

# Unlocking the Door to Community Living

*a guide for families of people with disabilities*

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## **INTRODUCTION**

*Jewish Family & Children's Service has created this guidebook with a very specific goal in mind: helping families take action that unlocks the door to community living for their adult children with disabilities.*

*Because planning the transition from family home to community living can be so challenging, families often have a hard time just getting started. For some, a lack of clear information is the problem. For others, information overload makes the planning process seem more daunting than it needs to be. For these reasons, this guidebook cuts to the chase, providing only the information you'll need to get started with confidence.*

*References to more comprehensive resource information are included throughout the workbook so you can learn more about each topic. In most sections, you will also find practical words of advice that will help you anticipate common frustrations or avoid them altogether.*

*If you're using the electronic version of the guidebook, you'll be able to access all of the referenced resources and documents by clicking on the links. You'll also be able to save and complete the worksheets and life planning documents on your computer, making it easier to update information as your circumstances change.*

*Whether you're just beginning the planning process or are well on your way, we hope you find this guidebook useful as you complete the work that unlocks the door to community living for your son or daughter, regardless of his or her disabilities.*

Betsy Closs, Director  
Services for People with Disabilities  
Jewish Family & Children's Service

## CREATING YOUR CHECKLIST

*The following worksheet almost certainly includes tasks you've already completed, tasks already on your "to do" list, and tasks that are not relevant to your circumstances. In any case, this tool can help you create a customized checklist that covers all the bases. Information you'll need to complete most of these tasks is provided in the following pages of this guidebook.*

✓To Do	Financial Planning	✓Done
	List all income and assets (page 6-4).	
	Apply for SSI and/or SSDI (page 2-3).	
	Project your son or daughter's long-term needs for financial support. To begin, see page 6-4.	
	Consult a lawyer and financial advisor with expertise in benefits and disability planning (see page 2-2).	
	Establish your son or daughter's financial independence (a legal construct) to facilitate access to benefits (page 2-2).	
	Execute a will and estate plan.	
	Create a special needs trust or join a pooled trust (page 2-7).	
	Discuss financial plans with your other children.	
	Review financial plan on a regular basis (page 6-18).	
✓To Do	Healthcare	✓Done
	Apply for MassHealth (page 2-4).	
	Develop plan for healthcare coordination (page 3-1).	
	Identify healthcare providers with expertise caring for people with disabilities and transfer care as needed (page 3-3).	
	Complete healthcare forms in Life Planning section and distribute to those involved in coordinating care (pages 6-12 through 6-15).	

✓To Do	Community Housing	✓Done
	Determine service needs (page 4-4).	
	Complete housing search worksheet (page 4-6).	
	Apply to suitable supported housing programs (page 4-1).	
	Identify and apply to potential funding sources for support services (page 4-2).	
	Learn about subsidized housing resources (page 4-10).	
	Complete subsidized housing action plan (page 4-12).	
✓To Do	Preparing for Independence	✓Done
	Evaluate independent living skills (page 5-2).	
	Get a formal evaluation (page 5-6).	
	Teach essential independent living skills (page 5-7).	
	Hire coach to teach independent-living skills (page 5-9).	
	Build social connections in the community (page 5-11).	
	Line up transportation resources (page 5-14).	
✓To Do	Building a Life Plan	✓Done
	Complete life plan worksheets (pages 6-2 through 6-17).	
	Solicit input from family, friends, and professionals.	
	Distribute life plan documents to selected individuals (page 6-18).	

## **FINANCIAL PLANNING FUNDAMENTALS**

*At the end of a long day, it's very hard to summon the energy to read a book on financial planning for people with disabilities, much less a guide to government benefits. Perhaps you've ignored the subject because you doubt this type of planning is relevant to your situation. Whatever the reason, you could be unaware of fundamental facts that make financial planning a top priority for parents of adults with disabilities.*

### **What Every Parent Should Know**

#### **Special education entitlements end at age 22.**

If your son or daughter continues to need services that were provided as part of his or her Individual Education Plan (IEP), you must find other ways of meeting these needs and may be faced with significant out-of-pocket expenses you hadn't anticipated. Even if your son or daughter qualifies for needed services through other government programs, access is not guaranteed and availability is often limited due to insufficient funding.

#### **Savings or assets in your son or daughter's name may make him or her ineligible for essential benefits and services.**

For most families, a primary goal of estate planning is to make sure the person with disabilities remains qualified for federal and state benefits programs including Social Security Disability Income (SSDI), Supplemental Security Income (SSI), Medicare, and/or MassHealth (Medicaid). Direct inheritance can trigger a loss of benefits until the inheritance is exhausted.

#### **Relying on siblings to meet future needs usually strains family relationships.**

When it is unclear how much of the family inheritance is to be reserved for the son or daughter with disabilities, disagreement among siblings is common and sometimes causes permanent family rifts.

#### **Government benefits may be essential, but they are also insufficient for sustaining a good quality of life.**

Three facts make this point clear:

- Supplemental Security Income (SSI) provides a maximum benefit of \$788.39 per month in 2010 for a Massachusetts resident with disabilities who lives alone.
- An adult living in a state-funded group home must pay 70 -75% of his or her SSI benefits to the group home provider to cover room and board.
- A person in a nursing facility whose care is covered by Medicaid must relinquish all cash benefits except a "personal needs allowance" of only \$72.80 per month (2010 figure).

#### **A financial plan that works today may not work tomorrow.**

Just like everyone else, most people with disabilities need more services and support as they grow older. Moreover, there are no guarantees that the public services and benefits available today will remain available throughout a person's lifetime.

In light of these hard facts, what should you do to protect your son or daughter's future? The elements of a wise strategy are laid out on the following page.

## Strategies and Resources

In most cases, families will need to take the following steps to safeguard the lifelong well-being of a family member with significant disabilities.

1. Consult an attorney and financial planner with expertise in benefits and disabilities planning. The **Academy of Special Needs Planners** is an organization of attorneys specializing in this area. For a list of members, visit their website at **[www.specialneedsanswers.com](http://www.specialneedsanswers.com)**.
2. Project long-term needs for financial support based on a comprehensive living-expenses budget that accounts for inflation and the possibility that service needs will increase over time. To begin this process, complete the budget worksheet on page 6-4.
3. Establish the financial independence of the individual with disabilities from a legal standpoint (unless doing so jeopardizes access to Social Security Disability benefits based on a parent's work record). In most cases, the person with disabilities will have greater access to government benefits if he or she is not claimed as a dependent on tax returns or any other legal document.
4. Apply for all government benefits for which the person with disabilities may be eligible (page 2-3).
5. Execute an estate plan – including a will – that addresses the long-term needs of the person with disabilities.
6. Create a special needs trust or join a pooled trust to meet needs that government benefits do address (page 2-7).
7. Create a Life Care Plan for the person with disabilities (page 6-1).



*For more information about financial and legal planning for people with disabilities, please see JF&CS's **Special Needs Planning Guide for Families**, available online at **[www.jfcsboston.org](http://www.jfcsboston.org)**.*

## **GOVERNMENT BENEFITS**

*The following summary of government benefits for people with disabilities won't tell you everything you need to know, but it does provide a straightforward introduction to the primary sources of public assistance for adults with disabilities. For more information about government benefits and financial planning, please see JF&CS's **Special Needs Planning Guide for Families**.*

### **Cash Benefits**

#### **Supplemental Security Income (SSI)**

**SSI** provides cash benefits for adults and children with disabilities whose income and assets fall below the limits established by each state. In Massachusetts, the maximum monthly benefit (and qualifying income) for a disabled adult under age 65 is \$788.39 (2010 figure). The actual benefit varies according to the individual's living situation and any other sources of income. To qualify for SSI, a single applicant may have no more than \$2,000 in assets excluding his or her home and a car used for medical and/or work-related purposes.

- ➞ If your son or daughter is currently receiving SSI, be sure to notify Social Security when he or she moves out of the house, as this change is likely to trigger an increase in his or her benefit. You should also consult an attorney who is knowledgeable about SSI before deciding to pay your son or daughter's rent as this financial support may be considered income and could decrease his or her benefit.

#### **Social Security Disability Insurance (SSDI)**

**SSDI** provides monthly income for disabled adults who qualify based on their own payroll contributions or the contributions of a retired or deceased parent. Like regular Social Security, the amount of the monthly check depends on insured person's total contributions to the program through payroll taxes. Unlike SSI, eligibility for SSDI does not depend on income or assets.

#### **SSI and SSDI Application Process**

To **apply for SSI or SSDI**, call **1-800-772-1213** (TTY 1-800-325-0778) and make an appointment to file a disability claim at your local Social Security office or to set up an appointment for someone to take your claim over the telephone. The disability claims interview lasts about one hour. If you schedule an appointment, a Disability Starter Kit will be mailed to you. This kit will help you get ready for your disability claims interview. You can also start your application on line by going to **[www.socialsecurity.gov/disability](http://www.socialsecurity.gov/disability)**.

- ➞ If you are approved for SSI and/or SSDI, your benefits will begin on the date you first contact Social Security. For this reason, it's important to make the initial contact as soon as possible.

You should also be aware that applications for SSI and SSDI are frequently denied. If you begin the process expecting that you will need to appeal the initial decision, you can be prepared to move ahead if and when you receive your denial. To conserve time and resources, it is usually advisable to complete the initial application yourself, then involve a lawyer to help you with your appeal if that becomes necessary.

#### **SSI and SSDI Work Incentives**

Special rules called "work incentives" allow beneficiaries to test their ability to work while keeping some or all of their cash benefits and health insurance.



The rules for SSI beneficiaries are simple: when an SSI beneficiary is employed, his or her benefit is reduced by *half* of his or her earned income after an \$85 exemption and deductions for “Impairment Related Work Expenses,” *i.e.* money spent on attendant care, transportation, and/or work-related adaptive equipment and supports.

SSDI beneficiaries receive full benefits regardless of how much they earn during a “trial work period.” The trial work period ends when the beneficiary earns more than \$720 a month in any nine months during a rolling five-year period. For three years after the trial work period ends (the “extended eligibility period,” the beneficiary receives full benefits any month his or her earnings fall below the “substantial gainful activity” level (\$1,000/month in 2010) assuming he or she is still disabled. For five more years, the beneficiary can ask for benefits to resume immediately while his or her disability status is reviewed. In short, as long as the individual earns less than the SGA level and remains disabled, he or she can retain full SSDI benefits indefinitely.

Please note that there is no extended eligibility period following the trial work period for disabled adults receiving SSDI based on their parents’ work record.

### **Emergency Aid to the Elderly, Disabled, and Children (EAEDC)**

**EAEDC** is a Massachusetts program that provides cash and medical assistance for people who are not receiving benefits from any other program. EAEDC payments are credited to the same electronic benefits transfer (EBT) card as food stamp payments.

You cannot receive EAEDC and SSI or SSDI at the same time, but you *can* receive EAEDC while waiting for SSI or SSDI approval, and benefits can begin within days of submitting an application. In 2010, EAEDC pays a maxi-

mum benefit of \$303 per month for a single person.

➔ **To apply for EAEDC**, go to the nearest office of the Department of Transitional Assistance (DTA). To find out where the nearest **DTA office** is located, Google “DTA offices” or call **1-800-249-2007**. Sign and date an application form even if no one is available to help you finish the application when you first go to the DTA office. If you qualify for EAEDC, your benefits will begin on the day you sign the form.

