



Cross Disability Advisory Council Meeting



February 19, 2026





AGENDA

- I. **Welcome Activities**
- II. **Waiver Service Modalities – Paid Family Caregiver**
 - a. Overview
 - b. PFCG in ND Today
 - c. Common PFCG Safeguards and State Examples of Safeguards
 - d. PFCG Guiding Principles
 - e. Discussion
- III. **Closing Activities**

Welcome Activities



Approach to February CDAC

- ❖ **Learn - Content Overview:** We want CDAC members to **understand:**
 - ❑ Examples of protections that other states have used for their paid family caregiving service
 - ❑ How have other states reduced the risks of fraud, waste, or abuse?
 - ❑ What safeguards have other states used for safety and health?

- ❖ **Discuss - Feedback:** We want CDAC's **input** on:
 - ❑ What are some ways North Dakota can both protect people and make the program sustainable?
 - ❑ How could ND manage costs to make sure the program is successful and can continue?
 - ❑ What ideas might work best to help keep waiver participants who use this service safe?

- ❖ **Create - Formal Guidance:** We want CDAC to **draft official guiding principles** for:
 - ❑ Paid family caregiving in North Dakota.
 - ❑ A&M has drafted starting guiding principles based on CDAC conversations. We will work together to edit these guiding principles.

Timeline Considerations: ND's 27-29 budget process will take place in ~late summer / early fall 2026. The 27-29 legislative session will happen ~Jan-May 2027. We are focusing on topics that impact the waiver's cost so that we have this information to share with the legislature.

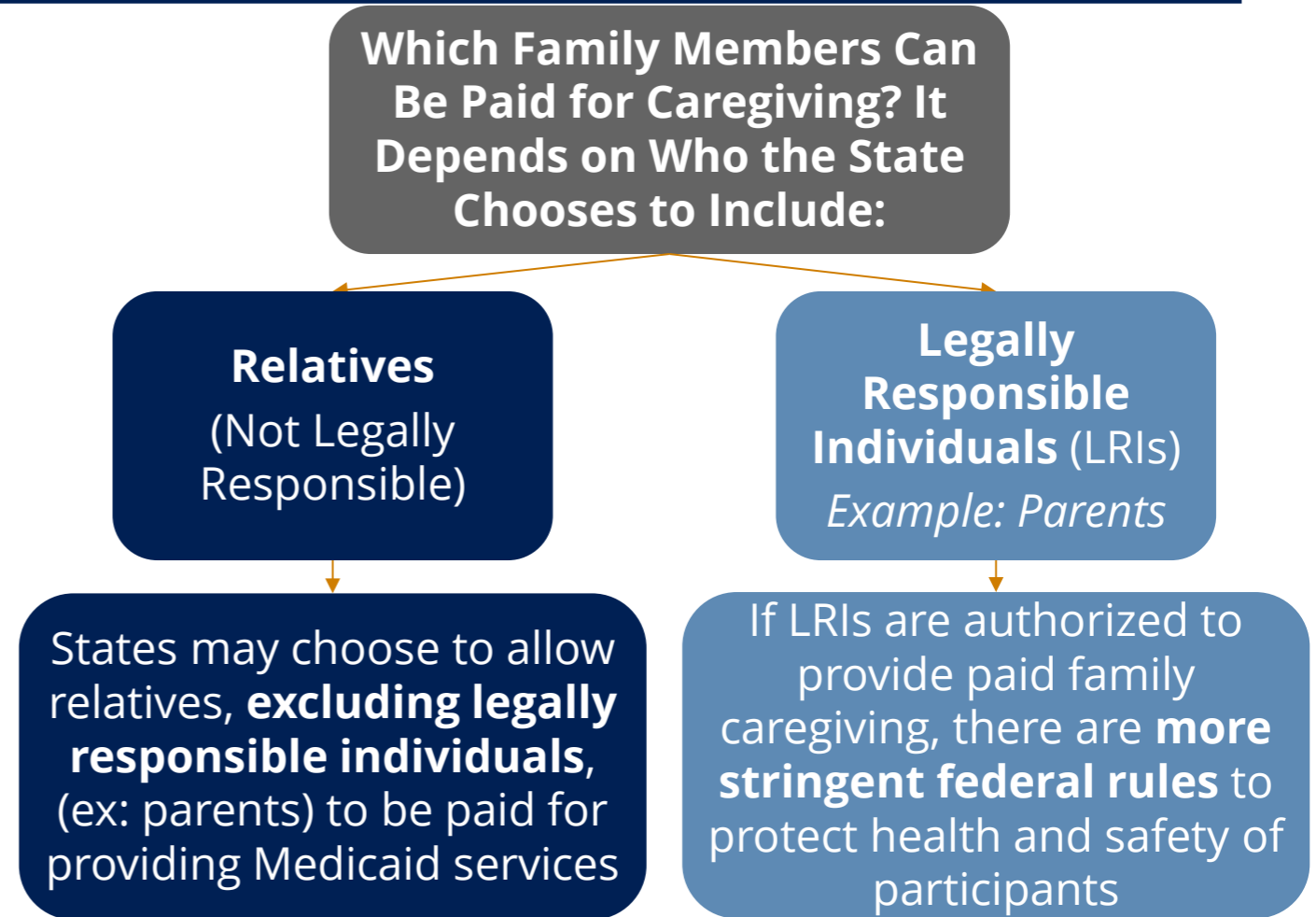


Paid Family Caregiver as a Modality – Overview



Key Elements of Paid Family Caregiving

- Paid family caregiving (**PFCG**) is **an optional service delivery method**; states may choose whether or not to authorize this modality
- If a State decides to pursue paid family caregiving, they can include this option for:
 - Medicaid State Plan Services; and / or
 - In some or all the State's 1915(c) waivers (most common method)

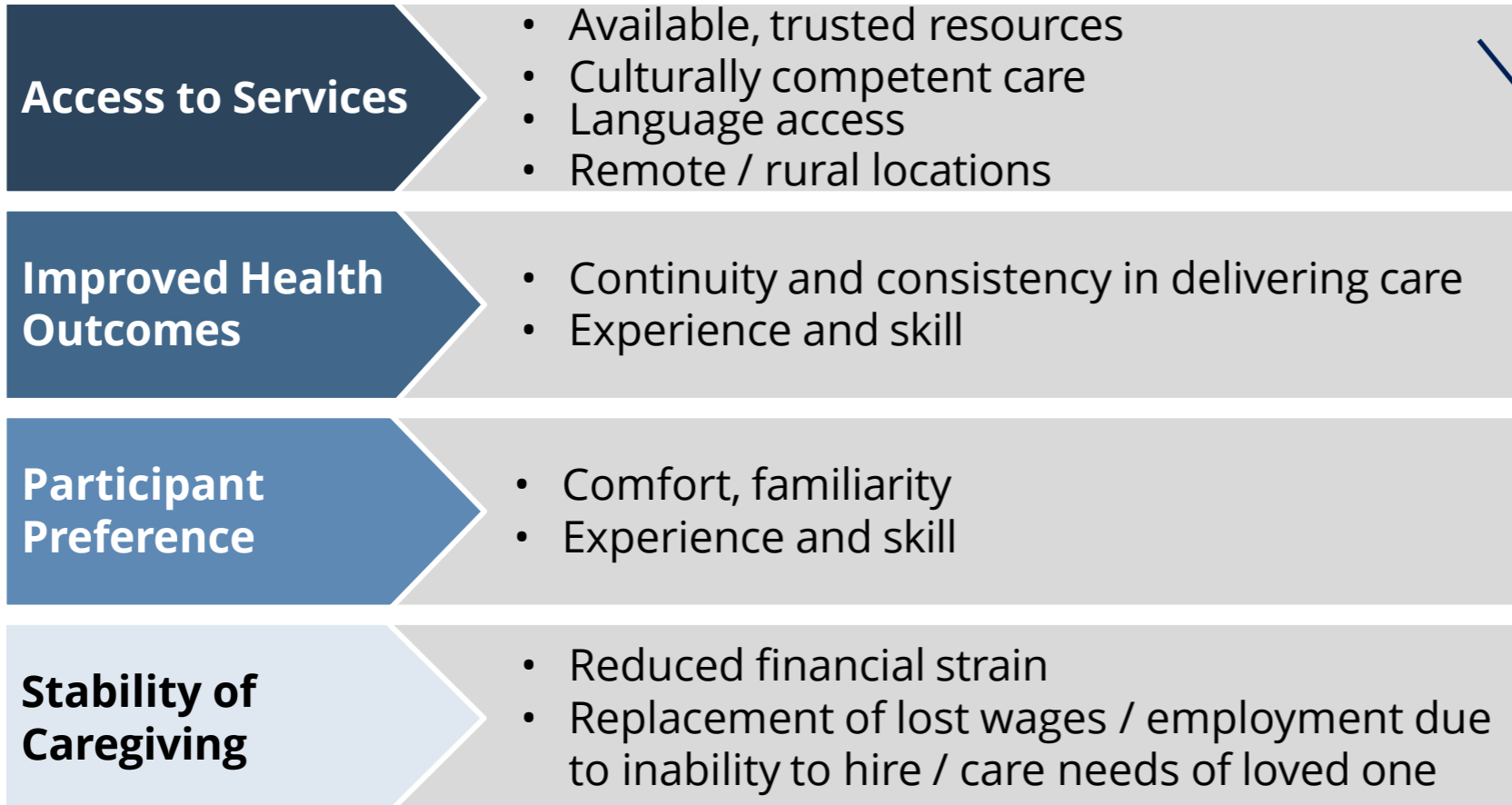


★ KEY TERM: Legally Responsible Individual / Relative (LRI)
This term typically refers to parents or spouses. In North Dakota, LRI means an individual who has a duty under law to care for the participant, including a biological or adoptive parent, nonentity custodian, guardian, or a spouse.



Paid Family Caregiver | Opportunities

Family caregivers fill an important role in home and community-based services.



During COVID-19, use of paid family caregiving increased. According to a Kaiser Family Foundation survey, 37 of 50 responding states reported allowing spouses and parents of minor children or other legally responsible relatives to be paid providers. 70% of these states (26/37) have (or plan) to sustain this policy as permanent.

Source: [KFF State Survey](#)



Paid Family Caregiver | Policy Considerations / Safeguards

States must carefully define who they consider a family caregiver, the type/scope of services available, participant choice in using family caregivers, and how they will provide monitoring/oversight to ensure safety, well being and choice.

Definitions / Criteria	<ul style="list-style-type: none"> • Extraordinary vs. ordinary care • Legally responsible individuals (state laws)
Scope / Limit	<ul style="list-style-type: none"> • Waiver services • Type of family caregivers • Service limits / requirements
Choice / Best Interests	<ul style="list-style-type: none"> • Integration • Supported decision making • Conflict of interest / financial dependency
Oversight / Monitoring	<ul style="list-style-type: none"> • Qualifications • Program integrity • Administration / costs • Health, welfare and safety

Following COVID-19, some states opted to end previously authorized policies, including workforce flexibilities. According to the Kaiser survey, 11 states reported that they intended to stop allowing legally responsible relatives such as parents to be paid providers. States who have opted to keep provisions for paid family caregiving must ensure careful program safeguards, and meet federal requirements.

Source: KFF State Survey



The Importance of Balancing Opportunity with Risk

To fully benefit from the opportunities of paid family caregiving, North Dakota needs to establish safeguards that will limit risk and help set this option up for long term success.

