



Family to Family Health
Information Center



UPDATES TO MEDICAID, MEDICAID WAIVERS, AND FAMILY CAREGIVING

The Arc of Illinois, Family-to-Family Health Information Center
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GOALS FOR TODAY

Learn about Medicaid waivers in Illinois



Find out which programs offer paid family caregiving



Discuss potential changes to waivers from HR 1 (OBBBA)



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];
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Full Medicaid
Coverage

Extra Home
and Community
Based Services

WHY DO PEOPLE NEED WAIVERS?

Waivers are typically the only way to fund disability services in the United States

Direct care like personal assistance or home nursing

Day programs or group homes

Respite



Waivers wrap around insurance/Medicare to reduce costs and tackle underinsurance



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

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

Likely will transition to one waiver in 2026

+ 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; may move to one unified waiver in 2026
- 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 or \$17,500 per individual; counts 401(k)

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 younger children 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
- Can wrap around private insurance



Receive full Medicaid coverage plus extra services

- Most receive in-home supports
- 2 times SSI amount in benefits
 - Personal Support
 - Behavioral Services
- Home and Vehicle Modifications



ADULTS WITH DEVELOPMENTAL DISABILITIES WAIVER

Adults with developmental or intellectual disabilities and related conditions

- Ages 18+
- Extensive waiting list (PUNS)
- Cannot need 24-hour nursing
- Intellectual disability, developmental disability, autism, cerebral palsy, or epilepsy
- Can wrap around private insurance



Receive full Medicaid coverage plus extra services

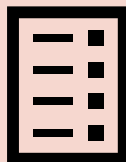
- Most receive in-home supports
- 3 times SSI amount in benefits once out of school
 - Personal Support
 - Behavioral Services
 - Community Day Programs
- CILA (small group home) living option



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 2022 and 2023, 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
Adults with DD	18+	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 Assistive	Behavior Intervention	Respite
MFTD Waiver	✓ *		✓	✓	✓	✓ *	✓
Home Services Program	✓ *	✓	✓		✓	✓ **	✓
Support Waiver - DD	✓ *	✓	✓	✓	✓	✓ ^	
Residential Waiver - DD	✓ *				✓	✓ ^	
Adults with 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; may be available in all waivers in 2026
 ^ Through state plan for children under 21 with additional behavioral waiver services

COMPARING INCOME REQUIREMENTS FOR CHILDREN



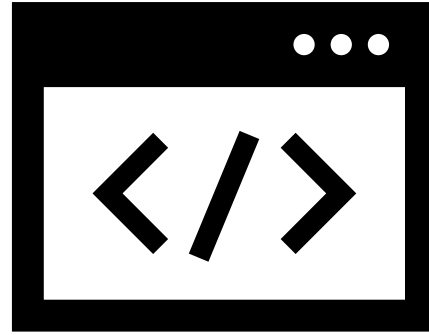
Program	Income Waiver?	Info
Medically Fragile Technology Dependent Waiver (MFTD)	YES	Only the income and assets of the CHILD are counted
Home Services Program (DRS Waivers)	NO*	Parent income is counted for a minor and asset limit is \$35,000; family can earn up to 318% FPL (just over \$100K for a family 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	2020 (in 2026)	
Home Services Program (DRS Waivers)	none	37,854 (PWD), 3375 (BI), 1263 (HIV) (in 2025)	
Support Waiver for Children and Youth with DD	YES	1440	PUNS – 10,532 children ages 3-21 as of 8/1/2025
Residential Waiver for Children and Youth with DD	none	295	
Adults with DD	YES	27,758 (in 2026)	PUNS – 10,628 age 18+ as of 8/1/2025



PAID FAMILY 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

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

PAID PARENT CAREGIVING FOR ADULTS



DRS Home Services Program

- Personal Assistance
- CNA, LPN, RN if medically required

Adults with DD (Home-Based) Waiver

- Personal Support
- Over age 18

MFTD Waiver

- LPN or RN ONLY
- CNA coming soon

THE ONLY CURRENT PROGRAM FOR PAYING
PARENTS OF CHILDREN UNDER AGE 18:
DRS HOME SERVICES PROGRAM



Began March 2024

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

40 hours per week maximum per child

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

ALMOST THERE! 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

- Parent will be hired by child's nursing agency

Status: Waiting on approval from the federal government. Estimated start date is ANY DAY NOW.

COMING EVENTUALLY... FAMILY HEALTH AIDE PROGRAM



New Program included in the 2025 Medicaid Omnibus Bill. State CAN but DOES NOT HAVE TO create the 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

New Certification

- Training through Hospital, Transitional Facility, or Nursing Agency
- Parent will be hired by child's nursing agency

Timeline and Issues

- Several years at minimum
- Requires actions of several agencies, including IDPH and IDFPR
- Requires Medicaid and waiver amendments
- May be delayed due to federal Medicaid cuts

HOW DO I BECOME A PAID PARENT CAREGIVER?



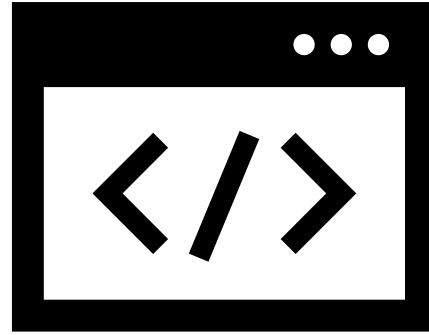
MFTD Waiver: DSCC Care Coordinator – call (800) 322-3722

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](#)



MEDICAID WAIVER CHANGES DUE
TO HR 1 (OBBBA)

HOWEVER...

