

ReThink Medicaid

Jenny Hobbs

Co-founder, Advocates for Medically Fragile Kids NC and
Mom of Melanie, Michael, Meredith and Madison
&

Stacy Taylor, JD

Deputy Director, Office of Genetics and People with Special Health Care Needs, Maryland
Department of Health and
Mom of Faye, Ben, Marshall and Sam



Objectives and Ground Rules

- Learn the basics about Medicaid
- Learn about Medicaid waiver programs
- Learn how to how to find state-specific information
- This is a safe space to share
- This is a judgement free zone
- Everything that is shared here is confidential
- Please speak up if there is anything you need to help you participate more easily



What is Medicaid?

- A health insurance program for low-income kids, adults, seniors, and people with disabilities.
- Helps millions of Americans get and stay healthy by seeing the doctor when they are sick, getting check-ups, filling prescriptions, and going to the hospital without fear of choosing between their health and groceries or paying the rent.



What is Medicaid?

History

- Enacted in 1965 as part of the Social Security Act, alongside several other general support programs (Medicare, Unemployment, Maternal & Child Health Block Grant and more).

Joint Federal-State Program

- Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.
- Federal Government provides funds for 50-75% of the cost for all eligible individuals and services.
- Federal law mandates coverage of some populations and benefits, but states have discretion on coverage of groups in addition to core groups, income eligibility limits, covered services, premiums & co-pays, and payments to providers.



What is Medicaid?

If you've seen one Medicaid program,
you've seen one Medicaid program



Medicaid and CHIP

Medicaid programs provide health coverage for low-income people.

Children's Health Insurance Program (CHIP)

- Signed into law in 1997
- Provides federal matching funds to states to provide health coverage to children in families with incomes too high to qualify for Medicaid, but who can't afford private coverage.
- All states have expanded children's coverage significantly through their CHIP programs, with nearly every state providing coverage for children up to at least 200 percent of the Federal Poverty Level (FPL).



Delivery of Care

States determine how to deliver care. Approaches include:

- Fee-for-Service (FFS)
State contracts directly with providers and pays them for covered services
- Managed Care
State contracts with Managed Care Organization(s) (MCOs) oversee delivery and payment of services
- Premium Assistance
Medicaid and CHIP funds are used to purchase private insurance that is cost-effective and comparable
- Combination of these approaches



Why do I want Medicaid

- Standalone health insurance
- Secondary health insurance
- Coverage of:
 - Inpatient and Outpatient hospital services
 - Physician services
 - Laboratory and x-ray services
 - Home health services
 - Prescription medications
 - Case management
 - Therapies, including physical, occupational, and speech therapy
 - Durable medical equipment and supplies
- No co-pays for children / minimal co-pays for adults



Medicaid Waivers

States may apply for formal waivers of some statutory requirements from the Secretary of the U.S. Department of Health and Human Services (HHS).

- Waiving certain requirements of the Federal Medicaid Statute
- Waivers are generally referred to by the section of Social Security Act granting the waiver authority
- Waivers are categorized either as program waivers or research and demonstration projects

Section 1915(b)

- Permits states to implement service delivery models (e.g., those involving managed care plans) that restrict choice of providers

Section 1915(c)

- Authorizes states to provide Home and Community-Based Services (HCBS) as an alternative to institutional care in nursing homes, intermediate care facilities for individuals with intellectual disabilities.

Section 1115

- Gives broad authority to the Secretary to authorize “any experimental, pilot or demonstration project likely to assist in promoting the objectives” of the programs; gives states flexibility to experiment with different approaches to program operation, service delivery, and payment.

TEFRA

- Tax Equity and Fiscal Responsibility Act (TEFRA)/Katie Beckett. Eligibility pathway for the Medicaid Program. For certain children who have long-term disabilities or complex medical needs and live at home. Allows children to receive services at home with additional supports, instead of in an institution. Under TEFRA/Katie Beckett, only the child’s income and resources are considered (not those of the parents).

