FOR RETARDED CITIZENS, INC. (GWARC)**

56 Chestnut Street Roz Rubin  
Waltham, MA 02453 Executive Director  
PH: (781) 899-1344 rrubin@gwarc.org  
FX: (781) 899-2197 gwarc@gwarc.org  
www.gwarc.org

### **MINUTE MAN ARC FOR HUMAN SERVICES**

1269 Main Street Rosalie Edes  
Concord MA 01742 Executive Director  
PH: (978) 371-1515 redes@minutemanarc.org  
FX: (978)371-9790 postmaster@minutemanarc.org  
www.minutemanarc.org

### **NORTH SHORE ARC**

64 Holten Street Gerard McCarthy  
Danvers MA 01923 Executive Director  
PH: (978) 762-4878 jmccarthy@nsarc.org  
FX: (978) 777-6149 www.nsarc.org

### **NORTHERN BRISTOL COUNTY, The ARC OF**

141 Park Street Michael Andrade  
Attleboro MA 02703 Executive Director  
PH: (508) 226-1445 www.arcnbc.org  
FX: (508) 226-1476 mandrade@arcnbc.org

### **NORTHERN ESSEX COUNTY, THE ARC OF**

57 Wingate St., Ste. 301 Luis Bachman, Exec.  
Haverhill MA 01832 Director of Advocacy  
PH: (978) 373-0552 Pamela Weiner, Exec.  
FX: (978) 373-0557 Director of Operations  
arc.nec@verizon.net

### **PLYMOUTH, THE ARC OF GREATER**

Cordage Park Commerce Alex Perez  
10 Cordage Park Circle Executive Director  
Suite 208 info@thearcofgp.com  
Plymouth, MA 02360 www.thearcofgp.com  
PH: (508) 732-9292  
FX: (508) 732-9229

### **SOUTH NORFOLK COUNTY ARC THE ASSOCIATION/ SNARC**

789 Clapboardtree Street Dr. William Abel  
Westwood MA 02090 Executive Director  
PH: (781) 762-4001 abel@sncarc.org  
FX: (781) 461-5950 (or dwood@sncarc.org)  
www.sncarc.org

### **THE ARC OF THE SOUTH SHORE**

371 Rivers St David Calhoun x  
2211  
N. Weymouth MA 02191 Executive Director  
PH: (781) 335-3023 info@arcsouthshore.org  
FX: (781) 335-3682 www.southshorearc.org

### **SOUTHERN WORCESTER COUNTY ARC CENTER OF HOPE**

P. O. Box 66 James Howard  
Southbridge MA 01550 Executive Director  
PH: (508) 764-4085 howard@thecenterofhope.org  
FX: (508) 765-0255 www.thecenterofhope.org

### **THE UNITED ARC**

111 Summer Street Edward Porter  
Greenfield MA 01301 Executive Director  
PH: (413) 774-5558 arc@unitedarc.org  
FX: (413) 774-2585

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## **I. Legal Resources**

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### **DISABILITY LAW CENTER**

Boston Area Office  
11 Beacon St., Suite 925  
Boston, MA 02108  
Voice (617) 723-8455 or 1-(800) 872-9992  
TTY (67) 227-9464  
Fax (617) 723-9125  
www.dlc-ma.org

### **DISABILITY LAW CENTER**

Western MA Office  
32 Industrial Drive East  
Northampton, MA 01060  
Voice (413) 584-6337 or 1-(800) 222-5619  
TTY (413) 582-6919  
Fax (413) 584-2976  
[For all legal assistance inquiries please telephone the DLC at their Boston office.]

