

# **A GUIDE TO UNDERSTANDING HOME & COMMUNITY BASED WAIVERS**



**Utah Parent Center**

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# CONGRATULATIONS!

## YOU ARE OFF THE WAITLIST!



*"We just had our first meeting with the DSPD person that helps us get ready to get services starting in December. It's so overwhelming to go from nothing to so many options! My head is exploding, but we'll get there. We're excited, overwhelmed, and grateful. We have no idea what we're doing!"*

*-New Waiver Family*

**Many families feel overwhelmed and confused when they come off the DSPD waitlist or they receive a one-time funding opportunity.**

The language is all new. Who is a support coordinator (SCE), and what is their role? How do I find providers? What if I want to change providers? How can I use my budget?

What is a Person-Centered Support Plan (PCSP) and why is it so important? What if I want to change my PCSP? What is the Settings Rule? What are budget codes? What is SAS?

We know you must have so many questions. We are here to help. We will answer all of these questions and more in this Home and Community-Based Services training resource. **The majority of this book is written for and to the person with disabilities. However, based on your situation, a family member might be the caregiver.** If you have questions, you can reach out to the Utah Parent Center at 801-272-1051 for support. Or contact your DSPD Temporary Transition Coordinator, your support coordinator, or DSPD Constituent Services. Constituent Services can be reached at 801-538-4091 or online at <https://dspd.utah.gov/>.

### How long will I have these services?

**As you age and your circumstances change, your services will be adjusted to meet your needs. In addition, your budget will change to match your identified needs and services. However, you need to stay financially eligible which we will discuss.**



# HELP ME UNDERSTAND BASIC WAIVER LANGUAGE

The language in this publication is directed to the individual with a disability. If you are a caregiver and are reviewing this information, please be aware of this viewpoint so you can apply this information to your situation as you review the material.

**HCBS** - Home and Community-Based Services (Medicaid Waiver Programs)

**(PCSP) Person-Centered Support Plan** - A plan that reflects the services and supports that are important to you and that meet your needs. Supports and services are identified through an assessment. The PCSP also reflects your delivery preference for supports and services.

**Providers** - Agencies and staff that provide services & supports.

**(SAS) Self-Administered Services** - A service option that allows a person to hire, train, and supervise employees to provide their support, and manage their allowed budget.

**(SCE) Support Coordinator External** - A person who helps individuals write a yearly Person-Centered Support Plan (PCSP) and will make sure individuals get their needed support.

**Setting** - Where individuals receive services.

**Supports** - Help or tools an individual needs to do something successfully  
Examples: respite, supported employment, residential supports, day programs, after-school, and respite





# THE PAST & HOW IT PAVED THE WAY FOR YOU



## Acknowledging the Past Helps Us Look to the Future

You have certain rights and entitlements while participating in any of the HCBS waivers. The purpose of the waivers is to help you participate fully in the community and lead a self-determined life. In the following pages, we'll give you important details about each waiver.

However, first, it is important to understand how the disability community arrived where we are today. Acknowledging the past will help you and your family members advocate for rights and access to services in the future.

## The Importance of Self-Advocacy & Advocacy

Advocacy is not always easy. In fact, it can be challenging at times. Advocacy requires knowledge, practice, and patience. There are multiple laws impacting individuals with disabilities. It is important to be aware of the different laws and their implications so you can understand your rights. Use this URL and QR code for more advocacy training and resources.

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



# KATIE BECKETT WAIVER

The Katie Beckett Waiver was instrumental in allowing individuals with disabilities to receive care and services outside of a hospital setting. In the time since the waiver has been established, more than a half-million children have received life-extending medical care at home under the Beckett Waiver. Improved medical technology, and close attention from nurses, aides, and parents – all made possible by the funding – have allowed these children to grow up with improved health, despite having severe disabilities. (The Katie Beckett Waiver is not currently available in Utah)

## Katie Beckett Story

Katie, a four-month-old baby, contracted viral encephalitis, leaving her partially paralyzed, unable to swallow, and barely able to breathe on her own. Her parents wanted to manage her care at home with a ventilator. However, insurance would only cover her care in a hospital or institution. Her parents began lobbying politicians and bureaucrats. The case led to what is known as the Katie Beckett Waiver.

Katie Beckett's story gained the attention of then president Ronald Reagan and showed the nation the absurdities of a system that will pay more to care for a child in a hospital but will not provide that child's family with the health coverage and support they need to care for the child at home, even when the cost is much lower.



## Disability Legislation

- Americans with Disabilities Act 1990 (ADA)
  - Olmstead Decision 1999
- The Rehabilitation Act Section 503, 504, & 508
- ADA Amendment 2008
- Individuals with Disabilities Education Act (IDEA)
- Workforce Innovation and Opportunity Act (WIOA)

# UNDERSTANDING THE PAST GUIDES THE FUTURE



## Olmstead Decision

In addition to the Katie Becket Waiver, the Olmstead Decision was instrumental for individuals with disabilities. Lois Curtis and Elaine Wilson were voluntarily admitted to a psychiatric unit in a state-run hospital. However, due to their disabilities, they remained institutionalized for many years after the completion of their treatment. They sued for their freedom and the resulting Supreme Court decision benefitted the entire disability community.

This decision reshaped the ADA and was the birth of supported decision-making for individuals with disabilities, specifically intellectual disabilities and developmental disabilities. The Olmstead Decision is often considered the most important decision in the history of disability rights. It was instrumental in moving individuals out of institutions and into the community.

Olmstead ruled that public entities must provide community-based services to those with disabilities when:

- Services are appropriate
- The person does not oppose community services
- They can be reasonably accommodated

### Olmstead Information

<https://bit.ly/3Wb1cC4>

<http://bit.ly/3lwTqF1>

## Continuum of Care

**Olmstead and the Katie Beckett Waiver made it possible to waive institutional care and to have services provided outside of an institution as well as in the community. Services are unique to an individual. For example, a person may live at home and only receive respite and support coordination whereas another individual may need full residential and full day support.**





# WHAT ARE THE 12 GUIDELINES IN THE SETTINGS RULE?

The Settings Rule was established in 2014 and is a vital part of the broader effort to promote community integration for people with disabilities. It prioritizes individual choice and full access to the community and offers individuals greater control over where they live, with whom, how they earn money, and how they spend their time including controlling their own schedule. People with disabilities have the same rights to make choices and access the broader community.

**In keeping with this rule, providers, organizations, and programs offering home and community-based services must meet the following requirements.**

1. The setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
2. The setting is selected by the person from among setting options including non-disability-specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences, and for residential settings, resources are available for room and board.
3. The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.





# THE SETTINGS RULE CONTINUED

4. The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
5. The setting facilitates individual choice regarding services and supports, and who provides them.
6. The person has a lease or other legally enforceable agreement.
7. The setting ensures the person has privacy in their sleeping or living unit including lockable doors, choice of roommates, and freedom to furnish or decorate the unit.
8. The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
9. The person can have visitors of their choosing at any time.
10. The setting is physically accessible to the person.
11. The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
12. The setting enforces the Home and Community-Based Settings Regulation requirements.

## Settings Summary

The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.





# FAQS & HOW THE RULE IMPACTS ME & MY LIFE

**Q:** How does the settings rule apply to people and individual situations?

**A:** The Settings Rule requires the places where individuals receive Medicaid HCBS services to offer full access to the benefits of community life. If you are on a waiver, you are receiving Medicaid services. Although waiver services have been available since the 1980s, many people with disabilities still do not have the opportunities they would like to be active and included members of their communities. Use the resources in this book to advocate for yourself and for individuals utilizing waivers.

**Q:** What are common HCBS Waiver Services?

**A:** Waivers are designed to provide services statewide to help persons with intellectual or developmental disabilities remain in their homes or other community-based settings. Services can include things like personal care, respite, transportation, employment services, residential support, and other items. These services are provided in the community instead of in nursing homes, institutions, or other settings that may isolate individuals from the general community. There is a difference between institutional services and community services.

**Q:** What rights do you have while using a waiver?

**A:** You have the right to privacy, dignity, and being free from coercion, and restraint (including physically holding you, using physical restraints, locking doors, withholding food as punishment, bed alarms, or medication to control actions).

Respect is others treating you with kindness and consideration. These rights must be protected where you live and where you work. Your service provider will support you in accessing employment, activities, and things you want to do in the community. Services can be provided in a non-disability setting.





**Q: Do I have the right to control my money and resources?**

**A:** You have the right to control your money (with support if needed). If you have a guardian, they may help you with or take care of this responsibility. If you have an SSI Representative Payee, they may be taking care of your resources. They should make sure resources are used properly for your care and that no one is taking advantage of you. They should also respect your wishes and desires unless it causes harm. Each situation is different. However, it is important to maintain eligibility for services (waiver, SSI, Medicaid) and not have more than \$2,000 in assets (cash, bank accounts, etc.) in your name. Reach out to your support coordinator if you have questions or need assistance.

**Q: Can an individual make choices for what they want to do during the day?**

**A:** Individuals get to control their schedules and with whom they choose to spend their time. You get to decide what time you get up, what time you go to bed, and what you do during the day. Does this mean you get to watch TV all day? Probably not. You may need to make adjustments based on what time you need to go to work or other activities you've chosen for your day. If you have roommates, you need to consider their rights too. Sometimes you need to compromise. For example, taking turns with the TV.

**Q: Am I allowed to eat when I want, where I want, and what I want?**

**A:** Providers must ensure you can get food and drink whenever you want. People who receive services should have access to food and drink just like people without disabilities. Sometimes individuals have medical conditions that say they should limit some foods or when they eat. However, this isn't the case for most people. If someone wants to limit you, this **MUST** be discussed with you, written into your person-centered plan, and you **MUST** agree to the restriction. The restriction may go to a Human Rights Committee for review. You need to be part of the discussion.

If one of your roommates has a food restriction, it doesn't mean you will be restricted as well.





**Q: Can I choose where I live?**

**A:** Yes, based on what your budget allows, you get to control where you live and whether you live with someone, alone, or in a disability or non-disability setting. You are allowed to choose your roommate. You should also be able to come and go as you like, and you should be able to receive visitors. The place you live should be accessible to you. These rights may not be restricted or modified unless there is a reason. If someone wants to limit you, this **MUST** be discussed with you, written into your person-centered plan, and you **MUST** agree to the restriction. The restriction may go to a Human Rights Committee for review. You need to be part of the discussion.

You must have a lease or other legal agreement providing similar protections. The lease protects you from being forced to leave without a reason. The lease outlines other components like whether you can paint your walls, or put holes in your walls.

The rules need to be similar to the rules other people without disabilities would have in their lease. For example, Landlords can't tell you you can't eat in the living room. You are also entitled to privacy in your bedroom if you live with others. Or, privacy in your home if you live alone. You have the right to lock your door and have your own key or access code. If you aren't happy with your living arrangement, you can tell your staff or support coordinator. Check your lease for limitations.

**Q: What should I do if I am not happy with the community access being provided to me?**

**A:** If a person is restricted, there are options available to them. An earlier section of this guide discussed restrictions and modifications and when they are allowed.

If you are unhappy with your services or your provider is not following the settings rule, you are able to call a person-centered support plan meeting and/or talk to your support coordinator. This guide will also explain what to do if you don't like your support coordinator or provider and if you want to find a new support coordinator or provider. You can also call DSPD Constituent Services. Their contact information is 1-844-ASK-DSPD (1-844-275-3773) OR 1-801-538-4200. You can also provide feedback to the Department of Health and Human Services by contacting [HCBSSettings@utah.gov](mailto:HCBSSettings@utah.gov) or the Office of Disability Ombudsman by contacting Angie McCourt at 801-538-4580 or [amccourt@utah.gov](mailto:amccourt@utah.gov).



**Q:** The provider says they are following the settings rule, but I may have very little choice or real access to the community.

**A:** Any modifications of the settings rule requirements, like community access restriction, must be supported by a specific assessed need and justified in the Person-Centered Support Plan (PCSP), with the following items documented in the plan:

1. Identify a specific and individualized assessed need.
2. Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
3. Document less intrusive methods of meeting the need that have been tried but did not work.
4. Include a clear description of the condition that is directly proportionate to the specific assessed need.
5. Include regulation collection and review of data to measure the ongoing effectiveness of the modification.
6. Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
7. Include the informed consent of the individual.
8. Include an assurance that interventions and supports will cause no harm to the individual.

For example, a provider may communicate you can go into the community at any time. However, you may feel like you are not able to leave unless you are with a staff member or at certain designated times. If this type of restriction were to be implemented, the 8 steps outlined above would need to be followed. A provider may not restrict access or rights without documenting these 8 steps. Communicate with your SCE if you have any questions or concerns. A grievance process detailed later in this book is available to you if you feel you need it.

**Q:** How can I be sure that my hopes, dreams, goals, etc. are being met while using a waiver?

**A:** It is key to utilize your Person-Centered Support Plan (PCSP) and communicate with your Support Coordinator. In your PCSP meeting, you should be leading your meeting (with support if needed). You should be involved in these discussions and in the planning process as much as possible. Caregivers should encourage you to be as independent as possible.





**Q:** What else should I consider when thinking about my services?

**A:**

#### **Residential Providers**

- Can I come and go at will?
- Is there a curfew or other time limitations?
- Do I have access to public transportation? Are there bus stops or taxis available? Is there an accessible van available for my appointments, shopping, etc.?
- Am I able to work in an integrated community setting?
- Are meaningful non-work activities in a community setting available?
- Does the setting facilitate integration within the greater community with access to restaurants, businesses, and residential areas? It should NOT be located in a facility that provides inpatient treatment or is adjacent to a public institution.

#### **Non-Residential Providers**

- Does the setting provide opportunities for regular meaningful non-work activities in an integrated community setting?
- How many people in the setting have jobs in the community?
- What job training opportunities are available for me?
- If the setting does have vocational training on site, does it pay subminimum wage?
- Is the work available something I'm interested in doing?
- Does the provider support my access to Voc. Rehab.?
- Is information provided regarding accessing age-appropriate activities including competitive work, shopping, attending religious services, medical appointments, dining out, etc.?
- Is there freedom to move about inside and outside?
- Is the setting among other residential buildings, private businesses, retail businesses, restaurants, etc.?
- Does it encourage visitors to be present regularly?





**Q: If my parent or guardian passes away, who will ensure I continue to live the best life possible?**

**A:** If an individual is their own guardian, they continue to be their own guardian until someone else petitions for guardianship. Many individuals with waiver services are their own guardians. If a parent had guardianship and put a co-guardian in place, the co-guardian would become the sole guardian. If the parent had guardianship and did not put a co-guardian in place, another guardian would need to be appointed. The Office of Public Guardian is an option depending upon the situation. They can be reached at: (801) 538-8255. Guardianship is a legal proceeding and would need to be finalized by filing new paperwork and going before a judge in court.

There are also alternatives to guardianship. Supported Decision-Making, Power of Attorney, and Advance Health Care Directives are also options depending upon your situation and where you need the most support.

