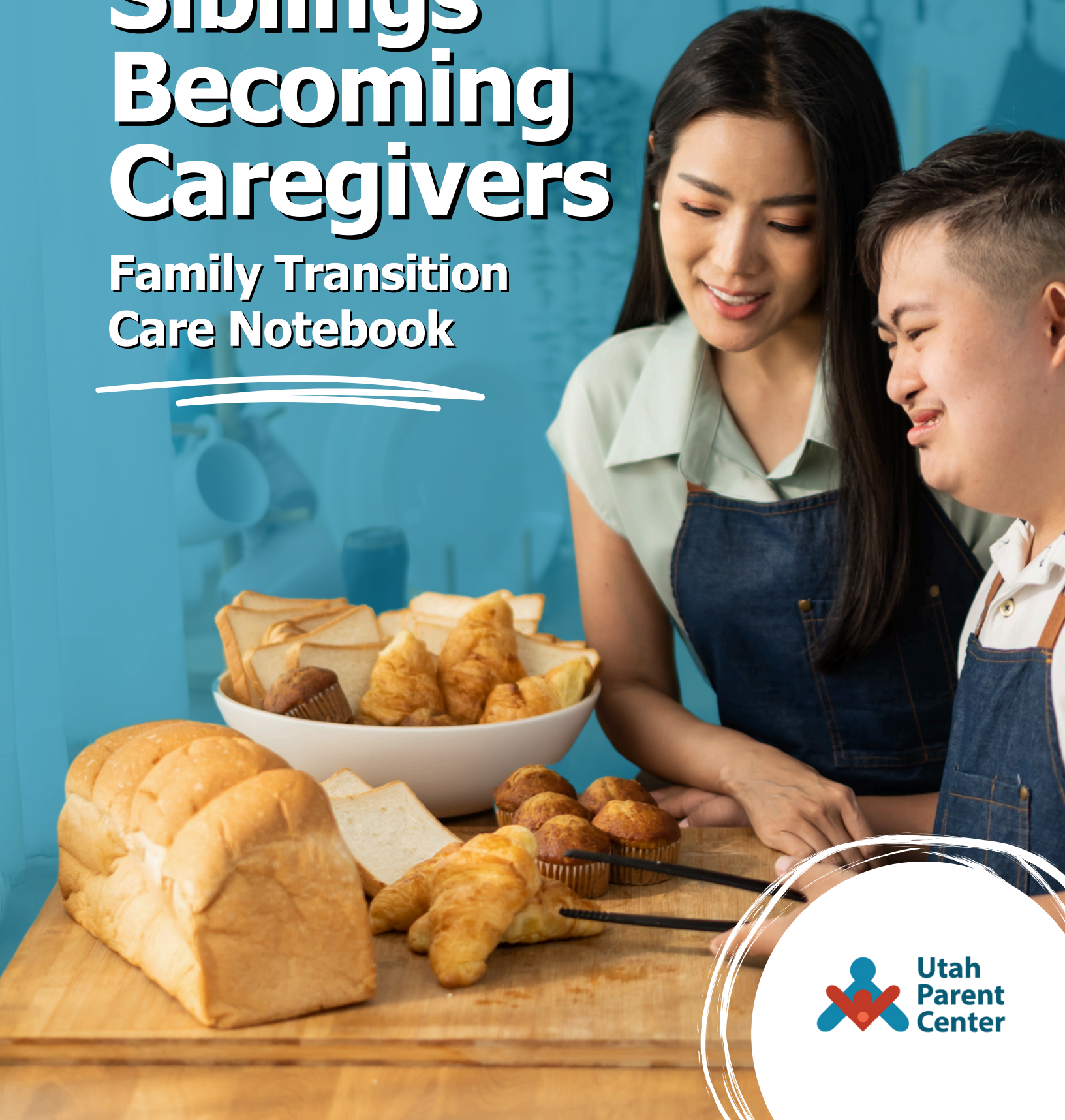


The Sibling Project Presents

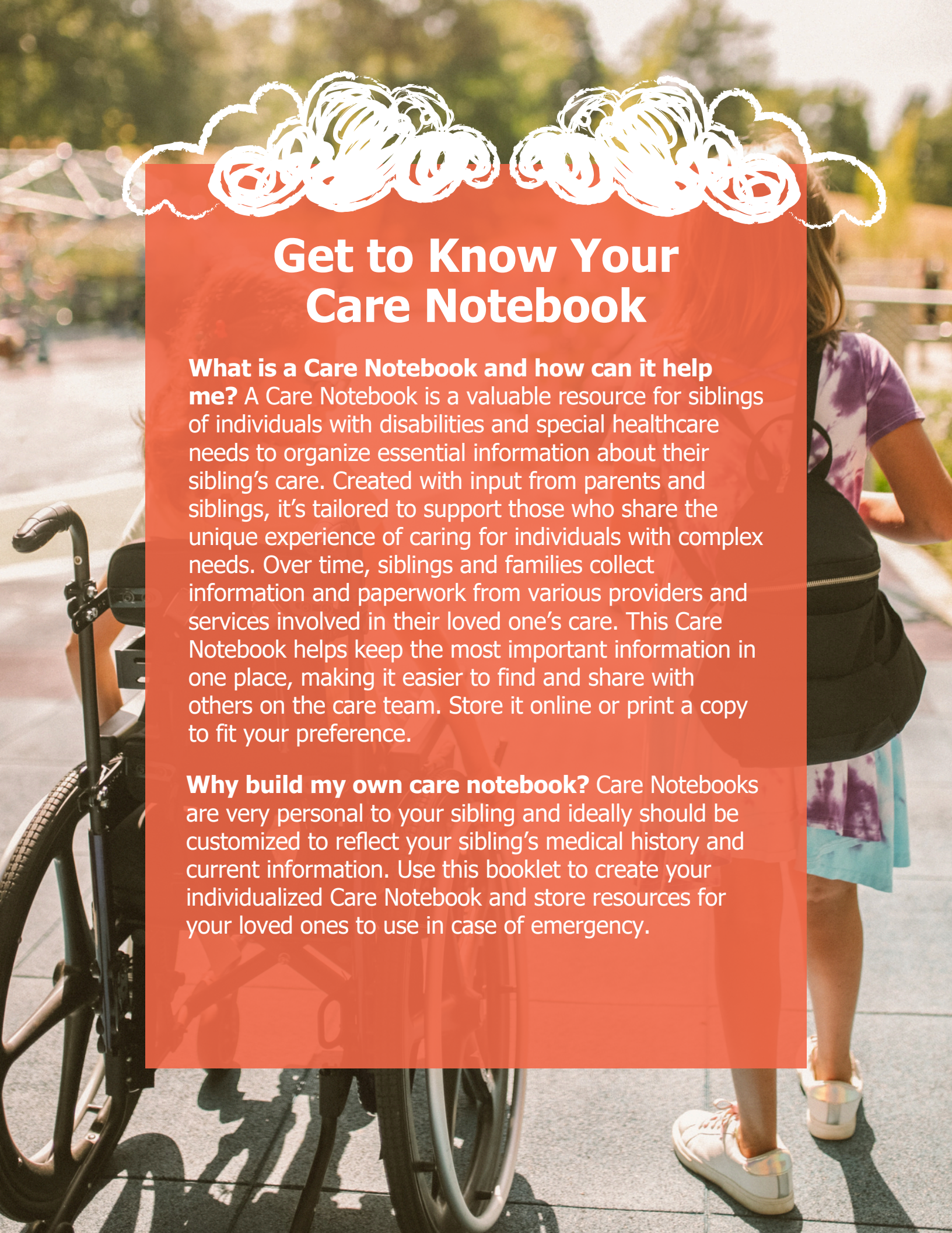
# Siblings Becoming Caregivers

Family Transition  
Care Notebook

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# Get to Know Your Care Notebook

**What is a Care Notebook and how can it help me?** A Care Notebook is a valuable resource for siblings of individuals with disabilities and special healthcare needs to organize essential information about their sibling's care. Created with input from parents and siblings, it's tailored to support those who share the unique experience of caring for individuals with complex needs. Over time, siblings and families collect information and paperwork from various providers and services involved in their loved one's care. This Care Notebook helps keep the most important information in one place, making it easier to find and share with others on the care team. Store it online or print a copy to fit your preference.