### **Supplemental Nutrition Assistance Program (SNAP)**

Low-income people with disabilities can also alleviate financial stress by applying for SNAP (formerly known as **food stamps**). SNAP provides beneficiaries with an EBT card that can be used to purchase nutritional food. In 2010, the maximum monthly allotment placed on the card is \$200 for a single person.

For information about applying for SNAP, go to **[www.gettingfoodstamps.org](http://www.gettingfoodstamps.org)** or call the Application Information Hotline at **1-800-249-2007**.

### **Health Insurance**

#### **Medicaid (MassHealth)**

Funded jointly by the state and federal governments, Medicaid (called MassHealth in Massachusetts) covers most acute-care and long-term care expenses, including prescription medications, for low-income people with qualifying disabilities. *In most cases, SSI recipients automatically qualify for Medicaid.*

For information about **MassHealth** programs, coverage, eligibility, and application procedures, go to **[www.mass.gov](http://www.mass.gov)**, call the MassHealth Enrollment Center at **1-888-665-9993** (TTY 1-888 665-9997), or call the MassHealth Customer Service Center at **1-800-841-2900** (TTY 1-800-497-4648).

### Medicare

Funded entirely by the federal government, Medicare provides partial coverage of approved healthcare costs for people with disabilities who qualify based on their own pay-roll-tax contributions or the contributions of a retired or deceased parent (see SSDI description above). Low-income people with Medicare may also qualify for coverage of copayments and deductibles through the Medicaid program. In fact, many people with disabilities have both Medicare and Medicaid coverage. For more information about Medicare, go to [www.medicare.gov](http://www.medicare.gov) or call 1-800-633-4227 (TTY 1-877-486-2048).

### Commonwealth Care

Massachusetts subsidizes private health insurance for adults with income below 300% of the Federal Poverty Level (less than \$32,496 for individuals in 2010). Qualified consumers may choose from a list of managed care providers and pay monthly premiums and copayments based on their income. For residents of the Boston area with 250-300% of FPL, the monthly premium for Commonwealth Care ranges from \$116 - \$151 per month, considerably less than market rates for individuals who cannot access insurance through their employers. For more information, go to [www.mahealthconnector.org](http://www.mahealthconnector.org).

### **In-home Care**

#### Adult Family Care

Massachusetts' Adult Family Care program provides a monthly stipend of \$578 - \$1,492 (2010 rates) for caregivers of people with disabilities age 16 and over. To qualify for this program, the person with disabilities must live with the caregiver, need daily assistance with personal care, and be eligible for Medicaid (see below). Stipended caregivers may be relatives or non-relatives including the care recipient's parents, but not his or her legal guardian. *When deciding whether to*

*become your son or daughter's legal guardian when he or she turns 18, you should know that this step will disqualify you from receiving an Adult Family Care stipend.*

For more information about this program, go to [www.massresources.org](http://www.massresources.org) and search for "**adult family care**."

### Personal Care

MassHealth (Medicaid) provides in-home support services through the **Personal Care Attendant Program** (PCA), **Adult Family Care**, and **Group Adult Foster Care** (GAFC) programs. To qualify, applicants must be MassHealth/Medicaid eligible and need daily assistance with personal care (not just household management and personal organization) to continue living in the community. Go to [www.massresources.org](http://www.massresources.org) for more information about these programs.

The **Department of Developmental Services** (DDS) provides funding for in-home support through its residential programs as well as its flexible respite care and cash assistance programs. For more information contact the **area office** serving your location. To find your area office, go to [www.mass.gov](http://www.mass.gov) and search for "**DDS area office locator**."

### **Independent Living Services**

In addition to vocational rehabilitation services, the Massachusetts Rehabilitation Commission (MRC) provides community living services for working-age adults with any disability except blindness. (The Massachusetts Commission for the Blind serves people with vision impairment.)

MRC's independent living services include **homemaking assistance** for adults with disabilities age 18 - 59 (*i.e.* help with shopping, meal prep, light cleaning, errands) and case coordination services (including 24-hour

access) for adults with physical disabilities who want to live independently.

The MRC waiting list for homemaker services is currently closed (as of December 2010), but may re-open in the future. Call **(617) 204-3853** for up-to-date information.

MRC also collaborates with **Independent Living Centers** (ILCs) throughout Massachusetts. ILCs provide advocacy, skills training, peer counseling, and information for adults with disabilities who want to live with maximum independence and autonomy. For more information, go to [\*\*www.mass.gov/mrc\*\*](http://www.mass.gov/mrc).

### **Housing Subsidy**

People with disabilities obtain subsidized housing in one of two ways: living in a low-income housing development or obtaining a rental assistance voucher from a local housing authority. Either way, rent is typically set at 30% of the tenant's income. For information on accessing subsidized housing, see page 4-10.

### **Fuel and Utility Assistance**

There are several sources of fuel and utility assistance for low-income people in Massachusetts. For up-to-date information, go to [\*\*www.massresources.org\*\*](http://www.massresources.org) and click on "**Energy/ Utility Assistance**."

### **Vocational Services**

Both the state and federal governments fund comprehensive services for preparing people with disabilities to enter the workforce, helping them find employment, and supporting them on the job. The "Ticket to Work" program is the Social Security Administration's comprehensive system for helping SSI and SSDI recipients enter or re-enter the workforce. The Massachusetts Rehabilitation Commission (MRC) provides most "Ticket to Work" services in the Boston area.

For more information about Ticket to Work, go to [\*\*www.ssa.gov/work\*\*](http://www.ssa.gov/work). For information on services available through the Massachusetts Rehabilitation Commission (MRC), go to [\*\*www.mass.gov/mrc\*\*](http://www.mass.gov/mrc).

## SPECIAL NEEDS TRUSTS

*A special or supplemental needs trust has two purposes: 1) to manage funds for someone who cannot do so due to disability and 2) to preserve eligibility for government benefits.*

*A special needs trust is an excellent way to provide for the needs of a person with disabilities after the death of his or her parents.*

### Basic Definitions

**Trust:** a form of ownership in which one person (*the trustee*) manages the property or asset for the benefit of someone else (*the beneficiary*). The trustee must follow the instructions laid out in the trust agreement regarding distribution of the trust income and principal.

**Third-party trust:** a trust created and funded by someone other than the beneficiary (*i.e.* by the parents of a person with disabilities).

**Self-settled trust:** a trust created and funded by the beneficiary with his or her own assets.<sup>1</sup>

**Safe-harbor trust:** a special type of self-settled trust that allows a beneficiary to shelter his or her own assets, retain eligibility for public benefits, and remain a continuing beneficiary of the trust.<sup>2</sup>

**Pooled trust:** a third-party or self-settled trust funded for multiple beneficiaries and

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<sup>1</sup> JF&CS offers **third-party and self-settled pooled trusts** with funds managed by the Combined Jewish Philanthropies portfolio manager. For information, call **781-647-5327**.

<sup>2</sup> In Massachusetts, there are two types of safe-harbor trusts: single-beneficiary and pooled trust. The single-beneficiary trust must use funds remaining in the trust following the beneficiary's death to reimburse the Commonwealth for expenditures it has made on the beneficiary's behalf. A pooled trust is not required to reimburse the state upon the death of the beneficiary as long as funds are retained for the benefit of other beneficiaries with disabilities.

administered by a non-profit organization with the ability to manage normal trustee responsibilities and understand the care needs of beneficiaries with disabilities.

### Trustee Selection

The trustee(s) of a special needs trust must fulfill the normal functions of a trustee (accounting, investments, tax returns, and distributions) *and also be able to meet the needs of the beneficiary with disabilities*. To fulfill this dual responsibility, parents often appoint a family member to serve as co-trustee with the professional trust officer. When there is no family member who can serve as co-trustee, parents can direct the professional trustee to consult with named individuals who know and care for the person with disabilities. Or, they can use a pooled trust.

Since professional fees can be unreasonable in relation to the size of a trust of less than \$50,000, many families choose one of the following options: 1) appointing a family member as sole trustee and hiring the appropriate professionals (lawyer, accountant, investment advisor) to help administer the trust or 2) using a pooled trust.

### The Letter of Intent

A letter of intent is a written document that provides guidance for the trustee(s) and others who will be involved in meeting the current and future needs of a family member with disabilities. By carefully preparing this document, families can minimize disruptions and ease transitions that will inevitably occur in response to changing circumstances over a

lifetime. The letter of intent helps trustees and others make decisions that honor the unique needs, values, strengths, preferences, and relationships of the person with disabilities.


A Life Care Plan can also serve the purpose of a letter of intent while providing additional information that will be useful to the trustee(s) and his or her advisors. See pages 6-1 through 6-18 for instructions.

### **Funding the Trust**

Parents face tough questions when it comes to funding a special needs trust:

- Should their estate be divided equally among their children, regardless of need?
- What if the estate – however it's divided – is insufficient to meet the projected needs of the family member with disabilities?

For many parents, a permanent life insurance policy is a means of addressing these equity and sufficiency dilemmas. Assets created by the policy can supplement the portion of the estate designated for the special needs trust.

 *For more information about special needs trusts, please see JF&CS's **Special Needs Planning Guide for Families**, available online at [www.jfcsboston.org](http://www.jfcsboston.org).*

## **COORDINATING HEALTHCARE**

*Coordinating healthcare for a person with disabilities is a complex and time-consuming job. Before your son or daughter moves from the family home, it is essential to identify who will take responsibility for each of the components described below.*

### **Managing Medical Appointments**

If you were to keep records of time spent managing your son or daughter's medical appointments over a 12-month period, you might be shocked at the number of hours you've logged. Depending on how much your son or daughter can handle independently, your total would include time spent on the following tasks:

- Scheduling (and re-scheduling) appointments.
- Preparing your son or daughter for the appointment; letting him or her know what to expect.
- Securing necessary referrals.
- Arranging time off from work for appointments.
- Getting your son or daughter ready on the day of the appointment; making sure any pre-exam instructions are followed.
- Providing transportation to and from the appointment.
- Providing emotional support while in the waiting room and, when needed, during the exam.
- Helping your son or daughter communicate with the doctor.
- Accompanying your son or daughter for testing (lab work, radiology, etc.).
- Reviewing the visit with your son or daughter to make sure he or she understands what has occurred.

- Making follow-up appointments.
- Making sure medical records are sent to specialists, as needed.
- Communicating medical diagnoses and instructions to all others involved in your son or daughter's care.
- Being available after the appointment to receive calls from the physician regarding test results and follow-up treatment.

How will your role change when your son or daughter moves to community housing? Who will be responsible for these tasks if you are no longer involved? Again, your plans should address these questions specifically.

### **Following Medical Instructions**

Often, what happens between medical appointments has the greatest impact on health and well being of the individual. In other words, being able to consistently follow medical instructions is essential. These instructions typically involve the following:

- Dietary requirements and restrictions.
- Prescribed exercise and rest.
- Activity restrictions following a procedure or injury.
- Post-operative self-care.
- Environmental modifications (e.g. allergen reduction, adaptive equipment installation, etc.).
- Use of home-health equipment.
- Medication management (see page 3-4).

When making plans that address your son or daughter's future healthcare needs, it's important to consider his or her need for assistance carrying out instructions in each of these areas.