**Q: My loved one is my guardian. They are making decisions about my care that do not align with my wishes. Do I have any rights?**

**A:** Even if someone is appointed to be your guardian by the court, you are still entitled to certain rights. The Utah Courts' website emphasizes that "the protected person retains decision-making authority not given to the guardian or conservator, including decisions about his or her religion, friends, whether to consume legal substances, whether to marry or divorce and other decisions." Even under full guardianship appointment, the protected person retains certain basic rights. These rights and additional tools and resources are listed on the following pages.





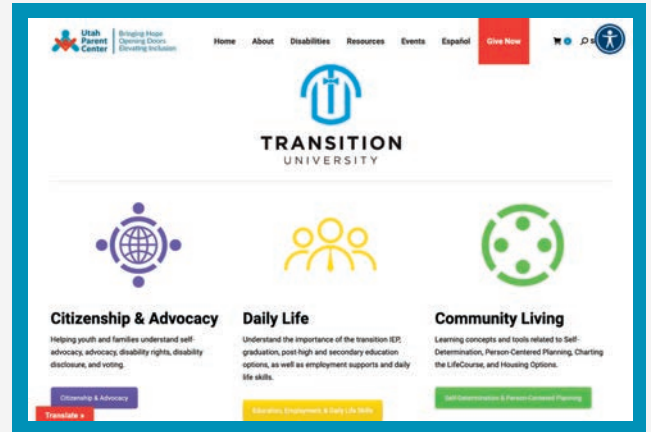


## Additional Guardianship Resources

The following website has:

- Training modules
- Guardianship resources
- Alternatives to guardianship
- Workbooks & reference guides

To access these materials, use the Transition University QR code and link listed.



Transition University

<http://bit.ly/40NPi3q>



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

The guardianship process for incapacitated individuals who are not citizens or residents can move forward. Although language may be a barrier. The Utah Courts' website, OCAP, and the OCAP Self-Help Center can help you with additional questions.

Tribal Laws

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



Self-Help Center

<https://www.utcourts.gov/selfhelp/>







## Guardianship & Dignity of Risk

**Dignity of risk** is the idea that self-determination and the right for an individual to take reasonable risks are essential for dignity and self-esteem. Individuals with disabilities should not be impeded by excessively-cautious caregivers, concerned about their duty of care. Protection is often used to justify violating the rights of people with disabilities. To deny someone the opportunity to make mistakes is to violate the right to make decisions about their own lives. Many self-advocates see the dignity of risk as a human right.

Being the guardian of an individual permits the guardian to make choices that are in the best interest of the individual. However, the guardian should also consider the incapacitated individual's values, stated preferences, and expressed desires when making decisions for them. A supported-decision making tool is recommended to ensure the wishes of the incapacitated person are being heard and that they are living as self-determined life as possible.

The extent to which the protected person can make decisions depends on their individual needs. The Utah Courts' website emphasizes that "the protected person retains decision-making authority not given to the guardian or conservator, including decisions about his or her religion, friends, whether to consume legal substances, whether to marry or divorce, and other decisions." Even under full guardianship appointment, the protected person retains all the basic rights listed here. As guardians, it is important to understand the balance required to protect a loved one while also allowing them to engage in their community.



### Supported Decision Making

<http://www.supporteddecisionmaking.org/>

### Incapacitated individuals are entitled to:

- make or change a will or trust
- marry or divorce
- vote
- practice religion
- send and receive mail, email, and telephone calls
- keep personal relationships with family and friends
- be represented by a lawyer
- control personal spending money
- consume legal substances
- ask the court to end the guardianship or conservatorship; and
- ask the court to change the guardian or conservator or to change their authority.

Protections of the individual's rights are explained here:

<https://www.utcourts.gov/howto/family/gc/rights.html>

# TELL ME ABOUT Utah Medicaid Waivers Options

A Medicaid waiver is a type of Medicaid program designed to serve people with varying disabilities. In Utah, Medicaid waivers are administered by the Utah Department of Health and Human Services. Each waiver is slightly different in terms of the services 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.

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



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

Use this QR code or URL for more information on any of the Home and Community-Based Services (HCBS) Waiver Programs in Utah Please visit:

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

## Acquired Brain Injury Waiver

This 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.

### Waiver Services

- Behavior Consultation
- Chore Services
- Cognitive Retraining
- Companion Services
- Day Supports
- Financial Management Services
- Non-medical Transportation
- Residential
- Respite
- Supported Employment
- Supported Living



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>



## Acquired Brain Injury Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Acquired Brain Injury Waiver. The following aspects of the Settings Rule apply to the ABI Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

### Settings Summary

The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.

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



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

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

## Community Supports Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Community Supports Waiver. The following aspects of the Settings Rule apply to the CSW Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options including non-disability-specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences, and for residential settings, resources are available for room and board.
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The person has a lease or other legally enforceable agreement.
- The setting ensures the person has privacy in their sleeping or living unit including lockable doors, choice of roommates, and freedom to furnish or decorate the unit.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

**Setting Summary: The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.**



## 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
- Requires that an individual has lived in an ICF

### 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>

## Community Transitions Home Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Community Transitions Home Waiver. The following aspects of the Settings Rule apply to the CTH Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options including non-disability-specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences, and for residential settings, resources are available for room and board.
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The person has a lease or other legally enforceable agreement.
- The setting ensures the person has privacy in their sleeping or living unit including lockable doors, choice of roommates, and freedom to furnish or decorate the unit.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

**Setting Summary: The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.**

## 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 annual spending cap of \$20,834\* per year. There are limited service options to allow people with disabilities, their families, and support teams flexibility in determining and changing needed services. \*Funding amount varies based on available funding and needs. \*Funding could change each year.
- 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. If circumstances change, service/waiver needs can be re-evaluated.

### 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

- Your DSPD Support Coordinator will meet with you and educate you about available services on the LSW. You can bring anyone to this meeting. They are your coordinator. You do not need to hire an SCE. They can answer questions and can help you determine your needs/wants for your plan.
- 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

- |                                               |                                 |
|-----------------------------------------------|---------------------------------|
| • Assistive Technology                        | • Individual Goods & Services   |
| • Attendant Care (In-person & via Telehealth) | • Integrated Community Learning |
| • Behavior Supports                           | • Non-medical Transportation    |
| • Family & Individual Peer Support            | • Remote Supports               |
| • Environmental Adaptations (Home & Vehicle)  | • Respite                       |
| • Financial Management Services               | • Specialized Medical Equipment |
|                                               | • Supported Employment          |
|                                               | • Waiver Support Coordination   |



## Limited Supports Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Limited Supports Waiver. The following aspects of the Settings Rule apply to the LSW Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

### Settings Summary

**The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.**

## Medically Complex Children's Waiver

This program provides medical assistance to children who are medically complex. This waiver includes 13 hours of respite that could also be used for Caregiver Compensation. At various times there is no waitlist for this waiver. 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 Supplemental Security Income (SSI) disability designation through the Social Security Administration or a disability determination by the State Medical Review Board. This will be coordinated as part of the MCCW application process

## New Choices Waiver

The 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>



## Medically Complex Children's Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Medically Complex Children's Waiver. The following aspects of the Settings Rule apply to the MCCW Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

### Settings Summary

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## New Choices Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the New Choices Waiver. The following aspects of the Settings Rule apply to the NC Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options including non-disability-specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences, and for residential settings, resources are available for room and board.
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- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
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- The person has a lease or other legally enforceable agreement.
- The setting ensures the person has privacy in their sleeping or living unit including lockable doors, choice of roommates, and freedom to furnish or decorate the unit.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

**Setting Summary: The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.**

## Physical Disabilities Waiver

The 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



## Physical Disabilities Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Physical Disabilities Waiver. The following aspects of the Settings Rule apply to the PD Waiver.

### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

### Settings Summary

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## 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 people may be served by this program. A person 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

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.

## Technology Dependent Waiver & the Settings Rule

The settings rule is a rule that ensures services delivered to people with disabilities outside of an institutional setting meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections. The rule applies to the services you are entitled to receive on the Physical Disabilities Waiver. The following aspects of the Settings Rule apply to the PD Waiver.

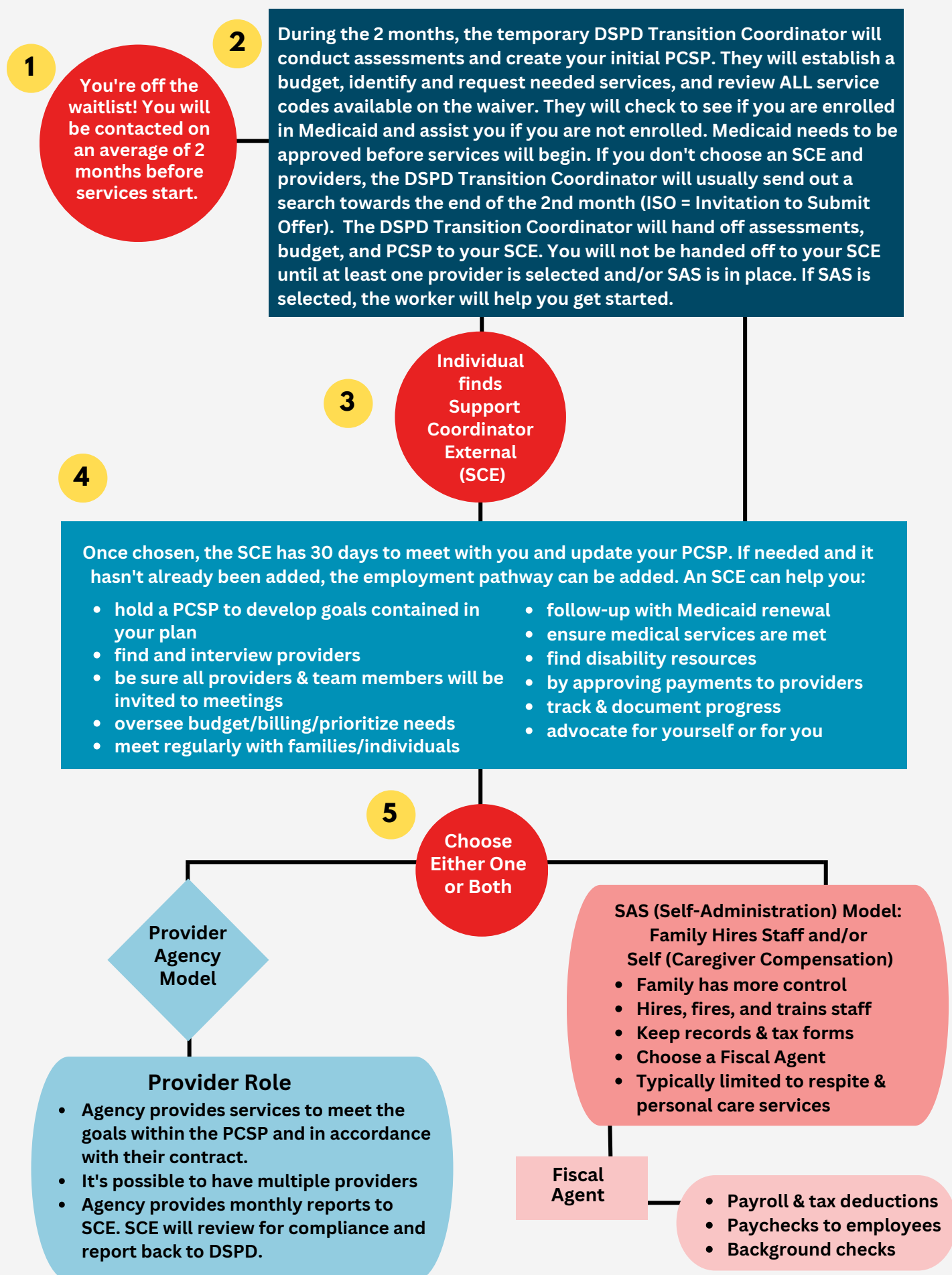
### You are entitled to:

- Setting is integrated in and supports full access of people receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the person from among setting options. The setting options are identified and documented in the person-centered service plan and are based on the person's needs, and preferences
- The setting ensures a person's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- The setting optimizes, but does not regiment a person's initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.
- The setting ensures the person has the freedom and support to control their schedule and activities and have access to food at any time.
- The person can have visitors of their choosing at any time.
- The setting is physically accessible to the person.
- The setting ensures that any modification of the HCBS Settings qualities and conditions is supported by a specific assessed need and justified in the person-centered service plan.
- The setting enforces the Home and Community-Based Settings Regulation requirements.

### Settings Summary

**The Settings Rule is in place to ensure you have choices in the services you receive and to make sure you can participate in your community in whatever ways you choose. The service system is here to serve you on your own terms.**

# THE PROCESS: CHOICES AND WAIVER TIMELINE AT-A-GLANCE



# SAMPLE CASE STUDY

## BEN'S DSPD STORY

**Ben's case study will help to paint a picture of how a family can navigate coming off the waitlist. This is just one example. Please refer to the flow chart on the previous page for another visual explanation. Work with your DSPD Transition Coordinator and SCE to understand options for your specific situation.**

Lisa, Ben's temporary DSPD Transition Coordinator, notified Ben that in two months Ben will be coming off the waitlist. In the meantime, Lisa is going to conduct assessments and create Ben's initial PCSP or Person-Centered Support Plan. Lisa will also assist Ben in accessing Medicaid since he does not currently have Medicaid. Lisa explains to Ben how she will request services and establish a budget for him based on the assessment she will complete. It's possible not all services requested will be approved, or they might not be approved at the funding level requested. Lisa also explains to Ben about the need for a support coordinator (SCE). If Ben is unable to find an SCE, Lisa can help him. Before Lisa hands off information to the SCE, Lisa will make sure Ben has at least one provider in place. If SAS is selected, Lisa can assist Ben with that information.

After interviewing several SCE's, Ben decides to select John as his SCE. John has 30 days to meet with Ben. John will review the assessments and budget given to him by Lisa. John will update Ben's PCSP and help Ben find providers (if needed) and ways for Ben to meet the goals identified in Ben's PCSP.

Ben can either choose a provider model, a SAS or Self-Administered model, or a combination of both. If Ben chooses a SAS model, he also has the option to choose Caregiver Compensation as a part of the SAS model. John will be Ben's guide and help Ben understand his budget, his goals, and services, help Ben interview and hire providers (if needed), will oversee Ben's budget and billing, track and document Ben's progress, and advocate for Ben, etc. If Ben chooses a provider model, providers send reports to John monthly. John will review information for compliance and report to DSPD.

### **To Achieve Ben's Goals, Ben's PCSP might include:**

- Respite Care
- Day Supports
- Chore Services
- Supported Living

Ben's PCSP will be reviewed each year. Ben understands he can contact his SCE at any time for help or to update his plan. Ben also understands he can change his staff at any time. If Ben isn't satisfied with his providers, his SCE can help Ben make a change. Ben also understands he needs to maintain eligibility in order to keep his services. His SCE can help Ben understand how to maintain eligibility.





## MY DSPD TRANSITION COORDINATOR GAVE ME A SCHEDULE OF SERVICES. WHAT DOES THIS MEAN FOR ME?

In between the time you are notified you are coming off the waitlist and when your services begin, your temporary DSPD Transition Coordinator will conduct the UCANS assessment. Your UCANS assessment is usually completed during the intake meeting. UCANS = Utah Comprehensive Assessment of Needs and Strengths. A link and QR Code to the UCANS Guidebook is listed below. Your UCANS will be updated annually by your SCE.

