

## **LETTER OF INTENT**

**Caregiver Hopes and Plans for a Secure Future  
for their family member with a disability**

**The Future is Now  
A Project of Hamilton County DD Services  
with funding support  
from the Ohio Developmental Disabilities Council**



Developed by Hamilton County Developmental Disabilities Services, based on adaptations from “Family Future Planning” by the Rehabilitation Research and Training Center on Aging and Developmental Disabilities; Department of Disability and Human Development, University of Illinois at Chicago.

Funded by the Ohio Developmental Disabilities Council under the Developmental Disabilities Assistance and Bill of Rights Act

Revised March 2019

## LETTER OF INTENT

### PURPOSE

A Letter of Intent is a way for caregivers to outline hopes and plans for the future of their family member with a disability. Older caregivers can gain peace of mind by knowing they have a plan that others can turn to when the caregivers are unable to continue to provide care.

A Letter of intent:

- *Helps family and friends ‘get on the same page’* about supporting a good life for the person with the disability after the caregivers are no longer able to do what they do now.
  - Talking together about hopes and plans is one way to clarify if and how siblings, family members, and others might be involved now and in the future.
  - Getting on the same page about what a ‘good life’ looks like in the future makes it possible to use our time well now.
- *Offers a practical structure* for learning about topics that make up a good plan – such as personal networks, housing and benefits.
  - Learning about what’s available and what’s possible helps assure that future plans are based on accurate and up-to-date information.
  - Learning what supports are available to older caregivers - -as well as the family member with a disability – makes it possible for the family to live well together for as long as possible.
- *Serves as a guide* that others can turn to when the caregivers are unable to continue to provide care.
  - Knowing that hopes and plans are outlined in one place can give older caregivers peace of mind.
  - Understanding the hopes and wishes of the caregivers can be a useful guide to those who want honor the caregivers’ intent.

A Letter of Intent is not a legal document. It can, however, be used in conjunction with legal documents such as a will or trust to provide more detail and make your wishes and plans known. If the family member receives services from a County Board of Developmental Disabilities, you can also share the Letter of Intent with the Service and Support Administrator (SSA).

This Letter of Intent is designed primarily for use by older caregivers who are living with and providing some level of support for their family member with a disability. With creativity and adaptations, others may find this material useful as well.

## HOW THE LETTER OF INTENT IS ORGANIZED

The first pages of this Letter of Intent offers general information about the Future is Now project, and contains pages for entering general information about the family member with a disability.

This Letter of Intent is organized into six main sections, each corresponding with an important issue concerning the future:

- Section One: Expressing Hopes and Worries About the Future
- Section Two: Strengthening and Expanding Your Family Member's Personal Network
- Section Three: Planning for Housing --Where Your Family Member Will Live
- Section Four: Making the Most of Public Benefits and Protecting Personal Assets
- Section Five: Supports and Care for Older Caregivers
- Section Six: Who Holds the Story? Who Keeps the Dream?

Each of these six sections offers basic information about the topic, "Helpful Tips" for turning ideas into action, and a page called Reflections and Plans. These Reflection and Plans pages are the heart of the Letter of Intent, where the caregivers can:

- State their intent – convey what others need to know and do
- Make plans for what the caregivers will do now - with their time remaining - to put the family member on a path to a good future
- Names who the caregivers will ask for help – so that caregivers don't carry this alone

The Worksheets in the Worksheet Section offer a way to explore some of the content in more depth. The completed worksheets can be kept with the Letter of Intent. The Future is Now family sessions offer an opportunity to get started on these worksheets.

The Resources section contains additional information that can be useful in learning more about the topic.

## FUTURE IS NOW PLANNING SESSIONS

In January 2017, Hamilton County Developmental Disabilities Services (DDS) received a five year grant from the Ohio Developmental Disabilities Council (ODDC) to help older caregivers plan for the future of their family member with a disability. As part of this grant, Hamilton County DD Services offers Family Sessions for families with an older caregiver to learn from experts and each other about the six topics listed above. If you are participating in a Future is Now Planning Sessions, you can complete this Letter of Intent one section at a time as you learn more about each topic.

Families not participating in the planning sessions can develop this Letter of Intent with help from the Information and Resources section of this booklet and by taking advantage of other family sessions posted on the Hamilton County DDS web page:

<http://www.hamiltongdds.org/futureisnow>

## A NOTE ABOUT LANGUAGE

- This resource has been prepared primarily for families living in Hamilton County, Ohio. Other users in Ohio can check with the County Board of DD to learn how the information applies in their county.
- The Letter of Intent is written to and for older caregivers. Throughout this document, “you” and “yours” refers to older caregivers.
- “Caregiver/s” is used to refer to the biological parents, step-parents, foster parents, grandparents, an older adult sibling, or some other person who has assumed a primary caregiving role.
- Though “caregivers” is sometimes used in plural form, we acknowledge that often there is a single caregiver.
- “Siblings and/or extended family members” refers to the brothers and sisters of the family member with a disability and/or grandparents, in-laws, nieces, nephews, cousins or any other extended family member.

## GETTING STARTED

- ✓ Complete this Letter of Intent using the format that works best for you. Families participating in the Future is Now family sessions will receive a copy of this document at the first session. Other options include:
  - Download and print a copy from the Hamilton County DDS website <http://www.hamiltondds.org/futureisnow>
  - Download a ‘writable’ version and complete your responses online
- ✓ Complete the Letter of Intent as you have time – in small steps. Use what you learn in the Future is Now family sessions to work on a section at a time.
- ✓ Don’t do this alone! Use this as an opportunity to talk with your spouse, partner, children, and/or other family members and close friends.
- ✓ Listen to your family member with a disability. Some people with disabilities can speak directly about their preferences and hopes, others speak through their actions and behavior. Use this as an opportunity to talk and listen about their hopes and fears so that this plan reflects their ideas as well as yours.
- ✓ Keep this Letter of Intent in a safe place. Since this document contains personal information, you’ll want to keep it with other important documents. Make sure that a few key people know where to find this document.
- ✓ Invest in learning more about the ideas and topics outlined in this letter of intent. Check your local county board of DD web site or newsletter to stay up to date on information sessions and events for families.
- ✓ Update this Letter of Intent as you learn more and as things change!



We are grateful to the many people who have informed the content of this Letter of Intent. Many of the ideas and exercises in this workbook are taken from the work of John O'Brien, Connie Lyle O'Brien, Jack Pearpoint, Lynda Kahn, Jo Krippenstapel, Beth Mount, Janet Klees, Marcie Brost, Tom Kohler, David Hsu, Jack Pealer and David Pitonyak, all the good people connected with Good Life Networks and Starfire.

Books and materials by these leaders can be found in the "Helpful Tips" and at: <http://www.inclusion.com/books.html> -- or google any of them to find more!

**GENERAL INFORMATION**

Name of Family Member with a Disability \_\_\_\_\_

Date of Birth \_\_\_\_\_

Current Primary Caregiver/s for this person

Name \_\_\_\_\_ Relationship \_\_\_\_\_  
Name \_\_\_\_\_ Relationship \_\_\_\_\_

People who helped create this Letter of Intent

Name \_\_\_\_\_ Relationship \_\_\_\_\_  
Name \_\_\_\_\_ Relationship \_\_\_\_\_  
Name \_\_\_\_\_ Relationship \_\_\_\_\_

Date \_\_\_\_\_

**KEY INFORMATION**

The information on this page can be used in the event of an emergency involving the primary caregivers, or in a situation where the caregivers are temporarily unavailable for any reason (illness, accident, etc.). Caregivers can use this space to share key information that might get lost if they are they not present to share it.

What’s most important for others to know about your family member?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What’s most important to know when talking with or listening to your family member?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What’s most important to know about your family member’s routine and schedule?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other key information

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**EMERGENCY CONTACT INFORMATION**

List people to contact in the event of an emergency – in order of preference for who is to be contacted first. (Be sure to read the ‘helpful tips’ section below.)

