



North Dakota
Cross Disability
Advisory Council

JAN 31, 2025

**CROSS-DISABILITY
ADVISORY COUNCIL**



AGENDA

- I. Action Items and Points of Business
- II. Overview of Paid Family Caregiving
- III. Federal Requirements Related to Paid Family Caregiving
- IV. National Scan and Selected State Case Studies
- V. Survey Results
- VI. Closing Items

ROLL CALL



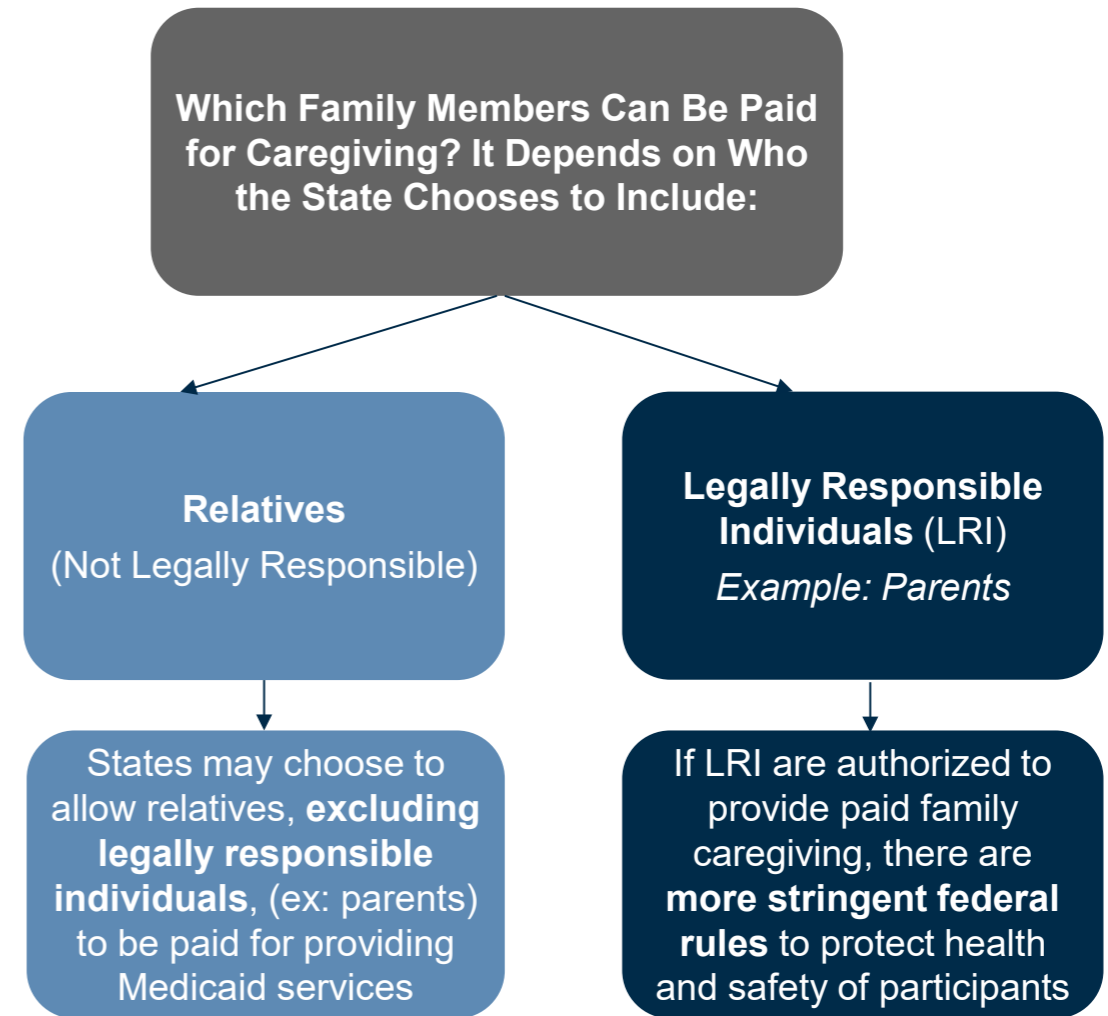
MINUTES



Overview of Paid Family Caregiving

Key Elements of Paid Family Caregiving

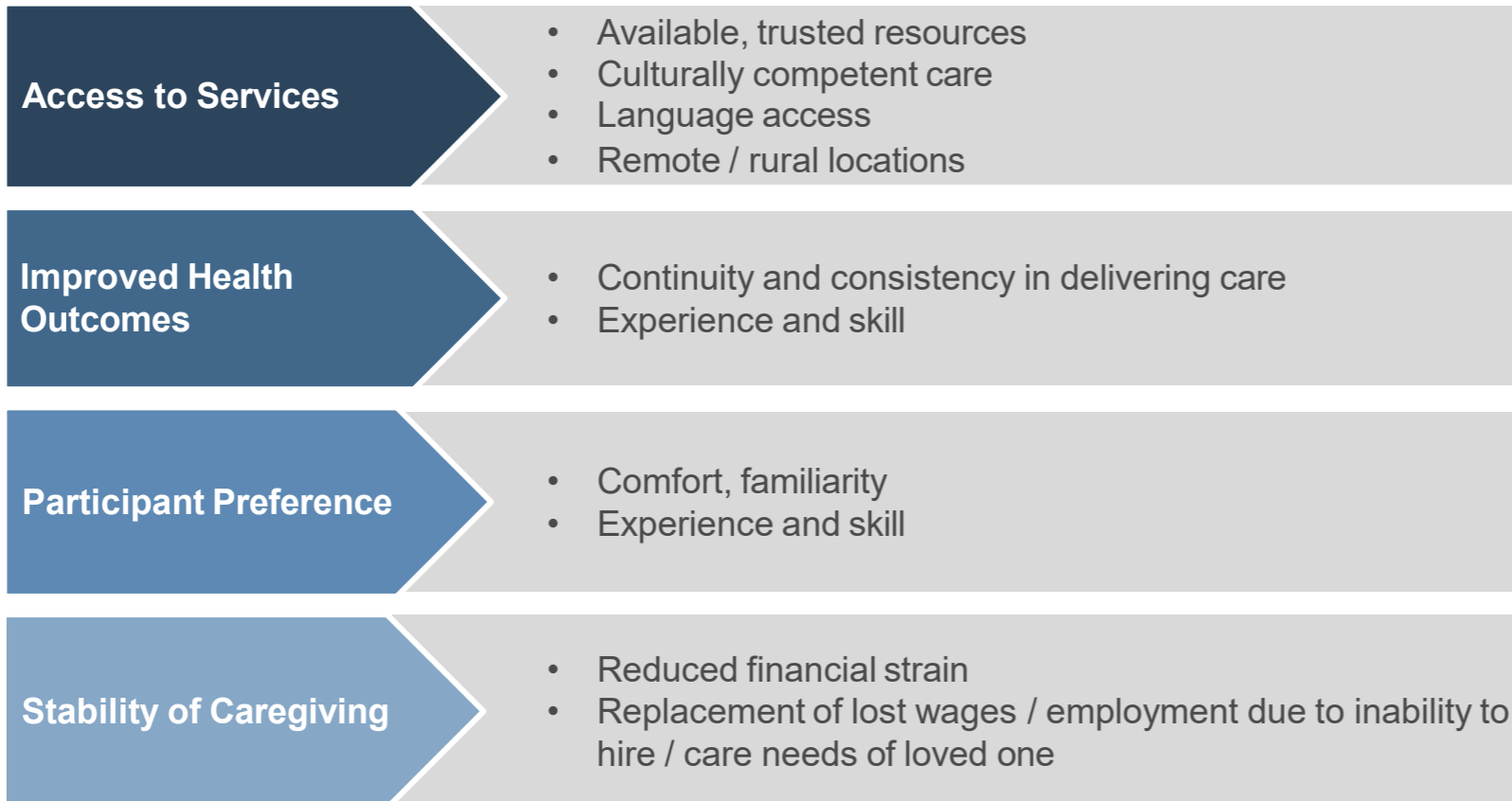
- Paid family caregiving is **an optional service delivery method**; states may choose whether or not to authorize this modality
- If a State decides to pursue paid family caregiving, they can include this option for:
 - Medicaid State Plan Services; and / or
 - In some or all the State's 1915(c) waivers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

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



Federal Requirements Related to 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.