**Why build my own care notebook?** Care Notebooks are very personal to your sibling and ideally should be customized to reflect your sibling's medical history and current information. Use this booklet to create your individualized Care Notebook and store resources for your loved ones to use in case of emergency.





## **Tips for Using Your Care Notebook**

**Fill out your care  
notebook ASAP**

**Tell family & other  
siblings where  
this notebook is  
located in case of  
emergency**

**Store your  
notebook in an  
easy to find  
location**

**Update this notebook at least once a year.  
To make it easy, you could do it every year  
on your sibling's birthday.**



## FAMILY TRANSITION CARE NOTEBOOK

# CONTENTS

### IN CASE OF EMERGENCY

- Me, My Sib, and Our Family
  - My Sib & Me
  - Our Goals
  - Our Supports
  - Supported Decision Making

### HEALTHCARE

- You're a Caregiver, Now What?
- Online Logins
- Natural Supports
- Insurance & Coverage
- Professionals
- Medications & Pharmacy
- Nutrition & Allergies
- Medical Supply Information
- Durable Medical Equipment
- Dental & Orthodontist

### ACCESS & ACCOUNT INFO

- Phone & Finances

### LEGAL & FINANCIAL INFORMATION

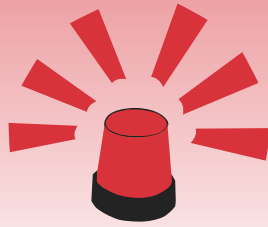
- Disability Rights Laws
- Transition University Resources
- Guardianship & Alternatives
- SSI/SSDI
- Financial Supports
- Parent's Will & Final Arrangements

### MENTAL HEALTH

- Mental Health and Healthcare Resources
- Help Lines
- Iceberg???
- Notices & Acknowledgements







# In Case of Emergency

Name: \_\_\_\_\_

Preferred Name: \_\_\_\_\_

Birthday: \_\_\_\_\_

Primary Diagnosis: \_\_\_\_\_

Medical Needs & Special Considerations (ie - do they wear oxygen, prone to seizures, etc.)  
\_\_\_\_\_

Essential Medications: \_\_\_\_\_

Preferred Hospital: \_\_\_\_\_

Allergies (Medication Specific): \_\_\_\_\_

Allergic to Pencillin  Yes  No

Medication Sensitivities: \_\_\_\_\_

## The First 90 Days

Emergencies can happen when you least expect them. This page is here to help you feel prepared and confident, if you suddenly need to step in and take care of your sibling with a disability. Go through this workbook and, if there's any other essential information one would need to care for your sibling, add it here:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# Me & My Sib

Child's Name: \_\_\_\_\_ Pronouns: \_\_\_\_\_

Nickname: \_\_\_\_\_

Age: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

(If you don't have a diagnosis, that's okay! It's important to remember your own physical, mental, or emotional needs.)

Likes: \_\_\_\_\_

Dislikes: \_\_\_\_\_

Favorite Food: \_\_\_\_\_

Favorite Color: \_\_\_\_\_

Hobbies: \_\_\_\_\_

Bucket List: \_\_\_\_\_

Dream Vacation: \_\_\_\_\_

I like to calm down by: \_\_\_\_\_

I like to prioritize myself by: \_\_\_\_\_

My needs feel met when: \_\_\_\_\_

# Me & My Sib

Child's Name: \_\_\_\_\_ Pronouns: \_\_\_\_\_

Nickname: \_\_\_\_\_

Age: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

(If you don't have a diagnosis, that's okay! It's important to remember your own physical, mental, or emotional needs.)

