Brief History of Disability Rights

- As recently as the 1960’s, individuals with disabilities were primarily institutionalized in order to receive care, support and treatment.

- Individuals with Disabilities Education Act (IDEA) passed in 1975 which makes a free, appropriate education available to eligible students with disabilities and ensures specialized education and related services.

- Americans with Disabilities Act (ADA) in 1990 makes it illegal to discriminate against anyone with a disability in employment, public services, transportation and telecommunication.
1982/1991 Federal Medicaid Waiver programs allowed states to provide services to consumers in their homes and communities.

- Katie Beckett, who required ventilator assistance, had a mother who advocated for her to receive services at home until President Reagan heard her case and established the “Katie Beckett Waiver program” which developed into the waiver services we have today.

- *Olmstead v. L.C.* in 1999 created an obligation for states to demonstrate a commitment to deinstitutionalization, and against segregation of people with disabilities.
Brief History of Disability Rights continued

- 2014 Home and Community-Based Services (HCBS) Settings Rule is enacted which:
  - Fulfills the promises of ADA and *Olmstead*.
  - Ensures that people with disabilities have the right to live, work and play in the community, like those without disabilities.
  - Mandates that settings (service providers) which receive Medicaid dollars in the form of HCBS Waivers must comply with HCBS Settings Rule.
  - Gave providers until March of 2022 to come into compliance with the rule.

*Waivers administered by the Division of Services for People with Disabilities (DSPD) are HCBS Waivers.*
Center for Medicare and Medicaid Services (CMS) is the federal agency responsible for funding waiver programs.

CMS provides matching funds to states to offer Home and Community-Based Services (HCBS) through HCBS Waivers.

In order to receive matching funds, states (and their service providers) must follow the HCBS Settings Rule.

The Division of Services for People with Disabilities (DSPD) is tasked with providing supports for more than 6,000 people with disabilities on HCBS Waivers in Utah and ensuring providers comply with the HCBS Settings Rule.
Is the Settings Rule Necessary?

A general person’s connections

A person in services can be separated from their connections

The Settings Rule seeks to have services improve a person’s connections

*Images courtesy of Charting the LifeCourse, lifecoursetools.com*
What Services Does the Settings Rule Impact?

- Residential services help a person to gain or maintain skills to live as independently as possible and fully participate in a community setting of their choosing.
- Employment services are intended for those people who may not be able to work in the community without some form of support.
- Day services are intended for those who need more supervision and support developing work and community living skills.
Home and Community-Based Services (HCBS) Settings Rule

Providers, organizations and programs that offer home and community based services must do these things:

- Be integrated in and support full access to the greater community;
- Be selected by the individual from among setting options;
- Ensure individual rights of privacy, dignity, respect, and freedom from coercion and restraint;
- Improve self-determination and independence in making life choices;
- Provide an opportunity to work in a job in the community (called “competitive integrated employment”);
- Facilitate choice regarding services and who provides them.

These requirements will be explained in detail further on in the presentation.
Informed Choice

**Options**: people must have more than one option to choose from

**Information**: people must have information on each of the options

**Experience**: people must have experience, or know someone with experience of each of the options
Home and Community-Based Services (HCBS) Settings Rule in Residential Settings

Provider-owned or controlled residential home and community based service settings must also ensure that the individual:

- Has privacy in their unit including locking doors, choice of roommates, and freedom to decorate and furnish the unit;
- Controls their own schedule, including access to food at any time;
- Has a lease or legally enforceable agreement which provides protections to landlord and tenant;
- May have visitors at any time;
- Is physically able to access the setting.
Modifications

- Any modifications of the settings rule requirements must be supported by a specific assessed need and justified in the person-centered service plan.

- There are eight requirements that must be documented to show a specific need, what has been done to address the need and to justify the modification.

https://dspd.utah.gov/settings-rule/
The following items must be documented in the person-centered service plan regarding any rights modifications:

1. A specific and individualized need based on an assessment
2. Explanation of the services and supports that were tried before the modification
3. Approaches/strategies to meeting the need that have already been tried but did not work
4. Clear description of the condition that is directly proportionate to the specific assessed need
5. Data collection/review to measure the ongoing effectiveness of the modification
6. Specific time limits to review if the modification is still necessary (i.e. helping the individual meet their goals) or whether it can be brought to an end
7. The individual/representative must agree to the modification
8. An assurance that the modification will not cause harm to the individual
Important to Note:

Your family member will not lose access to services and supports in their individual plan because of the HCBS changes.

