

# CHOICES

**A comprehensive guide for families**

PUBLISHED SEPTEMBER 2022



Learn to navigate Supported Decision-Making, alternatives to guardianship, SSI / SSDI, Medicaid, ABLE Accounts, financial & estate planning, Person-Centered Planning, and health care

*brought to you by*



# Understanding the many CHOICES related to transition

The transition years are those wonderful years when our children are maturing from teenagers into young adults and reaching adult milestones. As youth begin to exit the school system, they may be wanting greater independence and autonomy.

As caregivers, this period of life is also a transition. There are many choices needing to be evaluated and made. Is guardianship or an alternative to guardianship suitable? How do I help my young adult navigate support systems like Social Security, waivers, and Medicaid? How can I protect my young adult financially, make arrangements to help with their future, and help them navigate their health care?

The resources located in this Choices booklet can help caregivers to be more aware of the choices needing to be made during this time of life. This booklet can also introduce young adults to tools that can help to support them in their lives and help them to be even more successful. Please reach out to the Utah Parent Center if you have additional questions or need support.



## *A note to parents and families:*

**This guide has been designed for young adults and their families, and anyone supporting them through a transition period in their life. If you feel you need additional support with transition, refer to the Utah Parent Center's Transition Resources.**

- **Transition Guide for Parents**
- **Transition Youth Workbook**
- **Guardianship Booklet**

***Be sure to check our website often for updated resources and information:***

***utahparentcenter.org***

***801-272-1051***

***5296 S. Commerce Drive, Ste. 302***

***Murray, UT 84017***

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<https://bit.ly/3rrgche>



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# Daily Living and Successful Transitions

**There is not just one pathway from childhood to adulthood. Each youth's transition experience will be unique. As youth prepare to leave school, there are many support services available to them.**



<https://bit.ly/3rrgche>

Use this QR code and link to access the UPC's Youth Transition Workbook as well as the following information.

**The Successful Transitions for Youth with Disabilities Book will cover most of the topics in this book and additional topics such as:**

- ✓ The Transition IEP
- ✓ Identifying an Individual's Strengths
- ✓ Education Options after High School
- ✓ Transitioning from School to Employment
- ✓ Daily Living Skill Checklists
- ✓ Employment Supports
- ✓ Soft Skills for Employment
- ✓ Community Living



Both the Youth Workbook and this Choices book are color-coded by topic. The yellow section of the Youth workbook will provide QR codes, links, training information, and resources for daily living topics.

Helping youth to know what they are good at and what they enjoy can help individuals when they are trying to decide what type of school options, employment, and community supports might be the best option for them.

The key to success in life is to focus on goals, not obstacles!

***Success is achieved by developing our strengths, not by eliminating our weaknesses.  
- Marilyn vos Savant***





# SAFETY & SECURITY FOR THE FUTURE

**A goal without a plan is just a wish.**  
*- Antoine de Saint-Exupéry*

## My child is becoming an adult. I want them to be independent but also protected. As a caregiver, what should I consider?



As caregivers, we want the best for our youth as they transition to adulthood. Regardless of the situation, it can be challenging and emotional to know what is the best course of action with regard to helping our young adults make decisions. We want them to be independent, but we also want them to be safe. As caregivers, we must consider whether guardianship or alternatives to guardianship are appropriate. The best interest of the young adult is what should be taken into consideration. It might be challenging as a caregiver to allow your youth to make more of their own decisions once they turn 18 years of age. Caregivers are used to making all the decisions about their youth's life. As a caregiver, it also might be very clear to you that your adult child still needs guidance and support.

Each individual is different and has unique needs and abilities. Some people will be able to make most life decisions with a little support while others may be more successful with a Supported Decision-Making model. However, for some, the protections associated with limited or full guardianship may be the best fit.

When trying to make decisions about the youth's future, here are a few things to consider: Can the young adult make decisions on their own? Can they navigate their own healthcare? Can they manage their own finances, housing, education, etc? If the answer is yes, or yes with support, then Supported Decision-Making or another form of support may be the best option. If the answer is no, full or limited guardianship in select areas where support is needed might be the best choice. Caregivers should talk about options with their young adult. Teachers, professionals, and physicians can also be consulted for input if caregivers are unsure of what course of action to take. Ultimately, the goal should be for the young adult to have opportunities for independence and to live as much of a self-directed life as possible.

**The following pages list alternatives to guardianship. For detailed information on guardianship and how to obtain guardianship, please reference the UPC's Guardianship booklet through this QR code.**



<https://bit.ly/UPCGofACBook>



# Supported Decision-Making Compared to Guardianship

## Supported Decision-Making (SDM)

SDM is an alternative to guardianship. Rather than a guardian making decisions for an individual with a disability, SDM allows the person with a disability to make his or her own decisions with support from a trusted team. SDM allows for changes as an individual's preferences/needs change.

However, Utah law does not currently recognize Supported Decision-Making as a legal, formal support option for adults with disabilities.



- A way for young adults to plan their lives by collaborating with a team of trusted supporters in order to make their own decisions.
- The support team is built based on the individual's desires and input.
- The individual is responsible for deciding the areas and types of support they feel are needed.
- The individual accepts responsibility and the consequences of their decisions. Their preferences are more important than their best interest.

## Guardianship

A court process where a judge determines the youth's guardian. The State of Utah allows for two types of guardianship; plenary, or full, and limited. A guardian must be willing to make or help make many life decisions for individuals and decide the type of support needed. You can have guardianship and still utilize SDM so the individual can make their wishes known to their guardian. A guardian is not liable to a third person for acts of the ward solely by reason of the guardianship.

### Plenary (full) Guardianship:

A plenary guardianship transfers most rights from a ward to a guardian. Examples of exceptions: marriage/partnership, travel, driving, work, voting, etc.

### Limited Guardianship:

Limited guardianship means with court approval a guardian has decision-making authority in limited areas in a ward's life. Examples of decision making powers a limited guardian may hold are:

- Medical
- Habilitative (training and treatment)
- Education
- Residential
- Financial

***For guardianship situations involving tribal or indigenous people, tribal laws may take precedence. The following link can provide you with more information.***

<http://bit.ly/3TYcNlv>



## Is Supported Decision-Making Complicated?

No, we all engage in Supported Decision-Making (SDM) on a daily basis; we just may not realize we are in fact utilizing this tool. Each time we consult with family, friends, colleagues, or classmates before we make important life decisions, we are practicing and implementing Supported Decision-Making.

Supported Decision-Making promotes one's ability to be self-determined, have control over life decisions, and empower people to be more self-sufficient and independent.

Individuals with disabilities may need assistance making decisions about living arrangements, health care, relationships, and financial matters. But they do not necessarily need a guardian to make those decisions for them. A trusted network of supporters can field questions and review options to help the person with the disability make their own decisions.

Supporters are selected by the person with the disability. They can be family members, co-workers, friends, and past or present providers. The person should select supporters who know and respect their will and preferences, and who will honor the choices and decisions the individual makes. Supported Decision-Making is flexible, and can be adapted to meet a person's situation and needs. The process is unique and customizable for each individual depending on his/her wants, needs, goals, and dreams.

### Additional SDM Tools

For additional SDM resources and worksheets for your youth, use this QR code to access the Transition Youth Workbook. The Youth Workbook will guide your youth through SDM using young adult-friendly language.



<https://bit.ly/3rrgche>



The materials in this LifeCourse QR link are designed to help a person, family, or a professional explore areas where any person might need decision-making support, plan for what it looks like and how it can happen, and seek out the needed support. Portions of this curriculum can also be found in this the green section of this book.

<https://bit.ly/3rmmS0c>



**What characteristics are required for SDM to be effective as an alternative to guardianship?**

- A person's interest in self-determination and self-advocacy
- Possess self-motivation and the ability to follow through with goals and plans
- Ability to demonstrate good decision-making which results in improved quality of life with assistance from team members
- Willingness to try new ideas and explore different possibilities
- Willingness to evaluate strengths and weaknesses when determining needed areas of support
- Willingness to work cohesively with a team of supporters to achieve desired goals
- Willingness to accept the responsibilities and consequences associated with choices and decisions made
- Willingness to put ideas down on paper and modify/adjust them as necessary with the help of support team members

***The following 4 steps will walk you and your young adult through the basics of SDM.***



## STEP

## 1

**Young adults can talk to friends, family members, and trusted support teams about their ability to make good decisions with their team's support.**

Everyday life requires each of us to make decisions on a daily basis. Some of these decisions are quite easy; however, others can be quite complex and require a great deal of decision making capabilities.

#### Examples of Easy Decisions

- What do I want to eat?
- What do I want to watch?
- What do I want to do with my free time?
- What do I want to wear?

#### Examples of Difficult Decisions

- Where do I want to live?
- How will I spend my money?
- What are my long and short-term goals?

Supported Decision-Making is all about how friends, family, and even professionals can help young adults make good decisions. However, it is imperative to remember, the individual with the disability is the one with the final decision. By having this responsibility, it will be important for young adults to show others they are determined, responsible, and capable of making decisions that will improve the quality of their life.

**When young adults are making a decision, they should focus on:**

- 1 Preferences** - What does the individual like or dislike?
- 2 Values** - What is important to them?
- 3 Needs** - What things do they need to live a happy and independent life?



**STEP  
2****Young adults will identify the areas of their life where they feel they will need support or help.**

A young adult's support system wants them to succeed. However, the young adult has to know when and how to ask for help. Remember, everyone needs help at one time or another during their journey through life. There is absolutely nothing wrong with seeking assistance, asking for guidance, or needing help. Young adults need to learn to speak up and make their wishes known.

According to Psychology Today, being resourceful is the second defining element of emotional strength. It involves embracing the dependent side of one's nature; it takes feeling vulnerable, courageous, and comfortable enough within yourself to recognize when you need help. When young adults are able to do that, they are more apt to openly and genuinely acknowledge their specific needs and limitations. This acknowledgment enables them to take the next, most essential move—that of asking for help. Asking for help is part of what it takes to be emotionally strong.

**Young adults can consider the following life areas and reflect upon whether or not they might benefit from help:**

- Safety
- Daily Living
- Mental Health
- Physical Health
- Financial
- Transportation

Remember, these life areas are simply for the individual's consideration. This is not an all-inclusive list. Add any life areas you feel would be beneficial in helping them achieve their goals and omit those not applicable.

After they have identified the life areas where they desire help, they can sit down with their support team and expand upon those areas to develop a clear plan of action. Encourage the individual to be specific and direct with their support team. Remember, it is imperative they convey their wants, needs, and desires. In doing so, the individual is educating their support team and increasing their odds of achieving successful and effective support.





**STEP**  
**3**

## Young adults should select the people in their life who are willing to support and assist them.

Young adults can greatly increase their odds of success. They should include the following information in their Supported Decision-Making Agreement:

- 1 Who listens to them when they need to talk to someone? \_\_\_\_\_
- 2 With whom do they share good or bad news? \_\_\_\_\_
- 3 Who appreciates them? \_\_\_\_\_
- 4 Who supports them, even when they might not totally agree with what they're doing? \_\_\_\_\_
- 5 Who do they talk to when they need advice? \_\_\_\_\_
- 6 Who helps them when they have a problem? \_\_\_\_\_
- 7 Who helps them make decisions when they need to think through options and consequences? \_\_\_\_\_

### The Role of Family/Supporter:

- ✓ Support self-advocacy
- ✓ Practice making decisions
- ✓ Discuss types of decisions and what impact they may have
- ✓ Discuss how values, preferences, and needs influence decisions
- ✓ Build skills needed to succeed

### Natural Supports:

- Parents
- Community Groups
- Family
- Individual
- Neighbor
- Social Groups
- Friends

### Eligibility and Paid Supports:

- Teachers & Counselor
- Support Coordinator
- Vocational Rehab Counselor
- Doctors & Nurses
- Support Staff
- Job Coach

*Help others achieve their dreams and you will achieve yours.*  
 - Les Brown





**STEP  
4****Create a Supported Decision-Making Agreement.**

**To help young adults identify their support network, they should consider the following:**

- 1 Name, address, telephone number, and email
- 2 The names and contact information of the people who will be supporting them
- 3 A place for the supporter/supporters to sign and voluntarily agree to help them make decisions in the areas of life they choose
- 4 A place where they identify the "life areas" they will need help with in order to be healthy, safe, and successful
- 5 A place for them and their supporters to sign and date the agreement
- 6 A place to talk about how the agreement can be changed or updated

**A sample of a Supported Decision-Making Agreement is on the following page. Please note, this plan is a sample only, and should only be used for planning purposes. Ultimately an individual with a disability will craft their own agreement. The following plan is a compilation of several plans from other states that recognize Supported Decision-Making as a legal alternative for supporting individuals with disabilities as adults.**



**Use this QR Code for additional information on SDM through the Center for Public Representation.**



<https://bit.ly/35hqA3k>

# Sample Supported Decision-Making Agreement

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Phone: \_\_\_\_\_ Email: \_\_\_\_\_

## I need supporters to help make decisions in the following areas: (Check all that apply)

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Finances   | <input type="checkbox"/> Personal Care |
| <input type="checkbox"/> Legal      | <input type="checkbox"/> Daily Life    |
| <input type="checkbox"/> Healthcare | <input type="checkbox"/> Other: _____  |

## I express myself and state my desires in the following ways:

- Verbally notifying people my likes and dislikes
- Verbally notifying people what I do and do not want to do
- Choosing from two or more things that are written down for me
- Other: \_\_\_\_\_



**Supporter #1** \_\_\_\_\_

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

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

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship to me: \_\_\_\_\_

**Requested Support:**

Finances       Healthcare       Employment       Legal Matters

Housing       Social Relationships       Other \_\_\_\_\_

Areas where I do not want assistance from Supporter #: \_\_\_\_\_

**Supporter #2, #3, #4, etc.**

You can have as many people in your Support Network as you desire. You may consider having one member act as a Support Network Coordinator to assist in managing your team. Simply add as many supporters to your contract as you desire.

**If I have more than one supporter, they will act:**

Jointly (working together)       In the order listed

**I understand that I can add new support network members if necessary, and change them whenever I need to.**

**Network Supporter Statement - Each Supporter Should Sign a Statement**

I understand as \_\_\_\_\_'s supporter, my job is to honor and present his/her expressed wishes. I know I should not make decisions for this person, and I should assist them in reaching a decision and communicating his/her choice. I agree to support this person's decision to the best of my ability.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## What is Conservatorship?

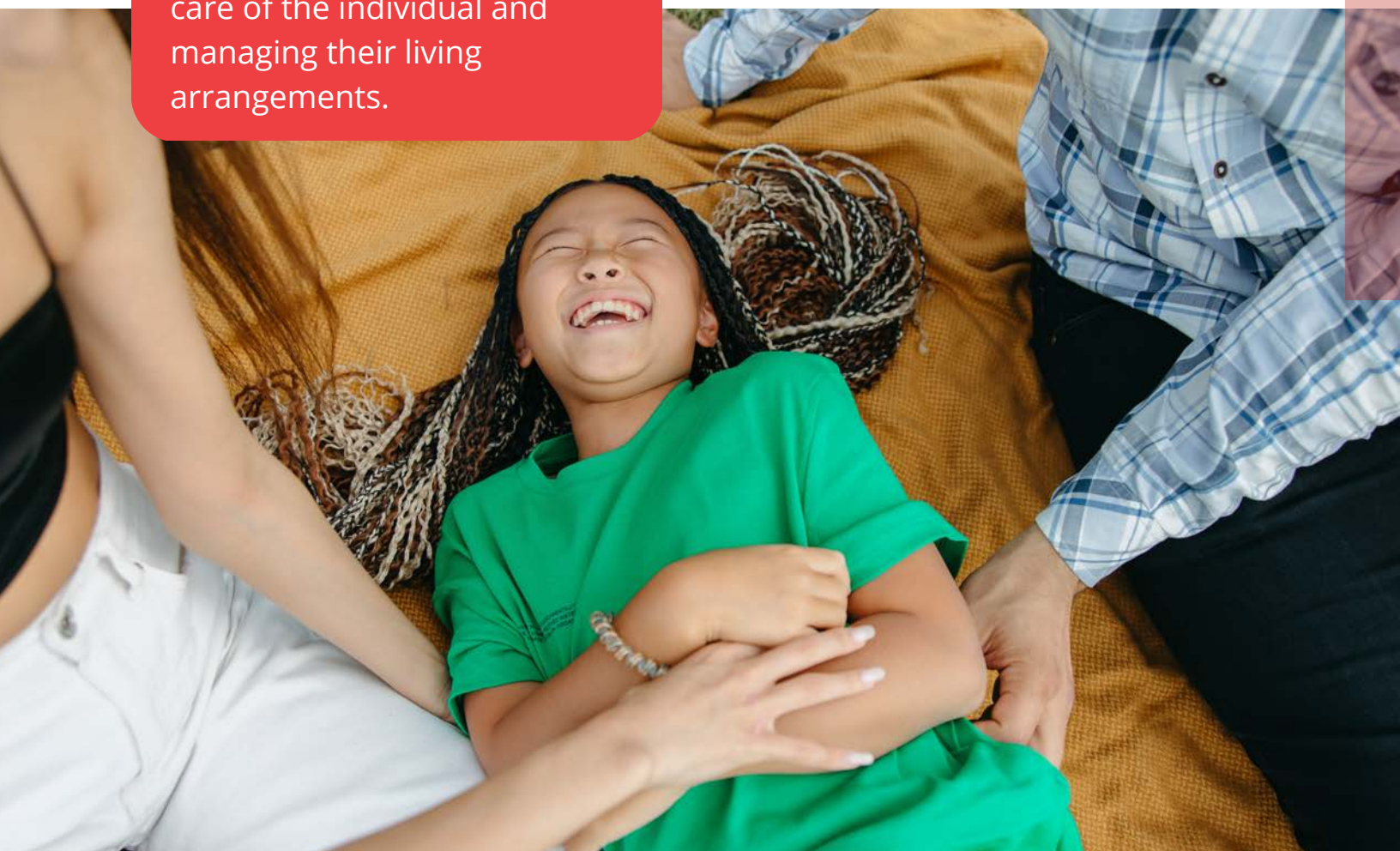
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Conservatorship is a legal status that is a companion to guardianship. It does not replace it. The court appoints a conservator or person to manage the financial and personal affairs of a minor or incapacitated person. A conservator may also serve as a guardian who is responsible for establishing and monitoring the physical care of the individual and managing their living arrangements.

### When is a Conservator Appropriate?

A conservator may be appointed if the respondent is unable to manage their property and finances effectively because of:

- mental illness
- mental deficiency
- physical illness
- physical disability
- advanced age
- chronic use of drugs
- chronic intoxication
- confinement
- detention by a foreign power
- disappearance
- some other cause





Additionally, the respondent's property must be at risk of being harmed unless proper management is provided, or funds are needed for the support, care, and welfare of the respondent or those entitled to be supported by the respondent and protection is necessary or desirable to obtain or provide funds.

The petitioner must be able to prove the above listed requirements by a "preponderance of evidence."

The Utah Courts define preponderance of evidence as: Evidence which is (even minimally) of greater weight or more convincing than the evidence which is offered in opposition to it. This is the standard by which a plaintiff must prove his/her case in a civil suit.

A conservator is a person or institution appointed by the court to make decisions about a protected person's estate (such as property and finances), but does not include other areas such as medical.