Name #1 \_\_\_\_\_

Relationship to the family member with a disability \_\_\_\_\_

Phone \_\_\_\_\_

Name #2 \_\_\_\_\_

Relationship to the family member with a disability \_\_\_\_\_

Phone \_\_\_\_\_

Name #3 \_\_\_\_\_

Relationship to the family member with a disability \_\_\_\_\_

Phone \_\_\_\_\_

**BENEFITS INFORMATION FOR THE FAMILY MEMBER WITH A DISABILITY**

Health Plan \_\_\_\_\_ Member ID \_\_\_\_\_

Medicaid card? (If yes, list #) \_\_\_\_\_ (no)

Medicare card? (If yes, list #) \_\_\_\_\_ (no)

Social Security Card (if yes, list #) \_\_\_\_\_ (no)

Instructions on where to find the cards:

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**GUARDIANSHIP– ALTERNATIVES TO GUARDIANSHIP INFORMATION**

In the event of an emergency involving the caregivers, others may need to know if the family member with a disability has a legal guardian(s), and/or if alternative arrangements (e.g. power of attorney) are in place to support decision-making. See the Information and Resource section to learn more about Guardianship and Alternatives.

Has guardianship been established through the courts? \_\_\_\_\_ (yes) \_\_\_\_\_ (no)

If yes, list the name of the guardian/s here:

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If alternatives to guardianship have been put in place, list those here:

Instructions on where to find these documents:

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**COUNTY BOARD OF DD & OTHER SERVICES**

In the event of an emergency involving the caregivers, others may need to know about the services your family member receives. If your family member receives support from the county board of DD, the family member may have a Service and Support Administrator (SSA), sometimes called ‘case manager’ who helps organize supports and services for your family member. In case of emergency, siblings and/or extended family can contact the SSA for information and resources. (See Helpful Tips for more information on this.)

SSA/ Case Manager Name \_\_\_\_\_

Phone and/or Email \_\_\_\_\_

List the agency and contact information for any services or programs such as day programs, in-home supports, respite services, counseling, recreation, or other services.

Agency Name _____	Contact # _____
Agency Name _____	Contact # _____
Agency Name _____	Contact # _____
Agency Name _____	Contact # _____
Agency Name _____	Contact # _____
Agency Name _____	Contact # _____

**HEATH/MEDICAL INFORMATION**

Doctor Name _____	Phone _____
Doctor Name _____	Phone _____
Doctor Name _____	Phone _____
Pharmacy _____	Phone _____

**Medications**

If your family member takes medication, and is not able to administer these without assistance, others will need to know how to help your family member with medications. If this information is listed elsewhere, you can use this space to inform others about where to find this information, or who to contact to get up-to-date information about medications.

Where to find the list of current medications:

\_\_\_\_\_

If you are using this space to list medications and supplements, please remember to list the name of the medication, the dosage, and when/how often it is administered. Include any additional information such as where they are stored, how much help is needed, etc.

\_\_\_\_\_  
\_\_\_\_\_

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Allergies, diet or other important health information

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- ✓ If your family member receives services from a County Board of DD, your family member may have a Service and Support Administrator (SSA). As part of the caregiver’s ongoing communication with the SSA, the caregivers can let the SSA know who to contact in the event that the primary caretakers are not able to be actively engaged due to an emergency or death.
  
- ✓ In case of an emergency involving the caregivers, others who are stepping in to help (siblings, extended family, and friends) can contact the SSA right away. The SSA may be able to provide information or supports to help out. The SSA will have information about day programs or other services that the family member currently receives through the county board. Especially in situations where the caregivers can no longer share information directly, the SSA may have some of the information that can be of immediate help to siblings and others who are stepping in to help.
  
- ✓ If your family member receives services from the Hamilton County Developmental Disabilities Services (DDS), your family member has a “My Plan” that outlines services and supports received through DDS. The SSA is responsible for convening the My Plan meeting. This plan is completed annually. The SSA can only share information with people listed as team members on the My Plan. *Be sure to list people as team members on the My Plan if you want them to have access to your family’s members information in the event that you are no longer able to share information directly yourself.*
  
- ✓ If you want to update the list of people who have access to your family member’s information, and don’t want to wait for the My Plan meeting, you can simply request that the SSA send out the current plan to new team members, and ask that these people receive any new plans moving forward.

## SECTION 1: HOPES AND WORRIES ABOUT THE FUTURE

As caregivers, you have hopes and worries about the future of your family member with a disability – including what’s possible after you are no longer able to provide care for your loved one. You may be looking for a way to talk about this with your extended family and friends. You know that talking openly about hopes and fears is one way to secure a better future. This section offers a way to do that.

Complete the “Hopes and Worries” worksheet. If you are participating in the Future is Now family sessions, you will have an opportunity to get started on the worksheet during the session. After the session, you can share the worksheet with extended family and friends. Be sure to consider all the questions on the back of the worksheet. Keep the completed worksheet with this Letter of Intent so that others can understand your hopes and worries about your family member’s future.

The purpose of the worksheet is to encourage you to think and talk about what it will take to get on (or stay on) a path that leads toward your hopes for a good life. You can use the time you have to make the path as clear and strong as you can.



- ✓ Listen to your family member with a disability about their hopes and worries. Do this in whatever way works for your family member. Some people don’t use words, but are still able to communicate their feelings and preferences.
- ✓ Ask others – especially siblings and extended family – about their hopes and dreams for your family member with a disability. Look for the common ground.
- ✓ Engage the younger generation. Nieces, nephews, and younger cousins can carry the hopes and dreams after the older generation is no longer able to do so.

**Complete the Worksheet for this Section**

## SECTION 1: HOPES AND WORRIES ABOUT THE FUTURE \*\*\* INTENTIONS & PLANS PAGE

### Intentions

Use this section of your Letter of Intent to state your intent about your family member's future.

When you are no longer to play the role you do today – what are the most important things that you want others to know or do so that your family member has a good future?

I want others to do and know these things:

- 1.
- 2.
- 3.

### Plans

Use this section of your Letter of Intent to outline what you'll do now so that your family member is on the path to achieve the hopes and dreams.

With the time you have now – what are the three most important things that you – as caregivers – will do now for your family member with a disability to get on the path or stay on the path to a good life?

- 1.
- 2.
- 3.

### Who can you ask for help?

- 1.
- 2.
- 3.

## SECTION 2: BUILDING A PERSONAL NETWORK

Caregivers often say that their deepest hope is that their family member with a disability be known and loved. They often say that their biggest fear is that their family member will be alone and lonely.

Some caregivers say that their main hope is that the person be ‘safe’ – and safety, for anyone with or without disabilities, depends on people who care about us standing with us and standing up for us. Services can help, but services alone cannot keep people safe.

This section addresses ideas and strategies to bring more people into the life of the family member with a disability. This is a crucial building block along the path toward a good life. It’s never too early, and never too late to build a personal network. It does take time – so there’s no better time to start than now.

Our personal network includes all the people in our life. It includes those closest to us, as well as neighbors down the street and people at work or in our faith community that we don’t know well, but recognize and interact with. Strengthening connections with *anyone* in our personal network is one of the powerful things anyone – with or without disabilities – can do to counteract loneliness and isolation.

It can be helpful to imagine that each of us is surrounded by three circles of people:

- An inner circle of people who are closest to us. These people know what matters to us and ‘have our backs’ when we need them. We have strong ties with our inner circle.
- A middle circle of people in our everyday life with whom we have moderately strong ties – these people often help us navigate our day-to-day world. Some work friends or neighbors might fall in this circle. Our ties with this circle aren’t strong enough to be considered ‘inner circle’, but are stronger than the ‘weak ties’ of the outer circle.
- An outer circle of those with whom we have weak ties. This circle might include people at work, in your neighborhood, merchants, faith community, or recreational activities.<sup>1</sup>

### Strengthen the Inner Circle

A personal network includes an inner circle of people who people who know and care deeply for your family member. This is sometimes called a ‘circle of support’. This inner circle takes your family member’s life seriously. They understand what a good life means for your family member, and take steps to preserve and build this good life. They speak up and take action to avoid the ‘fears and worries’ about the person’s future. Some siblings, extended family and others may already be part of your family member’s inner circle now, even if you’ve not used those words to describe it. On the other hand, not all siblings or extended family is ‘automatically’ in the inner circle – it depends on the strength of relationship.

