SAILing to Your IDD Housing Solution

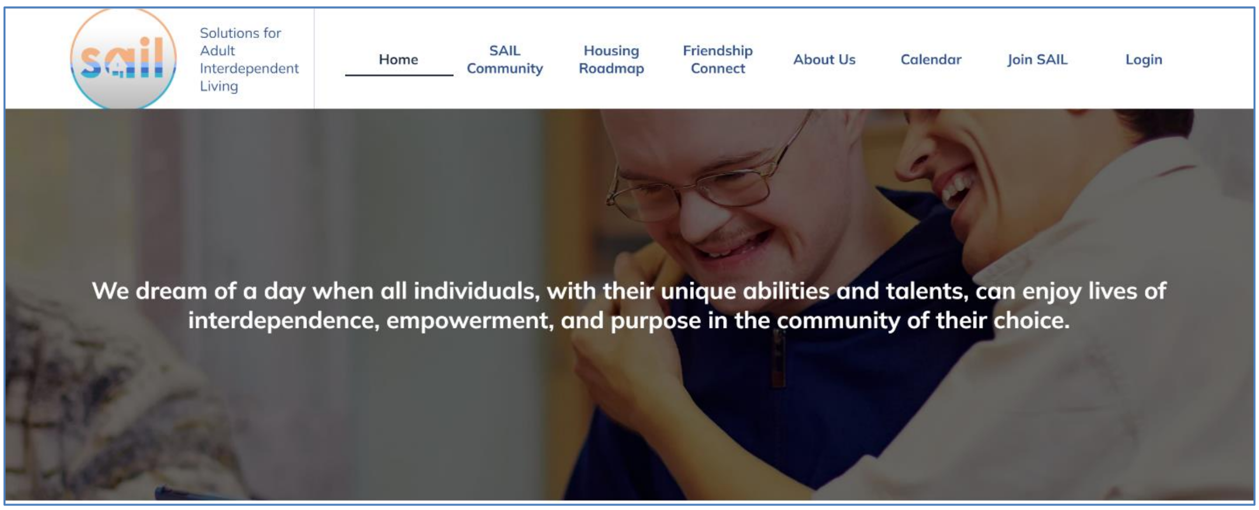
A Guide for Parents Seeking IDD Housing Solutions

Solutions for **A**dults **I**nterdependent **L**iving

Edition
2026 | V1.0
GSD 1.3

About SAIL

The genesis of SAIL can be traced back to October 2018 when a group of parents[1] came together with the purpose of finding a housing solution for their Adult Child[2] with Intellectual or Developmental Disabilities (IDD). Rather than waiting around for a Housing Solution to come knocking on their front door, the parents decided that by working together they could create their own Housing Solutions, provide support and guidance to one another, and document their collective wisdom, steps & missteps, and helpful tips along their journey to support other parents that are faced with this daunting challenge.



SAIL is a 501c3 non-profit organization that partners with community leaders, public and private organizations, and individuals to inspire sustainable, creative housing solutions that empower adults with disabilities to thrive, actively participate in, and contribute to their communities for a lifetime.

Within the SAIL family there is a shared vision and mission to create an environment that fosters the development of interdependence among individuals with an IDD, fellow parents and the surrounding community. It is our belief that with interdependence our loved ones

[1] Parents – Refers to Parent, Sibling or Guardian of an individual with Intellectual Developmental Disabilities
[2] Adult Child – Refers to an individual with Intellectual Developmental Disabilities, although that individual might be an adult

will experience an ecosystem of mutualism with their peers, both neurotypical and differently abled. This mutualism is a relationship where all benefit, but none are completely dependent on the other.

As human beings we are instinctually communal and thrive when we stand shoulder to shoulder. We at SAIL believe that any individual can live independently when they have the right supports in place. We believe that everyone has the right to lead a fulfilling life as a contributing member of the community. Therefore, it is important to plan carefully and assemble the right crew!

Please use the links below to contact SAIL for more information.

Visit SAIL at	www.SailHousingSolutions.org
Email SAIL at	info@SailHousingSolutions.com

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References

SAIL is forever indebted to the Center for Independent Futures (CIF) of Evanston, IL and their invaluable training which laid the foundation for SAIL's journey. Much of the material contained in this document was taken from the CIF document, *A Guide for Forming and Implementing Community Partnerships*.

Throughout this document, information from The Cleveland Foundation's *Innovative Independent Living Project* was utilized. This document, which was published in 2011, provides a model for creating community living for individuals with an IDD.

The Arc of Oakland County's webinars, presented by Tom Kendziorski, *Planning a Secure Future* & *MI ABLE* are an absolute **Must Read** for parents just starting their journey or for those seeking a better understanding of the alphabet soup of Government agencies.

The Coleman Foundation Center for Independent Futures	A Guide for Forming and Implementing Community Partnerships	https://independentfutures.com Email: center@independentfutures.com
LEAP - Linking Employment, Abilities and Potential	The Innovative Independent Living Project	https://www.leapinfo.org/services/living-with-technology/the-illp
The Arc of Michigan	The Arc of Michigan	https://arcmi.org/
The Arc of Oakland County	The Arc of Oakland County	https://www.thearcoakland.org
	Resource List	https://www.thearcoakland.org/informational-resources/additional-links/

Resources

Community Resources	
Angel's Place	https://www.angelsplace.com
Community Housing Network	https://communityhousingnetwork.org/
Community Living Services of Oakland County – **CLS**	http://www.comlivserv.com
The **Dani** Plan	https://daniplan.com/
Detroit Wayne Integrated Health Network - **DWIHN**	https://www.dwihn.org/
Easterseals | MORC Macomb Oakland Regional Center	https://www.morcinc.org
Home Help (administered by MDHHS)	https://www.michigan.gov/mdhhs

Community Resources

Homes Giving Hope	https://homesgivinghope.org/
Jewish Association for Residential Care **JARC - Integrative Neighborhoods**	https://www.jarc.org/integrativeneighborhoods
Macomb County Community Mental Health - **MCCMH**	https://www.mccmh.net/
Michigan Department of Health & Human Services - **MDHHS**	https://www.michigan.gov/mdhhs
MI Bridges – State of Michigan	https://newmibridges.michigan.gov
Oakland Community Health Network – **OCHN**	https://www.oaklandchn1.com
On My Own of Michigan	https://onmyownofmi.org
Social Security Administration	https://www.ssa.gov

Purpose

SAILing to Your IDD Housing Solution is intended as a *Parent-to-Parent Guide* that provides practical advice and guidance on the numerous challenges that parents of an individual with an Intellectual or Developmental Disability (IDD) take on when attempting to create a viable housing solution for their Adult Child. This document attempts to organize and define the steps parents should consider along their journey and the tasks involved when attempting to create a sustainable IDD[3] housing solution. Along with the *SAILing to Your IDD Housing Solution* guide, SAIL has created numerous worksheets, accompanying documents, and practical tools to help families along their path in creating an IDD Housing Solution for their son or daughter. These additional, supplemental documents are available on the SAIL website.

SAIL's goal is that all adults with disabilities will find a housing solution for them to thrive, actively participate in, and contribute to his or her community.

Overview of SAILing to Your IDD Housing Solution Process

Please keep in mind that this document describes **a** process, and not **the** process, that must be followed by all parents seeking an IDD Housing Solution. SAIL recognizes that everyone's journey towards a housing solution for his or her Adult Child is different. By using this straightforward process, SAIL hopes to help readers understand both the Big Picture and where they are on their unique journey.

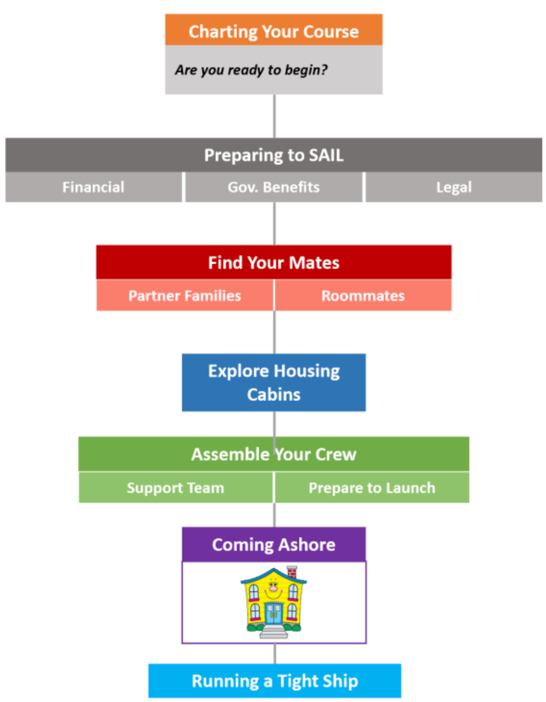
Steps of the SAILing to Your IDD Housing Solution Process

The diagram below contains the key SAILing steps and milestones that are involved in building a safe and sustainable IDD Housing Solution for your Adult Child. This guide will further

[3] Intellectual or Developmental Disability

expand on each of the steps and highlight SAIL reference documents and resources to support your efforts.

Although every family's journey to their IDD Housing Solution will vary, the steps and processes that are defined within this document will emphasis the importance of finding **Partner Families**[4] with compatible roommates for your Adult Child in the ***Find Your Mates*** step before serious consideration should be given to looking for the physical residence. It's important to understand that the SAILing process does not begin or end with finding the physical home for your son or daughter. Rather the ***Exploring Housing Cabins*** step is squarely in the middle of the SAILing process. Indicating that there is plenty of work to do both before and after this step.



Charting Your Course
- Reality Check … Is this right for your Child?
- Are you ready to build your Housing Solution?

Preparing to SAIL
- Planning a Secure Financial Future
- Obtaining Governmental Benefits
- Legal Measures to consider

Find Your Mates
- Connect and work with Partner Families with similar Goals & Vision
- Foster relationships with Roommates

Explore Housing Cabins
- Investigate types of Housing & Ownership Models
- Investigate community resources
- Obtain Housing

Assemble Your Crew
- Coordination with an IDD Service Provider; update PCP / IPOS
- Investigate Staffing Agency vs. Employer of Record Models
- Move Out Readiness Checklist

Coming Ashore
- New Residency To-Do Checklist
- Establish House Guidelines
- Cooperative Living Chore List

Running a Tight Ship
- Support Staff Record Keeping & Feedback
- On going meetings with Families and Support Staff …

Being the architect of your son or daughter's IDD Housing Solution can seem overwhelming at first. Therefore, to help parents, this SAILing guide breaks down the critical steps & milestones into separate chapters with supportive documents and aides. There are critical

[4] Partner Families – Parents that share a common IDD Housing Vision and whose children are potential roommates that have decided to work together in pursuing an IDD Housing Solution.

milestones that should be achieved within each step. A description of each SAILing step is provided below.

SAILing to Your IDD Housing Solution Step	Milestones to Obtain
Charting Your Course	As you begin to think about and plan your Adult Child's future, a future in which you will have less of an everyday role, there are important questions to consider about what lies ahead, from both an emotional and practical vantage point. It is important to reflect upon these questions and assure that you are ready to set forth and build an IDD Housing Solution for your son or daughter.
Preparing to SAIL	In football parlance, this step would be called *"Blocking & Tackling."* That is getting a stable foundation established for your Adult Child. What are the IDD services & supports from the Government that are available for my son or daughter and how should I go about establishing these benefits? Obtaining SSI or SSDI, Medicaid insurance benefits and understanding the legal issues associated with the long-term care of your Adult Child are vital.
Find Your Mates	The SAIL process that is described within this document is fundamentally built upon finding fellow parents that share your Housing Vision to partner with and together begin to collaborate in building your IDD Housing Solution. The goal of the *Find Your Mates* step is for you to find fellow parents to work with that have an Adult Child (potential roommate) that is compatible with your son or daughter.
Explore Housing Cabins	Once you have found fellow families to work alongside with and compatible roommates for your son or daughter, the next step is to find housing that fulfills the Housing Vision you have for your Adult Child. Decisions regarding the type of home, ownership model, location, and consideration of a formal legal

SAILing to Your IDD Housing Solution Step	Milestones to Obtain
	structure should be discussed.
Assemble Your Crew	Being the architect of your child's Housing Solution will require you to build and properly prepare a team of Direct Support Care Givers to be there with your child. Different Care Giver staffing models will be discussed along with the need to have strong cooperation with your child's Support Coordinator. Preparing your Adult Child for a safe transition to their new home will require close collaboration with your entire Support Team, fellow parents, and your child and their soon to be "roommates".
Coming Ashore	The *Coming Ashore* step signifies your Adult Child preparing and ultimately moving into their new residence. Preparing your son or daughter for a transition to their new home will require a great deal of hands-on training, role playing and reinforcement of the skills your Adult Child will need to live with their fellow roommates. Preparing your son or daughter for their soon to be independent life will make a safe and smooth transition more likely.
Running a Tight Ship	As your Adult Child's independence grows, you'll want to continue working with your support team and fellow parents in providing a safe and nurturing environment. Maintaining good communication with your support team and all the roommates will allow you to better collaborate with your Partner Families to make the needed adjustments for your son or daughter.

1 Charting Your Course

If you are beginning to think about housing options for your Adult Child, this document can help to guide you through your unique journey towards creating a sustainable Housing Solution and provide valuable insights, recommendations, and resources. The basis of the *SAILing to Your IDD Housing Solution* guide is that through collaboration with fellow parents your journey will have support and guidance, direction and progress, and inspiration along the way.

Charting Your Course	
• Reality Check – Are You Ready? • Sharing & Collaboration • Open Minded	• Adult Child’s Vision • Setting Priorities • Self-Determination

To succeed in developing a home where your son or daughter can live happily and independently you must begin with a ***realistic view*** of what is required to make this happen. If you begin with the idea that it will be easy, or that somehow it will be done “for” you, it is unlikely you will reach your goals. The *Charting Your Course* step poses some questions for you to evaluate your Adult Child’s and family’s needs accurately and honestly. For families considering the housing options discussed in this guide, it is important that they ask themselves the following questions before starting.

1.1 Reality Check – Are You Ready?

A. Are you ready to make a sincere commitment to move?

This is a question for the heart and mind. Maybe your family has been eagerly looking forward to this transition for many years, or maybe you have just begun to consider housing options for your son or daughter’s future. Whatever the case, now is the time for your Adult Child and for each supporting family member to answer this soul-searching question honestly. The decision to move involves an emotional component that can outweigh all practical considerations.

B. Are you ready to invest significant time and energy to create your Housing Solution?

Most likely, your time is just as valuable to you as your money, and equally limited by the number of things you must do. Unless you can make creating a Housing Solution for your Adult

Child a <u>High Priority</u>, you will unfortunately have a <u>Low Probability</u> of succeeding in this venture. It is helpful to include other members of your son or daughter's circle of support in this endeavor.

C. Are you able to collaborate and openly share information with others?

If you are not prepared to collaborate and openly share information with others, this parent-directed housing solution guide is probably not for you. Whether your Adult Child ends up living with roommates or alone, the process will require communication and interdependence with other families and agencies to reach your goal. In establishing a home, cooperation with others is unavoidable. Collaboration is hard work. You will face challenges as you strive, as a diverse group, to meet the needs of multiple individuals. There will be problems to solve, irritations to tolerate and compromises to reach.

D. Are you willing to let go of some control in the life of your loved one and prepare your Adult Child for more independent living?

Most likely you have taken care of your Adult Child for decades. You are aware of all the ways that your son or daughter is unique and able. You know what makes your son or daughter happy or sad and what brings anxiety or comfort. Most likely you have been doing more for your Adult Child than is necessary because you are comfortable, and your family has fallen into a routine that works. For all these reasons and more, taking a step back and letting someone else be in charge – including your Adult Child is often hard to do, but it is an essential part of making this transition a success.

E. Are you open to ALL caretaking responsibilities being completely taken over by a support staff?

Let's face it, care for your Adult Child is probably on your mind 24 x 7. There is a good chance that your daily schedule and that of your family is built around providing support for your Adult Child. Accepting the reality that an independent future for your Adult Child involves relinquishing the daily caretaker responsibilities to others is essential.

F. Are you comfortable with other parents and staff members being in the home with your son or daughter?

No one can ever replace you and the special care you provide to your Adult Child. As you prepare yourself to consider your son or daughter's independence, you must allow yourself to be comfortable with other people being part of your Adult Child's life – even when you are not present with your son or daughter.

G. Are you willing to allow others to set limits for your son or daughter?

Your Adult Child's independent life will require growth and adaptation; just like everyone's life does. As your son or daughter grows, you must ask yourself if you are comfortable with limits and challenges being set by the support team you have put in place, rather than by yourself.

H. Are you willing to allow others to assist your Adult Child with decision making?

Caring for an Adult Child with an IDD most likely means that you are involved in practically all decisions that impact your son or daughter. An IDD Housing Solution for your Adult Child will require you to embolden and trust others to support your Adult Child in your son or daughter's decision-making process.

I. Are you able to handle a healthy transition?

Moving to an independent home may be the biggest single change event that your Adult Child has ever experienced. The transition will likely involve your son or daughter's first time living apart from parents, learning to cooperate with roommates, moving to a different community, and building a greater level of independence. That is a LOT of transition all at once! You must prepare yourself and be aware of the stress that transitions can bring and monitor how you, your family and your Adult Child are handling it.

If you've answered Yes to these questions, then this guide is for you – keep reading!

1.2 Helpful SAIL Resources for - Charting Your Course

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Charting Your Course step.

File Name	Description
My Housing Vision	Begin to define and write down your vision of your child living on their own.
Reality Check - Are You Ready?	Questions to answer to confirm that you are ready to begin this journey.

2 Preparing to SAIL

Although daunting and sometimes confusing, obtaining Government Benefits – namely Supplemental Security Income **SSI**[5] and **Medicaid** or Social Security Disability Insurance **SSDI**[6] is essential before you can realistically move forward towards sustainable a housing solution. This chapter includes information and resources to help you with three critical topics – Government Benefits, Financial Assets, and Legal Measures required for securing a safe and sustainable future for your child. In this chapter of the SAILing Guide, the Preparing to SAIL milestones are discussed in the following order.

1. Applying for and obtaining Government Benefits
2. Setting up Financial accounts to help conform to the regulations associated with government benefits
3. Seeking legal advice for long term care of your Adult Child.

Preparing to SAIL		
Government Benefits	**Financial Assets**	**Legal Measures**

• Appy for SSI or SSDI
• Obtain **Medicaid** insurance coverage
• MDHHS – County Agencies; examples:
  ○ DWIHN – Wayne County
  ○ Macomb County Community Mental Health
  ○ Oakland Community Health Network
• IDD Service Providers Examples:
  ○ **CLS**
  ○ **Easterseals | MORC**
• Person Centered
	• Establish an **MI ABLE** Account
	• View the Arc's Resource List - **Public Benefits & Planning for Adulthood**
	• Investigate a Special Needs Trust
		• **Professional Legal Council**
		• Guardianship vs Power of Attorney
		• Power of Attorney
		  ○ Medical
		  ○ General
		• **Arc of Michigan**
		  ○ Forever Plan
		  ○ Legal Advocacy
		• Letter of Intent | The Dani Plan

[5] SSI - Supplemental Security Income
[6] SSDI - Social Security Disability Insurance

Preparing to SAIL		
Government Benefits	**Financial Assets**	**Legal Measures**
Planning & Individual Plan of Service – **IPOS** • **MI Bridges - Food Assistance Program**		

2.1 Where to start?

If you've asked yourself this question and struggled with the answer, a sound piece of advice might be "*let's ask the experts*." The Arc of Michigan provides a wealth of information and resources to parents of an Adult Child with an IDD. Once your Adult Child turns 18 years of age, the transition to adulthood and where to begin on the maze of government benefits can often seem overwhelming. The following steps can provide a guideline and are published in the Arc's Profiles[7] newsletter.