**Use this QR code and URL to access the Utah Courts website for the Procedure for Appointing a Conservator for an Adult webpage.**



<https://bit.ly/3iyc0rn>

# POWER OF ATTORNEY

## Power of Attorney

### What is a power of attorney?

Another alternative to guardianship is a power of attorney document. A power of attorney is a legal document in which one person (called the "principal") gives to another person (the "agent," or sometimes called the "attorney in fact") authority to act on behalf of the principal. The person who is the agent only has the authority to act in the areas outlined in the power of attorney forms (ex: financial and/or medical, but not over all the areas of a person's life). A power of attorney can be very broad, allowing the agent to perform a variety of tasks. For example:

- handling bank accounts
- selling real property
- running a business
- applying for public benefits

### Two types of power of attorney:

- Durable - effective on the date it is signed
- Springing - becomes active when an individual can no longer handle their affairs and may be active for a limited period of time and/or when outlined conditions have been met.

It can also be very limited and restrict the agent to one or more very specific tasks. For example, selling one specific piece of real property. The agent cannot use the principal's assets in a way that is against the principal's wishes. A well-written power of attorney can be a helpful legal tool to allow someone else to handle a person's financial matters without the need for more complex arrangements like a trust or a court-appointed guardian or conservator, which removes many or all of the person's decision making authority. A well-written power of attorney can also help protect against possible financial exploitation and abuse.

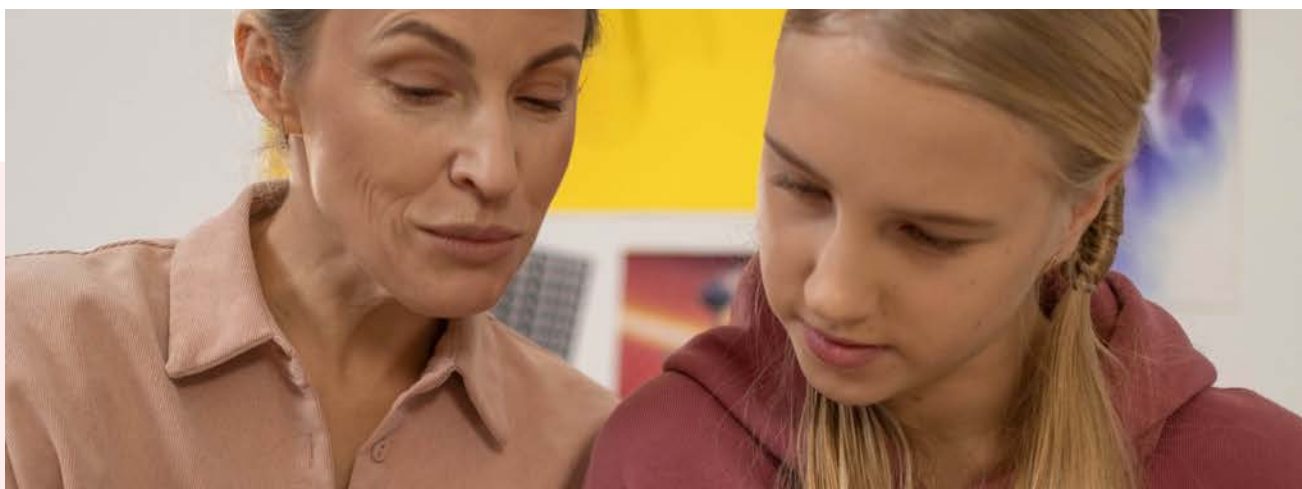
A lawyer experienced in estate planning is the most appropriate person to write a power of attorney and give advice about what is needed in specific and unique situations. There are also several power of attorney forms available on the internet but they may be too general for a specific circumstance. They may not follow the requirements of Utah law, or they may not protect against financial exploitation and abuse.

### **Benefits of a Power of Attorney:**

- The agent is chosen by the individual
- Low cost or free in some cases
- No court time required
- Authority is outlined in the document
- The form is easily accessible

### **Limitations of a Power of Attorney:**

- The principal has to have the capacity to understand what they are signing
- If the document is challenged, the court may be needed to enforce it
- The principal can choose anyone to be the agent, creating the possibility of being taken advantage of
- The document is usually over limited areas of the person's life.





## The agent

The agent is the person appointed by the principal to handle the duties stated in the power of attorney document. See Utah Code Section 75-9-114 for the full list of an agent's duties.

## A principal

A principal can appoint more than one agent and have two co-agents, for example. Unless the power of attorney states otherwise, each co-agent may exercise their authority independently. In addition, a principal can nominate a successor agent or agents to step in if the first agent resigns, dies, becomes incapacitated, is not qualified to serve, or declines to serve.

If the power of attorney is drafted to also include medical, the agent also has the authority under HIPAA (the federal Health Insurance Portability and Accountability Act) to access the principal's private health care information and communicate with the principal's health care providers unless the power of attorney specifically restricts that authority. If outlined, the agent is also able to make medical decisions for the principal if they are unable to do so themselves.

A separate document, Utah's Advance Health Care Directive also includes a HIPAA release, living will, outlines the principal's wishes, and allows the agent to make medical decisions.



**Refer to the QR code for Utah's Advance Health Care Directive Act for more information and forms.**

<https://bit.ly/3JGBbnB>



## Executing a power of attorney under Utah law:

The power of attorney document must be signed by the principal before a notary public. If the principal is not able to physically sign the document, then another person acting at the principal's direction in the principal's conscious presence may sign the document before a notary public.

If the principal lives or is about to live in a hospital, assisted living, skilled nursing, or similar facility, at the time of execution of the power of attorney, the principal may not name any agent that is the owner, operator, health care provider, or employee of the hospital, assisted living facility, skilled nursing, or similar residential care facility unless the agent is the spouse, legal guardian, or next of kin of the principal, or unless the agent's authority is strictly limited to the purpose of assisting the principal to establish eligibility for Medicaid.

For more details, changing, revoking, or terminating power of attorney, or related information, refer to the State of Utah's power of attorney QR code.

Utah law provides a statutory power of attorney form (the Uniform Power of Attorney Act, Utah Code 75-9-101 to 403). The form can be used by any adult who has the capacity to complete it. At the time of signing the power of attorney, the principal must have sufficient mental capacity to understand that he/she is appointing an agent to handle their affairs. The principal does not have to understand how the agent will manage the principal's affairs.

**Use these links and QR codes to access more information and Power of Attorney forms**



<https://bit.ly/3LfLAXt>



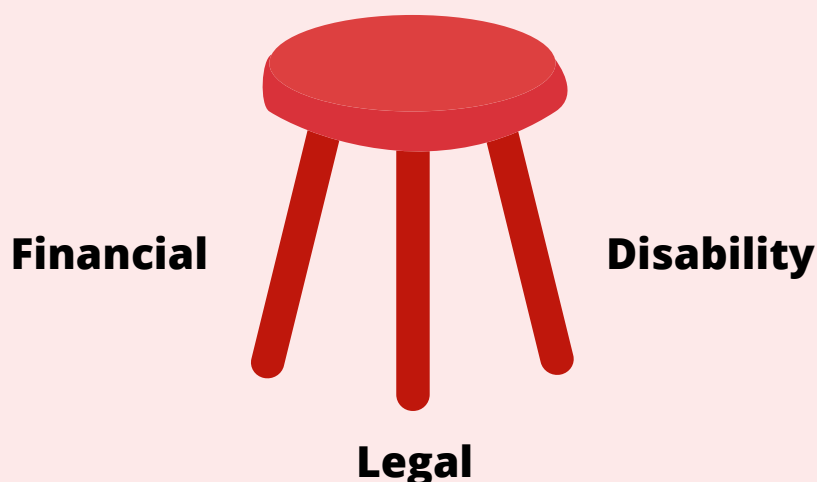
[https://bit.ly/UTpowerofattorney.](https://bit.ly/UTpowerofattorney)



## Planning for the Future

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Comprehensive planning for our loved ones encompasses three different professional disciplines: legal planning (estate planning), disability planning (creating a team of caregivers, benefits selection, management and the letter of intent), and financial planning (knowing the financial commitments required to ensure an individual can live comfortably for their entire lifetime). There is a balance required for effective planning, much like that of a three-legged stool. It is imperative proper planning takes place to ensure an individual does not lose precious benefits. In addition, the needs and desires of other family members should also be considered so their goals and dreams can be accomplished as well.



## Who will care for my child when I pass away? And, other questions parents ask themselves...

- My child had an IEP, does that qualify them for public benefits?
- Should my child stay in public school until age 22?
- Will I be able to retire?
- What would happen to my child if I became disabled?
- Will my child need to live with me forever?
- Could my child lose public benefits?
- Can't their siblings just inherit the money and take care of them?
- What if they can work?
- How do I choose a guardian or trustee?
- We don't need public benefits. Why do I need to know about them?
- How will I ever retire?

*Households that include members with a disability have a higher cost of living. Data from the National Disability Institute indicates the average household that includes someone with a disability needs 28 percent more income or an additional \$17,690 to achieve the same standard of living as a household of the same size and income where no one has a disability.*

**We appreciate our partners at the Special Abilities Network for their collaboration and contributions to the information in this section of the booklet.**



# What is the difference between SSI and SSDI?

*The Social Security Administration (SSA) operates two disability benefits programs. When you apply for disability benefits for your child, you need to be aware of the difference between Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).*

## SSDI

SSDI supports individuals who are disabled and have a qualifying work history, either through their own employment or through a family member. SSDI determination is based on disability and work credits. A Disabled Adult Child (DAC) could receive benefits based upon their parents' work history.

## SSI

SSI determination is based on age or a disability that is expected to last 12 months (excluding blindness) or result in death. Not performing SGA.

## Terms

SGA: Substantial Gainful Activity or earning more than a certain amount  
TWP: Trial Work Period - test ability to work while receiving social security

Factor	SSI	SSDI
<b>Eligibility based on</b>	Age (65+) OR blindness (any age) OR disability (any age) that is expected to last 12 months and not be performing SGA	Disability expected to last 12 months AND sufficient work credits through own/family employment
<b>When benefits begin</b>	First full month after the date the claim was filed or, if later, the date found eligible for SSI	Wait 5 full months after the onset of the disability before receiving benefits. There may be up to 12 months retroactivity
<b>Maximum benefit (monthly) There are also max. family amounts</b>	\$841 (single) in Jan. 2022 (based on income)	\$3,345 in 2022 (based on work history)
<b>Health Insurance</b>	While you should qualify for Medicaid, you are required you to file a separate Medicaid application.	Automatically qualifies for Medicare after a 24-month waiting period from time benefits begin (no waiting with certain medical conditions)



### How do I determine if my child is eligible?

Prior to beginning the application process, it may be beneficial to determine eligibility here: <https://ssabest.benefits.gov/>



# What is Supplemental Security Income (SSI)?

SSI is a federal program funded by general tax revenues and is a needs-based program. It provides monthly payments to meet an individual's basic needs for food, clothing, and shelter.

Not everyone receives the same benefits. To receive SSI, the person receiving benefits should not have **countable resources worth more than \$2,000 for an individual or \$3,000 for a couple. This is the *resource limit*. Countable resources are the things the person owns that count toward the resource limit.** When your child turns 18 they are considered their own household so family resources are not considered as countable for them when they apply for SSI.



## Examples of resources:

- ✓ cash
- ✓ bank accounts, stocks, U.S. savings bonds
- ✓ land
- ✓ life insurance
- ✓ personal property
- ✓ vehicles
- ✓ anything else you own which could be converted to cash and used for food or shelter

**Generally, the following do not count toward the resource limit:**

- The home the person lives in and the land it is on
- One vehicle, if the individual or a member of the household uses it for transportation
- Household goods and personal effects
- Life insurance policies the individual owns with a combined face value of \$1,500 or less
- Burial plots or spaces for the individual or their immediate family
- Burial funds of up to \$1,500 each for the individual and their spouse's burial expenses
- Property the individual or their spouse uses in a trade or business, or for their job if they work for someone else (see the SSI Spotlight on Property Essential to Self Support)
- If they are disabled or blind, money or property they have set aside under a Plan to Achieve Self-Support (PASS)
- Up to \$100,000 of funds in an Achieving a Better Life Experience (ABLE) account

## How do I apply for SSI for my child?

Individuals who believe their child may qualify for Social Security Disability can submit an initial application for disability benefits on the internet, over the phone, or in-person at a local Social Security Administration (SSA) office. It is also important to note that when applying for adult SSI, Social Security runs the application through SSDI and SSI because there may be a situation where an individual has work credits that need to be used through SSDI before the person can access SSI. Some individuals may get a letter back after submitting their application informing them that they do not qualify for SSDI. This is an indication the Social Security Administration has conducted a review to determine if the individual has any unused work credits.

If you choose not to apply for your young adult online, you can schedule, reschedule or cancel an appointment with the SSA by calling: 1-800-772-1213 (TTY 1-800-325-0778) between 8:00 am – 5:30 pm, Monday through Friday; or contact the Salt Lake City Social Security Office  
175 East 400 South, suite 500  
Salt Lake City, UT - 84111  
866-851-5275.



**Apply Online**  
<https://bit.ly/3iTRulf>

# Where can I get help with the application process?

Navigating the application process can be challenging. If you find yourself in need of assistance the following resources are available:

## Utah Legal Services

A nonprofit law office incorporated in 1976 committed to making equal justice a reality by providing free legal help in non-criminal cases to low-income Utahns who meet qualification criteria. Find out if you qualify here:

<https://www.utahlegalservices.org/>  
1-800-662-4245 (outside Salt Lake)  
or 801-328-8891 (within Salt Lake area)

## Utah Family Voices

Provides statewide assistance in a variety of ways to families of children and youth with special health care needs and disabilities as well as professional providers and partners. Utah Family Voices is a project of the Utah Parent Center and is run by parents of children with disabilities.

<https://utahparentcenter.org/projects/ufv/>  
801-272-1068





## What documents do I need when applying for my child?

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You may not need all of the documents listed below because, on occasion, one document can substitute for another. The list provided is not all-inclusive; however, it is a good idea to have the following documents readily available as you begin the application process.

- Social security card
- Proof of age
- Citizenship or alien status record
- Proof of income
- Proof of resources
- Proof of living arrangements
- Medical sources if filing as blind or disabled
- Work history



<https://bit.ly/3JH6WwN>

**Understanding Supplemental Security Income Documents You May Need When You Apply**

## SSDI Work Credits

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If you have a question about whether or not your young adult qualifies for SSDI, know it will depend upon the number of years the individual has worked. For some people, working 10 years or having 20 work credits would qualify the individual for SSDI. For others, a qualifying disability prior to age 22 will generally require 1.5 years of work (or 6 credits) in the three years prior to their onset of disability to receive SSDI. Use the QR codes for more detailed information and to determine how SSDI guidelines apply to your unique situation.



Utah Work Incentive Planning Services (UWIPS)

<https://bit.ly/3wNYqsg>



How You Earn Credits

<https://bit.ly/37YsRBq>

## What happens after I submit the application?

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If the application is filled out properly and all documentation is in order, applicants should receive a letter containing the SSA's decision to approve or deny the claim within three to five months.

If the SSA's decision is favorable, the claimant may be awarded a monthly benefit payment along with backpay.



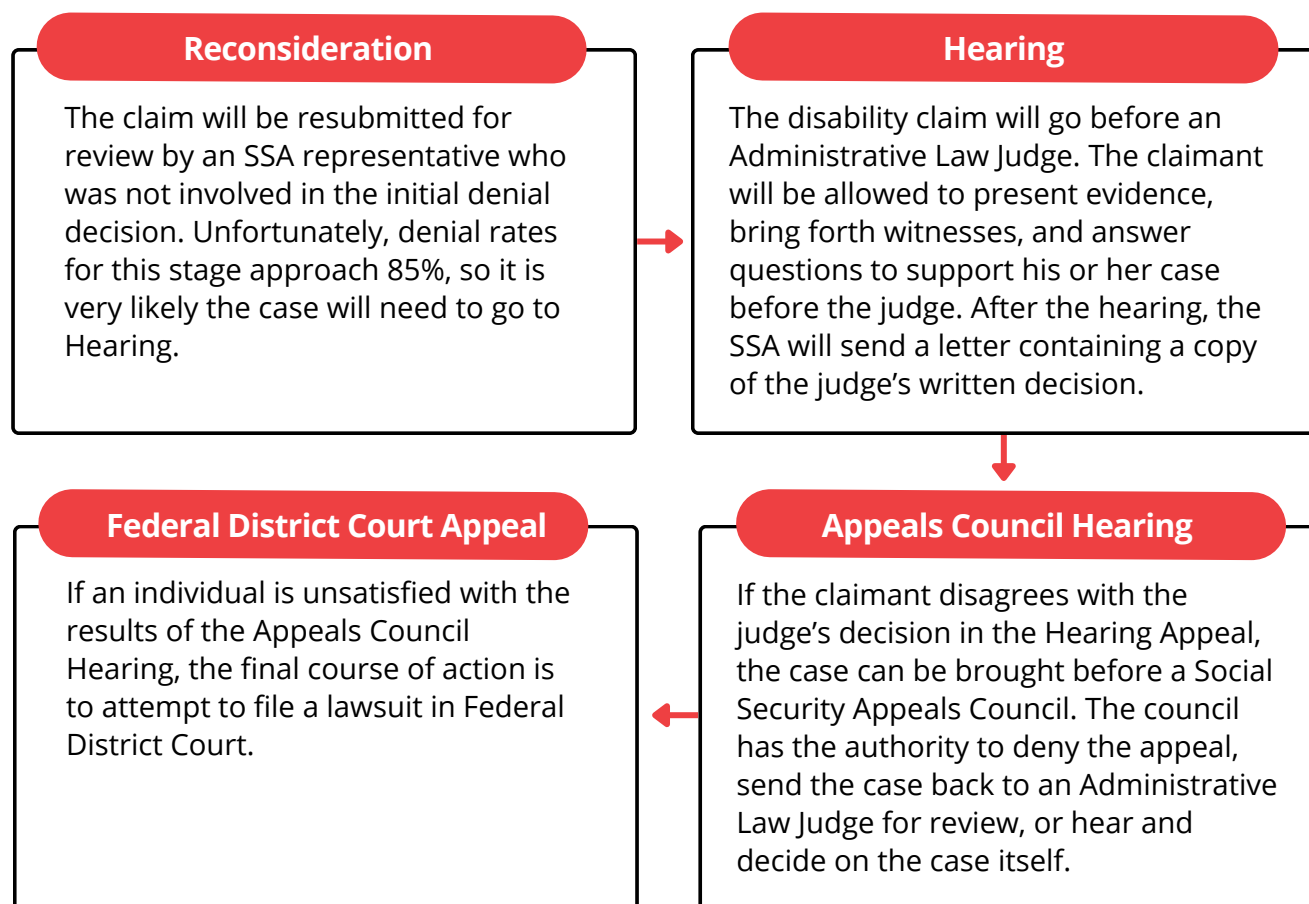
## What if the application is denied?

If an unfavorable decision is received and the caregiver feels the Social Security Administration has chosen to deny the claim in error, an appeal to have the decision reviewed may be submitted. Generally, the SSA must receive an appeal 60 days after the notice of the decision. Don't lose hope. Call the Utah Parent Center if you are denied so you can understand your options or what additional information you may need to supply.

Make sure you understand which program has sent you the denial. It is common for an individual to receive a denial from SSDI if they have not had a job and earned work credits. A denial from SSDI does not mean your child is being denied SSI benefits. The SSI application may still be in process.

