



North Dakota
Cross Disability
Advisory Council

DEC 11, 2024

**CROSS-DISABILITY
ADVISORY COUNCIL**

ROLL CALL



MINUTES



FUTURE MEETING DATES

- **Apr 11th - Thursday**
- **May 9th - Thursday**

9:30am to 4:00pm

Please plan to come in person for the May meeting!





AGENDA

- I. Action Items and Points of Business
- II. Recap of CDAC's Progress
- III. Basics of Paid Family Caregiving
- IV. National Perspectives on Family Caregiving
- V. Learnings from North Dakota's Pilot
- VI. Public Comment

Recapping the Progress of CDAC's Work


Plain Language Purpose


The Department of Health and Human Services (HHS) is planning to create a new cross-disability children's waiver. The Cross-Disability Advisory Council (CDAC) was created by law to help by sharing ideas. These ideas will help HHS develop the new waiver.


This initially includes:


1. How people can apply to the new waiver, once created.
2. What supports people need.
3. What supports from case management are helpful.
4. What quality looks like.

Core Areas for Advisory Input (as defined in statute)

Access 
How people can apply to the waiver

Services 
What supports people need

Case Management 
What supports from CM are helpful?

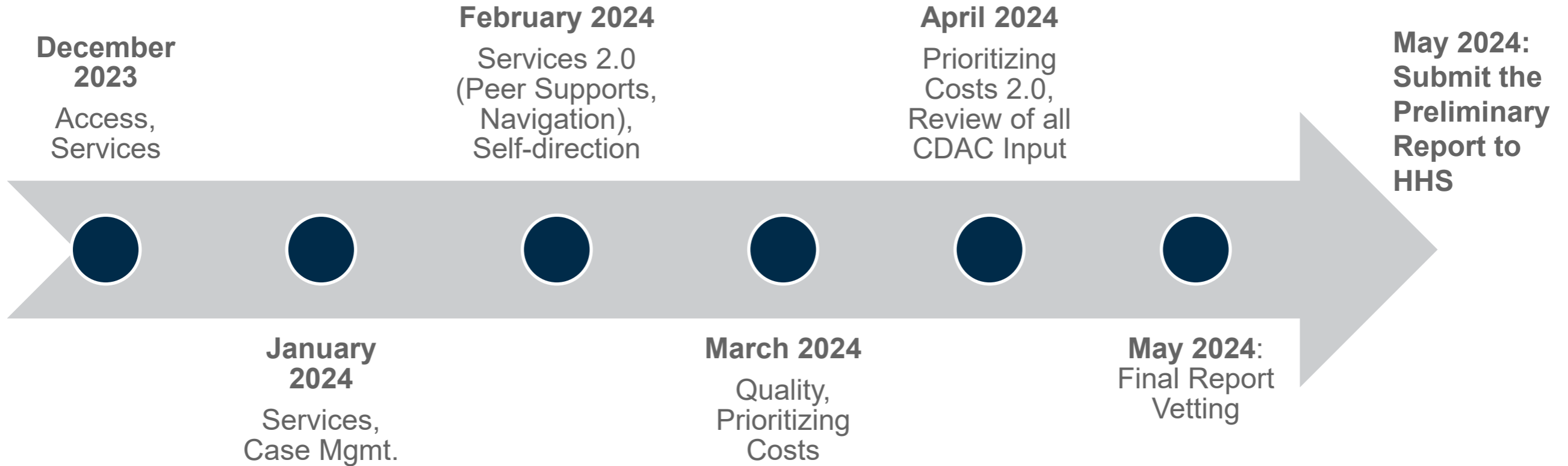
Quality 
What does quality look like?



CDAC members are the experts on their own lives and will provide advice and feedback to HHS based on what they have experienced, what is working well, and what could be better in the future. It is the State's responsibility to use CDAC feedback to define specific technical elements of the waiver such as level of care (LOC).

CDAC's Work to Guide the Design a New Waiver Cross-Disability Waiver (Initial Phase Complete)

CDAC met monthly from December 2023 – May 2024 to provide input regarding the design of the new cross-disability waiver



✓ *September 2024: Present CDAC report to legislative committee*

High-Level Roadmap for Waiver Innovation: Mapping North Dakota's Path Forward

Laying the Groundwork for Successful Change

- Before implementing major system changes, ND will first work on achieving “quick wins” in the current state.
- These actions will help improve the system’s functionality families immediately.
- ND will continue to collaborate with stakeholders who will advise and guide HHS actions.