1. Contact the MI Secretary of State to obtain a state of Michigan ID.
2. Apply to the Social Security Administration ("SSA") for Supplemental Security Income ("SSI") benefits after your child turns 18 years old. This provides automatic Medicaid eligibility. If you are retired and are receiving Social Security retirement benefits, your dependent with a disability may be eligible for Social Security Disability Income (SSDI), which is based on your Social Security and may be higher than SSI.
3. Apply at the Michigan Department of Health and Human Services ("MDHHS") for "Adult Home Help Services" once Medicaid is established. The Home Help program is administered by the Michigan Department of Health and Human Services (MDHHS) and provides personal care services to individuals who need hands-on assistance with Activities of Daily Living (ADLs) and assistance with Instrumental Activities of Daily Living (IADLs).

[7] https://www.thearcoakland.org/wp-content/uploads/3rd-Quarter-2022-PROFILES.pdf

4. Apply for the MI Bridges - Food Assistance Program on the Michigan Bridges website or at a local Michigan Department of Health and Human Services office. This is also known as the “Bridge Card,” and provides a monthly amount for the purchase of food.
5. After obtaining Medicaid eligibility, apply to the County’s Community Mental Health agency where the individual who will be receiving services resides for long-term developmental disabilities support services. You’ll want to request an ACCESS screening with your county’s Community Mental Health service provider.
6. All males, age 18, must register with the Selective Service System (www.sss.gov).
7. Consider establishing a Power of Attorney, a Patient Advocate Designation, or perhaps Guardianship.
8. Special education: plan for Transition Services (post-high school program).
9. Consider opening an MI ABLE Act savings account.
10. Consider your estate plan, in particular, creating a “Special Needs Trust” to protect loss of future governmental benefits.
11. Contact Michigan Rehabilitation Services (“MRS”) and open a casefile for the development of an employment plan when your child is ready to pursue competitive employment support.
12. Consider personal income tax issues by obtaining a copy of The Arc of Michigan’s Annual Income Tax Guide.

2.2 Obtaining Government Benefits

The first step along your journey into the world of Government Benefits available for your Adult Child is to contact your local **Social Security Administration** office and begin the process of applying for Supplemental Security Income – SSI for your Adult Child.

You might want to check the Social Security Administration’s list of Compassionate Allowance Conditions[8]. Compassionate Allowances are a way to quickly identify conditions that, by definition, meet Social Security's standards for disability benefits.

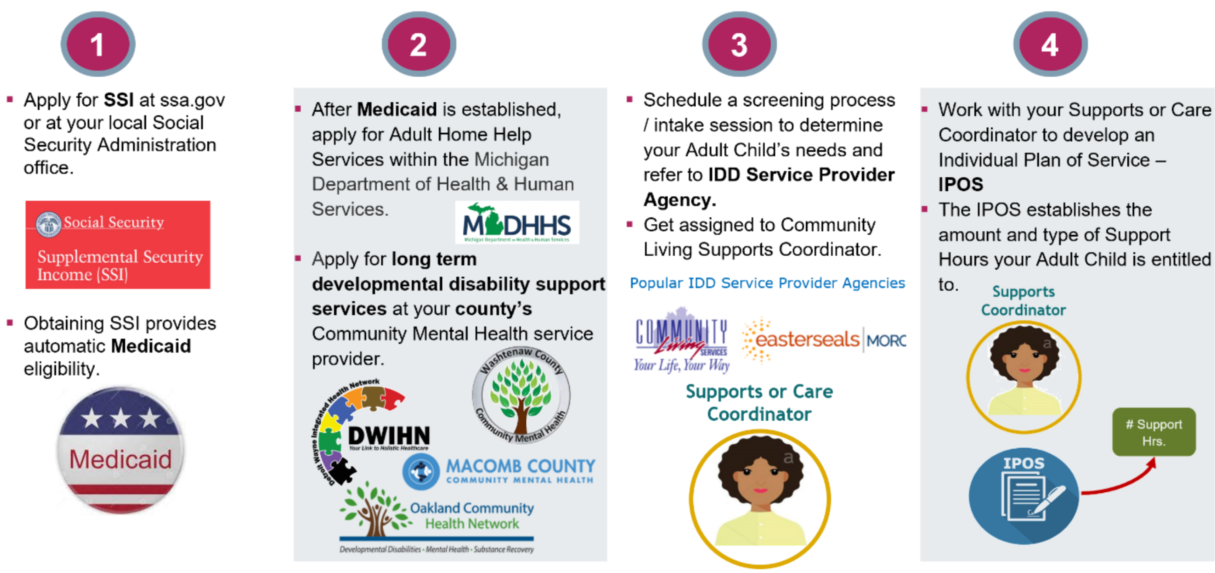
Obtaining **S**upplemental **S**ecurity **I**ncome for your Adult Child will have two immeasurable benefits for your son or daughter and his or her life of independence.

1. Monthly Income

[8] https://www.ssa.gov/compassionateallowances/conditions.htm

2. Automatic enrollment in Medicaid health care insurance program

The importance of obtaining Medicaid for your Adult Child and how Medicaid health insurance benefits are used to pay for your son or daughter's Direct Support Staff is highlighted in the diagram below. The SAILing Guide attempts to break this process into 4 Steps from the initial step of obtaining Supplemental Security Income & Medicaid to the fourth step of working with your Adult Child's Support Coordinator and developing an Individual Plan of Service. Your son or daughter's Individual Plan of Service will contain the number of support hours that are



eligible for Medicaid reimbursement. The diagram below attempts to provide an overview of the steps involved in obtaining SSI & Medicaid and the Individual Plan of Service. The IPOS will determine the number and type of support hours that your Adult Child is entitled to and that are also covered by Medicaid insurance.

2.2.1 STEP #1 Obtaining Medicaid

Upon your Adult Child's 18th birthday, you are encouraged to apply for Supplemental Security Income at your local Social Security Administration office. Further on in this document, the differences between SSI – Supplemental Security Income and SSDI – Social Security Disability Insurance are mentioned.

Social Security manages two distinct disability programs.

1. Supplemental Security Income (SSI) which is for individuals who have not contributed to FICA.
2. Social Security Disability Insurance (SSDI) which is based upon an individual's contribution to FICA[9] while employed.

2.2.1.1 Supplemental Security Income (SSI) Benefits

The Supplemental Security Income (SSI) program is administered by the Social Security Administration and provides monthly payments to adults and Adult Children with a disability or blindness who have income and resources below specified amounts. SSI can provide income to meet basic needs for food, clothing, and shelter.

Once your Adult Child is eligible to receive SSI, he or she will automatically become eligible for **Medicaid**.

https://www.ssa.gov/benefits/ssi/

SSI provides minimum basic financial assistance to older adults and persons with **disabilities** (regardless of age) with very limited income and resources. Federal SSI benefits from the Social Security Administration are often supplemented by state programs.

Below is an overview of the eligibility requirements for **Medicaid**[10] in the state of Michigan.

> **Eligibility overview:** Michigan has Medicaid programs for low-income children, adults under 21, people with dependent children and adults who are elderly, blind, or **disabled**. Families living below a certain income level may also qualify. Under its expansion, adults making less than 133% of the FPL[11] can get coverage.
>
> Remember once your child receives **SSI benefits**, he or she is automatically enrolled in **Medicaid**.

[9] FICA – Federal Insurance Contributions Act; FICA is a U.S. federal payroll tax.
[10] https://www.policygenius.com/blog/a-state-by-state-guide-to-medicaid/

[11] FPL – Federal Poverty Level

2.2.1.2 *Applying for SSI – Do's and Don'ts*

Below is a helpful list of Do's & Don'ts to keep in mind when applying for SSI – Supplemental Security Income, which was compiled from the Bobby Dodd Institute[12].

Do's

DO check if the disability is a Compassionate Allowance - These are conditions Social Security has predetermined as medically eligible, which means the individual does not have to prove severity and impact of the condition – just providing proof of the condition is enough.

DO use ABLE accounts as "safe harbors" for financial resources - Individuals with more than $2,000 in resources/assets will not pass the means-testing requirement for SSI. By using an ABLE account instead of a savings account, an individual can save up to $15,000 each year without violating the regulations restricting resources to $2,000 or less.

DO gather as much documentation as possible to prove your Adult Child's condition meets the criteria listing in the Social Security Blue Book Open - To know what you need to provide, do a simple internet search on Social Security Blue Book and include your diagnosis. You will find all the criteria that needs to be met in order to be determined medically eligible.

DO provide your medical records that clearly show not only the diagnoses of your condition but also demonstrate the severity and impact of the conditions(s) such that you cannot perform substantial gainful activities - The best documentation includes psychological evaluations, letters of medical necessity, DMA6 forms, and IEPS.

Don'ts

DON'T apply early - An individual who is 17 will still be viewed as a minor and the parents' household income will be a factor. Wait until after the 18th birthday to file for SSI.

DON'T forget that child support is considered income - Child support is not viewed as income only when the child support is directed into a Supplemental Needs Trust as decreed by the separation agreement.

DON'T rely on the Release of Information from Social Security to secure your medical records - By securing and compiling your medical documentation and providing this documentation with the application, you are controlling the narrative of your case. Simply signing a Release of Information for Social Security to request your medical records on your behalf means your case is left in the hands of too many people.

DON'T provide only dated medical records - While it's good to show longitudinal data regarding a condition over time, if all of the documentation is dated, then the strength of the case wanes. It's difficult for an adjudicator to make a judgment on your case if your last evaluation was as an adolescent/child. Different assessments are used at different developmental stages, so it's important that you provide full, current, and relevant medical

[12] BDI - https://bobbydodd.org

Do's

DO request additional documentation - A letter of medical verification from your treating health care provider will help to strengthen your case.

Don'ts

documentation that demonstrates how your condition prevents you from working.

DON'T give up, even if you aren't successful with the initial application - Nearly half of all cases are approved at the appeals level.

2.2.1.3 Social Security Disability Insurance (SSDI) Benefits

SSDI supports individuals who are disabled and have a qualifying work history, either through their own employment **<u>or a family member (spouse/parent</u>**). SSDI is a Social Security Administration program that gives money each month to people who have a disability that meet Social Security disability rules and who, in the past, worked and paid FICA taxes for enough time to qualify, or whose spouse/parents did so. SSDI has no income limits and no resource limits. The amount you get in SSDI benefits depends on your Social Security earnings record or those of the spouse/parents of the person with a disability. After getting SSDI benefits for two years, you automatically qualify for **Medicare** health coverage.

The major difference between SSI and SSDI is that SSI determination is based on age/disability and limited income and resources, whereas SSDI determination is based on disability and work credits.

2.2.1.4 Comparison of SSI and SSDI

Factor	SSI	SSDI
Eligibility based on	Age (65+) OR blindness (any age) OR disability (any age) AND limited/no income and resources	Disability AND sufficient work credits through own/family employment

Factor	SSI	SSDI
When benefits begin	1st full month after the date the claim was filed or, if later, the date found eligible for SSI	6th full month of disability; 6-month period begins with the first full month after the date SSA decides the disability began
MI Average benefit (monthly) ages 18-64	$733.36 (as of JAN 2024)	$1,508.94 (as of March 2024)
Maximum benefit (monthly)	$967 for an individual and $1,450 for a couple in MI for 2025	$3,822 in 2024 (based on work history)
Health insurance	Automatically qualifies for **Medicaid** upon receipt of SSI (in most states)	Automatically qualifies for **Medicare** Part A & Part B after a 24-month waiting period from time benefits begin (no waiting period for people with ALS)

The link below provides an overview of the federal government's Social Security Disability programs.

https://www.ssa.gov/redbook/eng/overview-disability.htm

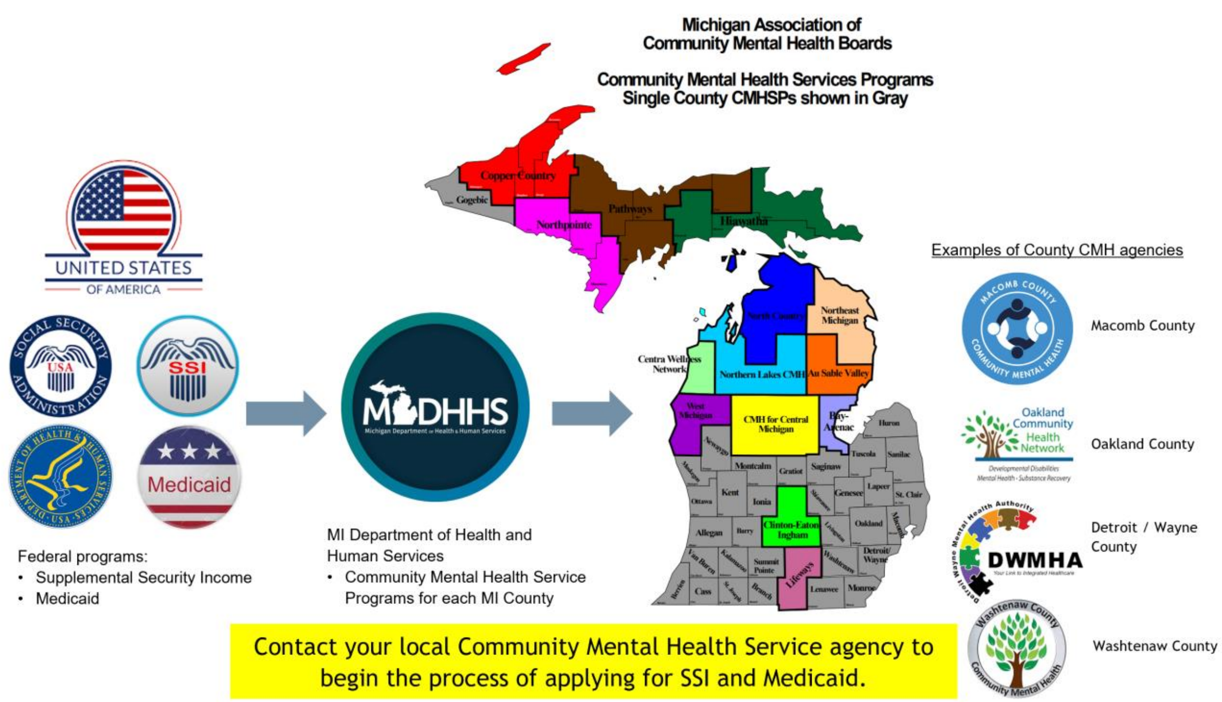
2.2.2 Freedom to Work

Freedom to Work is designed so that if you have a disability, you can work without worrying that you'll lose your Medicaid health coverage. This is an option for those individuals who have transitioned from SSI to SSDI and want to maintain Medicaid coverage. An individual enrolling in the Freedom to Work program may pay a monthly premium to keep or obtain current Medicaid services. Medicaid insurance coverage is essential for continuing to utilize government benefits (Medicaid) to pay for your adult child's direct care workers.

Once you are covered by Freedom to Work, your unearned income must stay at $3,138 per month or less, but it doesn't matter how much you earn, as long as you have some earned income. You can get a great job and still have Freedom to Work coverage.

2.2.3 Step #2 Contact Your Local Community Mental Health Services Programs (CMHSPs)

After qualifying for SSI and subsequentially obtaining Medicaid, you'll want to contact the Community Mental Health Services organization in the county where the individual resides who will be receiving services. Keep in mind that SSI and Medicaid are federal programs that are administered at the state level within Michigan by the Michigan Department of Health and Human Services – **MIDHHS**. MIDHSS then uses local county-based Community Mental Health Services agencies throughout the state to coordinate and implement Medicaid benefits. Based upon the county in which your Adult Child resides, you should contact that county's Community Mental Health Services department. The SAIL website, under the SAILing Roadmap & Resource page contains a list of the Michigan Department of Health and Human Services Community Mental Health Services Programs.



Once your child has obtained Medicaid insurance coverage, you should contact your local Community Mental Health Service agency to set up an intake session (screening process).

Remember - Most people who receive services through your county's Community Mental Health Service agency have Medicaid insurance coverage. In Michigan, both individuals with disabilities and individuals with mental illness receive services through the same agencies, which is centralized through your county's Community Mental Health agency. Individuals are given a choice of IDD Service Providers and are connected with the IDD Service Provider of their choosing.

Below are the public mental health organizations for Detroit – Wayne, Macomb, Oakland and Washtenaw counties.

County	Agency	Website
Detroit & Wayne	Detroit Wayne Mental Health Authority	https://www.dwihn.org/
Macomb	Macomb County CMH Services	https://www.mccmh.net/
Oakland	Oakland Community Health Network	https://www.oaklandchn.org/
Washtenaw	Washtenaw County Community Mental Health	https://www.washtenaw.org//839/Community-Mental-Health

2.2.4 Step #3 – Select an IDD Service Provider and Supports Coordinator

After you select an IDD Service Provider Organization agency, your Adult Child will be assigned a Supports Coordinator or "Care Coordinator". The Supports Coordinator will become an integral part of your son or daughter's life and be instrumental in helping to assure that the needed support is put in place for the move towards independence.

2.2.5 Step #4 – Determine Available Support Hours

The amount and type of support hours that your son or daughter is eligible for will be documented by your Supports Coordinator in your Adult Child's Individual Plan of Service. The IPOS is a living document that will be reviewed and updated throughout your Adult Child's life. Your Adult Child's IPOS will document the goals along with the type of support and amount of support needed to safely achieve those goals. Below is an example of the IPOS Authorizations and description of services. Each authorized service will have a code associated with it for the purposes of invoicing Medicaid when service is provided. While your Adult Child is residing with you, the Community Living Supports will most likely be identified as 1:1 support. This means that there will be 1 Direct Support Professional and 1 individual receiving support services. Once your Adult Child moves into an independent living situation and has a roommate(s), the Community Living Supports might include "Shared Hours".

Example IPOS Authorizations

Authorization Service Description	Scope	Units Authorized	Units Available
H2015 Community Living Supports	Staff to provide community living support in home & community 54 hrs./week; 10 1:1 hrs.; 44 shared hrs.	216 per week	5,678
A0080 Non-Emergent Transportation per mile	Staff to provide up to 60 miles per week of non-emergent transportation	60 per week	1,578
T1016 Supports Coordination	ISC to provide support coordination services at least one hour per month	60 per auth.	60
H0045 Respite Care	Respite care services in out-of-home setting	120 per auth.	120

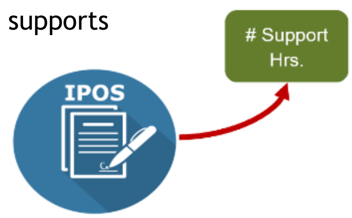
2.2.5.1 Person Centered Plan and Individual Plan of Service

You will work with your Service Provider Supports Coordinator to engage in the Person-Centered Planning (**PCP**) process and develop an Individual Plan of Service (**IPOS**) that is used to determine the number and type of Support Service Hours for which your Adult Child is eligible.