- North Dakota should embrace the opportunity to work with stakeholders to think proactively about program decisions that will allow the State to **protect against known risks and help ensure program sustainability moving forward**



- **The case for caution:**

- We know there are some states that used paid family caregiving but stopped using this method due to challenges
- There are legitimate concerns about issues like health and welfare, participant choice, isolation, state budgetary limits, and potential misuse of the program



- **The case for optimism:**

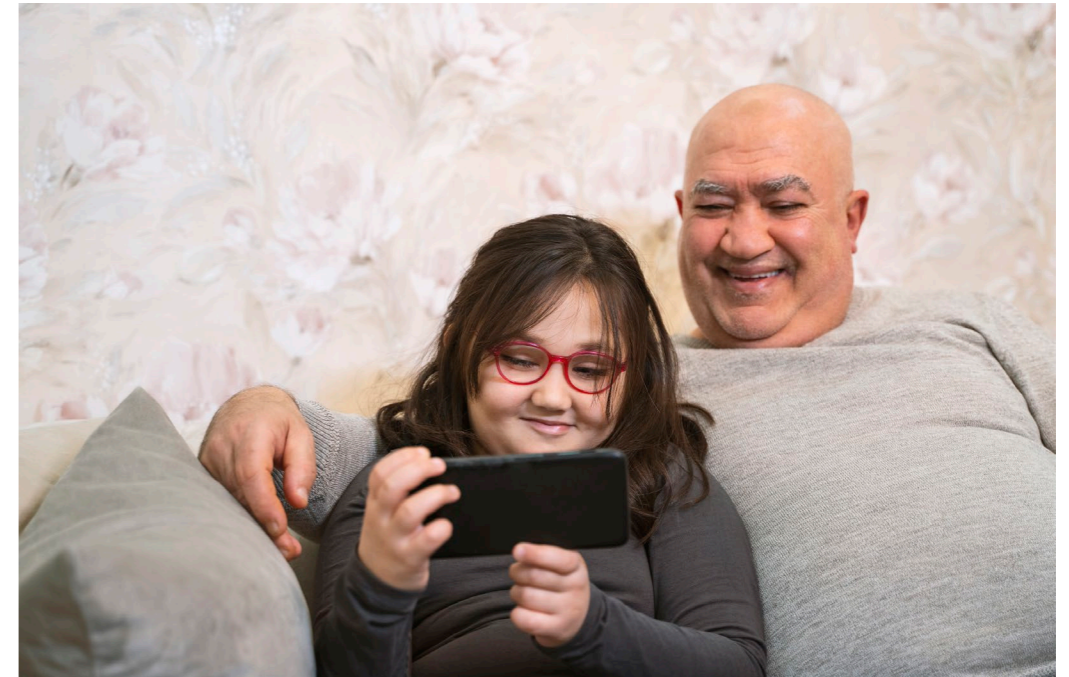
- Groups like CDAC are passionate about helping the State design paid family caregiving in a way that works long-term
- Technology such as EVV can provide a lower-effort way to help protect against potential risks such as fraud/waste
- North Dakota can learn from other states across the country



Federal Requirements Around Paid Family Caregiving (1 of 2)

There are federal rules about paid family caregiving.

- **Service Type:** Personal care, or related service (ex: home health aide, homemaker, chore, and companion services)
- **Provider Qualifications:** Providers of paid family caregiving must meet the same standards as other providers of similar waiver services
- **Extraordinary Care:** Payments may only be made to **legally responsible individuals when services are deemed extraordinary care**, and not for tasks falling under ordinary care. States use various assessment forms to measure an individual's need for extraordinary care.



Federal Requirements Around Paid Family Caregiving (2 of 2)

States must show that a parent is providing extraordinary care to qualify for paid family caregiving.

- CMS requires states to assess whether individuals demonstrate need for extraordinary care when screening for paid family caregiving provided by LRIs (ex: parents).
- CMS defines extraordinary care broadly but leaves flexibility for states to further define this term.
- It is the responsibility of states to assess and measure extraordinary care vs ordinary care.

Defining Extraordinary Care: An Excerpt from CMS Guidance ([Source](#))

"A state may elect to make payment for personal care or similar services that are rendered by legally responsible individuals when such services are deemed extraordinary care so long as the state specifies satisfactory criteria for authorizing such payments. **The criteria must include how the state will distinguish extraordinary from ordinary care.** By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization"

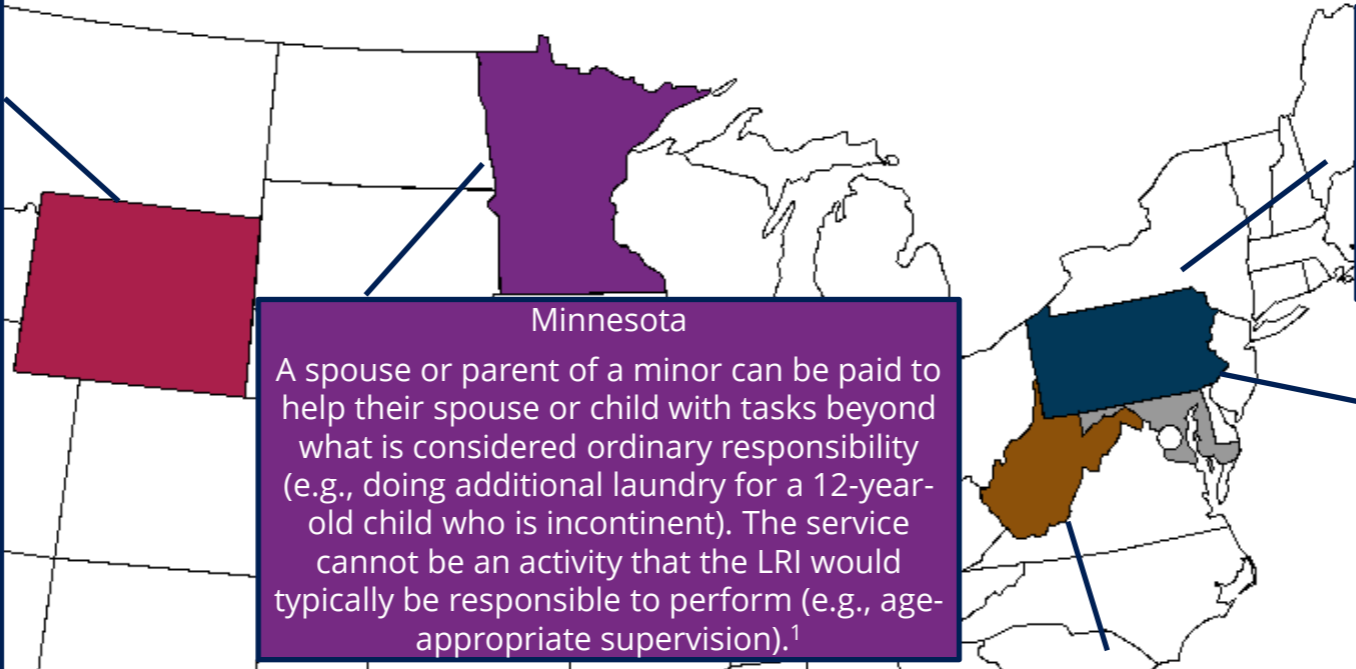


A Sampling of Various State Definitions for Extraordinary Care

States may only pay legally responsible individuals for personal care waiver services if the care provided qualifies as "extraordinary care". It is up to states to set the definitions and assessment protocol for extraordinary care.

Wyoming

Cases shall meet the following criteria: 1. The participant's Adaptive Behavior Quotient is 0.35 or lower on the ICAP assessment; and 2. The participant needs assistance with ADLs or IADLs exceeding the range of expected activities that a LRI would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and to avoid institutionalization. (Example: A 12 year old needing assistance with dressing and bathing, whereas the average 12 year old does not); or 3. The participant requires care from a person with specialized medical skills relating the participant's diagnosis or medical condition as determined appropriate by the participant's medical professional and the Division.⁵



Pennsylvania

Support that goes beyond what would be expected to be performed in the usual course of parenting, and when needed supported exceeds what is typically required for a child of the same age.⁴

Minnesota

A spouse or parent of a minor can be paid to help their spouse or child with tasks beyond what is considered ordinary responsibility (e.g., doing additional laundry for a 12-year-old child who is incontinent). The service cannot be an activity that the LRI would typically be responsible to perform (e.g., age-appropriate supervision).¹

Maryland

Care exceeding the range of activities that a LRI would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age and which is necessary to assure the health and welfare of the participant and to avoid institutionalization.²

Louisiana

Care that is extraordinary from that of a child without a disability of the same age. The State further defines extraordinary care as behavioral or nursing care needs such as but not limited to tube feeding, suctioning or diapers after age 3, behavioral care requiring the intervention of a neurologist, psychologist or other specialist.³

West Virginia

Support that goes beyond what would be expected to be performed in the usual course of parenting, and when needed supported exceeds what is typically required for a child of the same age.



1. MN Source
2. MD Source
3. LA Source
4. PA Source
5. WY Source
6. WV Source



Establishing the Regulatory Foundation for North Dakota to Achieve Sustained Program Success

Excerpt from CDAC 1.0

DRAFT

ND will work to balance flexibility with regulation to create a service option that can stand the test of time.

North Dakota must establish rules and parameters for the paid family caregiver program that meet the needs of varied stakeholders and address the State's responsibilities to these groups.

Federal Regulatory Agencies

- About 50% of the funding for paid family caregiving will come from federal Medicaid.
- CMS requires states to show they are meeting national rules.
- Most critically, CMS specifies that states must assess whether individuals meet the criteria for extraordinary level of care before approving payments to LRI.

ND State Policy Makers

- Public policy makers in ND are also investing in this program through both the current pilot, and in the future through Medicaid funds.
- Policy makers want to be sure that HHS is using money as intended.
- By establishing guardrails, HHS can help ensure they are being good stewards of public dollars.

ND Families and the Individuals Served by Waivers

- Paid family caregiving will require families to operate in a new role as formal service providers.
- Families will need help understanding how to meet their responsibilities in this new role.
- This option is not right for everyone – a core function of HHS is to help ensure this is the best fit for individuals receiving services.



Understanding the Impact of Federal EVV Regulations on Paid Family Caregiving

Excerpt from CDAC 1.0

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The 21st Century Cures Act requires states to implement EVV for all Medicaid personal care services (PCS) and home healthcare services that require an in-home visit by a provider.

- PCS provided by family caregivers who live in the same home with the participant do not require EVV.
- When services are provided by a family caregiver who does not live in the same home as the participant, EVV is required.
- States are may choose to expand beyond the requirements of the 21st Century Cures Act and implement EVV for all family caregivers, and we have seen many states choose this option as a safeguard for paid family caregiving.

Potential Benefits of EVV

- ❖ Decreased reliance on maintaining and retaining paper records due to electronic service records.
- ❖ Automation of service verification, electronic service records, and assurance that payment is based on actual service delivery at recorded check-in and check-out times and locations.
- ❖ Assurance that payment for waiver services is based on assessed participant need as identified on the individual's person-center service plan.