Please see the Roadmap section for more details on the timeline, including quick wins

Objective #1: Implement New Cross-Disability Children’s Waiver

- Outline service array that includes community-based interventions to help families and their children.
- Build strong support for service navigation, person-centered planning, and self-direction.
- Combine existing ASD/Medically Fragile Waiver (MFW)/IDD level of care for children during the waiver launch to ensure continuity.
- For children aged 3-5: Include expanded eligibility to address the “cliff” that occurs when children turn 3.

Objective #2: Refine LOC Across Waivers, Including New Cross Disability Waiver (CDW) and Existing IID/DD Waiver

- Create modernized level of care for comprehensive IDD waiver to match AAIDD, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition DSM-5, and ICD-11 definitions.
- For children ages 5+: Use the new IDD LOC to modernize who qualifies for both the comprehensive IDD waiver and the Cross-Disability Children’s Waiver.
- *Critical note: significant testing will be necessary to ensure there are no unintended effects of the LOC changes; parallel testing will be needed.*

Excerpts from Senate Bill No.2276

Duties:

The cross-disability advisory council shall participate with and **provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver**, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, **and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers.**

Selection Criteria:

The cross-disability advisory council consists of up to fifteen voting members. **A majority of the council members must be family members of individuals with a disability or must be individuals with a disability themselves who receive Medicaid home and community-based services.** The remaining council members must be appointed based on their professional subject matter expertise or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities relevant to the Medicaid home and community-based services.

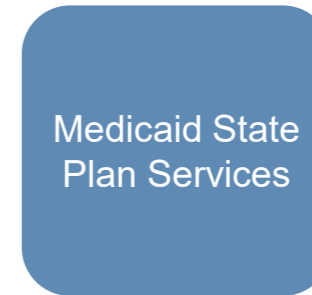
Upon department's request, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

CDAC's Role in Shaping North Dakota's Medicaid Supports and Services

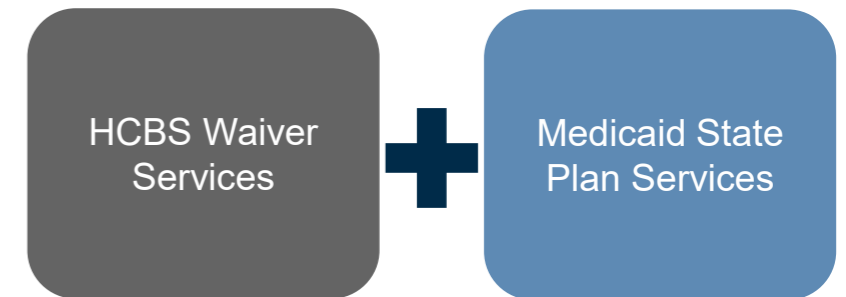
CDAC Scope

Medicaid State Plan	HCBS Waivers - AKA 1915(c) Waivers
<p>Medicaid is a program that helps pay for medical services for qualifying low-income adults, children, pregnant women, older adults, and people with disabilities.</p> <p>Medicaid also provides initial and periodic health check-ups for children from birth until age 20 years old through a program called EPSDT.</p> <p>Examples of services:</p> <ul style="list-style-type: none"> • Pediatrician visits • Ambulance • Hospitalization • Dental care • Prescription drugs • Therapies 	<p>Waivers are a type of Medicaid program targeted to specific populations of people based on demonstrated needs/types of disability. Waivers provide services that help people meet their needs in a home and community setting instead of institutional settings.</p> <p>HCBS waivers have a different qualification process than general State Plan Medicaid.</p> <p>Examples of services:</p> <ul style="list-style-type: none"> • Supported employment • Independent habilitation • Environmental adaptation • Equipment and supplies

Individuals eligible for ND Medicaid can access:



Individuals eligible for ND HCBS Waivers can access:




Cross-Disability Waiver Services

Examining CDAC's Current and Future Role *(Excerpt from Legislative Report)*

Progress Update on CDAC's Legislative Duties

CDAC's work to date has focused on advising HHS regarding design for a new cross-disability children's waiver. Remaining areas for future input include level of care design/reform, and paid family caregiver services (currently in pilot)

Area for Input	CDAC Status Update	Anticipated Future CDAC Role
Cross-disability children's waiver	CDAC has compiled detailed recommendations to advise the State on key principles in the design of a potential new cross-disability children's waiver.	CDAC will serve as a key input into the continued planning and implementation of the new waiver, if legislative funding to support the new program is passed.
Level of care design / reform	Level of care work was not funded as part of the first CDAC term. This complex work needs dedicated funding to support activities like testing and coordination with subject matter experts.	Level of care is anticipated to be the next focus area for CDAC, if HHS receives legislative funding for the parallel testing and subject matter expertise needed. CDAC would serve a critical role by offering perspectives on how level of care impacts families in need of support.
Paid family caregiver 	HHS is currently piloting paid family caregiver services and collecting further information on this potential new waiver service	CDAC will review learnings from the paid family caregiver pilot (scheduled for Dec. 11 th meeting) and provide input into the design of this service, including its inclusion on the potential new cross-disability children's waiver

→ Paid Family Caregiver is the topic of today's meeting

The Basics of Paid Family Caregiving

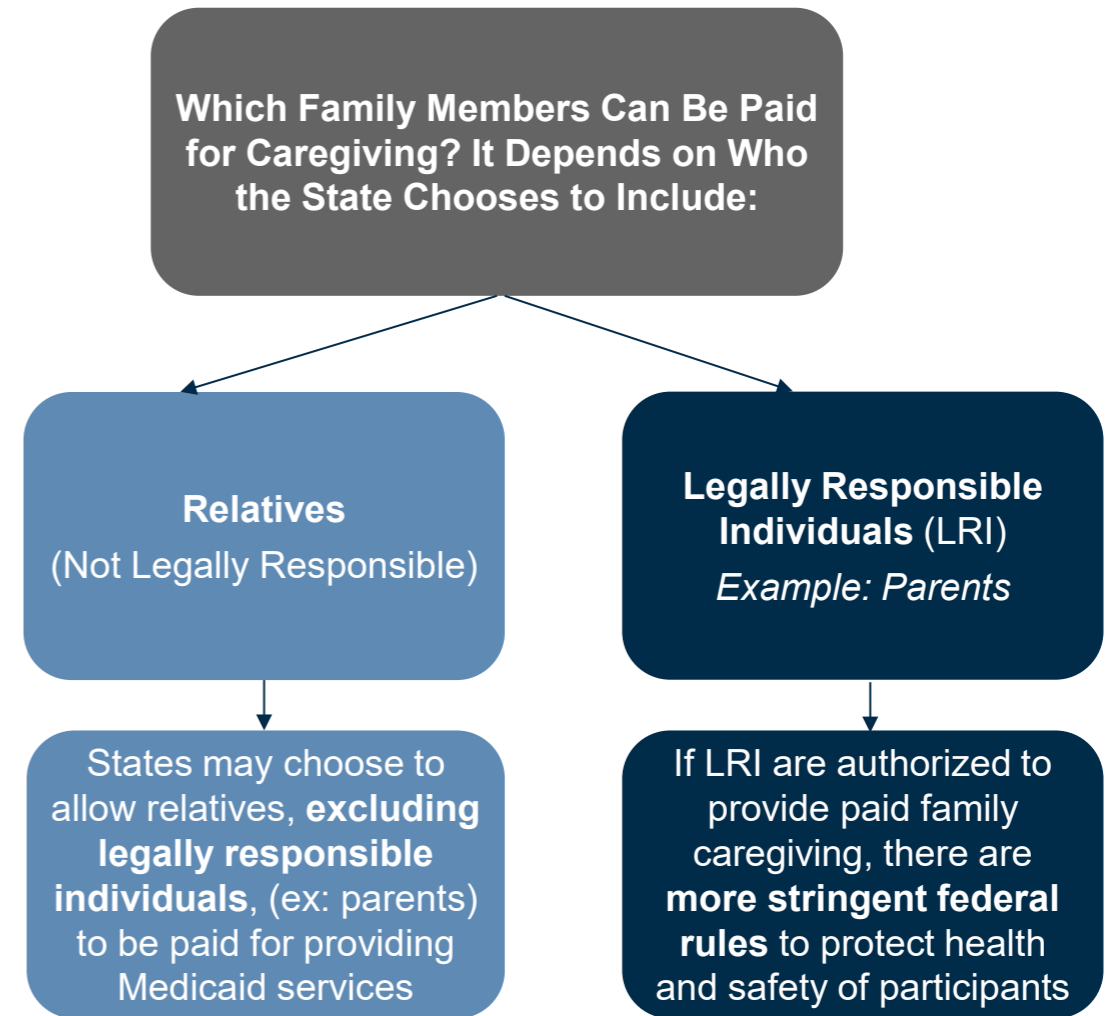
CDAC Recommendations: Paid Family Caregiver