Person-Centered Planning is a way for individuals to plan their lives with the support and input from those who care about them. The process is used for planning the life that the individual aspires to have—taking the individual's goals, hopes, strengths, and preferences and weaving them in plans for a life with meaning. PCP is used anytime an individual's goals, desires, circumstances, preferences, or needs change.[13]

Through the PCP process, an individual and those who support him or her:

a) Focus on the individual's life goals, interests, desires, preferences, strengths, and abilities as the foundation for the planning process.
b) Identify outcomes based on the individual's life goals, interests, strengths, abilities, desires, and preferences.
c) Make plans for the individual to work toward and achieve identified outcomes.
d) ***Determine the services and supports*** the individual needs to work toward or achieve outcomes including, but not limited to, services and supports available through the community mental health system.
e) Develop an **Individual Plan of Service** (IPOS) that directs the provision of supports and services to be provided through the community mental health services program (CMHSP).



Your Adult Child's IPOS is a living document that will be used to determine the number of Medicaid funded support hours for your son or daughter. You'll have to work with your Adult Child's Supports Coordinator to revise and adapt this document as your son or daughter moves towards independence.

Example IPOS Authorizations

Authorization Service Description	Scope	Units Authorized	Units Available
H2015 Community Living Supports	Staff to provide community living support in home & community 54 hrs./week; 10 1:1 hrs.; 44 shared hrs.	216 per week	5,678
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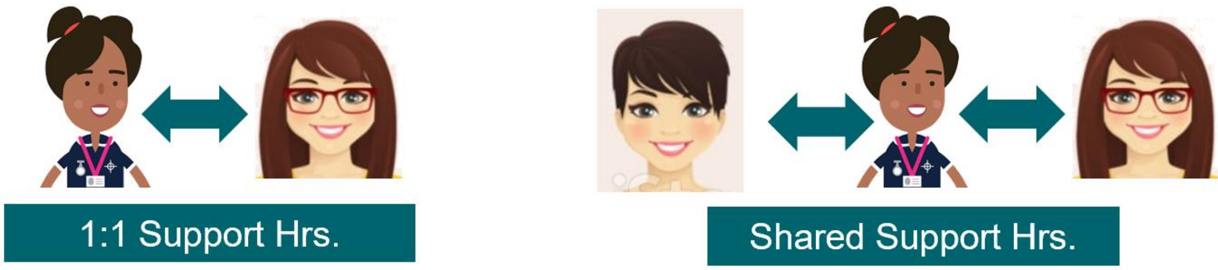
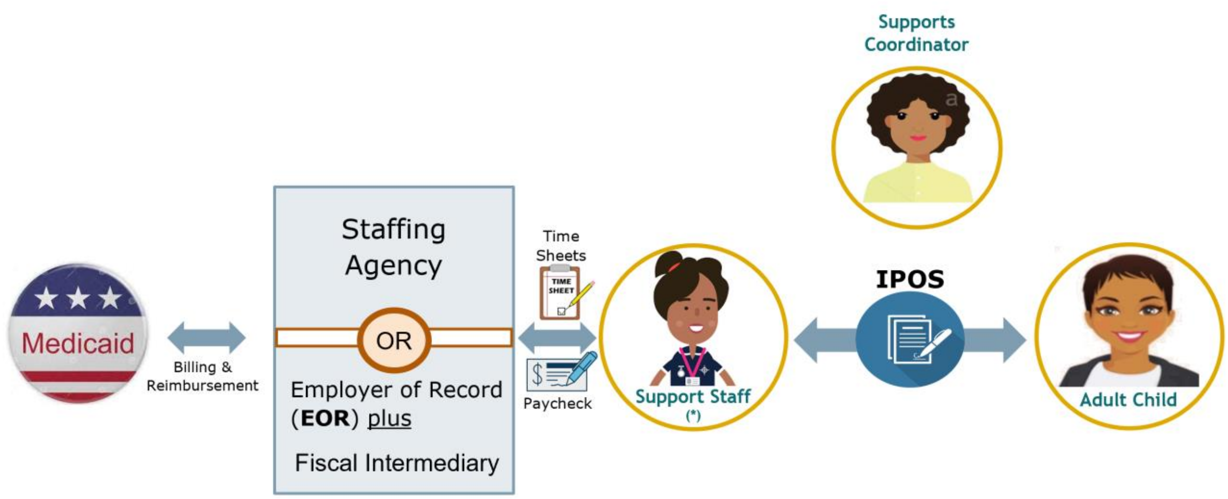
[13] Person Centered Planning Policy and Practice Guideline; https://www.michigan.gov/documents/mdch/2011_Tab_Index_9_update_11_15_11_368654_7.pdf

The diagram below shows how your Adult Child's IPOS is used to link the activities of the Direct Support Professional to your son or daughter's goals and required support. Invoicing Medicaid and paying for the Direct Support Provider is realized through either the Staffing Agency model or the Employer of Record model.

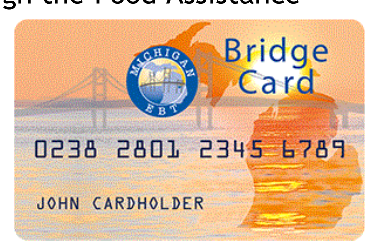




2.2.6 *Food Assistance Program (FAP)*

Parents are encouraged to apply for the Michigan Food Assistance Program and consider FAP membership as an integral part of your child's income.

If you receive SSI, you may be able to get help to buy food through the Food Assistance Program (FAP), formerly known as Supplemental Nutrition Assistance Program (SNAP) or food stamps. Parents should consider Food Assistance benefits as monthly income for their Adult Child that can help provide a stable and secure future.



Parents can apply for Food Assistance benefits through MI Bridges.

https://newmibridges.michigan.gov

The **Bridge Card** is Michigan's EBT[14] card. An EBT card is a card that looks and works like a debit or credit card but is loaded with Food Assistance benefits. You can use it at stores that accept EBT. You will get the Bridge Card once you're approved for **Food Assistance benefits**.

What You Can Buy: The U.S. Department of Agriculture decides which food items can be purchased with the EBT card in Michigan. Fresh produce, fresh meat, frozen goods, canned goods, pasta, milk, cheese, and eggs are all eligible to buy with your EBT card. In fact, most food items are.

2.2.7 Michigan Combined Application Project (MiCAP) food benefits

MiCAP, or the Michigan Combined Application Project, is a specialized program designed to simplify the process of obtaining food assistance benefits for individuals receiving Supplemental Security Income (SSI). The MiCAP program reduces the paperwork and application complexity, making it easier for qualifying individuals to access food benefits. SSI recipients can automatically qualify for a Bridge Card (Michigan's food assistance card) through MiCAP.

While anyone in Michigan who qualifies for SNAP (Supplemental Nutrition Assistance Program) benefits can receive a Bridge Card, MiCAP is specifically tailored for individuals already receiving Supplemental Security Income (SSI) benefits. MiCAP offers a simplified, streamlined path to food assistance for these individuals by reducing paperwork and minimizing eligibility checks, making the process more efficient for this specific demographic.

2.3 Financial Assets

One of the main objectives of this chapter is to stress the importance that Government benefits will have on providing income and thus sustainability for your child. Whether these Governmental benefits are in the form of month SSI payments, Food Assistance Program payments, State of MI Supplemental Check, or Medicaid insurance benefits that pay for your child's direct care support staff, it is paramount to establish these benefits for your child. Later

[14] Electronic Benefit Transfer

in the Exploring Cabin Options chapter, you'll be asked to draft an initial Housing Budget for your child and list the various sources of monthly income. Parents should consider the Governmental benefits as main contributors towards their child's monthly income in addition to any monthly income from employment or other resources.

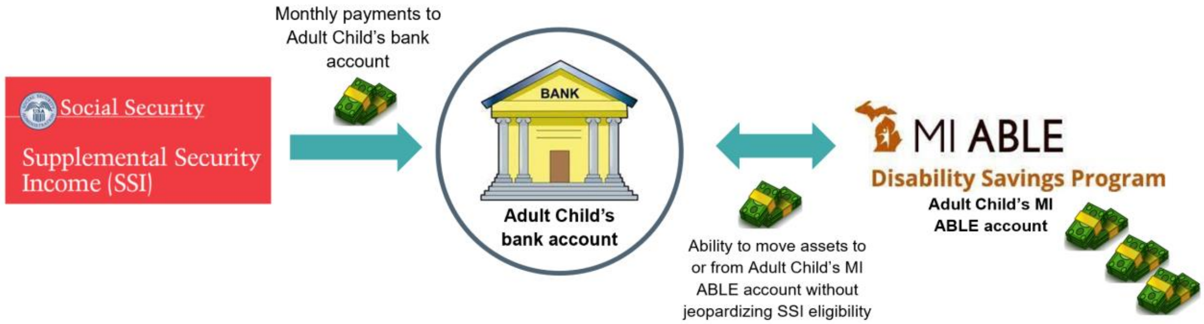
Whether your child is eligible for Medicaid will depend on his or her income and the amount of assets in his or her name. Eligibility for public benefits (SSI, SNAP, Medicaid) require meeting a means/resource test that restricts eligibility to individuals with **less than $2,000** in liquid resources, such as cash savings, non-ABLE checking and savings accounts and some retirement funds. If your child has a Checking, Savings or other Financial Investment accounts set up in his or her name, you might want to consider moving some of these funds to an ABLE[15] account or Special Needs Trust for your Adult Child to meet the income requirements of public benefit programs, i.e., SSI and Medicaid. A person with a disability who has **more than $2,000** in countable assets, such as bank accounts, mutual funds, certificates of deposit, etc., is not eligible for Medicaid benefits.

[15] **A**chieving a **B**etter **L**ife **E**xperience - savings accounts that will largely not affect a child's eligibility for SSI, Medicaid and means-tested programs such as FAFSA, HUD and SNAP/food stamp benefits.

- Once your Adult Child begins receiving SSI, you will have to keep a close eye on their bank accounts to make sure their balance does not exceed **$2,000** or whatever financial assets limit the Government has in place for Medicaid eligibility.
- Exceeding the $2,000 limit could jeopardize your Adult Child's eligibility for receiving monthly SSI payments.
- If your dependent is at risk of losing benefits because his or her monthly balance exceeds $2,000, you can work with your local Social Security Administration office, you can adjust the amount monthly SSI payments your Adult Child receives so that the $2,000 limit is not exceeded; however, you **should not** stop the SSI payments.
- It is easier to adjust the monthly SSI payments upward or downward, rather than having the SSI payments stopped completely and then having to re-qualify for Medicaid (SSI payments) at some future date.
- A MI **ABLE** account is an ideal place to transfer money into from your Adult Child's bank account so as not to exceed the $2,000 account balance limit.

2.3.1 MI ABLE Account

MI **ABLE** (**https://savewithable.com/mi/home.html**) accounts are tax-advantaged savings and investment accounts for individuals with disabilities. More importantly - holders of MI ABLE savings accounts do not need to worry about losing Supplemental Security Income or other government benefits. Please refer to the MI ABLE website for deposit and asset limits and all Guidelines of a MI ABLE account. The diagram below depicts monthly Government SSI or SSDI payments being deposited into your Adult Child's bank account. To have you Adult Child stay within the financial guidelines that the Social Security Administration (SSA) imposes for SSI, a MI ABLE account can be used to transfer monies to & from your Adult Child's bank account into your son or daughter's MI ABLE Disability Saving Program account to avoid violating the SSA guidelines.



2.3.2 *State of Michigan Supplemental Check*

In the State of Michigan, individuals are entitled to the state's supplement of $42 a quarter ($14 / month), when they receive at least $1 of SSI benefit. If for some reason, an individual's earnings are such that they are not entitled to receive SSI payment, they would not be entitled to receive the state's supplemental for that month either.[16]

2.4 Legal Measures to Consider

Once a child reaches **the age of 18 years** the parents' status as guardian terminates automatically by law. This is true for any child including those with a developmental disability. Only through appointment as Guardian by a probate court, where a judge declares someone legally incompetent, can this formal legal relationship continue.

Parents of Adult Children with a disability should be concerned with who will make medical and financial decisions once the **child turns 18**. The *Adult Child* is presumed to be an adult and therefore has the ability to make his or her own decisions. Therefore, it is imperative that you seek legal advice and consider establishing a Guardianship, partial Guardianship, a Power of Attorney, or perhaps a Patient Advocate Designation so you can continue to care for your son or daughter as your son or daughter reaches the age of 18.

The Arc of Oakland County – Legal Advocacy is a valuable resource in helping to understand the important legal measures for you to consider.

[16] Arc – Understanding Your Child's Social Security Benefits; Volume 47, No. 4-6

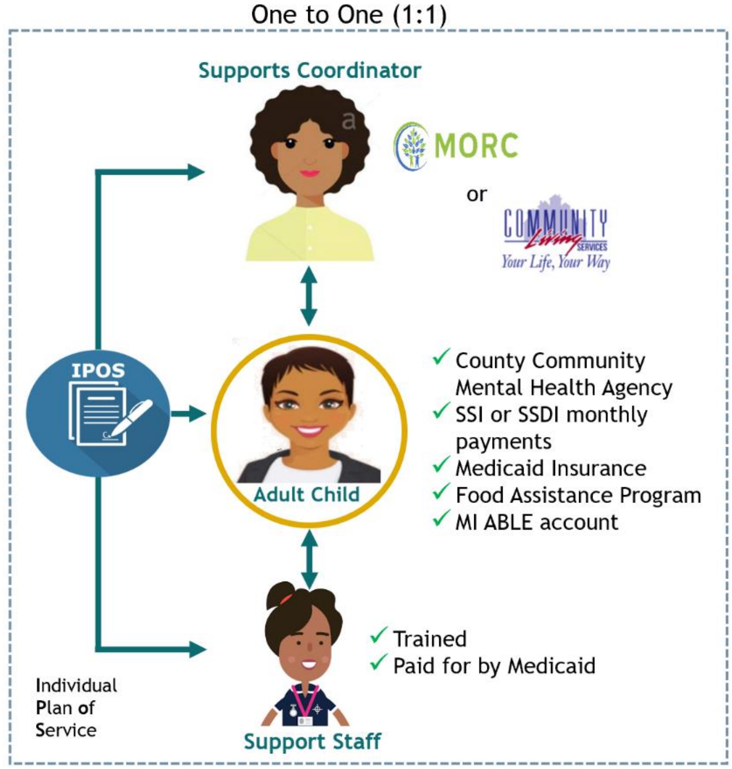
https://www.thearcoakland.org/programs-services/legal-advocacy/

2.5 Example of Support Staff for Adult Child Living at Home

Before we leave this chapter, let's summarize the *Preparing to SAIL* milestones regarding Government benefits. Parents are encouraged to establish these benefits for their Adult Child – *even while the Adult Child is living at home with you*.

As your Adult Child begins to move towards an independent IDD Housing Solution, his or her IPOS will adapt to reflect the additional goals for independence and the required support hours. The IPOS is used to provide guidance to the Direct Care Support Staff[17] when working with your Adult Child towards their goals.

Typical Support Staff for Child Living at Home with Parents
One to One (1:1)



In the *Assemble Your Crew* step, which appears later within this document, we'll focus on expanding and building a support team for not only your Adult Child but also for your son or daughter's roommate(s).

- **Get your Adult Child's benefits – SSI, Medicaid, and Food Assistance Program FAP … NOW while you have the energy & ability.**
- **Having Governmental Benefits is vital in providing a secure and sustainable future for your adult child. Monthly Income! Paying for Support Staff!**
- **Seek Legal help to fully understand the steps you must take towards your Adult Child's future.**

[17] Direct Care Support Staff or Direct Support Professionals

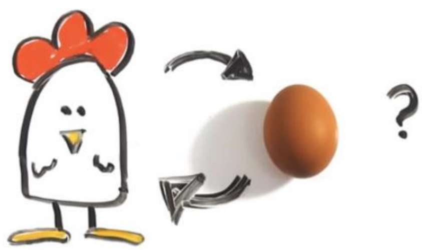
2.6 Helpful SAIL Resources for – Preparing to SAIL

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Preparing to SAIL step.

File Name	Description
Person Centered Plan and Individual Plan of Service	Informational overview of the PCP and IPOS your adult child's Support Coordinator will be using.
SIS Assessment and the PCP / IPOS	Explanation of how the Support Intensity Scale assessment tool is used within the PCP / IPOS process.
Preparing to SAIL Checklist	Individual worksheet to keep track of progress on obtaining Government and other benefits.
SAIL Ready to Launch Checklist	Individual worksheet to keep track of all the key steps and milestones within the SAILing process.
Skill Development Checklist	Individual worksheet to identify your adult child's skills for independence and potential areas of needed support or further training.
Supports Coordination	Overview of Support Coordinator's role.
Understanding Michigan Food Assistance	Overview for understanding and navigating through MI's Food Assistance Program with many helpful links.

3 Finding Your Mates

Finding compatible families to collaborate with who happen to have an Adult Child that is compatible with your son or daughter is the ultimate Chicken & Egg scenario. No one knows which one came first, but you certainly need both.



As a single-family unit, it can be difficult for you to meet all the housing needs of your Adult Child. Together, a group of families have more resources (time, money, energy, talents, networks …) to contribute to meeting the housing needs of their family members. By connecting and partnering with other families, parents can find roommates for their son/daughter, expand their thinking, meet friends for mutual support, and discover a network of people that have similar goals. SAIL's structure is set up to allow families with a common IDD Housing Vision to work more closely together and form "Partner Families." A **Partner Family** is a group of families united by their Adult Children as potential Roommates and a Common Housing Vision who have agreed to work together in building their IDD Housing Solution.

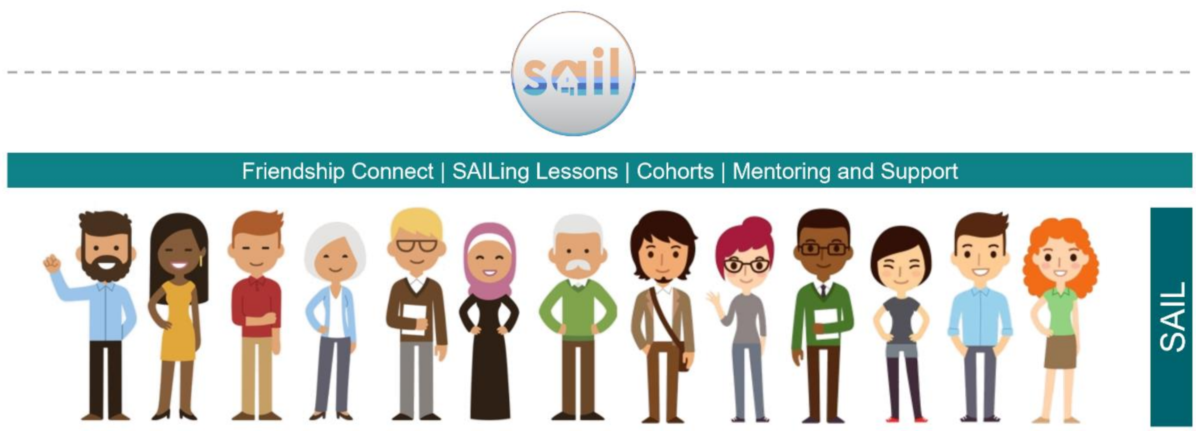
Finding Your Mates	
Partner Families for Collaboration	**Finding Roommates**
• Working with other Families • Common Housing Vision • Compatibility & Building Trust • SAILing Lessons • House Guidelines – Part #1	• Meeting & Getting to Know Potential Roommates • All About Me • Roommate Compatibility • Friendship Connect

3.1 Forming Partner Families for Collaboration

For many parents, a vision of long-term independent living for their Adult Child includes at least one or more roommates. This can be because of the financial burdens of maintaining a separate household and / or because they want to avoid the social isolation that often comes with living alone. The process of finding the right Partner Families can often be very lengthy and rather discouraging. While you will have to make compromises on some things, you must make sure that your core set of values and requirements are met.