Waiver Payment Rate Options and Considerations

Understanding the Basic Structure of Medicaid HCBS Waiver Payments and the Impact on Providers

Federal Guidelines on the Rate Development Process

- CMS sets guidelines for rates, including minimum and maximum payment rates, and requires state to establish rates that, “are consistent with efficiency, economy, and quality of care, and are sufficient to enlist...providers.”¹
- Within the CMS framework, Medicaid payment rates vary widely by state, waiver, and specific service provided.
- States must detail their rate methodology in a transparent manner and provide opportunities for public comment.

Provider Requirements for Rate Reimbursement

- Providers must bill according to the available unit rate options established by the State for the service in question
- The two primary reimbursement units states use for Medicaid waiver services are:
 - A) **15-minute unit of service** – example: ND currently offers in-home supports as a service on the DD Waiver. This service is also subject to **EVV** through Therap.
 - B) **Daily unit of service** – example: the ND paid family caregiving pilot provided authorization for a daily rate of \$162.73 (this will increase again on 7/1/26).
- **Providers cannot bill for a direct care service such as in-home supports at the same time as another direct care service like respite. This means there can only be one daily unit of direct care service provided each day.**

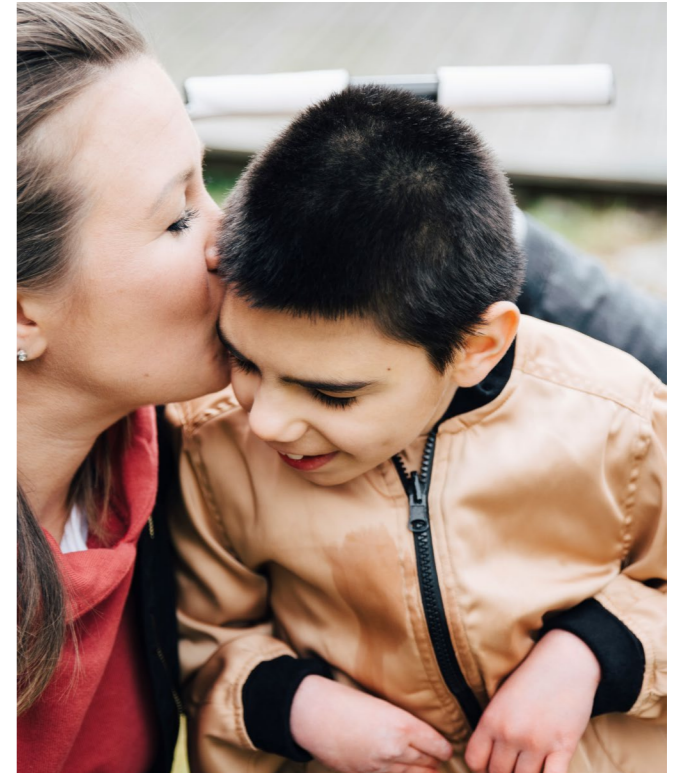
Paid Family Caregiver as a Modality – CDAC and ND Today



CDAC 1.0 and 2.0 Feedback on Paid Family Caregiving

CDAC members value the option for paid family caregiving (PFCG).

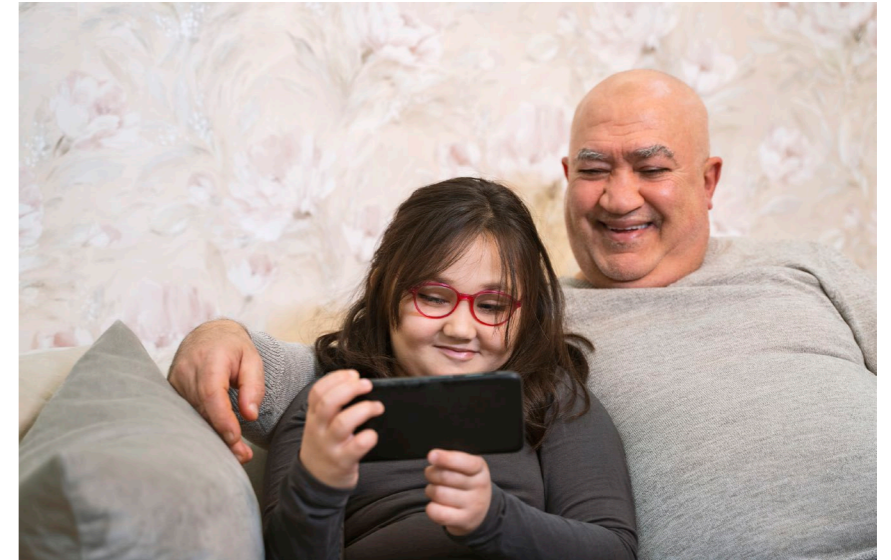
- **We have heard from members of both councils how PFCG has made a positive impact in their lives and the lives of their children.**
- Members of both CDAC 1.0 and CDAC 2.0 have been very supportive of including the option for paid family caregiving.
- ND's **Aging & Physically Disabled Waiver**, which serves adults, also offers **PFCG through its Waiver Personal Care service.**
 - ND is also testing out PFCG as a pilot for some of its waiver participants.
 - PFCG is different for children than for adults, which is why a pilot helps.
- CDAC talked about the opportunities PFCG gives families, including flexibility and control. It also helps increase access to providers in more rural areas.
- CDAC also talked about needing protections for safety, and to make sure the service is the right fit for the child.
- **We will be formalizing CDAC 2.0's feedback on PFCG.**



Overview of Paid Family Caregiving in ND Today

North Dakota is currently running a pilot on paid family caregiving.

- Under the pilot program, family members who provide extraordinary care to either a child or adult enrolled in one of the following Medicaid 1915(c) waivers may receive payments from the state:
 - Autism Spectrum Disorder Birth Through 17 Waiver.
 - Children with Medically Fragile Needs Home and Community-Based Services Waiver.
 - Children's Hospice Home and Community-Based Services Waiver.
 - Traditional Individual with Intellectual Disabilities and Developmental Disabilities Home and Community-Based Services Waiver.



One-time state funding for a pilot program was approved with the passage of Senate Bill 2276 during the 2023 legislative session. **Additional, one-time state funding was appropriated during the 2025 legislative session to extend the pilot for another two years with Senate Bill 2305.**

How is “Extraordinary Care” Defined?

When a family member provides care for someone with medical or behavioral needs that is beyond what a legally responsible individual would typically perform.



PFCG in ND Today is a Time-Bound, State-Funded Pilot

The ND Legislature has only allocated state funds for a temporary PFCG pilot. Currently, there has not been any legislative activity mandating PFCG in any form.

One-time state funding for a pilot program was approved through Senate Bill 2276 during the 2023 legislative session.



Additional, one-time state funding was appropriated during the 2025 legislative session to **extend the pilot** for another two years with **Senate Bill 2305**.



These bills mean that there is currently no funding for a PFCG pilot to continue after June 30th, 2027. This also means that there is no guarantee that PFCG, in any form, continues after this date.

SECTION 3. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY CAREGIVER SERVICE PILOT PROJECT - PROJECT COORDINATOR. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$2,500,000, or so much of the sum as may be necessary, to the department of health and human services for the purpose of establishing and issuing payments as part of a family caregiver service pilot project, for the biennium beginning July 1, 2023, and ending June 30, 2025. Of this amount, the sum of \$300,000, or so much of the sum as may be necessary, may be used by the department of health and human services for the purpose of hiring up to one full-time equivalent position to serve as the family caregiver service pilot project coordinator, who would be responsible for implementing the pilot project and for establishing a payment portal. Participation in this service pilot project is capped at 120 individuals. The department of health and human services is authorized one full-time equivalent position for this purpose.

SECTION 2. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY PAID CAREGIVER SERVICE PILOT PROJECT. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$7,300,000, or so much of the sum as may be necessary, to the department of health and human services for the purpose of establishing and issuing payments as part of the family paid caregiver service pilot project, for the biennium beginning July 1, 2025, and ending June 30, 2027.



ND Options for PFCG in the Future

Because there is currently no guarantee that PFCG will continue in any form beyond June 30th, 2027, it is important for CDAC to share insight on future options that ND could consider for PFCG.

- ND is currently doing PFCG in a unique way.
 - In other states, PFCG is not usually its own pilot program. It is usually a waiver service modality.
 - This could make it confusing to talk about options that ND could consider for continuing PFCG.
- Today we are going to talk about the differences between PFCG as a state-funded pilot program and PFCG as a waiver service modality, in waivers that use state and federal funds.
 - A separate, state-funded PFCG pilot gives more flexibility and control, but fewer funds.
 - *The ND Legislature would need to appropriate more funds beyond June 30th, 2027.*
 - A PFCG waiver service modality creates more funds (and could serve more people), but more rules and less flexibility and control.
 - *The ND Legislature would to appropriate HHS' entire budget for all programs (including waivers), and HHS would need to submit a waiver application for federal approval.*



CDAC will continue to play an important role - learning about how other states do PFCG and what their experiences are, to share insight with HHS on what options ND could consider.



Paid Family Caregiver as a Modality – Overview of Safeguards



Safeguards for PFCG (1 of 2)

In January, CDAC continued its deep dive on PFCG. Members asked for more information on examples of program safeguards.

- We have talked about how PFCG can help families.
- We also have talked about the risks that PFCG has:
 - Without thoughtful planning and internal controls, its **costs can grow uncontrollably**.
 - Not being able to control costs **creates a risk** that the **PFCG modality** – or even the **entire waiver** – **must end**, meaning no family can benefit from the option.
 - PFCG can also risk **isolating the waiver participant**.



KEY TERM: Paid Family Caregiver (PFCG)



Safeguards for PFCG (2 of 2)

Today, we will talk about some examples of safeguards used in other states' PFCG programs.

- Today, we are going to talk about five examples of common safeguards used to help control PFCG's costs and reduce the risk of isolation.
- We will explain the safeguard and then talk about how it is used in other states. These safeguards are:
 1. Who can be an LRI
 2. What Services LRIs Can Be Paid for
 3. How Many Hours an LRI Can Be Paid for, and When
 4. LRIs Working for a Provider
- Then we will continue doing deep dives on some other states' experiences with PFCG that ND could learn from.



KEY TERM: Legally Responsible Individual / Relative (LRI)



Budgeting for PFCG (1 of 2)

Budgeting for PFCG when it is a waiver service modality is different than when it is a separate pilot program.

- Before we talk about safeguards for PFCG, it is important to understand how states approach budgeting for PFCG.
- In a pilot like ND's, PFCG is the only cost to consider. It can be easier to manage a smaller budget of one distinct program.
 - This pilot is capped, meaning that there is a maximum amount that can be spent on the pilot.
- When **PFCG is a service modality** like in other states' waivers, it is now **just one cost** of an entire waiver program made up of **many different costs and factors that influence the waiver's budget**.
- This means that **states must evaluate PFCG in the same way they evaluate all services and modalities** for the whole waiver.
- This is **necessary because of federal requirements that waivers cost less than institutionalization** and because of **all states' budget processes**.



Budgeting for PFCG (2 of 2)

This is important to understand when talking about PFCG safeguards against uncontrollable costs.

- When developing budgets for waivers, **states are required by federal regulations** to project many things, such as:
 - How many people will use a service
 - How many hours will be used
 - What that service's rates are
 - Who can provide that service
- These questions influence the waiver's budget and total cost.
- When PFCG is a waiver service modality, states must ask these questions while thinking about the entire waiver program's many different costs.
 - This means that **states need to calculate and use limits for PFCG** that will help **make sure the entire waiver stays within budget.**
 - We will talk about examples of these limits next.



