

# Understanding Medicaid Waivers

Alie Springgate, Able South Carolina June 16th, 2025

### Who We Are



Able SC is a disability-led organization seeking transformational changes in systems, communities, and individuals.

Since 1994, we've remained a consumer-controlled, community-based, cross-disability nonprofit that seeks to make South Carolina a national model of equity and inclusion for all people with disabilities.

- We are the state's oldest and largest federally recognized disability-led organization.
- More than ¾ of our staff are people with disabilities, as are over half of our Board of Directors.

We practice coequality, disability justice and representation, and true inclusion through consumer-driven independence and disability pride.

We didn't just learn this.

As people with disabilities, our work doesn't end when we leave the office. Disability is part of who we are. We live this every day.

## What do access, equity, & inclusion mean for people with disabilities?



- Access for people with disabilities means ensuring that there are no barriers to services in the community. This could mean providing modifications. This is not special treatment.
  - Access Example: All buses have a wheelchair lift, so people don't have to wait a long time for an accessible bus to pick them up
- Equity for people with disabilities means ensuring they have support to thrive in any setting not given special treatment.
  - Equity Example: a disabled person is treated fairly for their skills and not overlooked based on their disability. This could be with or without accommodations
- **Inclusion** for people with disabilities means ensuring events and activities are planned with **integration in mind**—not randomly including disabled people to check off a box.
  - Inclusion Example: A disabled person feels like they belong in an environment and can participate in the same activities as everyone else, with or without accommodations

## **Objectives**



- To understand a basic overview of Medicaid and relevant/available waivers
- To understand qualifications and requirements for eligibility
- To understand EPSDT and its use in partnership with waivers
- How to assist with applications for those meeting eligibility requirements
- To understand what supports are available to people who do not meet eligibility

## Medicaid



- South Carolina Medicaid is a program, a state/federal partnership, run by the government of South Carolina that helps people with low incomes pay for medical expenses. Medicaid varies from state to state.
- It covers all healthcare services such as:
  - doctor visits,
  - hospital stays,
  - · home services and therapies
  - prescription medications, and more.
- People that qualify for South Carolina Medicaid need to meet certain income and other requirements set by the state or be eligible due to a disability.
- Medicaid helps cover the costs of your healthcare, making it more affordable for you to get the medical care you need.
- People (and children) that receive Social Security Insurance (SSI) are automatically enrolled in Medicaid, with a couple of exceptions.
- All children in foster care are automatically eligible for and enrolled in Medicaid, as well as all children who are adopted from the state welfare system (more information: <a href="https://dss.sc.gov/media/4442/foster-care-and-adoption-4-28-23-from-dhhs.pdf">https://dss.sc.gov/media/4442/foster-care-and-adoption-4-28-23-from-dhhs.pdf</a>)

## Eligibility in SC



- South Carolina Medicaid is called "Healthy Connections"
- SC residents are encouraged to apply for Medicaid if:
  - They are pregnant or think they may be pregnant
  - They are or have a child or teenager age 18 or under
  - They are or their child is in foster care or adopted
  - They have been diagnosed with breast or cervical cancer
  - They are blind
  - They have a disability or disabilities
  - They need nursing home care
  - They are over the age of 65
  - They have very low or no income
- If someone is not eligible for Medicaid, they are encouraged to look through affordable options in the federal Marketplace (through HealthCare.gov).

### **TEFRA**



- TEFRA (Tax Equity and Fiscal Responsibility Act -- also called the "Katie Beckett" program) is a Medicaid program for children and youth with disabilities who would not ordinarily be eligible because their parents' income and/or resources exceed the limit.
- TEFRA is a coverage group for children who qualify for institutional care\*, but whose families can, and want to, provide care in their homes. Although administered by the state, there are certain federal rules that govern eligibility and a child must meet several criteria in order to qualify. It is important to understand that a child may have a number of medical support needs and still not qualify for TEFRA.
- In order to be eligible, they must have total monthly income below \$2,901 and countable resources at or below \$2,000.
- Only the child's income and resources are counted toward income eligibility not the parents'/family's.

### Waivers



- Community Choices (CC) Waiver (23,140 individuals waiting as of 01/2025)
- Community Supports (CS) Waiver (16,129 individuals waiting as of 01/2025)
- HIV/AIDS Waiver (461 individuals waiting as of 01/2025)
- Intellectual Disabilities/Related Disabilities (ID/RD) Waiver (19,822 individuals waiting as of 01/2025)
- Head and Spinal Cord Injury (HASCI) Waiver (312 individuals waiting as of 01/2025)
- Palmetto Coordinated System of Care for Children (PCSC) Home and Community Based Waiver (85 individuals waiting as of 01/2025)
- Medically Complex Children's (MCC) Waiver (1,967 individuals waiting as of 01/2025)
- Mechanical Ventilator Dependent (Vent) Waiver (45 individuals waiting as of 01/2025)
- Currently, around 61,000 SC residents are on a waiting list for enrollment into one or more waivers. Not every waiver has a waitlist, but many do.