Likes: \_\_\_\_\_

Dislikes: \_\_\_\_\_

Favorite Food: \_\_\_\_\_

Favorite Color: \_\_\_\_\_

Hobbies: \_\_\_\_\_

Bucket List: \_\_\_\_\_

Dream Vacation: \_\_\_\_\_

I like to calm down by: \_\_\_\_\_

I like to prioritize myself by: \_\_\_\_\_

My needs feel met when: \_\_\_\_\_



# Our Goals

The tools on the next few pages can help identify the level of support your sibling needs to make important decisions, using three categories:

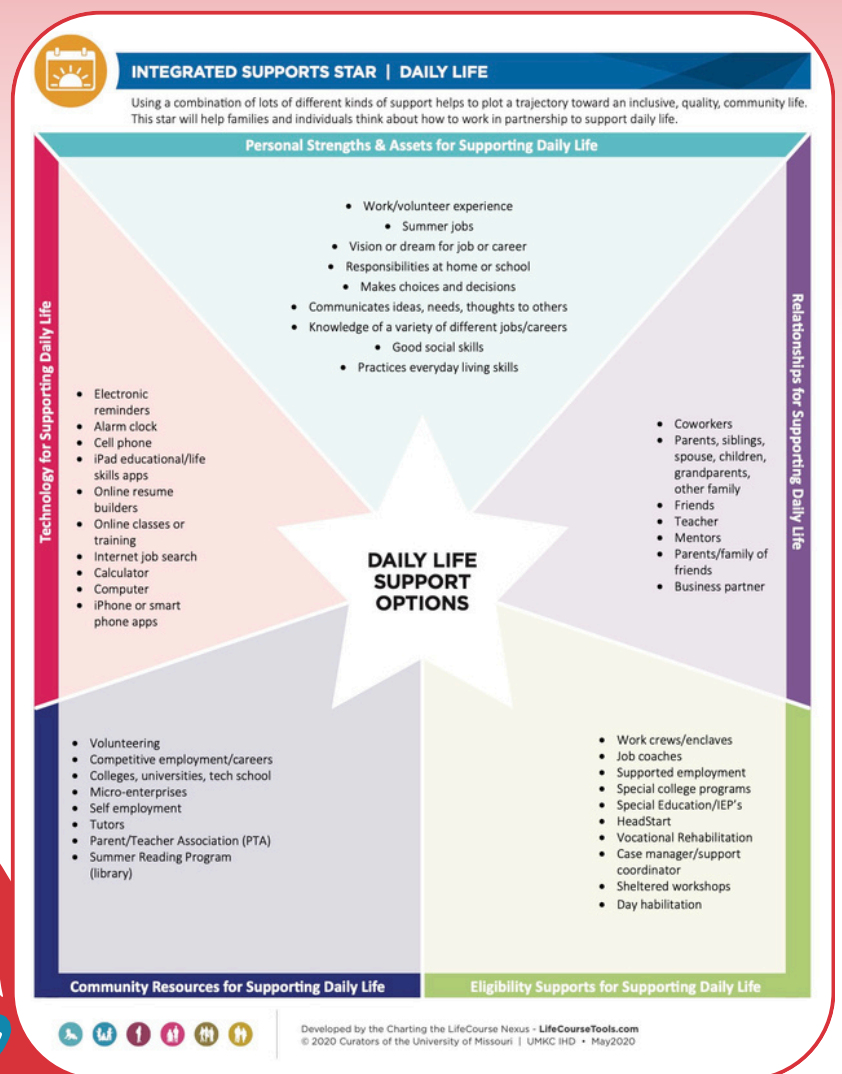
- 1 Independent decisions
- 2 Decisions with support
- 3 Decisions made by someone else.

Answer questions across life domains to determine support needs, spark deeper conversations, and set goals for building self-advocacy.

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



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







# 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? \_\_\_\_\_

<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>			
	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 >>







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?			