3.1.1 Overview of SAIL Structure

The diagram below reflects the structure of SAIL and SAIL's mission to bring families together that share a goal of finding or helping others find an IDD Housing Solution for their Adult Child. Families within SAIL have the opportunity to network with other families that share the need of developing an IDD Housing Solution through SAIL's Friendship Connect and SAILing Lessons initiatives. SAIL's initiatives of *Friendship Connect* and *SAILing Lessons* allow parents to meet with one another and determine if they are on a similar journey and explore the possibility of working together as *Partner Families* on their IDD Housing Solution.



3.1.2 Partner Families

Families that share a common **IDD Housing Vision** and who would like their Adult Children to become Roommates[18], may form **Partner Families** and work together towards turning their IDD Housing Vision into an actual IDD Housing Solution. Your Partner Family can be formed with other SAIL families or with families that you have met outside of SAIL. Of critical importance in forming Partner Families is finding fellow parents that are willing to collaborate, share your level of commitment, and are willing to work as hard as you are in building an IDD Housing Solution.

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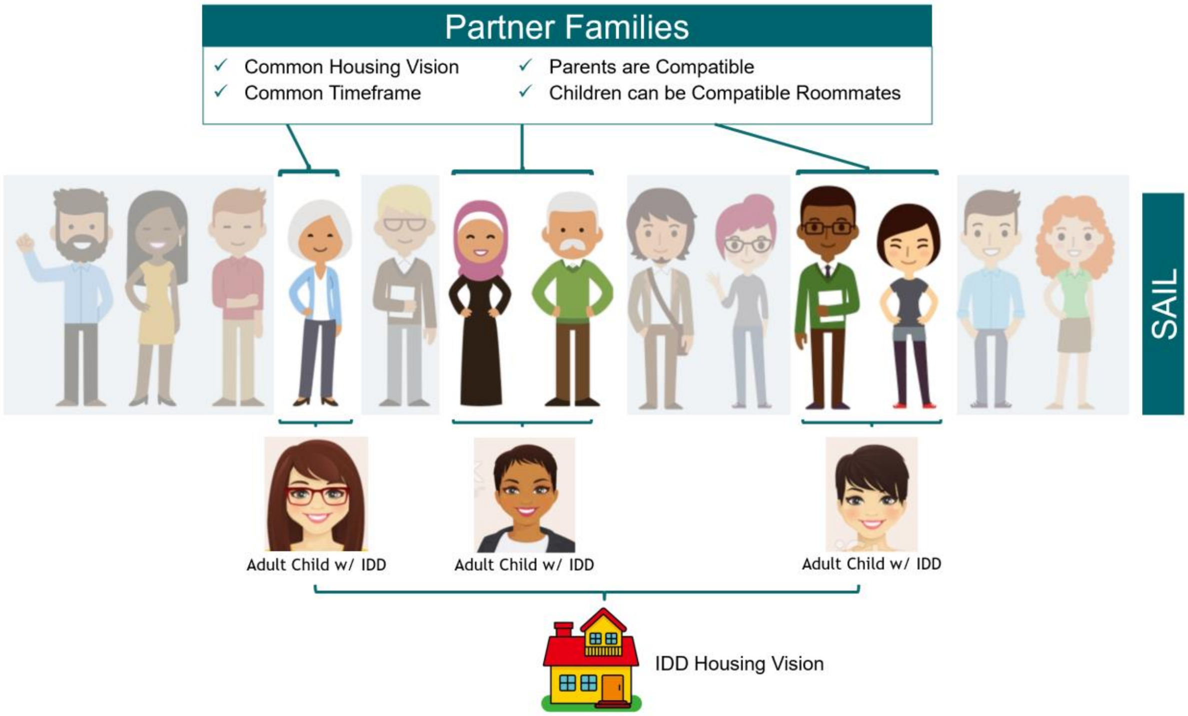
[18] Roommates – The term Roommates refers to conventional Roommates, House Mates, and IDD Individuals whose parents share a common financial interest in their Housing Solution.



3.1.3 Connecting to Partner Families with a Common Vision

Finding the right Partner Families can be one of the most challenging and time-consuming aspects of developing a Housing Solution for your Adult Child – and one of the most critically important aspects for success. Remember that if all goes well, your Adult Child might be living with these roommates for perhaps the rest of his or her life, and you will be continuing to collaborate with these families to make the home as safe, secure, and sustainable as possible. Realistically the best way to find those families with similar goals & vision for their Adult Child is by **networking**. This means telling anyone you think might be interested or might know of someone else who is searching for a housing solution for their Adult Child about your situation.

Once you find someone who might be interested, you will have to take the initiative to contact them. From that initial discussion, you should know whether to follow up with more meetings.

3.1.4 Networking to Find Partner Families

Think about who you know. Do you talk to the other moms or dads who also pick up their sons or daughters from special recreation programs? Are you part of a support group for parents with Adult Children with disabilities? Does your son or daughter have friends from school or transition programs who are getting ready to move away from home? Start conversations with people from different groups that you belong to, whether it is the PTA or a book club. Likely there are individuals just like you in your social circles who are searching for Housing Solutions for their son or daughter. If you don't ask, you'll never know, so start those conversations!

3.1.5 Tips for Getting Started with Partner Families

Below are some insights and suggestions to help you begin to think about finding fellow parents to work alongside.

Be Familiar - It is often beneficial if you have an existing personal relationship with the members of the Partner Family group. Understanding their son/daughter's story and trusting them to contribute to the group's mission will create a good foundation for your group

Start Small - Eventually you will need a core group of families – "Partner Families" who are invested in creating a housing solution. At the beginning of this process, start by talking to one or two people you know. If you end up with a large group of interested families, great! Each family's commitment level will differ. Assemble the core working group at the start of the process and keep other families informed and interested.

Be Open - It is important to consider families of individuals of all abilities. People with different abilities bring different gifts, and this variety contributes to more robust interaction and complimentary support. Be open to suggestions of different places and partners.

Change Perspectives - As a parent of a son/daughter with a disability, you are often in "advocacy mode." You look out for the best interests of your Adult Child, making sure that they feel comfortable, are accepted, and have the services they need to thrive. Developing a successful Partner Family group requires a change in perspective from being an advocate to being a co-creator of something new and different from the status quo.

Get Organized - Forming the group will take organization and persistence. Send a few emails, make a few phone calls, or set up a Zoom meeting. Find a place that's easy to locate in your community and hold a preliminary "Call to Action" meeting to gauge interest. Identify a convener and communicator to maintain momentum as the group gets started.

3.1.6 Building Community and Trust Amongst Partner Families

Community is based on a philosophy of shared commitment. A distinguishing characteristic of community is that everyone has a voice, and in turn, shares responsibility, gifts and talents, accountability, and celebration. Family groups combine individuals with many different interests and motivations. Getting to know what motivates the people sitting around the table can help the group as a whole see common purposes, trust one another, and recognize the depth of the issue at hand. Community is not built in an empty room, but rather around a table brimming with lively conversation, laughter, and mutual understanding. Community building activities and processes can help create an environment conducive to working cooperatively. Building trust is a key element of community building and working in a group. In a trusting setting, problem-solving and decision-making will be more efficient.

Tips for building trust:

- Keep your commitment and be reliable
- Be honest and open
- Volunteer information and share concerns
- Agree to disagree
- Maintain consistency in your actions
- Avoid gossip and exclusion
- Be personal

Tips for leading change:

- Establish a team committed to change
- Create and communicate a vision
- Identify obstacles
- Build capacity, skills, and tools to support the vision
- Empower Action

Insights from William Bridges, Peter Sange, and John Kotter

3.1.7 Tips for Building Successful Partner Families & Trust

1. **Participate in team-building activities**: Team-building activities are an initial step that supports working together as a group. These activities allow individuals to get to know each other better. Team building can highlight interest, experiences, skills, and passions.

a. Share Stories: Have each family bring in a photo of their son or daughter or present their *All About Me*[19] presentation. Go around the room and share one success that your Adult Child has had and one challenge you see for the future. This activity will bring the individuals

[19] All About Me – A SAIL created PowerPoint template that provides parents a method for sharing information about their Adult Child.

with disabilities to the center of the conversation and focus the group on why they are there.

b. Hang out: Don’t underestimate how much you can learn about group members and build trust from fun, informal gatherings. Make time for social activities!

2. **Acknowledge self-interests and differences**: Every family has an idea of what they want for their son/daughter and what their son/daughter wants for him/herself. Begin there. After their self-interests and differences are voiced, see where there are commonalities across the group.

3. **Build consensus**: Most groups consist of many individuals with different ideas and opinions. To make decisions as a group, it is important that the group discusses each idea, notes agreements and disagreements, carefully thinks through the proposed ideas, and then evaluates the different proposals until one seems right for the group. This process allows everyone to participate and work together toward solutions that may not be the first preference for any one individual but will be an agreed-upon decision that reflects the shared vision of the group. While the process of consensus building is more time-consuming than a voting process, it is important to recognize its benefits.

- **Collaborating with other families has enormous value and will be vital towards your success.**
- **Meetings and discussions with your Partner Families will be beneficial by bringing up issues & sound advice that you might not have considered on your own.**
- **Collaboration with other families will keep you focused and moving forward.**

3.1.8 Assessing Individual Gifts and Talents

Each one of you has individual gifts and talents to contribute to the cause of finding and developing your Housing Solution. If you are thinking, "I don't really have any talents," think again. Your talent for making people feel comfortable, your passion for working with youth with disabilities, or your gardening skills may all be useful when working toward creating Community Partnerships with new organizations, helping people with disabilities transition to a new housing arrangement, or fixing up the physical appearance of the property's grounds. Your son/daughter also has gifts, talents, and expertise to contribute to a new housing arrangement. For example, maybe your son knows all the bus routes in town. Maybe another family's son knows how to cook. If these men live together, they can share their expertise, and both develop new skills. You do not always need a "professional" to learn new things. If each person relies on the knowledge of the others in the group, everyone benefits with minimal cost!

> ***Criteria for Success in Family Collaboration:***
>
> Work continually to develop mutual understanding.
>
> Care about the whole house, not just your own loved one.
>
> Contribute your own unique expertise and skills to the group.
>
> Establish clear roles and accountability. (Who will do what, and when?)
>
> Decide on effective ways to handle stress/conflict regarding both philosophical issues & daily concerns.
>
> Protect the confidentiality of other individuals and families.

When each person involved in the family group shares his/her experiences with one another, the group develops a sense of mutual responsibility. Instead of dependence on government entitlements, disability service providers, and health professionals, family groups can build an interdependence focused on individuals' capacities. Partner Family groups can build dynamic and flexible or responsive support systems as individuals grow, change, and mature.

3.2 Assessing Family Compatibility

Once you have found someone(s) who might "click" with your family, it is important to get to know them as quickly as possible. Remember the **Roommates <u>AND</u> Parents** must be compatible to have a successful Housing Solution for your Adult Child. The following list of basic "starter" questions can be used to guide an early conversation with the family of a potential roommate.

3.2.1 Some Family Compatibility Questions to Think About

General Questions

- What is your ideal housing solution for

Location & Type of Housing

- Do you have a strong preference for a certain your Adult Child?

- What are your reasons for moving forward now in establishing a home for your Adult Child?
- How soon would you be ready to move if things could be put in place?
- Do you expect your Adult Child would do best with one or more roommates?
- Would any / all potential roommates be a person with or without a disability?
- Do you have time to devote to this effort?
- Do you already have someone else in mind as a potential roommate?

city or area?

- Does the home need to have special accessibility accommodations?
- Do you prefer to rent or own?
- Do you prefer an apartment, condo, or house?
- How close to shopping areas do you want to be?

Family Background / Routines

- What is your general family situation (work, community involvement, care of other Adult Children, aging parents)?
- Are there other family members who will help?
- What activities does your family enjoy together in leisure time?
- What does a typical weekday / weekend look like for your family?
- What are your thoughts on food & nutrition?
- Which holidays do you celebrate and how? Is it important to you to continue your family traditions? Would you envision your Adult Child returning to your house for these?

Family Values

- How important is work to you and your Adult Child?
- Presently, what does a typical day look like for your Adult Child?
- What would happen if your Adult Child's situation changed (e.g., laid off from work, change of support program, etc.)?
- How important is recreation? What are your ideas for how this might be incorporated into the new home?
- What are the important factors for happiness to your Adult Child?
- Are religious services important to your Adult Child? If so, what type and where?
- Can the residents have beer, wine, or other alcohol in the home?
- Is smoking allowed in the home?

Supervision & Control

- Do you expect your Adult Child to come home on weekdays / weekends / holidays? Always? Sometimes? Never?
- Would you drop your Adult Child off in a

Personal

- What are your worst fears about this situation?
- Is your style more collaborative or confrontational?
- Has your Adult Child ever lived away from you?

public place without supervision?
- Can your Adult Child remain in the home alone without supervision?
- Can the roommates have visitors? What about overnight visitors? Boyfriends or Girlfriends?
- How do you discipline your Adult Child if needed?
- Are you willing to transfer authority to other adults (support staff or fellow parents)?

3.2.2 House Guidelines – Part #1

As you begin to work more closely with your Partner Families, it is important to have an open and honest discussion about some things each parent sees as **absolute musts** and **absolute must-nots**. These are called "**Deal Breakers**" and it is better to get these out in the open now, rather than right before your Adult Child is ready to move into their new residence. Later in the section Prepare to Launch - House Guidelines Part #2, you will have the opportunity to go into greater detail and further define the perceived set of House Guidelines. But at this point, the parents should discuss with each other their answers to the following questions and determine if their Family Partnership can continue or are there items that cannot be overcome and therefore it is probably best for each family to seek other families to partner with.

Parents should reflect upon and thoughtfully answer the following questions:

1. What **must** exist in this future home?
2. What **can never** exist in this future home?
3. What are your **Deal Breakers**?

Deal Breakers are your "non-negotiables", i.e., those things about which you believe you have no flexibility in how the house will operate. You should disclose them to potential family partners and discuss the reasons these items are so important to you and your Adult Child. The other families will have their own requirements to share. Understanding each other's needs is a crucial step to deciding if you want to further explore a long-term relationship.

Be honest with other families about what is important to you. Many families want so much to find other families to partner with that they say what they thought the other family wants to hear. After investing much time and effort, eventually it becomes clear that their Family Collaboration will not work, and they must start over again seeking other families.

3.3 Finding Roommates[20]

Finding potential roommates for your Adult Child and compatible collaborative partner families can be one of the most challenging aspects of developing a Housing Solution. Getting this right is crucial to the success of your Adult Child's home.

3.3.1 Assessing Roommate Compatibility

If your Adult Child will be sharing a home with one or more roommates, it is important to ensure a good match among roommates. This does not necessarily mean that they need to do the same things all the time, but roommates and families must be comfortable with choices the others will make. Everyone needs to be aware of those areas where their basic traits differ substantially and discuss how they will cope to make the home comfortable for all.

3.3.2 Some Roommate Compatibility Questions to Think About

Using the questions below is a good starting place to communicate the preferences and traits of potential roommates in relationship to one another.

General Questions

- What is unique to your son or daughter's life experience?
- Does your son or daughter currently work? What type? Where? and When?
- What is meaningful to your son or daughter?
- What makes your Adult Child come alive?
- What creates peace, connection, and engagement for your Adult Child?
- What would your son or daughter love to be doing with his or her life?

Lifestyle Preference

- Does your Adult Child tend to "Go with the Flow" or is having a consistent routine important?
- Does your Adult Child wake up early and begin their day right away?
- Is your son or daughter a night owl and a late sleeper?
- Does your son or daughter like noise & commotion or calm & quiet?
- Is your Adult Child neat & tidy or rather messy?
- Does your Adult Child like to be on the go and out seeing people? Or is your Adult Child more of

[20] Roommate is a general term that includes Housemates or occupants sharing a common living space.

- What relationships are important, satisfying?
- What contributes to their sense of safety & security?

a homebody?

Care Giver & Support

- Does your Adult Child currently receive Support Services?
- If “Yes”, can you describe the amount and type of support services?
- What “Support” do you provide that you envision being handed over to a Direct Care Worker?
- Which IDD Service Provider do you work with, Easterseals | MORC, CLS, or some other agency?

3.3.3 Getting to Know the Roommates Better

It is important that parents openly and honestly share information about their son or daughter with families that they are considering partnering with on a Housing Solution. One of the fundamental questions that you were asked to think about back in the Charting Your Course step was,” Are you able to openly share information about your Adult Child”? Now is the time to put this theoretical question into practice.

For some parents, sharing information about their Adult Child can be difficult and rather emotional, but remember your Partner Family community and fellow parents are there to help you. The better your Adult Child’s unique situation is understood, the better your Partner Family community can help. To reduce some of the emotional burden of sharing information about their Adult Child and to provide this information in a simple & consistent manner, SAIL recommends using the All About Me PowerPoint presentation method.

3.3.4 All About Me - PowerPoint

The SAIL *All About Me* PowerPoint is a simple & highly effective method for informing fellow parents, potential roommates, and support staff about the important pieces of information they need to know about your Adult Child in order to provide a safe and comforting environment.

As a parent of an Adult Child with an IDD, how many times have you tried to describe your son or daughter to someone? Making sure to include all their amazing traits, strengths, and things that bring joy and make them "come alive"; while also making sure you accurately describe some of their challenges and things to avoid? *All About Me* is simply a PowerPoint template that allows parents and their Adult Child to document the major characteristics of their son or daughter that you would want a care giver or fellow parent to know.