## How does the Appeal Process work?

The Social Security application process contains four levels of appeal, any of which can overturn all or part of previous decisions made by the SSA:





## What if my young adult needs help managing their benefits?

A Social Security Income (SSI) Representative Payee (Rep Payee) provides benefit payment management for SSI beneficiaries who are incapable of managing their Social Security or Supplemental Security Income (SSI) payments independently.

- The Social Security Administration (SSA) appoints a suitable rep payee who manages the payments on behalf of the beneficiary.
- The rep payee receives the payment from the government and is responsible for paying bills like rent, utility payments, and other monthly expenses for the beneficiary.
- If there is excess money after all bills have been paid, the rep payee and the beneficiary can collaborate to decide how to best allocate those funds.
- Generally, family or friends may serve as a rep payee.
- When friends or family members are not able to serve as rep payee, the SSA will look for qualified organizations to fulfill the necessary tasks.
- Rep payees may receive an annual resere to account for the benefit payments received.
  - The following rep payees are not required to complete an annual Representative Payee Report:
    - Natural or adoptive parents of a minor child beneficiary who primarily reside in the same household as the child
    - Legal guardians of a minor child beneficiary who primarily reside in the same household as the child
    - Natural or adoptive parents of a disabled adult beneficiary who primarily reside in the same household with the beneficiary
    - Spouse of a beneficiary
- All rep payees are responsible for keeping records of how the payments are spent or saved, and making all records available for review if requested by SSA.



**Contact 1-800-772-1213 (TTY 1-800-325-0778) for additional information.**

<https://www.ssa.gov/payee/>

## Will my child's SSI benefits be affected when they turn 18?

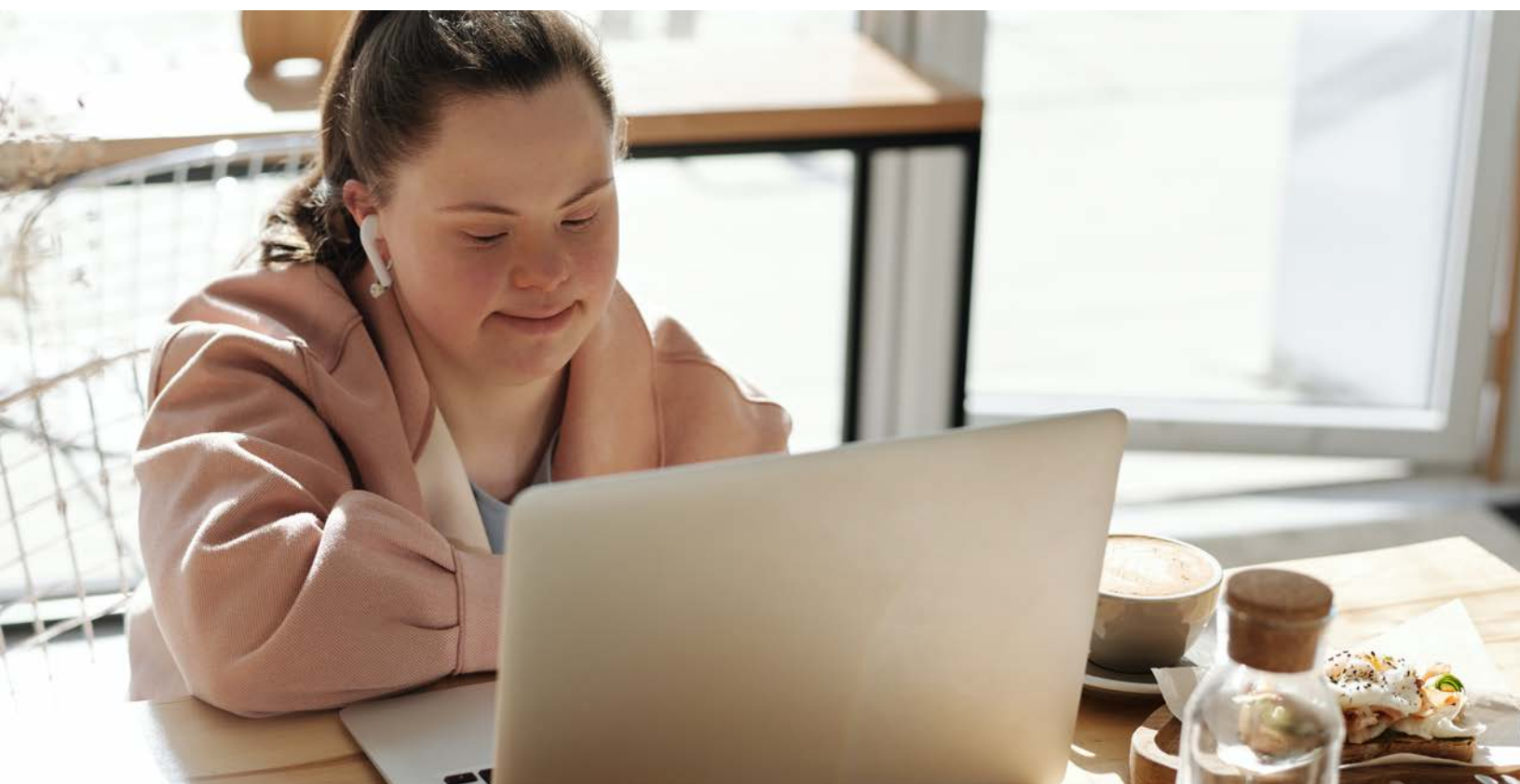
Yes, the Age-18 Redetermination Process begins after the individual turns 18. The SSA will review your child's eligibility for continued SSI benefits based on the disability rules for adults, including non-medical eligibility rules (income, resources, residency, citizenship, etc.), which are different from the rules that were applied when the individual was a child. The SSA will make sure that the individual is aware of this important change and the process for providing them with any needed information. The SSA will usually contact families within a year of the individual's 18th birthday. During this review, the SSA will send a letter to ask for the following information about the individual's disability.

- Names of any medicines
- Hospital stays and surgeries
- Visits to doctors and clinics
- Work activity
- Counseling and therapy

Go to the following link for more information about SSI when turning 18.



<https://bit.ly/3qEn9LH>



# If approved, what benefits can I expect for my young adult?

Maximum Federal Supplemental Security Income (SSI) payment amounts increase with the cost-of-living increases that apply to Social Security benefits. The latest such increase, 5.9 percent, became effective in January 2022.

## SSI amounts for 2022

The monthly maximum Federal amounts for 2022 are \$841 for an eligible individual, \$1,261 for an eligible individual with an eligible spouse, and \$421 for an essential person.

### Calculation details

Recipient	Unrounded annual amounts:		Monthly amounts 2022
	2021	2022*	
Eligible individual	\$9,530.12	\$10,092.40	\$841
Eligible couple	\$14,293.61	\$15,136.93	\$1,261
Essential person	\$4,775.99	\$5,057.77	\$421

\*The unrounded amounts for 2022 equal the unrounded amounts for 2021 increased by 5.9 percent.

## Payment reduction

The monthly amount is reduced by subtracting monthly countable income. In the case of an eligible individual with an eligible spouse, the amount payable is further divided equally between the two spouses.





## Do living arrangements affect benefits?

Yes, it certainly can. Living arrangements are a factor used to determine how much Supplemental Security Income (SSI) the individual is eligible to receive. Therefore, SSI benefits may vary depending on where the young adult lives. The SSA may reduce SSI benefits because of living arrangements when the individual has the following circumstances:

- Lives in another person's house, apartment, or mobile home, and they pay less than their fair share of your food or housing costs
- Lives in their own house, apartment, or mobile home, and someone else pays for all or part of their food, rent, mortgage, or other things like electricity and heating fuel
- Is in a hospital or nursing home for the whole month and Medicaid pays for over one-half of the cost of your care
- Is a minor child in a hospital or nursing home for the whole month and private insurance and/or Medicaid together pay over one-half of their cost of care
- Is in a public or private medical treatment facility and Medicaid is paying for more than half the cost of their care. If they are in the facility for the whole month, their SSI benefit is limited to \$30 (plus any supplementary state payment)



## What is In-Kind Support and Maintenance (ISM)?

In-kind support and maintenance is food, shelter, or both that somebody else provides for the young adult. The SSA counts in-kind support and maintenance as income when they calculate the amount of SSI benefits. For example, if someone helps pay for rent, mortgage, food, or utilities the SSA may reduce the amount of SSI benefits. Therefore, it is imperative to understand that receiving in-kind support and maintenance can reduce monthly SSI benefits by as much as one-third, depending on the value of the help received.

Therefore, if the individual lives in their own place and pays for their own food and shelter costs, regardless of whether they own or rent, they may be eligible to receive up to the maximum Supplemental Security Income (SSI) amount payable.

They also can get up to the maximum if they live in someone else's household as long as they pay their share of food and shelter costs.



The SSA does not count in-kind support and maintenance if the young adult:

- Lives alone and pays for their own food and shelter
- Lives only with their spouse and minor children and nobody outside the household pays for their food and shelter
- Lives with other people and pays their share of the food and shelter expenses.



## What Do I Need To Know About Room and Board and SSI?

If your disabled child lives with you, they can be considered a separate household living within your household. To maximize SSI benefits, some families put in place a written room and board / rental agreement, covering the individual's proportional share of household operating expenses.

The agreement should include the individual's and landlord's names, the rental address, the amount, purpose, and frequency of payment. Upon request, the renter should be able to produce rent receipts. Families should also document prevailing rents and utility costs in the area (water, sewer, electric, gas, etc.). Call the UPC to understand options based on the situation.

An important condition is that the individual pays fair market value for what is received and understands the portion of the home the individual utilizes.

**Use this form for any change in your situation. For example, starting to charge your youth for room and board or fair market value rent. Another example would be a change in address or employment.**



<https://bit.ly/3DnTco1>

### Utah Work Incentive Planning Program

**(UWIPS)** helps people who are currently receiving Social Security disability benefits (SSI/SSDI) and would like information on how employment may affect their Social Security and other benefits (Medicaid, Medicare, food stamps, housing, etc). UWIPS also educates people about helpful work incentives and community resources. They also teach how to report earnings to Social Security.

**For more information on UWIPS go to the following link.**



<https://bit.ly/3wNYqsg>  
801-887-9530

### Disability Law Center's Benefits Planning Program

One of the biggest obstacles to competitive and integrated employment for Utahns with disabilities is a fear of losing their Social Security check or Medicaid on which they depend. While the DLC's benefits planning service is primarily intended for transition-age youth (14-25) and day program participants, they will work with anyone with a disability who is eligible for or receiving SSI/Title II (SSDI/CDB/DWB), Medicaid, Section 8/housing assistance, food stamps (SNAP), Family Employment Program (TANF), VA benefits, etc. They can also work with individuals not eligible for or enrolled in Vocational Rehabilitation (VR).



<https://bit.ly/3wO9XHU>

## Social Security Work Incentives

### Impairment-Related Work Expense (IRWE)

are costs for items or services that are needed in order to work because of a disability. Social Security will deduct the costs of an IRWE from countable income when determining eligibility for Social Security disability benefits. An IRWE must meet all of the following criteria:

- The item(s) or service(s) enable the individual to work
- The item or service is needed because of a physical or mental impairment
- The young adult pays for the item or service themselves and are not reimbursed by another source (such as Medicare, Medicaid or a private insurance carrier)
- The cost is "reasonable," meaning that the cost represents the standard charge for the item or service in the community

**What is IRWE? Use this QR code to access additional information:**



<https://bit.ly/3uv1d6K>





### Plan to Achieve Self Support (PASS)

is an SSI provision to help individuals with disabilities return to work. If the young adult receives SSI or could qualify for SSI after setting aside income or resources so they can pursue a work goal, they could benefit from a PASS.

- PASS allows a disabled individual to set aside money and things he or she owns to pay for items or services needed to achieve a specific work goal.
- The objective of the PASS is to help disabled individuals find employment that reduces or eliminates SSI or SSDI benefits.
- Allows persons with disabling conditions to set aside money for purchases, installment payments, and down payments for things like a vehicle, wheelchair, or a computer if needed to reach their work goal.
- Contact a local SSA office; SSA work site or a Voc. Rehab counselor to apply. Form: <https://www.ssa.gov/forms/ssa-545.pdf>



<https://bit.ly/3iKKUNQ>

### Ticket to Work

supports career development for Social Security disability beneficiaries age 18 through 64 who want to work. The Ticket Program is free and voluntary. The Ticket Program helps people progress toward financial independence. Individuals who receive Social Security benefits because of a disability and are ages 18 through 64 probably already qualify for the program. The Ticket to Work (Ticket) program is a good fit for people who want to improve their earning potential and are committed to preparing for long-term success in the workplace.

The Ticket program offers beneficiaries access to meaningful employment with the assistance of Ticket to Work employment service providers called Employment Networks (EN). If an individual does end up qualifying for either SSI or SSDI they can also ask to be enrolled in the Ticket to Work program so they can identify how employment can help or impact a person's benefits. If an individual contacts the SSA with questions about how employment impacts benefits, they will automatically be referred to UWIPS (Utah Work Incentive Planning Program).



<https://www.ssa.gov/work/>

## Student Earned Income Exclusion

A blind or disabled individual under 22 years of age, who is a student regularly attending school, college, or university, or a course of vocational or technical training, can have limited earnings that are not counted against his or her Supplemental Security Income (SSI) benefits. For 2022, the student earned income exclusion amounts increase by 5.9 percent to \$2,040 per month but not more than \$8,230 in 2022.

## Employment-related Personal Assistance Services (EPAS)

EPAS is a Medicaid service for people with disabilities who work and need personal assistance in order to maintain their employment. EPAS may be available to a person who:

- Has been determined to have a disability by SSI or the Medical Review Board
- Is gainfully employed in an integrated community setting earning at least minimum wage
- Is currently working a minimum of 40 hours per month or is self-employed
- Needs personal assistance in order to maintain employment



## Employment-related Personal Assistant Services (EPAS)

<https://bit.ly/3ISX6a9>

Employment Impact on Public Benefits

**+QUICK REFERENCE TO SOCIAL SECURITY BENEFITS**

Adapted from Matrix Advocacy Project—Philadelphia, PA

<p><b>TITLE XVI: Supplemental Security Income (SSI)</b></p>	<p><b>TITLE II: Social Security Disability Insurance (SSDI) or Childhood Disability Beneficiaries (CDB) (SSDAC) or Disabled Widow(er) (DWB)</b></p>
<p><b>Eligibility:</b> to be eligible for TITLE XVI based on a mental or physical disability that is expected to last at least 12 months (excluding blindness) or result in death, an individual must: Not be performing SGA; Can get credit for subsidy or IRWE at initial application; (no SGA test after eligibility is established); Have limited income/resources (under \$2000 ind./\$3000.00 couple); Be a citizen of the United States or a legal alien, and be a resident of the Country; File an application and file for any other benefits for which they may be eligible.</p> <p><b>Cash Payment:</b> The maximum amount for which one can be eligible is the sum of the Federal Benefit Rate (FBR) plus any State supplement. This amount may be lower if the individual receives other Income or support.</p> <p><b>Checks Begin (Recipient):</b> Payments begin with the 1<sup>st</sup> full month of eligibility after the applications is filed.</p> <p><b>Medical Coverage:</b> Medicaid – Usually no waiting period. (209bStates have different requirements.)</p> <p><b>Work Incentive Available while on TITLE XVI:</b> Individuals on TITLE XVI can go to work and retain some, if not all of their payments through the use of the Work Incentive provisions of the Social Security Act. These include: Earned Income Exclusion; *Impairment-Related Work Expenses (IRWE); *Plan for Achieving Self-Support (PASS); *Student Earned Income Exclusion; (up to age 22) *Blind Work Expense (BWE); *Property Essential to Self-Support; 1619(a) and Extended Medicaid [1619(b); Section 301 Vocational Rehabilitation Client; Expedited Reinstatement of Benefits; ☞ State Medicaid Buy-In if available *These WIs can be used to establish income levels at initial application. *Subsidy (only at initial application).</p> <p><b>Checks Stop:</b> An individual who has been receiving TITLE XVI will no longer receive checks when: That person is determined to be no longer disabled; “Countable Income” exceeds the “Break-Even Point” (<i>relates to cash payment</i>) (FBR x 2+GIE + EIE=BEP or when the countable unearned income plus the countable earned income exceeds the current FBR); or Resources exceed the individual limit of \$2000/\$3000.00 couple. The charted threshold amounts for 1619b eligibility: <b>2019 Threshold:</b> (<i>Note Individual Thresholds can be determined by SSA</i>)</p> <p>Utah                      \$49,816 (<i>for 2022</i>)</p> <p>☞ Income is counted when it is received. ☞ SSI supplements and secures income from either earned or unearned sources, up to the FBR.</p>	<p><b>Eligibility:</b> to be eligible for TITLE II based on a mental or physical disability including blindness, that is expected to last 12 months or result in death and individual must: Have worked and paid Social Security taxes (FICA), have the required # of quarters to be insured, or the disabled widow(er) (DWB), or the adult disabled child (DAC) of a qualified worker; Not be performing SGA; Be a citizen of the United States, or a legal alien, and, File an application. There are some restrictions as to what countries checks can be mailed.</p> <p><b>CDB/SSDAC Eligibility:</b> Disability began before age 22; Must be 18 years old and unmarried; The qualified worker (QW) (parents, sometimes grandparents) must meet one of the following criteria: Deceased; Receiving Title II Retirement or Disability benefits;</p> <p><b>Disabled Widow(er)’s Eligibility:</b> Disability occurred within 7 years of QW’s death; at least age 50; not remarried prior to age 60</p> <p><b>Cash Benefit (Entitlement):</b> The payment amount is based on the individual’s lifetime average earnings covered by Social Security. Worker’s compensation payments and/or public disability payments may reduce the payment amount.</p> <p><b>Checks Begin:</b> An individual must wait five (5) full months after the onset of the disability before receiving TITLE II benefits (exception, DAC). There may be up to 12 months of retroactivity, if applicable.</p> <p><b>Medical Coverage:</b> Medicare, after two years of benefits.</p> <p><b>Work Incentives Available While on TITLE II:</b> TITLE II beneficiaries can return to work and retain their benefits through the proper use of the Work Incentive provisions of the Social Security Act. These include: Higher SGA level for Beneficiaries who are Blind; A Trial Work Period; Extended Period of Eligibility; *Impairment Related Work Expenses (IRWE); *Subsidy; Medicare for People with Disabilities who Work; Section 301 Vocational Rehabilitation Client Expedited Reinstatement of Benefits, Extended Medicare; ☞ State Medicaid Buy-In if available *These WIs can be used to establish income levels at initial application. ☞ Although PASS is legislatively a Title XVI WI, TITLE II beneficiaries can use their cash benefit to pay for PASS expenditures only if the employment goal will likely result in earning above SGA or to replace current benefits, which ever is higher.</p> <p><b>Checks Stop:</b> An individual who has been receiving TITLE II will no longer receive checks: When a person is determined no longer disabled; The first month after the end of the Extended Period of Eligibility when earnings are SGA and the Grace Period has been used. ☞ Income is counted when it is earned. ☞ Considered Unearned Income.</p>

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For questions about employment and the impact employment would have on public benefits, contact UWIPS. More information about UWIPS can be found on pg. 36. For updated information on pgs. 40 and 41, contact your local SSA.



