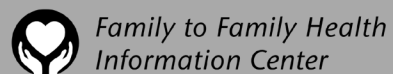


CHILDREN'S MEDICAID WAIVERS AND PAID PARENT CAREGIVING

The Arc of Illinois, Family-to-Family Health
Information Center

Susan Agrawal, Director



GOALS FOR TODAY

Learn about Medicaid waivers for children in Illinois



Find out which programs offer paid parent caregiving

Discuss future strategies and advocacy for waivers and paid parent caregiving



MEDICAID WAIVER PROGRAMS

WHAT IS A MEDICAID WAIVER?

A program to provide extra home and community based services (HCBS) for people with disabilities

Most
commonly a
1915(c) waiver

State-federal
partnership

Each one is
different

WHAT DO PEOPLE GET IN A MEDICAID WAIVER?

Medicaid
Waiver



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graph TD; A[Medicaid Waiver] --> B[Full Medicaid Coverage]; A --> C[Extra Home and Community Based Services];
```

Full Medicaid
Coverage

Extra Home
and Community
Based Services

WHY DO CHILDREN NEED WAIVERS?

Waivers **sometimes** grant Medicaid access for those who do not qualify financially



Waivers wrap around insurance to reduce costs and tackle underinsurance



Waivers provide HCBS - specialized services to live in the community

Personal care services and home nursing

Home or vehicle modifications

Specialized therapies or equipment

WHAT IS WAIVED?

ALL waivers waive comparability

- People in waivers get MORE services than other people in Medicaid

SOME waivers waive parent/spouse income

- Option to use institutional income and asset rules
- Mostly used to give children access to Medicaid

OCCASIONALLY waivers waive geography

- Targeted to a specific city or county
- Targeted to a region
- Targeted to a type of area (rural or urban)

EVERY WAIVER IS DIFFERENT!

Different Disabilities

- Intellectual disability, developmental disability, or autism
- Physical or health disabilities
- Mental or behavioral health
- **Must have institutional level of care**

Different Ages

- Children only
- Adults only
- Elderly only
- All ages (lifespan)
- Targeted age group like early childhood

Different Services

- Case management
- Homemaker
- Home health aide
- Personal care
- Adult day health
- Habilitation
- Respite care
- Day treatment
- Other services to avoid institutionalization
- Expanded habilitation services
- Services for the chronically mentally ill

Different Numbers

- Very small waivers – 15 people is smallest
- Large waivers – many have more than 20,000 people
- **Can have waiting lists**

ILLINOIS: 9 WAIVERS

Children Only Waivers

- Medically Fragile Technology Dependent Children*
- Support Waiver for Children & Young Adults with DD
- Residential Services for Children & Young Adults with DD

* If a child enters before age 21, they can stay in MFTD Waiver as long as they continue to qualify medically

DRS Home Services Program (All Ages)

- Persons with Disabilities⁺
- Persons with Brain Injury (BI)
- Persons with HIV or AIDS

Will be transitioning to one waiver in 2025

+ Currently must enter before age 60

Adult Only Waivers

- Adults with DD
- Persons who are Elderly
- Supportive Living Program



MEDICALLY FRAGILE TECHNOLOGY DEPENDENT WAIVER (MFTD)

Main Purpose



- To provide participants with Home Nursing Care

MUST have Medical Technology



- Trach
- Vent, CPAP, BiPAP
- Central IV Line
- Feeding Tube
- Other Respiratory Support

MEDICALLY FRAGILE TECHNOLOGY DEPENDENT WAIVER (MFTD)



Basics

- Enter before age 21 but can stay through adulthood
- **No waiting list**
- **Does not count parent income**
- Receive full Medicaid coverage plus extra services
- Can wrap around private insurance

To Apply

- Contact Division of Specialized Care for Children (DSCC)
- 800-322-3722
- Through Hospital Social Worker or Case Manager

Additional Services

- Respite
- Home and Vehicle Modifications
- Adaptive Equipment and Assistive Technology (new in 2025)
- Nurse Training
- Family Training

DRS HOME SERVICES PROGRAM



Also called DRS or DoRS Waiver

- Currently includes 3 waivers; will be moving to one unified waiver in 2025
- All ages, with some exceptions for those over 60
- **No waiting list**
- Counts parent income for those under 18 for full program*
- Asset limit is \$35,000 per family for minors

Aimed toward those with severe disabilities

- Must score 29 or higher on Determination of Need (DON) tool
- DON also determines how much assistance and funding you get
- Hard for children under 18 to qualify due to how DON tool is constructed
- While primarily for those with physical disabilities, some with DD/ID and functional limitations may qualify