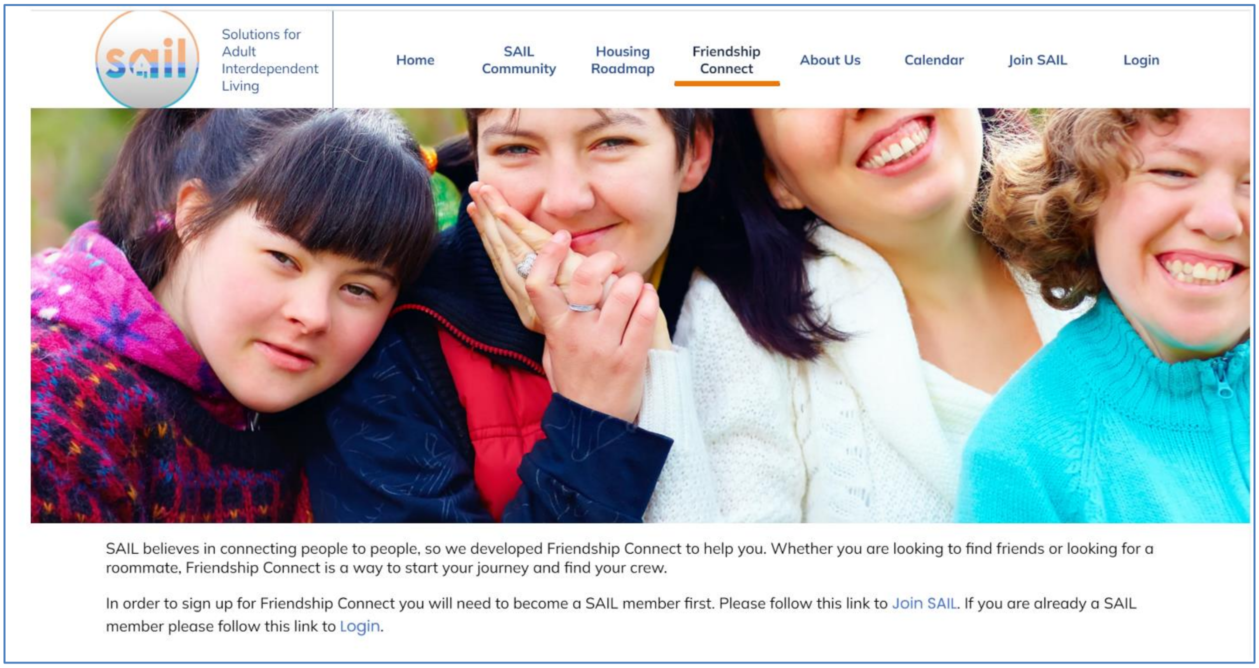
Below is a list of the topics contained in the All About Me PowerPoint template slide. You can include additional topics that you feel are important when describing your Adult Child.

- About Me
- Activities I Enjoy
- Communication
- Strengths
- Challenges
- Learning Style
- Likes & Dislikes
- Eating & Nutrition
- Medical & Health

Roommates can present their All About Me presentations with each other and to their IDD Service Provider Supports Coordinator and Direct Support Staff.

3.4 SAIL Friendship Connect

SAIL has created **Friendship Connect** as a method for connecting Families to Families and Friends to Friends. Friendship Connect is part of the SAIL website and is intended to promote networking and social interaction among parents and individuals with an IDD. Friendship Connect participants are individuals with an IDD that with the consent and perhaps guidance of their parents fill out a **Friendship Connect Profile** that includes



basic information along with personal traits such as: Likes & Dislikes, Hobbies and Things You Enjoy Doing for Fun. Friendship Connect participants and their parents can use the Friendship Connect portal to search for other individuals with an IDD that share similar interests, explore establishing friendships and even seek out potential roommates.

3.4.1 Friendship Connect Sample Profile

Friendship Connect profiles are used to help bring together SAIL families together whose Adult Children share common interest in the hopes of promoting social activities as well as finding potential roommates. Below is an example of a SAIL Friendship Connect Member Profile.

SAIL FRIENDSHIP CONNECT ONLINE PORTAL

Members enter information that allows for SAIL parents to connect and explore friendship or roommate possibilities.

RACHEL G.

Age: 25

Location: Northville

Activities: Going to movies and shopping

Hobbies: Puzzles, Arts & Craft, watching TV

Parent's Contact: (555) 867-5309

CHANDLER B.

Age: 29

Location: Berkley

Activities: Walking my dog, going to movies and the zoo.

Hobbies: Computers, Legos, Painting

Parent's Contact: (555) 867-5309

MONICA G.

Age: 32

Location: Troy

Activities: Exercising, Board games, reading

Hobbies: Arts and Craft, Going to movies

Parent's Contact: (555) 867-5309

ROSS G.

Age: 34

Location: W. Bloomfield

Activities: Bowling, swimming, watching TV

Hobbies: Computers, walking, Craft, video games

Parent's Contact: (555) 867-5309

Please contact SAIL for more information about Friendship Connect and Friendship Connect events.

- **Finding Partner Families and compatible roommates for your child is probably the most difficult and the most important step along your IDD Housing Solution journey.**
- **There's no magic formula for finding compatible families & roommates. Be open to sharing your situation and always on the lookout.**

3.5 Helpful SAIL Resources for – Finding Your Mates

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Finding Your Mates step.

File Name	Description
Assessing Family Compatibility	Guide to help families determine if they can become Partner Families.
Getting to Know Me	PowerPoint template for introducing your Adult Child to fellow parents.
Roommate Compatibility Questions	Guide to help families determine if their adult children can be compatible as roommates.

Team Decision Making Process and Team Building Activities	Guide for building trust and understanding with your fellow Partner Families.

4 Explore Cabin Options

Congratulations! You've found fellow families to partner with and a roommate(s) that are compatible with your Adult Child. Now you're ready to get serious about turning that IDD Housing Vision into an actual IDD Housing Solution.

When choosing the type and location of your Adult Child's new home, your decision will be based on a combination of personal preferences, collaborative choices, and practical realities. The Exploring Cabins Options step presents issues for families to consider and some information about various housing models and types of ownership to consider.

Exploring Cabin Options	
• Shared Housing Vision • Type of Home • Housing Budget ○ Purchase or Move In Cost ○ Operating Expenses • Define Housing Search Parameters	• IDD Housing Options • Type of Ownership • Legal Considerations • Funding Model • Visit other IDD Housing Solutions

Deciding on the type of housing, the type of ownership, the type of legal structure required of your group, and the initial investment and operating budgets will have a major impact upon your Partner Family Group. It is important that you take the time and effort to share everyone's input and any concerns. Try to be open to different housing options while being true to your son or daughter's Housing Vision.

4.1 Overview of IDD Housing Models

There are four common IDD Housing Models that SAIL encourages its members to become familiar with when deciding on moving their adult child towards a life of independence. Remember that there is not a single IDD housing model that is the right fit for every individual. Your choice will be a personal decision and will largely depend upon creating the best environment for your adult child to live his or her fullest life.

Direct Caregiver Staff	Staffing Agency	Staffing Agency or EOR[21]	Staffing Agency or EOR	Staffing Agency or EOR
Location	Fixed	You can select location	You can select location	Existing IDD Housing is fixed, but option to develop your own IDD housing
Roommates (Housemates)	Typically, minimum of 4	You can select number of roommates	You can select number of roommates	Based upon IDD Housing guidelines
Medicaid benefits	Managed by Group Home	Self-Directed	Self-Directed	Self-Directed

The type of IDD Housing Model and your decision towards the type of direct caregiver staff will greatly influence your role in developing and maintaining your IDD Housing Solution. Since 1992 Michigan Medicaid began offering self-directed Medicaid services [22] as part of its MI Choice Waiver Program. Self-Directed Medicaid services, also known as "consumer-directed" services, allow Medicaid participants to have greater control and decision-making authority

[21] EOR – Employer or Record; direct hire and management of caregiver staff
[22] Self-Directed Services – https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html

over certain services that are critical in creating and maintaining an IDD Housing Solution, such as:

- Where will my adult child live?
- With whom will they live with?
- Hiring and management of support caregiver staff

Although housing and support arrangements are individualized, there are some general categories. These categories vary based upon the level of individual control and independence:

4.1.1 Licensed Group Home – Community Living Arrangement

A Community Living Arrangement (CLA), sometimes called a licensed group home, is a professionally managed house where a few individuals with intellectual and developmental disabilities live together under the care and supervision of the group home management company. The home has a direct caregiver staff to help provide services and support. Medicaid typically pays group home management companies to provide services for residents. A "licensed group home" is a residential facility that is legally permitted to operate and provides care to a group of individuals, while an "unlicensed group home" facility can offer similar care services but operates without the required state license, meaning it does not meet the legal standards for quality and safety set for community living arrangement facilities.

LICENSED GROUP HOME

In a CLA | Licensed Group Home, the direct caregiver services in these homes are usually implemented by a service provider under an agreement with the county's community mental health organization. Support and supervision are typically provided on a 24-hour x 7-day a week basis. Although your individual considerations will differ based upon the requirements of your adult child, below are some common questions that you should keep in mind when evaluating if a CLA is the right IDD housing solution for you.

General Questions

- What is the group home's resident limit?
  - Range of ages
  - Male or Female
  - Level of independence

Funding Questions

- How does the funding model work?
- Does the group home accept Medicaid benefits for rent and living expenses?
- Are additional funds required to offset and

- Are there living accommodations of residents that I should be aware of?
  - Allergies
  - Behavioral issues
- What is the direct caregiver staffing arrangement?
- What is the ratio of caregiver staff to resident?
- Does the home have the required safety and accessibility provisions?
- How many bedrooms? How many bathrooms?
- How are cooking and house chores conducted?

Lifestyle Questions

- What is the typical schedule during weekdays (M-F)?
- What is the typical schedule during weekends?
- Does the group home provide transportation services?
- Can residents have visitors?
- What are the social programs and activities?
- What does a typical meal plan look like?

shortfall in Medicaid benefit payments?

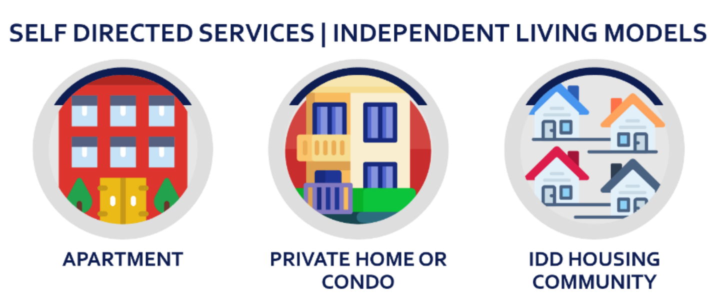
- What are the typical monthly out of pocket expenses?
- What is the typical move in expenses?

House Guidelines | Safety Questions

- What are the house guidelines and expected behavior?
- How are conflicts amongst the residents resolved?
- What's the process for terminating a resident's stay based upon non-adherence to the housing guidelines?
- What is the feedback / communication method for keeping parents & guardians informed?
- What role does the group home play in reviewing my child's IPOS with the Supports Coordinator?

4.1.2 Self-Directed | Independent Living Models

In a Self-Directed Independent Living housing solution people can live in a home of their own choosing in a variety of settings. Most often this involves either owning or renting a place to live and housing can vary from apartments and condos to single-family homes or an IDD housing community.



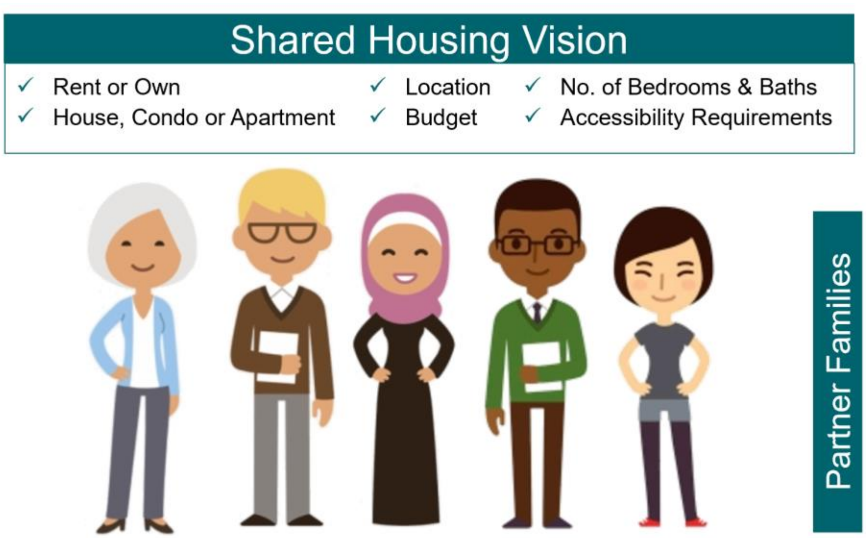
A self-directed | independent living model allows the participants to determine if he or she would like to hire and manage their direct caregiver staff or utilize a staffing agency. Roommate selection is also possible under the self-directed | independent living model, whereas in a licensed group home, the roommates and fellow residents are determined by the group home management company. Parents and guardians will play a larger and more active role in creating and maintaining a self-directed independent living model

4.2 Creating a Shared Housing Vision

Now it would be a good time to revisit your initial Housing Vision for your Adult Child that you previously shared with your Partner Families. It is helpful to step back and articulate a unified Housing Vision for the group that all members support. A vision statement describes the world as it should be—a possible future we keep creating. A vision requires a stretch of expectations, aspirations, and performance. It explains the purpose of the group and gives everyone a united focus. The key is to make sure that everyone in the group shares their input and is content with the final statement.

> ***"Vision without action is merely a dream; Action without vision just passes the time; Vision with action can change the world."***
>
> ***– Joel Arthur Barker***

Remember those common items that formed your Shared Housing Vision with your fellow Partner Families. Now would be a good time to review and discuss these aspects with your Partner Families. You want everyone within your Partner Family group to be on the same page, before you spend energy on searching for housing that may not appeal to your group.



As you consider your housing criteria, your Partner Families should consider the following questions and reach agreement or at least acceptable answers from all families before you begin your housing search.

General Questions

- What type of home should we consider?
  - Single Family House
  - Condominium
  - Apartment
  - Other
- Do we need safety and accessibility provisions?
- How many bedrooms? How many bathrooms?
- Do we need a designated space for support staff?
  - Home office for support staff
  - Secure place for storing medication
- What transportation services do we need?
- Do we have a list of Must Haves? Must Not Have?
- What locations will be in our primary target focus
- Do we have a realistic Ready to Move Out date?

Home Ownership

- What type of home ownership should we consider?
  - One Family owns, the other Families pay rent
  - Separate Legal Entity owns the home
  - Third Party owns the home, all pay rent
- What is the financial capacity of the group?
- What Funding Model should we consider?
  - Self-Funded
  - Fund Raising
- Do we need legal assistance?

Answering these questions will breed more questions, so be prepared for this step of the process to be quite time-consuming.

4.2.1 Researching Existing IDD Housing Options

Once the questions above have been identified, you will need to explore housing possibilities. One of the most important ways to get information is to tour existing IDD residences. Talk to other SAIL families that have created IDD housing for their loved ones and make it a priority to visit existing IDD residences. Whether you see something you like or something you dislike, visiting existing IDD housing options will help families envision the possibilities and continue articulating their own vision for housing. This will help your group to get ideas about what you like and what you do not like. Partner Families should look at options that are offered by current IDD Agencies, i.e. Group Homes, as well as alternatives created by fellow SAIL Partner

Families. At this stage it would also be a good time to talk with the service providers[23] in the county that you're considering for your adult child to live about what the service providers offer so you can learn what is currently available versus what you want to create. Talk with individuals with disabilities and their families who already live in the community to learn what is going well and what they would change about their situation.

4.2.2 Create Initial Housing Budget

The search for the physical residence of your Housing Solution must take into consideration the collective financial capacity of your Partner Families for both the initial investment, including startup, move-in costs, and the ongoing monthly living expenses (operating budget). Whether you decide to own, or rent will have a significant impact on the budget for your initial investment. If your group is considering borrowing money to purchase a property, then you should consult an expert in the Mortgage / Lending industry to obtain a better understanding of the costs and fees associated with the initial investment and ongoing monthly mortgage payments.

When creating your initial housing budget, try to fully understand the monthly sources of income that your adult child will have and how that income can be used to cover typical expenses that you'll encounter.

The diagram below provides an overview of typicall sources of income and expenses for a person with an IDD diagnosis.[24]

	Income Source		Expense
Social Security Supplemental Security Income (SSI)	• SSI – supplemental security income • SSDI – social security disability insurance	→	• Rent • Utilities
SNAP Supplemental Nutrition Assistance Program	• SNAP – supplemental nutrition assistance program	→	• Food

[23] Service providers such as Easterseal MORC or Community Living Services
[24] Annette Downey – Community Living Services

- Adult Home Help
- Habilitation Supports Waiver (HSW) or (HAB)
- Medicaid

- Direct Care Support Staff
- Support Coordinator
- Fiscal Intermediary Services
- Transportation

- Medicaid

- Medical care

- Employment income
- Small gifts
- Special Needs Trust
- SSI personal allowance

- Clothing
- Recreation
- Entertainment
- Vacation
- Extras …

The sample housing budget below highlights the various sources of income, that include – SSI and SSDI benefits; SNAP MI Bridge account; employment income, and other sources of monthly contributions that can considered income.

INCOME	Roommate #1 Estimated Monthly Income	Roommate #1 Estimated Yearly Income	Roommate #2 Estimated Monthly Income	Roommate #2 Estimated Yearly Income
INCOME SOURCE				
SSI	$0.00	$0.00	$945.00	$11,340.00
SSDI	$1,125.00	$13,500.00	$0.00	$0.00
Employment Income	$1,050.00	$12,600.00	$725.00	$8,700.00
SNAP / EBT / Bridge Card	$40.00	$480.00	$145.00	$1,740.00
Family Support	$0.00	$0.00	$150.00	$1,800.00
Special Needs Trust	$0.00	$0.00	$0.00	$0.00
MiABLE Account Withdraw	$0.00	$0.00	$80.00	$960.00
Other Sources of Income	$0.00	$0.00	$0.00	$0.00
TOTAL INCOME	$2,215.00	$26,580.00	$2,045.00	$24,540.00

The **Initial Housing Budget** should include all possible sources of monthly income for each resident (Adult Child) and estimated monthly expenses. You'll have the opportunity to refine the Initial Housing Budget estimate with a more accurate expense projection once your actual housing solution and associated costs are better known. For now, it's important to come up with a realistic estimate that all parents agree upon. The diagram below shows a sample housing budget with a focus on the various monthly income for each roommate. Monthly income from SSI and/or SSDI as well as the MI Food Assistance Program should be included in the monthly income projection.

INCOME		Roommate #1 Estimated Income		Roommate #2 Estimated Income		Roommate #3 Estimated Income	
	BUDGET ITEM - INCOME	Monthly	Yearly	Monthly	Yearly	Monthly	Yearly
	SSI	$794.00	$9,528.00	$0.00	$0.00	$300.00	$3,600.00
	SSDI	$0.00	$0.00	$1,228.00	$14,736.00	$0.00	$0.00
	Resident Income / Job	$0.00	$0.00	$540.00	$6,480.00	$800.00	$9,600.00
	MI Food Assistance Pgm	$185.00	$2,220.00	$81.00	$972.00	$0.00	$0.00
	State of Michigan	$14.00	$168.00	$0.00	$0.00	$14.00	$168.00
	Family Support / Allowance	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00
	Trust	$0.00	$0.00	$0.00	$0.00	$200.00	$2,400.00
	ABLE Acct	$200.00	$2,400.00	$0.00	$0.00	$0.00	$0.00
	Other	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00
	TOTAL INCOME	$1,193.00	$14,316.00	$1,849.00	$22,188.00	$1,314.00	$15,768.00

In addition to estimating your Adult Child's monthly income, you should also estimate the monthly expenses. Partner Families should try to be as realistic as possible when developing their initial budgets. Contacting fellow SAIL parents and discussing the types of expenses their Adult Child incurs is a great source of information and will help to give some credibility to your budget. Does the community that you are considering provide Free or Low-Cost services that you may be unaware of? You want to understand and take advantage of every community service that would be appropriate for your Adult Child.