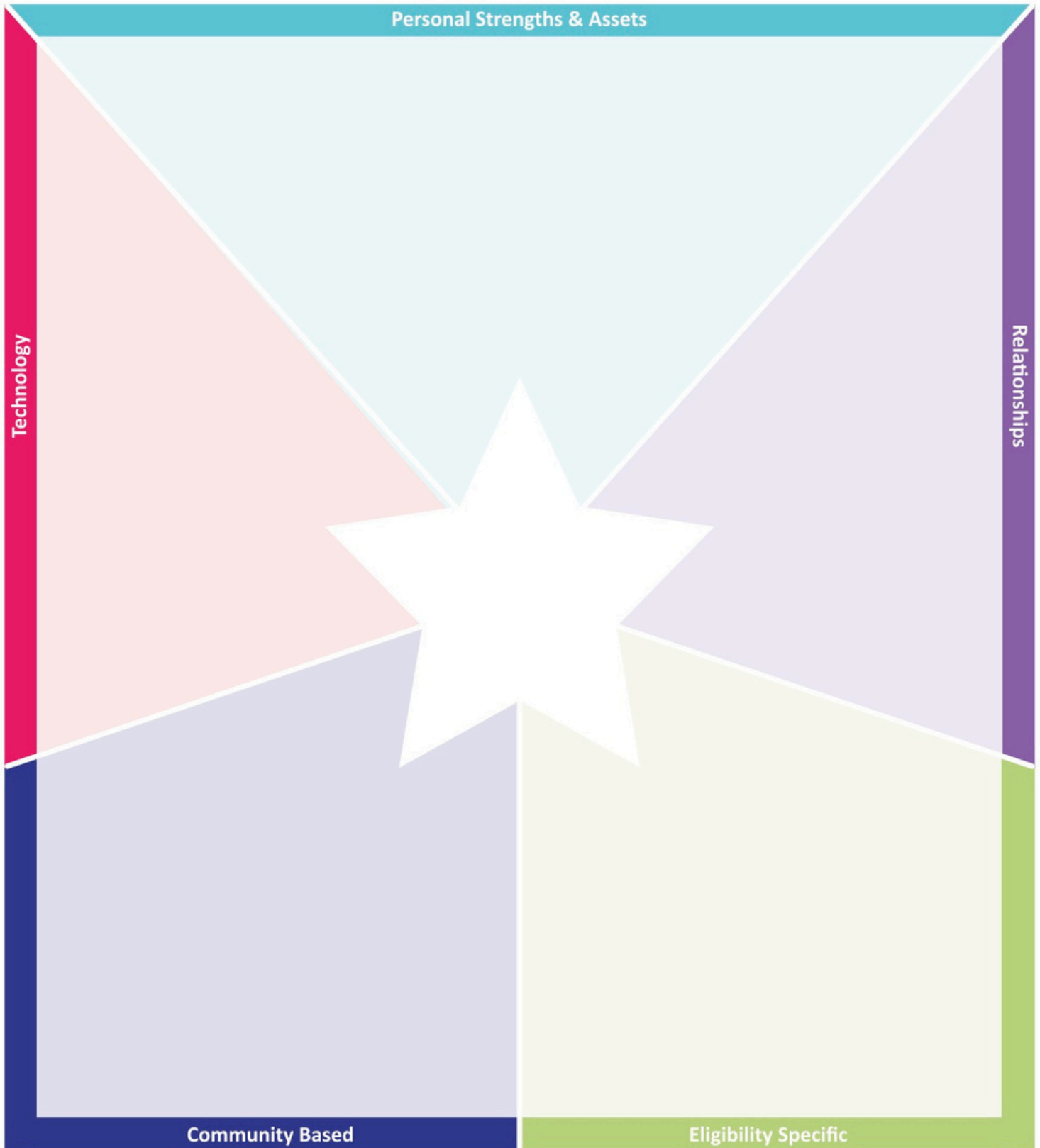
**Advocacy & Engagement**

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.)			





# INTEGRATED SUPPORTS STAR





## Creating a Supported Decision-Making Agreement.

- 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

## 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



A photograph of a family walking in a park. A young boy is seated in a wheelchair, holding the hand of a woman walking beside him. A man stands behind the wheelchair. The scene is overlaid with a semi-transparent red filter. The word "Healthcare" is written in large white letters across the center of the image.

# Healthcare

## 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





Bringing Hope  
Opening Doors  
Elevating Inclusion

# You're a Caregiver, Now What? Utah Family Voices Resources

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Each link below will take you to a resource on these topics. We try to keep our resources up to date. If you have a problem opening any of the links, we would appreciate you letting us know.

