

Aging Transition - Planning For the Future

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This document was written with the knowledge that we, as caregivers, need to have our documents in order while preparing and protecting the future life of our loved one with a disability (son, daughter or family member) when we are no longer here. It is a very difficult task. It can be made easier by talking about it and sharing the information with those who are important in our loved one's life.

It is advisable that you capture all your information in one place. Make sure you record and document significant changes in your loved one's Individual Support Plan (ISP). Purchase a notebook or tablet where you can record all of your information. Make sure your children or family members know where that notebook is when it is needed. Talk about it with them.

Planning now can help make the transition for your loved one to move smoothly to a life in the community when you are no longer able to provide for their care. It can provide direction to others when you are no longer here. Following and implementing the outline in this document can provide you with a sense of security in knowing that plans are in place and will give you the satisfaction in knowing you have made the best plans possible and they are known to those who succeed you. Most often, those who will assume the role of caregiver are unfamiliar with the many necessities and resources available to help them.

Beginning the process.

There are many planning tools that were developed by families for families as well as professionals organizations who are helping to create a vision and strategy to implement an *Everyday Life* for your loved one. You may know them by names such as, Essential Lifestyle Planning, Making Action Plans (MAPS), Positive Approaches, LifeCourse Tools, etc. to name a few. We are encouraging the use of a personal planning tool to assist in developing a rich and positive outcome for your family member. It will provide a solid starting point that you can use to provide a springboard for completing the following information. It is this Vision and suggested strategies that you want passed on to your successors who'll provide your loved one's support in the future. The tools provide a concise look at the vision, current support (both paid and natural), and strategies for developing and maintaining that path. From here, you can then expand in more detail the specifics regarding your loved one's support for each of the life domains.

How You Will Be Using Your Planning Tools:

- Create and maintain an updated version of your loved one's vision tool or Individual Support Plan (ISP) for an *Everyday Life* and what are the desired experiences to achieve those goals.
- Update the ISP with outcomes consistent with your loved one's path and Vision.

ISP - Using Your Son or Daughters Individual Support Plan as a Living Document

The ISP is a critical document for planning the future and for obtaining services. It does more than just look at what the individual is interested in doing or would prefer. It sets goals or outcome statements. Then it looks at what actions are needed to make those interests and preferences happen.

The ISP takes on the importance of a primary document for requesting services. It lays out the services being requested and provides the justification for those services. If you do not provide adequate justification for service in the ISP it will result in denial of that service.

So what makes the ISP so important? It puts in writing the plan to support the needs and desired outcomes and dreams of the person. It makes sure that those needs are assessed and that they are met. It is viewed as an agreement between a person and the Administrative Entity (AE)/County. It shows that important information in the ISP is accurate, comprehensive and up-to-date.

This is an ideal time for people to get together and discuss what is important to the person and what supports or services need to be put in place. It is time for you, your son or daughter, family and friends, employer, coworkers, teachers, supports coordinators, advocates, direct care professionals, and the providers of services - all the people who are important to the person. This is a time when real discussion can take place and plans for the future can be laid out and set in place. The individual support plan is an absolute springboard for needed discussions, solid foundations and an opportunity for growth.

Additional Considerations

Some legal documents are necessary to guarantee that your successors have the authority and resources to support your loved one throughout the lifespan with their decisions for the Everyday Life you've prepared above. In the following pages you can list or reference any or all legal documents. For example: Who will function as your successors for the below, if applicable, and how is their successor determined?

- a) Name of Attorney or Legal Representative
- b) Insurance Policy
- c) Last Will and Testament – both yours and your loved one's.
- d) Special Needs Trust, Trustees and guidelines
- e) Power of Attorney
- f) Guardianship
- g) Living Will and/or Medical Directives
- h) Representative Payee
- i) Common Law or Managing Employer
- j) Microboard

Caring About and Caring For

After your vision for a good life for your loved one, the next important step is to document who cares about and cares for your loved one now and after you're incapable.

Caring About – These are the people who demonstrate affection and interest and/or who provide guidance and self-esteem for your loved one. It's people who have deep understanding and knowledge about your loved one and people who have a long term commitment to your loved one's well-being.


Examples might be employer, friend, relative, and of course primary caregivers.


Caring For - The people who provide the direct support for your loved one's activities or needs. It's people who might provide material or financial support or people who advocate for your loved one. It could be the people who provide inclusion opportunities for your loved one.

Examples: Direct Support Professional (DSP,) Employer, Support Coordinator (SC), Support Broker, community leaders.

Some may function as both, such as primary caregivers. Some, like a DSP or employer, may begin interaction with your loved one only to provide a service (caring for) but overtime could develop into someone committed and cares about your loved one's long term well being.

On the next 2 pages list the people who care about and care for your loved one. On the first page use the 2nd column to enter the name(s) of those who currently care about that aspect of your loved one's life. In the next column list who will care about that aspect when you are no longer capable. Do the same on the next page regarding who now cares for, provides a service, and who will care for when you're incapable.

	Who cares about this now:	Who will care about this when I'm incapable:
<p>Affection and Self-Esteem: People who can have a mutual relationship; celebrate birthdays and holidays; honor family culture and traditions.</p>		
<p>Repository of knowledge: People who know the history and the vision for the future; knows what the person wants and needs to be successful, healthy and happy.</p>		
<p>Lifetime commitment: People who will be there for the long haul; Who will be in the person's life long term.</p>		

	Who cares for this now:	Who will care for this when I'm incapable:
<p>Provider of Day to Day Care: Making sure the person's needs are met for food, shelter, comfort, medical care, and quality of life.</p>		
<p>Material and Financial Needs: Providing for OR helping manage, money, property, other things needed to accomplish daily activities and needs.</p>		
<p>Facilitator of Inclusion: Helping create and maintain friendships, community connections and opportunities for life experiences.</p>		
<p>Advocate for Support: Speaking up and supporting the person to speak up for their, rights, needs, and good life.</p>		

Life Categories

LifeCourse Tools uses the term Life Domains to categorize the different aspects and experiences of life that we all consider as we age and grow. As we plan for our loved one's care after we're gone, we need to plan the support necessary to maintain and grow our loved one's experiences and goals for each life domain or category. The categories (domains) are: Daily Life and Employment, Community Living, Social and Spirituality, Healthy Living, Safety and Security, Citizenship and Advocacy, and Supports and Services.

The following pages list the life categories with space to inventory and plan the support of your loved one with a disability. **Plan as if you'll be incapable tomorrow of providing your role; then update periodically when significant changes occur.**

You may find some responses belong in multiple categories. It doesn't matter where you place the response. What matters is that you've captured at least once the idea, plan, or support need for your loved one somewhere in the document.

Each category will have the following sections:

- *Considerations or Things to Think About*
- *What does your loved one have now*
- *What does your loved one want that he or she doesn't have now*
- *List references or pertinent documents and their location (ISP, Vision Tool, etc.)*

Resources:

1. *Checklist for My Family - A Guide to My History, Financial Plans and Final Wishes.*
Author, Sally Balch Hurme. AARP.org/Bookstore.
2. *Mapping the Future - A Workbook to Prepare For The Future of Your Loved One With Special Needs* - Contact the Advocacy Alliance for a free copy at 1-877-315-6855
3. Family Health Information Recording System (FAMILY-HIRS). Philadelphia Coordinated Health Care, PMHCC, www.pchc.org
4. Charting the LifeCourse – Missouri Family to Family, UMKC-IHD, UCEDD, <http://www.lifecoursetools.com/planning/>