### **Dealing with Insurance and Billing Problems**

In many respects, medical insurance and billing are money management issues and can be addressed by your plans for meeting your son or daughter's needs in that arena. However, when it comes to healthcare, money management issues are also access issues. If your son or daughter's insurance plan does not cover a medication that has been prescribed, who will negotiate the issue with the health plan, the physician, and/or the pharmacy? If special authorization is needed in order for the drug to be covered and the pharmacist is unable to reach the doctor, who will follow up? If your son or daughter could benefit from services from a provider who is not in the plan's network, who will advocate for coverage? Who can authorize private payment if that is in your son or daughter's best interest? A complete plan will provide answers for these types of questions.

### **Maintaining a Healthy Lifestyle**

While insuring access to appropriate medical care is obviously essential to your son or daughter's well being, maintaining a healthy lifestyle will be equally important, yet this aspect of planning for future needs rarely receives comparable attention. If your son or daughter will need support to maintain a healthy diet, get enough exercise, interact with others, and engage in meaningful activity on a regular basis, how does your plan address those needs? For suggested approaches and resources, see pages 5-13.



## **FINDING THE RIGHT HEALTHCARE PROVIDERS**

*As any parent can attest, it isn't easy to find primary care physicians, dentists, therapists, and other specialists with the experience and sensitivity needed to provide quality care for a person with disabilities. The right provider makes a world of difference, and the loss of a trusted doctor or therapist – due to changes in insurance, relocation, or other changes – can be traumatic. When a person with disabilities prepares to establish an adult life in the community, it is an excellent time to evaluate satisfaction with all medical providers.*

### **Basic Questions**

Taking the time to address concerns raised by the following questions before your son or daughter moves from the family home will improve the chances of a successful transition.

- Does this provider have experience treating other patients with my son or daughter's issues?
- Is my son or daughter at ease with this provider?
- Did he or she have a better relationship with another provider? What were the qualities that made that relationship more successful?
- Does the doctor understand my son or daughter's way of communicating symptoms and needs?
- Does the doctor allow the extra time that may be required to conduct an exam or diagnose a problem?
- Does he or she show active interest in maximizing my son or daughter's health and quality of life?
- Does the doctor collaborate directly with other providers involved in my son or daughter's care or does he or she rely on the parent to be the go-between?

If your answer to any of these questions is "no", you may want to consider replacing the provider. In most cases, the best way to identify a great provider for your son or daughter is to ask other parents of people with disabilities. Anyone who has found a provider who is truly sensitive to their child's needs will be happy to help other families by sharing the information.

### **Meeting Future Needs**

Even if you are confident in the healthcare your son or daughter is receiving, planning for independence raises a tough question: Who will help your son or daughter find new providers when they are needed? Who will advocate for access to specialists (especially outside of an insurance plan)? Who will oversee the transfer of medical records? Who will make sure new providers are oriented to his or her special needs and sensitivities? A good life plan will provide answers to each of these questions, specifying who will assume these responsibilities and providing guidance that will help them fulfill their role.



## **MANAGING MEDICATIONS**

*Like every other aspect of healthcare coordination, medication management isn't one task, but many – and every single one of them is critical. Your son or daughter may be quite independent with some, but not others. When planning for the future or preparing for a move, it is important to identify every aspect of your involvement in medication management and determine how those responsibilities will be met after your son or daughter moves from the family home. The following is a list of essential tasks.*

1. Receiving prescriptions (at the doctor's office or through the mail).
2. Picking up prescriptions at the pharmacy, managing the ordering process by mail, and/or arranging for home delivery.
3. Making alternative arrangements for filling a prescription if the regular pharmacy is out of stock or if a prescribed drug is not covered by insurance.
4. Covering co-payments.
5. Properly storing medications.
6. Ordering refills before supplies are exhausted. Keeping track of remaining refills and getting new prescriptions as needed.
7. Keeping an up-to-date list of medication allergies and/or sensitivities, current medications and doses, former medications, and all associated dates.
8. Making sure all providers (primary care physician, mental health providers, and specialists) are kept up-to-date regarding all medications and supplements the person with disabilities is taking.
9. Creating and monitoring a system for taking medications as prescribed. Tasks may include filling a medication cassette on a weekly basis; setting reminder alarms on wristwatch or cell phone; providing medication reminders as needed; monitoring self-administered medication compliance; or providing complete assistance.
10. Observing and recording responses to medications.
11. Understanding all possible side effects and knowing when to notify medical personnel.

➡ **Please note:** *If your medication management plan involves more than one person, you should clearly define each individual's role to avoid the crises that miscommunication or assumptions can cause.*

## **SUPPORTED HOUSING OPTIONS**

*The following overview summarizes current supported housing options, associated costs, and potential funding sources.*

### **Supported Community Living**

Supported living programs typically serve people with disabilities who do not need 24-hour support. Housing, support services, and meals are arranged and paid for separately, then coordinated in an overall plan that makes it possible for the client to live as independently as possible.

Supported living clients live in their own homes or apartments – with or without a roommate – and receive individualized support services to maintain their health, safety, and wellbeing. Services may include assistance with money management, medication management, personal care, healthcare coordination, and grocery shopping as well as homemaking services, life-skills coaching, and on-call emergency assistance from program staff. Clients of a supported living program may also share one or more meals per week and participate in social activities organized by the program provider.

Since supported living programs serve such a diverse population, out-of-pocket costs and sources of funding vary dramatically, depending on the individual's needs, housing choice and eligibility for public benefits. To estimate the basic recurring costs of a supported-living plan, families need to add up the costs of the service, housing, and food components.

**Service costs:** If support services are provided by a qualified agency that takes full responsibility for staff screening, training, scheduling, supervision, and emergency back-up, families should expect to pay from \$700 to \$2,000 or more per month for this component of the supported living plan, depending on the level of services needed.

**Housing costs:** Unless the individual obtains subsidized housing (see page 4-10), the housing component of a supported living plan may cost as much as the service component. Rents in the Boston area continue to be among the highest in the country with one-bedroom units typically renting for \$1,200 or more per month.

**Food costs:** Obviously, food budgets can vary tremendously depending on an individual's diet, the number of prepared meals purchased, and the degree to which food costs are shared. Based on JF&CS's experience as a supported living program provider, we recommend that parents estimate a cost of \$300-\$500 per month.

### **Sources of Funding**

Because the components of a supported living plan are paid for separately, and because supported living serves adults with such a broad range of abilities, funding comes from several different programs administered by several different public agencies. In most cases, these funding sources will only cover a portion of the total cost of a supported living plan. Almost always, private resources are also needed, underscoring the importance of financial planning to secure the future of the person with disabilities. The following chart lays out the basic categories of supported living expenses and possible funding sources for each.

### Potential Sources of Public Funding for Supported Living Plans

	Agency*	
<b>Support Services</b>	Department of Developmental Services (DDS)	<ul style="list-style-type: none"> <li>• Individual Support Services</li> <li>• Community Residential Services</li> </ul>
	Department of Mental Health (DMH)	<ul style="list-style-type: none"> <li>• Community Based Flexible Supports</li> </ul>
	MassHealth (Medicaid)	<ul style="list-style-type: none"> <li>• Personal Care Attendant program (PCA)</li> <li>• Adult Family Care (AFC)</li> <li>• Group Adult Foster Care (GAFC)</li> </ul>
	Mass Rehab Commission (MRC)	<ul style="list-style-type: none"> <li>• Homemaker services</li> </ul>
<b>Rent</b>	Public Housing Authorities	<ul style="list-style-type: none"> <li>• Section 8 Housing Choice Vouchers</li> <li>• Project-based Section 8</li> <li>• Subsidized housing developments</li> </ul>
<b>Food</b>	Department of Transitional Assistance (DTA)	<ul style="list-style-type: none"> <li>• Food stamps</li> </ul>
<b>Utilities</b>	<i>Various</i>	<ul style="list-style-type: none"> <li>• Fuel assistance</li> <li>• Discounted utility rates</li> </ul>

*\*For more information about these agencies and programs, go to [www.MassResources.org](http://www.MassResources.org).*

#### Shared Living or Home Sharing

Shared living (also called home sharing) is a housing arrangement in which the person with disabilities lives with a caregiver or companion who provides support services in exchange for room and board and/or a stipend. The person with disabilities may share his or her home with the live-in companion/caregiver or the caregiver may open his or her home to the person with disabilities. Other support services may be arranged to supplement the assistance provided by the housemate.

Shared living and home sharing arrangements can be appropriate for people who need 24-hour care as well as people who need more limited assistance. If the person with disabilities is eligible for DDS services or MassHealth (Medicaid), funds may be available to pay the caregiving housemate through DDS's Individual Support Services, MassHealth's Personal

Care Attendant program, or MassHealth's Adult Family Care program.

#### Adult Family Care

Massachusetts' Adult Family Care program provides a monthly stipend of \$578 - \$1,492 (2010 rates) to caregivers of people with disabilities age 16 and over. To qualify for this program, the person with disabilities must live with the caregiver, need daily assistance with personal care, and be eligible for MassHealth (Medicaid). *Stipended caregivers may be relatives or non-relatives including the care recipient's parents, but not his or her legal guardian.* Before deciding to become your son or daughter's legal guardian when he or she turns 18, please remember that this step will disqualify you from receiving an Adult Family Care stipend. For more information about this program, go to [www.massresources.org](http://www.massresources.org) and search for "[adult family care](#)."

### Small Group Living

Group living programs (often called “group homes”) provide housing, meals, case management, healthcare coordination, personal care, counseling, skill building, household management, social activities, and 24-hour on-site supervision. A typical program serves two to five residents living together in a house or large apartment that is usually rented or owned by a provider agency.

Total costs typically range from \$45,000 - \$80,000 per person per year depending on the number of residents living at a site and the level of staffing they need. Staffing expenses (including direct service, supervision, and program management) comprise approximately 80% or more of total program costs.

Typically, residents pay 70-75% of their SSI benefits to cover room and board costs. A combination of MassHealth (Medicaid) and

Department of Developmental Services (DDS) or Department of Mental Health (DMH) funding typically covers the balance of program costs.

Eligibility for DDS funding for residential services has become extremely restrictive. To qualify for any DDS service, an individual must have an IQ of 70 or lower. In order to receive funding for residential services, the individual must also have significant need for medical and behavioral support services. DDS clients who do not qualify for residential services may qualify for individual support services, which can be integrated into a supported living plan.

➡ *For information about supportive housing programs throughout the Greater Boston area, contact JF&CS's **Disabilities Resource Network** at 781-647-5327, extension 1940.*

To learn about new housing opportunities as they arise, join JF&CS's **Housing Opportunities Network**. As a member you will receive the Network's bi-monthly e-newsletter, which provides information about new and upcoming housing opportunities you might not otherwise discover. Members can also sign up for Housing Now e-mail alerts regarding time-sensitive housing opportunities for people who are ready to respond immediately.

To join the Network, go to [www.surveymonkey.com/s/S9T2NQW](http://www.surveymonkey.com/s/S9T2NQW) and complete a very short registration survey. Results of this survey help JF&CS tailor its housing programs to meet the needs of HON members.

