

**Home and
Community Based
Services for
Children**

Medicaid Waivers



Imagine *Different* ... Achieve *Different* Coalition

We believe all children should grow up in families, and with the right supports, this can happen for all children with disabilities.

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Medicaid

Medicaid, also called Medical Assistance (MA), is a federally created program, administered by the states, to provide healthcare to individuals who have low incomes or disabilities.

States must follow federal rules to receive federal matching funds for the care they provide.



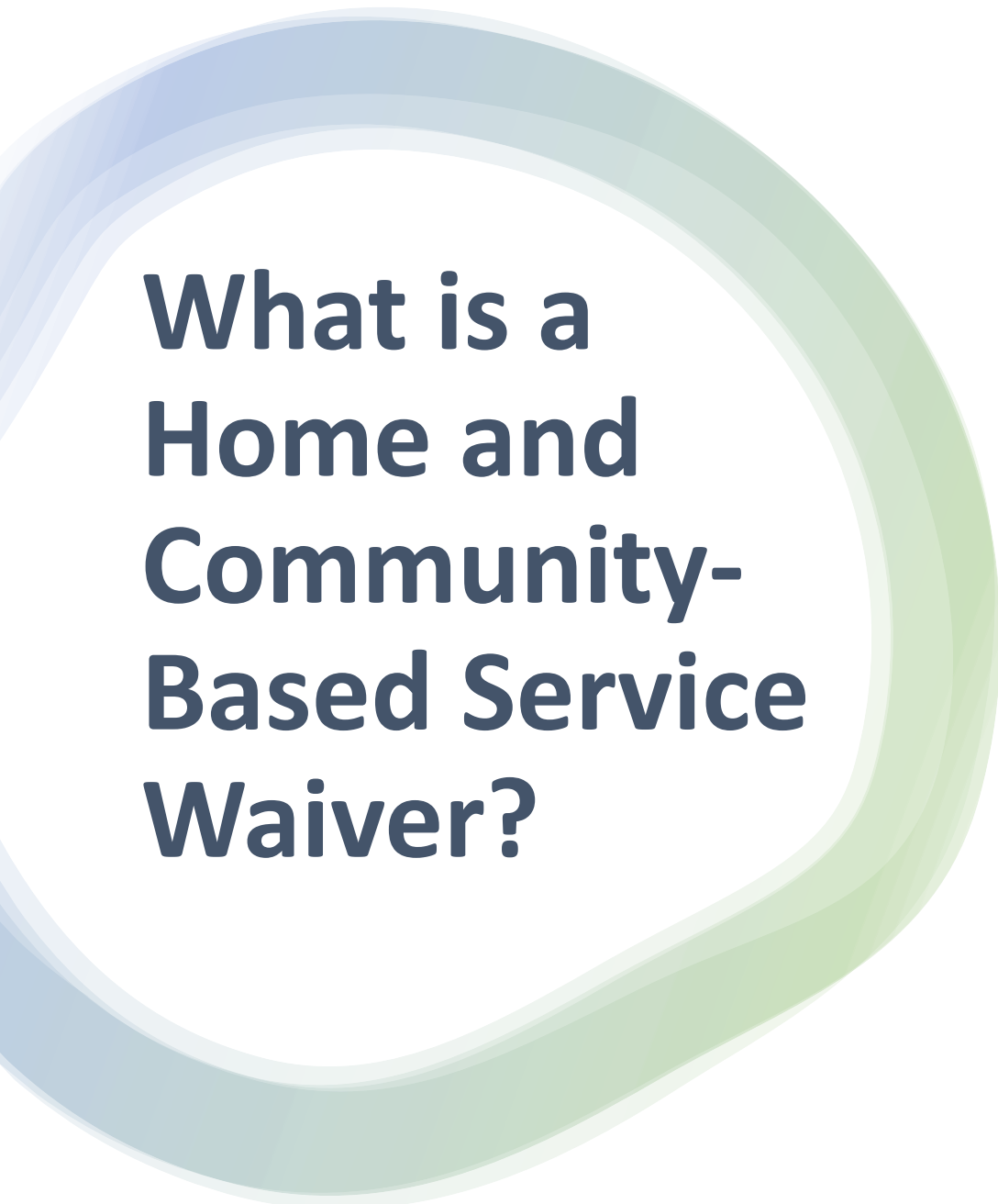


MA Services

Federal MA rules require states to provide coverage for a comprehensive range of services to all MA-recipient children – more comprehensive than that offered by private insurance plans.