The CDAC looks forward to learning from the Paid Family Caregiver pilot program and will make additional recommendations about how this should work in the new waiver at that time

#	CDAC Recommendations	A&M Response
S.14	The new children’s cross-disability waiver should include options for paid family caregiver.	Agree
S.15	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.	Agree. This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.
S.16	Work with the CDAC to inform the Paid Family Caregiver option for the Cross Disability Children’s Waiver.	Agree

Key Elements of Paid Family Caregiving

- Paid family caregiving 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)
- See the appendix for more information about the different federal options available to states



★ **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.

Brainstorming Activity: The Opportunities and Risks of Paid Family Caregiving

Paid family caregiving presents both potential advantages and challenges compared to traditional service provision

Activity #1: Identifying Opportunity

States have chosen to pursue paid family caregiving for a variety of reasons. What are some benefits you think about with this option?



Menti.com code:
1592 3227

Activity #2: Recognizing Risk

Some states have chosen not to allow, or started and then later stopped allowing, paid family caregiving. What are some concerns you think about with this option?

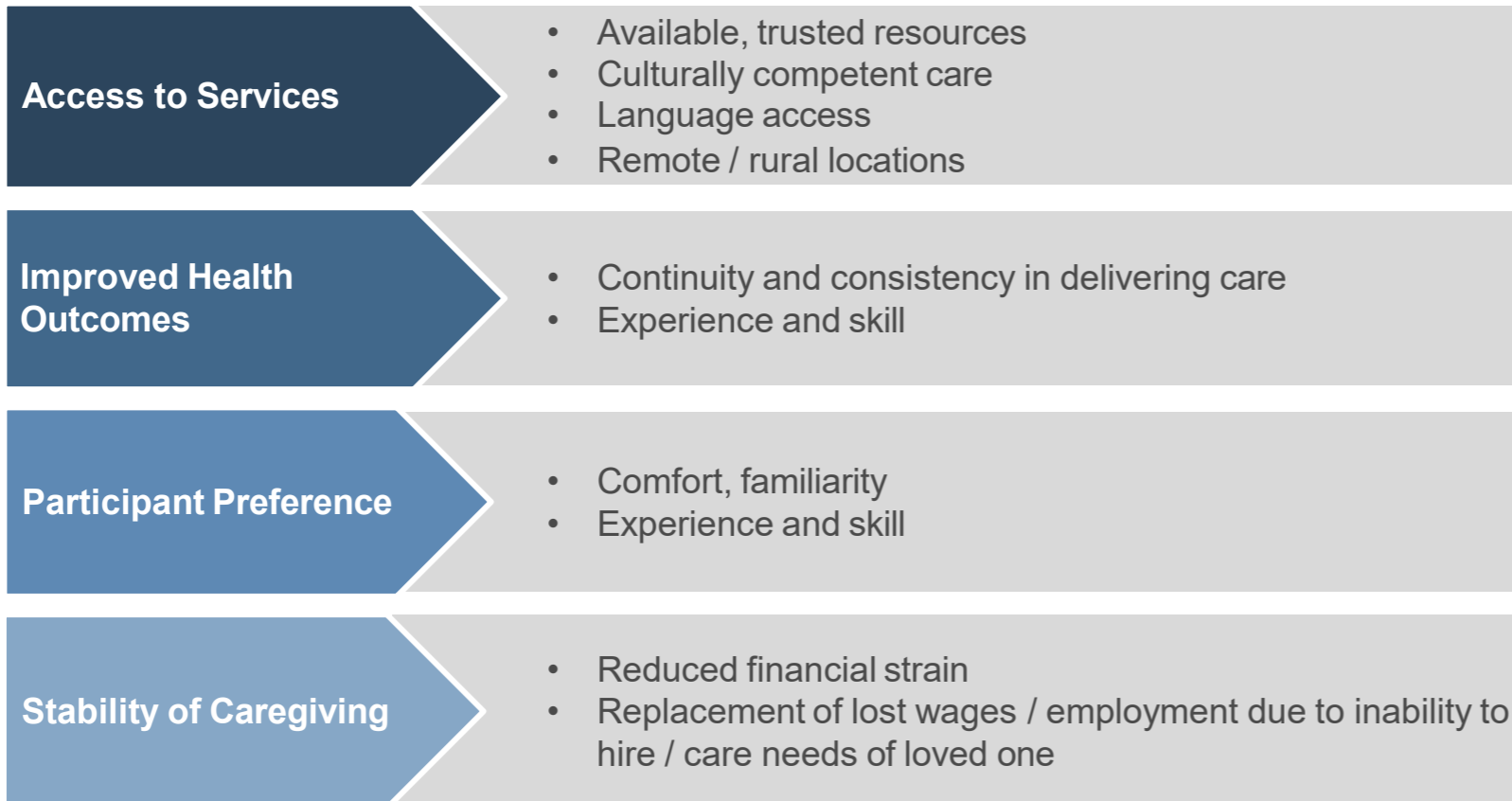


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NOTE: We are focused broadly on Paid Family Caregiving here; not the specific elements of the ND pilot

Paid Family Caregivers: 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 Caregivers: 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 and oversight to ensure safety, well being and choice

Definitions / Criteria

- Extraordinary vs. ordinary care
- Legally responsible individuals (state laws)

Scope / Limit

- Waiver services
- Type of family caregivers
- Service limits / requirements

Choice / Best Interests

- Integration
- Supported decision making
- Conflict of interest / financial dependency

Oversight / Monitoring

- 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



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

North Dakota 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 also not right for everyone – a core function of HHS is to help ensure this is the best fit for individuals receiving services

National Landscape of Paid Family Caregiving

Understanding the Federal Requirements Around Paid Family Caregiving

States must meet several federal requirements to authorize paid family caregiving, especially in the case of LRI

- **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 (ex: personal care)



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.

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"

Brainstorming Activity: How Can HHS Help Families Be Successful in This New Role?

Paid family caregiving asks families to operate in a brand-new role as an official paid service provider

Activity: Navigating the Responsibilities of Paid Family Caregiving

Many family members have played a caregiving role for years. Becoming a paid family caregiver is a distinct change to this role, because you are now considered a provider of Medicaid services. As such, paid family caregivers need to follow federal and state regulations, including completing new administrative duties such as time tracking for specific caregiving tasks.

ND wants to help set up families for success navigating these new responsibilities. What kind of guidance or communication from HHS would be helpful to you as a paid family caregiver?