For updated information contact UWIPS - see pg. 36

## Trial Work Period Month (TWP) and Substantial Gainful Activity (SGA) Amounts

Beginning and End Date	TWP Amount	SGA Amount
<b>2022</b>	<b><i>\$970/80 hours a month self-employment</i></b>	<b><i>\$1,350/\$2,260 for individuals who are blind</i></b>
2021	\$940/80 hours a month self-employment	\$1,310/\$2,190 for individuals who are blind
2020	\$910 / 80 hours a month self-employment	\$1,260 / \$2,110 for individuals who are blind
2019	\$880 / 80 hours a month self-employment	\$1,220 / \$2040 for individuals who are blind
2018	\$850 / 80 hours a month self-employment	\$1,180 / \$1,970 for individuals who are blind
2017	\$840 / 80 hours a month self-employment	\$1,170 / \$1,950 for individuals who are blind
2016	\$810 / 80 hours a month self-employment	\$1,130 / \$1,820 for individuals who are blind
2015	\$780 / 80 hours a month self-employment	\$1,090 / \$1,820 for individuals who are blind
2014	\$770 / 80 hours a month self-employment	\$1,070 / \$1,800 for individuals who are blind
2013	\$750 / 80 hours a month self-employment	\$1,040 / \$1,740 for individuals who are blind
2012	\$720 / 80 hours a month self-employment	\$1,010 / \$1,690 for individuals who are blind
2011	\$720 / 80 hours a month self-employment	\$1,000 / \$1,640 for individuals who are blind
2010	\$720 / 80 hours a month self-employment	\$1,000 / \$1,640 for individuals who are blind
2009	\$700 / 80 hours a month self-employment	\$980 / \$1,640 for individuals who are blind
2008	\$670 / 80 hours a month self-employment	\$940 / \$1,570 for individuals who are blind
2007	\$640 / 80 hours a month self-employment	\$900 / \$1,500 for individuals who are blind
2006	\$620 / 80 hours a month self-employment	\$860 / \$1,450 for individuals who are blind
2005	\$590 / 80 hours a month self-employment	\$830 / \$1,380 for individuals who are blind
2004	\$580 / 80 hours a month self-employment	\$810 / \$1,350 for individuals who are blind
2003	\$570 / 80 hours a month self-employment	\$800 / \$1,330 for individuals who are blind
2002	\$560 / 80 hours a month self-employment	\$780
2001	\$530 / 80 hours a month self-employment	\$740
7-01-99 to 12-31-00	\$200 / 40 hours a month self-employment	\$700
1-01-90 to 06-30-99	\$200 / 40 hours a month self-employment	\$500
12-31-89 and earlier	\$75/ 40 hours a month self-employment	\$300

### SSI Cost-of-Living Adjustment and Other Automatic Increases for 2022

	Applicable Dates	Individual	Couple
<b>SSI Federal Payment Standard:</b>	<b>2022</b>	<i>\$841</i>	<i>\$1,261</i>
<b>SSI Resources Limits:</b>	1989 through 2022	<i>\$2,000</i>	<i>\$3,000</i>
<b>SSI Student Exclusion:</b>	2022 rates	Monthly limit <i>\$2,040</i>	Annual Limit <i>\$8,230</i>

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Revised by UWIPS 12-15-2021

## Terms

**SGA:** Substantial Gainful Activity or earning more than a certain amount  
**TWP:** Trial Work Period - test ability to work while receiving social security



# Additional SSI Resources

Medical Home Portal



<https://bit.ly/3DiRcxu>

The Red book is a resource to help answer your SSI questions.



<https://bit.ly/3tJrRK0>

Frequently asked Questions



<https://bit.ly/3JPCoZM>

Utah Legal Services



<https://bit.ly/3DgFsM2>

Do I have to pay taxes on Social Security?



<https://bit.ly/35hvihu>

Income Reporting for Social Security Disability Benefits



<https://bit.ly/3NsWStH>

# ABLE Accounts

## Achieving a Better Life Experience (ABLE) Account:

ABLE Accounts are a tax-advantaged savings account for individuals with disabilities. Because the amount of SSI an individual receives is based on their assets as an adult and is affected by how much money they have in their bank account, it can be important to have one of these special savings accounts that allow excess money to be saved without it affecting their benefits.

ABLE Accounts dramatically increase the ability to save money for future needs. Before ABLE accounts, a person with a disability could not save over \$2,000 or they would risk losing Medicaid and SSI benefits. Now, with ABLE Utah, individuals with a disability can save well over \$2,000 and keep their public benefits. The account is owned by the individual with the disability and allows for investment benefits.

### SSI Considerations

- Balances over \$100,000 count as a resource. However if an account reaches \$100,000 SSI is merely suspended, not terminated.
- If money is held onto from one calendar month to the next, then housing expenditures count as resources.
- Beneficiary's own wages still count as income even if contributed to an ABLE Utah Account.
- **Utah Work Incentive Planning Services (UWIPS) helps people on Social Security understand how working impacts their Social Security and other benefits.**

**STABLE CARD:** A loadable prepaid debit card participants can use to easily spend money from an ABLE Utah account and can be used anywhere Visa is accepted. However, it does not pull money directly from an ABLE account to better protect spending. STABLE Cards are available at no cost to all ABLE Utah account holders. There is no overdraft, no cash access (from an ATM), allows for online spending records and annotated expenses, and sends notifications for low balances. You can have a STABLE card for the beneficiary and also for the authorized legal representative.

Customer Service  
800-439-1653  
Monday - Friday  
7am - 6pm MDT  
team@stableaccount.com

## ABLE Utah Information



<https://bit.ly/36W6QCE>

## ABLE Account Details

- To be eligible for the account, individuals must have a disability that onset before age 26 and either be eligible to receive SSI or SSDI due to disability; or have a condition listed on SSA's "List of Compassionate Allowances Conditions"; or have self-certification. For self-certification, an individual needs a diagnosis of a physical or mental impairment that causes "marked and severe functional limitation" and a condition that has lasted or is expected to last for at least 1 year. An individual does not need to send in a written diagnosis but must have it on hand.
- The beneficiary of the account is the account owner, and income earned by the account will not be taxed when used to pay for qualified expenses.
- Costs of establishing an account will be considerably less than a Supplemental Needs Trust or Pooled Trust. There is a \$25 minimum opening deposit. The monthly fee is \$3.25 per month (\$9.75 quarterly). Asset-Based fees are between 0.19% and 0.33%.
- To fund the ABLE account, individuals can transfer funds from a bank account to an ABLE Account. Contributions to the account, which can be made by any person (the account beneficiary, family, friends, Special Needs Trust or Pooled Trust), must be made using post-taxed dollars and will not be tax deductible for purposes of federal or state income tax earnings.
- Users can use the money saved in ABLE accounts to pay for any expense related to their disability — not just medical expenses not covered by Medicaid. The expense must relate to the disability and help maintain or improve health, independence, or quality of life.
- These include but are not limited to:

- Education
- Transportation
- Housing/Rent
- Basic Living Expenses
- Assistive Technology
- Financial Management
- Health & Wellness
- Legal Fees
- Employment / Training
- Personal support services



## ABLE Account Details

- As of March 2022, users can contribute up to \$16,000 per year.
- Able to Work Act Contribution: If employed, individuals can contribute an additional \$12,880 of income on top of the allowed \$16,000 per year. Their wages can fund the full \$12,880, but contributions from all other sources (ex. family members and other financial accounts) are restricted to the \$16,000. Keep in mind, that if the account holder or their employer is contributing to a retirement plan – including a defined contribution plan [e.g. 401(k), annuity plan 403(b)], or deferred compensation plan [457(b)] this calendar year – the account holder is not eligible to make ABLE to Work contributions.
- ABLE Accounts can receive distributions from a trust. ABLE Accounts also can pay for shelter and food where a Supplemental Needs Trust does not. However, if a trust owns cash assets including a home, the trust can pay for the home and the individual can pay rent to the trust so SSI is not negatively impacted. It is best to consult with a financial planner and/or an attorney for an individual's specific situation.
- Rent can be paid from the ABLE Account either by transferring money to the young adult's personal account or having a check issued to the landlord. However, if the individual has SSI, rent should be paid in the same month the ABLE Account transfer takes place. For example, if the money were transferred to the personal account in June, rent would need to be paid in June. If the money stayed in the personal account until July, it would impact SSI and be a countable resource.
- ABLE Accounts have a gift option where other people can contribute to the individual's ABLE Account and it does NOT count as a resource or income for public benefits eligibility.
- The maximum lifetime limit for Utah is currently \$501,000. New contributions can not be made if the overall balance is \$501,000 or above (although the account can continue to accrue earnings). Once the balance drops below the lifetime limit, contributions may resume.
- **Even though the limit is \$501,000, SSI benefits will be stopped if the account reaches \$100,000. Once the account drops below \$100,000, SSI benefits can be restored.**



### Additional ABLE Utah Information

<https://bit.ly/3LkAXCJ>

<https://bit.ly/3LlKxFx>





## ABLE Account Details

- Investment tools include four Vanguard mutual fund-based investments and one FDIC-insured savings option. Monitor your investments, make contributions, and request withdrawals all online.
- Account owners have control of their funds.
- Free withdrawals without limits. Money can be transferred to the individual's personal checking or savings, pay with a third-party check, or transfer funds onto the individual's STABLE Card. ABLE Utah will not ask where the funds are being spent, but benefit agencies and the IRS can.
- When the beneficiary passes away, the account will pass to the account holder's estate. The estate administrator notifies ABLE Utah and the estate can take over the ABLE account access. If the beneficiary does not have a will then the account will go through a normal probate process. Medicaid will be reimbursed from any funds in the account. Medicaid payback is only from the date the account was opened. Before Medicaid reimbursement takes place, the estate can pay for funeral expenses and pay any outstanding bills. Paid Medicaid buy-in premiums can also be deducted.

*Created as a result of the passage of the Stephen Beck Jr. Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. The State of Utah, along with other states, has partnered with the state of Ohio and their national ABLE program is known as STABLE Account. This partnership allows Utah's program, the ABLE Utah Savings Plan, to offer STABLE Accounts to eligible Utah residents with lower annual investment fees, a free loadable debit card (STABLE Card), customer service, and other benefits. The terms ABLE Utah and STABLE Account essentially have the same meaning. ABLE Utah is powered by STABLE Account and these accounts are considered to be under the ABLE Utah Savings Plan.*



# Additional Financial Supports to Consider

## Low Limit Credit Cards

Credit cards can be very challenging for many people to manage. It can be tempting to use them to pay for things when funds are not available. However, if the entire balance isn't paid off each month, interest fees will be incurred. One way to help young adults learn how to responsibly purchase things on credit is to start with a low spending limit card so they avoid buying items they can not really afford and learn to buy only those things they can pay off quickly.

## Joint Bank Account

A parent or another trusted adult who is on the young adult's support team can have a joint bank account with the young adult. This makes it so the young adult can manage their own finances, but they have the safety net of another person looking at their statements and bank balances to make sure everything is in order. If a member of your support team notices that something is not like it should be, for example, they missed an important payment, they can help correct the problem. Electronic deposits, direct deposits, and/or electronic bill payments are additional options to consider.

## UTMA and 529 Accounts

Uniform Trust Minor Account provides a way to transfer a wide variety of assets to a minor beneficiary. The funds can be spent on anything that benefits the minor. When the child reaches a designated age, the assets are theirs. These do become a child's assets, so keep this in mind when qualifying the child for public benefits. These funds can be moved into an ABLÉ Account. However, there are limits on how much you can transfer into an ABLÉ account per year. UTMA funds are the child's money so it is a countable resource when trying to qualify for SSI and Medicaid. Therefore, this money would not be able to be moved into a Supplemental Needs Trust.

A 529 plan is a savings account that is specifically intended to help pay for educational expenses. Both accounts have pros and cons. Work with a financial advisor to determine what is best for your family. Be aware of assets that are or will be in the name of your child with a disability and how that might impact their ability to qualify for SSI and Medicaid. They can have no more than \$2,000 in their name, unless the funds are in an ABLÉ Account.

## Financial and other Types of Power of Attorney

For information regarding Power of Attorney, please see pages 18 - 21 including a detailed explanation and resources.

# Wills & Trusts

## Will vs Living Will

A traditional will states what will happen to assets and property when you pass away. A living will, is a legal document designed to direct loved ones (agents) on how to handle certain aspects of your life if you become incapacitated, such as healthcare.

### For example, in the case of a parent having a will, the will:

- Allows you (as parents) to direct the distribution of property and leave assets to your children, grandchildren, charities, or other heirs.
- Allows you to name a guardian for your minor children.
- If you die without a will state law determines how to distribute your assets. A child with disabilities would likely receive assets of more than \$2,000 and become ineligible for SSI, Medicaid, and DSPD
- Make sure you include language in your will and/or revocable trust that says any distribution to your child with disabilities shall be distributed for their benefit to their Supplemental Needs Trust.

**A Living Will** is a legal document that lays out your preferences regarding health care, such as your refusal or acceptance of a medical treatment, in addition to the optional selection of a chosen agent or decision maker. Utah's Advance Health Care Directive also includes a living will.





# Special Needs / Supplemental Needs Trusts


A young adult receiving SSI will lose benefits if they retain more than \$2,000 in assets in their name. Two options discussed in this book that can assist families with navigating financial resources are ABLE Accounts and Supplemental Needs Trusts. The disability community commonly refers to this type of trust as a Special Needs Trust, when in fact, they mean a Third-Party Supplemental Needs Trust.

## Third-Party Supplemental Needs Trust

A legal arrangement that allows an individual with a disability to have access to funding without potentially losing the benefits provided by public assistance programs like SSI, Medicaid, or Medicare. The wording in these trusts has to be very exact and specific and must align with Medicaid language.

A Supplemental Needs Trust can be used to cover the supplemental needs of a person that are not covered by public assistance programs. The assets held in the trust are not considered countable resources when qualifying for public benefits. Distributions from the trust should not be used to pay for items or services covered by any public benefit; for example, shelter and food. Some things to consider are:

- No limits on contributions
- Income generated is taxable
- No Medicaid payback
- Trusts are managed by someone other than the beneficiary
- There could be start-up costs/trustee fees



**Work with a qualified Estate Planning Attorney and Financial Planner to create a plan that meets the needs of your family.**



# Pooled Trust

The goal of a pooled trust is to provide resources for individuals with disabilities who do not have the financial ability to set up a first or third-party trust. A pooled trust is another option for managing financial assets for people with disabilities without compromising their government benefits. The trust is intended to provide extra and supplemental services for the care, support, comfort, education, and training of the beneficiary over and above public and/or private benefits. Food and shelter are NOT supplemental needs. The trust money CANNOT be used for groceries, rent, or mortgage payments if the beneficiary receives Supplemental Security Income (SSI). Supplemental needs are anything that is not considered a necessity. (Outings and entertainment, phone service, medication if other funds are not available, drug and alcohol treatment, mental health support, etc.)

Pooled trusts are managed by non-profit organizations that facilitate the combination of assets from multiple donors. One example of a pooled trust is TURN Community Services' Pooled Trust (formerly The ARC of Utah Special Needs Trust). An individual with a disability, family members, or others deposit money into the pooled trust for a specific individual with a disability. For investment purposes, the money individuals or families deposit is pooled together with other participants' funds and invested as one pool of money. However, each person in the Trust has a sub-account that contains the money put into the trust specifically for them. Income generated by the investment of the pooled money is allocated back proportionally to each person's account.

- The minimum deposit for trust accounts is \$1,500. It has been recommended to open an account with just \$1,500 so the 2% fee is smaller. It does not cost anything additional to make future deposits. The fees to open the account are: \$250.00, a one-time fee to set up an account and 2% of the initial contribution.
- 1% of current balance annually, to start one year from the beneficiary's initial deposit.
- Recommended that each person in the account keep a minimum balance of \$25.00 to keep the trust open to avoid another setup fee at a later time.
- Upon their passing, any tax due is paid, ½ of the remaining funds go to repay Medicaid, and ½ will stay with the Trust to assist others with disabilities.



**Use this QR code to access more information on TURN Utah's Pooled Trust. This is one example of a Pooled Trust.**

<https://bit.ly/3NZh2KZ>

# Revocable, Living & Irrevocable Trusts

## A Revocable Living Trust

Is a trust created by an individual (called a grantor, usually the parent) that can be changed over time. Revocable trusts are used to avoid probate and to protect the privacy of the trust owner and beneficiaries. You can have a supplemental needs trust that is revocable or irrevocable. A revocable trust becomes irrevocable after the grantor passes away.

## An Irrevocable Trust

Describes a trust that cannot be modified after it is created without the trustee's consent.

## Third-Party Trust

"Third Party" refers to the individual who is establishing and funding the trust. For example, when a parent places assets in a third-party supplemental needs trust, they are acting as a third party. The beneficiary, or the person with a disability, is the first party. With a third-party trust, Medicaid does not have a claim on trust assets for Medicaid payback.

## First-Party Trust

"First Party" refers to the individual with a disability. A first-party special needs trust typically has a Medicaid payback provision after the beneficiary passes away. For example, these types of trusts are sometimes used when an individual with a disability receives a large legal settlement due to injury and requires Medicaid. The legal proceeds are placed in a first-party special needs trust such that the beneficiary can remain eligible for Medicaid. After the beneficiary passes away, Medicaid has a claim on trust assets to pay back for services received.

### Just a reminder...

When establishing your estate plan, you must work with a qualified estate planning attorney who is engaged in drafting Supplemental Needs Trusts on a regular basis. For most families, the Third-Party Supplemental Needs Trust is most appropriate.

### Keep your documents updated!

Laws and circumstances change. Your legal documents, letter of intent (discussed in the following three pages), and Care Notebook (discussed in the blue Health section of this book) should be revisited and amended with each change in life. It would be a good idea to sit down with your documents each January and update any areas that may need to be revisited.

# Letter of Intent

A letter of intent should encompass the plan for your child's future. Your child might outlive you by 40 years. What is the plan? Where will your child live? Will they be living independently? Is your child interested in employment? What social and recreational needs are there? What is it that others must know about your child if you are not here? What is the child's medical history? Who will be the trustee? Who will manage taxes/money? Does this person understand public benefits? Who will be the child's advocate/guardian? Who will be a friend to your child?

No one can be a substitute for you. However, if you can document the supports you have in place and your wishes, you will help to build continuity and support for your child. Please be aware that a letter of intent is not legally binding.

- Who are the relatives? Are they helpful?
- Who is on your child's team? How do we contact them?
- Your philosophy about medical care?
- How would you like hygiene, relationships, and things like table manners, self-care, chores and household responsibilities managed?
- How do you praise and set realistic expectations?
- How do you want their money handled?
- Does your child know what to do: in an emergency, if they suddenly feel ill, get lost, or if there is a fire?
- How will we know your child is satisfied and happy?



**There are many different templates for Letters of Intent. However, there are 10 basic things every Letter of Intent needs to address.**

### **1 Family History**

Where and when you were born, raised, married, something special about siblings, grandparents, and other relatives, special friends, description of your child's birth, when, where, your feelings, etc.

### **2 General Overview**

A brief overview of your child's life to date and your general feelings about the future.

### **3 Education**

Summary of educational experiences and desires for future education; regular classes, special classes, special schools, related services, mainstreaming, extracurricular activities and recreation; types of educational emphasis, i.e., vocational, academic, total communication, etc.; the name of specific programs, school, teachers, related services providers.