* For those who don't qualify for Medicaid, the extra HCBS services ONLY (without Medicaid) can still be provided through state dollars

DRS HOME SERVICES PROGRAM

Example Services

- Personal assistant
 - Parents can be paid and receive benefits to provide personal assistant services
- Adult day care
- Assistive equipment
- Respite
- Environmental (home) modifications

To apply

- Find your local DRS Office
- (800) 843-6154
- Online form



SUPPORT WAIVER FOR CHILDREN AND YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES

Children with developmental or intellectual disabilities and related conditions

- Ages 3-22
- Extensive waiting list (PUNS)
- **Parent income is waived**
- Cannot need 24-hour nursing
- Intellectual disability, developmental disability, autism, cerebral palsy, or epilepsy



Receive full Medicaid coverage plus extra services

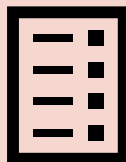
- Can wrap around private insurance
- Most receive in-home supports
- 2 times SSI amount in benefits
 - Personal Support
 - Behavioral Services
- Home and Vehicle Modifications



PUNS: THE BASICS

PUNS is NOT a Program!

- PUNS is a database or waiting list
- Waiting list for anyone who may need services now or in the future



Who qualifies?

- Ages 3+ (can apply at age 2.5)
- Intellectual disability (IQ<70)
- Developmental disability
- Related condition
 - Autism
 - Cerebral Palsy
 - Epilepsy

Waiting list info

- Must be in "Seeking Services" category to be on waiting list
- First on, first off waiting list
- Exceptions for those in crisis situations
- PUNS list "resets" at age 18

HOW DO I GET ON THE PUNS LIST?

Locate your Independent Service Coordination (ISC) Agency

- Helpline: 800-843-6154
- 888-DDPLANS
- Find your office online
 - Choose “Developmental Disability Services” and enter county and zip code

Set up an appointment

- Initial assessment
- Annual appointment to update case



HOW LONG IS THE WAIT TO BE SELECTED FROM THE PUNS LIST?



Children

- Children are rarely selected unless in crisis (homeless, abuse/neglect, caregiver injury/death)
- Some were pulled in the past couple years, but mostly ages 18-22

Adults

- Wait time for individuals on the PUNS (age 18+) is 5 years and sometimes less
- Those 18-22 may be pulled for Children's Support Waiver



CHILDREN'S DD RESIDENTIAL WAIVER

Children with developmental or intellectual disabilities, including cerebral palsy, epilepsy, and autism

Ages 3-22

No waiting list

Parent income is waived

No 24-hour nursing



Placed in a small child group home

To apply

Independent Service Coordination (ISC) Agency

1-888-DD-PLANS

COMPARING WAIVER GROUPS

Program	Ages	Official Categories	Level of Care
Medically Fragile Technology Dependent Waiver (MFTD)	0-21 to enter; all ages	Medically Fragile, Technology Dependent	Hospital Nursing Home
Home Services Program (DRS Waivers)	All ages ⁺	Physical Disability, Brain Injury, or HIV/AIDS*	Nursing Home
Support Waiver for Children and Youth with DD	3-22	Intellectual Disability, Developmental Disability, Autism, CP, Epilepsy	ICF/DD
Residential Waiver for Children and Youth with DD	3-22	Intellectual Disability, Developmental Disability, Autism, CP, Epilepsy	ICF/DD

* Because the Determination of Need looks at Functional Limitations, those without a physical disability, brain injury, or HIV but significant functional limitations may also qualify

+ With some exceptions for those over 60

COMPARING WAIVER SERVICES



Program	Nursing	Personal Care	Home Modification	Vehicle Modification	Adaptive Equipment Assistive Tech	Behavior Intervention	Respite
MFTD Waiver	✓ *		✓	✓	✓	✓ *	✓
Home Services Program	✓ *	✓	✓		✓	✓ *+	✓
Support Waiver - DD	✓ *	✓	✓	✓	✓	✓ ^	
Residential Waiver - DD	✓ *				✓	✓ ^	

* Through the Medicaid state plan for children; Personal Care should also be provided through the state plan for all children under 21 but is not currently available

+ Currently Brain Injury waiver only provides additional Behavioral Counseling; will be available in all waivers in 2025

^ Through state plan with additional behavioral waiver services

COMPARING INCOME REQUIREMENTS FOR CHILDREN



Program	Income Waiver?	Info
Medically Fragile Technology Dependent Waiver (MFTD)	YES	Only the income and assets of the CHILD are counted
Home Services Program (DRS Waivers)	NO*	Parent income is counted for a minor and asset limit is \$35,000; family can earn up to 318% FPL (just under \$100K for a family of 4)
Support Waiver for Children and Youth with DD	YES	Only the income and assets of the CHILD are counted