## **Community Choices Waiver**



- Group served:
  - Elderly (ages 65 and older) and people with physical disabilities ages 18-64 who meet nursing facility level of care criteria
- Admin/Operating Authority:
  - Operation housed at SCDHHS
- Waitlist: 23,140 as of 01/2025

#### Available services:

 Case Management **Personal Care Services Attendant Care** Companion Care - Agency Companion Care - Individual Home Delivered Meals Adult Day Health Care Adult Day Health Care Nursing Respite, Institutional Respite, CRCF Respite, In-Home Personal Emergency Response System, Installation Personal Emergency Response System, Monitoring **Telemonitoring** Home Accessibility Adaptations - Environmental **Modifications** Specialized Medical Equipment & Supplies Residential Personal Care II Pest Control

## **Community Supports Waiver**



- Group served:
  - Diagnosis of intellectual or related disability
  - All ages
  - ICF-IID level of care (Intermediate Care Facilities for Individuals with Intellectual Disabilities)\*
- Admin/Operating Authority:
  - Operation housed at DDSN with administrative authority by DHHS
- Waitlist: 16,129 individuals waiting as of 01/2025

#### Available services:

Personal Care Services
 Adult Day Health Care Services
 Adult Day Health Care Nursing
 Respite Care Services

Environmental Modifications
Assistive Technology and Appliances

Assistive Technology and Appliances Assessment/

Consultation

Incontinence Supplies

**Private Vehicle Modifications** 

Private Vehicle Assessment/Consultation

Behavior Support Services

Day Activity

**Career Preparation Services** 

**Community Services** 

**Employment Services** 

**Support Center Services** 

In-Home Support Services

Personal Emergency Response System (PERS)

Waiver Case Management (WCM)

## **HIV/AIDS Waiver**



- Group served:
  - Individuals with a diagnosis of HIV or AIDS who are currently located in S.C. or intend to locate in S.C.
  - All ages
  - At-risk of hospitalization level of care
- Admin/Operating Authority: DHHS
- Waitlist: 461 as of 01/2025

- Available services:
  - Case Management
  - Personal Care Services
  - Attendant Care
  - Companion Care Agency
  - Companion Care Individual
  - Home Delivered Meals
  - Pest Control
  - Nursing Services
  - Home Accessibility Adaptations -Environmental Modifications
  - Specialized Medical Equipment & Supplies

## Intellectual Disabilities/Related Disabilities Waiver



- Group served:
  - Diagnosis of intellectual or related disability\*
  - All ages
  - ICF-IID level of care\*
- Admin/Operating Authority:
  - Operation housed at DDSN with administrative authority by DHHS
- Waitlist: 19,822 individuals waiting as of 01/2025

#### Available services:

Personal Care Services
 Residential Habilitation
 Environmental Modifications
 Private Vehicle Modifications
 Private Vehicle Assessment/Consultation
 Specialized Medical Equipment, Supplies
 Assistive Technology Assessment/Consultation
 Incontinence Supplies
 Respite Care
 Audiology Services

Adult Companion Services
Nursing Services

Adult Dental Services
Adult Vision

Adult Day Health Care Services

Adult Day Health Care Nursing

Adult Attendant Care Services

Behavior Support Services

Career Preparation Services

**Employment Services** 

Day Activity

Community Services

Support Center Services

Personal Emergency Response System (PERS)

Pest Control Treatment

Pest Control - Bed Bugs (Advanced Pest Control)

Waiver Case Management (WCM)

Independent Living Skills

## Head and Spinal Cord Injury Waiver



- Group served:
  - Diagnosis of traumatic brain injury, spinal cord injury, or related disability
  - All ages
  - Nursing facility of ICF-IID level of care\*
- Admin/Operating Authority:
  - Operation housed at DDSN with administrative authority by DHHS
- Waitlist: 312 individuals waiting as of 01/2025

#### Available services:

Career Preparation Services

Day Activity

**Employment Services** 

Attendant Care/Personal Assistance Services

Health Education for Participant - Directed Care

Peer Guidance for Participant - Directed Care

Residential Habilitation

Specialized Medical Equipment, Supplies and Assistive Technology

Incontinence Supplies

Respite Care Services

Personal Emergency Response System

Physical Therapy

Occupational Therapy

Psychological Services

Behavior Support Services

**Nursing Services** 

Speech and Hearing Services

Private Vehicle Modifications

**Environmental Modifications** 

Assistive Technology Assessment/Consultation

Private Vehicle Modification Assessment/Consultation

Pest Control Bed Bugs (Advanced Pest Control)