**The responses on your UCANS indicate what is important to you and what support (services) you need. The services you need will determine your budget. It is important your responses accurately describe your life's circumstances, complexities, and challenges.**

With your input and/or the input of your caregivers, and your UCANS responses, the transition coordinator will create your initial Person-Centered Support Plan (PCSP) and give it to your SCE, or if you are assigned one, your Nurse Care Manager.

Your services will be needs-based rather than wants-based. Your PCSP will determine your services. The waiver descriptions outlined in the previous pages, describe the services available through each waiver.



### EXAMPLES OF AVAILABLE SERVICES

<http://bit.ly/3XskMu8>

- Behavior Supports
- Caregiver Compensation
- Chore Services
- Day Services
- Environmental Adaptations
- Host Home Services
- Professional Parent Supports
- Respite Care
- Support Coordination
- Supported Living
- Transportation Services

Be open and honest with your DSPD Transition Coordinator about the type of support and services you need to be successful and independent so your budget will adequately reflect your needs.



# SERVICE CODES

## WHAT DO THEY MEAN?

As of January 2023, the following are the current descriptions of DSPD provider-based services and their correlating service code. Work with your SCE to understand which codes are available on your waiver and which codes are tied to services like Vocational Rehabilitation. Discuss your needs with your SCE if a certain code is not available to you or if a provider is not available to provide a service.

### Behavior

Behavior Consultation (BC) provides support to individuals with behavioral needs, by creating behavior goals that increase the individual's ability to transition into the community.

- BC1/BC2: Mild aggression, property destruction, eating, toileting, or other comparable behaviors.
- BC3: Extremely complex or challenging behavior, such as a life-threatening danger to themselves or others.

### Chore & Homemaker

Provides assistance to keep an individual's home clean, and sanitary.

- Chore (CHA/CH1): provides support with heavy household chores. CH1 is typically routine, and helps to maintain a clean, sanitary, and safe living environment for a Person when they are unable to complete the chore activities on their own. CH1 can only be provided when there is no other relative, caregiver, landlord, or other volunteer that is capable of, or responsible for, the chore. CH1 may include: washing floors, walls, and windows; snow removal and lawn care; securing loose rugs, tiles, and moving heavy furniture to provide safe access.
- Homemaker (HSQ/HS1): provides support for general household activities. HS1 helps to maintain a Person's home in a clean, sanitary, and safe living environment. Activities include: meal preparation, laundry, and light housekeeping. HS1 can be a routine service when the Person is unable to complete the household activities themselves, and there is no other relative, caregiver, or volunteer capable of providing the support. It can also be provided when the individual usually responsible for such activities is temporarily absent, or is unable to do them.

**Services are selected based on needs and your individual circumstances. What services do you need to be more independent and successful?**



## Companion Services

- Companion Services (COM/CO1) provides one-on-one non-medical care, socialization, and supervision for a Person. CO1 includes assistance with tasks like meal preparation, shopping, and laundry; and occasional assistance with light housekeeping chores necessary for the care and supervision of the Person. CO1 may include transportation such as driving the Person to social activities.

## Day Supports

Provides safe daily support, supervision, and skill building.

- Day Support Group(DSG/DSP): Group setting
- (DSI): Individual setting or one-on-one.
- Employment preparation services (EPR): Time-limited (24 months) support for an individual to gain employment skills. Such as communication skills with co-workers, customers, and supervisors, following directions, and problem-solving.

## Family Training and Preparation

(TF1) provides short-term training of skills that are necessary to function effectively as a SAS Employer. Training may also include building skills for families in other areas such as parenting, daily living, social skills, advocacy, and communication.

## Personal Assistance

(PAC/PA1/PA2) provides hands-on care of both medical and non-medical support needs for a medically stable person.

PA1 must be used when the person is receiving services from someone who is NOT their spouse. Services include help with activities of daily living such as eating, bathing, dressing, toileting, transferring, using the phone, shopping, and preparing meals. PA1 may also include transportation such as driving the Person to activities and appointments. PA1 is intended to reinforce a Person's strengths while substituting or compensating for the absence, loss, or impairment of physical or cognitive functions.

PA2 must be used when the person is receiving services from an employee who is the spouse of the person and is also receiving Physical Disability Waiver services.





## Personal Budgeting Service

(PBA) Provides support to an individual with financial needs.

## Professional Medication Monitoring

(PM1/PM2) Provides medication management, medication monitoring, and medication and medical equipment education.

## Professional Nursing Services

(PN1/PN2) Provides skilled nursing services such as hands-on care, medical devices such as ventilators, G-tubes, urinary catheters, trachs, injections, g-tube feedings, and complex medication administration.

## Residential Services

Provides a supervised residential setting.

- Residential Habilitation Supports(RHS): Group setting.
- Professional Parent Support(PPS): For children to receive residential service in a family home.
- Host Home Services(HHS): For adults to receive residential service in a family home.
- Extended Living Supports(ELS): Provides supervision and support to individuals in residential services during times when the individual is unable to attend their day program.

## Respite

Provides relief to an individual's caregiver. Respite provides care to a Person to give relief to, or during the absence of, the normal caregiver. Respite can be provided in a Person's home, the Employee's residence, or other approved settings. Respite may include transportation.

- RP1: Provided one-on-one without overnight care.
- RP2: Respite without room and board (Non-overnight)
- RP3: Exceptional care (Required medical equipment, or higher medical or behavioral needs) without room and board.
- RP4: Respite with room and board
- RP5: Exceptional care with room and board.
- RP6: Overnight respite provided one-on-one
- RP7/RP8: Respite Group: Group care with up to 3 persons.
- RPS: Camp, dance, or summer program.
- 

\*RP3, RP5, RPS- available for CTW and CSW Waivers only\*





## Supported Employment

Support individuals to obtain, maintain or advance in employment.

- Supported Employment with a co-worker(SEC): (Already obtained natural support at the workplace) Pass through payment to the Employer of the co-worker.
- Supported Employment in a group (SED): Mobile work in a group setting to gain experience in differing jobs.
- Supported Employment Enterprise (SEE): Supports individuals with self-employment.
- Supported employment for an individual (SEI): Job coaching, such as role-playing, time management, assistance with communication, etc.

## Supported Living

Supported Living provides one-on-support, supervision, skills building, and assistance, for a person to live independently. Assistance and skills building include activities of daily living such as eating, bathing, dressing, toileting, transferring, using the phone, shopping, and preparing meals. Support may also include assistance and skills building with homemaker and chore responsibilities, managing money (budgets & bills), advocacy, communication, and personal care. This service may include transportation such as driving the person to activities, appointments, and access to the community.

- SL1: Supported Living provides one-on-one support, supervision, training, and assistance for a person to live independently.
- SL2: Supported living service when the Employee is the spouse of the person receiving the service.
- SL3: Typically used for Caregiver Compensation.
- (SLH)- The provider is responsible for maintaining the health and safety of the individual.
- (SLN)- The provider is NOT primarily responsible for maintaining the health and safety of the individual. Usually, the individual will have natural supports in place to help.

## Transportation

(MTP): Motor transportation payment provides transportation to and from day support and supported employment in a group.

(DTP): is a mileage reimbursement service. DTP may be used to help the person gain access to their community, and when there is a need to drive longer distances to support the Person. DTP can only be used when a service does not include transportation, and when family, neighbors, friends, or other community agencies are unable to provide the transportation. Additionally, DTP cannot be used for medical transportation.



# UNDERSTANDING BUDGETS FAQ

**Q:** My DSPD Transition Coordinator gave me a budget. How do I monitor my budget so there is enough funding for the entire year?

**A:** All services are billed in increments called UNITS. A unit could be multiple things; a daily unit, a session, a quarter-hour, or monthly, etc. Your budget is based on need. It is important to utilize the funding allocated to you. Budgets are reviewed every year. If funding is not utilized, your budget may be reduced to match your needs.

Your SCE Can help you manage your budget hours so you don't run out of funding before the end of the year. Your SCE can also communicate with DSPD if there is a need for additional hours. While additional funding is not guaranteed, it is your SCE's responsibility to advocate for you and your needs.

**Q:** What is a billing code and how are they used?

**A:** All services are billed in quarter-hour increments called UNITS. Each type of service is assigned a billing code. Refer to the following page for a list of service codes. Some types of service codes are paid at a higher rate. When you use a higher rate code, you will utilize more of your budget. It is important for you to understand the different codes, their rates, and the billing summaries you receive. If you have a question, reach out to your SCE for help.

Watching a movie is an example of when you would use an RP1 code (Respite)  
Going out into the community is an SL code (Supported Living)  
If you move home, you will no longer be able to utilize residential funding.

**Q:** Can I use funding with a provider and a SAS model?

**A:** You can utilize provider services and the SAS model for services depending on where your SCE assigns your budget. It is important to communicate funding preferences with your SCE.

For example, respite providers could be billed as a provider or through a SAS model. It would depend on whom you select as the provider. An after school program offered by a provider would be billed by the provider. An individual you hire to take you on outings after school would be billed through the SAS model. This could also be true of any weekend respite. Budgets and billing vary on whom you decide is going to serve you.



**Q:** I am using SAS. I have too much funding in my respite budget. Can it be reallocated for another service?

**A:** There may be times that more money was allocated to one service, such as Respite, and not enough in another, such as Supported Living. The Support Coordinator can move money from one area to another but you must let them know there is a need to do so. This is not an increase in budget but is a budget-neutral move. However, there are some codes, like day supports or residential services that cannot be moved.

**Q:** I'm using SAS. I'm unable to hire or keep staff. How will this impact my budget?

**A:** If there are times when you are not able to hire or keep staff, let your Support Coordinator know so the individual's notes can reflect this. If you are not paying staff, you will end up with an excess budget at the end of the year as a result. If you have money left over, it goes back into the general budget with DSPD to be redistributed. If that happens for multiple years with no good explanation, such as a pandemic, the budget can be cut. This is why it is important to document changes that occur within the family and for the individual.

If you are not using a specific service that has been budgeted for, let your Support Coordinator know. A review or change in services may be needed that better represents the needs of the whole individual.

**Q:** How are budgets allocated with a provider model?

**A:** If you are using a provider, your Support Coordinator is in charge of making sure that those services are allocated in prescription, which is the term used because they are Medicaid Waiver services, to make sure that they are budgeting correctly for the entire 12-month period. As with a SAS budget, if allocated funds are not meeting the needs, providers will work with the Support Coordinator to adjust services or request additional funds if needed.

**Q:** What if my budget is insufficient?

**A:** If the budget does not cover the anticipated or actual costs, DSPD has a Request for Additional Services (RAS) committee in place. Your SCE can fill out a RAS form. The RAS process can take about a month for you to receive an answer. Being thorough with information in the initial request can help save time in the long run. To assist your SCE: 1. Create a complete schedule of your day and indicate where support is needed. 2. Build documentation for why the increase is requested. (Ex: increased behavior, new medical issues, letters from doctors, your teacher, or family.)

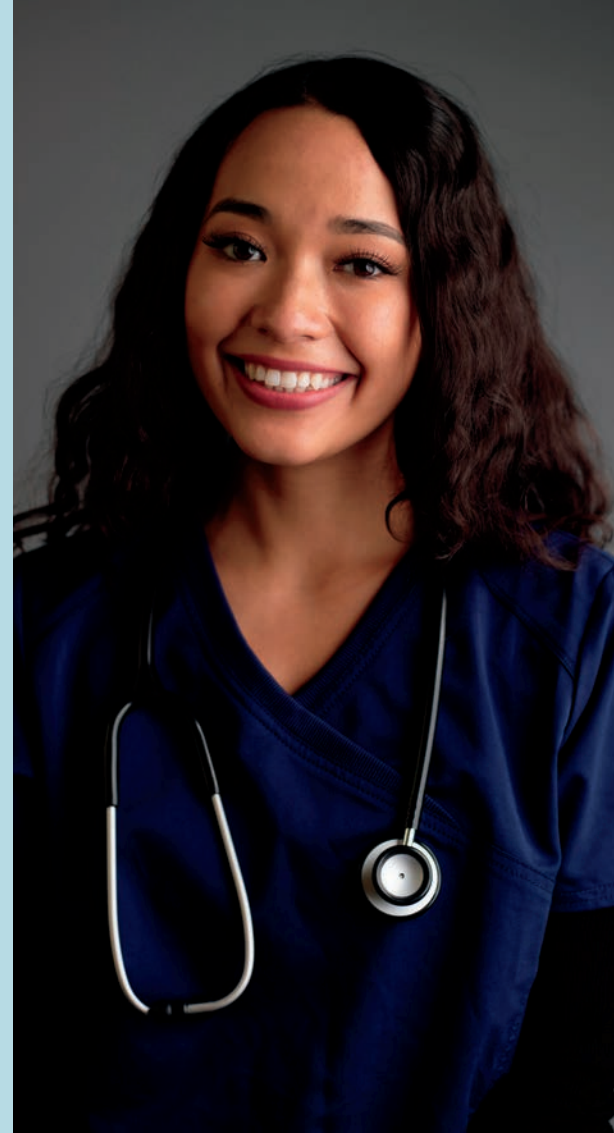


# WHAT IS A NURSE CARE MANAGER?

Depending upon the type of waiver you utilize, you may be assigned a Nurse Care Manager. For example, the Technology Dependent Waiver requires a Nurse Care Manager to be assigned to you. Services are provided by a registered nurse (RN). Your Nurse Care Manager will be your case manager rather than a support coordinator that so many of the other waivers utilize.

The Nurse Care Manager's role is to help you to access the services you need. For example, for the Technology Dependent Waiver, your RN may meet with you every 6 months. They will check your heart, lungs, and general health, and assess your needs and available services through the waiver. Service hours and other services that might apply are approved for the 6 month period. They also do an email check-in every month for any changes, appointments, and needs. They can help negotiate with Medicaid or supply providers to get you needed equipment and medical supplies, as well as medically necessary services.

Check your waiver guidelines to better understand how your Nurse Care Manager will interact with you.



## Navigating Rural Communities with Waivers

In addition to the support you receive from either your Nurse Care Manager, your SCE, and your providers, there are other agencies, resources, and tools available to you. Work with your SCE or case manager to identify what resources might be the best fit for you and your situation and the area where you live.





## STEP 1

# WHAT IS A SUPPORT COORDINATOR (SCE) & HOW DO I FIND ONE?

A Support Coordinator works with individuals with disabilities and their families to develop service and support plans, based on the individual's needs and wishes. These plans are referred to as Person-Centered Support Plans or PCSP's. Your SCE will also coordinate and monitor the services and supports that are provided to you. An SCE's responsibilities include:



Find an SCE  
<http://bit.ly/3HVS1xG>

- hold a PCSP to develop goals contained in your plan
- find and interview providers
- be sure all providers & team members will be invited to meetings
- oversee budget/billing/prioritize needs
- meet regularly with families/individuals
- follow-up with Medicaid renewal
- ensure medical services are met
- find disability resources
- approve payments to providers
- track & document progress
- advocate for you

### How do I find an SCE?

- Ask around and find out which SCE other individuals and families are using and how satisfied they are with the service they receive from the individual or company they have selected.
- If you know whom you want for your SCE, contact that SCE and see if they are willing to set up an interview with you.
- If you aren't familiar with any SCE's, you can find contact information for SCE's on DSPD's website. Or, ask your temporary DSPD Transition Coordinator for a list. You can also ask your coordinator to send out an Invitation to Submit Offer (ISO) to let them know you are looking for a new SCE. Private SCE's who are interested in becoming your SCE will contact your transition coordinator. You can also get a list of those who respond to the ISO from your transition coordinator.