PFCG Safeguards | 1. Who Can Be an LRI – Overview

All states are required to define extraordinary care. States must also develop an assessment that determines whether an LRI provides extraordinary care. This is needed to qualify someone as a paid provider for waiver supports.

- To become a paid provider, LRIs must **demonstrate that they provide extraordinary care** that is beyond what would be typical for a child without a disability.
 - We have talked about how other states define and assess for extraordinary care.
- In addition to demonstrating extraordinary care, the **state is responsible for ensuring** that an **LRI becoming a paid provider** is in the **best interests of the waiver participant**.
- These two things must both be true together – **extraordinary care and the best interest of the waiver participant**. This means PFCG is not designed to be an option for every family of children with disabilities receiving waived supports, but **only in select circumstances**.



PFCG Safeguards | 1. Who Can Be an LRI - Example

All states are required to define what extraordinary care is and to develop an assessment that determines whether an LRI provides extraordinary care that qualifies them to become a paid provider for some of that support.

State Case Study Example:

- Oregon only offers PFCG through one service, “Attendant Care Provided by a Legally Responsible Individual” on only one of its waivers, “Children’s Extraordinary Needs Waiver.”
- The waiver includes language about determining when an LRI provides extraordinary care and when paying that LRI for this service is in the waiver participant’s best interests:
 - “The state uses the following criteria to **determine** that the **provision of services** by a [LRI] is **in the best interest of the participant**.
 - Children requiring extraordinary care provided by a [LRI];
 - Who are **assigned to the highest service group** due to their **very high medical or very high behavioral support needs** according to their current, valid functional needs assessment;”

We will talk more about OR later in a separate case study.



LRIs can only be paid for providing services that are like personal care.

- Personal care-like services are a **range of assistance** to help people with disabilities accomplish **activities of daily living** (such as feeding, bathing, dressing).
- “Personal Care” is a Medicaid State Plan service. Many waivers have services that are similar to personal care.
 - These waived services are for those who need more support than what the state plan provides.
- Other services that are like personal care that LRIs can sometimes be paid for include:
 - In-Home Supports
 - Home health aide
 - Homemaker / chore
 - Companion services
- States can control PFCG costs by **limiting what services LRIs can provide**. States that allow PFCG usually limit the option to just a few waiver services.



LRIs can only be paid for providing services that are like personal care.

State Case Study Example:

- **Nebraska's** waivers have two distinct personal care services:
 - "Personal Care"
 - "Personal Care" could be provided by a provider agency or a relative (if self-directing), but not by an LRI.
 - "LRI Personal Care"
 - LRIs can only be paid for providing "LRI Personal Care". LRIs cannot be a paid provider for any other services on these waivers.
- Nebraska's waivers have rules that say "Personal Care" and "LRI Personal Care" can't be provided if other related services are provided on the same day.
 - One such service is habilitation.
- Creating two different personal care services and designating when the services can be provided helps to limit costs of PFCG and reduces the risk of isolation.

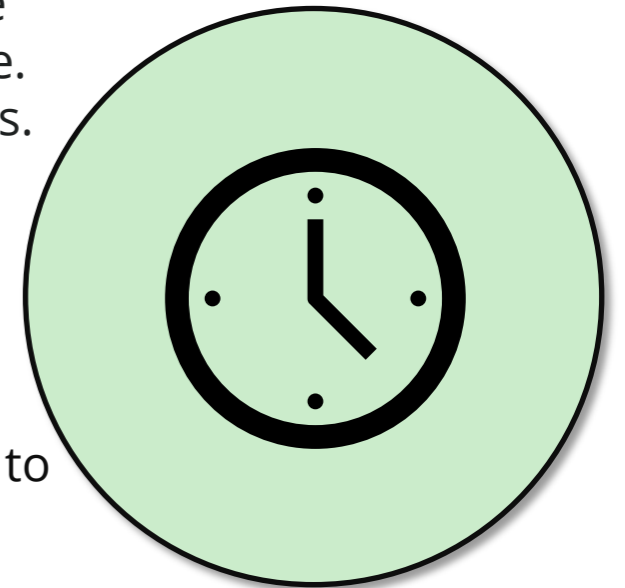


PFCG Safeguards | 3. How Many Hours LRIs Can Be Paid for, and When – Overview

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Many waivers have rules about services that cannot be provided on the same day. States usually have rules about not allowing LRIs to bill for services when other services are provided on the same day.

- States often limit how many hours a service can be provided and how much a service can cost per person. This controls how much the provider can be paid for that service. This is one of the **most important tools** to **control waiver costs**, not just PFCG costs.
- Limits on how many hours an LRI can bill and when helps **differentiate between when LRIs are providers and when LRIs are parents**.
- States have different requirements about how to bill time.
 - Some states use daily payment rates. This can mean only one service is allowed to be billed in one day.
 - Some states use 15-minute rates. Other services could be provided in the same day but not at the same time.
 - This typically requires LRIs to use Electronic Visit Verification (EVV). We have talked about the federal requirements, benefits, and some challenges of EVV.
- **Different billing approaches** and **different limits** on the **total hours** and **cost of services** that LRIs can be paid for can impact when an LRI is able to act as a provider v. as a parent throughout the year.



PFCG Safeguards | 3. How Many Hours LRIs Can Be Paid for, and When – Example

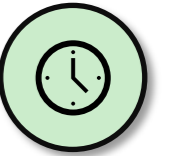
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Many waivers have rules about services that cannot be provided on the same day. States usually have rules about not allowing LRIs to bill for services when other services are provided on the same day.

State Case Study Example:

- **Connecticut's** waivers have a “combined cap of **800** awake hours of support annually” for all services LRIs can provide for their school-aged children (In-Home Supports, Respite, Individualized Day, Personal Supports)
 - Legal guardians – that are not LRIs – can provide up to **2100** awake hours of support for qualifying services annually.
- **Oregon** only allows 20 hours / week for “Attendant Care Provided by a Legally Responsible Individual” on its small waiver specifically for waiver participants who receive services from a paid LRI, “Children’s Extraordinary Needs Waiver”.

We will talk more about some of these states in separate case studies later.



PFCG Safeguards | 4. LRIs Working for a Provider – Overview

LRIs must follow state provider requirements. Some states require LRIs to become an employee of an ID/DD provider.

- To bill for Medicaid services, including waiver supports, all providers must meet a **state's requirements and qualifications**.
- LRIs who are paid to provide personal care-like services must meet the **same state standards as** other individual and **agency providers**.
- Some states monitor LRIs' adherence to provider standards on their own. This can take a lot of time.
- Other times, states require that LRIs **be employed by a provider agency**. The state monitors the agency. The agency monitors its DSPs and LRIs.
 - This method means LRIs are subject to the same training and reporting requirements as other DSPs. There may be more resources for the agencies than the state to ensure these standards are met by all individual LRIs.
- States may also require LRIs to have **specific certifications or licenses** to be a paid provider for certain services.



PFCG Safeguards | 4. LRIs Working for a Provider – Example

LRIs must follow state provider requirements. Some states require LRIs to become an employee of an ID/DD provider.

State Case Study Example:

- **Oregon** requires that to become a paid provider, LRIs must become a certified Direct Support Professional (DSP) and be employed by an OR provider agency.
 - LRIs must be employed by a provider and get all DSP-required trainings.
 - These trainings can also distinguish between requirements when acting as a provider v. acting as a parent.
- **Minnesota's** LRIs must enroll as individual providers with the state.
 - Every LRI must have an individual provider number.
 - This allows for better monitoring to ensure that billable hours stay within monthly limits and are not happening at the same time as other services.
- **Arizona** requires LRIs to be licensed by the AZ Board of Nursing and to be employed by a certified Home Health Agency to be a paid provider of nursing related services for their waiver participating children.

We will talk more about OR and MN later.



Paid Family Caregiver: Guiding Principle, Part 2



CDAC's Guiding Principles on Paid Family Caregiving (Part 1)

INITIAL DRAFT, NOT FINALIZED – CDAC WILL REVIEW THESE DRAFT GUIDING PRINCIPLES AND PROPOSE REVISIONS BEFORE VOTING IN UPCOMING CDAC MEETINGS.

DRAFT

CDAC Feedback / Recommendation	A&M Notes
<p>PFCG is an important program for families. It recognizes the additional responsibilities faced by parents who provide extraordinary care for their children with disabilities. This recognizes the economic impact of having a child with a disability and the level of care being provided.</p>	<p>We recognize that PFCG grew out of workforce shortages during the pandemic, and workforce turnover challenges since the pandemic. Today, some states require evidence that families could not find or sustain providers.</p>
<p>PFCG helps families have more consistency with the caregivers who support their children. Many parents of high-need children are skilled at providing complex care that is life-sustaining for the child.</p>	<p>It is also important for states to have standards that ensure parents participating in this program can meet their children's complex needs successfully.</p>
<p>Families who have participated in ND's PFCG pilot program have frequently shared about the benefits they've experienced from PFCG. They have shared that this allows them to provide consistent care for their children.</p>	<p>The testimony from the state's families has been valuable in advocating PFCG programs.</p>
<p>It is important to use an assessment approach that is age appropriate for the waiver participant. Questions may look different for younger children compared to older children.</p>	<p>Part of ND's waiver modernization work is enhancing assessment tools, including considering age appropriateness.</p>

Terms:

Paid Family Caregiving (PFCG)
 Legally Responsible Individual (LRI)
 North Dakota (ND)

Cross-Disability Waiver (CDW)
 Fraud, Waste, and Abuse (FWA)
 Centers for Medicare & Medicaid
 Studies (CMS)



CDAC's Guiding Principles on Paid Family Caregiver (Part 2)

INITIAL DRAFT, NOT FINALIZED – CDAC WILL REVIEW THESE DRAFT GUIDING PRINCIPLES AND PROPOSE REVISIONS BEFORE VOTING IN UPCOMING CDAC MEETINGS.

DRAFT

CDAC Feedback / Recommendation	A&M Notes
<p>Most families are not seeking PFCG to commit fraud, waste, and abuse (FWA). CMS cares about the steps states are taking to prevent FWA because of the rare instances when it does happen. Families have shared that Medicaid rules are confusing and that it can be difficult to understand how to follow PFCG rules.</p>	<p>Because CMS cares about how states are preventing FWA, it is important to focus on the safeguards and limits for the program that will keep it sustainable for families. Safeguards and enhanced educational materials for families can help clarify program rules to reduce the risk of unintentional waste.</p>
<p>PFCG can also present risks to the sustainability of home and community-based waivers and to the well-being of waiver participants, if not well-managed. Many states have seen an uncontrollable growth in costs due to PFCG that resulted in cancelling or significantly reducing the program. Many states require non-family members to be involved in service delivery to reduce the risk of isolation.</p>	<p>PFCG as a waiver service modality is different than as a pilot. When a modality, PFCG is subject to more limitations that keep the PFCG and the entire waiver sustainable. Layering multiple protections is a best practice, multiple safeguards can better help mitigate PFCG's risks.</p>
<p>Understanding federal and state requirements to create safeguards around PFCG's risks, CDAC believes that ND should continue to invest in sustainable opportunities to make PFCG a successful program.</p>	<p>Whether an LRI should become a paid provider for certain services depends on whether that is in the best interest of the waiver participant and the waiver participant's budget for authorized services.</p>

Terms:

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CDAC's Guiding Principles on Paid Family Caregiver (Part 3)

INITIAL DRAFT, NOT FINALIZED – CDAC WILL REVIEW THESE DRAFT GUIDING PRINCIPLES AND PROPOSE REVISIONS BEFORE VOTING IN UPCOMING CDAC MEETINGS.