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<sup>1</sup> Hsu, David. “Untethered: A Primer on Social Isolation”

<https://static1.squarespace.com/static/5a5e5e0451a584dcfaaf9917/t/5a78c1b0f9619a572a6729d9/1517863383978/Untethered+v+1.24.18+for+PDF+Download.pdf>

Caregivers can be intentional and thoughtful about nurturing the inner circle:

- ✓ Spend time together in ways that the family member with a disability can participate and be engaged.
- ✓ Nurture family relationships. Support the family member with a disability to be a good uncle/aunt, cousin, and brother/sister.
- ✓ Accept offers for help. People are in the inner circle because they care. Saying ‘yes’ strengthens ties.
- ✓ Celebrate. Have parties, send cards – find ways to show how much you mean to each other.

### **Grow More Weak Ties**

Weak ties are often underappreciated. Social scientists have recently studied the role that these weak ties play in our lives. Weak ties are often the source of simple joys and a feeling of connection. They can make a true difference in the quality of life. (See “Untethered: A Primer on Social Isolation for a thoughtful discussion of what we can do to reduce social isolation.

<https://static1.squarespace.com/static/5a5e5e0451a584dcfaaf9917/t/5a78c1b0f9619a572a6729d9/1517863383978/Untethered+v+1.24.18+for+PDF+Download.pdf> )

When caregivers recognize the value of weak ties, it can open the door to intentional commitment to strengthen and grow these weak ties. Caregivers can help their family member:

- ✓ Become a ‘regular’. Go to the same place, on a regular schedule.
- ✓ Go places where it’s easier to interact with people.
- ✓ Greet people. Ask their name – greet them by name next time.
- ✓ Put the best foot forward and have short conversations.
- ✓ Invest in helping your family member find their interests and gifts so that they can be known for something other than their disability. Notice what they like and are good at – and find ways to build on this over time.
- ✓ Help your family member participate in and contribute to family, faith and community activities.

### **Clarify the Role of Paid Staff**

A personal network is not the same as paid staff who provide the day-to-day care that your family member requires. Both are important, and each has its role and contribution. It’s helpful to think and plan for them separately.

Paid staff who provide needed services and supports can be important to your family member. Sometimes, paid staff ‘stick around’ long enough to become genuine friends to the family member with a disability, and may become part of the inner circle over time. Most direct care staff, though, will be around only for a short period of time. Relying on staff to be friends does not create a secure path to the future.

It’s also important to remember that, even with a strong and active personal network, many people with disabilities need and want paid services and staff. It’s important to plan for services

as well. If your family member receives services from the County Board of DD, this can happen in the annual planning process.

### **Build the Family Network**

Families and caregivers are at risk of isolation too. Older caregivers themselves are often lonely. When families and caregivers are isolated and lonely, they are at risk for all the health and mental health consequences of loneliness, just like everyone else. If the caregiver has a weak personal network, it's hard to build a network for their family member with a disability.

Caregivers can use these same ideas and strategies for themselves. Intentionally strengthening your own network is an investment in your own well-being as well as that of your family member with a disability.



- ✓ For a thoughtful discussion on social isolation, see “Untethered: A Primer on Social Isolation” <https://static1.squarespace.com/static/5a5e5e0451a584dcfaaf9917/t/5a78c1b0f9619a572a6729d9/1517863383978/Untethered+v+1.24.18+for+PDF+Download.pdf>
- ✓ To learn more about personal networks and relationship map, see Cincibility blog post “51 people” <https://cincibility.wordpress.com/2012/06/08/51-people/>
- ✓ Good Life Networks (GLN) is a family-led organization serving Southwest Ohio with a mission to help families build networks and plan for the future: [www.goodlifecincy.org](http://www.goodlifecincy.org) or <https://www.facebook.com/GoodLifeNetworks/>
- ✓ Starfire is a Cincinnati-based organization. See their website for stories and videos about families, connections and relationships: <http://www.starfirecouncil.org/stories.html>
- ✓ Host a planning session using PATH or MAPS to create a picture of what a good life looks like for your family member – and to build a network of people who support your family member in moving toward that good life. Contact GLN for more information.
- ✓ If your family member has services from a provider agency, share your hopes and plans with the provider – or find a provider – who will help build the personal network.
- ✓ Share your hopes and plans with your family member’s SSA (if they have one) and ask their help in aligning services with these hopes and plans.

### **Complete the Worksheet for this Section**

**SECTION 2: BUILDING PERSONAL NETWORKS \*\*\* INTENTIONS & PLANS PAGE**

**Intentions**

Use this section of your Letter of Intent to state your intent about your family member’s personal network.

When you are no longer to play the role you do today – what are the most important things that you want others to know or do so that your family member has a strong personal network?

What I want others to know or do:

- 1.
- 2.
- 3.

**Plans**

Use this section of your Letter of Intent to make plans for what you’ll do now to strengthen your family member’s personal network.

With the time you have NOW – what are the most important things that you will do to strengthen your family member’s personal network?

- 1.
- 2.
- 3.

**Who can you ask for help?**

- 1.
- 2.
- 3.

### **SECTION 3: PLANNING FOR HOUSING: WHERE WILL MY FAMILY MEMBER LIVE?**

Where we call “home” is key to our identity, lifestyle, and quality of life. With good planning, “home” can be a place that helps us move along the path to the good things in life. If not thoughtfully planned, however, it can get in the way of those good things.

Older caregivers have often provided a good home for many years for their family member with a disability. Caregivers can gain peace of mind by learning about options and resources and taking steps now to prepare everyone for the time when they can no longer provide the care and support that the family member needs.

Just like building a personal network, planning for where your family member will live takes time. It’s important to use your time now to learn and plan for your family member’s housing.

#### **Take Advantage of Technology**

Sometimes the family member with a disability can use technology to stay safe and live at home. Sometimes, use of technology can extend the time that the family member can live safely at home. In addition, technology can also make it feasible for the family member with a disability to move from the family home and live more independently.

Technology makes it possible to secure entryways, offer two-way visual communication, monitor for falls and medication – and much more. The combination of technology and ‘people support’ can make it possible for the family member to be successful after a move from the family home.

If the family member with a disability has a waiver, talk with your SSA (Service and Support Administrator) about using the waiver to provide technology supports. If the family member does not have a waiver, caregivers can explore a range of inexpensive off-the-shelf technology that can help with everyday life.

A range of assistance devices are available to help manage everyday tasks and increase safety and security. Click here to see videos about using technology:

<http://dodd.ohio.gov/IndividualFamilies/Pages/SupportiveTechnology.aspx>

The Southwest Ohio Council of Government (SWOCOG) has furnished a Smart Home, located in Lebanon, Ohio, that offers live demonstrations of a range of technology and devices. Families can visit the open houses. For more information about the Smart Home, open houses, and technology, see the Hamilton County DD Services web site

[Hamiltondds.org](http://Hamiltondds.org)

Home Think Tank is another source of information and ideas about using technology at home. See the ‘tips’ section for more information.

## **Modify Your Home**

There are lots of ways to modify homes so that they are safer and more functional for the family member with a disability and/or the older caregiver. Some resources include:

- Those who live in Hamilton County (and outside the City of Cincinnati) can take advantage of resources available through the Hamilton County Community Development Office. (513-946-8214)
- People Working Cooperatively (PWC) offers home modifications and home repairs. They have a storefront located at 4612 Paddock Road, Cincinnati, where you can view a range of home modification options (e.g. adapted bathtubs) Phone: 513-351-7921 or <http://www.pwchomerepairs.org>
- People with disabilities who have waivers through Hamilton County DD Services may be able to get help with home modifications. Contact your SSA.

## **Apply for a Voucher**

Many people with disabilities will move out of their family home and rent an apartment or home. If the family member has a Waiver, they will receive staff support from a provider agency. However, it's important for caregivers to know that *Waivers do not cover rent costs*. The person with a disability must use a portion of their earnings or benefits check to cover rent. This section explains how vouchers can be used to offset a portion of the cost of rent.