## STEP 2

# I HAVE SO MANY QUESTIONS....

### What should I look for in an SCE?

You may want to phone screen or meet with prospective support coordinators to see if they are available and willing to serve you. You may want to have someone you trust with you during the interview. They can help you observe the SCE and give you feedback after the meeting. You are able to pick whom you would like to be your SCE. You should not feel pressured to select a certain person.

If you are making the decision on behalf of an individual with a disability because the individual is a minor, or is unable to make the decision independently, try to include the individual in at least some part of the meeting so you can observe how the SCE interacts with the individual. Ensure the SCE has a realistic picture of the needs of the individual who is receiving support.

### Here are a few examples of questions you may want to ask during the interview:

- How long have you been a Support Coordinator?
- How often do you make visits to the individuals on your caseload?
- Do you work independently, or with a company? If you are with a company, how many other coordinators work there?
- How many hours do you usually work?
- What is your current caseload? (The state cap is 46 clients per Support Coordinator. Keep in mind that travel, level of client's needs, and other factors may affect a Coordinator's ability to effectively serve a high caseload.)
- What is your availability in terms of preferred days/times to be contacted?
- What is the preferred way to communicate with you? How long should I expect to wait for a response?
- What is your policy for contact during emergencies?
- Who covers for you when you are unavailable? How do I contact them?





# Ask Further Questions...

If possible, meet face-to-face with your top 2 or 3 SCE choices. Ask further questions to help you get to know the SCE and decide if they are a good match for you! Here are a few examples of questions you may want to ask them:

<https://dspd.utah.gov/services/support-coordination/>



**Please be aware that no Support Coordinator can make promises for extra funding. All Support Coordinators have access to the same funds.**

- What is your education and background related to working with individuals with disabilities and why did you choose this field of work?
- Tell me about a time when you successfully helped an individual with disabilities improve their quality of life and how you were able to do it.
- What is your business experience? Describe your ability to manage paperwork, finances, taxes, and the aspects of being self-employed (if you are self-employed).
- Are you confident in your ability to advocate for my needs? Are you familiar with disability rights and protection under the law? Have you had successful experiences working with DSPD and other agencies and organizations? Can you give me examples?
- Have you had experience working successfully with providers? Give examples.
- Review your budget and services and gauge the SCE's interest and ability to advocate for changes you need in your plan.
- Describe what you do when you come and visit me. What things do you monitor during a visit? How much time do you spend with me? Where do you prefer to meet with me?
- What do you see as your role in my life?
- Will you provide me with references, preferably from other individuals/families/ and/or providers that have experience with you as their SCE.
- Do you have experience with SAS (self-administered) model?
- Do you have experience with fiscal agents?
- How often do you review my PCSP? Do you review it with me and remind me what services are available to me?
- What is your experience working with special health care needs?



## STEP 3

# I SELECTED AN SCE LET'S GET STARTED

### After you Make a Decision

Once you select an SCE, contact your waitlist worker and let them know you have chosen a Support Coordinator. This can be done by email or phone call. The waitlist worker will help you through the paperwork of getting the Support Coordinator assigned to you. The waitlist worker will also contact the Support Coordinator to let them know they have been chosen.

Your new SCE is required to meet with you within 30 calendar days of being selected. If you don't hear back from the SCE within a week or two, you may want to consider choosing a new SCE. If you were on the waiting list for a long time, it is important to get supports started in a timely manner. A slow response from an SCE will only delay things further.

### What to Expect

After choosing your SCE, you should expect your new SCE to:

- Identify service options and communicate with you to determine and adapt services to meet your needs.
- Work with you to edit and build a PCSP reflecting your interests, preferences, and needs. Your PCSP should have meaningful support and foster independence. The PCSP should identify natural as well as needed Medicaid services. More information about the PCSP will be provided in a different section of this resource book.
- Your PCSP will identify your goals and areas where you need support.
- Will create a social history which includes information about hospitalizations, medications, skills, etc. It will also include details such as height, weight, presenting issues, and needs, likes and dislikes, and your schedule. This information will help your SCE create a robust PCSP.







## What to Expect Continued

- Develop an annual budget based on allotted DSPD funding. Make changes as necessary throughout the year. Monitor the use of funds. Review services and ensure funds are used as documented on the action plan.
- If you are using a SAS model, your SCE will train you, define your responsibilities, and help you become familiar with the required forms.
- Supply you with information about companies that contract with DSPD to provide services. Your SCE will work as an advocate and mediator with provider companies on your behalf.
- Will meet with you regularly to get to know your needs, monitor services for quality, and ensure your needs are met. If you are using SAS, your SCE should meet with you at least once every three months. If you are using a provider for services, your SCE should meet with you at least every other month.
- Assist you with meeting initial and annual documentation requirements.
- Provide information and referral to other agencies that may meet your additional needs.
- Help you fill out a Medicaid Release Form. Because you are receiving DSPD services, you are most likely eligible to receive Medicaid. Your services get paid by Medicaid. Your SCE will follow up with the Medicaid renewal that happens once a year. However, you are responsible to complete and submit the renewal.
- Ensure all medical services are being met through a Medicaid waiver.
- Assist you with the grievance process if you have a grievance. See the conflict section of this book if you have a grievance with your SCE.
- May help you use person-centered planning tools like Charting the LifeCourse as you develop your PCSP.





# WHAT IS A FAMILY'S ROLE WITH AN SCE?

## Responsibilities of Families

As a member of the team supporting your loved one, there are also responsibilities of families and caregivers. The Support Coordinator should be informed when changes occur in the family or individual's life, when there are concerns about a provider or services, or when other events impact the person's ability to receive or benefit from services.

- Keep the Support Coordinator informed on how goals are progressing. If they are not progressing, do you see something that could be getting in the way of a goal being achieved?
- Let them know about major life events and changes. This could include changes in physical and mental health, getting a job, family support including situations with extended family, and if you are moving.
- You will fulfill responsibilities for Self Administered Services (SAS), if applicable. Turning in monthly summaries and reporting on who is employed or if you do not have employees at the time.
- Collaborate and communicate with the provider(s), if applicable.
- Invite the Support Coordinator to important meetings such as IEPs with school, Vocational Rehabilitation, doctors, and other appointments. They may not be able to come but let them know. Keep the lines of communication open.
- Talk to your Support Coordinator any time you have a question or any time the needs change. If you are uncomfortable discussing an issue with your Support Coordinator, contact DSPD directly.





# WHAT IS THE PROCESS FOR AN SCE GRIEVANCE?

If concerns come up with the Support Coordinator you are working with, you should talk with them first about what is happening with you and your family. If you are not able to find a solution to your concerns, there is a grievance process you and your family are able to take part in with the individual companies associated with the Support Coordinator. The grievance process procedures should have been provided to you at the initial meeting and reviewed at least yearly at your PCSP meeting.

If there is no resolution after going through the grievance process, you may want to change your Support Coordinator. In that case, DSPD employees may reach out to you, your family, and providers to make sure it isn't a case of a provider wanting a change for a specific Support Coordinator or Support Coordination company. There may also be a concern that a Support Coordinator is promising unrealistic expectations like additional budget and equipment if the family changes and selects them. If everything seems in order, the individual and family can select a new Support Coordinator.

You should contact Constituent Services with DSPD if any of these concerns are happening, such as feeling pressured by a provider to change your Support Coordinator or being offered additional money or services by selecting a specific Support Coordinator or Support Coordination company.

**Call toll-free 1-844-ASK-DSPD (1-844-275-3773) OR 1-801-538-4200 and ask for Constituent Services. Or, email [DSPD@utah.gov](mailto:DSPD@utah.gov) or [DSPDinfo@utah.gov](mailto:DSPDinfo@utah.gov)**

**Remember you can choose to change your Support Coordinator at any time!!! Your Support Coordinator is the glue that holds everything together and if it is not working for you ... you can change.**







# FAQ'S

## UNDERSTANDING SCE'S

**Q:** How often does my SCE update my PCSP?

**A:** The PCSP must be reviewed and updated on a yearly basis at minimum, when your circumstances or needs change significantly, or when you request a change to the PCSP. You do not have to wait a full year to make changes to your PCSP.

**Q:** Is it important for my SCE to live/work in my community?

**A:** Location is something to consider. When choosing a support coordinator, look for someone who knows the resources and services in your area.

**Q:** Can I change support coordinators at any time?

**A:** You may choose a different Support Coordinator at any time! You have the right to choose any support coordinator. You should not feel pressured by anyone to make a particular choice.

When selecting a new SCE, you have 2 options:

- Contact DSPD for assistance, or
- Find your own SCE

When you have identified a new SCE, contact DSPD with your decision. However, unless you already know whom you want to hire as your new SCE, it may take time to identify, interview, and hire a new SCE. A change can take place at any time. Although DSPD implements changes at the beginning of the month. Changing SCEs at that time may make things easier.





**Q:** If I select an SCE, how do I hold them accountable?

**A:** Your SCE is a member of your team. If you feel you are not being served sufficiently by your SCE, you can make a change. However, it will take time to find, interview, and hire a new SCE.

**Q:** Can an SCE decide they don't want to have me as a client?

**A:** Yes. They have that right. It is important to build positive relationships with your SCE. If they decide to decline to serve you, they are required to give you a 30-day notice. It is okay to ask for help from your team if you need assistance communicating with your SCE. Read the terms of the agreement to understand how your relationship with your SCE should work and the responsibilities of each party.

**Q:** How often should I be talking to or meeting with my SCE?

**A:** Your SCE will be working with you on a monthly basis. If you are living at home, typically your SCE will see you in person at least quarterly. If you live in a residential provider environment, you should see your SCE in person monthly. However, you are able to contact your SCE as needed. Please be mindful of their business hours. Learning to communicate in a professional way is also important. This is an opportunity for you to learn self-advocacy and communication skills.

**Q:** I'm interested in Caregiver Compensation. What is it and how do I determine which service option is best for my family?

**A:** Work with your SCE to decide which service option is best for you. Provider, SAS and/or Caregiver Compensation, or a combination of all of your options. Caregiver Compensation allows a primary caregiver to be compensated financially for the caretaking of their loved one. Services provided are outlined in the PCSP. Work with your SCE to understand how Caregiver Compensation would apply to your situation.



**Q:** What am I allowed to ask for from my SCE?

**A:** Now that the goals are in place, you are able to talk about services. Here are some of the services that may be available to you as your Person-Centered Plan is developed. These are possible services that may or may not apply depending on your needs and the PCSP that is created. The services selected should support you in reaching your goals. This is not an all-inclusive list as other needs may be identified through this process. Unless otherwise noted, the list applies to both Provider and Self-Administered Service delivery models.

- Respite
- Day Programs - can be for those still in school
- After School / Summer Programs - can be for those still in school
- Massage Therapy
- Behavioral Supports
- Transportation Services
- Residential - Group Home, Host Home - Provider only
- Employment Services
- Supported Living - Activities, Working on Goals, Independent Living Skills
- Emergency Response Systems - Medication Reminders
- Housekeeping / Chore Services

**Q:** What is my SCE's role with Medicaid?

**A:** Your SCE will monitor that you maintain continuous Medicaid eligibility and will notify DSPD within 30 days of any changes in eligibility status.

**Q:** Does my SCE receive training?

**A:** SCE's are required to receive training to ensure they establish and maintain competency in the skills necessary to perform effective, ethical, and safe coordination of care. An SCE will complete DSPD training to acquire competency in the creation and implementation of a DHHS/DSPD Person-Centered Support Plans as well as other requirements for their role.



**Q:** Because I'm not living with my parents, who will make sure I am safe, my living quarters are clean, and my important information is given to (or available for) staff?

**A:** Your SCE should monitor that each facility and residence visited is free from any hazardous conditions and is maintained in a sanitary fashion. SCE's will attempt to resolve problems upon discovery. If not resolved, the SCE will report the problem.

The SCE will also make sure your residence maintains current and accurate records (medical, medication, behavioral plans and management). If facilities are not aligned, the SCE will report the problems and work to resolve them.

**Q:** If I use a SAS model, how is my SCE involved with my timesheets and how can they assist me?

**A:** SCEs are required to review three months of timesheets annually and assure you (or the family/SAS administrator) are completing the necessary documentation. If SCE's suspect fraud or Medicaid misuse, they are required to report it. Otherwise, timesheets are submitted to fiscal agents.

SCE's review the SAS agreement annually with the SAS administrator and have them sign it.

SCE's should assist with any questions or setting up of the SAS services. (ie: help families with the employee paperwork, help them with the support strategy, and collect the quarterly summary).

**Q:** Are fees for my SCE already included in my budget?

**A:** Yes. When your DSPD Temporary Transition Coordinator allocates your budget, the fee associated with your SCE is already included.



# WHICH MODEL SHOULD I CHOOSE? A PROVIDER MODEL, SAS, OR A COMBINATION APPROACH?

When coming into services with DSPD, you will need to select a service delivery model. There are different methods DSPD uses to provide support to individuals; typically private providers and/or the SAS Model which means Self-Administered Services. Caregiver Compensation is a new service code option under SAS. Your Support Coordinator can help you make this decision.

## SERVICE PROVIDER

Provider-based services are, like the name, services offered by a provider company. There are many different providers and a large variety of programs available. Providers may offer chore or companion services, day supports, employment support, residential or transportation services, respite, or supported living services. It is a matter of which services a provider is contracted by DSPD to provide from the supports identified in the Person-Centered Support Plan needed to reach goals.

## SAS (SELF-ADMINISTERED SERVICES WHICH INCLUDES CAREGIVER COMPENSATION)

Self-Administered Services (SAS) offer an alternative to Agency-Based Provider Services by allowing people with disabilities and their families to select services that are provided within their homes. While this allows families more flexibility, this model does require you to be an administrator so the program runs smoothly. For instance, it requires you to recruit, hire, and train staff. You make sure timesheets get submitted appropriately so your staff is paid on time.

All families who use the SAS model must hire a Fiscal Agent who is responsible to provide financial services for the person and assist with things such as payroll and employee background screening. A fiscal agent is a company contracted through DSPD to handle employee payroll, tax deductions, and issuing paychecks. Fiscal agents are also considered providers.





Caregiver Compensation is an option when utilizing SAS. Caregiver Compensation allows caregivers to be compensated financially for the caretaking of their loved one as outlined in the individual's PCSP. All families who use the SAS model must hire a Fiscal Agent, as explained on the previous page.

In the "Additional Resources" section of this guidebook, possible tax implications from Caregiver Comp and reportable income for benefits eligibility are outlined.