### **CENTER FOR PUBLIC REPRESENTATION**

Main Office  
22 Green Street  
Northampton, MA 01060  
VOICE/TTY: (413) 586-6024  
FX: (413) 586-5711  
info@cpr-ma.org  
www.centerforpublicrep.org

### **CENTER FOR PUBLIC REPRESENTATION**

246 Walnut Street  
Newton, MA 02460  
(617) 956-0776  
FX: (617) 928-0971

### **GREATER BOSTON LEGAL SERVICES**

Main Office  
197 Friend Street  
Boston, MA 02114  
(617) 371-1234 or 1-(800) 323-3205  
FX: (617) 371-1222  
www.gbbs.org

### **GREATER BOSTON LEGAL SERVICES**

Cambridge/Somerville Office  
60 Gore Street, Suite 203  
Cambridge, MA 02141  
(617) 603-2700  
FX: (617) 494 8222

**SOUTHEASTERN MASSACHUSETTS LEGAL ASSISTANCE CORP.**

30 Third Street, 3rd Floor  
Fall River, MA 02720  
(508) 979-7150 or 1-(800) 287-3777

**SOUTHEASTERN MASSACHUSETTS LEGAL ASSISTANCE CORP.**

21 South 6th Street  
New Bedford, MA 02740  
(508) 929-7150 or 1-(800) 244-9023

**SOUTHEASTERN MASSACHUSETTS LEGAL ASSISTANCE CORP.**

231 Main Street, Suite 201  
Brockton, MA 02301-4342  
(508) 586-2110 or 1-(800) 244-8393

**NEW CENTER FOR LEGAL ADVOCACY**

257 Union Street  
New Bedford, MA 02740  
1-(800) 244-9023  
TTY: (508) 990-7755  
[www.ncla.net](http://www.ncla.net)

**LEGAL SERVICES FOR CAPE COD AND ISLANDS, INC.**

460 West Main Street  
Hyannis, MA 02601  
(508) 775-7020 or 1-(800) 742-4107  
[www.lscii.org](http://www.lscii.org)

# VIII. *Appendix*

## Specific Housing and

## Partnership Models

FOUR DESCRIPTIONS OF EXISTING HOUSING  
SITUATIONS THAT INCLUDE:

1. PROFILES
2. STAFFING
3. FUNDING
4. PLANNING CONSIDERATIONS

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## Preface

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In Chapter IV, “The Dream as Reality,” we outline DMR definitions of housing options and staffing as well as discuss creating flexible options. These are four housing alternatives that are examples of what can be achieved.

### *Housing*

The purchase or rental of housing is a significant consideration in one’s budget. Consequently, it’s critical to find Section 8 or other subsidy support. Rent for a one-bedroom apartment in Massachusetts averages \$505 per month (2004 statistics). There is some variation across the state depending upon the region. You need to check what the going rates are and how much of the person’s Section 8 payments, along with client contributions (such as SSI), meet the rental expense.

### *Staffing Costs*

According to the U.S. Department of Labor’s Bureau of Labor statistics, the entry wage for direct support staff in community services is \$10.91 an hour. In addition, supervisors (frontline supervisors such as house managers) should demand a higher level of pay, approximately \$35,000. In some cases, agencies pay even more to have one person directly oversee more than one house. (Remember such costs would not include a small amount to pay toward program director or division director level of staff and senior staff in an organization. Some of this would be a percentage for general and administrative cost.) These are real costs of having an agency oversee services. In DMR you have multiple layers including the central office, regional offices, and area offices including service coordination staff. These are all paid by state dollars. In a provider agency you have to figure a cost for the organizational infrastructure to oversee services being provided.

If you decide to develop your own model or check on what is being projected for the housing cost of your own services, make sure you factor in staffing costs for both direct care and/or supervisory staff identified above.

In some cases we suggest you factor in fringe benefit or payroll tax cost. The cost of health-care is substantial and budgets need to take into account premiums for health care costs. In the alternatives where these factors are not considered costs it is because they are being projected in total fringe or through the PCA program where the payment is made directly for the benefit.

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## 1. Shared living apartment

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### **Description**

A two-family house (or larger) is purchased by family members. One apartment is home to the consumer and a peer or companion; the other unit provides rental income. The live-in companion is paid a stipend in addition to free rent. The stipend is based on the amount of support provided to the individual.