A Home Choice voucher (sometimes referred to as a 'Section 8 voucher') covers a portion of a person's rent if that person is age 18 or older and has limited income. Vouchers are issued by the local Metropolitan Housing Authority. If a landlord agrees to accept a voucher, the person's rent is reduced. This makes housing more affordable.

Many adults with disabilities qualify for a voucher, even if they are currently living with their family that does not have income concerns.

So, the cost of rent can be lower if the family member with a disability has a voucher. For many people with disabilities, having a voucher can make a critical difference in making rent affordable.

Not everyone who applies for a voucher will get one. In Hamilton County, the application process includes a wait list and a lottery system. See Information and Resources: "Vouchers: What and How". The SSA can help your family member with a disability on the waiting list.

Learning about vouchers and getting on the wait list is a critical step that caretakers can take now to get on the path to a good housing situation down the road.

## **Open a STABLE Account**

A STABLE Account is another way that caregivers can invest in a good future for the family member with a disability. Caregivers and others can contribute up to \$15,000 per year. If the family member with a disability is employed, he/she will be able to contribute more. (For more

information, see Section Four: Building Personal Assets.)

Money invested in a STABLE Account can be used to cover housing costs. This gives caregivers a way to help plan and invest in future housing costs without jeopardizing public benefits. If a caregiver contributes directly to funding housing costs (without using a STABLE Account), the value is attributed as income to the family member with a disability and could impact the SSI benefit.

There are a few simple guidelines provided on the STABLE Account web site:

Money you withdraw and use for housing expenses may also affect your SSI benefits if you do not spend the money right away. To avoid any impact to your SSI benefits, be sure to spend housing money within the same calendar month that you withdraw the money. For example, if you withdraw \$800 from your STABLE Account on June 3rd for rent, you must pay that money to your landlord by June 30th. As long as you do not hold housing funds over from one calendar month to the next, the funds will not affect your SSI benefits. For more information on how the Social Security Administration will treat STABLE Accounts, see their guidance [here](#).

### **Learn about Trusts**

A properly established trust can work in conjunction with a STABLE Account to provide long-term resources to the family member with a disability, including supports for housing, without impacting benefits. There are different kinds of trusts. Caregivers are encouraged to seek the counsel of a qualified Medicaid attorney with experience in establishing trusts.

Hamilton County DD Services offers regular sessions on trusts and STABLE Accounts. These are listed on the web site: <http://www.hamiltongdds.org/families>

### **Learn about Medicaid Waivers for Services and Supports**

Waivers are one way the family member can get the services and supports to live safely and well. There are three Medicaid waivers offered through the Ohio Department of Developmental Disabilities.

One of the three waivers is called an Individual Options (IO) waiver. It has the highest cap and is for people who need more supports. Many people with disabilities who require more support to live safely outside the family home use this waiver.

If your family member does not have a waiver now, or if you anticipate that he/she may need a different waiver in order to live safely away from home, it's important to understand how the wait list works so that you can plan and act accordingly.

The new waiver wait list process is described on this web site: [fixthelist.info](http://fixthelist.info)

Caregivers often wonder: what will happen if there's an emergency? According to the [fixthelist.info](http://fixthelist.info):

*If at any time, a person is in an emergency situation, they may contact their local county board. The county board is required to address the needs of people who present an emergency situation. The services offered to mitigate the risk may or may not be a waiver. The new DD waiver waiting list will identify these situations as people having an immediate need.*

The new wait list process also establishes a priority to serve those who have an "immediate need":

*An Immediate need means a person is in a situation that creates a risk of substantial harm to themselves, their caregiver, or another person if action is not taken within 30 calendar days to mitigate the risk. If at any time, a person or their guardian thinks that they have an immediate need, they may contact their local county board and request an assessment using the Waiting List Assessment Tool. The county board is required to address the needs of people who present an emergency situation. The services offered to mitigate the risk may or may not be a waiver*

### **Learn about Shared Living**

If your family member has an Individual Options (IO) Waiver, he/she can choose to live in a family home (instead of getting staff support at his/her residence). This is called Ohio Shared Living. People who open their homes to become Shared Living providers must undergo a certification and training process. They receive a monthly stipend. They are monitored by the County Board, as are other providers. Siblings, extended family members, and friends can apply to become certified. Once certified, the siblings or extended family and friends can open their home to your family member. For more information see [Ohiosharedliving.com](http://Ohiosharedliving.com) and/or ask your county board for more information.

### **Learn about Supported Living and Group Homes**

If your family member has a waiver, he/she can choose to receive supports in their own home or apartment. This is called supported living. A supported living provider, who receives required training and is monitored by the County Board, can provide from a few hours a week to 24/7 support depending on your family members support needs. Most people receiving supported living share costs with a roommate. Your family member can also choose to live in a group home, a licensed residence of four or more people sharing a home. Group homes are located throughout many neighborhoods in Hamilton County.

### **Strengthen Your Family Member's Personal Network**

Caregivers can use the time they have now to strengthen and grow their family member's personal network. If and when the family member moves from the family home, their quality of life and safety will be significantly strengthened by having people involved in his/her life in a variety of ways.

## **Attend Home Think Tank Sessions and Learn About the Housing Options Guide**

Hamilton County DDS has supported the work of Home Think Tank for over ten years. This is an informal network of family members, DDS staff, advocates and allies interested in helping people with disabilities secure inclusive, affordable and accessible housing. Home Think Tank meets quarterly. Meetings are listed on the DDS web site.

Home Think Tank has created a Housing Options Guide. The Guide will be posted on the DDS web site in 2019. The Guide offers information on nine community-based housing options. Caregivers can learn the pros and cons of each options and determine which, if any, of these might be a good fit for their situation. The Housing Guide can use the information to avoid costly mistakes.

Caregivers can use the Housing Guide to learn about:

1. Traditional rental from a third party
2. Property is placed in a Trust for the use of the family member with a disability
3. Parent owns a second property and rents only to the family member/s with a disability
4. Parent owns a second property and rents only to the family member/s with a disability and housemates
5. Property is donated to a service provider for use of the family member with a disability
6. Property is donated to a Housing Network for use of the family member with a disability
7. Form non-profit to own property for use of the family member with a disability
8. Form an LLC to own property for use of the family member with a disability
9. Person with a disability owns the property



- ✓ Learn about STABLE Accounts and how they can be used to maximize housing options
- ✓ Talk with your family member's SSA (if you family member has one) about any questions you may have about the waiver wait list
- ✓ Attend Home Think Tank and learn about how to plan for housing. Home Think Tank meets quarterly. Meetings are listed on the DDS calendar: [hamiltondds.org](http://hamiltondds.org)
- ✓ Explore the Housing Options Guide
- ✓ Learn about Trusts by attending a Future is Now information session. These are posted on the DDS calendar
- ✓ Talk with others about your hopes for the future living situation of your family member with a disability.

## **Complete the Worksheet for this Section**

One of the important first steps is to create a picture of what a good home might look like for your family member when they are no longer living the primary caregivers. When you know what a good home looks like, and can share those ideas with other people, it's easier for others to help explore and plan.

### **SECTION THREE: PLANNING FOR HOUSING \*\*\* INTENTIONS & PLANS PAGE**

#### **Intentions**

Use this section of your Letter of Intent to state your intent about your family member's future housing.

When you are no longer to play the role you do today – what are the most important things that you want others to know or do so that your family member has a home that's a good fit?

What I want others to know or do:

- 1.
- 2.
- 3.

#### **Plans**

**Use this section of your Letter of Intent to plan what you need to do so that your family member will have a good place to live.**

With the time you have NOW – what are the most important things that you will do or learn about housing?

- 1.
- 2.
- 3.

#### **Who can you ask for help?**

- 1.
- 2.
- 3.

## SECTION FOUR: MAKING THE MOST OF PUBLIC BENEFITS AND PROTECTING PERSONAL ASSETS

An important part of securing a good future is making the most of public benefits and protecting personal assets. The purpose of this section is to provide general information and offer tips for accessing more information.

It's important for the caregivers/s to understand which benefits the family member with a disability is receiving. Some benefits have income and resource limits, others do not. If the caregivers/s know which benefits their family member is receiving, then they can take steps to protect those benefits. This section includes information to better understand this.