### **4 Employment**

Types of work your child may enjoy; open employment with supervision, activity center, etc.; companies that you are aware of that may be of interest to your child and provide employment in the community.

### **5 Residential Environment**

To live with relatives, friends or others – specify; if not these people or these people pass away, who are the other options, i.e., a group home in the same community – specify size; describe the best living arrangement – single room, etc.

### **6 Social Environment**

Mention the type of social activities your child enjoys, i.e. sports, dances, movies, etc.; should they have spending money and how they should spend it; favorite foods and eating habits; does your child take and/or enjoy vacations.

### **7 Religious Environment**

Specify religion; local place of worship your family attends; local clergy that may be familiar with your family; has there been religious education and is this an interest to your child.



## 8 Medical Care

Current doctors, therapists, clinics, hospitals, etc., and how frequently your child attends and for what purpose; current medications, how are they given, for what purpose; list medications that have not worked in the past.

## 9 Behavior Management

Describe the current behavior management program that is being used; other behavior management programs that have not worked.

## 10 Final Arrangements

Desires for your child's funeral arrangements – including – prearrangements you have made (if any), choice of the funeral home, burial, cemetery, monument, religious service, and clergy.

You may also include any other information you feel will help the person(s) caring for your child provide the best possible care. This letter should be placed with all of your other relevant legal and personal documents concerning your child. Do not forget to sign and date the letter.

For information about documenting medical care, please reference the Health (BLUE) section of this book and the Utah Care Notebook available through the Utah Medical Home Portal.

### Care Notebook



<https://bit.ly/3tDGDlh>





# COMMUNITY LIVING

**"The greatness of a community is most accurately measured by the compassionate actions of its members"**

**- Coretta Scott King**



# Self-Determination and Living Options

Adults with disabilities should be able to determine where they live where and with the people they choose.

Just as in education we have “Least Restrictive Environment” as a guiding principle for placement, we use that same ideology when it comes to adult living arrangements. Everyone should have access and the ability to participate fully in their communities.

What is the environment in which your young adult can best thrive and learn?  
What supports will he or she need in order to live there?



## Questions to start asking now...

- Where does my youth want to live?
- How will they pay for it?
- Whom do they want to live with?
- Is it safe and accessible?
- Does it have easy access to transportation, shopping, and work?

## Options for Living Arrangements

- Private home or apartment with roommates or caretaker
- Living with family
- Living on own
- Customized by individual or family
- Co-ops

Options are listed in order of what would be considered least restrictive to most restrictive. All these options can be utilized with or without DSPD funding. Nursing services are available for all these options as needed. With DSPD support, a private home or apartment might include roommates who need similar support and can share staff. Living with family is great for saving money while exploring options for day programs, work, school, etc. Individuals that qualify can receive DSPD support in the home. Living on your own is a great option for someone who is ready to do so. Individuals need to be prepared to pay bills, budget, and ensure their own personal safety. DSPD services are possible in this setting but are rare.

Customized Living can be arranged where a roommate supports individual needs in exchange for rent. A Co-op is an arrangement where a group of people purchase a home and live in it together, sharing the cost and responsibilities of the home. Additional options include DSPD Waiver services such as a group home, Professional Parent Home, Supported Living in their own home, or an Intermediate Care Facility (ICF) for the intellectually disabled. An ICF is the most restrictive option.

## How can Person-Centered Planning (PCP) Help the Supported Decision-Making (SDM) Process?

Person-Centered Planning reinforces Supported Decision-Making (SDM) because it puts the person as the architect of what they want for their life. Person-Centered Planning (PCP) is a personalized approach to planning services and supports so individuals get both what is important to them and important for them to achieve the life they want to live. The person's choices, directions, and control are part of all stages of the PCP process.



Person-Centered Planning can help your youth make decisions and achieve a happy, fulfilled life by:

- Identifying what they do and do not want
- Identifying challenges that need to be overcome
- Discussing strengths and limitations
- Setting goals that move them toward the life they want
- Letting go of habits and actions that do not lead to a happy, fulfilled life

Person-Centered Planning with SDM should lead young adults to choose for themselves and live the life they want.



# Tool for Exploring Decision-Making Supports

The tool on the next page helps to explore the areas of life where people make choices and decisions. It also helps identify when and how much support might be needed for making and communicating decisions. It covers all six life domains with a variety of questions in each area to prompt thought and discussion.



## How to Use the Tool for Exploring Decision-Making Supports

The Tool for Exploring Decision-Making Supports identifies which areas a person will or will not need individualized supports to make important decisions. The tool identifies three decision-making areas: (1) I can decide with no extra support (shown in teal blue); (2) I need support with my decision (shown in purple); and (3) I need someone to decide for me (shown in green).

For each question, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse Domains. Under each of these domains are questions meant to be answered and spark other questions within each domain that are more unique to a person.

This is a great tool to use during a Person-Centered Planning meeting in order to receive feedback not only from the individual but those who have supported the individual in the past in some of these areas of decision-making. You can use this tool to both inform where a person can make the most independent decisions possible as well as where you can begin creating goals around building self-advocacy.

## Ongoing Use of the Tool for Exploring Decision-Making Supports

This tool is designed to be used and referred to repeatedly. It should be updated and changed to reflect changes in progress, growth, and new goals. The Tool for Exploring Decision-Making Supports can be utilized for each new situation that arises or needs addressing in the various life domains. It is designed to become a planning, or progress tracking process, not a tool to be completed once and then filed away.



## CHARTING THE LIFECOURSE | EXPLORING DECISION-MAKING SUPPORTS

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: \_\_\_\_\_

Name of person completing this form: \_\_\_\_\_

Relationship to individual (circle one): Self Family Friend Guardian Other: \_\_\_\_\_

How long have you known the individual? \_\_\_\_\_

<p><b>For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.</b></p>	 I can decide with no extra support	 I need support with my decision	 I need someone to decide for me
--	---	--	--



### Daily Life & Employment

Can I decide if or where I want to work?			
Can I look for and find a job? (read ads, apply, use personal contacts)			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time? (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			



### Healthy Living

Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			
Can I take medications as directed or follow a prescribed diet?			
Do I know the reasons why I take my medication?			
Do I understand the consequences if I refuse medical treatment?			
Can I alert others and seek medical help for serious health problems?			
Do I make choices about birth control or pregnancy?			
Do I make choices about drugs or alcohol?			
Do I understand health consequences associated with choosing high risk behaviors? (substance abuse, overeating, high-risk sexual activities, etc.)			
Do I decide where, when, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

Continue on back »





CHARTING THE LIFECOURSE | EXPLORING DECISION-MAKING SUPPORTS

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.



I can decide with no extra support



I need support with my decision



I need someone to decide for me



Social & Spirituality

Do I choose where and when (and if) I want to practice my faith?			
Do I make choices about what to do and who to spend time with?			
Do I decide if I want to date, and choose who I want to date?			
Can I make decisions about marriage? (If I want to marry, and who)			
Can I make choices about sex, and do I understand consent and permission in regard to sexual relationships?			



Safety & Security

Do I make choices that help me avoid common environmental dangers? (traffic, sharp objects, hot stove, poisonous products, etc.)			
Do I make plans in case of emergencies?			
Do I know and understand my rights?			
Do I recognize and get help if I am being treated badly? (physically, emotionally or sexually abused, or neglected)			
Do I know who to contact if I feel like I'm in danger, being exploited, or being treated unfairly? (police, attorney, trusted friend)			



Community Living

Do I decide where I live and who I live with?			
Do I make safe choices around my home? (turning off stove, having fire alarms, locking doors)			
Do I decide about how I keep my home or room clean and livable?			
Do I make choices about going places I travel to often? (work, bank, stores, church, friends' home)			
Do I make choices about going places I don't travel to often? (doctor appointments, special events)			
Do I decide how to get to the places I want or need to go? (walk, ask a friend for a ride, bus, cab, car service)			
Do I decide and direct what kinds of support I need or want and choose who provides those supports?			



Advocacy & Engagement

Do I decide who I want to represent my interests and support me?			
Do I choose whether to vote and who I vote for?			
Do I understand consequences of making decisions that will result in me committing a crime?			
Do I tell people what I want and don't want? (verbally, by sign, device), and tell people how I make choices?			
Do I agree to and sign contracts and other formal agreements, such as powers of attorney?			
Do I decide who I want information shared with? (family, friends etc.)			





# Charting the LifeCourse Tools

The Charting the LifeCourse (CtLC) tool was created by families of individuals with disabilities, among others, to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

The core belief of Charting the LifeCourse framework is that all people have the right to live, love, work, play, and pursue their own life aspirations. The framework encourages viewing individuals in the context of their families and considering their community. Instead of looking at a snapshot in time or a specific issue, CtLC wants you to look across the lifespan. What does or does not happen in one stage of life will impact the outcomes of another. Look at all areas of life (called Life Domains) when planning with and for our children.

These tools from Charting the LifeCourse can support Person-Centered Planning and Supported Decision-Making, and encourage conversations about what your youth's vision is for their life.

- Trajectory Worksheet for Exploring
- Trajectory Worksheet for Planning
- Integrated Supports Star
- Life Domain Vision Tool
- Tool for Exploring Decision-Making Supports

## Supported Decision-Making and Person-Centered Planning Tools



<https://bit.ly/3rmmS0c>

### Life Trajectory:

In every stage of life, each of us is paving a path that leads toward a vision for the future. Along this path, or trajectory, each of us will experience both ups and downs. The Trajectory Tool for Planning can help define your youth's vision and how past experiences have helped or hindered them in meeting their life goals. It will assist you and your youth in setting goals and itemizing any obstacles that have the potential to get in the way. The Trajectory Tool for Exploring provides space to explore the things going well in your youth's life or the things that are stopping them from reaching their good life.



# How to use the Life Trajectory Worksheet

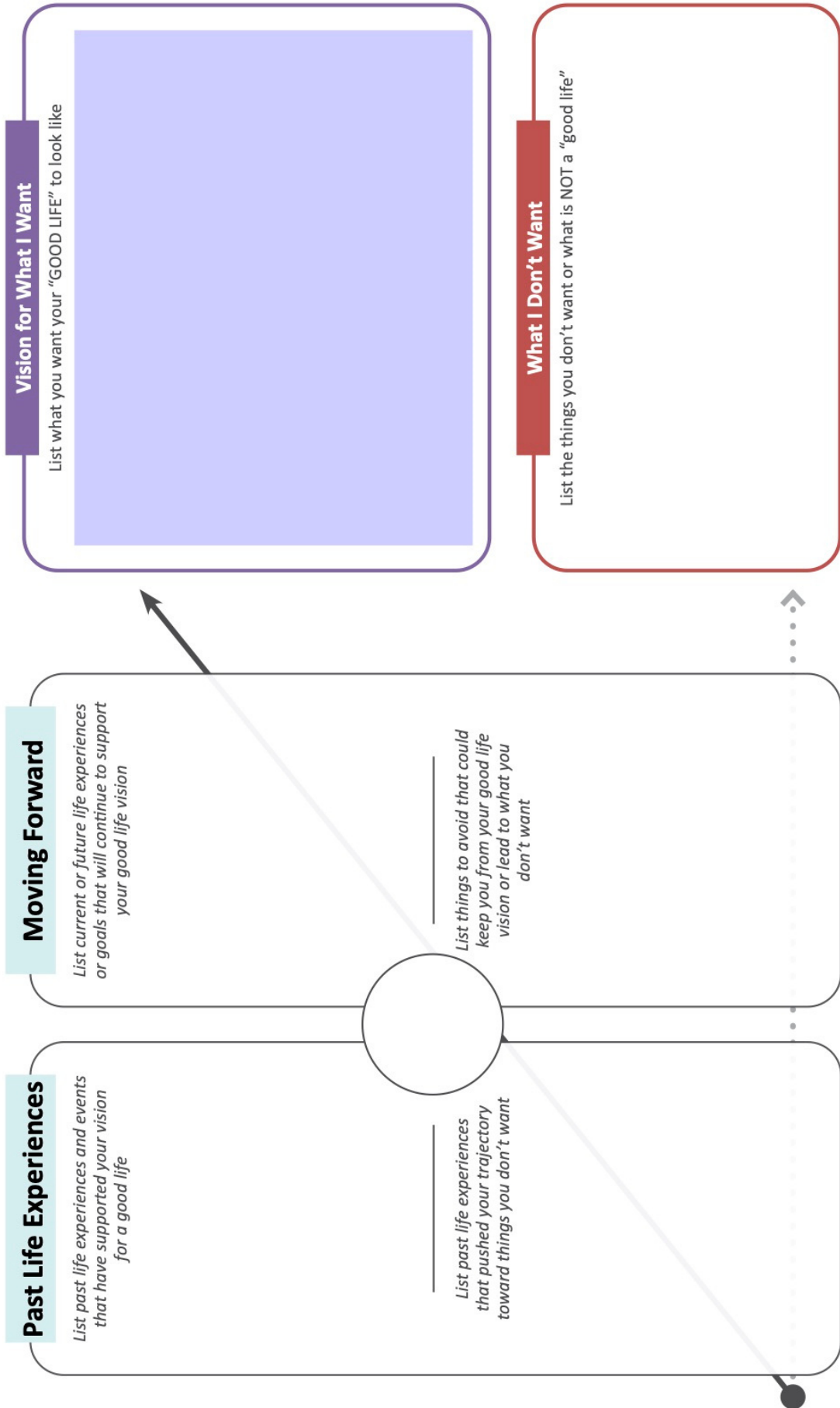
## Decide the Purpose

The trajectory tool will help begin planning for achieving a person's vision or goals.

- Start by having a conversation about what is going on right now.
- Determine the time frame being planned for.
  - Are short-term goals being considered (something achievable in the next month or year)?
  - Or are longer-term goals being considered (five to ten years in the future, at a certain age, or after a life event)?
- When developing a formal Person-Centered Plan for services, help the person think about the goals they want to accomplish in the next year, and to reflect on the past year. There is a circle in the middle of the page to write the age and name of the person or it could be used to write the date.
- Explore each part of the trajectory. It is recommended to start with the "Vision" boxes because this area will keep the focus on the person's vision or be a reminder of exactly what is not wanted. However, you can start anywhere on the tool.
- Have a conversation about the things in the past that helped or stood in the way of achieving the desired vision.
- If using the Trajectory for Planning, list what worked or didn't work in the "Past Life Experience" column. If thinking long-term, they might want to think back many years, or if planning for the current year, it might be helpful to only look back at the past year.
- In the "Moving Forward" boxes, discuss and list in the upper section the experiences and activities that could help gain what is needed to reach the desired vision. In the lower section list the things that could be a barrier or could move the trajectory toward what is not wanted.
- If using the Trajectory for Exploring, write the things that have, or may, work to move towards the vision above the top trajectory line. On the bottom line, write those things that didn't work or are likely to head the trajectory towards what is not wanted in the future.
- It is a good idea to go over the trajectory one more time with the person you are completing it with to make sure you have correctly depicted what they have said or meant and to avoid inadvertently reflecting your own vision or ideas.

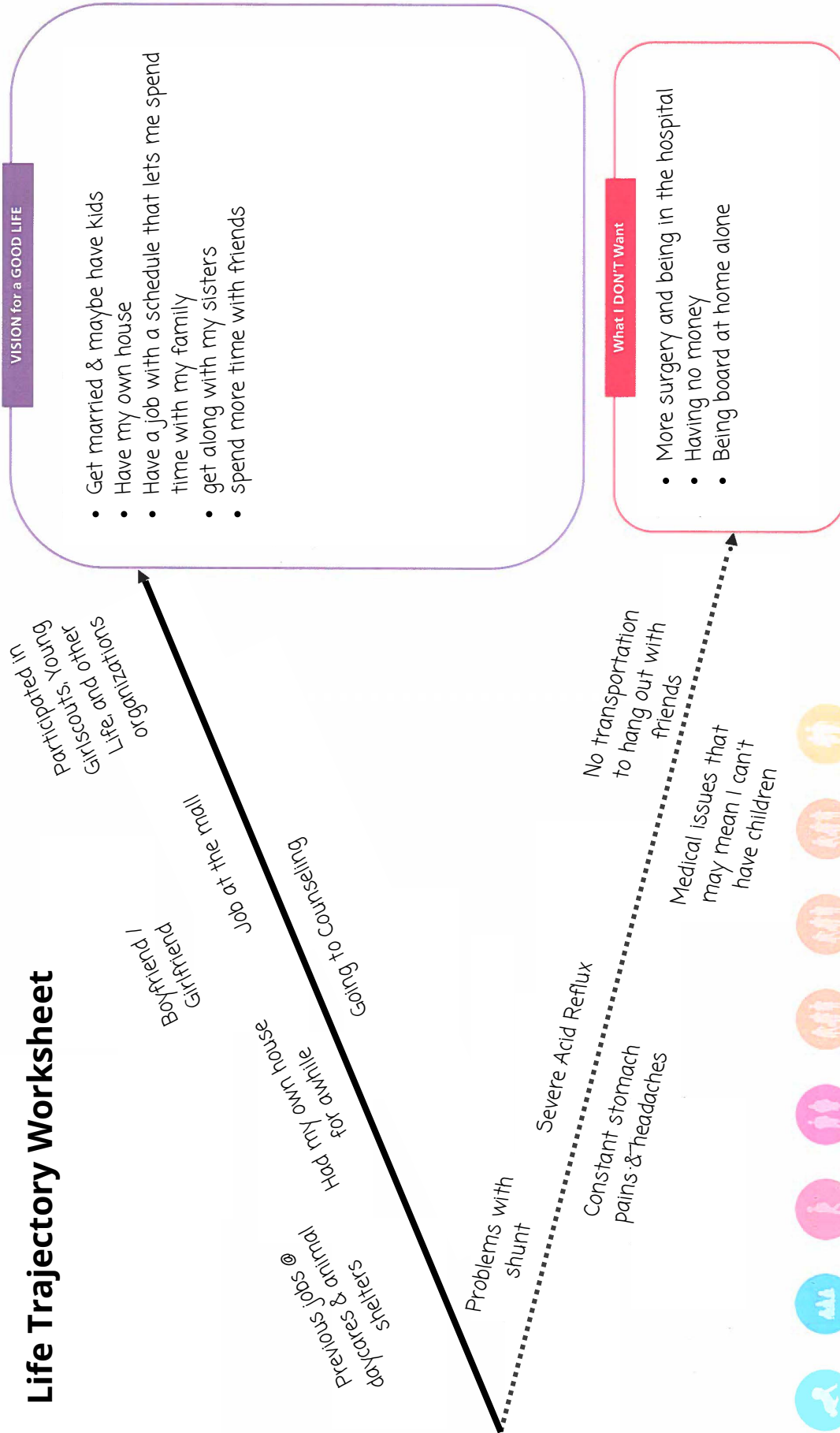
# Trajectory for Planning - Individual

## LIFE TRAJECTORY | PLANNING



# Sample Trajectory for Exploring - Individual

## Life Trajectory Worksheet



OCTOBER 2016

My LifeCourse Portfolio is a template of the UMKC IHD, UCEED. More materials at [lifecoursetools.com](http://lifecoursetools.com)

## Life Trajectory Worksheet: Good Life Family Perspective

Peyton, Age 13

Things that happened in the past that helped them get closer to good life goals. Ex: What are some things that helped my family member prepare for or move closer to the good life vision?