They may be delivered in a different way but the needed services and supports will still be there.
The setting must be **integrated** in and **help provide full access** to the **greater community**.

- Being “integrated” means that individuals with disabilities have the same chance of being an included member of their community as those without disabilities and are supported to interact with people without disabilities.
- “Help provide” means that the setting offers and supports opportunities for individuals to go out and participate in their community.
- The “greater community” includes people of all abilities.
- “Full access” means that individuals with disabilities are involved with the greater community in a number of different activities, events, and organizations.
The setting must be selected by the individual from among setting options.

- How does an individual choose a setting?
  - An individual chooses a setting by visiting other setting options (including non-disability specific settings or a private unit in a residential setting) or looking at provider organizations online, talking with their support team, and making an informed choice.

- What if there are limited options?
  - If there are limited setting options in the community that an individual is a part of, if that individual chose to be in that community, then the individual has exhibited an appropriate amount of choice.

- What would spending the day in a non-disability specific setting look like?
  - Examples of non-disability specific settings are attending a local fitness class, a knitting club, or working at the public library with people without disabilities in the community.
The Settings Rule reminds us that those receiving services have **the right to:**

- **Privacy** - be alone if desired, either in a bedroom or area of the home
- **Dignity** - feel good about themselves and be treated like people with value
- **Be free from coercion** - people cannot make them do something they do not want to do
- **Be free from restraint** - this includes physical restraints or other types of restraints on people or items they access, like food or entertainment
- **Respect** - be treated with kindness and consideration

*Dignity of risk* means allowing individuals the right to take reasonable risks as it is essential for their dignity and self esteem and should not be stopped by overly cautious team members
Breaking the HCBS Settings Rule down...

The setting must improve **self-determination** and **independence in making life choices**.

- **What is self-determination?**
  - Self-determination means that you are responsible and in control of your own life and future by making decisions based on your interests and preferences.

- **What does “independence in making life choices” look like?**
  - Independence in making life choices includes (but is not limited to) choosing your daily activities, your physical environment, and with whom you interact with.

- **How do you know if the setting improves self-determination and independence?**
  - You know if the setting improves self-determination and independence if individuals are making many choices and decisions on a daily basis.
The setting must provide an opportunity to work in a job in the community (called “competitive integrated employment”).

 Does this mean my family member has to work?

○ No, your family member does not have to work, but they have to be provided the opportunity to make an informed choice about whether or not they want to work

 What does “providing an opportunity to work” look like?

○ “Providing an opportunity to work” looks like having guided discussions with individuals about what possibilities and support options exist when it comes to employment, which may include exploring and experiencing possible work options

 What is “competitive integrated employment”?

○ Competitive integrated employment means that individuals with disabilities are paid at a rate comparable to those without disabilities who work in the same place (at least minimum wage)
Breaking the HCBS Settings Rule down. . .

The setting must facilitate choice regarding services and who provides them.

- What if there are only a few providers?
  - If there are only a few providers in the person’s community, if that is a community that the person is choosing to be part of, then that is the appropriate amount of choice. In this situation, choice regarding services and who provides them is more about location.

- What is “choice regarding services”?
  - “Choice regarding services” means that individuals can choose what services they receive such as day, employment, and residential services.
CMS funds HCBS waivers and put the Settings Rule in place.
CMS has charged DSPD, as well as other stakeholders, with ensuring that all providers are supporting clients in a way that provides integration into the community.

HCBS Waivers/Settings Rule support inclusion and integration of people with disabilities in the community.

DSPD has contracted with providers to provide services and supports for those individuals on HCBS waivers to live their everyday lives. DSPD is helping providers transform themselves to meet the Settings Rule mandate of community integration and inclusion.

Providers are transforming to meet the Settings Rule mandate.
If you have any questions, please feel reach out to any of the individuals below:

- **Utah Parent Center:** Lisa Wade, lisa@utahparentcenter.org, (801) 272-1051 or (800) 468-1160

- **Division of Services for People with Disabilities (DSPD):**
  - Amy Huppi, Program Administrator: Settings Rule, Documents, and Compliance, amyhuppi@utah.gov, (801) 538-4154
  - Ben Robison, Employment and Integration Program Administrator, brrobison@utah.gov, (801) 550-1419

- **Department of Health (DOH):** Heather Mossinger, hmossinger@utah.gov

- **Utah State University - Center for Persons with Disabilities:**
  - Aubrey Snyder, HCBS Integration Specialist, aubrey.snyder@usu.edu
  - Tricia Jones-Parkin, Employment and Community Integration Program Manager, tricia.jones@usu.edu, (435) 797-4276