**SAS can offer a variety of service codes. Work with your SCE to identify the best options for you.**

- Chore Services
- Companion Services
- Daily Transportation Payment
- Homemaker Services
- Personal Assistance
- Respite Care
- Routine Respite with Room & Board
- Supported Living
- Family Training & Preparation
- Caregiver Compensation

## A COMBINATION APPROACH

It is also possible to use a combination of all of the models. For example, you may choose to live with loved ones rather than in a group home. You may opt to have providers come into the house for respite rather than attending a day program. A respite worker could either be paid through a SAS model or a provider agency. You can have a provider-based day or employment support, while still having respite or supported living through the SAS model. You may have a parent or spouse choose to utilize Caregiver Compensation under SAS.





# SAS MODEL VS. PROVIDER MODEL

## Pros & Cons of SAS/Provider Models

Once your goals have been identified, your SCE will talk to you about providers and/or SAS and Caregiver Compensation service models. You will discuss whether or not to use a contracted DSPD provider for services, administer them yourself, or a combination of all of the above. It is likely your SCE will refer you to the model where they are most experienced. It is important for you to know your options. Once chosen, your SCE takes care of filling out and filing the paperwork with DSPD. Your SCE will train you on the expectations of SAS, Caregiver Compensation, and acting as an employer.

### Self-Administered (SAS)

- Hire, train, and supervise employees
- Caregiver Compensation. A caretaker can be the employee. Income may impact benefits eligibility.
- You are responsible for paperwork. Your SCE can assist you.
- Many services can be offered in SAS (except residential - ex: group home)
- Requires more family involvement
- **Must hire a fiscal agent to provide financial services**

### Providers

- Interview and hire a provider
- Provider handles all paperwork and billing
- Used for residential services (ex: group home)
- You can use multiple providers

### Combination

- It is possible to use multiple providers. Ex: A provider for employment, but SAS for respite and supported living.



# Handbook Information SAS (Self- Administered)

For more information on the SAS Model, you can review the following resources. These guide books explain all of the self-administered program limitations and requirements.



Self-Administered Supports Book  
Community Supports,  
Acquired Brain Injury,  
and Community Transitions

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



Self-Administered Supports Book  
Physical Disabilities

<https://bit.ly/3ZRJ9m7>



**SPANISH:** Self-Administered Supports Book  
Community Supports, and  
Acquired Brain Injury

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



**SPANISH:** Self-Administered Supports Book  
Physical Disabilities

<https://bit.ly/3D2IV1l>







# TEN TIPS HOW TO FIND CAREGIVERS

It may seem overwhelming to find and hire caregivers. Your SCE will be a great resource for you.

## 1 Let everyone know you are hiring a caregiver.

Approaching someone is a compliment that you think highly of them or their family. This may feel uncomfortable but having a loved one with disabilities is all about learning new skills, right? You can do this too!

## 2 Reach out to friends and family to find a caregiver.

Start letting your “inner circle” of family and friends know that you will be hiring a caregiver. Did you know a family member or friend can work as a caregiver?

## 3 Circle of acquaintances

Reach out to your “outer circle” neighbors, coworkers, and people who attend your church or whose children attend your children’s school. Talk with people who are already friends with your children.

## 4 People in your community

You can also find caregivers at local restaurants, parks, or coffee shops with whom you’ve become acquainted. It may feel awkward but it is important to find caregivers for your loved one. Do you take your dog to the dog park? Be friendly and chat with people. Let them know you are looking for a caregiver.

## 5 Elevator Pitch

Let’s jot down some notes in your phone that you will use as an elevator pitch. What’s an elevator pitch? If you saw someone in an elevator and they were getting out on a floor before you, what would you say to tell them what you are doing? An example would be “It’s great to see you. I’m hiring a caregiver to work with my son, Luke. Would you or anyone you know be interested? Luke likes to (mention two activities that Luke likes to do) kick a ball at the park or play video games. I’m paying \$20 an hour.” Help them picture what they might do with your loved one. Ask them if you can text them with what you need and the hourly rate of pay. Let them know it is a flexible job and you can work around a work, school, or college schedule.







## 6 What qualities are needed for your caregiver?

Anyone can be a caregiver but there might be some qualities that you like in your caregiver.

1. Caregivers who care do better work. They stick around.
2. Someone with the capacity to be kind and understanding.
3. Someone whose kindness motivates them to learn about you or your loved one.
4. Identify what other qualities are important to you and your situation.

## 7 Hire several caregivers

The number one quality is you want someone to WANT to work with your loved one as a caregiver. You don't want to hire just one person that will burn out. Hire several people with each caregiver working just a few times a week.

## 8 Diversify by hiring caregivers from different communities

Try to diversify your caregivers, so you can give caregivers time off for finals or a spring break with their families. Hire individuals from a local high school, church, age groups, etc.

## 9 Write a bio about your loved one

Help your caregiver succeed by onboarding them well. Write a bio about your loved one with a disability. Add to the bio at different times in your week, include important information, but also include their interests.

Use this QR code and web link for a sample one-page profile.

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



## 10 Expectations of your caregiver

The success of your caregiver is based on your expectations and willingness to train and communicate your needs. Are your caregivers organizing all events with your loved one? They may not know what mood your loved one may be in when they arrive. Did you know you can help your loved one's transition to a caregiver be successful? Remind your loved one they have a caregiver coming at a particular time in the day. Remind caregivers that being late can set your loved ones in the wrong mood. It might help to pre-plan and have three different activities for the caregiver and loved one to pick from during their time together. Start brainstorming and organize a bucket list of activities caregivers can do with your loved one. Gather what is needed for the activities. You won't always know what your loved one will be in the mood for so be sure to prepare several different options. Let your caregivers network with each other to share ideas or cover shifts if someone is not available.



# FISCAL AGENTS

A fiscal agent is an individual or entity contracted by DSPD to perform fiscal, legal, and management duties, including payroll processing duties for Self-Administered Services. If you use Self-Administered Services (SAS), you will be required to process payroll through a Fiscal Agent. You will also have responsibilities if you choose to use SAS. For example, you will need to ensure your employees are paid and you have submitted all required information to your fiscal agent. **For questions or help understanding or navigating fiscal agents, or providers who assist with fiscal responsibilities, work with your SCE. You can also refer to the SAS handbook for a list of your responsibilities as an employer.**

Note: A fiscal agent is a provider. Rates between providers may differ. A higher rate will impact your overall budget and in turn the amount of hours available to you for other providers.

## Fiscal Agent Responsibilities

- 1 Your fiscal agent should have a Utah-based customer service office.
  - The office will have available customer service staff to help in-person or via telephone between the hours of 9:00 AM and 5:00 PM, Monday through Friday (excluding legal holidays).
  - Fiscal agent staff will be able to help all clients including those who speak Spanish and have a hearing impairment.
  - Voicemail messages and email inquiries will be returned within twenty-four hours of their receipt Monday through Thursday. Messages and emails received Friday through Sunday evening will be returned on the Monday following the weekend.
- 2 Have a process for receiving and resolving grievances from the person, employers, and employees.
- 3 The fiscal agent should ensure the privacy of all identifying information of the person, employers, and employees. If a breach or suspected breach is discovered the fiscal agent will immediately notify the affected individual(s) and provide fraud protection for at least one year.
- 4 Provide the Employer with an enrollment forms packet for employment and payroll setup. The packet will include the fiscal agent's contact information, payroll schedule, and required enrollment forms. The fiscal agent will provide training and information to help the Employer correctly complete the required forms in the packet.
- 5 Monitor and maintain current records.



6

Provide training to employers in the effective administration of SAS services, including methods for interviewing, selecting, and hiring employees, legal requirements for retaining and discharging employees, methods for employee supervision, anti-fraud controls, and proper completion of employee timesheets.

7

When needed and approved by the person's support coordinator, provide additional training to the employer including:

- Identifying needs for successful service delivery and employee expectations
- Effectively communicating expectations to employees
- Employee management skills such as interviewing, hiring, scheduling, terminating, completing timesheets, evaluating performance, backup coverage and
- Addressing problems such as changing levels of personal needs, grievance procedures, emergency coverage, exploitation, and abuse.

8

Help to ensure employees meet qualifications for the services they will be providing.

9

Assist the employer in obtaining optional benefits for employees, including the processing of insurance premiums such as health or life, and manage any withholding for benefits when applicable.

10

Process worker's compensation insurance premiums.

11

Ensure employees follow background screening requirements by obtaining and processing, through the Office of Background Processing, a completed background screening application for all employees at the time of their hire and annually thereafter. The fiscal agent will provide notification to the employer of background screening approvals and denials within 24 hours of receipt from the Office of Background Processing.

- Employees will need to submit a copy of their driver's license or state identification card, a copy of their signed social security card, and fingerprints.
- Incomplete background screening applications will be returned to the employer with a request for the missing information or documentation.
- New employees must submit a background screening application prior to being paid, and payments will not be approved after 30 days of hire without an approved background screening unless there is a written approved extension from DSPD or the Office of Background Processing.

12

Ensure required payroll documentation is received and remains current prior to paying employees.



13

As an Employer, you need to ensure timesheets are submitted accurately and efficiently to the fiscal agent. If timesheets are not correct, the fiscal agent will not pay the employee. The fiscal agent's responsibility is to verify the timesheets are correct. Including:

- The name of the employee
- The Person's name and Personal Identification Number (PID)
- Proper authorization signatures
- The time the Employee started and ended service delivery, and when required by Medicaid, verified through Electronic Visit Verification (EVV). EVV is a process that uses electronic means to verify care provider visits for personal or home health care services. The data collected during visits includes the date of service provided, the start and end time, the type of service performed, the location of the service performed, and the service provider.
- The service code of the service provided
- A description of specific service activities provided

14

Process employee timesheets and issue payroll for employees.

- Payments will only be made to qualified employees. The fiscal agent will decline payments to employees who do not have an approved background screening or other required service elements.
- Employees will only be paid for services as outlined in the person's PCSP. Services that are not in the Person's PCSP will not be paid for.
- Make payments for services identified in the employee agreement, and per approved payroll documents.
- Wages will be directly issued to the employee.
- Wages are determined by the employer and must be between the federal minimum wage and the maximum allowed rate for the service. The fiscal agent will provide the Employer with a document showing the minimum and maximum allowable Employee hourly rate by service code.
- Payroll will be issued at least on a semi-monthly basis
- When requested, the fiscal agent will provide check-level details of expenditures with paychecks.
- As required by law, all judgments, garnishment, tax levies, and any related holds on an Employee's funds will be processed.

15

Have available to the employer, a monthly report showing the person's budget balance.





## STEP

# 1

## PROVIDER OPTION... WHAT IS A PROVIDER & HOW DO I FIND ONE?

DSPD has contracts with hundreds of private, provider agencies across the state to provide specialized services. Choosing a provider is similar to choosing a Support Coordinator. You can ask for recommendations. Your Support Coordinator can put out a Request for Service (RFS) and then you can interview companies that respond as being interested in taking you/your loved one on as a client. The Support Coordinator can also work with families to set up interviews, tours, and visits with providers.

Or you can research providers yourself. You can find a list of providers on DSPD's website (use QR code and link below) and do a search by county and service desired. You can contact the provider to ask questions, tour the facility or meet with the provider in the community to see how you feel about the program. The provider handles all paperwork for services to get things set up to start providing support and to submit invoices once services begin.

If you are having problems with the provider(s) selected, you can work through your support coordinator to resolve any issues or concerns. There is also a grievance process you can go through. See below. **You can change providers at any time.**



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

### Providers can offer:

- Behavior Supports
- Chore Services
- Companion Services
- Day Services
- Host Home Services
- Professional Parent Supports
- Residential Habilitation Supports
- Respite Care
- Supported Employment
- Supported Living
- Transportation Services
- A fiscal agent can also be a provider





## STEP 2

# I HAVE SO MANY QUESTIONS....

### What should I look for in a Provider?

You may want to phone screen or meet with prospective providers to see if they are available and willing to serve you. You may want to have someone you trust with you during the interview. They can help you observe the provider and give you feedback after the meeting. You are able to pick whom you would like to be your providers. You should have high, but realistic expectations.

You should not feel pressured to select a certain provider. If you are making the decision on behalf of an individual with a disability because the individual is a minor, or is unable to make the decision independently, try to include the individual in at least some part of the meeting so you can observe how the provider interacts with the individual. Ensure the provider has a realistic picture of the needs of the individual who is receiving support.

### Here are a few examples of questions you may want to ask during the interview:

- How long have you been a DSPD Provider? (FYI... Sometimes a great provider can be relatively new to providing services.)
- Do you work independently, or with a company? If you are with a company, how many other providers work there?
- How many hours do you usually work?
- Do you offer multiple services through the waiver?
- What hours are you available to provide services?
- During the day what hours do you take calls?
- What is the preferred way to communicate with you? How long should I expect to wait for a response?
- Who covers for you when you are unavailable? How do I contact them?



Use this QR code and  
link to check for  
licensed providers



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



## STEP 3

# I SELECTED MY PROVIDERS LET'S GET STARTED

### After you Make a Decision

You have to be willing to train care providers. Important information to share may include how your home works, or how your loved one interacts. You may need to explain behaviors and daily schedules. You can also take a provider out into the community to learn and understand your routine. Your provider can be the one to help you order, obtain food, use the restroom, etc. so they can learn what works best for you. Providers serve multiple people so it is important for them to understand how you prefer to receive care. For example, if you have a provider that is a respite provider, you could give them options of things they can do with your loved one that your loved one will enjoy. This may lessen as the provider gets to know your loved one. Tip: As you become more familiar with HCBS services, you may find it helpful to prepare a training sheet for new employees.

### What to Expect

After choosing your provider, you should expect your new provider to:

- Handle all paperwork for services
- Submit invoices for billing
- Communicate with you. You may need to initiate communication. It is important to build good relationships with your providers.
- Have staffing changes. Your care provider may change periodically.
- Require you to train them on your needs or the needs of your loved one. They will not come ready to serve you because each individual is unique and has different preferences.
- Learn new things. The system is not perfect, but everyone involved wants the best for you and your loved one. It is important to guide and work with people so they can understand your needs.







## Tips to Keep in Mind

- Providers do have age requirements.
- Sixteen-year-old providers can provide services but are not allowed to drive clients until they are 18.
- Keep your eyes open for new providers.
- Depending on the services required, it may take some time for a provider to begin services due to staffing. You may be on a waitlist for your desired provider.
- It's important to build respectful relationships. While you are free to change providers, a provider is also able to resign from serving you. You are both required to give a 30-day notice. It's important to be professional and direct rather than emotional when communicating.
- Keep a record of your communication with your providers. Follow up on emails and phone calls. Summarize phone calls in a follow-up email so you can both have a record of what was discussed and agreed to on the phone call.
- Say thank you when services have been provided. When expectations are met or exceeded, send them a thank you note or leave a good review.
- While you can choose providers, options may be limited depending on the service you need and availability in a program or with a certain provider.







# GREEN FLAGS & RED FLAGS

## FINDING A PROVIDER TO ADMINISTER SERVICES

When considering a provider, it is important to interview the potential provider, visit the program if it is not in the home, and meet the staff. You will want to ask to see the group home or setting where you will be cared for, where you might live, or where you will attend programming. The following are examples of things to consider when evaluating a provider.