### **Consumer Profile**

This model could apply to all ability levels with the variable factor being the staff support needed for daily living needs. In this specific profile the individual has the following abilities: activities of daily living, some meal planning/preparation; ability to manage money in the store for routine transactions; and getting to various routine destinations independently such as work, grocery, and social activities. Needs of the individual include support in: checkbook and budget management; planning non-routine outings and transportation; help in medical appointments including verifying instructions; and support during major changes.

## **Staffing**

Overnight support through companion (only needed for emergencies); 15 hours per week staffing; 3 hours per week staff direction needed. Staff direction time increases intermittently if changes in staffing or other events require it.

## **Technical Expertise**

A lawyer is needed for purchase/mortgage; a banker would help with financial options; and a Personal Care Attendant Services provider would aid in setting up PCA services. Ideally, a case manager/service coordinator or provider case manager would organize how the support services are provided.

## **Public Sector Portion**

Medicaid PCA reimburses at a rate of \$10.85 an hour. The number of hours per week at which Medicaid PCA reimburses is based on functional need, usually starting at 10 hours of staffing per week. To recruit staff at a higher salary, families may subsidize the equivalent of \$4 an hour or more through a weekly stipend (payroll tax included on this supplement but not on PCA payments). Although there is a small relief contingency, contingency for additional cost due to staff turnover or temporary staff increase is not projected. Other sources of funding: Social Security or Social Security Disability. Rental subsidy is possible through Section 8, which would decrease rental costs and make project even more affordable.

## **Planning Consideration**

How the house is purchased and under whose name is an essential planning step. You can have it under the individual's name if you are attempting special purchase with aid of subsidy or you can have it placed in trust. In the former you need to consider conservatorship or trustee appointment for the house depending upon the capability of the individual; in the latter the trust should both protect consumer through his lifetime in regard to benefits and avoid any premature eviction or removal from his/her house. The payment to the agency is modest and presumes active family involvement. The payment to the agency would more than double to duplicate this alternative if the host agency became totally responsible for new staff recruitment, covering gaps in support and related needs. The reason for this is that you would have to build in a payment for a managerial staff person on a regular basis through the year in addition to some percentage fee for general agency expenses.

## **Time Considerations**

If you need supplemental funding from DMR, that will take the longest to secure, so begin there. There is no guarantee that they will have funding. The PCA services can take about 4-6 months for eligibility determination. The reimbursement may take two months to begin. You should ask whomever you are working with for the estimated time for each of these steps. Take into account time for house identification, negotiation and purchase. This could take several months as in any purchasing situation. Finally, helping your son or daughter prepare for the transition is essential. Involve him or her from the very beginning.

**MONTHLY BUDGET:**

Rent	\$ 1200
House Contingency	146
Utilities	134
Phone	48
Food	247
Recreation	180
Direct staff	\$ 974
Support staff	266
Agency	180
<b>TOTAL EXPENSES:</b>	<b>\$3,375</b>

**REVENUE:**

Social Security	\$ 600
PCA (Medicaid)	660
30% Section 8	715
Fam/Rent. Income	400
DMR	1000
<b>TOTAL FUNDING:</b>	<b>\$3,375</b>

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## **2. Small house for two individuals requiring 24-hr staffing**

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### **Description**

A ranch house with an open floor plan was chosen to make it more accessible. The three bedrooms on the first floor also have access to common space from different rooms. The house's wide floor plan limited major expenses for accommodations mainly to the private bathroom and equipment. Second doors off each bedroom allow private access to the bathroom, which includes an assistive device. There is an additional bathroom for a roommate and guests.

Adaptations are in the private bathroom and there's an additional bathroom without adaptations for guests and a roommate.

### **Consumer Profile**

Both individuals are in their 70s. Both ladies use wheelchairs and need a significant amount of support for their activities of daily living. For example, they receive help in preparing meals, going to the toilet, grooming, and dressing. They eat independently.