- Gen Ed classes & after school programs
- Immediate consequences for actions/accountability
- Having chores, feeling successful

Things I would like my family member to work on to move toward good life goals. Ex: What are some specific next steps I would suggest for my family member? How could I help them?

- Give them time to warm up to new people
- Increased responsibility
- Help them have a routine.
- Find summer work experiences

### MY VISION

My vision for my family member's good life  
What do I think my family member's good life should look like?  
What would make them happy or give their life meaning?

- I want them to have friends
- Be able to play sports, especially basketball
- I want them to be happy and healthy
- Have stable and gainful employment when they are an adult
- To have real choice in adult living situations
- Able to negotiate transportation in their community
- To know how to stay safe
- Have a loving relationship/their own family feeling of accomplishment
- Belonging and acceptance

### DISLIKES

What I don't want for my family member's life  
What would make my family member unhappy in life?  
What are the things I don't want to see happen to them in their life?

- No employment or a sheltered workshop
- Group home/no choice in where to live or with who
- Predetermined schedules/no choice
- Unhealthy/sickness
- Dependence on only paid supports
- Loneliness, boredom, being controlled

Things that happened in the past that pushed away from good life/job goals. Ex: What has happened that has led my family member's path in a direction they didn't want or I didn't want them to go?

- People's low expectations
- Learned helplessness
- Riding Special Ed bus
- No accountability for actions
- Being segregated
- Not being allowed to take risks.

Things that might keep my family member from getting their good life? What are barriers or what might get in the way of my family member taking steps to reach their good life goals?

- People's negative assumptions
- Always having a caregiver (no fading of support)
- People being over-protective



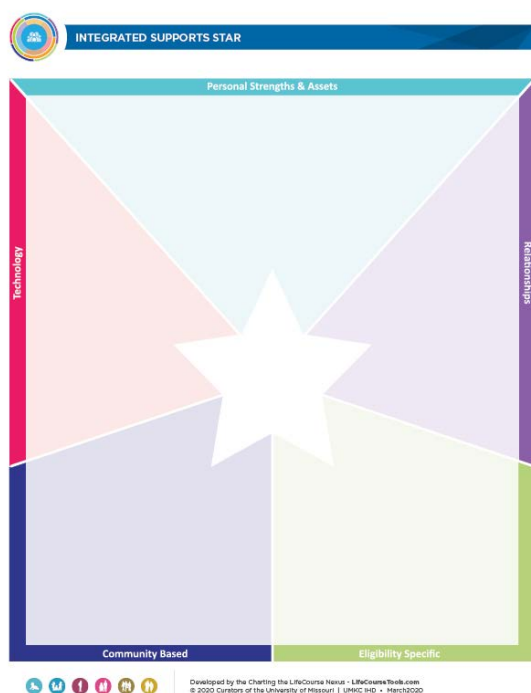
## On-going Use of the Trajectory

The trajectory is designed to be used repeatedly. It can be used as a reminder in working toward goals or to train caregivers and others on what is important to your youth so they can be supported in their vision. It should be updated and changed to reflect changes in progress, growth, and new goals. The trajectory can be utilized for each new situation that arises or needs addressing. It is designed to become a problem solving, planning, or progress tracking process. It shouldn't be a tool to be completed once and then filed away.

## Integrated Supports Star

This tool allows the individual to identify the supports currently being used, and think about other supports that might be helpful in the future. The right support can help ensure an individual's quality of life. Some supports are centered around relationships, technology, or personal strengths and assets, however, others are based on eligibility criteria or are supports that anyone in the community can access. Using a combination of various supports can help a person achieve their vision of a good life.

See page 68-69 for a larger version



CtLC tools are available free to download on their website, <https://www.lifecoursetools.com>.



Use this QR code to download the Integrated Supports Star and other Person-Center Planning Resources.

<https://bit.ly/3NxALIQ>

# How to use the Integrated Supports Star

The Integrated Supports Star invites you to explore supports available to the person in the following five different categories.

- **Personal Strengths and Assets** - Skills personal abilities, knowledge, or life experiences; Strengths things a person is good at or others like and admire; Assets personal belongings, and resources
- **Relationships** - Family and others that love and care about each other; Friends that spend time together or have things in common; Acquaintances that come into frequent contact but don't know well
- **Eligibility Specific** - Needs based services based on age, geography, income level, or employment status; Government paid services based on disability or diagnosis, such as special education or Medicaid
- **Community Based** - Places such as businesses, parks, schools, faith-based communities, health care facilities; Groups or membership organizations; Local services or public resources everyone uses
- **Technology** - Personal technology anyone uses; Assistive or adaptive technology to help with day-to-day tasks; Environmental technology designed to help with or adapt surroundings



### ► Decide the Purpose

The Integrated Supports Star can be used to explore many different situations. Decide if you are mapping supports or using it to work on a specific goal or situation and then use the center part of the star to write that purpose. If you are problem solving, put the specific problem or goal in the center of the star. If you are mapping current or future supports, write the name of the focus person.

### ► Explore Each Part of the Star

During this step, you are learning more about the person or their situation and what supports they are currently using that might be available to achieve the goal or solve the problem. This information can be gathered during a conversation by listening for the responses that could go in each area of the star. This is determined by the situation or the comfort level of the person guiding the conversation.

### ► Identify Specific Resources

You can now begin identifying additional resources or ideas for each part of the star to address the specific issue or support needs. The idea is to explore options that provide hope and relief for meeting their needs right now and in the future.

### ► Ongoing Use of the Star

The Integrated Supports Star is designed to be used over and over again. It can be repeated for each situation or problem that needs to be addressed. The completed stars can be used at meetings to add or delete things that have been accomplished. It is designed to become a problem-solving, planning, or progress tracking process, not a tool to be completed and put into a file.



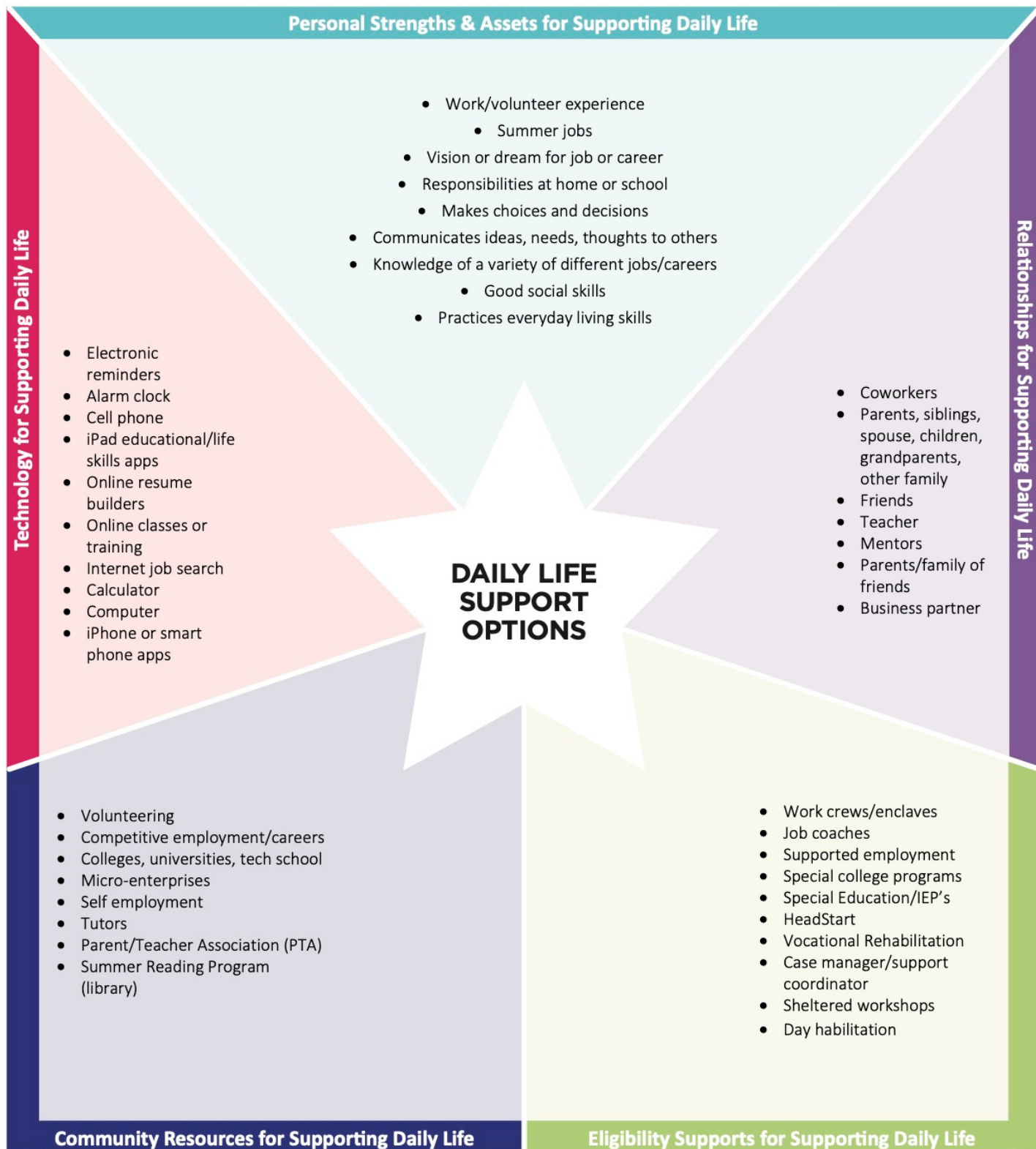


# Stars can be completed for every area of life



## INTEGRATED SUPPORTS STAR | DAILY LIFE

Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This star will help families and individuals think about how to work in partnership to support daily life.

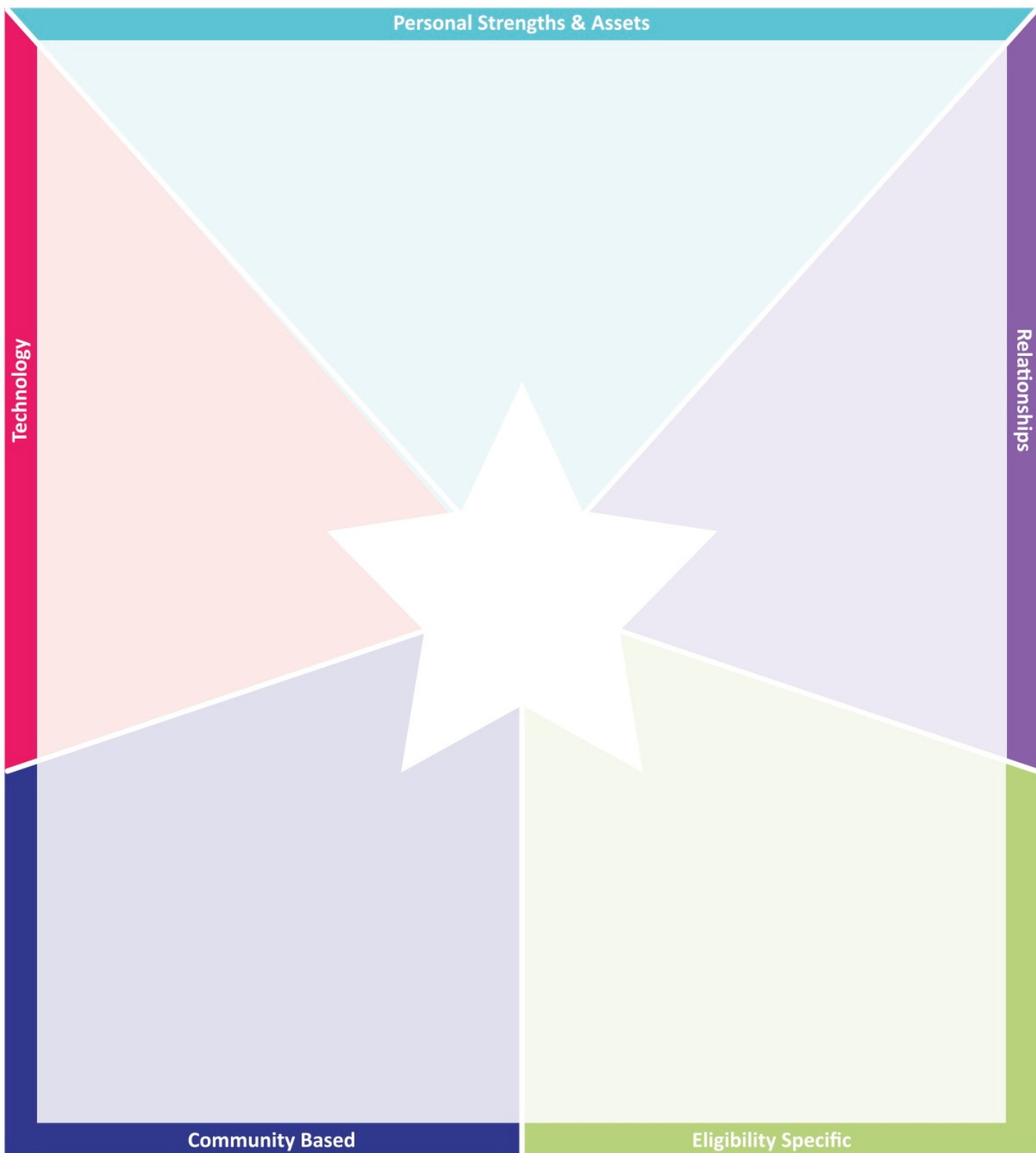


Developed by the Charting the LifeCourse Nexus - [LifeCourseTools.com](http://LifeCourseTools.com)  
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INTEGRATED SUPPORTS STAR



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# Life Domain Vision Tool

Charting the LifeCourse encourages exploration of six different life domains: Daily Living and Employment, Community Living, Safety and Security, Social and Spirituality, Healthy Living, Advocacy, and Engagement. Beginning a plan for the vision of the future in each of the life domain areas helps plot a trajectory for a full, inclusive, quality life in the community. The Life Domain Vision Tool is to help individuals of all ages start to think about a more specific vision for life in the future and narrow down what life domain(s) to focus on at this point in time.

The tool has two additional areas to discuss, Supports for Family, and Supports and Services.

## How to Use the Life Domain Vision Tool

Explore Each Part of the Tool. The Life Domain Vision Tool has a list of suggested questions in each section to prompt a discussion about what each means. Give examples of what each domain entails using things that are familiar to the person. Use the center column to write down what the person envisions for themselves in that life domain. This can be done in one sitting or over the course of a period of time. It is also acceptable to skip sections of the tool that are not applicable or important to pursue at this time.

## Identify Priorities





Using the column on the right, determine which sections are the highest priority at this time. That does not mean that the others aren't important but only that energy and focus will be on the area(s) noted as a high priority. Once progress has been made in that area, attention can turn to other priorities.

## Ongoing Use of the Life Domain Vision Tool





The Life Domain Vision Tool is designed to be used and referred to repeatedly. It should be updated and changed to reflect changes in progress, growth, and new goals. The Life Domain Vision Tool can be utilized for each new situation that arises or needs addressing in the various life domains. It is designed to become a problem-solving, planning, or progress tracking process, not a tool to be completed once and then filed away.

EXAMPLE

# Life Domain Vision Tool: Family Prespective

LIFE DOMAIN		My Vision for My Future	priority
 <p>Daily Life &amp; Employment</p>	<p>What do I think my family member will do during the day in his/her adult life? What kind of job/career might they have?</p>	<p>I would like Sarah to work in a job that she enjoys, where she has co-workers who are supportive and friendly -not "taking care of her," but really letting her be part of the team. I think working full time may be too tiring for her.</p>	
 <p>Community Living</p>	<p>Where and with whom do I think my family member will live in his/her adult life?</p>	<p>I would like Sarah to live in a home or apartment with her future husband, hopefully somewhere relatively close to me or to mom/dad in case of emergency.</p>	
 <p>Social &amp; Spirituality</p>	<p>How do I think my family member will connect with spiritual and leisure activities; have friendships &amp; relationships in his/her adult life?</p>	<p>I want Sarah to find a group of friends who enjoy similar things - maybe a horse riding group, or a church Bible Study.</p>	<p><b>1</b></p>
 <p>Healthy Living</p>	<p>How do I think my family member will live a healthy lifestyle and manage health care supports in his/her adult life?</p>	<p>Sarah should learn her medical history a little bit better - she knows some things, but doesn't know the full picture. She is able to distinguish her symptoms. I think eating healthier/exercising would be helpful to her.</p>	<p><b>2</b></p>

E X A M P L E (continued)

 <p>Safety &amp; Security</p>	<p>How do I think my family member will be safe from financial, emotional, physical or sexual harm in adult life?</p>	<p>Sarah has decent boundaries, and does a good job to talk to her family/friends about situations that make her uncomfortable. She tends to think the best of people and be somewhat naïve... we should continue to remind her about being aware of herself and her surroundings, and not trusting people too quickly.</p>	
 <p>Citizenship &amp; Advocacy</p>	<p>How do I think my family member will have valued roles, responsibilities, and control of how his/her own life is lived as an adult?</p>	<p>Sarah is an important member of our family, and has a valued role. I think having opportunities to volunteer and be more connected in the community are important for her to feel greater value/control overall.</p>	
 <p>Citizenship &amp; Advocacy</p>	<p>What supports do I think our family unit needs now or will need in the future?</p>	<p>Assistance with transportation so that she can go where she wants/when she wants; medical oversight for our peace of mind.</p>	<p><b>3</b></p>
 <p>Supports and Services for Individual</p>	<p>What do I envision for long term services and supports for my family member in the future?</p>	<p>I think she has a pretty integrated support system now... But I would like to do a trajectory with Sarah to make sure we are all working toward the same vision.</p>	





# HEALTHY LIVING & ADULT HEALTHCARE

It's never too early or too late to work  
towards being the healthiest you.

# Helping Youth Learn to Manage their Medical Care

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Does your young adult know what to do in a health emergency? If they have a chronic condition, do they know how to make the shift to an adult doctor? Does your young adult know how to find a new doctor or fill a prescription? Can your young adult manage their mental health? What can we do as caregivers to help make this transition to adult healthcare easier? What tools are available to parents, caregivers, and to our young adults? This section will help families navigate this important topic.

## **What if my young adult still needs support when they turn 18? What are my options?**

Once a child turns 18, they are considered an adult, and healthcare providers are not required to communicate with parents. In addition, you may not be allowed access to your young adult's medical records. Based on your young adult's needs you may want to consider limited guardianship for health care, medical power of attorney, or an Advance Health Care Directive.

In this section, you will learn about the various supports available to help your young adult make choices about their healthcare, receive support when needed, and effectively implement support plans developed by their team.





### HIPAA Release Form:

The HIPAA Privacy Rule (effective on April 14, 2003) introduced standards covering allowable uses and disclosures of health information, including to whom information can be disclosed and under what circumstances protected health information can be shared. The HIPAA Privacy Rule permits the sharing of health information by healthcare providers, health plans, healthcare clearinghouses, business associates of HIPAA-covered entities, and other entities covered by HIPAA Rules under certain circumstances.

HIPAA authorization is consent obtained from a patient or health plan member that permits a covered entity or business associate to use or disclose protected health information (PHI) to an individual/entity for a purpose that would otherwise not be permitted by the HIPAA Privacy Rule. Without HIPAA authorization, such use or disclosure of PHI would violate HIPAA Rules and could attract a severe financial penalty, and may even be determined to be a criminal act.