DRAFT

CDAC Feedback / Recommendation	A&M Notes
<p>ND's PFCG pilot is set to expire on June 30th, 2027. This could be disruptive for families who are currently involved in the pilot.</p> <p>In the upcoming legislative session, CDAC recommends that the ND Legislature:</p> <ul style="list-style-type: none">• Fund the PFCG state pilot for another biennium.• Allocate funds for a PFCG waiver service modality in the Cross-Disability Waiver.• Allocate funds for a PFCG waiver service modality in the other existing children's waivers (IID/DD, ASD, MF).	<p>Extending ND's PFCG pilot depends on the availability of state dollars. A state pilot allows for flexibility in the PFCG program but doesn't secure a federal match.</p> <p>The Governor's Office will release its proposed budget for the 2027-2029 biennium this year (2026). HHS must align its budget – including PFCG options – to the priorities set by the Governor's Office. The ND Legislature will then decide how to appropriate funds for the 2027-2029 biennium next year (2027).</p> <p>Given the well-documented examples of PFCG risks in other states (uncontrollable costs and participant isolation), we recommend starting small with PFCG as a waiver service modality with overlapping safeguards only in the capped CDW. Starting small in this way allows ND to study the impacts of PFCG and use lessons learned to potentially expand it in the CDW and possibly other waivers in more favorable budget years.</p>

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Paid Family Caregiver as a Modality – CDAC Discussion on ND Safeguards



CDAC Feedback on PFCG (1 of 3)

Thank you to everyone who completed the quick survey about PFCG after our January meeting!

We asked two questions about CDAC's thoughts on PFCG. Here are some things CDAC members shared:

1. PFCG options can have risks. Which risk worries you the most? Why does it worry you? How could it affect families and the CDW?

- Limited funding allocated (if a pilot) that could mean PFCG may not be available for every family who would qualify.
- Fraud, waste, and abuse that impacts the rest of the waiver's sustainability.
- Challenges in understanding the program's rules and requirements for qualifying by demonstrating extraordinary care.
- What happens if the LRI is the only provider and if they can't provide services (get sick, etc.).
- People taking advantage of a vulnerable system, dollars being used in the wrong way.
- Isolating the child from other service providers and community settings, especially in rural areas.



CDAC Feedback on PFCG (2 of 3)

Thank you to everyone who completed the quick survey about PFCG after our January meeting!

We asked two questions about CDAC's thoughts on PFCG. Here are some things CDAC members shared:

2. What ideas do you have to help North Dakota address these risks?

- Other waiver components – case managers, etc. – could help reduce waiver participant and family isolation.
- Not relying on one safeguard alone.
- Conducting regular, non-punitive check-ins and home visits and with DDPMs.
- Clearly explaining extraordinary care v. other parenting responsibilities to make the assessment and qualification decisions more understandable.
- Carefully designing at the beginning so the program doesn't end later.
- Educational materials and making sure program rules and assessment tools are family friendly.
- Using EVV to document service hours v. parent time and ensure good stewardship of funds.

CDAC Feedback on PFCG (3 of 3)

We have had great discussions today about options for making PFCG sustainable in a children's waiver – thank you for the engagement!

To close out our productive conversations today, let's do a Menti survey to document how we're feeling.

This survey will ask you to **rate** how helpful you think each PFCG safeguard might be. You can rate each safeguard on a sliding scale:

- Not Helpful At All
- Somewhat Not Helpful
- Not Helpful or Unhelpful
- Somewhat Helpful
- Very Helpful

The safeguards for paid family caregiver that we talked about today are:

1. Who Can Be a Legally Responsible Individual
2. What Services Legally Responsible Individuals Can Be Paid for
3. How Many Hours a Legally Responsible Individual Can Be Paid for, and When
4. Legally Responsible Individuals Working for a Provider



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Appendix – Paid Family Caregiver Continued

Paid Family Caregiver as a Modality – Specific State Case Studies



Oregon | PFCG as its Own Waiver (Case Study #1)

Oregon has created a separate waiver for its PFCG program, the "Children's Extraordinary Needs Waiver."



Population: 155 kids per year, ages 0-17. This waiver is limited to only children who need extraordinary care from an LRI.

- *"Children who do not require legally responsible individuals to provide extraordinary care may receive the other services provided in this waiver through ODDS' other 1915 (c) waivers."*



Covered Services: LRIs can only be paid providers for one service on the waiver, "Attendant Care Provided by a Legally Responsible Individual." This service is limited to 20 hours per week. This service is not offered on any other waiver. No other waivers allow for LRIs to be paid providers of any other service.



Assessment: "The state uses the following criteria to determine that the provision of services by a legally responsible individual is in the best interest of the participant.

- Children requiring extraordinary care provided by a legally responsible individual;
- Who are assigned to the highest service group due to their very high medical or very high behavioral support needs according to their current, valid functional needs assessment;"
- (Extraordinary care defined as - **care exceeding the range of activities** that a legally responsible individual **would ordinarily perform** in the household on behalf of a **person without a disability or chronic illness of the same age**, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.)"

Oregon | The Path Forward on PFCG (Case Study #1)

Oregon's Children's Extraordinary Needs Waiver started small and may grow as costs are better understood.

- In July 2023 OR passed a law that required ODDS to request a separate waiver that would allow for parents who provide extraordinary care to their children with disabilities to be paid for providing attendant care services.
- After submitting the waiver application and getting approval from CMS, this waiver became available in July 2024.
- At the time the waiver started, 1,557 kids were eligible, but the program only had enough money to serve 155 kids.
- OR requires that LRIs be employed by a provider agency in the state before becoming a paid provider. There are other state trainings that LRIs must take before becoming a paid provider.
- **Starting out small** in challenging budget cycles **can allow the program to grow** as outcomes and needs are better understood and more resources may be dedicated to the program in future budget cycles. This helps **reduce the risk of** all families **losing access** to this option if it started too large and had to be **cut or cancelled**.

In the Department's Own Words, on Next Steps:

"We understand the strong need for this program and its benefit for children. Being on the waitlist may be frustrating, angering and disappointing. We know many families on the waitlist were strong advocates for this program. The program exists because of your perseverance and hard work. Thank you for your advocacy."

After the program runs for a year, we will know the true cost per child. We may be able to increase the number of children served. Right now, our budget of \$3 million per year can't cover all eligible children. To serve more children, the Legislature would need to approve more funding."

Colorado | Challenges with PFCG (Case Study #2)

CO utilizes PFCG as a waiver service modality on **two** of its waivers for certain services.



Population: The Children's Extensive Support Waiver serves ~4,000-6,500k kids aged 0-17 with a DD. The Children's Habilitation Residential Waiver serves ~400 kids aged 0-20 kids with a DD and / or an SED.



Covered Services: Both services allow LRIs to be paid providers for the Community Connector service. This is "provided one-on-one to deliver instruction for documented severe behavior problems that are being demonstrated by the waiver participant while in the community." LRIs can be paid for ~520 hours annually for providing this service.

- *"When using substituted judgment, the legally responsible individual must actively try to understand the individual's desires and preferences, even if they are not explicitly stated, to make decisions that align with their best interests and avoid making decisions based on their own personal biases or convenience."*



Assessment: "Extraordinary care is determined by assessing whether an individual who is the same age without a disability needs the requested level of care, the activity is one that a parent **would not normally provide as part of a normal household routine** and the activity is one that a parent is not legally responsible to provide and **is necessary to assure the health and welfare of the participant and to avoid institutionalization**. During the service planning process the case manager uses the **Ages and Stages questionnaire** to help determine **what tasks are typical for the members' age and what is not typical** for their age. The Ages & Stages document developed by Iowa State University provides **guidance for the typical child's developmental milestones**. **Care and tasks that are not typical of their age would be considered extraordinary care."**

Colorado | The Path Forward on PFCG (Case Study #2)

Colorado has seen an explosion in the utilization of PFCG modalities, especially after investing in increasing the benefits offered to families through the program. This has created a fiscal crisis for the program.

- Colorado, like many other states, is facing a challenging budget cycle.
 - The state faced an expected \$850M shortfall for the state's entire budget in the next fiscal year (that starts in July of this year).
 - CO Medicaid spending grew 9% over the last decade. PFCG program-related costs rose 44% in the last 5 years.
- As of January 1st, 2026, CO's waivers reduced the rates that LRIs would be paid for providing Community Connector to create some of the necessary savings. The state is also working to enhance its extraordinary care assessment and requiring LRIs to take provider trainings.
- CO is another cautionary example of how PFCG programs are at risk of being cut or cancelled if the program starts out too large, or doesn't carefully follow federal guidance, and the costs threaten the sustainability of entire waiver programs. Facing cuts to benefits is a significant experience for families.

In the State's Own Words, on Next Steps:

The state's Medicaid officials said family caregivers, "due to conflicting department guidance," were paid a higher rate than they should have been and that the state is changing the rules to "clarify" its policy. LRIs were paid the same rates as non-relative staff that come into a participant's home to provide services, instead of being paid at the host home rate.

"There's two levers on Medicaid. One is how many people you cover and two is what you cover. There have been a number of benefits that have been added in recent years and some of those aren't sustainable over time." – Governor Jared Polis.

Idaho | The Initiation of PFCG (Case Study #3)

Idaho began allowing limited instances of payments to LRIs during the pandemic and extended this authority following the pandemic.

- During the COVID-19 pandemic, Idaho allowed payment of LRIs through Family Personal Care Services (FPCS)
- Idaho received positive feedback from stakeholders regarding this pandemic flexibility
- The State then extended the authority through March 1, 2025, with the goal of addressing the direct care workforce shortage, and in response to stakeholder feedback

Overview of Family Personal Care Services Benefit

- ❖ Based on the State Plan service personal care services
- ❖ Both children and adults are eligible for this service, meaning LRIs could include individuals such as parents or spouses
- ❖ Under this service, a personal assistant provides program participants with assistance with ADLs and IADLs such as bathing, grooming, dressing, toileting, meal prep, shopping, and laundry



Idaho | Challenges with PFCG (Case Study #3)

Idaho experienced significant challenges related to paid family caregiving, including rapid growth and lack of funding, and has since requested CMS approval to rescind this authority.

Challenges of Paid Family Caregiving

- The Department initially raised concerns that they had limited resources to oversee the program.
- Program costs rapidly expanded, nearly quadrupling from 2022 to 2024 (totaling almost \$8 million).
- Department leadership also raised concerns with fraud, stating that they were “aware of many inappropriate attempts to increase the number of authorized hours by families.”
- Idaho met with stakeholders in early 2024 to discuss potential changes to the program moving forward to address observed challenges.