THERE ARE NO
DIRECT CUTS TO
WAIVERS IN HR 1*

Waivers are optional Medicaid services, meaning the state does not have to provide them.

HFS has stated Medicaid Home and Community Based Services, including waivers, are “at risk”

Waivers are one of the only things that CAN be cut

WHY AT RISK? FEDERAL DOLLARS TO ILLINOIS WILL BE REDUCED DRAMATICALLY

HFS predicts \$51 billion less
over 10 years (Manatt Health
Analysis)

KFF predicts \$29-\$48 billion
less



WHY LESS FEDERAL DOLLARS?

Many reductions in federal dollars come from complicated Medicaid financing strategies

Provider Taxes

State Directed Payments

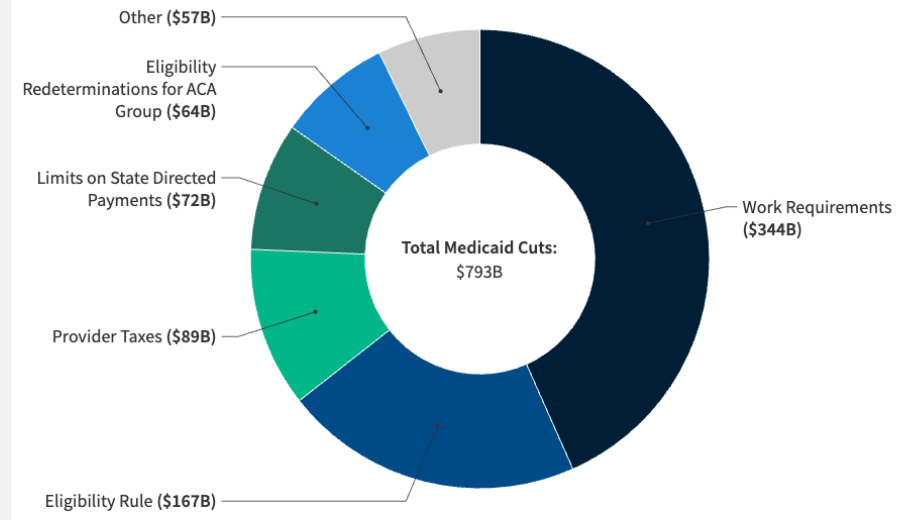


Other reductions from reduced enrollment and other changes

Figure 1

CBO Estimates of Federal Medicaid Cuts in the House Reconciliation Bill

10-year federal spending cuts, by policy



Note: Total includes \$70B in estimated Medicaid spending interactions. See Methods in "Allocating CBO's Estimates of Federal Medicaid Spending Reductions and Enrollment Loss Across the States: House Reconciliation Bill" for more details.

Source: [KFF analysis of CBO estimates of the House Reconciliation Bill](#) • [Get the data](#) • [Download PNG](#)



HOW COULD WAIVERS BE AFFECTED?

Reduce number of spots in a waiver, leading to new or longer waiting lists

Make it more difficult to qualify for a waiver

- Financially in terms of income and/or assets
- Acuity in terms of level of need

Reduce or eliminate waiver services

Limit or reduce cost maximums

Provider reimbursement cuts

- Could affect CILAs
- Could affect direct support staff, including DSP, PSWs, PAs, and home nurses

Unlikely: eliminate a waiver entirely

WHAT DOES HISTORY TELL US? 2011-12 REDUCTION IN FEDERAL DOLLARS

All 50 states reduced disability or HCBS services

Illinois cut home health HCBS participation by 11%

Illinois cut waiver spending by 4%

Almost all providers had a 3.5% reimbursement rate decrease

Adult dental, podiatry, and prescriptions cut or limited

MFTD Waiver heavily targeted with massive changes

Some programs had financial qualification limits reduced or had premiums/copays increased or added

WHAT ABOUT WORK REQUIREMENTS?

Work requirements exempt people with disabilities

- Those in waivers should be automatically exempted
- Those not in a disability-related program may have to repeatedly "prove" their disability

Caregivers of people with disabilities should also be exempt from work requirements

- May be difficult to automatically exempt caregivers
- How is caregiver defined?

WHAT ABOUT OTHER DIRECT CUTS?

Some people with disabilities in the ACA category may have more frequent redeterminations

Some people with disabilities in the ACA category may have new copayments

Dual eligibles may have more difficulty accessing Medicare Savings Programs

DISABILITY RIGHTS LAWS AND CONSENT DECREES PROTECT OUR WAIVERS



The Americans with Disabilities Act (ADA) protects the right to live in the community instead of an institution



The Integration Mandate, part of Section 504 of the Rehabilitation Act, also protects community living.

Various consent decrees in Illinois offer SOME protections to waivers

- Adult DD Waiver – Ligas
- MFTD Waiver – OB v. Norwood
- DRS – Williams and Colbert

But...the Department of Justice is not currently focusing much on Disability Rights Protection

HOW CAN YOU ADVOCATE?



Work with HFS (state Medicaid agency) and other divisions (DDD, DRS, DSCC) to make sure waivers are as minimally affected as possible



Contact the Governor and your state legislators to make sure waivers are not cut in the budget



VOTE and elect federal Representatives and a Senator in 2026 who will undo Medicaid cuts



Share your Medicaid story with The Arc and your elected officials (state and federal)

MY CONTACT INFORMATION



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