## **ASSESSING SERVICE NEEDS**

*Parents often underestimate the level of support their son or daughter will need when he or she first moves from the family home. On the other hand, many underestimate their son or daughter's ability to become more independent once he or she is out of the house. Without the right supports, chances of a successful transition to community living are slim—no matter how perfect the housing or its location. At the same time, support staffing can be the most expensive component of a housing plan for a person with disabilities. For all of these reasons, a realistic assessment of support needs is essential to the planning process.*

### **Professional Assessments**

If you decide to arrange for a professional assessment, be sure to request a written summary that can be shared with all the housing providers you are considering. Professional evaluations of independent-living skills and service needs are usually available through special-needs housing providers, including JF&CS.

The cost of a private assessment varies according to the comprehensiveness of the evaluation and the professional time required. A complete assessment will consider the following: health history, psychosocial needs, independent-living skills, motivation, and the results of other professional evaluations.

Even if your son or daughter does not need or want to move within the next year or two, a professional assessment can lead you to resources that will improve your his or her quality of life and independence in his or her current living situation.

See Section 5, page 6 for more information about arranging a professional evaluation.

### **Why Most Families Underestimate Service Needs**

As long as your son or daughter is living at home, much of what you do to meet his or her needs is simply part of the household routine. Perhaps you make sure your son is up while your coffee is brewing and check to make sure he has taken his pills before he leaves the house. At night, you lock up, set his alarm, and put out clean work clothes to make the morning easier. None of these “services” takes any time from your day, but what happens if you’re not there?

### **A Place to Start**

The worksheet on the following page will help you identify the many invisible ways you and others in your household support your son or daughter’s daily routine. With this simple inventory in hand, you will have a better idea of the services that would be needed if he or she were to move from the family home today.

For a more detailed life-skills inventory, please see page 5-2.

For each of the following tasks, indicate the type of help needed and how the need is currently met.  
Here are some possible answers:

**Type of help:** total, hands-on, supervision, reminders, back-up, no help needed.

**Frequency:** daily, 1-3 times per week, on a regular basis, often, occasionally.

**Source of help:** parents, other relative, friend or neighbor, day program, paid help.

Task	Type of help	Frequency	Source of help
1. Getting up on time.			
2. Choosing clothes; getting dressed.			
3. Taking care of personal hygiene			
4. Laundry and housekeeping.			
5. Grocery shopping.			
6. Menu planning & meal preparation.			
7. Scheduling medical appointments.			
8. Going to medical appointments.			
9. Following medical instructions.			
10. Filling prescriptions as needed.			
11. Taking medicine as prescribed.			
12. Keeping a schedule, staying organized, meeting deadlines.			
13. Handling the unexpected ( <i>e.g.</i> power outage, missed bus, <i>etc.</i> )			
14. Using public transportation.			
15. Taking safety precautions at home and in public.			
16. Shopping for clothes and toiletries.			
17. Paying bills and budgeting.			

## **FOCUSING YOUR HOUSING SEARCH**

*When it comes to finding the right housing for a person with disabilities, it's immensely helpful to know what you're looking for. The following worksheet helps you identify your needs and priorities in relation to several key features. When considering each item, ask yourself "What are my son or daughter's strengths and preferences? What makes her happy? What environment works best for her? What doesn't work?"*

	Necessary ( <i>non-negotiable</i> )	Desirable	Willing to consider	Does not meet needs ( <i>non-negotiable</i> )
<b>ACCOMODATIONS</b>				
Private apartment ( <i>no roommate</i> )				
Private bedroom in shared apartment or house ( <i>1-2 roommates</i> )				
Private bedroom in shared apartment or house ( <i>3-4 roommates</i> )				
Remain in current home				
<b>LOCATION</b>				
Pedestrian friendly				
Near public transportation				
Diverse neighborhood				
Grocery shopping within walking distance				
On-site parking				
Specific town or neighborhoods:				

	Necessary ( <i>non-negotiable</i> )	Desirable	Willing to consider	Does not meet needs ( <i>non-negotiable</i> )
<b>PHYSICAL FEATURES</b>				
Handicap accessibility				
No stairs				
Air conditioning				
Allergen-controlled environment				
Low noise levels; good sound insulation				
Ample space for pacing or withdrawing when senses are overloaded				
Control over personal space and possessions				
Outdoor space ( <i>garden, yard, deck</i> )				
Personal internet access				
Pets allowed ( <i>specify type</i> ):				
Other:				
<b>FINANCING</b>				
Market-rate purchased housing				
"Affordable" purchased housing				
Market-rate rental housing				
Subsidized rental housing				



	Necessary ( <i>non-negotiable</i> )	Desirable	Willing to consider	Does not meet needs ( <i>non-negotiable</i> )
<b>SOCIAL LIFE</b>				
Communal meals ( <i>at least once a week</i> )				
Housemates of similar age				
Housemates with similar interests and abilities				
Activities and outings organized by the housing provider				
Jewish Life programming ( <i>Shabbat and holiday observance, learning and service opportunities</i> )				
Other:				
<b>SUPPORT STAFFING</b>				
24-hour staffing in the home				
<u>In-person</u> assistance, reassurance, and coaching <i>At least once a day</i> <i>At least twice a week</i>				
Coaching and reassurance <u>by telephone</u> <i>At least once a day</i> <i>At least twice a week</i>				
Staff on call 24/7				
Other:				

	Necessary ( <i>non-negotiable</i> )	Desirable	Willing to consider	Does not meet needs ( <i>non-negotiable</i> )
<b>SERVICES</b> (regular assistance with)				
Money management				
Housekeeping and laundry				
Menu planning, meal prep				
Grocery shopping				
Other shopping				
Bathing, brushing teeth, dressing, etc.				
Scheduling medical appointments				
Going to medical appointments				
Communicating needs to healthcare providers				
Following medical instructions				
Filling prescriptions				
Taking medications				
Building a social life				
Keeping a personal schedule				
Arranging or using transportation				
Taking safety precautions at home and in public				
Other:				

## **SUBSIDIZED HOUSING RESOURCES**

*Finding affordable housing in the Greater Boston area requires planning, persistence, and the ability to move very quickly when opportunities do arise. The first step is to become familiar with the programs designed to make housing affordable for people with limited income.*

### **Rental Assistance Vouchers**

If you can get a “mobile” rental assistance voucher, you will pay only 30% of your income for rent and the government will pay the rest. You may choose any apartment that meets program guidelines, and you can keep your voucher if you decide to move. In other words, the subsidy is attached to you, not to a specific apartment or housing complex.

There are three mobile voucher programs in Massachusetts, the largest of which is the Section 8 Housing Choice Voucher Program financed by the federal government. To qualify for a Section 8 voucher, the applicant’s income can be no more than 50% of the area median (\$32,150 for a single person in the Boston area in 2010). Moreover, three-fourths of all vouchers must go to those with 30% or less of area median income (\$19,300 for a single person in the Boston area in 2010). These vouchers are obtained from local housing authorities.

#### **The Section 8 Centralized Waiting List**

Approximately 80 housing authorities in Massachusetts are currently collaborating to maintain a centralized waiting list for rental assistance vouchers. Whenever a voucher becomes available through any of the participating housing authorities, all applicants receive consideration based on the priorities and preferences of the issuing agency. Regardless of which agency issues your voucher, you may use it anywhere in Massachusetts.

#### **DHCD Section 8 Vouchers**

The Massachusetts Department of Housing and Community Development (DHCD) also issues Section 8 vouchers through the Regional Housing Agencies.

#### **Project-Based Section 8 Vouchers**

Project-based rent vouchers are tied to specific apartments selected by local housing authorities. To find out which housing authorities have open wait lists for project-based vouchers, contact the Regional Housing Agencies (see Action Plan, page 4-12).

#### **State-Funded Vouchers**

Massachusetts funds two mobile voucher programs: the Massachusetts Rental Voucher Program (MRVP) and the Alternative Housing Voucher Program (AHVP). Both are issued by local housing authorities.

#### **Availability**

With a few minor exceptions, there have been no increases in funding for rent vouchers in several years. Therefore, most vouchers are only available through turnover and some voucher waiting lists are closed. Even so, some applicants do receive vouchers every year, so it is wise to apply to the various agencies that issue vouchers as soon as possible.



*The array of voucher programs and application procedures can be confusing, but if you follow the Housing Search Action Plan on page 4-12 and the Housing Application Instructions on page 4-13, you won’t miss out on any opportunities to receive a voucher when one becomes available.*

### **Subsidized Housing Developments**

Public housing projects and privately sponsored subsidized housing serve low-income tenants who typically pay 30% of their income for rent. To qualify for a subsidized unit in a public housing development, applicants must have no more than 80% of area median income (\$45,100 for a single person in the Boston area in 2010). The income limit for privately owned subsidized housing is lower: typically 50% of the area median income (\$32,150 for a single person in the Boston area in 2010).

#### Availability

Most subsidized housing developments—both public and private—are fully occupied and many have lengthy waiting lists. Nevertheless, the wait for some types of apartments can be relatively short.

At present, people with disabilities are most likely to find an available unit in developments designated for seniors and people with disabilities, particularly if a studio apartment is acceptable or a wheelchair-accessible unit is needed.

Monitoring development of new affordable housing developments and submitting timely applications can also expedite your search.

For information about all available units, go to the Mass Access Housing Registry at [www.massaccesshousingregistry.org](http://www.massaccesshousingregistry.org). All listings include contact information.

### **Other Affordable Housing Options**

In addition to rental subsidy programs, other mechanisms for making housing more affordable include low-income housing tax-credit (LIHTC) financing and Chapter 40B, a Massachusetts state law that facilitates development of new affordable housing.

#### Tax-Credit Housing


In newly constructed or rehabilitated housing financed with tax credits, a percentage of the units must be occupied by tenants whose income is less than 50-60% of the area median. Rent is restricted, but *usually exceeds 30% of the tenant's income* since it is determined by the size of the unit and the *maximum* qualifying income – not the actual income of the tenant. To identify tax-credit housing throughout Massachusetts, go to [www.massaccesshousingregistry.org](http://www.massaccesshousingregistry.org).

#### Home Ownership Opportunities

In order to meet financing and/or permitting requirements, some new developments offer a certain number of units for buyers with an annual income less than 80% of the area median (\$45,100 for a single person in the Boston area in 2010). Demand for these below-market units typically exceeds their availability, so the opportunity to purchase them is typically determined by lottery. To find out about affordable home ownership opportunities and upcoming housing lotteries, go to [www.massaffordablehomes.org](http://www.massaffordablehomes.org).

- ➡ For more information about all of these subsidized housing options – including links to applications – go to [www.MassResources.org](http://www.MassResources.org) and click on **Housing Programs** in the main menu on the left side of home page.
- ➡ To receive timely notification of subsidized housing opportunities in the Greater Boston area, join JF&CS's **Housing Opportunities Network** and sign up for email alerts. See page 4-3 for more information.

## **SUBSIDIZED HOUSING ACTION PLAN**

 **Please note:** The applications and contact information referenced in the following action plan can be found in JF&CS's Subsidized Housing Applications packet. If you are accessing this guidebook online, just click on the links to download the necessary applications and information.