Pest ControlTreatment

Waiver Case Management (WCM)

Independent Living Skills

## Palmetto Coordinated System of able Care for Children



- Group served:
  - Youth with primary mental health diagnosis\*
  - Age 21 or younger
  - Hospital level of care
- Admin/Operating Authority:
  - Operation is housed at Continuum of Care with administrative authority by DHHS
- Waitlist: 85 as of 01/2025

\*Can be complex for youth with dual diagnoses

- Available services:
  - High Fidelity Wraparound (definition: a team-based, collaborative planning process for developing and implementing individualized care plans for children with behavioral health challenges and their families)
  - Respite
  - Individual Directed Goods and Services

## Medically Complex Children's Waiver



- Group served:
  - Children age birth to 21 with chronic physical/health condition(s) expected to last at least 12 months
  - Hospital level of care
- Admin/Operating Authority:
  - Administered and operated by SCDHHS, MCCW Staff. SCDHHS has contracts with SC Solutions to provide the RN Care Coordination along with the Wonder Center to provide the Pediatric Medical Day Care.
- Waitlist: 1,967 as of 01/2025

- Available services:
  - Nurse Care Coordination
  - Respite
  - Environmental Modifications
  - Pediatric Medical Day Care

### **Mechanical Ventilator Waiver**



- Group served:
  - Elderly (ages 65 and older) and people with physical disabilities ages 21 and older who require mechanical ventilation and meet the nursing facility level of care criteria
- Admin/Operating Authority:
  - Operation housed at SCDHHS
- Waitlist: 45 as of 01/2025

- Available services:
  - Case Management
     Personal Care Services
     Attendant Care
     Nursing Services
     Specialized Medical Equipment &
     Supplies
     Respite, Institutional
     Pagainte In Home
    - Respite, In-Home Personal Emergency Response System -
    - Installation
    - Personal Emergency Response System -
    - Monitoring
      Home Accessibility Adaptations -
    - Environmental Modifications
    - **Pest Control**
    - Home Delivered Meals

## Applying for Waiver Programs nt 1



#### For Community Supports, HASCI, and ID/RD:

- Request DDSN (Department of Disabilities and Special Needs) eligibility
  - o Call
  - Provide full name, date of birth, Social Security number, Medicaid number, home address, phone number, and email address
  - Answer questions to establish residency in SC
  - Answer questions related to your disability
  - Select 3 intake providers from a list who will help you through the eligibility process
  - Receive a letter from DDSN confirming application for eligibility
  - Wait to be contacted by chosen intake service provider, who will collect medical and educational records needed for eligibility
  - DDSN will notify the applicant in writing of their eligibility status
- Apply over the phone through DDSN
- Community Supports Waiver application: <a href="https://www.scdhhs.gov/sites/default/files/documents/CS%20-%20SC.0676.R03.00.PDF">https://www.scdhhs.gov/sites/default/files/documents/CS%20-%20SC.0676.R03.00.PDF</a>
- HASCI Waiver application: <a href="https://www.scdhhs.gov/sites/default/files/documents/HASCI-SC.0284.R05.06.PDF">https://www.scdhhs.gov/sites/default/files/documents/HASCI-SC.0284.R05.06.PDF</a>
- ID/RD Waiver application: <a href="https://www.scdhhs.gov/sites/default/files/documents/IDRD-SC.0237.R06.04.PDF">https://www.scdhhs.gov/sites/default/files/documents/IDRD-SC.0237.R06.04.PDF</a>

## **Applying for Waiver Programs**



#### For Community Choices Waiver:

- Apply through SCDHHS or the applicant's local Health and Human Services' Community Long Term Care Office (CLTC)
- American Council on Aging has a free Medicaid eligibility test that a person can take prior to filling out an application: <a href="https://www.medicaidplanningassistance.org/medicaid-eligibility-test/">https://www.medicaidplanningassistance.org/medicaid-eligibility-test/</a>

#### For HIV/AIDS Waiver:

o Apply through SCDHHS or a CLTC by contacting one of the regional offices in the applicant's area

#### For Palmetto Coordinated System of Care for Children Waiver:

- Referrals can be made to Continuum of Care for both youth with Medicaid and non-Medicaid youth by state agencies, private providers, or other individuals in the community
- o Parents/Legal Guardians can apply online through Continuum of Care