### Providers offering great services will:

- Be able to show current certification/licensing and that training is monitored
- Returns phone calls and emails
- Reliable
- Staff interacting with you
- Not only offer choices to you, but you are able to say what you want to do and where you want to go during the day/week.
- Experience: Does the provider have the knowledge and years of experience to handle your needs?
- A program that ensures you have a quality of life. This will look different for everyone. Some individuals need downtime and to be allowed to relax in a quiet space. Some individuals want nonstop activities, while others want to be working on skills. Evaluate if the program allows for your needs and desires to be met.



### Warning Signs to Consider:

- Unable to show certification/licensing and that training is monitored
- Lapsed certification
- High staff turnover
- Unreliable
- Communication difficulties. Doesn't return emails or phone calls
- Big promises without evidence the provider can deliver
- Too big or too small: Is the setting over-stimulating? Is the company too small to have the needed resources?
- Disengaged staff



# WHAT IS THE PROCESS FOR NAVIGATING A GRIEVANCE WITH A PROVIDER

If concerns come up with a provider you are working with, reach out to your SCE. Your SCE will help you navigate your next steps in the grievance process. Your SCE will help you understand what is a normal provider practice and where you may have a more significant issue. Your SCE might be able to shed light on the situation and help you develop a plan for moving forward.

**Remember you can choose to change your provider at any time as long as you give a 30-day notice. Your SCE can help you make these changes. Hiring a new provider would involve identifying and interviewing new providers. You may also be placed on a waitlist for a new provider. When switching providers there is the possibility of going without a provider while the change is being implemented.**

While you do have the right to switch providers, it is important to keep in mind that as an individual receiving services you also have a responsibility to train and work with your provider. Due to staffing shortages, it might be hard to replace a provider quickly. It is important to build professional relationships with mutual kindness and respect. Navigating relationships is also an opportunity for you to learn and utilize self-advocacy and communication skills.





# FAQ'S

## UNDERSTANDING PROVIDERS

**Q:** Do I have a choice in selecting a provider?

**A:** Yes! You have a choice in selecting a provider and are free to determine what services will provide you or your loved one with the best care for your situation.

**Q:** Are providers monitored for quality?

**A:** Yes! The state certifies and/or licenses these providers, and DSPD works closely with them to monitor the quality of the services they provide.

**Q:** How does the Settings Rule apply to providers

**A:** People with disabilities should be able to enjoy the same choices and options available to people without disabilities. Providers need to provide services in settings that:

**All Settings:**

- Are integrated into and support full access to the community
- Providing opportunities for employment in competitive integrated settings, engage in community life, and that control personal resources
- Selected by the person from various options, including non-disability-specific settings or a private unit (without roommates)
- Optimize individual initiative, autonomy, and independence in making life choices
- Are accessible to you.
- Facilitate choice regarding services and supports and who provides them

**Residential Settings:**

- Provide you with a lease or other legal agreement
- Provide privacy in your unit including lockable doors, choice of roommates, and freedom to furnish or decorate your unit.
- Ensure you can have visitors of your choosing at any time
- Ensure you have the freedom to control your schedule, and activities, and have access to food at any time.

You choose what you do with your time. where you live. with whom you live, how you spend your resources, and who supports you.



**Q: How do providers maintain safety in the setting and in the community?**

**A:** All providers are required to submit background screening applications to the Utah Department of Health and Human Services prior to a staff member working alone with a person in services. Staff members are also required to receive First Aid and CPR Training in addition to other required training. Providers plan activities that support goals and interests identified in the annual Person-Centered Plan Meeting. Providers work with a person's team (which often will include a behavior specialist or nurse) to integrate the person into the community in ways that maintain the health and safety of the individual. Pro Tip: When interviewing a provider, it can be helpful to ask this question to understand their specific approach to community support.

**Q: What can I do if I am having a problem with my provider or if I am unable to resolve my concern with a provider? How do I communicate concerns and when is it best to bring in support from my SCE, DSPD Case Manager, or Adult Protective Services?**

**A:** If you are having a problem with the provider(s) selected, you can work through your SCE to resolve issues or concerns. You can also change providers at any time. In addition, there is a grievance process you can go through that is discussed in this book.

You can also call DSPD Constituent Services. Their contact information is 1-844-ASK-DSPD (1-844-275-3773) OR 1-801-538-4200 and ask for Constituent Services. Or, email [DSPD@utah.gov](mailto:DSPD@utah.gov). You can also provide feedback to the Department of Health and Human Services by contacting [HCBSSettings@utah.gov](mailto:HCBSSettings@utah.gov) or the Office of Disability Ombudsman by contacting Angie McCourt at 801-538-4580 or [amccourt@utah.gov](mailto:amccourt@utah.gov). Adult Protective Services can be reached by calling (801) 538-3567







**Q:** What happens when you get a 30 day notice from a provider? What if you want to give a 30 day notice to a provider?

**A:** You can switch providers at any time. However, you are required to give your provider a 30-day notice. Your provider can also discontinue the services they provide to you as long as they provide a 30-day notice. In either case, you will need to find a new provider as soon as possible. Your SCE can assist you in your efforts.

**Q:** As a family member, I find it challenging to work with my loved one's provider. How can I advocate for my loved one and also build a relationship of trust with a provider?

**A:** Communication between an individual/family member is key. If you feel a provider is not being responsive, contact your SCE for assistance. Your loved one's desires, needs, and goals should be driving what happens in services. Providers should be communicating with an individual/family and providing choices. This is especially true for respite and supported living. Providers should be working with you rather than dictating a program.





# GROUP STAFFING BUILDING COMMUNITY

## Who Utilizes Group Staffing and How is Staffing Determined?

Certain types of providers use a service model that incorporates group staffing; Group homes and day programs are two examples. Support Coordinators and DSPD will work with your team to decide what level of staffing is needed for each hour you are in a program.

An example might be that someone living in a group home is fairly independent. However, they do need a lot of help cooking a specialized meal each day due to health concerns. This hour to prepare the meal would be staffed at 1:1. All other hours at the house may be staffed at 1:3 since this person only needs basic supervision and assistance which could be shared with other staff.

Another scenario might be more complicated due to medical or behavioral needs. This type of situation may require additional hours of 1:1, and 1:2, with the remaining hours being staffed at 1:3 to meet the individual's specific needs.

### Pros

- Group staffing can be more cost-effective than 1:1 supports
- Day and residential services offer more variety and complexity of services than many 1:1 service codes
- Socialization can be more natural when there are group services
- People in services can become more independent when they share support as opposed to a provider doing everything for them
- Programs are certified/licensed and training is monitored

### Cons

- Less individualized support
- Potential for conflict among peers
- Can be difficult for individuals who do not like being around others with disabilities
- Consider the individual's ability to adapt to flexible staffing





# Additional Resources and How to Use Them

In addition to the support you receive from an SCE and your providers, there are other agencies, resources, and tools available to you. Work with your SCE to identify what resources might be the best fit for you.

One idea to help you identify your needs, goals, and desires, is to use the Integrated Supports Star tool. A completed example and directions are included on the following pages. In addition to listing items in each area, you could also split each area in half. Write down what you currently have in place and what is missing, where you could use more support, any unmet needs, desires, goals, etc.

This visual tool can help you know what to talk about with your SCE and can help you begin to connect with the appropriate resources.

## Examples of Additional Resources

- **Independent Living Centers:** Training, education, social, etc.
- **Medicaid, Neurobehavior Home Program:** mental health and medical care (Huntsman)
- **Mobile Crisis Team:** Behavior and Mental Health
- **Nursing Services:** medical care
- **Social Security Programs:** SSI/SSDI
- **Utah Center for Assistive Technology (UCAT) & (UATT)**  
Utah Assistive Technology Teams: assistive technology information and technical services
- **Utah Developmental Disabilities Council (UDDC):** Advocacy Skills
- **Vocational Rehabilitation (VR) & Dept. of Workforce Services (DWS):** employment, job training, & education. Tip: If you are in school, be sure to connect with VR. Your VR data can be shared with DSPD and can help to determine services.



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

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







# THE IMPORTANCE OF A PERSON-CENTERED SUPPORT PLAN (PCSP)

## Understanding the PCSP Tool

The Person-Centered Support Plan (PCSP) is a tool to individualize services and supports for an individual with a disability. For example, the Division of Services for People with Disabilities (DSPD) uses the Person-Centered Support Plan (PCSP) as a way to develop and document meaningful supports and goals, assign paid services, and support specific goals to work on during the year.

### PCSP Tips:

- Support Coordinators (SCE's) use the PCSP to coordinate and monitor services and supports for the individuals they serve. At a later date, if you hold a review meeting or are updating your PCSP, your SCE will review timesheets and talk to employees and providers to acquire information that will help you update your plan and revise your goals.
- When you come off the waitlist, your SCE will meet with you to update your PCSP that was set up by your DSPD Transition Coordinator.
- The PCSP is the basis for all of DSPD's supports and services. The goals within your PCSP can be revised at any time. Life changes can happen with illness, loss of job, and other big changes. Please let your SCE know so they can help with the revision of goals and look for ways to support you with the goals.
- Individuals and their families are encouraged to be active participants in the process so they can maximize the potential to lead a self-directed life. You should be leading your PCSP meeting. This is your plan. [The following link/QR code will help you access an informative guide to help you create your Person-Centered Support Plan.](http://bit.ly/3KzjRnK)
- Service Providers, such as group home staff, use the PCSP to individualize supports, services, and strategies for individuals receiving DSPD Medicaid Waiver services. The plan should be based on the needs of the client (you), not what is best for the provider.
- The budget given to you by your DSPD Transition Coordinator lasts for a 12-month period.
- Moving forward, the PCSP is generally reviewed one month before your budget ends each year.



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







# SAMPLE CASE STUDY

## BEN'S PCSP MEETING

Ben's case study will help to paint a picture of how Ben or Ben's caregivers can prepare for and participate in his PCSP meeting. This is just one example. Please refer to the PCSP section of this resource book for more detailed information. Work with your SCE if you have any questions or if you need assistance understanding any aspect of PCP or PCSP meetings.

In preparation for Ben's meeting, Ben should have participated in a needs assessment from either his DSPD Transition Coordinator if he is coming off the waitlist, or from his SCE. In addition to the needs identified by the assessment, Ben should make a list of his desired goals/outcomes. Ben will use the Living the Life You Choose workbook (found in this guide's PCSP resource section) to identify his personal strengths and also his preferences for how and where services are provided. Ben and his caregivers should think about what supports are needed (paid and unpaid) to help Ben be as independent and successful as possible. Risk factors and measures put in place to reduce risk, along with backup plans should also be identified. If it is challenging to identify any needed PCSP component, Ben should work with his SCE to brainstorm ideas and possibilities. Ben can invite anyone he wants to his PCSP meeting; this can include caregivers, service providers, trusted individuals, teachers, specialists, etc.

During the PCSP meeting, Ben should feel listened to and respected. Ben and his caregivers will want to make sure his Transition Coordinator/SCE is writing Ben's plan in plain language or in a manner that is understandable to Ben. Since Ben is older than 14, employment options should be discussed as well as Ben's living arrangements. Ben should be satisfied with where he lives. Someone should also be identified as the individual who will be responsible for monitoring the plan. Ben has the right to agree or disagree with the plan being put in place. This is done through written and informed consent. Ben's providers who are responsible for carrying out the plan must also agree to and sign the plan. Ben's plan should be distributed to Ben, and others involved in the plan. Ben's plan should include any services Ben may choose to self-direct. The plan should also prevent any unnecessary or inappropriate services and supports.

Ben's PCSP will be reviewed each year. Ben understands he can contact his SCE at any time for help or to update his plan. Ben also understands he can change his staff at any time. If Ben isn't satisfied with his providers, his SCE can help Ben make a change.





## How to Create a PCSP / PCSP Meeting

A PCSP may seem similar to an Individualized Education Program (IEP). When a child is younger, the parent may have to rely on the “mom/dad knows best” card. But as they become older, the individual should have more input in what their goals are going to be so that as adults, they are the driver of their PCSP. You are part of this meeting and encouraged to use your voice to the extent possible.

At the meeting, the goals you have been working on are celebrated. To prepare for the meeting it may be helpful to think of new goals and review goals that may have been worked on in the past. Helpful tips would be to include information on school goals, employment goals, and independent living skills that you might want to work on in your updated plan. You should also be told how you can update your plan.

Your DSPD Transition Coordinator or SCE should educate you on how the meeting planning process works including how to schedule your own meeting, and how the development of the plan works. This includes knowing how you can update your own plan. You should also be made aware of service options so you can make a choice during the meeting. Example: Options for places to live.

The Employment Pathway Tool (if applicable) and the Utah Comprehensive Assessment of Needs and Strengths (UCANS) that was completed when you first met with the Support Coordinator will help with goal-setting. This is a strength-based assessment and helps solidify goals. It will be reviewed as part of the PCSP meeting.



**The waiver requirements state that those who provide waiver services, or those who have an interest in or are employed by a provider of waiver services for the person, must not provide case management or develop the person-centered service plan, except when the State demonstrates the only willing and qualified entity to provide case management and/or develop person-centered plans in a geographic area also provides waiver services.**



# How to use the Integrated Supports Star

The Integrated Supports Star on the following page is a person-centered planning tool that can help you prepare for your PCSP. You can refer to this tool during your PCSP meeting to identify supports that can help you move towards your goals. It invites you to explore supports available to you in the following five 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

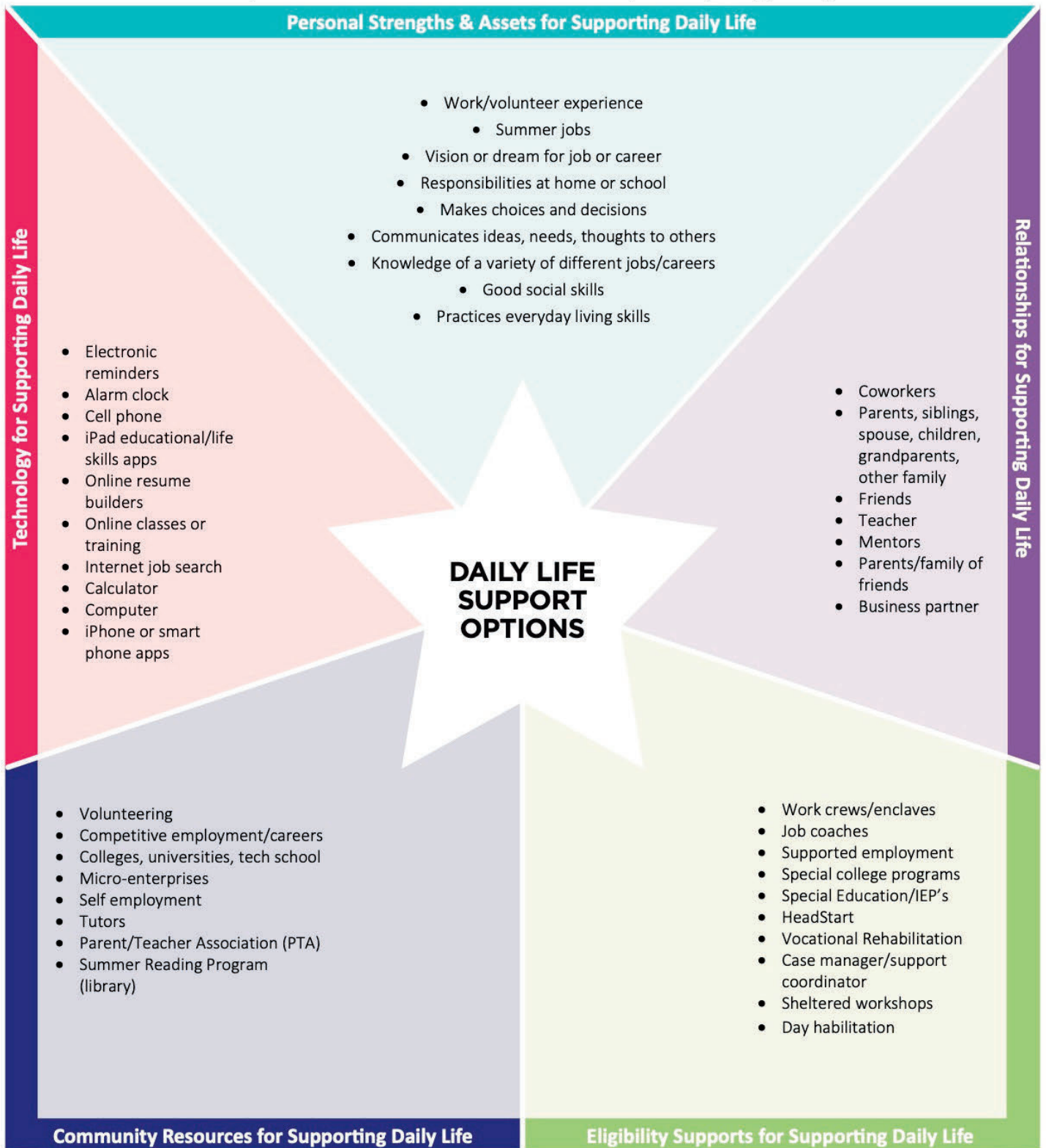






## INTEGRATED SUPPORTS STAR | DAILY LIFE

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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# WHO PARTICIPATES IN MY PERSON-CENTERED SUPPORT PLAN MEETING?

