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• 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.jccgbpecialneeds.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@jfcsboston.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*

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**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>	<b>_____</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>	<b>_____</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**

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

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

<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:*



## 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** \_\_\_\_\_