Families participating in the Future is Now family sessions will have an opportunity to ask questions and get information from a benefits expert. None of the information in this section should be considered legal or financial advice. Please use appropriate professional assistance before making legal and financial decisions.

One source of valuable information about benefits is Ohio Disability Benefits 101. Some of the information below is taken from this website:

[https://oh.db101.org/oh/programs/income\\_support/ssi/program.htm](https://oh.db101.org/oh/programs/income_support/ssi/program.htm)

### **Know which Social Security Disability Benefit Your Family Member Receives**

Social Security has different types of cash benefit programs with very similar names. The most popular ones are described below. See the web site above and other resources in 'Helpful Tips' for more information.

*Supplemental Security Income (SSI) gives cash benefits to people with disabilities who have low income and low resources. You do not need to have worked in the past to get SSI.*

- *If you have a disability, are blind, or are over age 65 and you also have low income and limited resources, you may qualify for SSI.*
- *Resource limit (in 2019) is \$2000 (\$3000 for couples)*
- *If you qualify for SSI, you get monthly cash payments to help pay for your basic needs. A person who is single can get up to \$771 per month in benefits.*
- *You also get Medicaid health coverage automatically*
- *If you get SSI benefits and start working, you'll probably end up better off financially. SSI's rules are designed to help you find work and make sure that your total income will be higher after you get a job.*

*Social Security Disability Insurance (SSDI) and Social Security Disability Adult Child (SSDAC) give cash benefits to people with disabilities who qualify because they used to work (SSDI) or have a parent who worked (SSDAC).*

- *Disability insurance /entitlement program based off work history of the person with a disability or parent. (Parent must be retired, disabled, or deceased).*
- *There is no resource limit.*
- *The amount of SSDI/SSDAC benefits is based on Social Security earnings record.*

- *After getting SSDI/SSDAC benefits for two years, you automatically become eligible for Medicare health coverage.*



Some people qualify for both programs at the same time. If you get benefits from Social Security, but aren't sure which ones you get, order a free [Benefits Planning Query](#) (BPQY) at your [local Social Security office](#) or by calling 1-800-772-1213 or 1-800-325-0778 (TTY).

#### *ABD Medicaid (Age Blind & Disabled)*

- *This program provides for basic healthcare needs as well as long term services and supports which aren't covered by other health insurance programs. ABD Medicaid is considered the 'payor of last resort' and will cover healthcare only after other health plans.*
- *The resource limit (in 2019) is \$2000 for an individual or \$3000 for a couple.*
- *Income limits also apply, however it may be possible to explore other Medicaid programs if income exceeds limits.*

#### **Learn about In-kind Support and Maintenance**

Understanding "in-kind support and maintenance" is key to protecting benefits and planning for the future. If a family member is receiving a benefit that has *income limits* (like Medicaid or SSI), then caregivers/s need to be aware that 'in-kind support and maintenance' to that family member, such as payment of the family member's rent, is considered as income to the family member. The Social Security Administration defines it this way:

*"In-kind support and maintenance is food or shelter that somebody else provides for you. We count in-kind support and maintenance as income when we figure the amount of your SSI benefits. For example, if someone helps pay for your rent, mortgage, food, or utilities, we reduce the amount of your SSI benefits."*

If the adult with disabilities lives at home with older caregivers, the caregivers need to charge a fair share of food and/or shelter, or maximum possible SSI benefits amount may be reduced.

*"The fair share is the amount that each individual in a household is responsible for spending each month on food and shelter. If you live alone, it is the full cost of food and shelter. If you live with others, it is an equal portion of the total food and shelter expenses. For example, if you and three other people live together and spend a total of \$4,000 per month on rent, utilities, and food, a fair share for each of you would be \$1,000. (Glossary db.101)"*

Consult a benefits expert for more information.

## **Learn About Ohio DODD (Department of Developmental Disabilities) Medicaid Waivers**

DODD offers three Medicaid Waivers: Individual Options (IO), Level-1, and SELF. A person must be eligible for Medicaid in order to receive a DODD Medicaid waiver. These waivers provide greater access to a range of services and supports than standard Medicaid.

DODD Waivers are a primary source of services and supports for many people with a disability. The County Board provides a portion of waiver funding, called the waiver 'match'. The county board can provide additional information about waivers. DODD offers user-friendly information on waivers as well:

<http://dodd.ohio.gov/IndividualFamilies/ServiceFunding/Pages/WaiverTypes.aspx>

It's important to protect your family member's Medicaid waivers. Your family member with a disability:

- May incur a patient liability if total countable income exceeds certain amounts
- May lose the waiver if countable monthly earnings exceed a certain amount and a Qualifying Income Trust (QIT) is not set up
- Can set up a Qualifying Income Trust (QIT) in order to maintain coverage
- Can check out Medicaid Waiver Buy-in for Workers with Disabilities. This offers incentives specifically designed to allow a person with disabilities to increase their earnings and resources without fear of losing Medicaid.

Consult a benefits expert for more information on protecting any of these benefits.

## **Learn About STABLE Accounts**

A STABLE Account is another way that caregivers can invest in a good future for the family member with a disability. Caregivers and others can contribute up to \$15,000 per year. If the family member with a disability is employed, he/she will be able to contribute more.

A STABLE Account is an investment account available to eligible individuals with disabilities. STABLE Accounts allow individuals with disabilities to save and invest money without losing eligibility for certain public benefits programs, like Medicaid or SSI. Earnings in your STABLE Account are not subject to federal income tax, so long as you spend them on "Qualified Disability Expenses."

STABLE Accounts have some similar features to normal bank accounts, but they are not checking or savings accounts. STABLE Accounts are investment accounts, similar to 529 college savings accounts or 401(k) retirement accounts. When you deposit money into your STABLE Account, your money will be invested in different options that you choose. While you can still withdraw and spend your money whenever you need it, a STABLE Account also allows you to grow your money and to save long-term for disability expenses.

Money invested in a STABLE Account can be used to cover housing costs. This gives caregivers a way to help plan and invest in future housing costs without jeopardizing public benefits. If a

caregiver contributes directly to funding housing costs (without using a STABLE Account), the value is considered to be “in-kind support and maintenance” and could impact the SSI benefit.

### **Learn how STABLE Accounts Protect Benefits**

A STABLE Account can help protect public benefits. According to the STABLE web site:

*One of the primary reasons that the federal ABLE Act was passed was to protect individuals with disabilities from losing certain benefits such as SSI or Medicaid.*

*With the exception of some special SSI rules (see below), your STABLE Account funds do not count against you for purposes of determining your eligibility for means-tested federal benefits programs. For example, if you have \$5,000 in your STABLE Account, that \$5,000 does not count as an asset when determining your eligibility for SSI or Medicaid.*

*In addition, your STABLE Account will not affect your eligibility for state-based means-tested benefits programs offered by Ohio. Residents of other states should check with their state benefits agency to verify that a STABLE Account will not affect state-based benefits.*

The STABLE Account web site is very user friendly. Information is easy to understand. Here is some basic information taken from the web site: <https://www.stableaccount.com/>.

Caregivers/s should review the web site and/or attend an informational session to get their questions answered.

*Using a STABLE Account will not make you ineligible for SSI. If, however, you have more than \$100,000 in your account, your SSI benefits may be suspended.*

*Here's how this will work: any STABLE Account funds over \$100,000 are treated as a countable resource for purposes of determining your SSI benefits. For example, if you have \$101,000 in your STABLE Account, the Social Security Administration will ignore the first \$100,000 but will count the next \$1,000 as your resource. The good news is that if your STABLE Account balance causes you to exceed the normal SSI resource limits, your SSI benefits will be merely suspended - you will not become ineligible for SSI. Once your account balance drops, you can notify SSA to have your SSI benefits resume.*

*Money you withdraw and use for housing expenses may also affect your SSI benefits if you do not spend the money right away. To avoid any impact to your SSI benefits, be sure to spend housing money within the same calendar month that you withdraw the money. For example, if you withdraw \$800 from your STABLE Account on June 3rd for rent, you must pay that money to your landlord by June 30th. As long as you do not hold housing funds over from one calendar month to the next, the funds will not affect your SSI benefits. For more information on how the Social Security Administration will treat STABLE Accounts, see their guidance:*

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740>

## Learn about Trusts

Establishing a trust is another way to protect benefits and maximize assets. There are different kinds of trusts. Caregivers are encouraged to seek the counsel of a qualified Medicaid attorney with experience in establishing trusts.