EXPENSES

BUDGET ITEM - EXPENSES	Roommate #1 Estimated Expenses Monthly	Roommate #1 Estimated Expenses Yearly	Roommate #2 Estimated Expenses Monthly	Roommate #2 Estimated Expenses Yearly	Roommate #3 Estimated Expenses Monthly	Roommate #3 Estimated Expenses Yearly
Summary	Monthly	Yearly	Monthly	Yearly	Monthly	Yearly
Total Income	$1,193.00	$14,316.00	$1,849.00	$22,188.00	$1,314.00	$15,768.00
Total Costs Rent + Insurance	$605.00	$7,260.00	$650.00	$7,800.00	$655.00	$7,860.00
Total Living Expenses	$63.99	$767.88	$0.00	$0.00	$48.00	$576.00
Total Other Budget Items	$190.00	$2,280.00	$176.00	$2,112.00	$165.00	$1,980.00
Total Support / Medical	$50.00	$600.00	$0.00	$0.00	$86.00	$1,032.00
Total Groceries Expenses	$150.00	$1,800.00	$150.00	$1,800.00	$150.00	$1,800.00
Net Budget	**$134.01**	**$1,608.12**	**$873.00**	**$10,476.00**	**$210.00**	**$2,520.00**

Please contact SAIL for a Housing Budget Template that can be used as

4.2.3 *Funding Model for Operating the Home*

Based upon the initial Housing Budget and the estimated monthly expenses to operate the home, Partner Families should discuss if additional sources of revenue are required. That is, will a Self-Funded Income Model be used or will a Fund-Raising Income Model for obtaining additional sources of income be utilized? The need for Fund Raising might bring about additional changes and responsibilities within the Partner Family Group such as:

- Becoming a 501c3 Non-Profit organization
- Additional accounting and financial reporting responsibilities
- Additional resources to implement Fund Raising events

4.2.4 *Types of Home Ownership Models*

Although Home Ownership models can generally be broken into two camps - #1 Own or #2 Rent, the following section contains an overview about various types of home[25] ownership that you may want to consider as you explore housing options.

4.2.4.1 *One Family Owner*

In this model, one Family purchases a home for their adult child and allows other adult children (Roommates) to also live in the home and pay rent. The family who is the homeowner will be the Landlord and the other adult children residing in the home are the tenants. It is important that the one family owner creates and use a lease with each tenant. The lease protects both parties by capturing in writing the expectations. In addition, tenants

[25] Home refers to a free standing, single-family dwelling "House" or Condominium / Townhouse

who receive SSI may be required to provide a copy of the rental agreement (lease) to their local Social Security office.

4.2.4.2 Separate Legal Entity Owns the Home

In this model, a group of families pool resources to purchase a home for their Adult Children. Families that prefer to share ownership of the home should consider seeking legal counsel to advise on forming a separate legal entity that holds the real property and protects the participating families from personal liability. For Partner Family directed housing, a Limited Liability Company (LLC) offers a great deal of flexibility, combines the best parts of partnerships & corporations, and may exist with one or more members.

Families that form an LLC may wish to create a separate agreement that addresses the operation of the home and is agreed to by all of the members. Even where there is no LLC, families whose Adult Children are sharing a home may wish to form an unincorporated association or a consortium for the purpose of managing the home and having a process that addresses conflict. The agreement may include as much detail as the families wish. At the very least, it should address the duties and obligations of the participating families and address major areas of potential conflict.

Other key areas that should be considered in the agreement:

- Decision Making Process – unanimous or majority rule? How often will the Family Group meet? Are designated officers required?
- Admission & Eviction Criteria – taking on a new resident due to a vacancy
- Member Contributions – financial, labor, or both?
- House Guidelines – refer to Prepare to Launch chapter
- Dispute Resolution – agreed upon process that will be followed in the event of a conflict
- Succession Plan – Policy that addresses if an original family member is no longer able to participate in the Family Group, and their Adult Child continues to live in the home

4.2.4.3 Third-Party Owns the Home

The Third-Party owner model is similar to the one family owner model, except that the Third-Party owner is not a parent to any of the tenants. A lease should be used for the same reasons as discussed above. If the landlord has a separate lease with each tenant, the tenants' duties and obligations are independent of the other tenants. On the other hand, if the lease is between the landlord and all tenants, all tenants may be obligated equally. For example, if the lease requires that tenants pay all utilities and one of the tenants does not pay his share, the remaining tenants may be legally obligated to make sure the utilities are paid.

4.2.5 Insurance for Your Adult Child

Whether the home is owned by an individual or an entity such as a limited liability company, the landlord should have a homeowner insurance policy that provides sufficient coverage for property damage and injury that occur on the premises. The tenants have a duty to pay rent and not cause damage to the premises. If the premises are damaged as a result of a tenant's action, the tenant may be liable to the landlord. Families may wish to purchase a tenant insurance policy "Renter's Insurance," which protects the tenant's personal property against loss, theft, or damage. In the unfortunate event of damage occurring to the home, the landlord's policy will not typically cover the tenant's personal belongings.

4.2.6 Engage a Professional Team to further define the Vision

When the Family Group has more established housing criteria, budget, and an overall vision for the housing options they want to invest in, it is time to get professional opinions and assistance. Professionals will have a better understanding of local housing market, guidelines and regulations, available resources, and needed expertise. Here are a few examples of members you may want on your professional team:

- Real Estate Agent
- Real Estate Attorney
- Financial Lender
- General Contractor

The final team you assemble will be based on the type of housing you desire, whether it currently exists or must be constructed, and what financial structure will be utilized.

4.2.7 Realistic Timing – Ready to Move

Finding suitable housing with an **Occupancy Date** is one thing, but keep in mind that it will take time, perhaps several months, to prepare both the Support Team as well as your Adult

Child for the **Move in Date**. Don't confuse the Occupancy Date or Start of Lease Date with the date your son or daughter must move into their new residency.

4.3 Helpful SAIL Resources for – Exploring Housing Cabins

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Exploring Housing Cabins step.

File Name	Description
Assessing Housing Location	Worksheet to help parents evaluate various locations and resources within a given location
Creating a Shared Housing Vision	Guide to help Partner Families create a unified IDD Housing Vision
SAIL Housing Budget	Worksheet template for developing a Housing budget
SAILing IDD Housing Research	Collection of numerous IDD Housing options
Supports Coordination and Your Housing Vision	Guide to help parents when working with their Support Coordinator as your Adult Child transitions to their new IDD Housing Solution

5 Assemble Your Crew

Now that you have found a new residence for your Adult Child, it's time to be laser focused on preparing the IDD Service Provider[26] and Direct Support Providers[27] or Care Givers. In addition to working with your support team, your son or daughter will need time & assistance to prepare for their new independence.

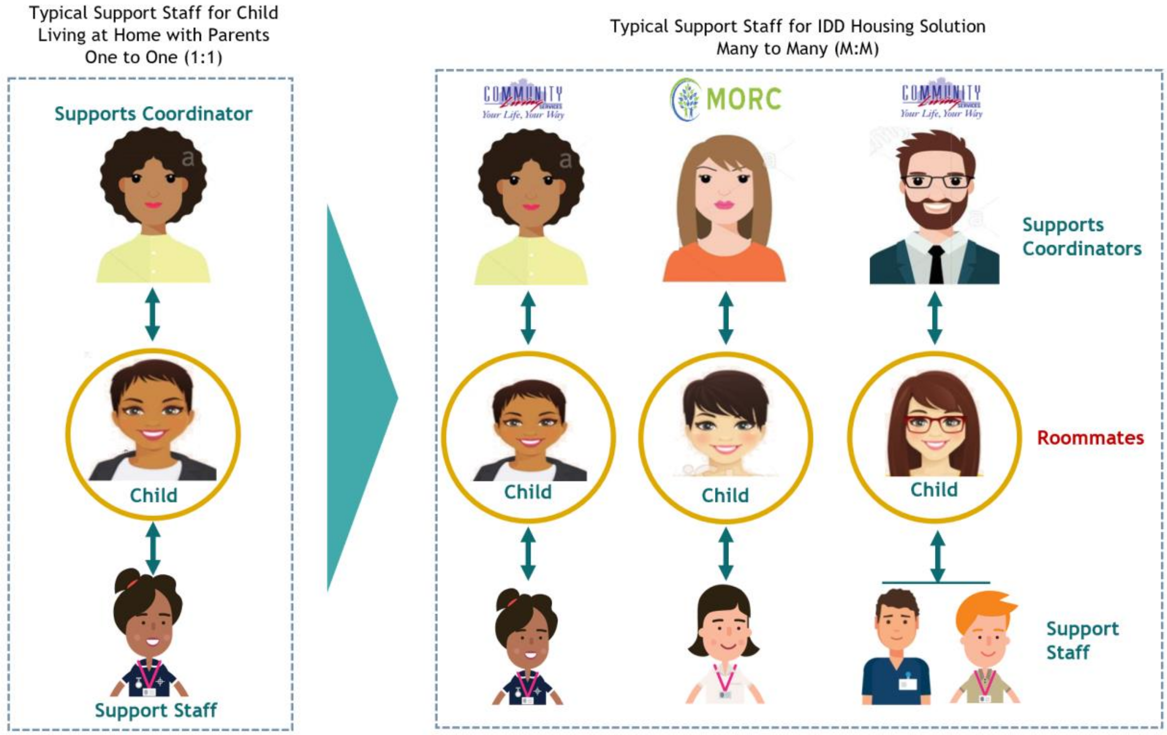
Assemble Your Crew	
Support Team	**Prepare to Launch**
• IDD Service Provider • Update PCP or IPOS • Direct Support Provider • Community Builder • Home Technology & Home Maintenance	• House Guidelines - Part #2 • Training for Independence • Engaging with future Roommates • Adult Home Help

5.1 Direct Caregiver Professionals – Support Team

Once a home is secured and roommates are selected, the families must decide on how support services are provided. Even if you've already been using Caregiver Professionals or Care Givers for your Adult Child while he or she is living with you, there's a good chance that you'll have to find new or additional Care Professionals due to your Adult Child's new residency and level of independence. Remember someone will have to take your place in providing the care and assistance that you have been giving your Adult Child throughout the years. The diagram below provides an overview of the different support structure you'll be encountering as your son or daughter moves in with fellow roommates, who most likely have been working with a Supports Coordinator and Direct Support Care Giver staff. An IDD Housing Solution will most likely have multiple roommates, support care givers, as well as support coordinators.

Caregiver Support Staff

[26] IDD Service Provider - OCHN recognized IDD agency such as Easterseals | MORC or CLS.
[27] Direct Care Worker – Trained individuals that directly work with your Adult Child

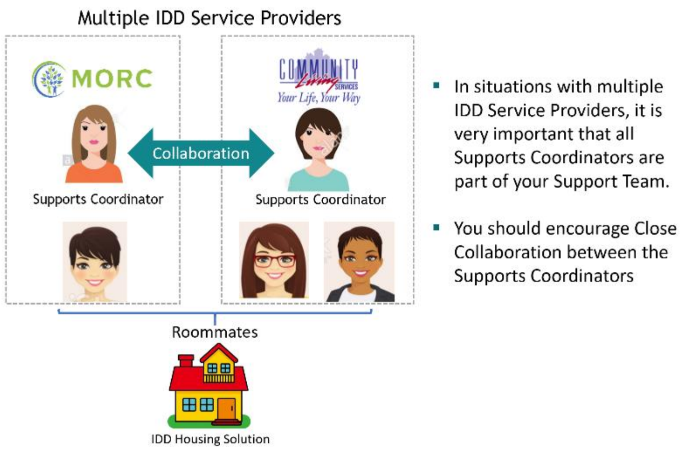


When putting together your Support Team and evaluating Direct Care Worker options, parents are encouraged to visit other IDD Housing Solutions and meet with fellow parents. Try to understand what works and what issues the parents had to overcome.

5.1.1 IDD Service Providers

It's now time to make your Adult Child's Supports Coordinator Worker (IDD Service Provider) an integral member of your Support Team – ***if you haven't done so already!*** As your Adult Child prepares to transition to a new home, you should work closely with your Adult Child's Supports Coordinator to update the PCP or IPOS files and consider the additional support hours your son or daughter will require.

If your Adult Child will be living with one or more roommates, there's a chance that one of the roommates may utilize a different IDD Service Provider than your Adult Child does. If this is the case, it is vital that all the Supports Coordinators Workers who will be supporting your Housing Solution are engaged and play an active role in preparing for a safe transition.

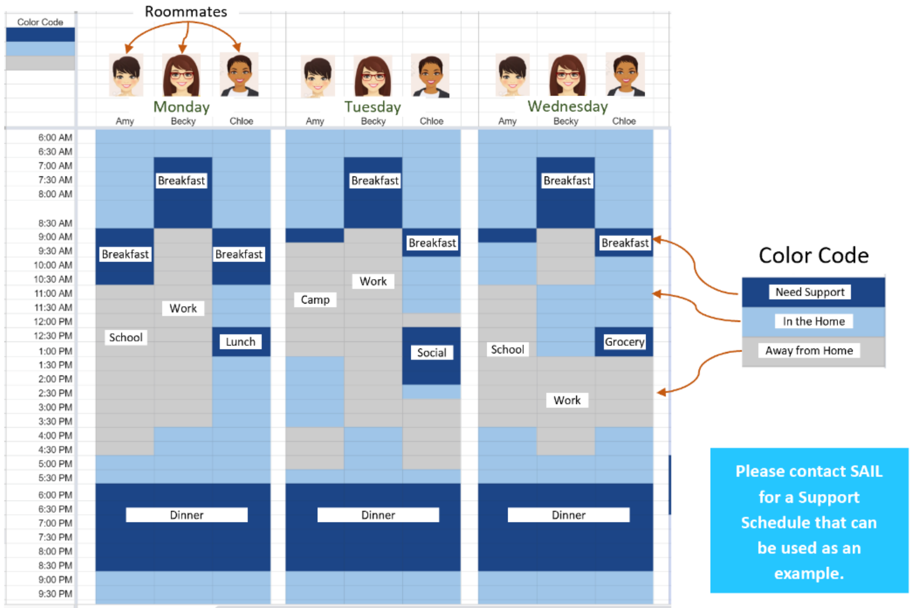


You should remember to consider the needs of the entire house and all roommates in your discussions with the Supports Coordinators. Supports Coordinators must understand the Big Picture of how the home will operate and what support services are required and when. A simple and useful method for conveying this information to your Support Team is developing a Support Schedule for the entire home.

- **Make it a practice to always be on the lookout for Support Staff.**
- **Teachers & Para-Pros that know your child are a great source along with Friends & Family.**
- **You'll want to have a "deep bench" of Support Staff that you can draw from in case of staff turnover**

5.1.2 Household Daily Schedule and Support Needs for the Home

As your Adult Child begins to make the transition from living with you to a new home that is shared with others, it is helpful to develop a weekly household support schedule that includes each of the roommates' perceived activities and where support is needed. This is also useful even if your Adult Child decides to live without a roommate. Work together with the other parents to identify what activities each of the roommates will be doing, when they expect to be out of the home, and what level of support is required. This will be useful in your discussions with your Direct Support Providers and IDD Service Provider Supports Coordinator(s).



The Household Support Schedule helps parents identify and understand the Big Picture of what type of support services are required and when they are needed.

5.1.3 MDHHS – Home Help Services

Home Help Services is a program administered by the Michigan Department of Health and Human Services (MDHHS). The program provides funding for qualified individuals to hire someone to assist them with their daily activities. It is designed to support individuals who wish to live independently in their home.

The program provides funding for qualified individuals to hire someone to assist them with their activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

5.1.3.1 Available Home Help Services

Home Help Services may pay for the following activities of daily living:

Home Help Available Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) services include

- Meal Prep & Clean Up
- Eating or Feeding
- Bathing
- Using the toilet
- Dressing
- Grooming / Personal Self-Care
- Moving throughout the home
- Transferring from one position to another

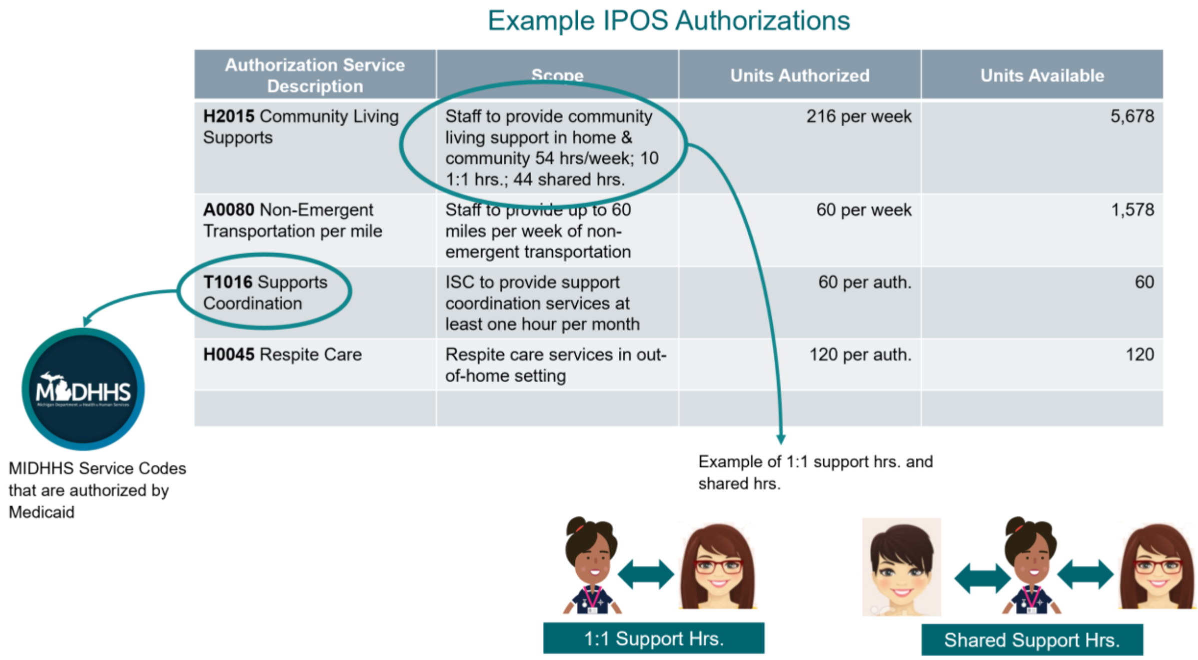
- Administrating or Setting up Medicine
- Shopping for essential items
- Laundry
- Light Housework

If you or your loved one need assistance performing daily activities, call or visit the Adult Services unit at your local county MDHHS office. If you need help finding your local MDHHS office, go to www.michigan.gov/contactMDHHS

5.1.4 Support Staff Schedule and Support Hours

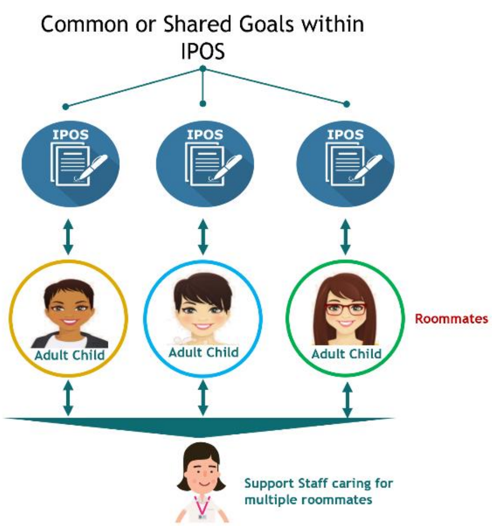
As Partner Family parents begin to define a combined schedule based upon all the roommates, parents should work closely with your Supports Coordinator(s) to develop a staffing schedule. The amount of staffing hours needed will be determined and incorporated into each Adult Child's IPOS based on both the goals of the individual Adult Child as well as shared goals between roommates, if applicable. Each goal in an IPOS will have a specified amount of time allotted to address that goal which will in turn impact the amount of support staffing hours.