One of the ladies is 75 years old. They recently celebrated her mother's 100th birthday party with her family! During the day the ladies attend a day habilitation program funded by Medicaid where they receive physical therapy and occupational therapy as well as other services. One of the women works part-time and both ladies are members of churches. One of them has two friends who were initially identified through a "community of friends" effort at the agency.

## Staffing

A roommate model is utilized as opposed to overnight staff or third shift. Roommate responsibility is to sleep at the house for 5 nights a week. The person is responsible for being within the house from 10 PM and can leave at 8 AM, which would allow time for the morning routine. Morning routine includes the activities of daily living as mentioned—dressing, toileting, grooming, breakfast and then helping the ladies to their van.

The roommate staff receives housing, utilities, a phone line and health insurance in return for the overnight support. Staff are paid hourly for the morning routine. If someone is sick, staff will stay until relief staff is available. Otherwise, the roommate comes and goes as she pleases when not on duty since this is also her home and she lives there.

On weekends, a relief worker is available for the overnight duty in the extra bedroom or on a pullout sofa in the den.

The staffing at the house is mixed between the agency “staff” versus the personal care attendant “PCA”. The staff helps people budget their money, coordinates contact with families and volunteers and helps individuals access the community (see section on PCA). The staff sees that the individual service plan (ISP) is implemented and he/she is on-site to supervise the PCAs as necessary. Technically a PCA is directed or managed by the person with the disability. Since this is not possible in the situation of the two ladies living at the house, one family member and one agency program manager have been identified as “surrogates” for each of the ladies. This allows them the right to supervise the staff as needed. In turn, they delegate the ongoing duty to the staff that works at the agency alongside the PCA. 63

There is a 1:1 ratio which includes a staff and one PCA for all hours. This means that there are two staff people working at the house during the morning, afternoon and evening hours.

The agency also asks the PCAs to sign up for possible relief duty as staff. This allows the agency to initiate the CORI (potential criminal background) check since PCA duty alone is not eligible for CORI review.

The ladies have a total of 132 hours of PCA time (62 & 70 hours, respectively). There also is one full-time staff position with 29 hours of direct time with the ladies. Other staff are included in costs as well. The program manager oversees services for 17-18 people so those costs would be distributed by a percentage. There are two sets of staff costs at the agency which relate to its philosophy around managing houses. They have a coordinator who handles all scheduling of staff. They feel this avoids burnout of supervisors who in the past felt forced to fill gaps in their schedules. The coordinator also interviews staff and schedules doctors' appointments, etc. There are two part-time persons who work on community connections and the “community of friends.” Costs in the budget are reflected in subcategories just to help you understand the different components.

## Planning Considerations

This model requires coordination between a Medicaid-funded program and DMR funding. It utilizes staff expertise and includes some reasonable hourly rates for direct or supervisory staff. The mixed funding is a blessing but requires additional work. For example, to get PCA authorization, someone who knows the person applying for this service has to break down in task analysis the amount of time that each person needs: e.g., how much time it takes to brush teeth, prepare meals, etc. Re-authorizations for the PCA funding need to be submitted on an annual basis. The utilization of the schedulers decreases non-essential tasks for support staff and minimize burnout. The cost of this is reflected in the budget. Much of the work in this project was done by the agency involved with input from individuals and family, and support from DMR staff.

### Technical Expertise

This is significant both from a support perspective for individuals and the details of contracting with the different agencies. Especially important is ensuring supervision of PCAs. Agencies cannot directly oversee such staff.

### Public Sector Role

This played a major funding and monitoring role in this situation. The project couldn't have been established otherwise. The level of staffing is significant as well as the associated costs.

### Time Considerations

The purchase of the house and modification would take several months. However, this is far less time than would be involved in dealing with new construction.