*There are other 1915 waivers, such as I, J, and K, that are wholly state-based, unless grandfathered into federal partnership.



TEFRA / Katie Beckett Waiver

The Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option, also known as the Katie Beckett Option, was developed to allow children with disabilities from near-poor and middle-income families to qualify for Medicaid.

It allows children to receive services at home with additional supports, instead of in an institution.

- Only children are eligible
- Eligibility is based on diagnosis
- Does not look at parent income, but does look at income/assets of the child
- Not offered in all states
- No wait list
- Generally, provides Medicaid coverage only
- Look at your State for specifics



Home and Community-Based Services Waivers (HCBS Waivers)

States can develop HCBS Waivers to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.

- Children and adults are eligible
- Eligibility is based on level of care, including diagnosis.
- Does not look at parent income, but does look at income/assets of the applicant (whether child or adult)
- Offered by most states (at least one, some states have more than one)
- May be a wait list
- Provides Medicaid coverage plus additional services
- Look at your state for specifics



HCBS Waiver Programs

The statute identifies services that may be considered home and community-based services, including:

- case management
- homemaker/home health aide
- personal care
- adult day programs
- habilitation
- respite care services



HCBS Waiver Programs

Other services needed to avoid institutionalization may also be approved.

Services vary from state to state. Other services may include:

- Home/vehicle modifications
- Assistive technology
- Adaptive Equipment – car seats, tricycles
- Conference registration fees



Waiver Programs /Case Management

How can a case manager help?

- Assist with referrals for in-home care, therapies, equipment, and supplies
- Recommendations for new providers
- Follow up on issues with providers
- Organization management
- Connect with local resources - support groups, non-profit orgs for non-covered items
- Assist with completion of paperwork for grants, etc.
- Referrals to wish-granting organizations
- Connections to studies
- Assist with transition to adult world - guardianship, new providers, adult waiver, etc.
- Follow up from hospital discharge or other post-visit questions
- Understanding of Medicaid eligibility, services, waiver programs

Recognize when you need help and delegate!



State-Specific Information

Kidswaivers.org





Welcome to Kids' Waivers!

Your source for information on children's Medicaid Waivers, Katie Beckett programs, and other Medicaid programs

Kids' Waivers is a compilation of information about Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs. This website is the product of years of ongoing research on these programs. To learn more about specific programs, you can compare states and obtain basic information using our sortable [full list of programs](#). We also have more detailed [pages for each state](#), which can be accessed by clickable map or text links.

Please note that Kids' Waivers does not operate any of these waiver programs, and we cannot place your child in a program, verify your child's application, or verify any details about your child's current program. We can only point you toward the programs that are available in your state.

Welcome to Kids' Waivers!

Your source for information on children's Medicaid Waiver programs

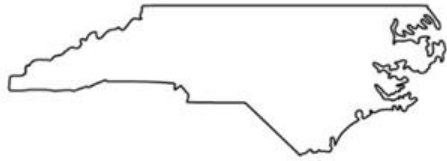
Kids' Waivers is a compilation of information about Medicaid waivers, Katie B... or medical needs. This website is the product of years of ongoing research o... states and obtain basic information using our sortable [full list of programs](#). You can also use a clickable map or text links.

Please note that Kids' Waivers does not operate any of these waiver programs, and we cannot place an application, or verify any details about your child's current program. We can only point you toward the state's Medicaid programs, which can be accessed by clicking on the state name.

This website is an ever-changing project. We update all listings annually in the fall, but due to interim... available from the federal government, some information may be outdated. For example, the most current information for waiting lists is from 2021. You can see the most recent [update information](#) at the bottom of this page.

Note about Pandemic Appendix K amendments: during the pandemic, states were able to modify the... Appendix K amendment. States also had the option to make other pandemic-related changes using 1135 waivers and other mechanisms. Because these

- A through F >
 - G through L >
 - M >
 - N >
 - O through T >
 - U through W >
- Nebraska
 - Nevada
 - New Hampshire
 - New Jersey
 - New Mexico
 - New York
 - North Carolina
 - North Dakota



parent income. See North Carolina's [services by population page](#) for general information.