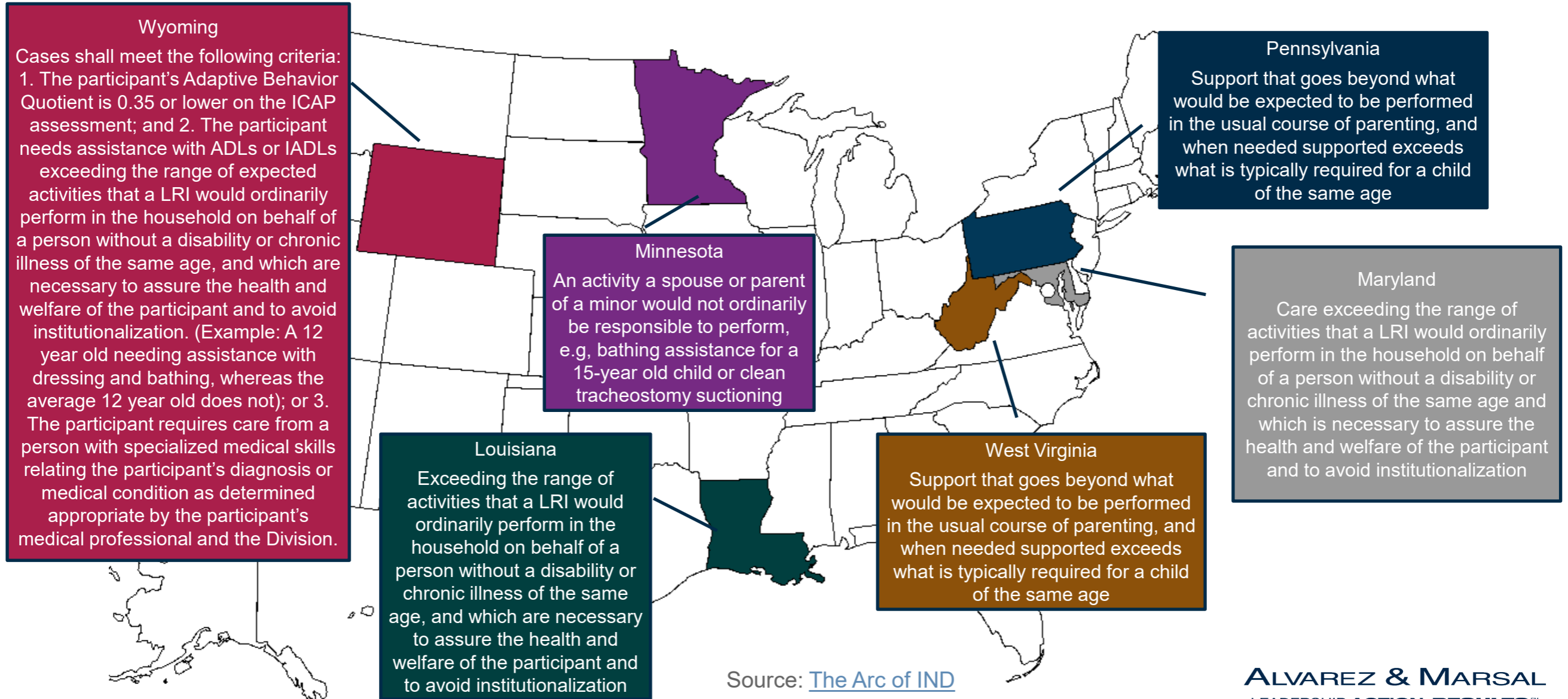


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NOTE: We are focused broadly on Paid Family Caregiving here; not the specific elements of the ND pilot

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.



Source: [The Arc of IND](#)

State Case Study: Oklahoma's Approach to Expanding Paid Family Caregiving to LRIs (1 of 2)

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 	

State Case Study: Oklahoma's Approach to Expanding Paid Family Caregiving to LRIs (2 of 2)

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.

State Case Study: Minnesota's Approach to Determining Age-Appropriate Dependencies

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

Minnesota's assessment scores dependencies across a variety of ADL's, including dressing, grooming, mobility, and positioning. 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?	

MOBILITY/WALKING, LTC SD

SCORE	CATEGORY	COMMENTS	R1	R2
00	Independent/age-appropriate dependency. Ambulatory without device.		FIELD 44	
01	Can mobilize with the assist of a device, but does not need personal assistance.		<input type="checkbox"/>	<input type="checkbox"/>
*02	Intermittent physical assistance of another. (Age appropriate for 0-24 months) (This does not include supervision for safety of a child under age 5.)		DEPENDENCY?	
*03	Needs constant physical assistance of another. Includes child who remains bedfast. (Age appropriate for 0-12 months)		<input type="checkbox"/>	<input type="checkbox"/>

POSITIONING (BED MOBILITY), LTC SD

SCORE	CATEGORY	COMMENTS	R1	R2
00	Independent/age-appropriate dependency.		FIELD 42	
01	Needs occasional assistance from another person or device.		<input type="checkbox"/>	<input type="checkbox"/>
*02	Needs intermittent assistance of another on a daily basis to change position. Child physically is able to participate.		DEPENDENCY?	
*03	Needs total assistance in turning and positioning. Child physically is unable to participate. (Age appropriate for 0-9 months)		<input type="checkbox"/>	<input type="checkbox"/>

State Case Study: Maryland's Approach to Ensuring Participant Choice/Best Interest

Maryland's application for Paid Family Caregiving asks participants to attest to why this option supports an individual's best interests, including independence and community integration.