## Utah Family Voices



## Finding Quality Info



To speak with a staff member from Utah Family Voices  
please call 801-272-1068 or email [info@utahparentcenter.org](mailto:info@utahparentcenter.org)

# Online Logins

## U of U Mychart, IHC Myhealth, myCase, USOR, etc.

Disclaimer: This is not a secure way to save passwords.

Utah ID (used to log into all State portals and accounts) \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_

Website \_\_\_\_\_

Username \_\_\_\_\_

Password \_\_\_\_\_

Default Email or Phone Number \_\_\_\_\_





# Natural Supports

Transportation, Social Supports, etc.

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DSPD Application



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

Employment



<https://jobs.utah.gov>

Medicaid Waivers



<https://dspd.utah.gov/medicaid-waivers/>

SSI Application



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

UtahID



<https://id.utah.gov>



# Insurance/Coverage



Insurance Name: \_\_\_\_\_  
Policy Number: \_\_\_\_\_  
Contact Person/Title: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Website/Email: \_\_\_\_\_ Fax: \_\_\_\_\_  
Medicaid (ACO Name, if applicable. This is the company name above your child's name and ID number on the Medicaid Card): \_\_\_\_\_

Insurance Name: \_\_\_\_\_  
Policy Number: \_\_\_\_\_  
Contact Person/Title: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Website/Email: \_\_\_\_\_ Fax: \_\_\_\_\_  
Medicaid (ACO Name, if applicable. This is the company name above your child's name and ID number on the Medicaid Card): \_\_\_\_\_

## Basics of Insurance



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

## What is Medicaid?



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

## Medicaid Screening



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

## Utah Medicaid



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



# Professionals

**Doctors, Therapist, Case Workers, Social Workers, etc.**

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_

Specialist Name & Specialty \_\_\_\_\_  
Online Portal \_\_\_\_\_  
Address \_\_\_\_\_ City \_\_\_\_\_  
Phone \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_  
Notes \_\_\_\_\_





# Medication & Pharmacy

Preferred Pharmacy: \_\_\_\_\_

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

Telephone: \_\_\_\_\_

Medication	Prescription #	Reason for Medication	Start Date	End Date







# Medical Supply Information

Supply Companies	Product Description	Product Code	Quantity

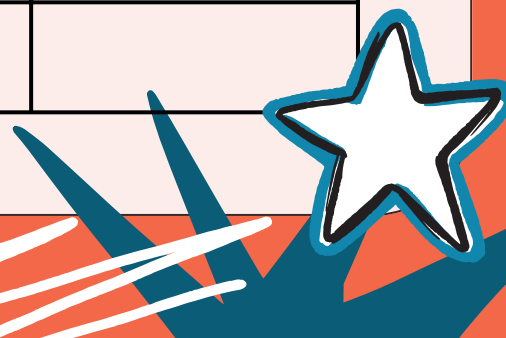






# Durable Medical Equipment

DME Prescription Number	Diagnosis Code	Physician	Follow Up Contact Details





# Dental & Orthodontist

Dentist's Name: \_\_\_\_\_

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

Telephone: \_\_\_\_\_

Dentist has been informed of child's medical condition and medical specialists

Orthodontist Name: \_\_\_\_\_

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

Telephone: \_\_\_\_\_

Ortho has been informed of child's medical condition and medical specialists

Dental Procedure History	Dentist / Ortho



A woman with her hair in a ponytail, wearing a ribbed turtleneck sweater, is clapping her hands in a classroom. In front of her is an open book. Other students are visible in the background, also clapping. The entire image has a semi-transparent orange overlay.

# **Access and Account Information**





# Phone Plan

Provider Name: \_\_\_\_\_  
Telephone: \_\_\_\_\_

Siblings have been added as an authorized user

# Finances

Banking Institution: \_\_\_\_\_

Siblings have been added as an authorized user

**Use the lines below to store other financial information like  
how to access trusts, ABLÉ accounts or estate plans.**

Disclaimer: This is not a secure place to store passwords.

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# Legal and Financial Information

Content for this section was taken from the Transition University Choices booklet and information from our partners at the Special Abilities Network.