Request for Early Termination of LRI Payment Authority

- Citing continued significant growth in costs, Idaho submitted a request in December 2024 to terminate FPCS authority prior to the scheduled expiration (request to end January 31, 2025)
- Idaho also recently passed a law which requires legislative approval of waivers, meaning the legislature would need to be involved in restarting the authority via waiver request (1115 demonstration)
- The Department is working with the legislature to identify potential paths forward, including additional safeguards and resources for oversight

Idaho | Better Understanding Program Concerns (Case Study #3)

Excerpt from CDAC 1.0

DRAFT

In a letter sent to the Idaho legislature in November 2024, Idaho's Director of the Department of Health and Welfare flagged concerns:

- **Rapidly expanding enrollment:** A 75% enrollment increase since 2023
- **Uncontrolled costs:** Expenditures at 90% above the \$4.2million budgeted
- **Evidence of fraud**, including identified instances of:
 - Sharing ways to manipulate the state's medical assessment "to maximize authorized hours of service" that Medicaid pays;
 - Sharing starting pay rates for provider agencies that led some program participants to switch agencies "exclusively to maximize the household's income;"
 - Performing other activities, like driving for a ride share company, while participants claimed to care for kids; and
 - Billing twice or three times for multiple kids at the same time, even when the program only lets providers care for one person at a time.

In the Department's Own Words, on Concerns of Fraud:

"While expenditures are based on authorized hours of services that are approved by clinical staff, we are aware of many inappropriate attempts to increase the number of authorized hours by families... As stewards of taxpayer dollars and in our role in overseeing this entitlement program serving vulnerable children and adults, we cannot continue to operate a program with such high rates of suspected and known fraud, waste and abuse and potential health and safety issues for participants."

Idaho | The Path Forward on Paid Family Caregiving (Case Study #3)

Excerpt from CDAC 1.0

DRAFT

Idaho's Director of the Department of Health and Welfare also offered a potential path forward in his letter to the legislature.

- Idaho's Department of Health and Welfare has expressed hope that the program is merely paused until the Legislature can approve a program extension with additional funding / safeguards
- In the interim, Idaho has committed to working with families to get coverage for the hours of PCS needed, and has cited a 10% growth in the direct care workforce over the past two years
- Idaho DHW has advised the legislature to consider "additional statutory provisions outlining the safeguards the legislature envisions to protect scarce taxpayer dollars and ensure services are direct to those truly in need."

As of January 2026, Idaho has continued to run into significant challenges with Medicaid budget sustainability. The Governor's Office budget proposal has outlined a path to cut \$45M in Medicaid, which includes removing all home and community based (HCBS) services. This means all HCBS waivers in the state are at risk.

In the Department's Own Words, on Next Steps:

"It is our hope that program advocates and participants can work with the Legislature to determine which safeguards are appropriate to resolve the troubling issues we are seeing on the ground, recognizing the need for additional staff capacity if labor-intensive safeguards are selected"

Minnesota | Basic Structure of Paid Family Caregiving in HCBS (Case Study #4)

Excerpt from CDAC 1.0

DRAFT

LRI in MN may provide specified services under the Minnesota Developmental Disabilities HCBS Waiver Program.



Population: The MN DD Waiver provides home and community-based services to eligible individuals with ID or DD ages 0 or older who meet an ICF/IID level of care.



Covered Services: LRIs may be paid for the provision of extended community first services and supports (CFSS). CFSS replaced extended personal care assistance in October 2024. CFSS covers services including:

- Activities of daily living such as eating, bathing, grooming and transferring;
- Health-related tasks;
- Instrumental activities of daily living, such as shopping, cooking, laundry and assistance with self-administered medications
- Observation and redirection of behavior



Assessment: The MnCHOICES assessment distinguishes ordinary care from extraordinary care using age-appropriate milestones. Public guidance is typically available online; however, MN is currently in the process of transitioning from a legacy platform.



Minnesota | Safeguards for Paid Family Caregiving in HCBS (Case Study #4)

Excerpt from CDAC 1.0

DRAFT

Minnesota has established guardrails for the paid family caregiving option to protect participant health and welfare and help support responsible usage of funding.

Provider Requirements

- LRIs must meet general provider standards including training and keeping of daily records.
- LRIs must pass a background check as specified in Minnesota Statutes.
- LRI must enroll as an individual CFSS provider with the Minnesota Health Care Programs.

Payment Assurances

- Participants must verify the workers' time documentation.
- Every support worker is required to have an individual provider number; this facilitates reporting to monitor that the billable hours are within the monthly limits and that they do not duplicate other claims.
- The department conducts quality assurance and compliance inquiries.
- MMIS sends letters to participants, providers, and case managers to notify them of potential overuse.

Best Interest of the Individual

- The assessment and support planning process is used to determine the participant's needs, including fit of LRI and amount of CFSS support needed.



Minnesota | Approach to Determining Age-Appropriate Dependencies (Case Study #4)

Excerpt from CDAC 1.0

DRAFT

Minnesota's assessment for age-appropriate assistance is publicly available online; see excerpt below.

Note: Minnesota's assessment scores dependencies across a variety of ADLs. If the assistance the child needs typically is provided by an adult for a child of that age, that assistance is not considered a dependency.

DRESSING, LTC SD

SCORE	CATEGORY	COMMENTS	R1	R2
00	Independent/age-appropriate dependency.		FIELD 38	
01	Intermittent supervision or reminders. May need physical assistance with fasteners, shoes or laying out clothes.		<input type="checkbox"/>	<input type="checkbox"/>
*02	Constant supervision, but no physical assistance. (Age appropriate for 0-48 months)		<input type="checkbox"/>	<input type="checkbox"/>
*03	Physical assistance or presence of another at all times, but child physically is able to participate. (Age appropriate for 0-36 months)		DEPENDENCY?	
*04	Totally dependent on another for all dressing. Child physically is unable to participate. (Age appropriate for 0-12 months)		<input type="checkbox"/>	<input type="checkbox"/>

GROOMING, LTC SD

SCORE	CATEGORY	COMMENTS	R1	R2
00	Independent/age-appropriate dependency.		FIELD 39	
01	Intermittent supervision or reminders.		<input type="checkbox"/>	<input type="checkbox"/>
*02	Help of another to complete task, but child physically is able to participate. (Age appropriate for 0-48 months)		<input type="checkbox"/>	<input type="checkbox"/>
*03	Totally dependent for all grooming needs. Child physically is unable to participate. (Age appropriate for 0-24 months)		DEPENDENCY?	



Ohio | Approach to PFCG for Children on HCBS Waivers (Case Study #6)

Excerpt from CDAC 1.0

DRAFT

Ohio allows LRIs to provide limited services for qualifying individuals via HCBS waiver.



Population: Ohio allows for LRIs to provide services in specified instances for both adults and children enrolled in the Ohio Individual Options Waiver (comprehensive waiver) and the Ohio Level One Waiver (family supports waiver). These waivers provide services for individuals with ID or DD age 0+ who meet ICF level of care.



Covered Services: LRIs may be paid for the provision of the following waiver services:

- Provider-managed Homemaker (LO waiver only)
- Participant-directed homemaker / personal care
- Personal care (IO waiver only)
- Waiver nursing (IO waiver only)



LRI Requirements: Services must meet extraordinary care requirements, as determined through Ohio's Extraordinary Care Instrument

- Assistance needs must exceed the range of activities a parent of a minor child would ordinarily perform on behalf of an individual without a disability or chronic illness at the same age
- This tool uses a ratings scale to indicate level of support needed to meet each need
- Ratings are 1-independent, 2-sometimes requires physical/verbal support, 3-always requires physical/verbal support
- Individuals must score a 3 in at least 3 of the listed needs



Ohio | Safeguards for PFCG in HCBS (Case Study #6)

Ohio has established guardrails for the paid family caregiving option to protect participant health and welfare and help support responsible usage of funding

Provider Requirements

- LRIs must be **employed through an agency** or employed by a self-directing waiver participant
- Services must be needed from the parent **while a willing & able direct care worker/provider is sought**
- LRIs must meet provider certification requirements for the service(s) provided

Payment Assurances

- Routine agency billing procedures apply
- Maximum number of hours that may be authorized is 40 hours per week

Best Interest of the Individual

- The health and safety of the individual must be assured through the parent of a minor child or spouse serving as a direct care worker.
- Increased care coordination oversight when the LRI allowance is implemented to ensure the best interests of the individual are met.

Ohio | Approach to Determining Age-Appropriate Dependencies, Part 1 (Case Study #6)

Excerpt from CDAC 1.0

DRAFT

- Ohio utilizes the Ohio Extraordinary Care Instrument, a publicly available tool posted online.
- The tool assesses level of assistance required across a number of needs such as bathing, feeding assistance, and toileting.
- Individuals must be scored as “always requiring assistance” in at least three areas to qualify.
- See definitions of assistance, below. More information about the scoring form and areas of need are included on the following slide.

Rating Scale	
Independent or N/A (0)	Requires Assistive Device (1)
<i>This should be scored if the individual does not have the need, the individual can meet the need without any assistance from another person, and/or if the individual's age falls within the range indicated.</i>	<i>This should be scored if the individual requires an assistive device to meet the need and the individual can use the assistive device on their own (without hands-on support and/or verbal direction from another person). Assistive devices may include wheelchairs, communication devices or apps, lifts, or walkers.</i>
Sometimes Requires Physical/Verbal Support (2)	Always Requires Physical/Verbal Support (3)
<i>This should be scored if the individual requires hands-on assistance and/or verbal direction from another person at least once daily, but not every time, to meet the need. This could include hands-on support and/or verbal direction from another person to use an assistive device.</i>	<i>This should be scored if the individual requires hands-on assistance and/or verbal direction from another person each time the need must be met. This could include hands-on support and/or verbal direction from another person to use an assistive device.</i>
<i>If the need must be met only once daily and the individual requires assistance each time, then that need should be scored as Always Requires Physical/Verbal Support.</i>	



Ohio | Approach to Determining Age-Appropriate Dependencies, Part 2 (Case Study #6)

Excerpt from CDAC 1.0

DRAFT

Ohio Extraordinary Care Instrument			
Individual's Name:	<input type="text"/>	Assessor's Name:	<input type="text"/>
Date of Birth:	<input type="text"/>	Date Completed:	<input type="text"/>
Instructions			
Use the scale below to assign a value that indicates the greatest level of support needed by the individual to meet each need or prevent unsafe behavior. Please note that there is an age range presumed as not applicable for some needs. For those needs, score as a (0). Only one value may be assigned for each need.			
Refer to <i>Ohio Extraordinary Care Instrument — Definitions</i> for additional instructions.			
Rating Scale			
Independent or N/A (0)		Requires Assistive Device (1)	
Sometimes Requires Physical/Verbal Support (2)		Always Requires Physical/Verbal Support (3)	
Need	Score	Need	Score
Turning/Positioning <i>Enter (0) for ages birth - 9 months</i>		Ambulation <i>Enter (0) for ages birth - 18 months</i>	
Transfer Assistance <i>Enter (0) for ages birth - 18 months</i>		Behavioral Health <i>Enter (0) for ages 0-4 years</i>	
Bathing <i>Enter (0) for ages 0-5 years</i>		Oral Hygiene <i>Enter (0) for ages 0-5 years</i>	
Dressing <i>Enter (0) for ages 0-5 years</i>		Toileting <i>Enter (0) for ages 0-5 years</i>	
Hair, Nail, and/or Skin Care <i>Enter (0) for ages 0-10 years</i>		Communication <i>Enter (0) for ages 0-16 years</i>	
Basic Purchases <i>Enter (0) for ages 0-16 years</i>		Basic Meal Preparation <i>Enter (0) for ages 0-16 years</i>	
Basic Household Chores <i>Enter (0) for ages 0-16 years</i>		Laundry <i>Enter (0) for ages 0-16 years</i>	
Accessing Transportation <i>Enter (0) for ages 0-16 years</i>		Managing Personal Funds <i>Enter (0) for ages 0-16 years</i>	
Cognition <i>Enter (0) for ages 0-16 years</i>		Medication Administration <i>Enter (0) for ages 0-18 years</i>	
Feeding Assistance		Seizure Protocol	
Respiratory/Pulmonary Care		Catheter or Ostomy Care	
Ohio Extraordinary Care Instrument Results			
If the individual scores a (3) in <i>at least three</i> of the items above, then the individual meets the standard of extraordinary care as defined by OAC 5160-XX-XX. A score of (2) or more in the Behavioral Health section indicates that referral to additional behavioral health resources should be considered by the assessor.			
Is The Behavioral Health Score At Least (2) Or Higher?		Are There At Least Three Ratings Of (3) For The Items Listed Above?	
Is The Individual Being Considered For Additional Behavioral Health Resources?		Does The Individual Meet The Standard Of Extraordinary Care As Defined By OAC 5160-XX-XX?	