## Medical Power of Attorney

Can also include a HIPAA release to access the principal's private health care information and communicate with the principal's healthcare providers unless the power of attorney specifically restricts that authority. If outlined, the power of attorney can also be used to make medical decisions for the principal if they are unable to do so.

## Utah's Advance Healthcare Directive

Outlines circumstances where another person can make medical decisions for an individual, and includes written instructions on the individual's desires, should they be unable to make decisions. If outlined, the directive can also include a HIPAA release, gives permission for the agent to talk to medical professionals and make decisions about the principal's care. A living will can also be included in the directive. Use the QR code for more information.

## Living Will

A legal document that lays out preferences regarding health care, such as refusal or acceptance of medical treatment, in addition to the optional selection of a chosen agent or decision-maker. A living will is also included with an Advance Health Care Directive or it can be a separate document. See the red section of this booklet for additional information on wills and trusts.

## Utah Declaration for Mental Health Treatments

A declaration that allows, or disallows, mental health treatment. It also gives the young adult the opportunity to appoint a person as their attorney-in-fact (the person named in a power of attorney to act on their behalf) to make mental health treatment decisions for them if they become incapable. Use the QR code for more information.



### Utah's Advance Healthcare Directive

<https://bit.ly/3JGBbnB>



### Utah's Declaration for Mental Health Treatment

<https://bit.ly/3Nyelek>







# Got Transition

Got Transition is the federally funded national resource center on health care transition (HCT). Its aim is to improve the transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families.

The online resource and booklet to assist young adults in transitioning from pediatric to adult healthcare can be found here:



<https://bit.ly/UDOHtransition>



<https://gottransition.org/>

## GOT TRANSITION - A FAMILY TOOLKIT



<https://bit.ly/3rz6xpD>

This toolkit was developed for families to use during pediatric-to-adult healthcare transition and includes resources for both parents/caregivers and youth/young adults. These tools can be used to better prepare youth and families for the transition to adult care. This toolkit can be downloaded for free on Got Transition's website at GotTransition.org.



<https://bit.ly/3Gxs8D6>

## SAMPLE TRANSITION READINESS ASSESSMENT

The purpose of the transition readiness assessment is to begin a discussion with youth about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes.

# Health Care Transition Timeline

## for parents/caregivers

Age 12-13

- Help your teen learn about their own health condition, medications, and allergies.
- Encourage your teen to ask their doctor questions about their own health.
- Ask your teen's doctor if and at what age they no longer care for young adults.

Age 14-15

- Learn what your teen knows about their own health, health care, and family medical history. Both you and your teen can take Got Transition's Transition Readiness Assessments\* and discuss this together and with the doctor.
- Have your teen carry their own health insurance card.
- Help your teen learn more about their own health and what to do in case of an emergency.
- Help your teen practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Encourage your teen to see the doctor alone for part of the doctor's visit to help gain independence in managing their own health and health care.

Age 16-17

- Encourage your teen to make doctor's appointments, see the doctor alone, ask the doctor questions they may have, and refill medications.
- Ask the doctor to talk with your teen about their privacy rights when they turn 18.
- Work with your teen and the doctor to make and share a medical summary.
- Before your teen turns 18 and becomes a legal adult, figure out if they will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your teen about the age they want to transfer to a new doctor for adult care.

Age 18-21

- At age 18, your child is a legal adult and legally responsible for their care. You cannot access their medical information or be in the doctor's visit unless your young adult agrees or certain legal forms have been completed.
- If you need local resources on supported decision-making, ask your Family Voices chapter.
- Learn if there are additional changes at 18 that affect your young adult (e.g., health insurance, Social Security Income).
- Encourage your young adult to ask their current doctor to find a new adult doctor. Make sure that the new doctor accepts your young adult's health insurance, and help them learn if there are any charges at the visit.
- Encourage your young adult to keep a copy of their medical summary and always carry their health insurance information with them.

Age 22-25

- Encourage your young adult to get care from their adult doctor, learn to manage their own health and health care, and update their medical summary.
- Encourage your young adult to stay insured. If they change health insurance, encourage them to make sure their doctor takes their insurance and learn if there are any charges at the visit.

For a Transition Readiness Assessment for youth, visit <https://gottransition.org/6ce/leaving-readiness-assessment-youth> and for a version for parents/caregivers, visit <https://gottransition.org/6ce/leaving-readiness-assessment-parent>.

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Got Transition (GotTransition.org) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) (U1TMC31756). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government.

# Creating your HEALTHCARE NOTEBOOK

## Your How-to Basics

A transition notebook is an organizing tool for youth with disabilities or chronic health illnesses. Use a transition notebook to keep track of important information about your young adult's health care and the services they need as they move into independence. They may get information and paperwork from many sources. A transition notebook helps you/them organize the most important information in a central place. A transition notebook makes it easier for you/them to find and share key information with others whom they choose to be part of their care team; such as a family, doctor, or other providers.

## Step 2

Create pages that could help you keep track of information about your young adult's health or care. Examples: a page to track medical events (event diary), medicine changes, phone numbers for providers or specialists, health history including surgeries, procedures, lab work, allergies, etc. Document any needed support services, medical supplies, or equipment.

## Step 3

Add new information to the notebook whenever the treatment, medication, or care changes. Decide which information is most important to keep. What information is referenced frequently? What information do people caring for your young adult need? Consider storing other information in a file drawer or box where you can find it if needed. Consider having your young adult take the notebook with them to appointments and visits so information will be easy to find.

## FOLLOW THESE STEPS TO SET UP YOUR NOTEBOOK:

### Step 1

Gather health information you already have about your young adult. Some of the information you may want to include are reports from recent doctor's visits, a recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

### Care Notebook



<https://bit.ly/3tDGDlh>

## Utah Medical Home Portal

A unique source of reliable information about children and youth with special health care needs (CYSHCN), offering a “one-stop shop” for their families, physicians, medical home teams and other professionals and caregivers.



<https://bit.ly/3mtdO6H>

## Genetics: What do I need to keep in mind as I transition from my pediatrician to an adult health care provider?

Adult health care providers may not know about the complexities of some genetic conditions with which pediatricians are familiar. The family may know more about the condition than the adult health care provider. Transition may include support from your medical home/primary care provider and other professionals working together as a team to help the young adult and family and to help the adult care provider “get up to speed.”



<https://bit.ly/3b2ER6o>



**Be aware of transition issues at each age range. Use this QR tool and website for guidance. The Transition to Adulthood section is full of additional information as you navigate this period of time.**

<https://bit.ly/3O00EKn>

**"...Transition is a process, not an event. The actual process should be gradual, occurring in harmony with adolescent and family development."  
(National Dissemination Center for Children with Disabilities)**





## What is Medicaid?

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by individual states, according to federal requirements. The program is funded jointly by states and the federal government.

\*People who are not US citizens can only get Medicaid to pay for a life-threatening medical emergency.



<https://bit.ly/3tEczWK>

## How do I know if my young adult is eligible for Medicaid?

To be eligible for Medicaid, your young adult must meet a program type and meet the rules for Utah residency, income, and citizenship. If you are unsure if your child qualifies for Medicaid, you should apply for them. They might be eligible depending on your household income, family size, age, disability, and other factors. They must be a United States citizen, a U.S. national, or have a satisfactory immigration status to be eligible for full benefits. Visit [HealthCare.gov](https://www.healthcare.gov) to take a quick screening to help you determine if your child is eligible for Medicaid/CHIP or other health insurance options.

### Medicaid Screening



<https://www.healthcare.gov/>

### Utah Medicaid



<https://bit.ly/3IK7S29>

# What is the process to apply for Medicaid?

***Apply for SSI first; the SSI application process streamlines the Medicaid application process in Utah.***

You may apply for Medicaid for your young adult in person, by mail, or online. When the application is received, the Department of Workforce Services (DWS) will contact you by mail or phone. DWS may need more information to determine if your child is eligible for a medical program. DWS will also notify you of what proofs you will be required to provide, like a birth certificate.

- **Apply Online:**

<https://jobs.utah.gov/mycase/>



- **Apply by mail:**

- Download a Medical Application.
- Mail completed application to:
  - Department of Workforce Services
  - PO Box 143245
  - Salt Lake City, UT 84114-3245

- **Apply by fax:**

- Download a Medical Application.
- Fax completed application to:
  - Department of Workforce Services
  - Fax: 801-526-9505
  - Toll-free Fax: 1-888-522-9505

- **Apply in person:**

- Download a Medical Application.
- You may apply at any Department of Workforce Services (DWS) office.

**Use this QR code and URL  
to download a medical  
application**



<https://medicaid.utah.gov/apply-medicaid/>



# Utah Medicaid Waivers

A Medicaid waiver is a type of Medicaid program designed to serve people with varying disabilities. In Utah the Medicaid waivers are administered by the Utah Department of Health and Human Services. Each waiver is slightly different in terms of the services that they offer and they are designed to serve a specific population of people. Waivers can vary based on the level of care, type of disability, age, and the level of skilled nursing required by the individual. To enroll your child and join the waiting list, use the following QR code or link. It can take many years to come off of the DSPD waitlist. **Even though your child may be on the waiting list for years, get them on as soon as possible so they can take advantage of any one-time funding or benefits that may become available.**

In addition, if your young adult has been denied SSI or Medicaid in the past, it is still worthwhile to apply for a waiver. Waivers don't necessarily look at SSI or Medicaid qualification guidelines.

**DSPD:** The Division of Services for People with Disabilities (DSPD) serves children and adults who have intellectual disabilities, physical disabilities, brain injuries, and autism. The Division of Services for People with Disabilities is part of the Utah Department of Health and Human Services and offers the following waivers to those who qualify:



<https://bit.ly/3J7ci46>

**Apply for DSPD. There is a waiting list. Individuals come off the waiting list based on available funding and the needs of the individual.**



## Acquired Brain Injury Waiver

Is designed to provide services statewide to help people with an acquired brain injury to remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver. Further information regarding limitations and services can be found at: <https://medicaid.utah.gov/ltc-2/abi/>

### Eligibility Requirements

- Be 18 Years of Age or older
- Have a documented brain injury
- Require nursing facility level of care
- Meet financial eligibility requirements for Medicaid
- Primary condition cannot be attributable to a mental illness.



Use this QR code to access the Department of Health and Human Services and information about various Utah Waiver Programs and updates.

<https://bit.ly/3INKNva>



Brain Injury Fact Sheet

<https://bit.ly/36yUgcV>



## Community Supports Waiver (CSW)

This waiver is designed to provide services statewide to help persons with intellectual disabilities or persons with conditions related to intellectual disabilities remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program.

### Eligibility Requirements

- Must demonstrate functional impairment in 3 or more areas of major life activity
- Onset of condition must occur before age 18 for intellectual disabilities
- Onset of condition must occur before age 22 for other related conditions
- Primary condition must not be attributable to a mental illness
- Meet level of care criteria for admission to an intermediate care facility for people with intellectual disabilities (ICF/ID). ICF/ID is equivalent to ICF/MR as described under Federal law
- Meet financial eligibility requirements for Medicaid
- There are NO age restrictions for this waiver
- Must be able to live safely in the community

### Limitations

- Serves qualifying individuals
- There is a waiting list to get on this waiver
- Individuals can use only those services they are assessed as needing

### Waiver Services

- Behavioral Consultation
- Chore Services
- Companion Services
- Day Supports
- Emergency Response Systems
- Environmental Adaptations
- Extended Living Supports
- Family/Ind. Training and Preparation
- Financial Management Services
- Homemaker Services
- Living Start-up Costs
- Massage Therapy
- Medication Monitoring
- Non-medical Transportation
- Personal Assistance
- Personal Budget Assistance
- Residential Habilitation
- Respite Care
- Specialized Medical Equipment
- Supported Employment
- Supported Living
- Waiver Support Coordination



Use this QR code to access information about the Community Supports Waiver.

<https://bit.ly/3IEdk6n>

## Community Transitions Home

This waiver is designed to provide services statewide to help persons with intellectual disabilities or related conditions transition out of an Intermediate Care Facility for People with Intellectual Disabilities (ICF) and into community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program.

### Eligibility Requirements

- Meet level of care criteria for admission to an ICF
- Onset of condition must occur before age 18 for intellectual disabilities
- Onset of condition must occur before age 22 for other related conditions
- Demonstrate functional impairment in 3 or more areas of major life activity
- Meet financial eligibility requirements for Medicaid

### Limitations

- Number of individuals served based on funding
- Individuals can use only those services they are assessed as needing

### Waiver Services

- |  |                                 |
|--|---------------------------------|
| • Behavioral Consultation                    | • Massage Therapy               |
| • Center-Based Prevocational Services        | • Medication Monitoring         |
| • Chore Services                             | • Non-medical Transportation    |
| • Community Transition Services              | • Nursing Services              |
| • Companion Services                         | • Personal Assistance           |
| • Day Supports                               | • Personal Budget Assistance    |
| • Emergency Response Systems                 | • Residential Habilitation      |
| • Environmental Adaptations                  | • Respite Care                  |
| • Extended Living Supports                   | • Specialized Medical Equipment |
| • Family/Individual Training and Preparation | • Supported Employment          |
| • Financial Management Services              | • Supported Living              |
| • Homemaker Services                         | • Waiver Support Coordination   |



Use this QR code to access information about the  
Community Transitions Home.

<https://bit.ly/3Aljx6P>

## Limited Supports Waiver (LSW)

This is a lifelong program for individuals with intellectual disabilities, other related conditions, or acquired brain injuries. It is designed to provide services throughout the state which help people of all ages to remain in their homes and be able to direct their support services and live as independently as possible.

- This waiver has an individual spending cap of \$16,400 per year and limited service options to allow people with disabilities, their families, and support teams flexibility in determining and changing needed services.
- This program serves a limited number of individuals based on available funding.
- There is a waiting list for this waiver program. Individuals interested in a more comprehensive waiver are able to receive LSW services while waiting for enrollment on other waivers.

### Eligibility

- Must meet financial eligibility requirements for Medicaid, and
- Be eligible for Division of Services for People with Disabilities (DSPD) services with an intellectual disability, related condition, or acquired brain injury level of care
- Must be able to live safely in the community and can be healthy and safe while using the LSW.

### The Process

- A support coordinator meets with you and educates you about what services are available on the LSW and answers questions about what you want and need. You can bring anyone you want to help you answer the questions.
- Choose what service delivery you want to use, Self-Administered Supports (SAS) or contracted services providers.
- Enroll in (SAS) services and hire your employees and/or meet with services providers and choose whom you want to work with.
- Create goals that are important to you.
- Monitor ongoing services and change them when needed.

### Waiver Services

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Assistive Technology</li> <li>• Attendant Care (In-person &amp; via Telehealth)</li> <li>• Behavior Supports</li> <li>• Family &amp; Individual Peer Support</li> <li>• Environmental Adaptations (Home &amp; Vehicle)</li> <li>• Financial Management Services</li> </ul> | <ul style="list-style-type: none"> <li>• Individual Goods &amp; Services</li> <li>• Integrated Community Learning</li> <li>• Non-medical Transportation</li> <li>• Remote Supports</li> <li>• Respite</li> <li>• Specialized Medical Equipment</li> <li>• Supported Employment</li> <li>• Waiver Support Coordination</li> </ul> |
|---|--|

## Medically Complex Children's Waiver

This program provides medical assistance to children who are medically complex. This waiver serves the following population:

- Children ages 0-18
- Children who have 3 or more specialty physicians
- Children who have 3 or more organ systems involved in their disability
- Children who are not meeting age-appropriate milestones for their activities of daily living; this includes eating, toileting, dressing, bathing, and mobility
- Children who have a SSI Disability Designation through the SSA or a disability determination by the State Medical Review Board, this will be coordinated as part of the MCCW application process

## New Choices Waiver

Is designed to serve individuals who are residing long term in a nursing facility, licensed assisted living facility, licensed small health care facility, or another type of Utah licensed medical institution (except institutions for mental disease). The program offers an option for these individuals to move into integrated community-based settings if they wish to do so and if their needs can be safely met in the setting that they have chosen. When an individual is enrolled in the New Choices Waiver program, they may receive an expanded package of supportive services through Medicaid which are intended to help with community-based living. Individuals can only access the services that they have been assessed to need. For more information on eligibility and application information visit the following site.



<https://bit.ly/3myUi9a>





## Physical Disabilities Waiver

Is designed to provide services statewide to help people with physical disabilities remain in their homes or other community based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program. It is designed to be consistent with a service delivery system that promotes and supports participant self-determination. Further information regarding limitations and services can be found at: <https://medicaid.utah.gov/ltc-2/pd/>

### Eligibility Requirements

- Be 18 years of age or older
- Have a physician certify the physical disability of the individual
- Have a physical impairment resulting in the functional loss of 2 or more limbs, and requiring at least 14 hours per week of personal assistance
- Be capable of selecting, supervising, and training his/her attendant
- Be capable of managing his/her own financial and legal matters
- Require nursing facility level of care
- Meet financial eligibility requirements for Medicaid
- Have at least one personal attendant trained (or willing to be trained) and available to provide the authorized waiver services in a residence that is safe and adequately equipped for the care of the individual



## Technology Dependent Waiver

Is responsible for the Medicaid delegated administrative activities for children and families served under the home and community-based waiver program to ensure services and supports are available to safely care for participants at home. <https://medicaid.utah.gov/ltc-2/tech/>



Only a limited number of children may be served at any point in time by this program. A child may qualify but be placed on a waiting list until an opening is available.



### Eligibility Requirements

- Be under 21 years of age at the time of admission.
- Qualify for Medicaid based on his/her income and assets (parent's income and assets are not counted in determining the applicant's eligibility).
- Meet admission criteria for nursing facility (NF) care.
- Have at least one caregiver trained and available to provide care.
- Require skilled nursing and/or rehabilitation services at least five days per week and be dependent on one or more of the following:
  - a mechanical ventilator;
  - tracheostomy based respiratory support;
  - continuous or bi-level positive airway pressure support (C-PAP or Bi-PAP); or
  - intravenous administration of nutritional substances or or medications through a central line.
- Choose to receive home and community-based (instead of nursing facility) services.

In addition to receiving "traditional" Medicaid benefits, recipients also receive the following "waiver" supports and services as needed in order to prevent institutionalization.

- Skilled Nursing Respite Care
- Family Support Services
- Home Health Certified Nursing Assistant
- Extended Private Duty Nursing
- In-Home Feeding Therapy
- Financial Management Services
- Family Directed Support

## Technology Dependent Waiver Continued...

Qualified waiver providers include Medicaid enrolled, licensed home health agencies that employ or contract with nurses, home health aides, licensed therapists, and certified child life providers who are capable of providing services to technology-dependent, medically fragile individuals in their homes and other approved community-based settings. Services may also be provided by Family-Directed Services. Families may hire individual employees to perform certain services. The family is responsible to manage the employee, training, scheduling, and assuring timesheet accuracy. The Family-Directed service method requires the use of Financial Management Services to assist with financial responsibilities.

**For more information on any of the Home and Community-Based Services (HCBS) Waiver Programs in Utah Please visit:**



<https://bit.ly/3INKNva>

**Or, for addition help, reach out to the UPC and ask to speak with our Utah Family Voices Project.**



## Additional Health Resources

### Additional Health Transition Resources

Use this link to find programs that help adolescents with chronic diseases or disabilities make a successful transition to adult health care providers. There is usually a period of co-management during which a child is seen by pediatric specialists and adult providers; and an adult care plan is generally developed by the team to document current diagnoses and therapies, and lay out guidelines for the frequency of medical visits to specialists and primary care providers, the role of each adult provider in the overall care plan, and the frequency of lab studies and other clinical evaluations.