(For adults, only some of those services are required to be in the state's benefits package.)

Even so, not *all* services needed by children with disabilities are covered.



What is a Home and Community-Based Service Waiver?

Some disability services that may be needed to enable a person to live at home - such as widening a doorway for a wheelchair – are not covered by the standard MA program, even for children.

So, in addition to the standard service package, federal rules allow states to apply for a “waiver” of some MA rules, allowing them to offer additional services to a limited number of people who are at risk of institutionalization.

Waiver Services

Home and Community-Based Service waivers can provide certain vital disability services that are not MA-covered. In Pennsylvania, these include:

- respite – to allow vacations and/or downtime for overwhelmed caretakers,
- home/vehicle modifications – such as widened doorways, decks for wheelchair lifts to land on, and van adaptations; and
- LifeSharing – payment and other support to a child’s family or alternate family for the child’s care
- Family Medical Support Assistance - nurse oversight and assistance with care management (e.g., making appointments, etc..)

HCBS Waivers Serving Children in PA

- PA has numerous HCBS waiver programs, but only 3 serve children (excluding Early Intervention for ages 0-3)
- They are:
 - Consolidated (unlimited service cost)
 - Community Living (\$85,000 annual limit) and
 - Person, Family, Directed Service (PFDS) (\$41,000 annual limit)



Waiver Eligibility for Children

These three waivers are available to children, from birth, who:

- have Intellectual Disability or Autism; or
 - are Likely to be diagnosed with ID or Autism by age 9; or
 - have a multisystem medical condition that requires nursing to assist with medical technology (medically complex)**
- and
- Meet an Intermediate Care Facility (ICF/ID or ICF/ORC) (i.e., institutional) level of need; and
 - Meet financial eligibility criteria, which virtually all such children do because their parents' income doesn't count.

Enrollment

One of the rules a state can have waived is the requirement to make the additional service available to all who need it. Instead, states can have waiting lists for these additional services.

Pennsylvania has waiting lists for all three waivers. There is an “emergency” list for those in need of services within six months, but there is even an “emergency” waiting list.

Applicants fill out a Priority of Urgency of Needed Services (PUNS) form. Enrollment is provided to those individuals who are determined to be most in need – not who applied first.

Enrollment of Children

Children have historically been a low priority due to a misconception that their needs can be met elsewhere ...BUT:

- Children who are currently in facility placements, are at risk of facility placement within 6 months, or whose health and safety is at risk, fall into the “emergency” category on the PUNS;
and
- For those with medical complexity (tech dependent), the state has reserved waiver slots specifically for them for which there is no current waitlist.

How To Get Started

- Register your child with your county office of Mental Health and Intellectual/Developmental Disability Services. (Different counties use different names for this office.)
- You will need to document the child's disability and institutional level of need (e.g., doctor's records and/or school records.)





What Next?

Make sure a PUNS form is completed and that your child is on the emergency list if he or she:

- is in an institutional placement; or
- is at risk of placement within 6 months, or
- is at risk of serious illness or injury without services – e.g., due to lack of nursing support you are trying to meet medical needs on no sleep.

If your child uses medical technology and nurses, make sure the county staff is aware that the state has reserved waiver enrollments for children with medical complexity in or at risk of institutional placement.

Supports Coordination

- Once registered with the county office of MH/ID services, you will be asked to choose an organization to provide Supports Coordination services.
- A Supports Coordinator (SC) will then be assigned to help with the waiver application.
- If your child is enrolled in an HCBS waiver, the SC will convene meetings with you and others of your choosing to determine service needs and will help access and coordinate these services.
- If your child is not enrolled, you can still contact the SC for help with other potential services or to report a change in circumstances that might bring your child to the top of the waitlist.



Additional Resources

- DHS Consolidated Waiver
- <https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Consolidated-Waiver.aspx#>
-
- Disability Rights Pennsylvania
- <https://www.disabilityrightspa.org/>
-
- Pennsylvania Health Law Project
- <https://www.phlp.org/en/>