Needs	
Turning/Positioning <i>Turning the individual's body and/or changing their body's position in a bed or seating to prevent bed sores, improve body function, and alleviate discomfort.</i>	Ambulation <i>Individual's ability to use their body to relocate to another desired location by walking, crawling, scooting, and/or using an assistive device. Assistive devices could include wheelchairs, canes, or lifts.</i>
Transfer Assistance <i>Physical assistance is required from at least one person to transfer the individual between surfaces. Examples include transferring the individual into their wheelchair, transferring the individual using a lift, or transferring the individual into their stander.</i>	Behavioral Health <i>Strategies are needed to prevent or mitigate injury due to unsafe behaviors such as verbal aggression, hitting, kicking, biting, property destruction, wandering or leaving caregiver supervision, sleep disturbances, fire setting, unsafe smoking, inappropriate sexual behavior, and/or cruelty to animals. This list is not exhaustive and may include any behavioral health concerns that pose a safety risk to the individual and/or others.</i>
Bathing <i>Completing all steps necessary to clean the individual's body in a shower, bathtub, and/or bed bath as their body requires to maintain their health and safety. Steps may include using and rinsing off personal hygiene products, choosing a safe water temperature, and preventing water overflow.</i>	Oral Hygiene <i>Completing all steps necessary to routinely care for the individual's teeth and gums as directed by their dental provider. Steps may include brushing teeth with toothpaste and a traditional toothbrush and/or using alternative means to clean teeth and gums such as xylitol wipes. This includes care for additional dental needs as directed by the individual's dental provider such as dentures, braces, or flossing.</i>



National Landscape of Paid Family Caregiving in ID/DD HCBS Waivers (1 of 2)

Excerpt from CDAC 1.0

DRAFT

A&M conducted a national scan of states allowing LRI to provide services and receive payment in 1915 (c) waiver programs for adults and children with ID/DD. There are 30 total states¹ currently offering the LRI flexibility.

State	Service Model	Service(s)
Alabama	Self-Directed and Traditional	Personal Care (and Personal Care Transportation) and Self-Directed Adult Companion
Alaska	Traditional	Court appointed services; In-Home Supports (for minors); Supported Living (for adults)
California	Self-Directed and Traditional	Community Living Arrangement Services
Colorado	Traditional and Self-Directed	Community Connector Service; Personal Care and Consumer Directed Attendant Support Services
Connecticut	Self-Directed and Traditional	Individualized Home Support, Respite, Individualized Day, Personal Supports and/or Senior Supports
Iowa	Self-Directed and Traditional	Most Comprehensive Waiver Services
Kansas	Self-Directed and Traditional	Personal Care
Kentucky	Self-Directed and Traditional	Personal Care or similar services
Louisiana	Self-Directed and Traditional	Any Family Support Waiver Services, All Comprehensive Waiver Services
Maryland	Self-Directed and Traditional	Personal Supports, Respite, Community Development, Personal Supports, Intensive Individual Support Services
Minnesota	Self-Directed and Traditional	Extended Community First Services and Supports
Montana	Self-Directed and Traditional	All Comprehensive Waiver Services
Nebraska	Self-Directed and Traditional	LRI Personal Care
Nevada	Traditional	Residential Support Services and Non-Medical Transportation (only to adult waiver participants)
New Hampshire	Self-Directed and Traditional	In Home Residential Habilitation
New Mexico	Self-Directed and Traditional	All Family Support Waiver Services
New York	Self-Directed and Traditional	Residential Habilitation in Family Care Homes; Community Habilitation; Habilitative Supports; Respite
Ohio	Self-Directed and Traditional	Homemaker/Personal Care and Waiver Nursing Services
Oklahoma	Self-Directed and Traditional	Habilitation Training Specialist services

1. Not all of these states' waivers serve youth 0-20, some only allow LRIs to be paid if the waiver participant is 21+.



National Landscape of Paid Family Caregiving in ID/DD HCBS Waivers (2 of 2)

Excerpt from CDAC 1.0

DRAFT

A&M conducted a national scan of states allowing LRI to provide services and receive payment in 1915 (c) waiver programs for adults and children with ID/DD. There are 30 total states currently offering the LRI flexibility.

State	Service Model	Service(s)
Oregon	Traditional	Attendant Care Provided by an LRI
Pennsylvania	Self-Directed and Traditional	In-Home and Community Support and Life Sharing
South Carolina	Self-Directed	Attendant Care
South Dakota	Self-Directed and Traditional	Personal Attendant Care, Respite Care
Tennessee	Self-Directed and Traditional	Personal Assistance
Texas	Traditional	Supported Employment, Employment Assistance, Residential Habilitation, Respite (age restricted)
Utah	Self-Directed and Traditional	Supported Living, Attendant Care
Virginia	Self-Directed and Traditional	Personal Assistance
West Virginia	Self-Directed	All Comprehensive Waiver Services
Wisconsin	Self-Directed and Traditional	Personal Care, Supportive Home Care, Employment Supports, Respite, or Skilled Nursing
Wyoming	Traditional	Personal Care



1. Not all of these states' waivers serve youth 0-20, some only allow LRIs to be paid if the waiver participant is 21+.

Peer State Approaches to Paid Family Caregiving in HCBS I/DD and ASD Waivers

Excerpt from CDAC 1.0

DRAFT

A&M reviewed ND's peers to identify which states allow LRIs to provide services and receive payment in 1915 (c) waivers.

State	Waiver	Target Pop.	Age	Payments to LRIs Allowed?
ID	Adult DD Waiver	ASD, ID, DD	Adult (18+)	No (Previously allowed for children and adults via State Plan)
IA	HCBS ID Waiver	ID	Lifespan (0+)	Yes, most comprehensive waiver services
KS	HCBS I/DD Waiver	ASD, ID, DD	Ages 5+	Yes, personal care only
KS	Autism Waiver	ASD	Youth (0-5)	No
MN	DD Waiver	ID, DD	Lifespan (0+)	Yes, extended community first services and supports
MT	HCBS Waiver for DD	ID, DD	Lifespan (0+)	Yes, residential, day, employment, personal and companion
NE	Comprehensive DD	ASD, ID, DD	Lifespan (0+)	Yes, personal care
NE	Family Supports Waiver	ASD, ID, DD	Youth (0-21)	Yes, personal care
SD	CHOICES Waiver	ID, DD	Lifespan (0+)	No (allowed in adult waiver only)
SD	Family Support Waiver	ID, DD	Lifespan (0+)	No (allowed in adult waiver only)
WY	Comprehensive Waiver	TBI, ID, DD	Lifespan (0+, unless TBI 21+)	Yes, personal care only
WY	Supports Waiver	TBI, ID, DD	Lifespan (0+, unless TBI 21+)	Yes, personal care only



South Dakota | Paid Family Caregiving for Adult Waiver Services Only

Excerpt from CDAC 1.0

DRAFT

South Dakota does not currently allow for paid family caregiving in children's waivers but does offer this option for some adults.



- Population:** SD only allows for LRIs to provide services in specified instances for adults only – not children
- The two waivers which cover individuals across the lifespan - Family Support 360, and CHOICES, - do not allow LRIs to provide services. This means there are no options for LRIs to provider services for children in SD currently
 - The Assistive Daily Living Services waiver provides services for individuals 65+, or 18+ who meet a nursing facility level of care. This waiver allows LRIs to provide some services



Covered Services: In the adult waiver only, LRIs may be paid for the provision of the following services:
Personal attendant care; Respite care



- LRI Requirements:** LRIs must
- Be employed by a provider agency
 - Meet all the qualifications and training requirements for a personal attendant or respite care worker
 - Maintain and submit EVV Records for hours paid (monitored by provider agency, with waiver manager annual random sample)



- Department Safeguards:** DHS enacts additional requirements for LRIs including:
- At least annual face-to-face visits, including opportunities for private participant visits with the case manager
 - At least annual physical examination
 - Quarterly reviews of health, safety, and welfare status of the client
 - Opportunity for unannounced visits
 - Quarterly reviews of expenditures

Oklahoma | Approach to Expanding Paid Family Caregiving to LRIs (1 of 2)

Excerpt from CDAC 1.0

DRAFT

A&M supported the State of Oklahoma to utilize learnings from the COVID-19 public health emergency flexibilities and plan for the expansion of paid family caregiving in the I/DD waiver to legally responsible individuals.

Paid Family Caregivers post PHE

<u>Stakeholder Perspectives</u>	<u>What is Working: To be Built Upon</u>	<u>Opportunities</u>
State I/DD System	<ul style="list-style-type: none"> • Families play a critical role in providing care/supports • Interest and efforts to grow self-directed services (SDS) and expand role of paid family caregivers • Experience with service caps for in-home family caregivers has worked well • Strong commitment to identifying opportunities to support individuals' flexibility and leverage the learnings through the pandemic 	<ul style="list-style-type: none"> • Identify services and safeguards to expand the role of paid family caregivers for minor children • Develop provider capacity building/workforce investment strategies to ensure access to blend/balance of family caregivers and providers for individuals
Families	<ul style="list-style-type: none"> • Families know their loved ones best and will consistently be there throughout their lives • Families fill critical roles in providing care and services • Families are trusted and available resources • Families value circles of support and relationships for their loved ones 	<ul style="list-style-type: none"> • Find ways to balance the role of paid family caregivers while also broadening/building relationships and personal networks beyond family • Create a model where reliance is not solely on family. 'Family as long-term support plan is not a long-term plan'. • Identify ways to address the high demand and financial impact on families. Families have lost wages, jobs, and insurance to care for family members. • Continue focus on provider capacity building efforts 'to address keeping pace with current need and waitlist reduction efforts
Providers	<ul style="list-style-type: none"> • Families are identified as a workforce recruitment strategy 	



Oklahoma | Approach to Expanding Paid Family Caregiving to LRIs (2 of 2)

Excerpt from CDAC 1.0

DRAFT

Oklahoma is currently working to stand up a new payment option for Legally Responsible Individuals (LRIs).