You are the one to determine who attends your PCSP meeting. You may be able to make this decision independently or need some support from the support coordinator, family, or others to do so. The support coordinator should also be at the meeting as they have specific duties to fulfill. Your SCE should monitor the progress you make, coordinate services from providers, manage the budget, and ensure your health and safety. If you don't want your support coordinator at the meeting, you should discuss it with someone you trust.

The Support Coordinator will reach out to everyone on the individual's team to be involved in the meeting. You can create a team to attend this meeting as you collaborate with and problem-solve to come to the best solutions for yourself. You can invite anyone to the meeting for support. This could include provider staff or your hired staff if using Self-Administered Services (SAS). It could also include your family or friends.



## Others who may participate in your PCSP are:

- guardians
- parents
- other family members
- close friends
- residential and day support providers
- employment providers
- therapists
- teachers
- a significant other
- or anyone who provides support (paid or unpaid) to you.

The meeting should be held at a time and place that is chosen by you and is convenient for all attendees. The location should be comfortable, accessible, quiet, and provide privacy. The PCSP should also reflect your cultural considerations.



# HOW DOES MY PCSP REFLECT MY NEEDS?

Your PCSP should be robust and comprehensive. Your services are built around the content of your PCSP. It should reflect your needs, and desires, and maximize your community integration. Review your PCSP to make sure your plan meets these criteria. A strategy should be in place for solving conflicts or disagreements during the PCSP process and should include conflict of interest guidelines.

- ☒ When you helped develop your support plan, did people ask you about things you are good at, and what you need to live your life the way you want to live it? Did they listen to you?
- ☒ Do you have choices in the support you receive and the people who help you? Were you given non-disability-specific options? (This means you may want to receive services or have a job where other people do not have disabilities.)
- ☒ You are supported to lead your life the way you want and you are supported to make life choices. This includes what you do each day, where you do it, and whom you do it with. You have a choice in what services you get and who provides them.

For instance, you may want to volunteer at your public library and spend your time there. Or, you may want to work at the Starbucks up the street. Or, you may want to live in an apartment or house because it is close to your church or synagogue and other people without disabilities live there. It is your right to have this option. The services you are provided should optimize individual initiative.

## How are Goals Documented

Goals that are identified by the UCANS, the Employment PathwayTool, and through your PCSP meeting are documented in your PCSP.

Your SCE will keep notes about your goals and progress. You have the right to ask your SCE for a copy of any PCSP notes at any time. If for some reason your SCE does not share notes with you, you can reach out to DSPD by calling 1-844-ASK-DSPD.





# DAILY LIFE WITH MY PCSP

## GOALS IN ACTION

Now that the goals are in place, you are able to talk about services and what is possible based on needs, and what supports may be available to reach your goals. Here are some of the services that may be available to an individual as a Person-Centered Plan is developed. These are possible services that may or may not apply depending on the need of the individual and the PCSP that is created. The services should support the individual in reaching their goals. Refer back to the section of this guidebook that outlines service code options. This is not an all-inclusive list as other needs may be identified through the process with the individual, family, and Support Coordinator. Unless otherwise noted, the list applies to both Provider and Self-Administered Service delivery models.

### Natural Supports

Creating natural supports is very organic. We all create these supports whether we realize it or not. Consider who naturally connects with you. (Family members, neighbors, friends, parents, and or friends.) Who has a career in the area in which you have an interest? What do you like to do in your spare time? (Sports, Special Olympics, church groups, support groups, etc.) Find the supports that fit your needs. You can ask these supporters to be a part of your team and to help you achieve the goals outlined in your PCSP. Goals don't necessarily need to be tied to a paid provider.

### Examples of Goals in Action

Supported living goals can focus on appropriate skills in the community. For example, Mia receives waiver services. Mia can run errands with her provider, Gabby, during her service time. While with Gabby, Mia is learning how to navigate the community.

Goals should also be aligned with the Settings Rule. You should be given choices about what you want to do during the day. For example, you are allowed to choose if you want to watch a movie or if you go out into the community.

You, your provider, and your family can create a choice basket with appropriate activities or activities you've previously selected. When your provider arrives, you can select something out of the basket you would like to do.







# QUALITY OF LIFE PCSP CONSIDERATIONS

Because you are accustomed to living your life without the assistance of waiver supports, you may not be familiar with the way waiver supports can help to increase your quality of life and your independence. When creating your PCSP with your team, consider the following areas of your life and where additional support may be beneficial.

## Advocacy and Engagement

Civic well-being includes, but is not limited to, privacy, protection under the law, and voting rights. Individuals can build valued roles, make choices, set goals, assume responsibility, and drive how their own life is lived. For example, a provider may talk with you and recognize you need help registering to vote.

## Community Living

Community Living includes where and how someone lives, housing, living options, community access, transportation, home adaptations, and modifications. Providers should take these factors into consideration when referencing the community living well-being quality of life measure. For example, a provider may help you determine activities in the community and where you need support.

## Daily Life & Employment

Daily Life well-being includes but is not limited to, personal development, choice and control, and employment. What a person does as a part of every-day life; employment, school, routines, volunteering, communication, life skills, etc. Providers should take these factors into consideration when referencing the daily life well-being quality of life measure. Talk with your SCE about your desire to have a job. Additional information about employment and employment resources can be found on upcoming pages.

## Healthy Living

Physical well-being includes but is not limited to, nutrition, fitness, and personal safety. Managing and accessing healthcare and staying well; medical, mental health, behavioral health, etc. Providers should take these factors into consideration when referencing the physical well-being quality of life measure. For example, you, with the support of your provider, may decide to meal plan nutritious lunches you can take to work.







# QUALITY OF LIFE CONTINUED

## Safety & Security

Safety and Security well-being includes staying safe and secure; emergencies, well-being, guardianship options, legal rights, etc. Providers should take these factors into consideration when referencing the safety and security well-being quality of life measure. Reach out to the Utah Parent Center if you need assistance with guardianship or alternatives to guardianship, Advance Healthcare directive, etc.

## Social & Spiritual

Social and Spiritual well-being includes community involvement and networks of support. Emotional well-being includes, but is not limited to, life satisfaction, religious belief, and self-esteem. It is important to build friendships and relationships, leisure activities, personal networks, social support networks, faith communities, etc. Providers should take these factors into consideration when referencing the social and spiritual well-being quality of life measure. For example, you and a provider may talk with you and decide together that you will attend a pottery class with your friend. Or, you, with the support of your provider, may decide you will attend the church service of your choice.

## Living the Life You Choose - Resource Guide

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

This workbook will walk you through all of the information you might need to prepare for your person-centered planning meeting. This information and the things you write in your workbook can help you plan for a great life! The main content goes from page 5 to page 21. The workbook elements start on page 22 through page 29. You can follow the links to navigate from the content to the workbook and back. There are also links which will take you to documents or websites outside of this workbook. You can complete any, all, or none of the workbook elements. This is your book to prepare for your meeting so use it however you want. If you do any of the workbook sections, you can share them with your support team.

**DSPD's Living the  
Life You Choose**

**A Tool for my Person-Centered  
Support Meeting**





# EMPLOYMENT, EDUCATION, AND MY PCSP

There is not just one pathway to getting a job. Ask your SCE what services you can access through the Division of Services for People with Disabilities (DSPD) and Vocational Rehabilitation (Voc. Rehab or VR). Explore your own interests and needs. You may not want or need to access every service, but you will want to know the options so that if the opportunity is available, you can access them.

The following are additional resources and examples to guide you. Most people have to try several things before they find the right fit.

## DSPD Employment Pathway Tool



<http://bit.ly/3Q2gG8L>

The Division of Services for People with Disabilities (DSPD) Employment Pathway Tool was developed to facilitate support for people receiving services in order to find and keep Competitive Integrated Employment (CIE). CIE means that people with disabilities work in the community alongside people of all abilities; are employed in a non-Service Provider setting or business; are compensated at or above minimum wage, or at a wage comparable to people without disabilities who work in the same place and who perform the same or similar work; and have access to opportunities for advancement and benefits. To this end, the DSPD Employment Pathway Tool has two major goals:

1. Identify the most appropriate employment pathway for you
2. Develop strategies to be included in your Person-Centered Support Plan (PCSP) that move you in the direction of CIE.

Use these links and QR codes to access additional employment resources.



Utah State Office of Rehabilitation

<https://jobs.utah.gov/usor/index.html>



Transition University's Employment Module

<http://bit.ly/3JQC4w6>





## 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



## Ready and Able

The purpose of the Ready & Able campaign is to help those with disabilities prepare for and find employment. Likewise, it is also to assist employers in hiring qualified and dependable employees who happen to have disabilities. The objective of this website is to increase awareness of the pool of qualified talent found among Utahns with disabilities, work to bridge the gaps between employers and potential employees and highlight existing employment-oriented resources. We support efforts by employers to overcome barriers and build capacity for employing people with disabilities.

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



## Education

Education can be an enriching part of your life. Use your PCSP to help you achieve your education goals. Do you need transportation to and from your school or education site? Are there goals you need to achieve before you can gain access to a certain program? Is there a post-high program opportunity that could be supported through your PCSP services? Utilize the following QR code and link to access the Utah Parent Center's Education module with Transition University for more information.



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







# MODIFICATIONS OR RESTRICTIONS IN YOUR PCSP

Sometimes your rights are restricted in order to keep you safe and to provide you with the best support. When you are not able to do something, or when someone controls you in some way, this is called a RESTRICTION. Before a provider can restrict any of your rights, they need to do a lot of paperwork to show that they tried to do everything possible to show they tried to avoid putting a restriction in place. You need to be involved in the discussions. The provider will need to show the following items in the PCSP.

1. Identify a specific and individualized assessed need.
2. Document the positive interventions and supports used prior to any modifications to the person-centered service plan
3. Document less intrusive methods of meeting the need that have been tried but did not work
4. Include a clear description of the condition that is directly proportionate to the specific assessed need
5. Include regulation collection and review of data to measure the ongoing effectiveness of the modification
6. Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated
7. Include your informed consent
8. Include an assurance that interventions and supports will cause no harm to you.

**While guardians do protect an incapacitated person, they also need to balance safety with the dignity of risk and allow individuals as much self-determination as possible. This topic was also discussed in the Settings Rule section along with guardianship.**







# PCSP WAIVER REQUIREMENT CHECKLIST<sup>1</sup>

Item	Requirement
1	The written plan must reflect that the setting in which the person resides is chosen by the person. The State must ensure that the setting chosen by the person is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as people not receiving Medicaid HCBS.
2	The written plan must reflect the person's strengths and preferences.
3	The written plan must reflect clinical and support needs as identified through an assessment of functional needs.
4	The written plan must include individually identified goals and desired outcomes.
5	The written plan must reflect the services and supports (paid and unpaid) that will assist the person to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.
6	The written plan must reflect risk factors and measures in place to minimize them, including individualized backup plans and strategies when needed.



# PCSP WAIVER CHECKLIST

## CONTINUED<sup>1</sup>

Item	Requirement
7	The written plan must be understandable to the person receiving services and supports, and the people important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited to English proficient.
8	The written plan must identify the person and/or entity responsible for monitoring the plan.
9	The written plan must be finalized and agreed to, with the informed consent of the person in writing, and signed by all people and providers responsible for its implementation.
10	The written plan must be distributed to the person and other people involved in the plan.
11	The written plan must include those services, the purpose or control of which the person elects to self-direct.
12	The written plan must prevent the provision of unnecessary or inappropriate services and supports.
13	The written plan must document that any modification of the additional conditions must be supported by a specific assessed need and justified in the person-centered service plan.



# ARE THERE TOOLS TO HELP ME UNDERSTAND A PCSP?

There are tools to help you and your family understand and create person-centered goals. Utilizing these tools will help you prepare for your PCSP meeting. Support coordinators are also encouraged to use these tools.

## Charting the LifeCourse



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

## Life Trajectory Exploring



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

## Life Trajectory Planning



<http://bit.ly/3Q28dT0>

## Exploring Decision- Making Supports



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

## Integrated Supports Star



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

## Life Domain Vision Tool



<https://bit.ly/3CaKCd8>

## Relationship Map



<https://bit.ly/3VvSLj9>

## One-Page Profile



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

## Good Day/Bad Day



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



# Additional PCSP Resources

## Family Perspective on Employment



<http://bit.ly/3C8ZZT8>

## DSPD Living the life You Choose



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

## DSPD PCSP Information & Resources



<http://bit.ly/3Q2fSke>

## Utah Parent Center PCSP Information



<https://bit.ly/3G1ZhbM>

## Problem Solving with your SCE



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

## Choosing or Changing your SCE



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

## Guide to Eligibility and Services



<http://bit.ly/3I5y1f3>

## Living the Life You Choose Workbook



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





## KEEPING SERVICES

Once you are off the waitlist and into services, you are required to maintain Medicaid eligibility. Your SCE will monitor your eligibility. If you are going to lose services on one waiver it may be possible for you to switch to another waiver that has different criteria.