There is a group of staff funded through overhead of this and other programs. These include:

Executive Director  
Business Manager  
Assistant Director  
Residential Director  
Maintenance Person

### MONTHLY BUDGET

#### Housing costs:

Mortgage	\$2,800
House Contingency	392
Utilities	145
Phone	140
Food	600
Recreation	300
<b>Total Housing:</b>	<b>\$4,377</b>

#### Staffing:

Direct PCA	6,073
Staff	1,746
Outreach	381
Manager	225
Benefits*	456
<b>Total Staff:</b>	<b>8,881</b>

**Staff & Housing:** 13,258

Overhead (15%) 1,989

**TOTAL EXPENSES: \$15,247**

#### REVENUE:

Social Security	\$1,200
PCA (Medicaid)	6,073
DMR Contract	7,974
<b>TOTAL FUNDING:</b>	<b>\$15,247</b>

*\*Benefits (19%\*, but benefits of PCA not included)*

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### 3. Shared house

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#### Description

Family members will purchase a small house for the individual to live in and it will be suitable for two individuals.

#### Consumer Profile

This particular example includes two young men who have moderate to minimal staff support needs. They have safety skills for transportation, dealing with strangers or emergencies. The gentlemen in this home do all their daily living activities independently. They have the following support needs: money management- budgeting (such as banking, check writing); preparing evening meal; laundry; overseeing house cleaning; planning for unusual expenses; getting to new destinations and planning some changes in schedule, shopping, etc. Support at medical appointments which are not routine and extended traveling support are also needed.

#### Staffing

The staffing needs are 30 hours per week total. Intense family involvement in supervisory and on-call support makes this work. Transportation is limited where they live so this is an impediment for more varied recreation and socialization of their own choosing.

#### Planning Consideration

How the house is purchased and under whose name is an essential planning step. You can have it under the individual's name if you are attempting special purchase with aid of subsidy or you can have it placed in trust. Working at getting partnership funding is essential. In this case one family bought the house and initiated readiness. A roommate with some "Turning 22" funding was identified and the two men turned out to be compatible. The hours of staffing are kept low because of family involvement for "on-call" situations and supervisory support when needed.

#### Technical Expertise

The following are needed: lawyer for purchase/ mortgage; a banker in helping with financial options; and a Personal Care Attendant Services provider to aid in setting up PCA services. Ideally a case manager/service coordinator or provider case manager will integrate the package of support services.

#### Public Sector Portion

Rental subsidy is possible through Section 8, which would decrease rental costs and make project even more affordable—it has been applied for.

DMR funding is essential to this solution.

#### Time Considerations

DMR supplemental funding will take the longest to secure, so, if you need it, begin there. There is no guarantee that they will have funding. Take into account time for house identification, negotiation and purchase. This could take several months as in any purchasing situation. Finally, helping your son or daughter to prepare for the transition is essential. Involve him or her from the very beginning.

#### MONTHLY BUDGET

##### Housing costs:

Rent	\$ 1,600
Utilities	50
Food	290
Clothing	110
Transportation.	45
Recreation	200
Insurance	30
Medical	40
Miscellaneous.	60
<b>Total Housing:</b>	<b>\$2,575</b>

<b>Staffing:</b>	
Direct (25 hours)	\$1,548
Case Manager	344
Relief	180
Benefits	378
Supervision (15%)	284
Indirect (8%)	
<b>Total Staff:</b>	<b>\$2,734</b>
<b>Staff &amp; Housing:</b>	<b>\$5,309</b>
<b>TOTAL EXPENSES:</b>	<b>\$5,734</b>

<b>REVENUE:</b>	
Social Security	\$1,200
SSI	140
Work	460
DMR	3,934
<b>TOTAL FUNDING:</b>	<b>\$5,734</b>

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## 4. Shared living with family member

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Note: Of course there's nothing new about shared living with family members. It's been going on for decades. Typically sons or daughters continue to live with their parents or parent until it is no longer possible. Sometimes this means that the young or middle-aged adult begins to lose out on social activities with peers as it becomes tougher for the older parent to provide transportation. With more flexible funding options available from DMR, some families are opting to fund support services within the family home (this is called "In-Home Family Partnership"). However if you choose this route make sure you have arranged for adequate funding and that you have a future plan. Is there a brother, sister or friend that will continue this "In-Home" arrangement? If not, will someone (friend or family) be available to advocate for further residential support when parents are no longer able to do that?