Residential Waiver for Children and Youth with DD	YES	Only the income and assets of the CHILD are counted

* Home Services Program allows those who don't qualify for Medicaid to participate in a limited state-based program for HCBS services ONLY.

COMPARING WAITING LISTS AND SPOTS



Program	Waiting List	Spots Available	Waiting List Info
Medically Fragile Technology Dependent Waiver (MFTD)	none	1804 Increasing to 2020 spots over next two years	
Home Services Program (DRS Waivers)	none	36,751 (PWD), 3375 (BI), 1263 (HIV) – spots will increase slightly	
Support Waiver for Children and Youth with DD	YES	1440	PUNS – 9850 children ages 3-21 as of 5/31/2024
Residential Waiver for Children and Youth with DD	none	295	

WHAT IS KATIE BECKETT OR TEFRA?

A way to provide Medicaid ONLY to children under 18 with any disability and an institutional level of care

- Optional for states
- Cannot have waiting list

NO program in Illinois



OTHER WAYS FOR CHILDREN TO GET HCBS IN ILLINOIS

State plan services for those who qualify financially for Medicaid

- Home nursing (non-waiver)
- Personal care services in theory
- Medical equipment, supplies, therapies

Grant-Based Respite

- Emergency respite
- Respite - group, in-home, residential, voucher

Title V – Division of Specialized Care for Children

- Core and Connect Care Programs – uncovered items, therapies, services

Insurance

- Home nursing very occasionally; may provide other services
- Some coverage for medical equipment, supplies, therapies

Medicaid Palliative Care Program

- Respite
- Nursing
- Expressive therapies

COMING SOON!

Department of Rehabilitation Services

- Vocational services
- Employment services

POTENTIAL ADVOCACY FOR CHILDREN'S WAIVERS



Personal care services provided to any child under 21 enrolled in Medicaid (when medically necessary)

- New guidance coming out this fall from federal government

Fixes for DRS Home Services Program to allow children to better access program

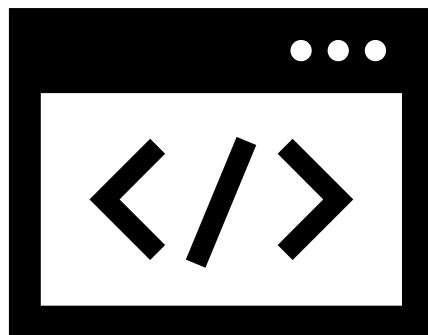
- Improve assessment process for children
- Add waiver to use institutional income and resources (waive parent income)

Expansion of existing children's ID/DD waivers

- There are potential Olmstead issues with waiting list

TEFRA or Katie Beckett option

- Expensive!
- Some legislators are interested



PAID PARENT CAREGIVING

WHAT IS PAID PARENT CAREGIVING?

When a parent, guardian, step-parent, or foster parent is paid to provide specialized services for people with disabilities

Skilled
nursing
services

Personal
care
services

Personal
support

WHAT IS A PARENT AND LEGALLY RESPONSIBLE INDIVIDUAL?

Parent

- Someone caring for a child of any age
- Usually includes parent, step-parent, foster parent, or guardian

Legally Responsible Individual (LRI)

- Someone with a **legal responsibility** to care for someone, usually a minor child under age 18
- May include spouses in some cases
- State defined
- Usually includes parent, step-parent, foster parent, or guardian

PROS AND CONS OF PAID PARENT CAREGIVING

Pros

- Option when there is a shortage of nurses and other direct service providers
- Source of income since parents often have difficulty holding down a job due to cancellations and gaps
- Improves family's financial situation
- Always know who is caring for your child
- Greater consistency

Cons

- Greater chance of parent burn out
- Potential for conflict between family members
- Possible fraud, neglect, or abuse issues
- Requires greater oversight
- Salary may make children ineligible for income-based programs

WHAT DOES THE FEDERAL LAW SAY ABOUT PAYING PARENTS?

Kids under 18

- Parents who are licensed can be paid (RN, LPN, CNA)
- Parents cannot be paid to provide personal care or assistance through the regular state Medicaid plan
- Parents can be paid through alternate mechanisms including:
 - 1915(c) waivers (exceptional care only)
 - 1915(j) and 1915(i) waivers
 - 1115 demonstration waivers
- States may impose limitations

Adults over 18

- Generally, no federal restrictions
- States may impose limitations

PAID CAREGIVING BY PROGRAM



Program	Minors under age 18	Adults over age 18
MFTD Waiver	RN or LPN only CNA coming soon	RN or LPN only CNA coming soon
DSCC Home Care Non-Waiver	RN or LPN only CNA coming soon	RN or LPN only (ages 18-21) CNA coming soon (ages 18-21)
DRS Home Services Program (all waivers)	Unlicensed parents CNA, LPN, or RN	Unlicensed parents CNA, LPN, or RN
Support Waiver for Children and Young Adults with DD	None	Unlicensed parents (ages 18-22)
Adults with Developmental Disabilities	Not applicable	Unlicensed parents