	Done
1. Complete the Section 8 Housing Choice Voucher Program <b><u>Centralized Waiting List Pre-application</u></b> and return to one of the housing authorities listed on the back of the application.	
2. Complete the <b><u>DHCD Housing Choice Voucher Pre-Application</u></b> and return it to the <b><u>regional housing agency</u></b> that serves the town where you currently live.	
3. Make a list of 10 towns where your son or daughter would be willing to live. <i>(See the attached list of <b><u>public housing authorities</u></b> to help you think of possibilities.)</i>	
4. Complete the <b><u>Universal Standard Application</u></b> for State-Aided Public Housing.	
5. Ask your doctor or social worker to complete the <b><u>Verification of Handicapped Status</u></b> .	
6. Mail or deliver copies of the Universal Standard Application and the Verification of Handicapped Status to the housing authorities of the 10 towns on your list. <i>(See the attached list of <b><u>public housing authorities</u></b> for addresses.)</i>	
7. Get a copy of your Social Security Benefits Letter and keep it in a folder with your Verification of Handicapped Status so you can respond to opportunities quickly when they arise. <i>(You can request a copy of your benefits letter online at <b><u>www.ssa.gov</u></b> or at your local Social Security office.)</i>	
8. Go to <b><u>www.massaccesshousingregistry.org</u></b> and search for "income based/subsidized" housing in the 10 towns on your list. Follow the application instructions included with each listing.	
9. Submit an application for a rental assistance voucher to housing authorities that do not participate in the Centralized Waiting List. Call each housing authority to find out whether their voucher waiting lists are open and to request an application. <i>(See the attached list of <b><u>public housing authorities</u></b>.)</i>	
10. Contact the Regional Housing Agencies to find out whether any wait lists are open for project-based rent vouchers. <i>(See the attached list of <b><u>regional housing agencies</u></b> for contact information.)</i>	

## **HOUSING APPLICATION INSTRUCTIONS**

*Please read the following instructions carefully to maximize your chances of finding subsidized housing.*

### **For the Centralized Waiting List and DHCD Housing Choice Voucher pre-applications:**

1. In the “Head of Household” blank, write the name of the person with disabilities, not the parents.
2. Only provide information about the income of the person with disabilities, not the family.
3. Check the box indicating that the “Head of Household” is disabled.
4. Indicate that one person will live in the unit (unless a live-in aide is required).
5. Be sure to indicate circumstances that will give you higher priority on the wait lists:
  - On the **Centralized Waiting List application**, check all that apply including “Disabled” and “Extremely Low Income” (if on SSI). If the current home is not fully accessible and accessibility is needed, check “Health Condition.”
  - On the **DHCD application**, check off “I am doubled up with friends or relatives” under “current housing situation” if the person with disabilities is living with his or her and no other description applies.

### **For the Universal Standard Application:**

1. Under “Type of public housing you are applying for,” check off the following:
  - Non-elderly, Handicapped
  - Family
  - MRVP (rental assistance voucher)
  - AHVP (rental assistance voucher)
2. Also check off “Elderly” if person with disabilities is 62 or over.

### **For the Verification of Handicapped Status:**

Prepare a completed form for the physician or licensed social worker to sign (see **sample**) and offer it along with a **blank form**. Most physicians will be happy to sign the completed form, which will expedite the process of getting this critical piece of documentation.

### **If the person with disabilities needs a live-in aide:**

Have a physician sign a letter similar to the **sample “Request for Reasonable Accommodation.”** This will be particularly helpful in towns where two-bedroom units are easier to obtain than one-bedroom units.

## **NO MORE WAITING!**

*Once you begin your housing search, it can take many months before the right opportunity presents itself. Rather than simply waiting, families can make great use of this time by helping the person with disabilities prepare for a life of greater independence and involvement in the wider community. By helping the person with disabilities build independent-living skills while still living in the family home, parents can ease the transition to community housing while decreasing the level of support that will be needed.*

### **First, Take Stock**

Which independent-living skills has your son or daughter mastered? Which do you think he or she can learn? By completing the skills inventory beginning on page 5-2, you'll evaluate where your son or daughter stands in relation to fundamental independent living skills.

### **Consider Motivation**

For a person with disabilities, acquiring a specific skill may have meaning that is quite personal, associated with his or her individual interests, fears, and desires. In any case, it is important to identify his or her motivation for making the effort – apart from the parents' agenda. Even more than innate capacity, motivation may be what determines whether your son or daughter succeeds in acquiring new independent-living skills.

### **Prioritize Learning Objectives**

By completing the independent-living skills inventory, you may identify a long list of skills your son or daughter currently lacks. If so, where do you begin? For a list of top priorities, please see page 5-7.

### **Find the Right Coaches and Teachers.**

Once you have identified and prioritized learning objectives, it's time to look for coaches and teachers that fit your son or daughter's needs, personality, and learning style.

Parents can be great teachers, especially if the person with disabilities is motivated and adolescent rebellion is no longer an issue. A person without disabilities who has recently mastered similar skills can also be an effective trainer for a person with mild impairments. In many cases, however, a paid life-skills coach will be the most effective choice. For information about coaches and coaching resources, see page 5-9.

### **Build Social Connections**

Unless your son or daughter already has a satisfying social life, helping him or her develop meaningful relationships beyond the family circle should be a top priority while waiting for community housing. By developing confidence, friendships, and a sense of belonging outside the family home, your son or daughter is far more likely to make a successful transition to community housing.

For strategies and resources that can help your son or daughter build a social life, see page 5-11.

## **TAKING STOCK OF INDEPENDENT LIVING SKILLS**

*Evaluating independent living skills is the first step in the process of preparing for community living. Use the following checklist to consider important skills that you might otherwise overlook in assessing your son or daughter's readiness to live independently. To help you complete this exercise as accurately as possible, you may want to arrange for a professional evaluation of your son or daughter's capabilities and potential for acquiring new skills.*

<b>Personal Hygiene</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Bathe and wash hair regularly.				
• Brush and floss teeth.				
• Groom hair and nails.				
• Use deodorant daily.				
• Change clothes daily.				
• Choosing clothes appropriate for the weather and activity.				
<b>Housekeeping</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Wash dishes and put them away.				
• Clean up spills in kitchen.				
• Clean the bathroom.				
• Keep clutter under control; put things away after using.				
• Take out garbage.				
• Vacuum and dust.				
• Do laundry at home.				
• Do laundry in a laundromat.				
• Change light bulbs.				
<b>Grocery Shopping</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Make a shopping list.				
• Find items in the local market.				
• Read labels.				
• Stay within a shopping budget; avoid impulse purchases.				
• Bring groceries home; put away properly.				



<b>Meal Preparation</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Make healthy meals that he or she eats willingly.				
• Read and follow preparation instructions on food packages.				
• Find ingredients.				
• Safely use correct utensils.				
• Safely use microwave oven.				
• Safely use stove and turn off when finished.				
• Safely use oven and turn off when finished.				
• Store food properly.				
• Recognize when food is spoiled and throw away.				
<b>Money Management</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Carry cash responsibly.				
• Use an ATM.				
• Make and follow a budget; keep track of paid and unpaid bills; pay bills on time.				
• Keep files and records.				
• Build savings to cover unanticipated expenses.				
• Use credit or debit card; avoid credit-card debt.				
• Keep files and records.				
• Write checks and balance accounts, manually or on the computer. Avoid overdrafts.				
• Make deposits, withdrawals, and transfers.				

<b>Social Connections</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Read facial expressions and body language. Pick up on indirect messages.				
• Initiate conversations.				
• Be a good listener.				
• Know when to be quiet; control impulse to speak.				
• Express thoughtfulness and consideration.				
• Join groups; be part of a group.				
• Make friends; be a good friend.				
• Use e-mail and social networking while protecting identity & safety.				
<b>Healthcare</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Recognize when he or she needs medical care.				
• Communicate needs to family, support staff, and health providers.				
• Obtain emergency care.				
• Manage medications.				
• Get regular exercise.				
• Choose healthy foods.				
• Follow dietary restrictions.				
• Control snacking.				
<b>Time Management</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Keep personal calendar.				
• Establish helpful routines.				
• Make lists; create reminder systems.				
• Initiate activity.				
• Transition from one activity to another.				
• Prioritize activity.				

<b>Telephone Use</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Answer the phone properly.				
• Retrieve voice mail messages.				
• Get phone numbers as needed.				
• Follow an automated telephone menu.				
• Use accepted telephone etiquette for business and personal calls.				
• Leave message on voice mail.				
• Use mobile telephone.				
<b>Appointments</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Make a call to schedule an appointment.				
• Write down appointments.				
• Cope with scheduling conflicts.				
• Keep appointments; set up reminder system.				
<b>Independent Travel</b>	Can and will do independently.	Can do with reminders.	Doesn't do.	May be able to learn.
• Use public transportation.				
• Follow road rules (e.g. traffic signals, crosswalks, etc.)				
• Read street signs.				
• Read maps.				
• Plan travel routes.				
• Recognize and avoid dangerous situations.				
• Cope with the unexpected (e.g. train delays, crowds, detours)				

## GETTING A FORMAL EVALUATION

*It is often difficult for parents to predict how much their son or daughter will be able to manage independently and how much support he or she will need after moving from the family home. In most cases, a formal neuropsychological or occupational therapy evaluation will be very helpful.*

### Definitions

#### Neuropsychological Evaluation

Conducted by a neuropsychologist, a neuropsych evaluation involves gathering and interpreting data regarding the way an individual's brain functions. Drawing on the results of interviews and a range of standardized tests, a neuropsych evaluation assesses intelligence, attention, memory, personality, problem-solving ability, language skills, perception, motor skills, executive functioning, and learning abilities.

#### Occupational therapy (OT) Evaluation

Conducted by an occupational therapist, this type of evaluation assesses daily living skills, gross and fine motor skills, motor planning skills, and sensory processing skills (*i.e.* the ability to take in, sort out, and respond to input received from the world.)

### Benefits

A formal evaluation can:

- Assess ability to live independently.
- Resolve differences of opinion between the person with disabilities and his or her family regarding his or her capabilities.
- Identify capabilities that the person with disabilities (or family members) didn't realize he or she had.
- Uncover invisible disabilities that have not been previously recognized, such as problems with executive functioning or non-verbal learning disabilities.
- Provide information that supports skill building: what to target, how to accom-

modate disabilities, best ways to teach skills.

- Provide documentation that will help you access subsidized housing, services, and benefits.
- Identify new strategies for maximizing recovery and independence.

### Funding

MassHealth (Medicaid) usually pays for neuropsychological evaluations and Medicare will sometimes pay, but private insurers often balk at covering this service. Some do, however, so be sure to check your policy or call your customer service representative to find out whether you qualify for coverage.

Occupational therapy evaluation is more likely to be covered by all types of insurance, but qualifying criteria differ so check your policy before arranging an evaluation.

If you pay privately for a neuropsychological evaluation, it will likely cost \$3,000 to \$4,500 depending on the scope of the evaluation and the credentials of the clinician conducting it.

### Arranging for an Evaluation

To arrange for an evaluation, ask your primary care or mental health provider for a referral or contact the Behavioral Neurology department of a major hospital. Most supported living programs also provide formal evaluations.

➡ *For more information about where and how to get a formal evaluation, call JF&CS's **Disabilities Resource Network** at 781-647-5327, extension 1940.*

## **PREPARING FOR SUPPORTED COMMUNITY LIVING**

*In supported living programs, clients live in their own homes or apartments and receive support services as needed. To prepare for a smooth transition and minimize service costs, JF&CS recommends that clients focus on meeting the following goals before moving out of the family home.*

### **Learn to get ready for the day without supervision or stand-by help.**

While living in the family home, many people with disabilities rely on their parents to make sure they get up on time, prepare a nutritious breakfast, take care of personal hygiene, and dress appropriately. By learning manage these everyday tasks without help, your son or daughter will not need daily a.m. care, which will significantly reduce service costs. Establishing a highly structured morning routine is often the key to achieving this goal.