Most likely, the support staff model while your son or daughter is living with you in your home is based upon 1 Support Care Giver and 1 Adult Child. This is referred to as a One to One (1:1) Support Staff model. If your son or daughter is planning on living with roommates with an IDD, you will have the opportunity to take advantage of Sharing Support Staff hours across the IDD individuals in the home. This will allow parents to maximize the number of hours that a support staff care giver is in your Adult Child's home.



Example IPOS Authorizations

Authorization Service Description	Scope	Units Authorized	Units Available
H2015 Community Living Supports	Staff to provide community living support in home & community 54 hrs/week; 10 1:1 hrs.; 44 shared hrs.	216 per week	5,678
A0080 Non-Emergent Transportation per mile	Staff to provide up to 60 miles per week of non-emergent transportation	60 per week	1,578
T1016 Supports Coordination	ISC to provide support coordination services at least one hour per month	60 per auth.	60
H0045 Respite Care	Respite care services in out-of-home setting	120 per auth.	120



Sharing staff across individuals requires coordination by everyone's Support Coordinators to make sure there are shared goals that are common amongst roommates and that each individual's IPOS reflects how many 1:1, 1:2, etc. support hours each individual will have based on their IPOS. Medicaid reimbursements, whether for individual 1:1 support hours or for shared support hours are managed through either the staffing agency or a fiduciary partner.

5.1.5 Support Staffing Agency or Independent Support Provider?

In finding your Direct Care Giver Support Staff, i.e., "Support Staff", there are two common staffing models that families should evaluate and then ultimately decide upon which model would work best for their situation. The two commonly used staffing models are:

1. Staffing Agency

2. Employer of Record | Direct Hire

Under the *Staffing Agency* model, the staffing agency is responsible for hiring, training, and timekeeping, and payment amongst many other things involved in managing their employees, which are the Direct Caregiver Support Staff. A Staffing Agency is basically a "One Stop Shop" model that handles all aspects related to the Support Staff.

Under the *Employer of Record | Direct Hire* model, the Adult Child or Adult Child's Parents are designated as the Employer and are responsible for hiring, training, and managing the Direct Caregiver Support Staff. This option provides more flexibility towards staffing; however, it also requires more responsibility and parental involvement. The Employer of Record model will also require working with a fiduciary partner or financial management service (FMS) company to handle the employee timesheets, invoicing Medicaid, and payment to the support staff employee.

5.2 Training of Direct Support Care Giver Staff

Whether you decide to utilize a Staffing Agency or the Employer of Record approach for you Care Give Staff, the training of Staff is important no matter what staffing model is chosen. A Staffing Agency will be responsible for ensuring that their employees are properly trained and certified. However, under the Employer of Record approach, the person being served (Adult Child) or the Adult Child's parents / guardians are responsible for making sure the Care Giver Staff is trained.

Below is an example of the training requirements for a Direct Support Care Giver. Parents should check with the Michigan department of Licensing and Regulation Affairs (MI LARA[28]) and with their Supports Coordinator to obtain the latest training requirements.

Required Training	Initial Due	Initial Resource	Renewal Due	Renewal Resource
Bloodborne Pathogens	Before Hire	www.dwctraining.com	Annually	www.dwctraining.com

[28] MI LARA - https://www.michigan.gov/lara/0,4601,7-154-89334_63294_27717-224979--,00.html

Required Training	Initial Due	Initial Resource	Renewal Due	Renewal Resource
Recipient Rights In Person	Before Hire	https://www.oaklandchn.org/index.php/training-online-tests		
Recipient Rights Online			Annually	https://www.oaklandchn.org/index.php/training-online-tests
CPR	Before Hire	Certified Instructor	2 Years	Certified Instructor
First Aid	Before Hire	Certified Instructor	2 Years	Certified Instructor

Families that decide to hire individual, qualified Direct Support Providers, i.e., using the "Employer of Record" model, have the greatest control over every aspect of the service; however, they also assume the largest responsibility. In this case, the Adult Child / Parents act as an Employer of Record, the family can hire the Care Giver(s) that they prefer, however the family must also plan for Care Giver sick or vacation days and ensure that there are adequate backup Care Givers in place of schedule changes. Families that decide to act as an Employer of Record and hire their care staff may also want to utilize a fiscal intermediary to handle such things as the employer – employee paperwork, time tracking, payroll, tax fillings and insurance issues. For example, if your Adult Child's Service Provider is with Easterseals | MORC, The Arc of Oakland County typically acts as the fiscal intermediary.

Utilizing a Support Staffing Agency relieves some of the day-to-day burdens from the parents; however, parents will have less direct control over the individual Direct Care Support Providers.

Advantages of Contracting with a Support Agency

- Agencies often have a collective wealth of experience and knowledge
- Agencies handle employment laws, employment taxes, and employee benefits.

Disadvantages of Contracting with a Support Agency

- Families have less control over who is hired or fired.
- Agencies tend to have higher turnover rate in staff.

- Many agencies have managers or program staff who can provide additional supervision and oversight.
- Agencies usually provide back-up staffing for vacation and sick days.

Advantages of Contracting Independent Support Providers

- Parents have direct control of who is hired
- Parents are involved in training and supervising the staff.
- Because a staffing agency is not charging for "overhead," Medicaid payments to the support staff is usually net out at a higher hourly rate of pay.

Disadvantages of Contracting Independent Support Providers

- It requires a substantially greater investment of time and energy.
- You are responsible for finding backup staff when someone calls in sick or goes on vacation.
- You must handle employee taxes, benefits, and employment laws, unless you utilize a fiscal intermediary.

All Direct Support Providers, whether Employer of Record or through a Support Staffing Agency, should be certified by the State of MI.

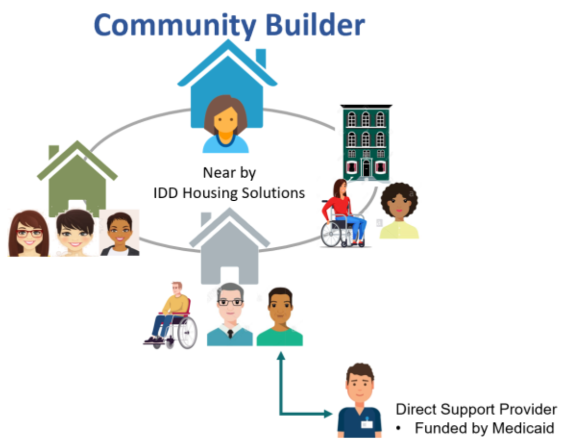
5.2.1 Parents and Family as Direct Care Professionals

Family members and parents may also elect to provide and get reimbursed for support service hours directly to their son or daughter's roommates. Parents and family members that fulfill all training certification requirements can provide support to their Adult Child's roommates based upon the roommate(s) individual or shared IPOS goals. These support hours are eligible for financial reimbursement through either your fiscal intermediary (EOR) or staffing agency, provided that you are an employee of the staffing agency. Please keep in mind, that if a parent is a Guardian or has Power of Attorney for their Adult Child, the parent cannot be a staff member directly for their Adult Child.

5.3 Community Builder

Parents may want to consider using a Community Builder as part of their Support Team. In general, a Community Builder's role is different from the role a Direct Support Staff or Care Giver provides. A Community Builder typically supports multiple individuals with an IDD or even multiple nearby IDD Homes and the Community Builder's activities are not necessarily centered around the Adult Child's IPOS (unless they are also paid using Medicaid funding).

A **Community Builder's** role and responsibilities differ from those of a Direct Support Provider



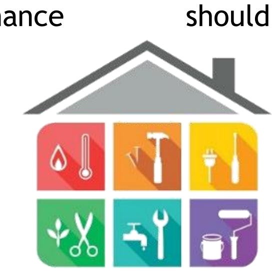
Community Builder
- Lives nearby and supports multiple Residents
- **First Responder**
- **Social Activity Director**
- Funded by Partner Families

Resident
- Adult Child with an IDD living safely & interdependently in a supportive community
- Receives individual support from Direct Support Provider

Parents may choose to use a Community Builder as a First Responder to the home should an issue occur, and the parents are not able to provide a timely response. Also, the Community Builder can serve to organize and implement social events and activities. The role, expectations, salary, and responsibilities of the Community Builder should be clearly defined by the parents. Typically, a Community Builder is an employee or independent contractor hired and managed by the parents. A Community Builder's salary typically isn't funded through your Adult Child' Medicaid dollars. Becoming an employer and hiring an employee, such as a Community Builder, may bring about other changes within the Partner Family Group's structure. The Partner Family Group will have to obtain an Employer Identification Number (EIN) and understand if the Community Builder is acting as an employee or an independent contractor.

5.3.1.1 Home Maintenance

Whether your Housing Solution is a typical Single-Family House, that comes with all the responsibilities of maintaining the interior and exterior of a home, or if your Housing Solution is an apartment / condominium, handling and paying for Home Maintenance should be discussed and agreed upon by all parents. As parents, you might be willing to do some of the Home Maintenance tasks; however, this might not be a feasible long-term solution.



If your Home Maintenance team consist of outside contractors such as a lawn service company, snow removal company or a “handyman” each parent and Adult Child should approve and be comfortable with how Home Maintenance will be paid for and implemented. Each parent and Adult Child must also feel comfortable with any outside, home maintenance personnel.

5.3.1.2 Home Technology

In today’s technologically connected world, the use of Home Technology can provide comfort and reassurance to you about the activities occurring in your Adult Child’s life. The goal of incorporating Home Technology is to increase your son or daughter’s level of independence in their new home & new community, while reducing, not eliminating, the need for support staff.

One of the most difficult issues for many parents when it comes to the usage of Home Technology is that while they conceptually believe Home Technology can help and want to use it, parents are often not certain of what specific Home Technology devices might be available and how to best implement and use them.

Parents that are considering using Home Technology in their Adult Child’s new home should set aside ample time to consider the following questions.

- What are the main safety issues or lifestyle support issues we are trying to solve?
- How do we want to interface and receive information from a Home Technology device?
- What type of information do we want to receive?
- What are the Must Haves and what are the Nice to Haves?
- *Does our use of Home Technology violate an Adult Child’s privacy?*
- Do we want separate systems and separate applications, or everything integrated into one system?
- How will Home Technology be accepted by our Adult Children?
- How will changes and updates be made to the Home Technology devices?

- Can we visit IDD Homes that are using Home Technology?
- Are we capable of doing this ourselves or do we need a professional company?
- What impact will Home Technology have on the Housing Budget? Startup? On Going Monthly costs?

Parents considering using Home Technology should take the time & effort to carefully evaluate different choices and the need for a professional company to implement the system. This is not an "impulse purchase."

5.4 Prepare to Launch

It is important to work closely with your Adult Child on the emotional and practical elements that will help with a safe transition to your son or daughter's new home. It is important to take the time and plan for a gradual transition for your Adult Child.

5.4.1 House Guidelines – Part #2

Deciding how the house will operate is an ongoing process with changes being made continually as your Adult Child's experiences evolve. It is time consuming and often difficult to figure out rules, roles, and responsibilities for both residents and supporters of the home; however, doing it right at the beginning will avoid problems later. Respectful honesty is crucial throughout this process.

A healthy home begins with a mutual understanding among the residents and families of what is important to each other about how the home will operate. Having a stable set of Guidelines gives everyone a sense of safety and ownership.

It is hard to know in the beginning of the process exactly what must be a "rule" (i.e., it is absolute, and everyone agrees it is too important to be broken) versus a "guideline" (i.e., everyone agrees that they would like things to operate this way, but they can be flexible, and it may change in the future).

The following are examples of questions that can help you explore many issues that families and roommates may encounter. You will not have Guidelines about all these issues, but the questions will help you think through what your home will need and will hopefully lead to a better understanding of what is important to each person. Remember – you don't have to decide everything at the beginning. Guidelines can be changed later if everyone agrees.

House Guidelines

- Will we have House Rules (vs. Guidelines)?
- How will overall Guidelines be decided?
- Are there any religious preferences which will guide the way the household operates?
- Should the "Guidelines" be only for shared spaces (family room, kitchen, etc.)?
- Who will enforce the Guidelines?
- Who will be able to discipline your son or daughter if needed?
- How often do you expect to visit?

Decision Making

- Will there be regular house meeting among the residents? Parents? Both?
- By whom / how will day to day decisions be made (what to wear, what to eat, etc.)?
- What kinds of decisions do you expect your Adult Child to make on his or her own?
- Is your Adult Child able to leave the home on their own? Without approval from you?

Problem Solving

- When your Adult Child becomes unhappy about something in the home, what will you do?
- What are some situations where you believe your presence would be needed in the home?
- If you became unhappy with a staff member within the home, what would be your first step?
- How will conflicts be resolved? What conflicts can roommates resolve without you?
- How will behavioral issues, if any, be handled?
- Will you expect roommates to report to parents if something is wrong, or if house Guidelines are not followed?

Food and Eating

- Do any diet, health or preference restrictions exist?
- What kinds of food does each resident like?
- When / how often will shopping be done?
- Who will decide what foods to buy?
- Will the group eat some meals together?
  - Who will plan the meals?
  - Who will do the cooking?
  - Who will do the cleanup?
- What time will the roommates usually have their meals?
- Are snacks OK? Where can they be eaten?
- Can there be alcoholic beverages?

Housekeeping

- What housekeeping task will be done by the residents?
- What are the resident's cleaning skills?

Money

- Who pays for what? Everything needs to be discussed.
- Who has access to money? How much? Where is

- Who will do which task? Are we going to have a Chore Chart?
- How will the residents be kept accountable to complete their task?
- Would you consider hiring a cleaning service for the home? Who will pay for this?

it kept?

- Is there a credit or debit card for the home?
- How are the accounts kept? Who keeps them?
- Can individuals borrow money from each other?
- Is there a household budget? Who is responsible?

Medications

- Can medications be stored in shared spaces (e.g., kitchen)?
- If your son or daughter gets sick, who determines when a doctor in needed? Who will take him / her to the doctor? How will you be notified?
- Who will be responsible for assuring your son or daughter takes his / her medication every day?

Personal Space

- Does each person need their own bedroom?
- Can individuals use each other's belongings?
- Is too much noise a problem for any resident? How should this be managed?
- How will each resident communicate when he or she doesn't want to be bothered?

People Other Than Staff

- How will you handle social interactions with people outside the home?
- Who decides who can visit?
  - Are non-family members allowed to visit?
  - What about Boyfriends or Girlfriends?
  - Any special Guidelines for these relationships?
  - Are overnight visits allowed?
- Can the residents have parties?
- Can the visitors eat household food (within reason)?
- Can visitors take residents out?
  - Do they need permission?
  - From whom?

Planned Activities

- What are your thoughts on planned activities?
- What role would families play in making them happen?
- What are your thoughts on these activities?
  - Family Night – family comes for a visit
  - Home Night – resident goes home to family
  - Cards / Games / Puzzles
  - Trips Out – movies, bowling, mini-golf …
- Community Service

5.4.2 The Council of Quality and Leadership of House Rules

Parents may want to refer to The Council of Quality and Leadership and their article on the realities of so called "*House Rules*" and the impact on independence, respect, and relationships.

https://www.c-q-l.org/resources/newsletters/the-realities-of-house-rules/

5.5 Developing Skills for Independence

Successful independent living will require development of individual daily living skills. The goal is for your Adult Child to learn specific and individually tailored skills that will reduce the amount of support your son or daughter will need in his or her new home. Skills Training will also improve self-esteem for your Adult Child.

The Supports Intensity Scale (SIS®) assessment tool is an excellent resource to identify skills for independence to work on with your Adult Child.

The list below **is not** intended to be a list of requirements to move out, but rather a general list of topics for parents to consider and understand how these areas will be fulfilled for their Adult Child in his or her new home.

Possible Target Skill Areas

- Meal Prep
- Cleaning
- Money Management
- Medication / Medical Management
- Laundry
- Personal Self-Care
- Bus or other Independent Transportation

The following questions may help guide your selection of Target Skills

- What tasks / activities is your son or daughter already comfortable doing independently?
- What independent living skills is your Adult Child interested or eager to learn?
- Are there any particular skills you do not want your Adult Child to learn?
- Which skills might you begin practicing right now with your son or daughter?
- What do you do for your Adult Child now that he or she might be able to do independently later?
- What tasks do you believe will always require assistance?
- What level of independence do you expect three years from now?

Try to create specific targets that are reachable, with measurable milestones, rather than general statements. For example, make a goal to “learn to cook scrambled eggs and sausage” rather than a general goal of “learn to cook.”

5.6 Helpful SAIL Resources for – Assemble Your Crew

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Assemble Your Crew step.

File Name	Description
Employer of Record Sample Care Staff Job Description	Staff hiring aide for EOR staffing model
Interview Questions for Staff	List of questions for parents using the EOR staffing model when interviewing potential support staff members
Parent Perspective on Care Giver Support Staff	Guide to help parents understand the different staffing models with key insights and resources
Parent Perspective on the use of Enabling Technology	Resource for parents that are considering the use of Home Technology for their Adult Child
Question for Community Support Partner / Staffing	List of questions when evaluating staffing agencies
Support Options	Overview of various support resources and organizations
Support Coordination and your Support and Staffing Needs	Guide for parents when working with their Support Coordinator and planning their staffing needs

6 Coming Ashore

Establishing and maintaining any type of home is an ongoing process. The goal of your son or daughter moving to their own home is to increase their independence and to secure their future for a time when you may no longer be able to – or want to – provide as much care and intervention as you do now. Each family will determine how much support is needed at each stage of the process, and how much they personally will be involved.

Over time, your Adult Child will build new skills for greater daily independence, and other supports will be put in place to provide care that you previously gave to your Adult Child. At the same time, you will take on demanding new roles in collaborative management of the home and in long-distance oversight of your son or daughter's activities and well-being. Giving up old roles and adapting to new ones will take time and effort on the part of your whole family.