HOW DO I BECOME A PAID PARENT CAREGIVER?

Individual enrolls in a program that provides paid family caregiving



Contact relevant case manager or care coordinator

HOW DO I BECOME A PAID PARENT CAREGIVER?



MFTD Waiver: DSCC Care Coordinator – call (800) 322-3722

DSCC Home Care Program: DSCC Care Coordinator – call (800) 322-3722

Home Services Program: Division of Rehabilitation Services (DRS) Case Manager – [find your office here](#)

Support Waiver for Children and Young Adults with DD: Independent Service Coordination (ISC) Agency Case Manager – [find your agency here](#)

Adults with Developmental Disabilities Waiver: Independent Service Coordination (ISC) Agency Case Manager – [find your agency here](#)

OTHER REQUIREMENTS

Register in IMPACT,
the Medicaid
provider system, OR
be hired by an
agency



Not have a history of
fraud, neglect, or
abuse



Pass a background
check



Complete training
requirements in
some programs



Be legally allowed to
work in the United
States



CAN I BE PAID FOR OTHER SERVICES?

MFTD Waiver

- Shift Nursing
- Respite Nursing when the provider lives in a separate home
- Transportation through Medicaid

DSCC Home Care Program

- Shift Nursing
- Transportation through Medicaid

Home Services Program

- Personal Care
- CNA, LPN, RN
- Occupational, Physical, Speech Therapist

Support Waiver for Children and Young Adults with DD

- Personal Support and Temporary Assistance for those aged 18-22

Adults with Developmental Disabilities Waiver

- Personal Support
- Temporary Assistance
- Non-Medical Transportation

WORKER BENEFITS

Agency Based – DSCC and MFTD

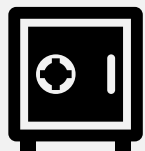
- Agency **may** offer health insurance, paid time off, or other benefits

Home Services Program – Self Directed

- Can join SEIU Healthcare union and receive health insurance

DD/ID Waivers – Self Directed

- None at this time



COUNTABLE INCOME AND TAXES

Countable income

- In most cases, income that parents earn as a paid parent caregiver can be counted by the state when determining benefits
 - Problematic for families of children under the age of 18 whose entire family income is counted for certain programs
 - Problematic if a parent receives Medicaid or other benefits based on their individual income as they may become ineligible for certain benefits

Taxes

- In most cases, payments are tax free - [IRS information](#)
- Paid parent caregiving may also affect tax and benefit situations if you claim your child over the age of 18 as a tax dependent

MFTD AND DSCC HOME CARE PROGRAM: NEW PARENT CNA PROGRAM



For children and adults receiving skilled nursing care at home

- MFTD Waiver
- DSCC Home Care Program non-waiver nursing through Medicaid
- Children under 21 who receive home nursing in DRS Home Services and DD Waivers

Parent must obtain CNA license

- Hope to eventually create a simpler pathway to CNA license for parents

Parent will be hired by child's nursing agency

- Not all agencies will likely participate
- Hour limitations are the same as for nurses under the Nurse Practice Act
- Monitoring every 60 days, pending federal approval

Status: State is in the process of submitting required federal documentation (waiver application and state plan amendment) and developing rules. Estimated start date is early 2025.

DRS HOME SERVICES PROGRAM: NEWER PAID PARENT CAREGIVING



Started during COVID, added to waiver as of 1/1/2024, and rolled out this spring

Child must need extraordinary care (care beyond what is typical for a child the same age), such as assistance with eating, bathing, incontinence, transferring

At least 2 unannounced visits annually to ensure safety and avoid fraud

40 hours per week maximum per child

Time sheets and service plans must be signed by an adult third party

POTENTIAL FUTURE STEPS FOR PAID PARENT CAREGIVING

New license type to allow parents to be paid for skilled care

Expansion to Children's DD waiver and/or personal care through the state Medicaid plan

- Parents cannot be paid through state plan for personal care, so requires a workaround

Expansion of Parent CNA Program to Other Groups

Many children with disabilities in Illinois have no access to Medicaid waivers due to waiting lists or parent income

We need **ADVOCATES**
to help fight for programs!

- Eliminate waiting lists
- Make waivers available to children with all types of disabilities
- Expand paid parent caregiving
- Expand the workforce

**YOUR ADVOCACY
IS IMPORTANT!**

MY CONTACT INFORMATION



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