An occupational therapist (OT) can help you break down the morning routine into specific skills that your son or daughter can learn. The OT can also help you design a structure for your son or daughter's morning routine that accommodates his or her needs and abilities. If your son or daughter is still in school, the person responsible for coordinating his or her service may be able to arrange for an OT to provide this assistance.

### **Acquire grocery shopping skills or the ability to order groceries online through Peapod.**

Since supported living programs do not include daily meal service, your son or daughter must know how to shop for groceries and keep healthy food in his or her new home.

### **Learn to prepare microwave and no-cook meals.**

Your son or daughter should be able to prepare at least six healthy meals before moving into his or her own apartment. The

process of selecting menus and learning to prepare them can be an occasion for developing healthier eating habits.

### **Learn to manage medications as independently as possible.**

To create a medication management plan that involves your son or daughter as much as possible, please see the suggestions on page 5-8.

### **Make sure your son or daughter has something to do every day.**

For any adult, regardless of his or her disabilities, having something to do is essential to physical and emotional health. Possibilities include:

- Volunteering in the community.
- Attending a social club meeting or event (see pages 5-11 and 5-12).
- Joining one of Massachusetts' clubhouses for people with mental illness (see page 5-12).
- Enrolling in classes at a community college or adult education center.
- Going to a healthcare appointment.
- Engaging in regular fitness activity (see page 5-13).
- Attending a worship service or social activity at a local synagogue, church, or mosque.

## **BUILDING MEDICATION MANAGEMENT INDEPENDENCE**

*By structuring a medication management plan that minimizes your son or daughter's need for daily supervision and support, you can significantly reduce the service costs of a supported living plan. The following list suggests alternatives to hands-on or in-person assistance for the basic components of medication management.*

### **Taking prescriptions to the pharmacy**

- Ask the medical provider to phone in or fax prescriptions whenever possible.

### **Picking up prescriptions**

- Select a pharmacy that delivers prescriptions.
- Arrange for prescriptions to be delivered by mail. MassHealth offers this service as do many private insurance providers and several local pharmacies.

### **Taking the correct doses**

- Select a pharmacy that prepares “bubble packs” for prescriptions, putting the correct doses of multiple medications in compartments labeled by date and time.
- Check the medication box or bubble pack weekly to make sure all medications have been taken. (You can do this yourself or include the task in your son or daughter's service plan.)

### **Remembering to take medication on time**

- Investigate the many devices on the market that provide medication reminders. To get started, simply Google “medication reminder devices.”

- Set alarms on a digital wristwatch or cell phone that remind your son or daughter when it's time to take the next dose from the medication box or bubble pack. Make sure putting on the watch or pocketing the cell phone is a part of your son or daughter's morning routine.
- Put a checklist on the back of the entry door to the apartment that includes “take morning medicine” and “put on watch” or “remember cell phone.”

### **Ordering refills before supplies are depleted**

- Use a pharmacy that automatically refills prescriptions and calls the physician when a new prescription is needed.
- If using a mail-order service, teach your son or daughter to order refills over the Internet or by phone. Set reminder notices in his or her computer calendar.

## **HIRING A COACH**

*Although you may be able to teach your son or daughter the skills he or she needs to develop before moving to supported living, attempting to do so may become a source of stress and conflict – especially if previous attempts have been unsuccessful. You'll be asking your son or daughter to do things independently that you've always done for him or her. In other words, established patterns of parent-child interaction can get in the way of learning new skills. For many families, the solution is to hire a qualified coach.*

### **Why hire a coach?**

Here are four reasons why a qualified coach may be the best person to help your son or daughter acquire new life skills:

- Coaches understand and address issues (other than innate capacity) that can keep a person with disabilities from mastering independent-living skills.
- Coaches can evaluate differences in learning styles and modify their teaching methods to accommodate them.
- Coaches are skilled at breaking down complex skills into achievable steps, making sure their clients experience success and avoid the frustration that undermines confidence and willingness to try.
- Coaches have experience using a variety of motivational techniques that can inspire your son or daughter to make the effort required to master a new skill.

### **How to find coaches**

- Call a disabilities organization that employs coaches and/or refers clients to independent coaches that have been vetted, including local **Arcs**, the **Asperger's Association**, and JF&CS.
- Network with other parents of people with disabilities. Families who have had a positive experience with a coach are usually happy to share their experience and make recommendations.

- Advertise on Craig's list or another on-line service, allowing email responses only so that you can review credentials before contacting good prospects
- Call JF&CS's Disabilities Resource Network at **781-647-5327**, extension 1940.

### **How to evaluate prospective coaches**

When evaluating prospective coaches, you should look for the following qualities:

- Experience with clients whose needs and goals are similar to your son or daughter's.
- Ability to give specific examples of how they have taught a particular skill and also how they tailor their approach based on the learning style and needs of the individual.
- Creativity and enthusiasm.
- Great references from other families.
- Formal training in identifying learning styles and learning disabilities.
- Access to professional supervision and consultation for problem solving and support.<sup>1</sup>

After selecting the best candidate, one critical step remains: a trial meeting, or a few trial meetings, to make sure the coach is a good match for your son or daughter.

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<sup>1</sup> While formal training and access to professional consultation can be very helpful, it's important to remember that many good coaches have neither.

**What will coaching cost?**

Typical rates range from \$50 - \$100 per hour depending on the educational credentials and experience of the coach. Faced with these rates, some families decide that this service is too expensive. Sharing the expense with another family can make coaching more affordable. In any case, life-skills coaching is a bargain when measured against the cost of support services provided year after year.



## **OVERCOMING SOCIAL ISOLATION**

*It would be hard to overestimate the cost of social isolation to people with disabilities and their families. By every measure – physical, psychological, intellectual, and spiritual – isolation diminishes the quality of life. While there are no easy answers, the benefits of overcoming social isolation more than repay the effort required. The following suggestions can help you get started.*

### **Prioritize social programming and the potential for friendships when considering housing options.**

When weighing your choices, you may find that opportunities to make friends and participate in group activities will be more important to your son or daughter's quality of life than the program's location or the type of housing provided.

### **Seek out community groups that your son or daughter can attend regularly, either on his or her own or with a companion.**

Local libraries, congregations, and adult education centers often have programs, clubs, or interest groups organized around particular interests or issues. Those that are ongoing and have a core group of regular attendees will be the best prospects, affording an opportunity for your son or daughter to develop relationships and a sense of belonging over time.

### **Investigate volunteer opportunities.**

While finding or creating the right volunteer opportunity can require intensive effort, the potential benefit is well worth the investment. Paid or unpaid, the right job offers priceless perks including interaction with colleagues, meaningful activity, structure, recognition, and self-respect.

### **Encourage your son or daughter to attend social gatherings for peers with comparable disabilities and interests.**

Many people with disabilities and their families reject these types of social opportunities before giving them a try. Even if a lifetime of

physical inclusion in mainstream classrooms and workplaces has never led to "after-hours" friendships or invitations, the person with disabilities and/or the family may continue to reject opportunities to socialize with other people with disabilities. Within these special groups, however, many people with disabilities find friendship and appreciation they don't experience elsewhere.

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*The Boston-area organizations listed below offer regular social programming for people with disabilities. When introducing your son or daughter to any of these programs, consider hiring someone of similar age to accompany him or her to the first meeting.*

### **Asperger's Association of New England**

(AANE) sponsors social groups for people with Asperger's syndrome throughout Massachusetts. For more information, call **617-393-3824** or visit [\*\*www.aane.org\*\*](http://www.aane.org).

**Chaverim Chaim** is a social group for Jewish adults with developmental disabilities, mental retardation, and/or autism. Free monthly programs include Shabbat dinners (often with a song leader or storyteller), movie nights, game nights, dances, and Jewish holiday celebrations. Chaverim Chaim is a collaboration of JF&CS, Jewish Community Centers of Greater Boston, and Jewish Big Brother Big Sister. For more information, call **781-647-5327**.

**Chaverim Shel Shalom** is a JF&CS program for Jewish adults living with chronic psychiatric illness. Members meet two to three times a month for social activities and “dinner & learn” programs with a Jewish theme. Chaverim Shel Shalom also sponsors a community Passover Seder, and members keep in touch with one another through a monthly newsletter that chronicles group activities. For more information, call **781-647-5327**.

**Clubhouses** are membership organizations that offer social activity, health and wellness programs, work and volunteer opportunities, and other supports for people with mental illness. Members work side by side with peers to run clubhouse programs. For a list of Clubhouses, go to **www.massclubs.org** and click on “MA Clubhouses” in the main menu.

**Friend 2 Friend**, a program of Jewish Big Brother Big Sister, creates meaningful friendships between adults (age 18 and over) who share interests and enjoy each other’s company. Each pair includes one adult who has a disability. MAGIC (Monthly Activity Groups in the Community) is an offshoot of Friend 2 Friend designed to expand opportunities for socializing in groups that include adults with and without disabilities. For more information, call **617-965-7055**.

The **Jewish Community Centers** of Greater Boston sponsor several social and recreational programs for adults and children with a wide range of disabilities. Programs include both center-based and community-based activities. For more information, call **617-558-6508** or visit **www.jccgbspecialneeds.org**.

**K’Sharim: Connecting People with Disabilities to Jewish Life** is an innovative program that designed to involve teens and adults with disabilities in all facets of synagogue life. Programs are held monthly at synagogues throughout the Greater Boston area. For a

schedule of events and specific information about programs, contact Sandy Slavet at **781-647-5327 x 1940** or **sslavet@jfcshoston.org**.

**Springboard** is a membership club operated by TILL (Toward Independent Living and Learning, Inc). With an emphasis on independence, Springboard provides social, recreational, cultural, and educational activities for adults and adolescents with learning disabilities and Asperger’s Syndrome. For information about programming and costs, call **781-302-4619** or visit **www.tillinc.org** and click on “supported service,” then “Springboard.”

**Stars of David** is a social group for adults with disabilities that meets monthly on Sunday mornings for brunch and an activity. The group meets at Temple Emmanuel in Newton and is sponsored by the congregation. For information, contact Pamela Goldstein at **781-986-0030**.

**Yachad / National Jewish Council for Disabilities** is a social/recreational and educational program for older teens and young adults with developmental disabilities and those on the Autism spectrum. The Boston branch holds two monthly programs as well as three Shabbat retreats a year. Yachad’s national office also offers summer travel and camping programs in the U.S., Canada, and Israel. Affiliated with the Orthodox Union, Yachad provides programs in a traditional Jewish inclusive environment. For more information, contact Peshie Rubin at **peshierubin@gmail.com** or **347-882-1512**, or visit **www.njcd.org**.