Coming Ashore	
• Obtaining Household Items • Getting My Own Address	• Chore Charts • What If Scenarios

Independence grows at a different rate for each Adult Child and each family. Remember that this is not only a huge transition for your Adult Child, but for parents and other family members too. Your son or daughter may surprise you by how much he looks forward to this move. The idea of greater personal independence or being like other adults who have moved away from home is often very motivating. This is not a personal rejection of the life your Adult Child has with you, but part of the normal transition most adults go through.

At many points during the transition, your son or daughter may show emotional regression or cling to you. He may be adamant about remaining in your home and not moving. Expect good days and challenging days. Be careful to avoid over-reacting to the "growing pains." These are normal as any Adult Child prepares to move to an independent situation but are often stronger for individuals with an IDD.

6.1 Making Headway towards Independence

Working with your son or daughter to grow and nurture their independent life skills will be critical to ensure a successful and lasting transition to their housing solution. Making headway[29] towards independence includes many activities that you can begin to work on while your adult child is still living with you. It is especially important to think about how these independent life skills will transfer to your son or daughter's new home as he or she engages with direct care staff and potentially roommates. SAIL encourages parents to begin now to incorporate these new skills and methods into your Adult Child's life.

Making Headway towards Independence activities that you can do while your adult child is living with you.

1	Develop a Relationship with your Supports Coordinator - Realize that your Support Coordinator (SC) is not charting your course...you are. You can also establish a sense of urgency with your SC by setting stretch goals with them and timeframes to achieve them. Schedule your next 3 months of meetings with your SC!
2	Start engaging with support caregiver staff now - Having a support staff of 1or 2 caregivers who people who know your loved one and that will continue to support your loved one when they move out will give both you and your loved one confidence and a start at building your staffing plan.
3	Set independent living skills goals while at home - Having loved ones do the most they can do will instill confidence and a sense of pride.
4	Assign chores - Give your loved one 3 mini goals a week and build on those! Challenge them to come up with helpful chores they could do!
5	Constructive unstructured time - Create some time block for your loved one to do something on their own – besides screen time.

[29] Moving forward; like a ship making headway through water.

6	**Cooperate with others | practice Cooperation** - Most housing solutions will have your loved one living with a roommate. Cooperating and compromise are critical to living an independent life.
7	**Find Social Opportunities in your Community** - Engage in Social opportunities in your area to encourage cooperation.
8	**Develop an Exercise / Movement plan** - Develop a workout/movement plan with preferred activities. Incorporate it into their daily & weekly schedule.
9	**Network with Parents** - Because you might meet someone who knows someone who is looking for a roommate or is a retired teacher that might become staff.
10	**Document Your Loved One** - Articulating what your loved one likes and dislikes, what triggers them, what their assets are is important when evaluating roommates, meeting with partner families and training caregiver staff.

6.2 Moving Out To-Do List

Parents should consider using the following items in their Moving Out To-Do List.

Moving into a New Home

- Inform OCHN and Easterseals | MORC / CLS of Change of Address
- Update State ID Card
- Arrange for Utilities & Electronic Payment
- Establish Cash withdrawal limits
- MI Bridges with new address information
- Obtain Needed Household Items
- Renters Insurance
- Open or Update Checking Account
- Establish automatic Bill Payments
- Open Credit Card in Adult Child’s name

6.3 Getting My Own Address Guide

The Community Housing Network – *Getting My Own Address Guide* is available for people with disabilities, family members, guardians and professionals who support them. Parents can contact the Community Housing Resource Center for more information about the GMOA program.

6.4 What If Scenarios

Prior to your son or daughter moving into their new residence, it's important to reinforce (and validate) their sense of independence. One straightforward method of doing this is by role playing with your Adult Child through a series of "*What If this happens …*" questions. You may want your Adult Child's Supports Coordinator or one of the Direct Care Workers to work with you son or daughter. SAIL has developed a series of "What If Scenarios" that cover such topics as:

- Safety
- Allowing Access to the Home
- Emergencies
- Personal
- Simple Home Maintenance

Please contact SAIL for a What If Template that can be used as an example.

6.5 Helpful SAIL Resources for – Coming Ashore

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Coming Ashore step.

File Name	Description
Community & Home Engagement Ideas	List of activities and fun destinations in the community
Employer of Record Sample Housing Organizational Tools	Employee management guide and resources for parents using the EOR model
Health & Safety Topics	List of topics & resources to help parents prepare their Adult Child for independent

File Name	Description
	living.
SAIL Cooperative Living Chore Chart	Template for developing Chore Chart
SAIL Household Item Checklist	Template for tracking various household living items
SAIL What If Scenarios	List of topics & questions to ask and review with your Adult Child to reinforce safety, personal, and other independent living skills / situations
Sample of Apartment Move In TO-DO List	

7 Running a Tight Ship

Running a Tight Ship	
• Letter of Intent • Meetings with Direct Care Workers	• Meetings with Support Coordinator • Letter of Intent | The Dani Plan

7.1 Practical Steps to Promote a Safe & Successful Transition

Consider the dynamics of the whole residence, including both the parents and all roommates

By now you have grown familiar with your Partner Families and have a better understanding of their Adult Child's strengths and needs. What special abilities have you noticed? Think about these as strengths for building a new household. Talk about ways to make the most of these relationships. In what ways can roommates help one another within their new home, based on their interest and skills. Be extra aware of each roommates' interactions during the first few days. Try to resolve issues before they become larger problems.

Don't stop Independent Living training now!

Continue training at the new home. This can be done by you or one of your support providers. Spend a few nights there with your son or daughter if possible. If you can, spend time there before the move, getting used to the house and its various features. You may want to consider getting someone other than yourself to do this training, perhaps another member of your Support Team.

Keep up the fun and friendship

There is a good chance that your Adult Child will still be getting to know his future roommates. Doing social and friendship building activities, whether in person or virtual, is a great way for the roommates to obtain a better understanding of one another. Remember that you are creating vital long-term connections for your son or daughter's support and well-being.

7.1.1 Parents in Transition

Parents can expect some "growing pains" too. Remember the following as you experience natural emotional ups and downs during the process.

Expect to experience a sense of loss and apprehension as your Adult Child makes the transition to a new house.

Do not feel guilty if you adjust to your son or daughter's independence at a different *pace than other families. Each parent makes adjustment in his or her own time.*

Work to keep your emotions positive with your Adult Child. Showing sadness or anxiety may hinder a healthy transition for your son or daughter.

Don't focus conversations on problems or uncertainties. Help your Adult Child focus on his or her increasing independence and new goals or activities.

To the extent possible, limit any other major life changes for now. The transition to a new home will be enough for everyone.

Be aware that other friends and family may not understand how much is still required of you even after your son or daughter has moved out. Be prepared to explain your continued involvement, but don't let their opinions discourage you. You know your Adult Child best and you must feel comfortable with the new situation.

To avoid confusions and emotional connotations of the word "home", call each house by the name of its location, such as "Maple Drive" instead of "old home" and "new home".

7.2 Legal Guardianship

As a parent of an Adult Child with an IDD you have most likely spent a great amount of time planning for your son or daughter's future. The fact that you are willing to put in the effort to create a safe, secure, and stainable Housing Solution for your Adult Child is an incredible testimony to your amazing character as a loving parent. However, as you step back an envision an independent future for your Adult Child, you should also

consider a future when you are no longer able to care for your son or daughter. Hopefully, you have obtained sound legal advice and have in place a Final Will & Testament that defines who should be there to continue the care for your Adult Child should this moment arise. That is, who will be your son or daughter's Legal Guardian and Guardian of their Estate.

Based upon your Adult Child's new independent lifestyle, there are two additional steps that you might want to consider.

1. *Informing your Partner Families of your intention for your son or daughter's guardianship.* Most likely your partner families have grown incredibly close to your Adult Child and understand his or her daily schedule and what support services are required to allow your Adult Child to continue live a full and wonderful life. No matter who you have appointed as your son or daughter's guardian, it is not realistic to expect that this person(s) will have the same level of understanding of your child's independence as your Partner Families do. As uncomfortable as this topic is, having each of the Partner Families share this information with one another will help to continue your son or daughter's way of life.

2. *Have your Adult Child's Guardians Visit your Housing Solution?* Being appointed as an Adult Child's guardian is a great honor and having family or friends that have agreed to fulfill this role should give you comfort. However, there's a good chance that your Adult Child's guardians have only known your son or daughter when he or she has been directly under your care. Your Adult Child's guardians may not be aware of your son or daughter's new independence and what support services you have put in place. If possible, parents should consider having their Adult Child's guardians visit their son or daughter in their Housing Solution to better understand how your son or daughter's life has changed.

7.3 Letter of Intent for Adult Child with Special Needs

At this point we can probably all agree on 3 things …

1. that no one knows your Adult Child better than you do
2. that no one can care for your Adult Child better than you can, and

3. Someday a time will come when you are no longer able to provide care for your Adult Child.

A Letter of Intent (LOI) for an individual with Intellectual and Developmental Disabilities is a future planning document that a parent can prepare for their Adult Child; however the LOI can also serve a useful purpose when explaining to your Direct Care Workers how best to support your Adult Child. The goal of a Letter of Intent is to assist your loved ones and those who will be caring for your child when you can no longer act as the child's primary caregiver. A letter of intent (LOI) outlines information on daily needs, critical support requirements, and legal and financial matters of a person with IDD. The letter of intent is not a legal document and does not have to be notarized but rather it’s a guide that will keep everyone in your Adult Child’s support network informed on what the he or she with IDD needs and wants to live a full life.

7.3.1 Key Letter of Intent Factors

Although there is not an official format or standard for a Letter of Intent, the following are key elements that you’ll want to consider when drafting a Letter of Intent.

Key Factors when drafting a Letter of Intent

- Emotional Factors
- Family & Support Network
- Financial Factors
- Government Benefits
- Legal Factors

The following section will provide additional information to consider when preparing a Letter of Intent.

7.3.2 Family and Support Factors

The Family and Support Factors section allows you to identify all the important people in your Adult Child's life, which will help you create a directory of resources to use today and for

future caregivers, so they will know who else plays an important role in your Adult Child's life and how those individuals can be contacted. This will be your Adult Child's Team to Carry On. A number of different individuals, professionals, organizations, and agencies will be in contact with your Adult Child. Some will be paid employees of government agencies and have specific responsibilities in their capacity to meet the needs of your Adult Child. You should identify the agency that each employee works for so that the future caregiver will know who to contact and what to expect from their services or support. There is often a high turnover of support staff in human services provider agencies throughout the country, so it is very important to be in regular contact with the agencies and to keep the contact information current. It is also a good idea to introduce future caregivers to these individuals early on.

Some individuals are fortunate enough to have family, friends, and extended family members who help and support them without monetary payment. If this is the case in your situation, it is important that you include enough money in your financial and estate planning to allow these individuals to continue to be a part of your Adult Child's life, regardless of their own personal financial abilities. You should also try to make it financially possible to continue any special traditions that are important to your Adult Child's life for holidays, birthdays, vacations, or special occasions.

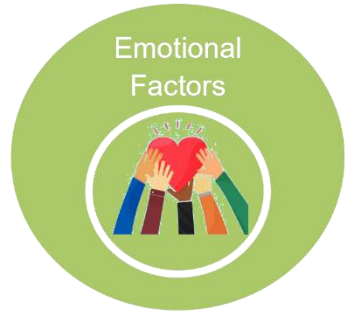
Family and Support Network Factors

- Family Information
- Information about your Adult Child with IDD
- Professional Support Information
- Social and Recreation Support Information
- Friends and Extended Family Support Information
- Other Family and Support Contacts

7.3.3 Emotional Factors

The Emotional Factors section allows you to provide your personal vision that you have for your Adult Child's future. Taking time to express this vision will accomplish three goals:

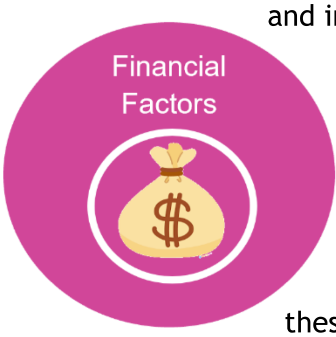
1) it helps you set personal goals for you to achieve for your Adult Child's future
2) it helps future caregivers to better understand your Adult Child and your wishes, and
3) it will help future caregivers understand your expectations of their roles in your Adult Child's life.



When faced with the responsibility and the reality of their role in your Adult Child's life, the future caregiver may feel emotions similar to yours when you first learned about your child's diagnosis. Depending on your child's age and the familiarity that the future caregiver has with your child and their routines, you may want to expand in some areas of this section more than in others. It is important to put yourself in the future caregiver's place and to look at it from the perspective that you first had — wanting to know as much as possible, as soon as possible. Some parents may wish to provide every detail of their child's being in this section — what makes their child the person that they are, what makes them happy, sad, or mad. They want to pass along their nurturing instincts so that the future caregiver not only sees their child from the outside, but also understands the child's heart. Other parents may be more analytical or factual about their child's future in this section. They may emphasize the accomplishments their child has made and set periodic milestones for both the family and the child to achieve. Only you can decide what type of information you provide. Whatever you decide, please remember that it is helpful for you to work together with your child's future caregivers and Team to Carry On in developing this LOI for your child.

7.3.4 Financial Factors

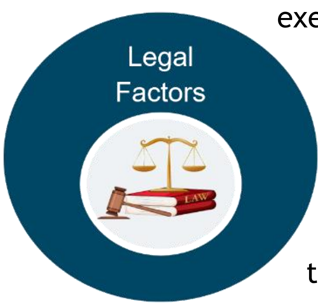
The Financial Factors section is where you should gather financial information that you feel is important to future trustees, a personal representative of your estate, a power of attorney,



and individuals who will handle your financial matters when you are no longer able to in the event of your disability or death. You should include all individuals who you have a professional relationship with, as well as those who assist you in making important financial decisions. A solid team of advisors is the key to assisting future caregivers follow through with your plans for you and your family. Do these advisors know each other and the role that they play in your overall financial plan? You may want them to have a copy of this LOI as a means of communication and/or perhaps introduction. This information will also be necessary when you begin to work with a financial and/or legal professional. You should also include the assets and income sources that you anticipate will assist in the future care needs of your child. This assumes that you have taken the necessary steps so that these assets will be properly directed into your child's special needs trust (SNT) when appropriate. Take some time to help guide those who you have entrusted with your financial resources to understand the values that you have about money. This should help them make important decisions about spending and perhaps investing your assets to meet your overall goals. This will help them maintain the lifestyle that you have achieved for your family and for your child. Personal and financial situations often change. As your Adult Child grows, his or her personal and financial needs will develop and change. These changes will affect how you divide your assets among your children and heirs. As you work with your advisors to modify your plan to adapt to these changes, so too should you modify the information in your LOI. This can also be attached separately with your financial statements and/or in your net worth summary. It is important to review this information regularly with your advisors and make any appropriate changes.

7.3.5 Legal Factors

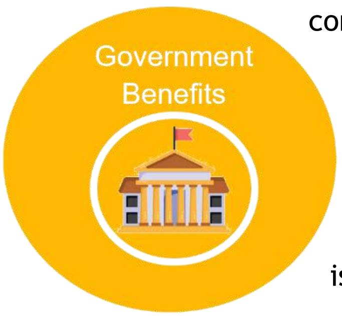
The Legal Factors section is where you should provide information about the legal and estate planning documents that you have prepared that will assist others in the event of your disability or death. You should also have a checklist of important documents and their location. If your important papers are in your safe deposit box, make certain that the executor of your estate or your power of attorney has proper authorization to access it and its contents. If you have a safe in your home, these individuals should also know how to access its contents. Not only is it important to identify those individuals who you hope will execute your wishes, but they should also have a copy of this LOI to use as a guideline in making important financial decisions. In fact, as you are completing your LOI, it may be helpful to share some of your thoughts with your child's future trustee because they will have the fiduciary responsibility involved in spending the money that will help fulfill your vision for your child's future. The clearer your vision and the details about your Adult Child, the easier it will be for the trustee to fulfill their expected role. When you work with your attorney to create your legal documents, you are creating the



vision that you have for the ultimate distribution of your estate. During this process, you should be clear in expressing to future trustees, guardians, powers of attorney, and health care proxies how you want your financial and legal matters tended to. The role of the attorney is to place those wishes in writing by utilizing the proper documents. Coordinating your financial resources with these legal documents is critical.

7.3.6 Government Benefit Factors

The Government Benefit Factors section is where you should include any and all government benefits that your child is currently receiving. You should also include how they are used for your child's needs. It is also helpful to provide a directory of state agencies and resources to



contact that may be utilized for future needs. Government benefits and eligibility are predetermined. Planning to maximize and protect your Adult Child's eligibility is paramount to your Adult Child's future security and independence. Many families, however, choose not to utilize government benefits for a number of reasons. If this is the case in your family, you should make certain to express it.

7.3.7 Letter of Intent – Template

The resources listed below have useful Letter of Intent templates that are fillable pdf documents that you may consider using. Although there is not an official LOI format or pre-defined documentation standard, both of these templates will step you through the main sections of a Letter of Intent for your Adult Child that will play a vital role in his or her long term care and support.

- The Arc – Resources Letter of Intent
    - https://thearc.org/resource/letter-of-intent/
- The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life[30]
    - Special Needs Financial Planning (specialneedsplanning.com)

[30] The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life, Second Edition by Cynthia R. Haddad and John W. Nadworny. Sequoia Financial Group; Copyright © 2022

7.4 The Dani Plan

The Dani Plan is a secure, online method of documenting all of the aspects contained in a Letter of Intent (Information) in a modern and convenient way. The Dani Plan allows for collaboration with your fellow partner families and sharing information with your Supports Coordinator, Direct Care Professionals or whomever you decided should have access to the information that is essential in caring for your Adult Child.

7.5 Helpful SAIL Resources for - Running a Tight Ship

The table below contains a list of some of the documents and resources that SAIL has created to help members of SAIL during the Running a Tight Ship step.

File Name	Description
Transition Period from a Parent Perspective	Reflections and helpful advice as parents go through this emotional process
Staff Shift Checklist	Example of daily checklist for managing the support staff
Individual Bill Payment Tracker Form	Helpful worksheet to record and track utility and bill payments

8 In Closing …

The SAIL organization and the *SAILing to Your IDD Housing Solution* guide make two fundamental promises to all those who wish to come on board.

1. ***Your Journey will be Unique***. Just like your son or daughter is unique with all his or her amazing gifts or the way their eyes light up when you've hit that certain note, no parents' journey to a Housing Solution for their Adult Child will be the same. Whether it's obtaining government benefits, finding Partner Families, or making sure your son or daughter's rent is paid – everyone will have different levels of challenges. While our end goal may be the same, our paths will differ. SAIL hopes that providing a guide with items to consider will help to prepare you and serve to reinforce you that you are on the right course.

2. ***You won't be Alone***. One of the essential elements of SAIL is through an established community of parents that are willing to share and support one another, no parent's journey to their son or daughter's Housing Solution must be done alone. While the circumstances you will face may be unique, with higher "Highs" and lower "Lows" always keep in mind that other parents of SAIL have traveled similar paths and are there to offer their support.