Choices  
Book





Bringing Hope  
Opening Doors  
Elevating Inclusion

# Understanding Disability Rights Laws

---

Each link below will take you to a resource on these topics. We try to keep our resources up to date. If you have a problem opening any of the links, we would appreciate you letting us know.

## Americans with Disabilities Act



## Section 504



## IDEA







Bringing Hope  
Opening Doors  
Elevating Inclusion

# Transition University Resource Guide

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Each link below will take you to a resource on these topics. We try to keep our resources up to date. If you have a problem opening any of the links, we would appreciate you letting us know.

## Transition University



## Choices Book



## Guardianship Book



## Youth Workbook





**Utah Courts website  
for the Procedure  
for Appointing a  
Conservator:**



<https://bit.ly/3iyC0rn>

## What is Conservatorship?

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.



## What is Guardianship?

In Utah, individuals are considered legal adults at 18, even if they have disabilities impacting their decision-making. While many can make decisions with support, some may need guardianship for areas like healthcare or safety. Guardianship can adapt to changing abilities and circumstances. Parents or caregivers are often given preference, and the process in Utah is now simpler and more affordable.

**Guardianship Book:**



**Guardianship,  
Conservatorship,  
Power of Attorney  
Information:**



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

# Power of Attorney

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## What is a power of attorney?

A power of attorney (POA) is a legal document allowing one person (the principal) to give another (the agent) authority to act on their behalf in specific areas, such as finances or medical decisions.

There are two types:

- Durable, effective immediately, and
- Springing, which activates under specific conditions.

A POA can be broad or limited to tasks like handling bank accounts, managing property, or applying for benefits, but it does not cover all aspects of a person's life.



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



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



<https://bit.ly/UTpowerofattorney>



General Power of Attorney



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

# Differences between SSI and SSDI?

## SSDI

SSDI provides support to individuals with disabilities who have a qualifying work history, either their own or through a family member, based on disability and work credits. Disabled Adult Children (DAC) may qualify for benefits through a parent's 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)

Determining if my sibling is eligible for SSI / SSDI:



<https://ssabest.benefits.gov/>

A basic explanation of Special Needs Trusts and how they work. It is recommended you consult an attorney to set up a trust.



[bit.ly/NoloSNTrusts](http://bit.ly/NoloSNTrusts)

General information on ABLÉ accounts, including a brief video:



[bit.ly/WhatisABLE](http://bit.ly/WhatisABLE)



# 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 ABLA Account. However, there are limits on how much you can transfer into an ABLA 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 ABLA 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.

# Will vs A Living Will

## Traditional Will

A traditional will states what will happen to assets and property when an individual passes away. A living will, is a legal document designed to direct loved ones (agents) on how to handle certain aspects of the individual's life if they become incapacitated, such as healthcare.

## Living Will

A Living Will is a legal document that lays out an individual's 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.

## A Letter of Intent

A letter of intent outlines your sibling's future plan, including living arrangements, employment, social needs, medical history, and financial management. It addresses who will serve as trustee, manage benefits, and act as an advocate or guardian. While not legally binding, it helps ensure continuity of care and support by documenting your wishes and existing supports to guide others in your absence.

## Creating Final Arrangements

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

Ask your parents to include any other information you feel will help the you or your other sibling's provide the best possible care for your affected brother or sister. This letter should be placed with all other relevant legal and personal documents concerning your the affected sibling. Do not forget to sign and date the letter.

# Mental Health You & Your Sib

Content for this section was taken from the Transition University Choices booklet and information from our partners at the Special Abilities Network.