➡ *For information about other socialization opportunities for people with disabilities, contact JF&CS’s **Disabilities Resource Network** at **781-647-5327**, extension 1940.*

## **DEVELOPING HEALTHIER HABITS: DIET & EXERCISE**

*You don't need to have a disability to have unhealthy eating habits or a sedentary lifestyle. Nevertheless, the prevalence of sedentary lifestyle and obesity is higher among people with many types of disabilities, including developmental disabilities, than it is in the general population. Parents often worry about the problem, but face so many barriers when trying to address it. For example, their son or daughter may have an extremely limited palate or low tolerance for the aches and pains that accompany the beginning of any exercise program. The good news is that every step toward a healthier lifestyle, no matter how modest, can make a difference in overall health and wellbeing. Here are a few approaches to try:*

### **Improving Diet**

- Find healthy foods that your son or daughter enjoys munching between meals, such as raw fruits and vegetables. Once you find healthy snacks that he or she enjoys, make sure these foods are always available.
- Create a chart of six healthy meals your son or daughter enjoys and can prepare independently or with some assistance. Post this menu on the refrigerator to reinforce these healthy choices, and create a shopping list with the ingredients to help him or her keep them in the house.
- Consult with a licensed registered dietitian with a track record of success helping people with disabilities adopt healthier eating habits.
- When selecting an apartment, consider a second or third-floor walk-up if stairs are not a problem.
- Find a group activity in the community that your son or daughter can join on a regular basis. Investigate swimming lessons, group sports, walking clubs, community gardening and any other traditional or non-traditional form of exercise he or she can enjoy.
- Join a local **YMCA** or **Jewish Community Center**. Most have discounted rates for people with disabilities and many offer fitness programs that accommodate people with a wide range of abilities.
- Consider engaging a personal trainer who has experience working with people with disabilities. Working with a trainer usually motivates people to exercise between sessions, particularly if progress is tracked and visibly posted in the home.

### **Increasing Physical Activity**

The key to increasing physical activity is to find an activity your son or daughter enjoys that can be incorporated into his or her daily routine. Here are some suggestions:

- If your son or daughter is (or will be) using public transportation, incorporate a walk of 10 minutes or more into every commute by choosing stops that are at least this far from his or her destination.

Better eating habits and physical fitness can also result from increasing activity outside the home. See page 5-11 for suggestions.

➡ *For more information regarding diet and exercise resources for people with disabilities, contact JF&CS's **Disabilities Resource Network** at 781-647-5327, extension 1940.*

## **TRANSPORTATION RESOURCES**

*If your son or daughter relies on you alone to get where he or she needs to go, his or her housing and activity options are unnecessarily limited. When planning for a transition to community housing (beyond the family home), it is important to explore all transportation options and help your son or daughter become comfortable using them.*

### **THE RIDE**

**THE RIDE** is the T's program for people who cannot use general public transportation due to a physical, mental, or cognitive disability. Using conventional sedans and vans equipped with chairlifts, THE RIDE provides door-to-door, shared transportation in 62 cities and towns in the Greater Boston area.

One-way fare is \$2.00, drawn from an account funded by the customer. THE RIDE requires two days notice for all transportation requests, which may be made by phone or on line. Customer accounts may also be managed on line.

#### Application Process

Before using THE RIDE, you must obtain prior approval. **Applications** can be downloaded from [www.mbta.com](http://www.mbta.com) or obtained from the MBTA Office for Transportation Access, 10 Park Plaza - Room 5750 Boston, MA **1-800-533-6282** (TTY 617-222-5415).

When reviewing applications, THE RIDE is primarily seeking documentation of mobility challenges. Therefore, if a physical therapist is involved in the applicant's care, it is best to have the PT complete the health-provider page of the application. If there is no PT involved, it is usually best to prepare the provider page yourself for another licensed professional to sign unless he or she has experienced completing successful applications for THE RIDE. You are likely to be more aware of your son or daughter's cognitive impairments as they relate to his or her ability to use regular public

transportation, and better able to express them on the application.

In the "Functional Assessment" section of the application, do not list diagnoses (*e.g.* mental retardation or psychiatric illness). Instead, describe specific impairments relevant to using transportation, *e.g.* "clumsiness and tendency to fall on stairs" (*especially if this has ever resulted in injury*), "difficulty standing for long periods," "inability to ask strangers for assistance," "panic reaction in crowds or emergency situations," or "tendency to fall sound asleep resulting in missed stops." Be sure to answer all yes/no questions as well.

#### Appeals Process

If the applicant does not have a physical disability, his or her initial application will likely be denied. However, approval may still be possible through the appeals process and is well worth pursuing. If there is no PT involved in the applicant's care who can complete the appeal application, you should do so yourself and have it signed by a licensed healthcare professional. Be sure to describe any mobility challenges, including poor balance or clumsiness, and translate cognitive challenges into transportation-related impairments such as "inability to change trains or buses due to reading difficulties," or "would not know what to do if he/she missed a stop." When describing stress or anxiety reactions in relation to common public transportation experiences (*e.g.* overcrowding, unexpected delays, *etc*), be careful to state that these problems would not pose any danger to the applicant or to others on the RIDE. Otherwise he or she may be

required to have an attendant whenever using THE RIDE.

### **Transportation Access Pass (TAP)**

By obtaining a **TAP CharlieCard**, individuals with disabilities can receive deep discounts on most MBTA fares. For example, most TAP CharlieCard holders only pay 60 cents for a subway ride – less than half of the regular \$2.00 fare.

Customers who are blind or visually impaired ride all MBTA services for free with a Blind Access CharlieCard.

For a **TAP application**, go to [www.mbta.com](http://www.mbta.com) or pick one up at the Reduced Fare Office at Back Bay Station, located next to the AMTRAK ticket window. The application provides instructions for documenting the qualifying disability. DDS and DMH clients will not need a physician to confirm the disability, but others will. For more information, call **617-222-5438** or **1-800-543-8287** (TTY 617-222-5854).

### *Accessibility on the T*

At present, all MBTA buses have accessibility features, including lifts, as do many subway stations. For more information, go to [www.mbta.com](http://www.mbta.com).

### **MassHealth's Medical Transportation**

MassHealth provides transportation to any medical service paid for by MassHealth when other forms of transportation are unavailable or inaccessible. Your medical provider must authorize this service by completing a Prescription for Transportation (PT-1) form for each location to which you need transportation and you must schedule rides 2 – 3 days in advance of an appointment, a process that can take up to 30 minutes on the telephone. For more information, go to [www.massresources.org](http://www.massresources.org) and search for "**MassHealth transportation.**"

### **Taxis**

Consider setting up an account with a cab company for your son or daughter, making it possible for him or her to use taxis without having to carry cash for fares and tipping. While using taxis is more expensive than using public transportation, the cost is almost always less than the cost of owning and operating a car.

## **LIFE CARE PLANNING**

*The information you record in your son or daughter's Life Care Plan will have a direct impact on his or her quality of life when you aren't available to influence decisions regarding healthcare, housing, spending priorities and other issues as they arise. This section of the guidebook provides a step-by-step template for creating a written plan that can be adapted or expanded to meet the needs of any individual.*

### **Getting Started**

Since the prospect of creating a Life Care Plan can be daunting, consider adopting the "Swiss-cheese approach." In other words, breeze through the worksheets beginning on page 6-2 to record all the information you can remember without doing any research or checking whatsoever. Simply pass over any item that gives you pause. Like Swiss cheese, the resulting document will be full of holes, *but it will still have value*. With minimal effort, you'll have created a useful reference tool for others interested in your son or daughter's well being.

### **Filling the Gaps**

To build a more complete Life Care Plan, you can draw on a variety of resources, starting with the worksheets in this guidebook, your own personal records, and written reports from recently completed evaluations. At some point in the process, you will also need to involve others, including your son or daughter with a disability.

Some aspects of your plan will require discussion with family members and professional advisors, especially inheritance issues and legal responsibilities. You might also consult with disabilities advocates and service providers for assistance with other aspects of the evolving care plan. JF&CS's **Disabilities Resource Network** can provide information regarding qualified advisors when you're ready to take this step.

### **Distributing and Updating the Plan**

Because your son or daughter's Life Care Plan will include confidential information, you will need to make careful plans regarding its distribution and security. To ensure its continuing accuracy and usefulness, the plan will also need to be reviewed and updated annually. To make sure this happens, pick a time when the review will happen each year – perhaps during the week following your son or daughter's birthday – and add a recurring reminder to your calendar.

➡ *For more information about life care planning, see JF&CS's **Special Needs Planning Guide for Families** available online at [www.jfcsboston.org](http://www.jfcsboston.org).*

## **BASIC INFORMATION**

**FULL NAME** \_\_\_\_\_ **Date** \_\_\_\_\_

Date of birth \_\_\_\_\_ Social Security # \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Home phone \_\_\_\_\_ Business phone \_\_\_\_\_

Mobile phone \_\_\_\_\_ E-mail \_\_\_\_\_

\_\_\_ *lives with parents*                      \_\_\_ *lives with other family*

\_\_\_ *lives in supported housing sponsored by: \_\_\_\_\_ (agency)*

\_\_\_ *lives independently without formal supports.*

\_\_\_ *single*              \_\_\_ *married*              \_\_\_ *separated*              \_\_\_ *divorced*

---

**PARENT or  
NEXT OF KIN**

Relationship \_\_\_\_\_

Date of birth \_\_\_\_\_ Social Security # \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business phone \_\_\_\_\_

Mobile phone \_\_\_\_\_ E-mail \_\_\_\_\_

**PARENT or  
NEXT OF KIN**

Relationship \_\_\_\_\_

Date of birth \_\_\_\_\_ Social Security # \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business phone \_\_\_\_\_

Mobile phone \_\_\_\_\_ E-mail \_\_\_\_\_

## **FINANCIAL INFORMATION**

**Name** \_\_\_\_\_ **Date** \_\_\_\_\_

### **Identification and Account Numbers**

Social Security \_\_\_\_\_

MassHealth (Medicaid) \_\_\_\_\_

Medicare \_\_\_\_\_

SNAP (food stamps) \_\_\_\_\_

Savings account (bank and number) \_\_\_\_\_

Checking account (bank and number) \_\_\_\_\_

Other \_\_\_\_\_

### **Power of Attorney, Guardian, or Rep Payee (if not parent)**

Name \_\_\_\_\_ Legal relationship \_\_\_\_\_

Address \_\_\_\_\_

Phone numbers \_\_\_\_\_

E-mail \_\_\_\_\_

Name \_\_\_\_\_ Legal relationship \_\_\_\_\_

Address \_\_\_\_\_

Phone numbers \_\_\_\_\_

E-mail \_\_\_\_\_

### **Special Needs Trust**

Trustee/Attorney \_\_\_\_\_

Address \_\_\_\_\_

Phone numbers \_\_\_\_\_

E-mail \_\_\_\_\_



**Monthly Income**

Employment ( <i>after taxes</i> )	_____
Disability Benefits: SSI/SSDI	_____
Other Government Benefits ( <i>e.g. food stamps, fuel assistance</i> )	_____
Pensions	_____
Annuities	_____
Interest from Savings	_____
Investment Income	_____
Other	_____
<b>Total Monthly Income</b>	_____

**Monthly Expenses** (please enter as negative numbers)

Rent or mortgage payment	_____
Utilities: <i>gas, electric, water</i>	_____
Food: <i>groceries and restaurant meals</i>	_____
Telephone: <i>home and/or cell</i>	_____
Internet Access and Cable Service	_____
Home Maintenance and Supplies	_____
Health and Dental Insurance	_____
Counseling/Therapy	_____
Co-payments: <i>prescriptions, office visits, dental care</i>	_____
Clothing	_____
Toiletries	_____
Public Transportation	_____
Car Expenses: <i>insurance, gas, repairs</i>	_____
Social/Recreational Activities	_____
Memberships: <i>health club etc.</i>	_____
Education/Tuition	_____
Vacations: <i>airfare, hotel, etc.</i>	_____
Other Discretionary Expenses	_____
<b>Total monthly expenses</b>	_____