### Utah Medical Home Portal Adolescent Health Transition Programs



<https://bit.ly/3QWi6Sl>



# Resources to help your young adult make important choices about their health

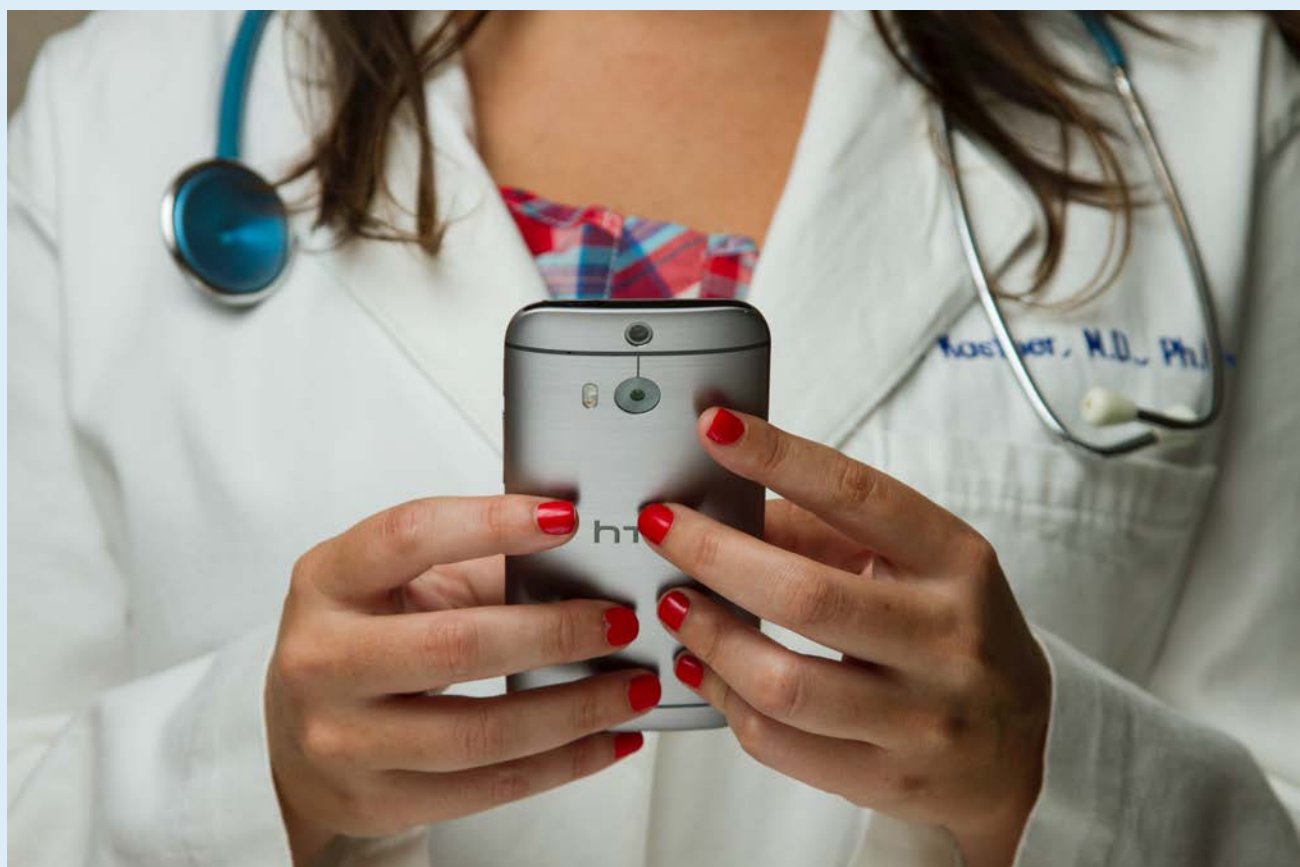
## Don't forget about Telehealth

Sometimes called telemedicine - lets your doctor provide care for your child without an in-person office visit. Telehealth is done primarily online with internet access on your computer, tablet, or smartphone.

There are several options for Telehealthcare:

- Your child is able to talk to their doctor live over the phone or video chat.
- Send and receive messages from their doctor using secure messaging, email, and secure file exchange.
- Use remote monitoring so their doctor can check on them at home. For example, you might use a device to gather vital signs or other vitals to help your doctor stay informed on your progress.

This may be a good option for individuals who have anxiety about leaving the home, have compromised immune systems, or find it challenging to get to a doctor's office. Telehealth can be very convenient for patients and allows for appointments to take place from anywhere.

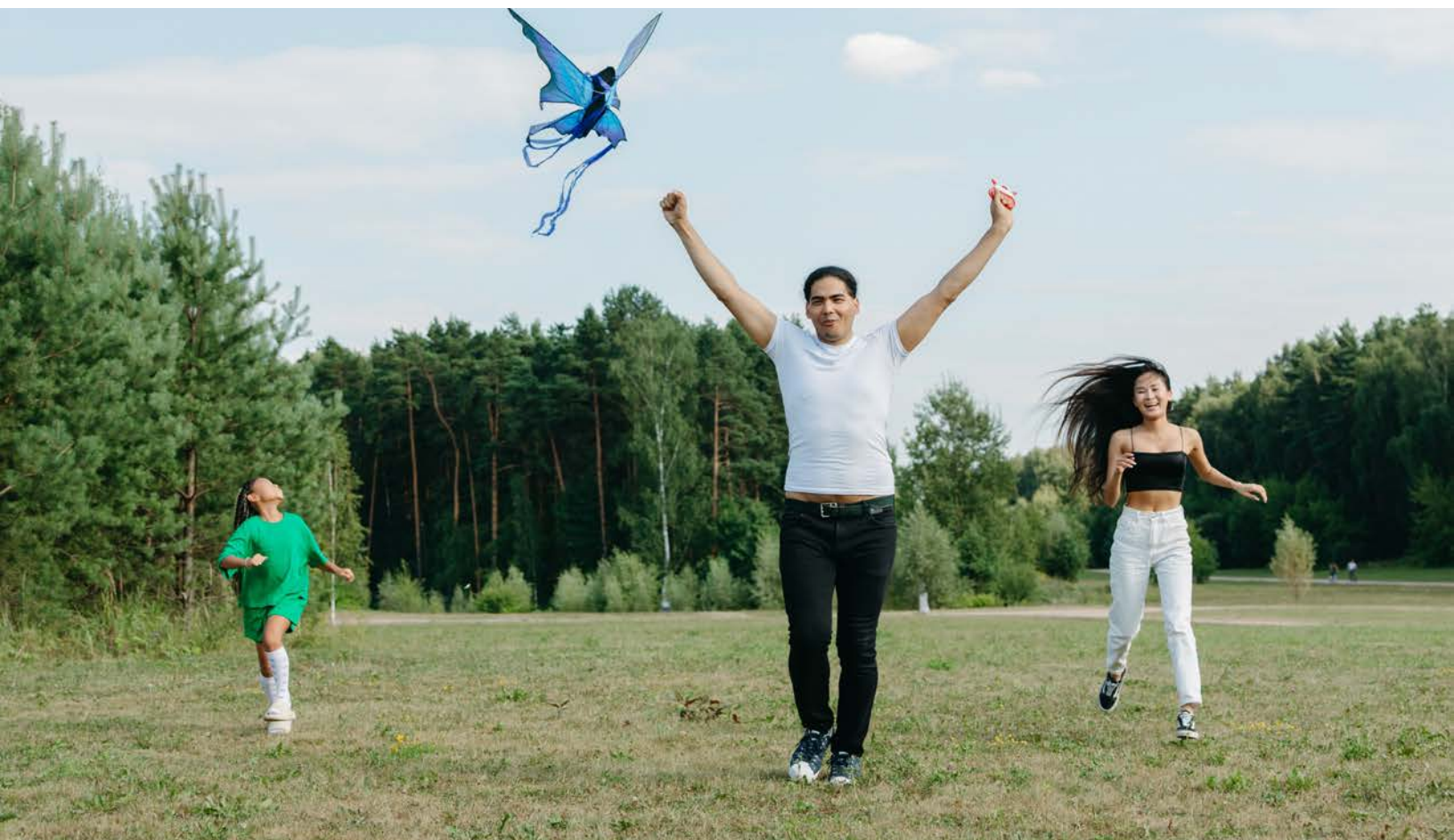




## Healthy Living and Charting the LifeCourse

Health is connected closely to many other life domains. If your child isn't healthy, they might not be able to have the job they want or be able to live where they would like. They might not be able to spend time with family and friends or be involved in the community and other desired activities. Planning for and looking after one's health and wellness can be an important factor in living the kind of life that your young adult wants. Making sure they get proper medical care, paying attention to nutrition and fitness, and looking after their mental health are all part of healthy living. Living a healthy life and keeping our bodies in good working order can take some planning and effort.

The Healthy Living LifeCourse tools will help you have conversations with your young adult, explore a vision, and plan experiences and supports to achieve a healthy life.



**Access Charting the LifeCourse**

<https://bit.ly/3rnbl0s>

## HEALTHCARE AND AN EXAMPLE OF HOW TO USE SUPPORTED DECISION-MAKING (SDM) WITH YOUR YOUNG ADULT

Youth with disabilities may need assistance making decisions regarding their health care. Although, they may not necessarily need a guardian to make those decisions for them. A trusted network of supporters can field questions and review options to help the person with the disability make their own decisions.

***In this scenario, your young adult, Jordan, has just visited the doctor to discuss Jordan's ongoing challenges. Jordan has been given a few options. Jordan can begin taking medication to try and delay surgery. Jordan can have a minor procedure to try and alleviate discomfort. Or, Jordan can opt for surgery now to correct the problem, but the recovery will be extensive. How can Jordan utilize SDM to make healthcare decisions?***

### 1 Select Supporters

Supporters are selected by the youth with the disability. They can be family members, co-workers, friends, and past or present providers. The individual should select supporters who know and respect his or her will and preferences, and who will honor the choices and decisions the individual makes. Supported Decision-Making is flexible, and can be adapted to meet an individual's situation and needs. The process is unique and customizable for each individual depending on his/her wants, needs, goals, and dreams. Remember Supported Decision-Making is not recognized as a legal agreement in Utah.

### 2 Decide How Supports Will Help

The supporter can help Jordan understand complex medical language and the potential side effects of taking medication. The supporter can help Jordan evaluate the pros and cons of each option. Supporters will help Jordan explain wishes and decisions in a clear way to Jordan's medical providers.

**The key is the person with a disability makes the decision about their own health care, with any requested assistance from the supporter.** It is important the supporter listens to Jordan and that the doctor and the supporter don't ignore or disregard Jordan in the decision-making process.

# PROVIDER HEALTHCARE TRANSITION TOOLKIT FOR PEDIATRIC PATIENTS GRADUATING TO ADULT CARE

This transition toolkit has been created to assist in the process of transitioning patients from pediatric-oriented healthcare to adult-oriented healthcare. The foundation for this toolkit has been modeled after the Got Transition® framework. This toolkit provides essential documents and information to help get your young adult started in the transition process.

## Transition Toolkit



<https://bit.ly/3xl3h2l>

## Understanding Health Insurance



<https://bit.ly/InsureVid>

How can I help my young adult with disabilities understand health insurance? This video explains the basics of insurance.

At age 26, when young adults leave their parents' insurance, they can either apply for Medicaid if they don't have it already or buy insurance from the Marketplace.

## Marketplace Insurance



<https://bit.ly/36P92Mf>



## Key things to know when transitioning from pediatric to adult health care:



- Are you ready?
- What are the timelines?
- How can you prepare?
- Who can help?

<https://bit.ly/UDOHtransition>



# Mental Health & Healthcare Resources

## Utah Suicide & Crisis Line 800-273-TALK or Dial 988

The Utah Suicide and Crisis Line provides compassionate support. We give referrals to anyone in need of mental health or emotional wellbeing services. Whatever age you are, you can call for help 24 hours a day, 7 days a week, 365 days a year. There is no cost. We have interpreters in more than 150 languages to help. The line is managed and staffed by certified crisis workers at the Huntsman Mental Health Institute (HMHI). This 800 number recognizes the area code of caller ID and transfers Utah area code numbers to the Utah team. If you are calling from a non-Utah area code, but you want a Utah response, call the local number 801-587-3000.



## CALL-UP: for Utah Medical Professionals

Utah now has a state-wide psychiatric consult service. HMHI (formerly UNI) has teamed up with the Utah State Division of Substance Abuse and Mental Health to create the Consultation Access Link Line to Utah Psychiatry (CALL-UP). CALL-UP is a new legislative-funded program designed to address the limited number of psychiatric services in Utah and improve access to them. This state program will help serve patients at no cost to providers or patients in the state of Utah. The goals of the program are to:

1. Optimize primary care providers' ability and confidence to diagnose and treat mild to moderate mental health issues;
2. Improve quality of care and health outcomes for patients by affording early interventions;
3. Promote and improve mental health and physical health integration; and
4. Ensure appropriate referrals for individuals with serious behavioral health concerns.

This psychiatry consult program will support primary care providers in meeting the treatment needs for their patients' mental health. Staff is available Monday - Friday from 12:00 pm to 4:30 pm by calling: 801-587-3636. Or the email is: [Callup@hsc.utah.edu](mailto:Callup@hsc.utah.edu)



## Warm Line 833-SPEAKUT (833-773-2588)

Talk to someone who's been there before and understands. Sometimes you may need a supporter as you heal and recover from your own personal struggles. If you need to talk with someone, you can call the Utah Warm Line for that support. The Utah Warm Line is free for all callers. When you call the Utah Warm Line, you will speak with a certified peer support specialist. Our peer support specialists have gone through specialized training. They have also lived through experiences like yours—mental illness and substance misuse that is disrupting your happiness. Call for support today!



**Utah's Mental Health Agency** - OSUMH  
Office of Substance Use and Mental Health



<https://dsamh.utah.gov/>

**Take Care Utah**, a Utah Health Policy Project initiative, is a network of <https://bit.ly/36P92Mf> nonprofit organizations focused on helping people with health insurance. It consists of about 50 enrollment specialists all across Utah. All services are provided free of charge. For any additional questions about Take Care Utah, contact Utah Health Policy Project (UHPP).



<https://takecareutah.org/>

## SafeUT App

Download the SafeUT and crisis prevention 24/7/365 to students, parents, educators and others. You can chat with a licensed counselor for support or submit a confidential tip right from your smartphone, or call 833-372-3388 to talk about what is on your mind.

## Stabilization & Mobile Response (1-833- SAFE-FAM)

For families with children/youth ages 0-20 experiencing mental health challenges. Over-the-phone support and problem-solving, mobile response services, and in-home stabilization services to help your family stabilize and self-manage future challenges. Free, family guided, and youth-driven. <https://hs.utah.gov/smr>

## Live On! Campaign

Statewide effort to prevent suicide by promoting education, providing resources, and changing our culture around suicide and mental health. Together we can get through, reach out, lift up, look ahead, and Live On. <https://liveonutah.org/> Like on Facebook. Follow on Instagram.

## Emotional Health Relief Line - 833-442-2211

Intermountain Healthcare is offering a free emotional relief hotline for anyone who needs mental health support related to COVID19. Caregivers are available 10AM to 10PM, 7 days a week.

## Healthy Minds Utah - TAKE A SCREENING

If you are concerned about yourself or someone you love, take a few minutes to complete an anonymous self-assessment.



<https://bit.ly/35l4P2C>

## myStrength

A free, online tool to help you live your best life. You'll find help for stress, anxiety, chronic pain and more. It's safe, secure and personalized – just for you. Track your health, enjoy activities, and become inspired. myStrength has recently added resources and supports surrounding COVID-19 and the behavioral health needs that you may have during this time.



<https://dsamh.utah.gov/>

## To learn about other Utah resources for crisis and suicide prevention, visit:

**National Alliance on Mental Illness (NAMI)**  
<https://www.namiut.org/>



**American Foundation on Suicide Prevention  
Utah Chapter** <https://afsp.org/chapter/utah>



**Utah Strong Recovery** 385-386-2289 (call or text), Email [utahstrong@utah.gov](mailto:utahstrong@utah.gov)  
If you or someone you know is experiencing stress, anxiety or depression because of COVID19, talk with a crisis counselor 7 days a week, 7AM to 7PM. All information is confidential and free of charge.

**Crisis and Suicide Prevention, Utah**  
<https://bit.ly/3JPbpgU>



### **Caring Connections**

The University of Utah, College of Nursing offers a variety of grief support groups throughout the year. Each support group is designed to help you cope with a different kind of loss and grief, including suicide. The groups are eight weeks in length and are facilitated by expert clinicians in the fields of social work, nursing, counseling, and psychology.

<https://bit.ly/3KCRIhx>



For additional resources in the human services/social services area, please call 2-1-1 or see <https://211utah.org/>





## It is our hope...

Helping our youth prepare for and transition from their teen years to adulthood can be stressful and overwhelming. As a caregiver, you may not know where to even start. It is our hope that this Choices booklet, along with the UPC's Youth Transition Workbook, Guide to Guardianship, and the other UPC Transition resources will help to guide you as you make critical decisions about the future.

Every young adult would like to live as independently as possible. They deserve our best at this monumental time of their life. At the Utah Parent Center, we strive to provide the most impactful and valuable resources available. This book was created to be a support for you and your young adult so you can be as successful as possible as you navigate this period of change.

Please reach out to the Utah Parent Center with any questions or concerns. We are parents helping parents.





# Notices and Acknowledgements



The development and update of information in this resource book have been completed with funding from multiple state and federal funding sources over time. The contents of this resource book were developed by Transition University (TU), with input from TU's Interagency Workgroup, and the Special Abilities Network, with funding from the following sources:

- A grant from the US Department of Education, #H328M200028, and funding from the Utah State Board of Education. However, the contents do not necessarily represent the policy of the US Department of Education nor the Utah State Board of Education, and you should not assume endorsement by the Federal Government or the State of Utah. The information is in the public domain unless otherwise indicated and may be duplicated with proper credit to the Utah Parent Center as the source.
- A grant by the Health Resources and Services Administration (HRSA) of the U.S. Dept. of Health and Human Services (HHS) as part of an award to Utah Family Voices Family to Family Information Center, a project of the Utah Parent Center, Grant Award # H84MC07996. The contents do not necessarily reflect the official views of, nor an endorsement by HRSA, HHS, or the U.S. Government.
- This work is supported by the Utah Developmental Disabilities Council, grant number 2101UTSCDD-02, from the U.S. Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$632,214.00 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.
- In addition, private grants funded through the Sorenson Legacy, Williamson Family, and Miller Family Foundations and a corporate grant from doTerra supported this work.

Credit has been given where necessary to other sources where information was taken. If no credit is given to a specific piece of information, it was developed by the Utah Parent Center and already contained within our resources. Any information used in this publication should be given proper credit as to sourcing.

This information has been independently reviewed by a financial planner and an attorney licensed in the state of Utah. Although the content has information provided by the Utah Courts and cites Utah regulations, the information contained in this publication should not be interpreted as legal advice. Every effort is made to provide accurate and complete information. All consumers are responsible to investigate further and make individual informed decisions for themselves.



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