- Oklahoma recently added the authority for LRI's to serve as paid family caregivers in their waiver
- The State has received CMS approval to add the option to the waiver and is currently working on operationalizing it
- Oklahoma is currently fine-tuning an assessment process for participants who wish to utilize a LRI as a paid family caregiving
- The assessment process is focused on identifying assistance needs for ADLs and IADLs and comparing them to typical age expected responses to identify extraordinary needs
- The state team is considering how best to measure needs throughout a child's life
- Oklahoma is also working to identify low-barrier options for participants, including keeping the assessment as short as possible and using virtual modalities

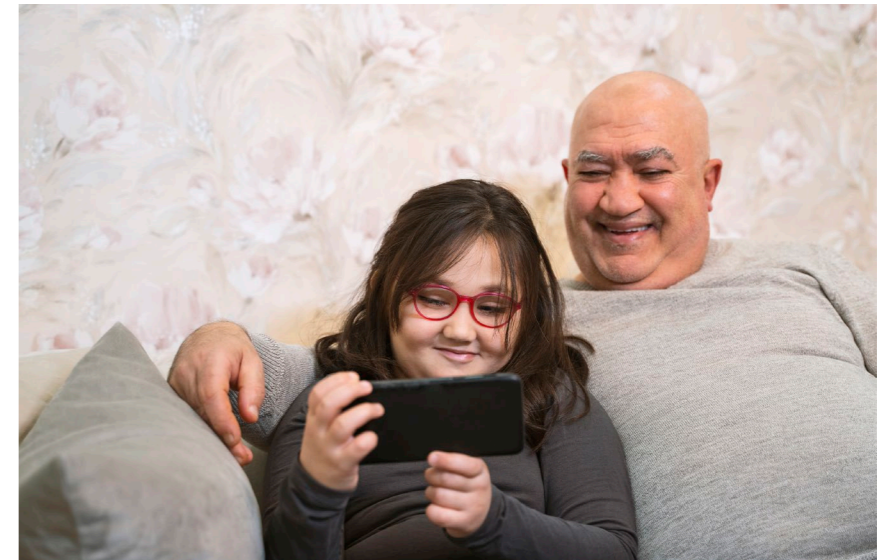
Key Takeaway: The assessment is an important tool to help target funds to the intended population. OK is working to balance ease of use with rigor to ensure approachability for families while also protecting OK from potential misuse of funds.

Appendix – North Dakota's Paid Family Caregiver

Overview of Paid Family Caregiving in ND Today (2 of 2)

North Dakota allows relatives who are not legal guardians to provide certain services in some waivers, with strict requirements.

- ND requires that relatives complete background checks, complete mandated reporter training, and meet Electronic Visit Verification (EVV) policies as needed.
- The Financial Management Services vendor or the licensed DD agency verifies that the relative is qualified to provide the specified service.
- Other safeguards differ by waiver and by service:
 - In some of ND's waivers and some services across the waivers, relatives must not live with the participant and must not be legal guardians and must also be over the age of 18.
 - In ND's IID/DD Waiver's in-home supports and respite services only, relatives can live in the same home as the waiver participant.



Future State of Paid-Family Caregiving in the CDW

CDAC 1.0 has recommended that Paid Family Caregiving will be an option on the new waiver. There would be extra protections.

- Paid family caregiver would no longer be a standalone service like it is in the pilot program, but a way to receive certain waiver services.
- Under federal law, this is option is only allowed for what is deemed extraordinary care.
- ND would need to show people meet this definition to qualify for this service delivery option.
- There will also be protections in place:
 - Making sure it is in the best interest of the participant.
 - Health and welfare of the waiver participant – such home visit requirements.



ND's Paid Family Caregiver Pilot Program

Family Paid Caregiver Pilot Program

Family members who provide extraordinary care to either a child or adult enrolled in one of the following Medicaid 1915(c) waivers may receive payments from the state:

- Autism Spectrum Disorder Birth Through 17 Waiver.
- Children with Medically Fragile Needs Home and Community-Based Services Waiver.
- Children's Hospice Home and Community-Based Services Waiver.
- Traditional Individual with Intellectual Disabilities and Developmental Disabilities Home and Community-Based Services Waiver.

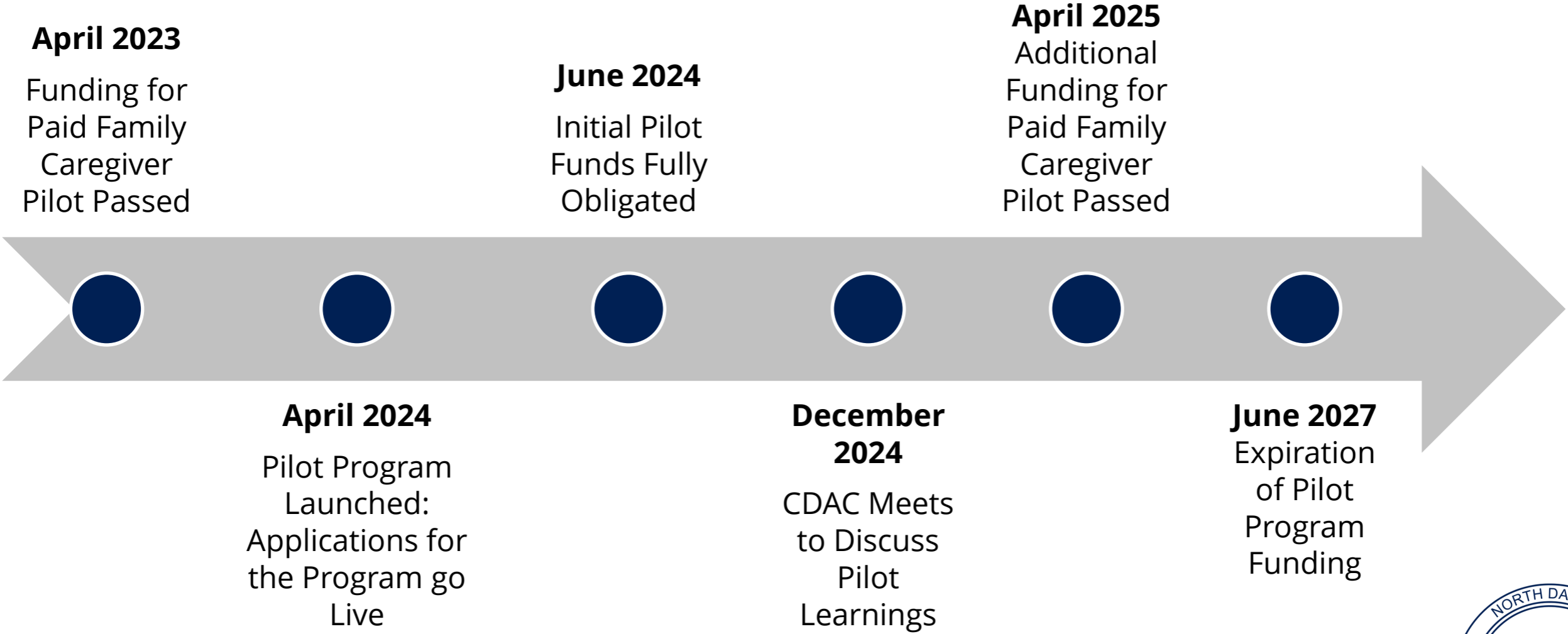
State funding for the pilot program was approved with the passage of Senate Bill 2276 during the 2023 legislative session.

How is "Extraordinary Care" Defined?

When a family member provides care for someone with medical or behavioral needs that is beyond what a legally responsible individual would typically perform.

Recommendation: Families on CDAC stressed the importance of offering an option for Paid Family Caregiver in the new waiver. Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children's Waiver. Consider parity between self-directed, and paid family caregiver rates. **Work with the CDAC to inform potential options for Paid Family Caregiver on the Cross Disability Children's Waiver.**

Paid Family Caregiver Pilot High-Level Timeline



North Dakota's Paid Family Caregiver Pilot: Overview of Applications and Funds

Excerpt from CDAC 1.0

DRAFT

Pilot Program Start: 4/1/24 (Data as of 12/3/2024)

Submitted applications: 444

Waiver*:

Traditional IID/DD HCBS Waiver:
342 (Total enrolled: 6106) = **5.6%**

Autism Waiver:
40 (Total enrolled: 345) = **12%**

Medically Fragile Waiver:
24 (Total enrolled: 26) = **92%**

Children's Hospice Waiver:
0 (Total enrolled: 0) = **0%**

Unknown: 38

**Based on the waiver selected in the application by the person applying.*

Age:

0-17: **76%**

18+: **24%**

Approved Applications: 50*

Waiver:

Traditional IID/DD HCBS Waiver: 96%

Autism Waiver: 2%

Medically Fragile Waiver: 2%

Age:

0-17: **62%**

18+: **38%**

**This includes 50 paid caregivers (49 applicants – 1 applicant/2 different households).*

Daily Rate:

Age: 0-17—**\$77.45/day**

Annual average of \$20,137

Age: 18+ = **\$154.89/day**

Annual average of \$40,271

Pending Applications: 17

Waiver:

Traditional IID/DD HCBS Waiver: 16

Autism Waiver: 1

Age:

0-17: **71%**

18+: **29%**

Additional applications reviewed once funding from appeals is able to be released.

Waitlist: 182

Total Funds Appropriated for Direct Services:
\$2,200,000

Total Funds Authorized:
\$1,252,245.67

Held for Appeals:
\$609,131.25

Held for Pending Applications: \$338,623.0818



North Dakota's Paid Family Caregiver Pilot: Denials And Appeals

Pilot Program Start: 4/1/24 (Data as of 12/3/2024)

Denied: 172

Primary Denial Reason:

Applicant not enrolled in a 1915c waiver: **62**

Assessed needs did not meet extraordinary care criteria: **97**

Support needs are otherwise compensated: **4**

Program funds not available: **0**

Application incomplete: **0**

Family Caregiver did not meet program requirements: **9**

Revoked: **2**

Withdrawn: **17**

Closed: **4**



Appeals: 21*

\$256,741.55 currently held in appeals

\$352,389.70 currently held in appeal rights timelines

**Anyone who has been denied for an appealable reason would have appeal rights where the funding is held until 30 days after the decision date (unless appealed further, then the funding continues to be held)*

Cost of appeals from the Attorney General (AG) and Office of Administrative Hearings (OAH)*:

\$35,614.93

Costs are through October 2024.

**Funds to cover these costs do not come from the funding allocated through Senate Bill 2276. These costs are covered using HHS funding.*



North Dakota's Paid Family Caregiver Pilot: Implementation Costs and Portal

Excerpt from CDAC 1.0

DRAFT

Pilot Program Start: 4/1/24 (Data as of 12/3/2024)

Implementation costs from Senate Bill 2276:

IT – Portal: \$73,401.03*

**Does not include IT maintenance & operations for portal.*

FTE/Salary Costs: \$81,072.30

Portal Functionality

Within the Family Paid Caregiver Portal, an applicant can:

- Submit an application
 - Extraordinary Care Assessment and Child Abuse and Neglect Background Inquiry documents can be uploaded for review.
- View status of submitted application(s)
- View authorization(s)
- Request payments
- View payment status



Guiding Framework for Waiver Service and Modality Design

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. As we think about what services and modalities should be in the CDW, we will want to think about their impact across all life domains.



Daily Life & Employment

What a person does as part of everyday life—school, employment, volunteering, communication, routines, life skills.



Community Living

Where and how someone lives – housing and living options, community access, transportation, home adaptations and modifications.



Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness and nutrition.



Safety & Security

Staying safe and secure – emergencies, well-being, guardianship options, legal rights and issues.



Social & Spirituality

Building friendships and relationships, leisure activities, personal networks, and faith community.



Advocacy & Engagement

Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.

Source: *Exploring the Life Domains – LifeCourse Nexus* (lifecoursetools.com)