This example is included because some brothers or sisters strongly consider shared living situations with a sibling who has a disability. Sometimes what prevents such an arrangement from taking place is financial—needing a larger living situation or needing to ensure that a certain amount of respite is available if support on a daily basis is needed from the sibling.

### Description

A condominium is shared with the family of a younger brother (husband, wife and child). On the weekends, beginning after work on Friday, the individual goes to stay at parents' house within 40 minutes of the condominium. Parents are in their mid-70s. The condo is near the center of town, allowing the individual to get to a coffee shop-bakery by himself and attend a social activity independently that he used to have his father drive him to for years. The family is committed to continuing the shared living even after the weekend routine is no longer possible.

## **Consumer Profile**

He is in his 40s and he is independent in his activities of daily living. He works with the assistance of a part-time job coach but this is a relatively new job and he will not need much support in the future. His experience in the world of work has helped him become more independent socially and he is financially aware. He is capable of staying home alone overnight or late by himself. Moving in with his brother's family has enhanced his independence as he goes to activities or to town by himself. He is very active socially with a full range of programs through the Parks Department or family outings.

## **Staffing**

In the future, intermittent respite support may be needed, but at the present time transportation is the key issue. He uses The Ride when needed for work and elsewhere. He is able to get to town and some activities by walking, due to proximity. Parents have been away for several weeks during the year and there has been no need for formal additional support.

## **Planning Consideration**

This is really a lifestyle decision and one that reflects matching of personalities. The decision involves some sacrifice on the part of family members to share their lives. In planning the family schedule there is now one more person to consider. The benefit is the enjoyment and satisfaction that the family experiences in seeing the individual with the disability continue to grow and lead a more interesting life style.

This is also a decision that needs to be shared by both spouses. The brother's wife encouraged this development and her family also thought it was a great idea. The extended family has been very welcoming. He is included in all family outings with the wife's extended family.

Geography and transportation is a big consideration. This move is a plus. But if someone lives in a rural setting, you need to consider how the transportation will work and additional funds may be needed.

The parents plan to leave a trust for their son. This will allow some additional support after they die. This was discussed with the entire family when the arrangements were made so other siblings would understand that some additional arrangements and funds were being set aside for the son with the disability and indirectly to their other son as well.

The plan for support is geared to the needs of the individual with the disability. If a man or woman requires help with daily living tasks such as dressing, a family may be less inclined to play this role unless there is some ongoing in-home support. But then that means having "staff" or "home health aides" come into your shared living area. It is something to think through and possibly "try out" first before making a final decision. Thoughtful planning is the key.

## **Technical Expertise**

By trying things out first one can see if there are specific things which are particularly difficult. Involve DMR staff or case managers early on to see what the possibilities are for state funding. Make sure your assessments of strengths and weaknesses have been done.

## **Public Sector Portion**

The funding from the state and monthly stipend from Social Security is utilized toward utilities and housing costs.

## **Time Considerations**

This is not very time consuming in relation to housing development. The hardest part in this plan is decision making and looking at changes in routine for family and the individual with disabilities.

## Monthly Budget

The budget reflects typical categories of a household budget, including living expenses of an additional family member. Transportation is usually provided by sibling or spouse of sibling. At times The Ride is used (through MBTA), which has a nominal fee. Some of the social activities have fees. Income from a job is used for personal expenses and savings.

It makes sense to project a monthly amount to address future needs in the event of more necessary staffing, emergencies, and related costs. This money could be banked in a separate account to be used as needed.

### MONTHLY BUDGET

This can vary greatly based on family, needs and location. The cost factors to consider are:

Rent

Utilities

Social Activities

Transportation

Staff (to provide additional support)

#### ***Revenue will include:***

Social Security

DMR funding

Work earnings

Supplemental needs trust