**NET** (*income minus expenses*)

## PERSONAL PROFILE

Name \_\_\_\_\_ Date \_\_\_\_\_

### **Social Network**

Religious affiliation/congregation \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Clergy/religious advisor \_\_\_\_\_

*Comments:*

Club or group \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Primary contact \_\_\_\_\_

*Comments:*

Club or group \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Primary contact \_\_\_\_\_

*Comments:*

### **Other Affiliations**

Educational institution(s) \_\_\_\_\_

Years attended \_\_\_\_\_

Favorite subjects \_\_\_\_\_

Degree or certificate \_\_\_\_\_

Camp(s) \_\_\_\_\_

Dates attended \_\_\_\_\_

Favorite activities:

**Employment** *(paid or volunteer)*

Organization \_\_\_\_\_

Responsibilities \_\_\_\_\_

Dates \_\_\_\_\_

Supervisor or contact person \_\_\_\_\_

*Comments:*

Organization \_\_\_\_\_

Responsibilities \_\_\_\_\_

Dates \_\_\_\_\_

Supervisor or contact person \_\_\_\_\_

*Comments:***Interests and Preferences**

<b><i>Activities</i></b>	<b><i>Likes</i></b>	<b><i>Dislikes</i></b>
Music		
Computers		
Crafts <i>(e.g. knitting)</i>		
Movies		
Television		
Museums		
Books		
Magazines		

<i><b>Activities, continued</b></i>	<i><b>Likes</b></i>	<i><b>Dislikes</b></i>
Trips and travel		
Outdoor activities		
Spectator sports		
Participatory sports		
Exercise		
<i><b>Environment</b></i>	<i><b>Likes</b></i>	<i><b>Dislikes</b></i>
Indoor temperature		
Weather		
Light qualities		
Sound qualities (level and pitch)		
Tactile qualities (furniture, flooring, bedding, etc.)		
Personal space		
Pets/animals		
<i><b>Clothing</b></i>	<i><b>likes</b></i>	<i><b>Dislikes</b></i>
Colors		
Fabric (texture, content)		

<b><i>Clothing, continued</i></b>	<b><i>likes</i></b>	<b><i>Dislikes</i></b>
Style and fit		
Closures (buttons, zippers, Velcro, etc)		
<b><i>Food</i></b>	<b><i>likes</i></b>	<b><i>Dislikes</i></b>
Breakfast		
Lunch/Dinner		
Fruits		
Vegetables		
Beverages		
Texture		
Temperature		
Ethnic foods		
Other		

**Food Allergies or Sensitivities**

**Fears or Aversions** (*e.g.* lightening, dogs, bugs, crowds, elevators, needles, *etc.*)

**Personal Strengths and Talents**

**Personal Values and Priorities**

*(What matters most to your son or daughter? What motivates him or her? What matters least?)*

## PERSONAL RELATIONSHIPS

Name \_\_\_\_\_ Date \_\_\_\_\_

### **Family Members**

Full Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Date of birth \_\_\_\_\_ Place of birth \_\_\_\_\_

Relationship \_\_\_\_\_

*Comments:*

Full Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Date of birth \_\_\_\_\_ Place of birth \_\_\_\_\_

Relationship \_\_\_\_\_

*Comments:*

Full Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Date of birth \_\_\_\_\_ Place of birth \_\_\_\_\_

Relationship \_\_\_\_\_

*Comments:*

*Copy this page as needed to add other family members.*

**Friends and Mentors**

**Full Name:** \_\_\_\_\_

Address: \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Age \_\_\_\_\_ Length of relationship \_\_\_\_\_

*Comments:*

**Full Name** \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Age \_\_\_\_\_ Length of relationship \_\_\_\_\_

*Comments:*

**Full Name** \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Age \_\_\_\_\_ Length of relationship \_\_\_\_\_

*Comments:*

*Please add pages as needed to list other friends.*



## HEALTHCARE PROVIDERS

Name \_\_\_\_\_ Date \_\_\_\_\_

### **Primary Care Provider**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:*

### **Nurse/Care Manager**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:*

### **Psychiatrist/Neurologist**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:*

**Therapist**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:***Dentist**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:***Specialist**

Name \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Comments:**Please add pages as needed to list additional providers.*

## HEALTHCARE ISSUES

Name \_\_\_\_\_ Date \_\_\_\_\_

Diagnosis \_\_\_\_\_

Current treatment or management strategy:

Followed by *(physician or therapist)* \_\_\_\_\_

Diagnosis \_\_\_\_\_

Current treatment or management strategy:

Followed by *(physician or therapist)* \_\_\_\_\_

Diagnosis \_\_\_\_\_

Current treatment or management strategy:

Followed by *(physician or therapist)* \_\_\_\_\_

*Please add pages as needed to document all diagnoses and care plans.*

## **CHALLENGES**

**Name** \_\_\_\_\_ **Date** \_\_\_\_\_

### **Cognitive**

(*e.g.* developmental disability, learning disability, non-verbal learning disability, memory loss, brain injury)

**Emotional, Neurological, or Behavioral** (*e.g.* depression, anxiety, ADD/ADHD)

**Mobility** (*e.g.* balance, strength, flexibility, motor control)

**Sensory** (*e.g.* sight, hearing, touch sensitivity, light and sound sensitivities)

## SERVICE PROVIDERS

Name \_\_\_\_\_ Date \_\_\_\_\_

Agency or Service \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

Agency or Service \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

Agency or Service \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

**Agency or Service** \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

**Agency or Service** \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

**Agency or Service** \_\_\_\_\_

Contact person \_\_\_\_\_

Title \_\_\_\_\_

Address \_\_\_\_\_

Main phone \_\_\_\_\_ Voice mail \_\_\_\_\_

Pager \_\_\_\_\_ E-mail \_\_\_\_\_

*Services provided:*

## **PLAN DISTRIBUTION AND REVIEW**

*A written procedure for distributing and maintaining your son or daughter's Life Care Plan will help insure its accuracy and usefulness while protecting his or her privacy. You can meet these objectives by completing the following form and including it in your plan.*

**Life Care Plan for** \_\_\_\_\_

*The following individuals have copies of the complete Life Care Plan:*

Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Relationship \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Relationship \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Home phone \_\_\_\_\_ Business \_\_\_\_\_ Mobile \_\_\_\_\_

E-mail \_\_\_\_\_

Relationship \_\_\_\_\_

JF&CS recommends limiting the number of copies to protect privacy and ensure accuracy. Relevant information may be shared with others involved in the individual's care on a need-to-know basis.

The Life Care Plan should be reviewed on an annual basis and changes should be recorded as they occur. The following person (one of the individuals named above) takes responsibility for overseeing the review process, revising the plan as needed, destroying old copies, and distributing the updated copies:

**Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**DATE OF LAST REVIEW** \_\_\_\_\_

## JF&CS SERVICES FOR PEOPLE WITH DISABILITIES

*The following services are grounded in the belief that all people with disabilities should live with dignity in the community and enjoy the rights afforded their peers regardless of their differences. Services reflect the values of individual autonomy, community inclusion, and care continuity. These services also make it possible for people with disabilities to maintain a Jewish home and participate in cultural and religious activities in the manner that is most meaningful for them.*

- **Family Circle Programs**  
Information, consultation and support for people with disabilities and their families, including the **Disabilities Resource Network** and **Family Futures Planning**.
- **Supported Housing Programs**  
Daily living supports and community for adults with disabilities who seek to live independently in their own apartments or in small group settings.
- **Independent Living Supports**  
Case management and direct services that help people with disabilities maintain stability and independence while pursuing their personal goals.
- **Day and Work Supports**  
Weekday programs that build vocational and independent-living skills through volunteer and paid work experience, social interaction, and small-group learning.
- **Specialized Case Management**  
An integrated program offering case management, advocacy, education, and peer support for people with mental illness.
- **Social Programs**  
Jewish Life programming including **Chaverim Shel Shalom** and **Chaverim Chiam**, social groups that offers recreation, celebration, learning, friendship, and support for adults with developmental disabilities or psychiatric challenges.
- **Special Needs Trusts**  
A means of setting aside funds for a person with disabilities without impacting access to Social Security and state-funded health insurance benefits.
- **Yesodot**  
Family-centered and family-directed programs for families of people with disabilities including parent and sibling support, family recreation outings, educational materials and workshops, public awareness activities, and an assistive technology project.

*For more information, please call 781-647-JFCS (5327) or visit [jfcsboston.org](http://jfcsboston.org).*



## *More services for people with disabilities*

SUPPORTED BY



**The CJP Disabilities Housing Initiative** is working with JF&CS and other partners to expand the number of supportive housing units for people with disabilities. For more information on the Housing Initiative, contact Elizabeth Sternberg at 617-457-8593 or [elizabeths@cjp.org](mailto:elizabeths@cjp.org).

**Jewish Big Brothers Big Sisters' (JBBBS) Friend 2 Friend Program** matches volunteers and adults with disabilities (18 and older) in one-to-one friendships. In the traditional program model, our matches meet 2-4 times per month doing fun community activities of their choosing. In the MAGIC model, matches meet one weeknight each month to enjoy a variety of events with other pairs of friends. For more information, visit [www.jbbbs.org](http://www.jbbbs.org).

**The Jewish Community Centers of Greater Boston** offer a wide variety of programs for people with disabilities of all ages including early intervention, adapted aquatics, martial arts, summer camping experiences, teen friendship groups, adult activity groups, social groups, and Jewish learning. The JCC also works with advocates and families on inclusion issues through its "Beyond the Ramp" conferences and committees. For more information, contact Judy Pearl at [jpearl@jccgb.org](mailto:jpearl@jccgb.org) or 617-558-6508, or visit [www.jccgbspecialneeds.org](http://www.jccgbspecialneeds.org).

**Jewish Vocational Service (JVS)** provides a wide range of employment and training-related services to individuals with disabilities, including identification of educational opportunities, vocational assessment, computer skills training, employer based training, job search techniques, job development, job placement, on-site job coaching, post-placement/educational support services and career ladder advancement opportunities. For information, please contact Rebecca Pyle at 617-399-3204 or [rpyle@jvs-boston.org](mailto:rpyle@jvs-boston.org).

**K'Sharim: Connecting People with Disabilities to Jewish Life** is an innovative program that designed to involve teens and adults with disabilities in all facets of synagogue life. Programs are held monthly at synagogues throughout the Greater Boston area. For a schedule of events and specific information about programs, contact Sandy Slavet at 781-647-5327 or [sslavet@jfcsboston.org](mailto:sslavet@jfcsboston.org).

**Stars of David** is a social group for adults with disabilities that meets monthly on Sunday mornings for brunch and an activity. The group meets at Temple Emmanuel in Newton and is sponsored by the congregation. For information, contact Pamela Goldstein at 781-986-0030.

**Yachad, National Jewish Council for Disabilities** is a social/recreational and educational program for older teens and young adults with developmental disabilities and those on the Autism spectrum. The Boston branch holds two monthly programs as well as three Shabbat retreats a year. Yachad's national office also offers summer travel and camping programs in the U.S., Canada, and Israel. For more information, contact Peshie Rubin at [peshierubin@gmail.com](mailto:peshierubin@gmail.com) or 347-882-1512, or visit [www.njcd.org](http://www.njcd.org).