A properly established trust can work in conjunction with a STABLE Account to provide long-term resources to the family member with a disability, including supports for housing, without impacting benefits. Caregivers can arrange for a trust to make regular, ongoing deposits into the family member's STABLE Account. While STABLE Accounts have many good features, they are not designed to act as vehicle for estate planning. Trusts can offer features and benefits that a STABLE Account cannot. With planning, caregivers can use a trust and a STABLE Account together to do what neither can accomplish alone.



- ✓ Hamilton County DD Services offers regular sessions on trusts and STABLE Accounts. These are listed on the web site: <http://www.hamiltondds.org/families>
- ✓ Hamilton County DDS provides the services of a benefits expert, Antonio Akins who can assist people served by DDS and their families. He can be reached at Antonio.Akins@hamiltondds.org or (513) 559-4353
- ✓ The STABLE Account web site offers many easy-to-understand features: <https://www.stableaccount.com>.
- ✓ Ohio DODD (Department of Developmental Disabilities) web site offers more information about waiver eligibility and assessment <http://dodd.ohio.gov/IndividualFamilies/Pages/default.aspx#>
- ✓ For more information on Individual Options, Level-1, and SELF waivers and what services are covered under each: [odd.ohio.gov/IndividualFamilies/ServiceFunding/Pages/WaiverTypes.aspx](http://odd.ohio.gov/IndividualFamilies/ServiceFunding/Pages/WaiverTypes.aspx)
- ✓ Valuable information about benefits can be found at Ohio Disability Benefits 101. [https://oh.db101.org/oh/programs/income\\_support/ssi/program.htm](https://oh.db101.org/oh/programs/income_support/ssi/program.htm)

**SECTION FOUR: MAKING THE MOST OF PUBLIC BENEFITS AND PROTECTING PESONAL ASSETS**  
**\*\*\* INTENTIONS & PLANS PAGE\*\*\***

**Intentions**

Use this section of your Letter of Intent to state your intent about your family member’s public benefits and personal assets.

When you are no longer to play the role you do today – what are the most important things that you want others to know or do so that public benefits and personal assets are protected?

What I want others to do or know:

- 1.
- 2.
- 3.

**Plans**

**Use this section of your Letter of Intent to plan what you need to do so that your family member’s public benefits and personal assets are protected.**

With the time you have NOW – what are the most important things that you will do or learn about public benefits and personal assets?

- 1.
- 2.
- 3.

**Who can you ask for help?**

- 1.
- 2.
- 3.

## **SECTION FIVE: SUPPORTS AND CARE FOR OLDER CAREGIVERS**

Many caregivers hope to continue to live with their family member with a disability for as long as they can do so safely and with quality of life for all concerned. For older caregivers, this means paying attention to their own needs and addressing issues that arise because of their own aging process. Sometimes, ‘caring for the caregiver’ is the very thing that makes it possible for the family to stay together longer.

### **Care for the Caregiver**

Caregivers age 60 and older may be eligible for a range of services that help them stay at home and manage the demands of caregiving. Some senior caregivers may be eligible to receive these services at no cost; others may be asked to pay a fee based on their income. Some aging caregivers find it useful to get services like home modifications to improve accessibility, technology (like fall alert devices), meal delivery, or homemaker services.

The Council on Aging of Southwest Ohio is the ‘front door’ for aging services in the Southwest Ohio region. You can get information about services and supports that might help you live safely and well in your own home for as long as possible. You can reach the Council on Aging at [www.help4seniors.org](http://www.help4seniors.org) or by calling (513) 721-1025.

The Council on Aging offers an extensive Resource Guide on their website. This is one way to get ideas about the range of resources available. They also offer an intake and referral service designed to help you find what you need.

Council on Aging’s (COA) Caregiver Support Program provides free support and connection to resources for caregivers 60 years old who live in Butler, Clermont, Clinton, Hamilton or Warren counties. The program works to:

- reduce caregiver stress, burden and injuries
- increase caregiver confidence and knowledge
- improve the quality of care
- help caregivers balance their lives and caregiving responsibilities.

Call (513) 721-1025 for information or see:

<https://www.help4seniors.org/Downloads/fact-sheets/CaregiverSupportProgram2017.pdf>

### **Streamlining Aging and DD Services**

If your family member receives supports from the Hamilton County Board of DD, caregivers can be aware that Hamilton County DDS is partnering with the Southwest Ohio Council on Aging to strengthen the collaboration among the two agencies. Both agencies are committed to serving the whole family, and helping the family stay together safely and live well together for as long as possible.

## Modify Your Home

There are lots of ways to modify homes so that they are safer and more functional for the older caregiver. Some resources include:

- People Working Cooperatively (PWC) offers home modifications and home repairs. They have a storefront located at 4612 Paddock Road, Cincinnati, where you can view a range of home modification options (e.g. adapted bathtubs) Phone: 513-351-7921 or <http://www.pwchomerepairs.org>
- If you live in Hamilton County (and outside the City of Cincinnati) there are resources available to support some modifications. Contact the Hamilton County Community Development Office. (513-946-8214)
- Aging caregivers who need help with home modifications can contact the Council on Aging to get information. . You can reach the Council on Aging at [www.help4seniors.org](http://www.help4seniors.org) or by calling (513) 721-1025.



- ✓ ProSeniors, Inc. offers limited free legal advice: 800-488-6070 for people age 60 and older
- ✓ You can get information about services and supports that might help you live safely and well in your own home for as long as possible. You can reach the Council on Aging at [www.help4seniors.org](http://www.help4seniors.org) or by calling (513) 721-1025.
- ✓ The Caregiver Assistance Network (CAN) offers monthly support groups for more than 340 caregivers throughout Greater Cincinnati where caretakers meet to gain the support they need in their care Hamilton, Butler, Warren, Clermont & Clinton County caregivers are eligible: <https://ccswoh.org/services/seniors/caregivers/>
- ✓ CAN also offers CAREline – a toll-free hotline providing resource information 513-869-4483, referrals and support.

## SECTION FIVE: SUPPORTS AND CARE FOR OLDER CAREGIVERS \*\*\* INTENTIONS & PLANS PAGE

### Intentions

Use this section of your Letter of Intent to state your intent about the support and care you need – as a caregiver.

What are the most important things that you want others to know or do so that you (caregiver) can get the care and support you need?

What I want others to know or do:

- 1.
- 2.
- 3.

### Plans

Use this section of your Letter of Intent to plan what you need as a caregiver.

What are the most important things that you will do or learn in order for you to get the care that you need as a caregiver - now or in the future?

- 1.
- 2.
- 3.

### Who can you ask for help?

- 1.
- 2.
- 3.

## SECTION SIX: WHO HOLDS THE STORY? WHO KEEPS THE DREAM?

When caregivers reflect on their hopes and worries, they often say that one of their biggest worries is that their family member will be ‘unknown – not known for who they are – just a client’. When asked their hopes and dreams, many caregivers say that they want the family member be ‘known for who they are’.

This final section of the Letter of Intent offers an opportunity to reflect on ways to create and hold the story of your family member. It invites caregivers to ask others to hold the story and keep alive the dreams for your family member’s future when the caregiver is no longer alive.

### Who Holds the Story?

As a caregiver, you have held your family member’s story for many years. You know the significant events in his/her life, what matters to them and why, and who they are as a person.

You have held the story – and shared it in ways that have helped others know and understand your family member. Who will hold your family member’s story when you are no longer on this earth?