Section 2: Family as Staff

I will be paying the following relatives (natural or adoptive parent, stepparent or sibling) as a member(s) of my staff:

Name of Person	Relationship to Me	Job They Will Have	Rate of Pay	Hours Per Week

IMPORTANT:

1 - Relatives can only have jobs for the following DDA Waiver services:

- Personal Supports (PS),
- Respite Care Services,
- Ongoing Job Supports,
- Support Broker (SB) Services,
- Community Development Services (CDS),
- Nursing Support Services (NSS),
- Supported Living (SL), or
- Transportation

2 - Examples of a "Job They Will Have" include CDS Staff, PS Staff, Transportation, and Job Coach.

Please describe why hiring the person(s) listed above is in your best interest?

Developmental Disabilities Administration Find Out More: 844-253-8694 | dda.health.maryland.gov Revised: 01.31.2022
Page 2 Issued: 11.09.2021 Version: 2

Please describe how:

Having a family member as your staff will help you to be more integrated in your community?

Having a family member as your staff will increase your independence?

Having a family member as your staff will expand your circle of support or natural supports?

Any special circumstances (such as location of home, time of day supports are needed, etc.):

Attestation:

- ✓ This is my choice and is supported by my team.
- ✓ My team and I will review and discuss if the staff I have chosen are meeting my needs at least once a year or when needed.
- ✓ There is a lack of qualified staff to meet my needs.
- ✓ My family member provides no more than 40-hours per week of the service unless otherwise authorized by the DDA.
- ✓ My family member has unique abilities to meet my needs such as knowledge of who I am, ability to communicate with me, availability, connect me to the community, special skills or training.
- ✓ My family member will help increase my independence and community participation, integration and belonging.
- ✓ I have a Participant Agreement that identifies people, beyond family members, who will support me in making my own decision.
- ✓ My relative(s) agree to implement my PCP and provide services as required by the federal and State rules, laws and regulations of this program.

Note: It is important for the participant and team to make plans for when the family is no longer available.

Signature

By signing below, I, the participant and, if applicable, my legal guardian or designated representative, hereby acknowledge that I have received and agree to this document. I am aware that if I have any questions, I should contact my Coordinator of Community Services (CCS).

Participant Name: _____

Participant Signature: _____ Date: _____

Legal Guardian Name (if any): _____ Relationship to Participant: _____

Legal Guardian Signature: _____ Date: _____

Designated Representative Name (if any): _____ Relationship to Participant: _____

Designated Representative Signature: _____ Date: _____

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North Dakota's Approach to Paid Family Caregiving

Paid Family Caregiver

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 the Paid Family Caregiver option for the Cross Disability Children’s Waiver.

Note:

This topic is on the agenda for the next CDAC meeting, scheduled for December 11, 2025. There will time available for public comments.