#### For Medically Complex Children's Waiver:

o Referrals can be made online through the SCDHHS Phoenix System by providers

#### For Mechanical Ventilator Waiver:

 Apply through SCDHHS or the person's local Health and Human Services' Community Long Term Care Office (CLTC)

## **Intent of Waiver Program**



- De-institutionalization:
  - From DHHS: "The program permits a state to furnish an array of home and communitybased services that assist Medicaid beneficiaries to live in the community and avoid institutionalization."
- Waivers are intended to keep people in the community.
- Olmstead Act
  - o Due to the 1999 case of Olmstead vs. L.C., the U.S. Supreme Court ruled that people with disabilities have the right to live in the least restrictive environment, allowing the greatest amount of independence. States were then mandated to produce plans that should show how the state will provide services to individuals with disabilities living in the community so they are not forced into institutions. A quarter century later, South Carolina still needs to develop an Olmstead Plan and continues to force people to live in institutions. Currently, 56,753 people are living in institutional settings in SC.

## What if a person is ineligible for able Medicaid?

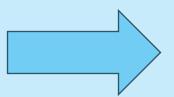


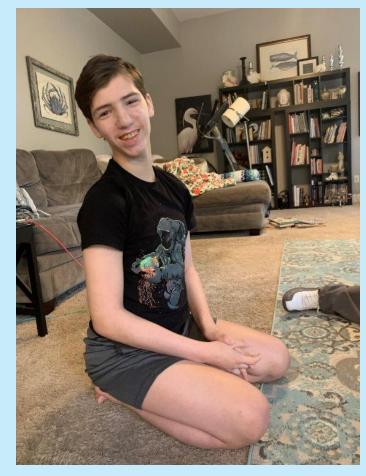
- If desired, an appeal can be submitted to request a fair hearing
  - Information about fair hearings and other relevant topics provided by Disability Rights South Carolina: <a href="https://www.disabilityrightssc.org/medicaid-fair-hearing/">https://www.disabilityrightssc.org/medicaid-fair-hearing/</a>
- Whether they are eligible for Medicaid or not, connect the person with available resources in the community, such as:
  - A Center for Independent Living (such as Able South Carolina)
  - Family Connection of South Carolina (for families of children with disabilities)
  - SC Thrive
- Marketplace for affordable health insurance options (HealthCare.gov)

## Jack's Story











## **EPSDT**

## What is EPSDT?



- The Early, Periodic, Screening, Diagnosis, and Treatment program (EPSDT) is a federally mandated Medicaid program aimed at providing free, comprehensive healthcare services to children and youth under the age of 21 who have Healthy Connections Medicaid.
- The program emphasizes preventive care, early identification of health issues, and timely intervention to address health problems and promote optimal growth and development in children.
- EPSDT is key to ensuring that children and youth receive appropriate dental, mental health, developmental and specialty services as soon as possible.

## Intent of EPSDT



• EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services.

## **EPSDT** barriers



- Families are unaware of it. They are focused on the waivers.
- There aren't enough providers in the state to focus on the treatment part of EPSDT
- Kids not being prepared for adult life due to not having services. Kids are being set up for failure.
- Kids are being pushed to institutions, some out of the state.
- The transition to adult life is even more difficult.
- Teenagers with autism are being impacted the most.

## HCBS – what is it?



- HCBS stands for Home- and Community-Based Services.
- Long-term services and supports encompass the range of medical, personal care, and social services that may benefit an older adult, person with disabilities, or person with other chronic health conditions.
- The Administration for Community Living estimates that 69% of people will use long-term services and supports during their lifetime.
- Many different groups of people use long-term care, including older adults, people with intellectual and developmental disabilities (I/DD), people with physical disabilities, and people with mental health conditions.

## Intent of HCBS



- The intent of the HCBS rule is help people reach their highest level of independence.
- SCDHHS recognizes that all individuals have different support needs, and it is the intent of the new HCBS rule requirement for person-centered planning to keep this in mind.
- The new HCBS rule is designed for the individual and family to have more control over how services are provided and received.

### **EPSDT** and the transition to HCBS



- EPSDT should provide the services and treatment to ensure the child is receiving the necessary services to be successful.
- EPSDT ends at the age of 21.
- Upon turning 21, an individual can make a decision to transition to HCBS or pursue other options.

#### However...

- HCBS is not mandated
- There are often provider issues
  - Lack of accessibility, capacity, availability, etc.
- State Medicaid plan is underfunded, and SC is not an expansion state
- HCBS are often only provided through Medicaid Waivers

## **EPSDT/HCBS** tool



• Tool provided in online PDF via the QR code below:





## Questions?

## Stay in touch



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