Many of the ideas in this section are taken from an article by David Pitonyak entitled: “Who Holds Your Story?” <http://dimagine.com/wpcontent/uploads/2018/03/WhoHoldsYourStory.pdf>  
A copy of the article is shared at the FIN Family Sessions. The article points out:

*Being known is critical to our well-being. Having our stories held and told by others gives us a sense of place in the world, a sense of belonging...A sad and all too common truth for people who experience developmental disabilities is that little, if anything, is known of their stories. Reams and reams of paperwork are generated each year, but only a fraction of what is generated describes the person’s connection to the world. The file is instead a collection of things that the service system wants — a chronicling of interventions, evaluations, signatures, data points. There is no unfolding of things in these files, no character development, no plot. (Page 2)*

When a person’s story is lost, they are at risk of becoming ‘just a client’, unknown and misunderstood. When others hold your family member’s story, they are more likely to be seen as fully human, an interesting person with a full life story that can be respected and honored.

As the article points out, when the family member’s personal history is known, it can help others:

- *Understand the bright spots in the person's past and figure out how to increase the number of such bright spots going forward*
- *Take advantage of the strengths and capacities the person has demonstrated in the past*
- *Avoid the occurrence or repetition of experiences that would be damaging*
- *Understand "how things have been" ... so that our understanding about what really matters and our conviction about "how things could be" can be strengthened.*

### **Find a Way to Tell the Story**

A person's story is more than just the big events in their life - it includes who the person is as a result of the story. It describes the most important things to know and understand about the person.

There are many ways to tell a person's story. No matter what the approach, it's critical to include the family member's ideas and perspectives. How this is done will depend on the person – it's always possible to include the person in some way. If a person doesn't use language, for instance, we can show the person several photos from the past, and ask them to pick the one that matters most to them. Or we might talk about past events and people and see when the person lights up.

Here are some ways to tell a person's story:

- Create a simple timeline: draw a line across the middle of a piece of paper. Put the person's birthdate on the left and their current age on the right. Jot down key events. If you know what these events have meant to the person, include those as well.
- Create a simple video. Use a smart phone to 'interview' people who have known the family member at different points in his/her life. Ask them to tell stories about what they remember about the person at key ages. Ask them how the past has shaped who the person is today. Ask what the most important things are to know and remember about the person's life.
- Create an album, scrapbook or personal history book (do this online if it's easier). Include photos and other objects that represent key events and experiences.
- Keep the dreams alive – end the timeline, video or album with reflections on the future. Describe the hopes and dreams of the family member. Describe the hopes and dreams that others hold for this person.
- Use any combination of these ideas –or invent your own.

### **Ask Others to Hold of the Story and Keep the Dream**

Caregivers can gain peace of mind when they know there are people who can hold the story and keep the dream. People who hold your family member's story can also be 'keepers of the dream' – people who keep the hopes of the caregiver/s and family member alive after the caregiver/s can no longer do this.

Caregivers can turn to those in the inner circle of the family member to find a person – or people – to play this role. After the caregiver/s is no longer alive, people in the ‘inner circle’ may or may not be able to provide day-to-day support, but will want to play a role in your family member’s life. Asking a few of these people to be ‘tellers of the story’ and ‘keepers of the dream’ gives them a clear and specific way to be engaged.

The role of the holders of the story and the keepers of the dream is different than formal, legal roles like guardian or trustee. The role of guardians and trustees is defined by the legal system. The role of holders of the story and keepers of the dream is an informal, voluntary role.

It is possible for one person to act in multiple roles, for example, and service as both the guardian and holder of the story and keeper of the dream. However, just because a person has agreed to act in legal role, such as guardian or trustee, the caregiver should not *assume* that the person is willing or able to act as holder of the story or keeper of the dream.

A sibling who is great with numbers and understands allowable expenditures may make a great trustee for a Special Needs Trust, but may not be as capable or interested holding the story of the family member with a disability. Both are valuable roles – and they are different. As caregivers plan for the future, they can be intentional about inviting people to play a role that fits best.

Caregivers can shift away from asking “Who will take care of my son/daughter when I’m no longer here?” and shift toward: “What are all the roles that need to be filled, and who are the best people for each role?”

### **Make a Specific ‘Ask’**

Sometimes it can be helpful to make a specific request about what you’d like the ‘holders of the story’ and ‘keepers of the dream’ to do. Caregivers might have a conversation like this:

“You’ve been part of \_\_\_’s life for a long time. I am grateful for that. I hope that after I pass on, you will continue to be part of \_\_\_’s life. One of the specific ways you can help is to make sure that others know about who he is as a person and help them understand my hopes for what a good life can look like for him.”

Depending on the situation, you may ask the ‘holders of the story’ and ‘keepers of the dream’ to share the person’s story with new friends, service providers and SSAs using any approach that fits, including any of these:

- Arrange a time to stop by and meet with the staff and family member. Informally share stories that help reveal the person’s story and help staff see the whole story.
- Create a simple, one-page summary of key ideas and ask that it be kept in a prominent place so that staff can see.
- Ask to be invited to a team meeting so that you can share about the person’s story and the caregiver/s hopes and dreams.

- Host a birthday party – or a potluck—and invite staff and others. Use the occasion to informally share stories that help others appreciate the person’s history and understand who she/he is now as result.
- Stay alert to new people in the person’s life – people they may meet at work or church. Seek these people out and share the story of who this person is, using any of the ideas above.
- Engage the person in sharing their story in whatever way works, using any of the ideas above.

**Be Intentional – Don’t Wait**

There’s no need to wait till the caregiver/s incapacity or death. Engaging the ‘holders of the story’ and ‘keepers of the dream’ in an intentional way, over time, will increase the chances that they will stay engaged later.

## SECTION SIX: WHO HOLDS THE STORY? WHO KEEPS THE DREAM?

### \*\*\* INTENTIONS & PLANS PAGE

#### **Intentions**

Use this section of your Letter of Intent to state your intent about who holds the story and who keeps the dream of your family member with a disability.

When you are no longer to play the role you do today – who might be the holders of the story and keepers of the dream? What do you want these people to do? (Use the ideas on previous page to jump start your thinking).

- 1.
- 2.
- 3.

#### **Plans**

**Use this section of your Letter of Intent to plan what you need to do so that your family has others who hold the story and keep the dream.**

With the time you have NOW – what are the most important things that you will do or learn so that there are people who hold the story and keep the dream?

- 1.
- 2.
- 3.

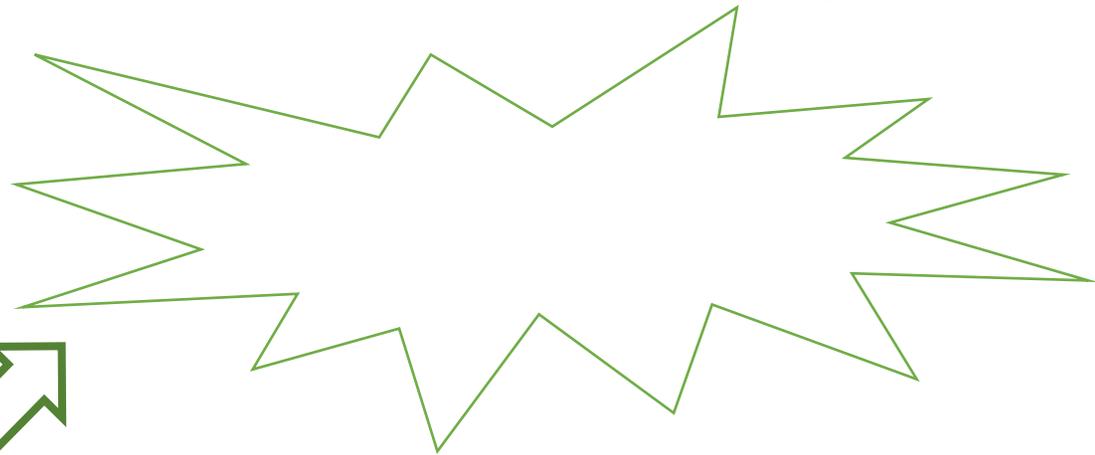
#### **Who can you ask for help?**

- 1.
- 2.
- 3.