Choices  
Book





# 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)





**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 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/>

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

### 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!

### 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/>

## 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>

## 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.

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



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

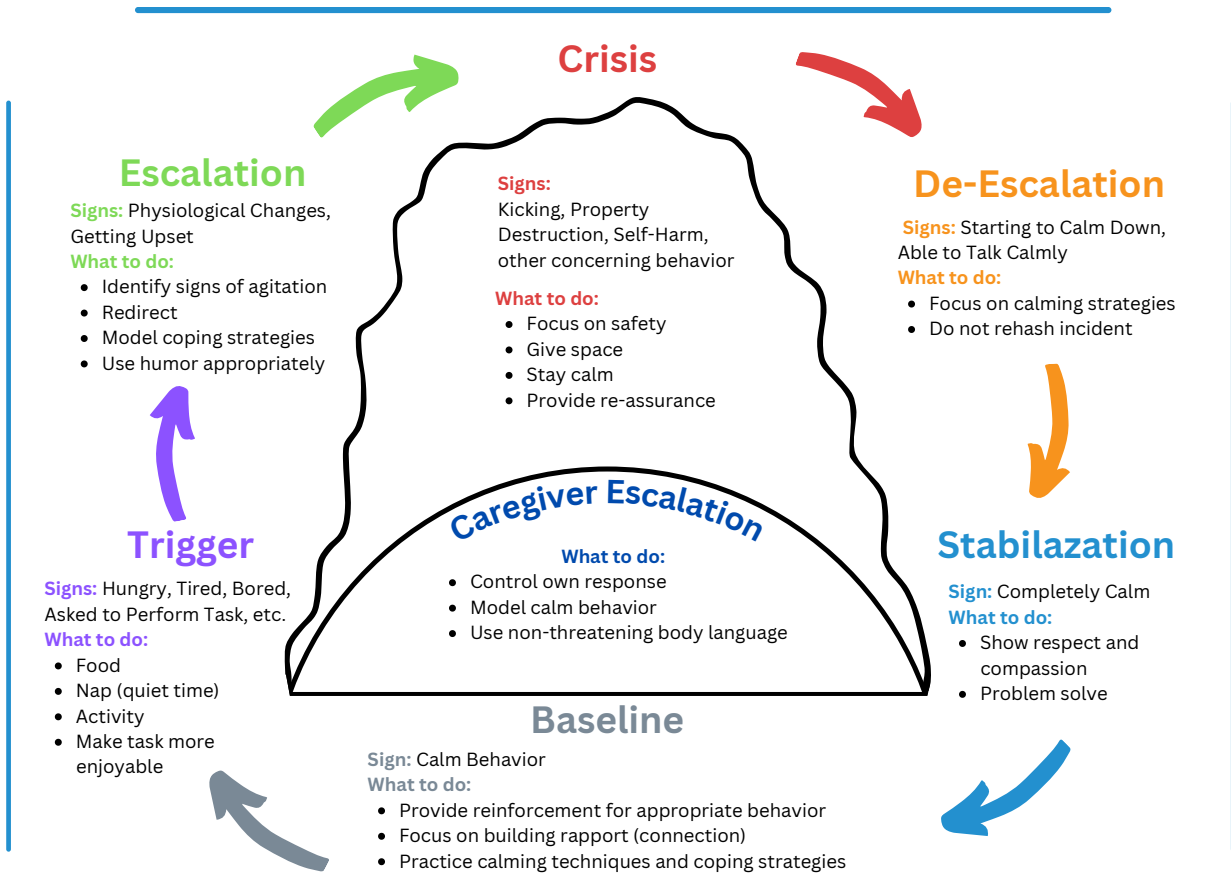


### **Caring Connections**

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>





**Escalation**  
**Signs:** \_\_\_\_\_  
**What to do:**

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- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Trigger**  
**Signs:** \_\_\_\_\_  
**What to do:**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Crisis**  
**Signs:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
**What to do:**

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- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**De-Escalation**  
**Signs:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
**What to do:**

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- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Stabilization**  
**Signs:** \_\_\_\_\_  
 \_\_\_\_\_  
**What to do:**

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- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Caregiver Escalation**  
**What to do:**

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- \_\_\_\_\_
- \_\_\_\_\_

**Baseline**  
**Signs:** \_\_\_\_\_  
 \_\_\_\_\_  
**What to do:**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



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**The Sibling Notebook was inspired by the archived  
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Medical Home Portal.**



**Scan to view the  
archived resources:**



Medical Home Portal

For more information from Utah Family Voices  
call 801-272-1068, visit [utahparentcenter.org](http://utahparentcenter.org),  
or email [info@utahparentcenter.org](mailto:info@utahparentcenter.org)

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