As an individual covered by Medicaid, your assets should not exceed \$2,000. This would include any bank accounts or assets in your name. To reduce the amount of assets in your name, you may need to "spend down" some of your funding. Your SCE can guide you. For example, if your bank account had \$2,500, you could spend \$500+ on something you need for your care. For example, a mattress, clothes for work, etc.

The \$2,000 limit rule only applies to the person on Medicaid. When an individual is in waiver services, family assets do not impact waiver eligibility unless the family assets are in the individual's name who is being served by the Medicaid waiver. If a family had assets they wanted to give to their loved one, they would want to utilize a Third-Party Supplemental Needs Trust in order to protect assets as well as their loved one's Medicaid eligibility. For more information on estate planning, please refer to the Utah Parent Center's Choices Book in the **RED** section.

Based on your eligibility, if it is determined your Medicaid coverage will be changing, you will be sent a notice of agency action and how to appeal the Medicaid decision.



The Choices Book and additional information can be found here:  
<https://bit.ly/UPCChoices>



# HOW DO WAIVERS INTERACT WITH MEDICAID & SSI?

## Medicaid Overview

Qualifying for waiver services allows you to gain access to Medicaid if you do not already have Medicaid in place. Your services through an HCBS waiver are paid for by Medicaid.

Your SCE will help you fill out any required forms, including the Medicaid Release Form. Your SCE will monitor your eligibility monthly to ensure you maintain continuous Medicaid eligibility and will notify DSPD within 30 days of any changes in eligibility status. DSPD will also notify your SCE if reviews have not been turned in. If reviews have not been turned in, your SCE will notify you and remind you to get reviews submitted. Reviews are critical. If reviews are not completed, it may compromise your loved one's ability to receive services. Your SCE can help you navigate any questions you have about Medicaid.

## Monthly Touch Point

Your SCE or Nurse Coordinator should check in with you each month. This could vary depending on your waiver. For example, with the Physical Disabilities Waiver, you may only connect every 3 months. This can be done via, email, text, phone call, or in person. Your SCE/NCM contacts you to check in and discuss your current situation. This should take place regardless of who is the SSI Representative Payee. More information about about Rep. Payee can be found below in this section.

## Annual Review

Medicaid requires there to be an annual review of your eligibility. A review also takes place to ensure your medical services are up to date. This review is completed by Medicaid. You will receive a communication from Medicaid about your annual Medicaid review. This could be delivered via email, a letter, or through a case manager. However, if you are the SSI Representative Payee, you are responsible for making sure an annual review is completed and submitted. If you are feeling overwhelmed with this process, please contact your SCE/Nurse Case Manager.





## Medicaid Managed Care Plans

Managed Care Plans (MCPs) provide medical, dental, and behavioral health services to eligible Medicaid and CHIP members. When starting Medicaid services, you will be able to select plan provider. There are a variety of plans to choose from. It is important to pick a plan that participates with your physicians and clinics. Prior to using a provider, verify that the provider accepts your Medicaid at that location. This is similar to the "in-network" or "out-of-network" concept used in private insurance companies. If you want to change providers, you can do so during open enrollment in July.

For additional information on any of the Managed Care plans, please contact a Health Program Representative at 1-866-608-9422.

<https://medicaid.utah.gov/managed-care/>

## Medicaid & Residential

Review the benefits of your particular waiver. Some waivers do not offer residential services. If your waiver does cover residential, it is funded based on need. If your loved one is in need of residential services and funded, your SCE will help you navigate residential care while utilizing DSPD and Medicaid. It is possible to also utilize a Section 8 Housing Voucher with waiver services.

## SSI & Medicaid Eligibility

For a minor child, Medicaid and SSI look at the assets of the child's parents or the primary parent they are living with at the time. To access these services eligibility is based on financial assets.

If you have come off the waitlist and have accessed waiver services, you are now entitled to Medicaid without parental income being considered. The income review will instead be based on the child's assets and the child can have no more than \$2,000 in assets in the child's name.

However, SSI eligibility still reviews parent income for eligibility for a minor child on waiver services. If parents are not living together (divorced), you report who is the primary parent. Any child support received is reported as income to the child. This could impact your child's SSI eligibility.

When a child reaches the age of 18, the youth is considered an adult and will be eligible based on their own assets (income) rather than the assets of their parents. If your loved one is on waiver services, they will receive Medicaid. However, their SSI eligibility still considers the youth's income. The rule of having no more than \$2,000 in assets in their name applies to both Medicaid and SSI.



## What is a Representative Payee

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.

If an individual receives residential services and resides in a facility like a group home, usually the home is the Representative Payee. The residential facility provides a monthly statement detailing how all funding is being used. This report is given to your SCE for review.

- 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 report 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/>**





# ADDITIONAL INFORMATION REGARDING SSI

For additional information and resources about Social Security and essential tools for planning for the future, please refer to the Utah Parent Center's Choices Book. The topic of SSI is explored in detail in the RED section of the book. Other topics include Social Security Work Incentives, In-Kind Support and Maintenance, a youth turning 18, managing benefits and benefit planning programs, Ticket to Work, Student Earned Income Exclusion, Employment-related Personal Assistance, ABLE Accounts, estate planning, and more.

## **As a Caregiver, 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.

**Spanish Choices  
Opciones**



<https://bit.ly/3Jor75g>

**Choices Book  
English**



<https://bit.ly/UPCChoices>

**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>



# ADDITIONAL INFORMATION

## 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](mailto:team@stableaccount.com)

**ABLE Utah Information**



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



# CAN CAREGIVER COMPENSATION IMPACT OTHER BENEFITS?

## Caregiver Compensation, SSI and Medicaid

If your loved one is still living in your household, and as a parent, spouse, or guardian you will be providing caregiver support, the Caregiver Compensation money you receive is just like any other income and will be considered gross income.

**However, it is possible Caregiver Compensation, if received through waiver funding, will be not taxed as income on your federal or state taxes. Even though it might not be taxed, it IS reported as income and could impact your SSI, Medicaid, SNAP, or other benefits eligibility. Working with a tax professional is important so you can better understand how Caregiver Compensation and your situation could impact your taxes, benefit eligibility, and if you want to receive SSA Work Credits.**

**If you are not in HCBS waiver services, receive one-time DSPD funding, and opt for Caregiver Compensation, your Caregiver Compensation could be paid through ARPA or Cares funding. If this is the case, your Caregiver Compensation income could be taxable and could also impact benefits eligibility. It is important to identify the source of the funding and consult with a tax professional.**



For a link to IRS Rule 131, Notice 2014-7 Rule, use this link and QR code. The Utah Parent Center does not give tax advice and would refer you to a tax professional to discuss your needs and situation.

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

## MyCase / MySteps & Medicaid

**MyCase** is a Department of Workforce Services (DWS) electronic program. You are able to signup when you are accepted into any DWS program (ex: SNAP, or VR). MyCase is also the entity that determines eligibility for Medicaid. When an individual starts receiving DSPD waiver services, you become part of the DWS system as well. DWS will send you a letter detailing how you can sign up for MyCase and how to use it. You can use MyCase to check on your eligibility status and find information there. You may find you don't use MyCase frequently. However, you may want to access it once a year for the eligibility review.

**MySteps** is the software DSPD uses for enrolling individuals on the DSPD Waitlist. Individuals can log into MySteps to see what number they are on the waitlist and their assigned waitlist worker. There are plans in the future to have more information related to waiver services available in MySteps.



# WHAT DOES THIS MEAN?

## ACRONYMS & DEFINITIONS

**Advocate/Advocacy** - To actively promote the fundamental principles of self-determination for all individuals with disabilities.

**AT** - Assistive Technology: Any type of device or service that can be used to increase, maintain or improve the capabilities of persons with disabilities.

**ABIW** - Acquired Brain Injury Waiver: A home and community-based services waiver that assists people age 18 and older who have an acquired brain injury (ABI) with services outside of a nursing home.

**CHEC** - Child Health Evaluation and Care: A preventative care program for children up to 21 years of age that tries to identify and treat health problems before they become disabling.

**CHIP** - Children's Health Insurance Program: An insurance program for children 19 years of age and younger whose family does not qualify for Medicaid and cannot afford health insurance.

**CSW** - Community Supports Waiver: A home and community-based services waiver that assists people of all ages who have an intellectual disability or related condition with services outside of an intermediate care facility (ICF/ID).

**Day Programs (DSG or Day Support Groups)** - provides daily and hourly support, supervision, and training. DSG provides a safe, nonresidential, community habilitation program in a structured programmatic setting, other naturally occurring environment or community setting where people can gather in groups during the day to avoid becoming isolated and participate in and contribute to their community.

**DHHS** - Department of Health and Human Services is the overarching department that houses several agencies and divisions serving individuals with and without disabilities. DHHS is the state agency responsible for all of the parts of Medicaid waivers. DSPD is under DHHS.

**DSPD** - Division of Services for People with Disabilities: A state agency within the Department of Health and Human Services responsible for the administration of state and federal funding to provide services for people with eligible disabilities.

**EI** - Early Intervention: Programs and services for children with disabilities from birth to age 3.

**Eligible Disability** - Intellectual disability or related conditions, brain injury, and physical disability as defined in Administrative Rule R539-1.





# WHAT DOES THIS MEAN?

## ACRONYMS & DEFINITIONS

**Eligibility** - Determining whether a person qualifies for DSPD services based on specific criteria outlined in Administrative Rule R539-1.

**Family to Family Network:** A statewide parent support network run by volunteers, designed to educate, strengthen, and support families of persons with disabilities, especially those who are on the waiting list or are in services with DSPD. A program of the Utah Parent Center.

**Family Training and Preparation:** Training provided to families to assist them to self-administer their services.

**Fiscal Agent/Intermediary** - A company that is hired to handle payroll duties for those who use the self-administered services model.

**Guardian** - The person who makes decisions on behalf of another person who is considered incapacitated.

**Guardianship** - The legal process parents/families go through to become legally appointed to make decisions on behalf of a person with disabilities who is eighteen years of age or older and considered incapacitated.

**HCBS/HCBW** - Home and Community-Based Services/Waiver: An approval to waive certain requirements in order to use Medicaid funds for an array of home and community-based medical assistance services as an alternative to institutional care.

**HMO** - A form of private insurance otherwise known as a Health Maintenance Organization.

**Host Home** - Specially trained individuals or families who care for an adult who may need out-of-home placement for a short or extended period of time.

**ICF/ID** - Intermediate Care Facility for Persons with Intellectual Disabilities: A 24-hour residential facility for persons with intellectual disabilities and related conditions.

**IDEA** - Individuals with Disabilities Education Act: A federal law requiring all children with disabilities to have a free and appropriate public education.

**IEP** - Individual Education Plan that directs the services for a child with a disability in a school district or charter school.



# WHAT DOES THIS MEAN?

## ACRONYMS & DEFINITIONS

**ISO** - Invitation to submit offer. Your support coordinator will send out requests to providers to try and help you find a service provider that is the right fit.

**Inclusion** - The process of enabling persons with disabilities to be educated, live, work and participate socially in the same environment as others who are not labeled disabled. Inclusion is also used by educators to refer to the integration of children with disabilities into regular classes for part or all of the school day.

**Independent Living** - A community living situation in which a person with disabilities lives alone or with others with the necessary support from paid staff and natural support.

**Informed Consent / Choice** - A decision based on knowledge of the advantages, disadvantages, and implications of choosing a particular course of action. You have options, experiences with the options, and enough information about the options to make a decision.

**Least Restrictive Environment** - The most integrated, appropriate setting for an individual with disabilities, so they can interact as much as possible with peers who do not have disabilities.

**Local Interagency Council** - Local agencies that work together to improve service delivery to children and youth at risk who are experiencing multiple problems and who receive services from more than one state agency.

**Medicaid** - A federal program that pays for health care and long-term support expenses for people who meet eligibility requirements. Benefits are paid with federal and matching state dollars.

**Monthly Summary** - A summary of daily notes is required at the end of each month to be given to the Support Coordinator.

**Natural Supports** - The family and people in the community who support a person with a disability without payment.

**NAQ or Needs Assessment** - A questionnaire assessment often referred to as the NAQ, is used by DSPD to rank order individuals on the waiting list. Individuals are ranked according to need.



# WHAT DOES THIS MEAN?

## ACRONYMS & DEFINITIONS

**PASS Plan** - Plan to Achieve Self-Sufficiency, allows a person receiving Social Security benefits to set aside money received to help achieve self-sufficiency without losing benefits.

**PCPP creates PCSP** - Person-Centered Planning Process: A process that describes the strengths, preferences, needs, and dreams of the individual along with the services required to maintain health and safety. The developed plan is the Person-Centered Support Plan or PCSP.

**PDW** - A Physical Disabilities Waiver is an approval to waive certain requirements in order to use Medicaid funds for people age 18 and older with physical disabilities to help them maximize their independence in their choice of home, work, school, community, and daily activities.

**PPS** - Profesional Parent Supports is available for individuals under 22 years old, to live in a private residence with a family or caregiver who may or may not be related to the individual.

**Progress Notes** - See “Monthly Summary”

**Provider Companies/Provider Agencies** - Independent companies that contract with DSPD to deliver support and services to people with disabilities.

**Rates** - The amount that DSPD pays to a provider, company, or individual for each service/support for an individual.

**Respite** - Temporary relief from the day-to-day care of a family member with a disability.

**RFS** - Request for Service is a process to request a change to the budget and/or services

**RHS** - Residential Habilitative Services are residential options like a group home.

**Self-Advocate** - A person with disabilities who advocates for their own support, rights, and self-determination.



# WHAT DOES THIS MEAN?

## ACRONYMS & DEFINITIONS

**Self-Determination** - The philosophy of developing and making your own choices, plans, and directing some or all aspects of your life.

**SAS** - Self-Administered Services: Services directed by the person/family receiving the service.

**SCE** - Support Coordinator External: The person who works with individuals with disabilities and their families to develop a person-centered support plan based on the individual's needs and wishes; and coordinates and monitors the services and supports provided.

**Support Strategies** - The detailed steps for accomplishing the goals of an Action Plan

**SSI** - Supplemental Security Income: A federal government assistance program based on the income and disability of the person.

**Transition** - The process of moving from one environment or stage of life to another. This often refers to a person with a disability leaving the school system and entering the adult world.

**UPC** - Utah Parent Center: The mission of the Utah Parent Center (UPC or Center) is to help parents help their children, youth, and young adults with all disabilities to live included, productive lives as members of the community.

**VR** - Vocational Rehabilitation: VR supports individuals with disabilities in obtaining competitive, integrated employment through professional vocational counseling and guidance, and through partnerships with employers, school districts, higher education, and other agencies.

**Waiting List** - A list of eligible individuals who have completed the application process for services and are not yet funded. The list is prioritized according to a critical need.



# NOTICES AND ACKNOWLEDGEMENTS



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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 is already contained within our resources. Any information used in this publication should be given proper credit as to its sourcing.

This information has been independently reviewed by the Division of Services for People with Disabilities (DSPD) and the Disability Law Center. Although the content has information provided by DSPD, the information contained in this publication should not be interpreted as legal advice. Every effort was made to provide accurate and complete information based upon resources and policies at the time of the creation of this document. All consumers are responsible to investigate further and make individual informed decisions for themselves.



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