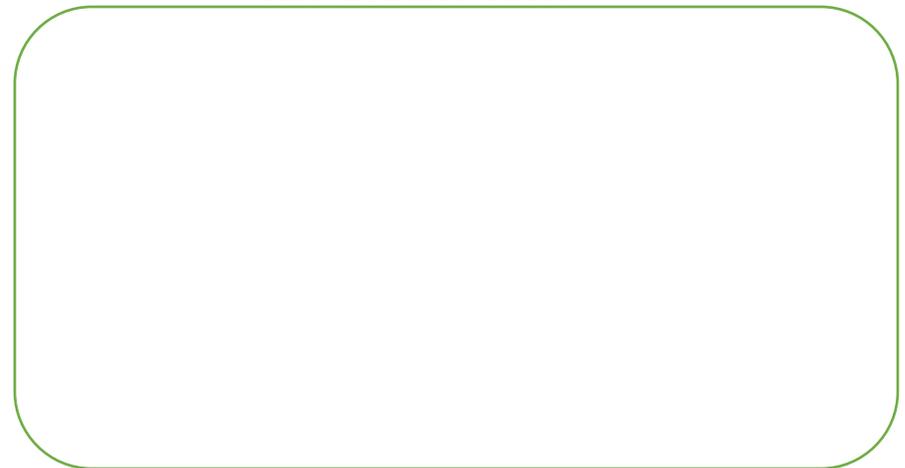
**LETTER OF INTENT WORKSHEETS**

## HOPES AND WORRIES ABOUT OUR FAMILY MEMBER'S FUTURE

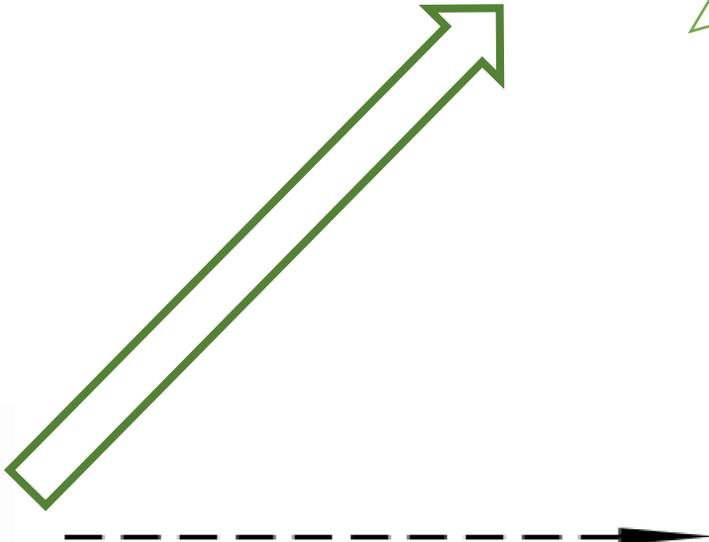
Our hopes for our family member's future:  
What a good life looks like



Our FEARS for our family member's future:  
What we DON'T WANT



NOW



## HOPES AND WORRIES ABOUT OUR FAMILY MEMBER'S FUTURE

### Worksheet Guide

- Start with hopes or worries – whatever is easiest
- Write or draw a few simple words or images that represent your hopes for a good life. Put these in the star at the top
- Write or draw a few simple words or images that represent your worries: put these in the box at the bottom of the page
- Include your family member's hopes and fears as well as your own

#### Talk About

- What stands out for you about the 'hopes'?
- What stands out for you about the 'worries'?
- Think about where your family member is NOW (left corner of the worksheet). What good things are in place now that put your family member on a path to reach the 'hopes' and the 'good life'? How might these be strengthened? What else could put your family member on the path to a good life?
- Are there things NOW or IN THE FUTURE that might put your family member on the path to the things you don't want? What might you do about that?
- Are there things that you need to learn more about? Who could help you learn?
- Who else can you share this so that they know the hopes and fears?

#### Wrap Up

- Keep this worksheet with your Letter of Intent
- After you've had some time to reflect and/or talk to others, be sure to complete the Reflections and Actions page

## Personal Network Map

## PERSONAL NETWORK MAP Worksheet Guide

- Write your family member's name in the center.
- Notice that there are three circles:
  - 1.) INNER CIRCLE are people who know us well and care deeply about us. They take our life seriously. They celebrate important times – and are there when things are hard. They understand what's important to us, and offer moral support and/or practical help.
  - 2.) MIDDLE CIRCLE are people in our everyday life with whom we have moderately strong ties with – these people often help us navigate our day-to-day world. This might include people that we see as part of the daily or weekly routine, or people who provide care, such as dentists, doctors, or hair dressers. Some neighbors might fall in this circle. Our ties with this circle aren't strong enough to be considered 'inner circle', but are stronger than the 'weak ties' of the outer circle.
  - 3.) WEAK TIES are the outer circle and might include people at work, in your neighborhood, merchants, faith community, or recreational activities.<sup>2</sup> . They don't know much about us, but we have a weak common link (live on the same block, go to the same church, went to school together, etc.). Having lots of weak ties is valuable and important.
- Notice that the map has four sections: family, service providers, other people with disabilities, and other citizens.
- Take one section at a time. For example, starting with the "family section", list the names of family members who are in the inner, middle and weak ties circle. Complete all four sections.

### Talk about

- What's worth celebrating? What's the good news in this relationship map? How can you build on these strengths?
- What concerns does this raise?
- What might you, along with others, do about that?

### Letter Of Intent

After you've had some time to reflect and/or talk to others, be sure to complete the Reflections and Actions page. Caregivers can also complete their own network map and make plans to strengthen it over time.

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<sup>2</sup> Hsu, David. "Untethered: A Primer on Social Isolation"  
<https://static1.squarespace.com/static/5a5e5e0451a584dcfaaf9917/t/5a78c1b0f9619a572a6729d9/1517863383978/Untethered+v+1.24.18+for+PDF+Download.pdf>

## What Does a Good Home Look Like?

### Physical Environment

Does your family member need a barrier-free (accessible) floor plan now? Might they need a barrier-free (accessible) floor plan in the future?



Use this space to outline the most important aspects of the physical environment

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### Location

Does the location of the home matter? Is there a neighborhood or area that works best? Why? Does the location of the home need to be near public transportation? Use this space to outline the most important ideas about the location.

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### Housemates



Might your family member prefer to share a home with a person or family (without a disability) that provides a place to live and offers assistance? Live with a roommate (or roommates) with a disability and receive staff support? Live without housemates? Use this space to outline the most important ideas about housemates.

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How else would you describe “What a good home looks like?”

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## What Does a Good Home Look Like? Worksheet Guide

This worksheet invites you to describe what a good home looks like for your family member with a disability. It offers space to describe three features of a good home:

1. The physical environment
1. The location
2. Housemates

There may be others features of a good home that matter to your family member. List these at the bottom of the page.

### Talk about:

- What are the most important features of a good home? What matters most?
  
- What concerns does this raise?
  
- Are there things that you need to learn in order to make better plans?

### Wrap Up

- Keep this worksheet with your Letter of Intent
- After you've had some time to reflect and/or talk to others, be sure to complete the Reflections and Actions page

## ADDITIONAL RESOURCES



Lots of resources are listed in under “helpful tips”.

This sections does not repeat those – but does add a few additional:

- ✓ The ARC Center for Future Planning includes an online planning tool, informational resources, and stories and examples of how families have planned:  
<https://futureplanning.thearc.org/>
- ✓ Plan Institute has a number of resources about building personal networks and planning for the future: <https://planinstitute.ca/learning-centre/publications/>
- ✓ Information about the new waiting list rule: <http://www.fixthelist.info/>
- ✓ Guardianship in Ohio is explained in this brochure:  
[https://www.ucucedd.org/wp-content/uploads/2018/01/Ohio-DD-Council\\_Guardianship-in-Ohio\\_2017.pdf](https://www.ucucedd.org/wp-content/uploads/2018/01/Ohio-DD-Council_Guardianship-in-Ohio_2017.pdf)
- ✓ “Who holds your story?” by David Pitonyak, can be found here:  
<http://dimagine.com/wp-content/uploads/2018/03/WhoHoldsYourStory.pdf>
- ✓ The Charting the LifeCourse Framework was created by families to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.  
<https://www.lifecoursetools.com/>