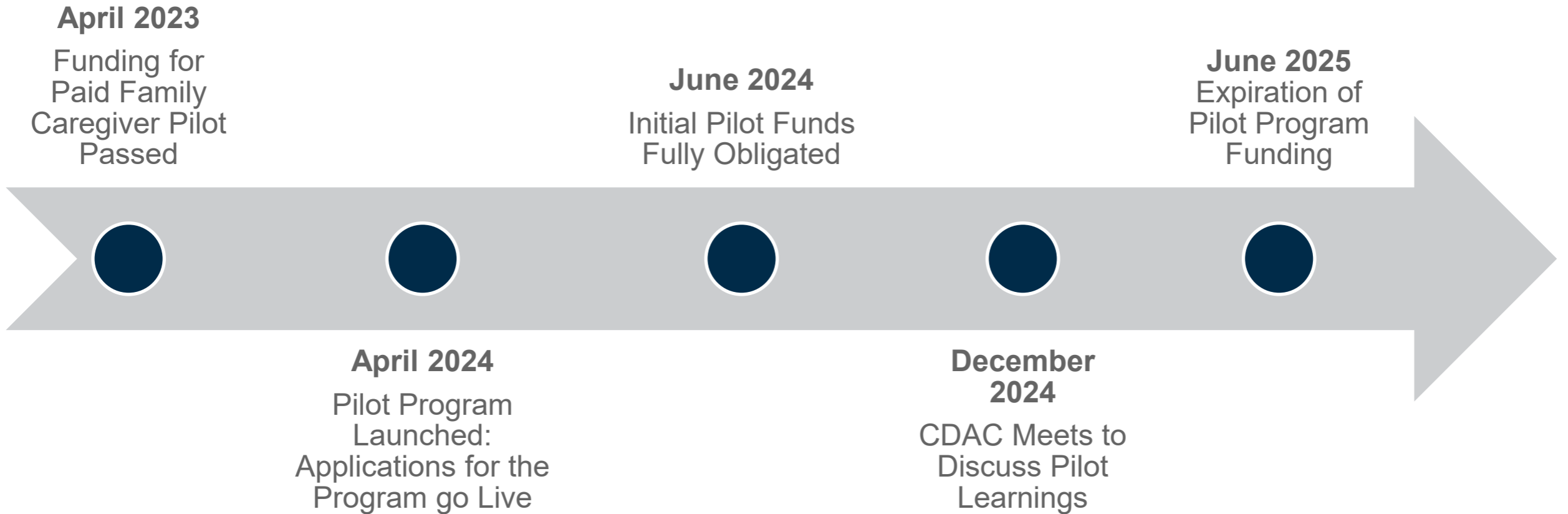
Statutory Authority for Paid Family Caregiver Pilot

Excerpts from Senate Bill No.2276

Family caregiver service pilot project - Report.

1. **The department shall establish the family caregiver service pilot project to assist in making payments to a legally responsible individual who provides extraordinary care to an eligible individual who is a participant in the Medicaid 1915(c) waivers**, excluding the home and community - based services aged and disabled waiver.
2. The family caregiver service pilot project may include funding for extraordinary care, which means care: a. Exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical or behavioral needs; and b. Is necessary to assure the health and welfare and avoid institutionalization of the individual in need of care.
3. The department may adopt rules addressing management of the family caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall utilize an assessment of an eligible individual to determine the level of care authorized and to determine the best interests of the individual in need of care. The pilot project may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.
4. A decision on an application which is issued by the department under this section may be appealed as provided under chapter 28 - 32. An individual may not appeal a denial, a revocation, a reduction in payment, or the termination of the family caregiver service pilot project administered by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family caregiver service pilot project for the biennium.
5. The department shall provide the legislative management with periodic reports on the impact, usage, and costs associated with the family caregiver service pilot project.

Paid Family Caregiver Pilot High-Level Timeline



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

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:
\$338,623.08

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

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

Public Comment on Paid Family Caregiving

Public Comment: Paid Family Caregiving in North Dakota

Please Note: We will be focusing this public comment on general topics related to Paid Family Caregiving, and the ND Pilot. We will not be discussing individual cases or applications at this time.

Additional Feedback to Share?

Submit written comments using
the ND CDAC comment box

www.NDCDAC.com



Appendix

Primary Options for Paid Family Caregiving Available to States

Medicaid State Plan Authority Options for Paid Family Caregiving Available to States:

- Personal Care Services
 - × LRI's may not provide personal care services under the State Plan
 - ✓ Non-legally responsible relatives and friends can provide State Plan personal care services if they meet provider qualifications
- Home Health Services (home health aides, skilled nursing specialized therapy)
 - ✓ Both LRI's and other relatives may provide home health services if they meet provider qualifications and are contracted or employed by a home health agency

HCBS Waiver Authority Options for Paid Family Caregiving Available to States:

- Waivers are the most common method that states use to authorize paid family caregiving
- States may select which HCBS waivers they wish to include paid family caregiving as an option for (it is not “all or nothing”)
- Providers must meet several additional requirements – see next slide for more details

*The above options highlight federal **pathways available to states** for paid family caregiving in Medicaid services; **states may elect not to utilize paid family caregiving**, or to only allow paid family caregiving in specific situations*