North Carolina also has two adult-only waivers, CAP/DA and TBI.

Advocacy Organizations in North Carolina:

- [Exceptional Children's Assistance Center](#)
- [Disability Rights North Carolina](#)
- [The Arc of NC](#)
- [North Carolina Child](#)
- [Advocates for Medically Fragile Kids NC](#)

Last updated 11/4/22

Programs in North Carolina

+ COMMUNITY ALTERNATIVES PROGRAM FOR CHILDREN

+ INNOVATIONS

+ OTHER PROGRAMS



[-] COMMUNITY ALTERNATIVES PROGRAM FOR CHILDREN

Also called CAP-C

- **Target Population:** Children who are medically fragile or technology dependent.
- **Ages:** 0-20
- **Levels of Care:** Nursing Facility, Hospital
- **Income Waiver:** Yes, the waiver is based on the child's income only. Parent income is not counted.
- **Waiver Type:** 1915(c)
- **Spots:** 4000
- **Expiration Date:** 2/28/2022; renewal is in process but still being negotiated
- **Description from medicaid.gov:** Provides in-home care aide service, financial management, assistive technology, case management, community transition, home accessibility and adaptation, institutional and non-institutional respite, participant goods and services, pediatric nurse aide services, specialized medical equipment and supplies, training, education and consultative services, vehicle modifications for individuals who are medically fragile, ages 0 – 20.
- **Online State Information:** [CAP-C Program](#) or [Program Page](#)
- **Official Federal Information**
- **How to Apply:** Contact your closest [Case Management Agency](#).
- **Waiting List:** There are 15,000 people with developmental disabilities and 824 people with physical disabilities on North Carolina's waiting list; however, this waiver typically does not have a waiting list.
- **Advocacy/Support Group:** [Advocates for Medically Fragile Kids NC](#)

When should I apply?



NOW!!!

Things to consider:

- Talk to someone from the Waiver Program first!
- Some programs have wait lists
- Some programs require that you also apply to SSI (Social Security Income)
- Your income and assets
- Your child's income and assets, including SSI
- Any inheritance (presentation during Symposium!)
- Look into Health Insurance Premium Payment program in your state

Questions/Discussion

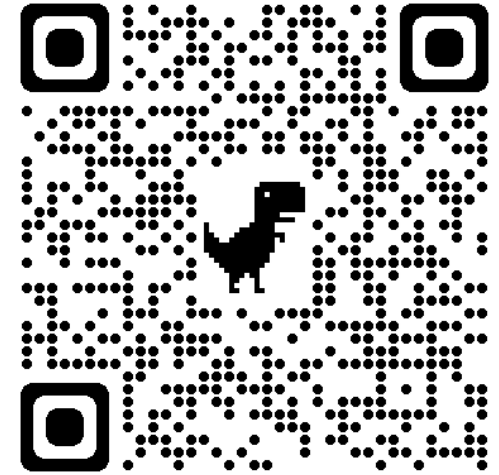


Resources

Glossary of Terms – QR code and in Mobile App

Important Links:

- Centers for Medicare & Medicaid Services
 - [CMS.gov](https://www.cms.gov)
- Medicaid/CHIP
 - [Medicaid.gov](https://www.medicaid.gov)
- Federal Poverty Level
 - aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines
- State-specific waiver info
 - [kidswaivers.org](https://www.kidswaivers.org)
- Kaiser Family Foundation
 - [kff.org](https://www.kff.org)



CONNECT!

Opportunities to connect after Symposium

- Parent/Caregiver Support Group / Monthly on the third Monday
- UMDF Ambassador program
- UMDF Social Media
- Diagnosis specific social media pages
- MitoAction or other mito-focused organizations
- Symptom-specific organizations
- Social worker or case manager at hospital and/or mito clinic