Federal Guidance on Extraordinary Care

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

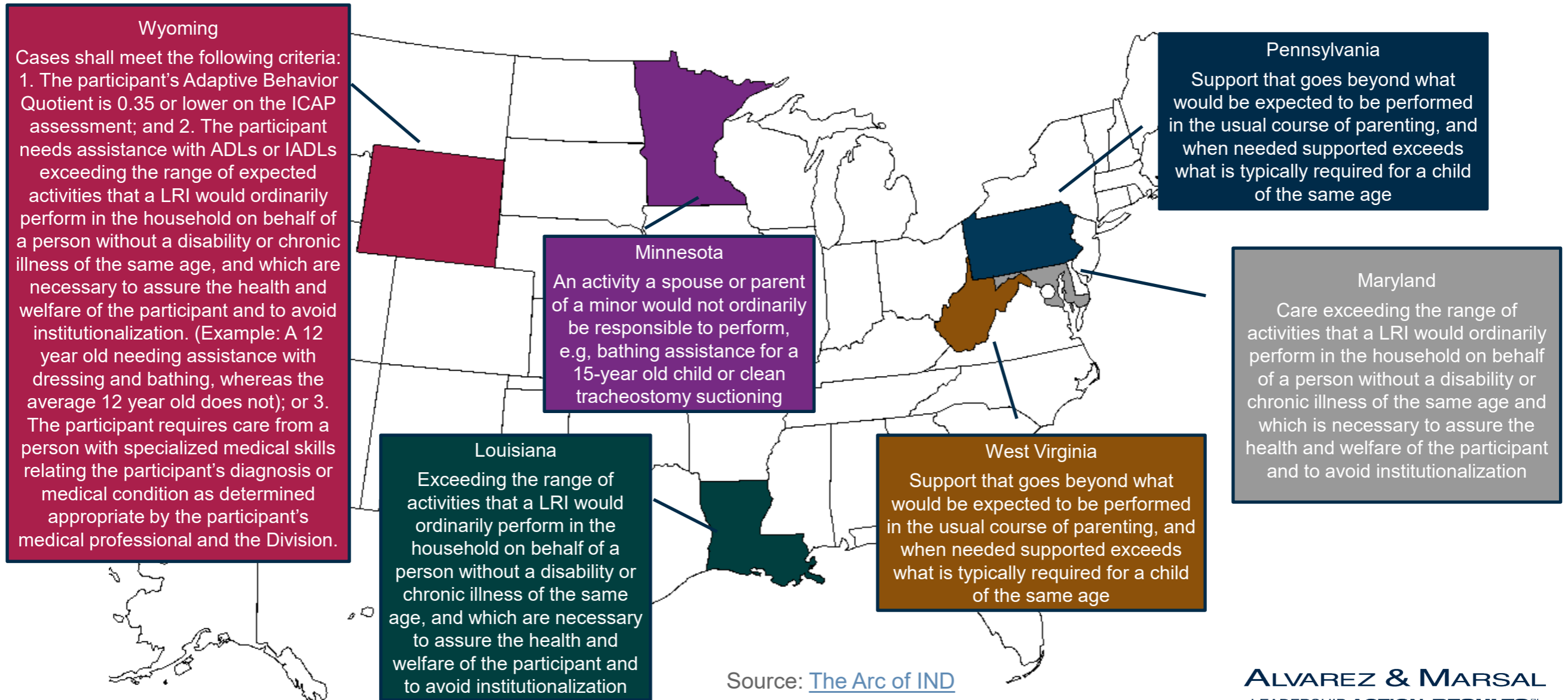
- CMS requires states to assess whether individuals demonstrate need for extraordinary care when screening for paid family caregiving provided by LRIs (ex: parents)
- CMS defines extraordinary care broadly, but leaves flexibility for states to further define this term (see next slide)
- It is the responsibility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



Source: [The Arc of IND](#)

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

Understanding the Impact of Federal EVV Regulations on Paid Family Caregiving

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 \$154.89.
- **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 service₅ provided each day.**

National Overview and Selected Case Studies

National Landscape of Paid Family Caregiving in I/DD HCBS Waivers

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 intellectual and developmental disabilities. There are 19 total states currently offering the LRI flexibility

State	Service Model	Service(s)
Alabama	Self-Directed	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	Community Living Arrangement Services
Connecticut	Self-Directed and Traditional	Individualized Home Support, Respite, Individualized Day, Personal Supports and/or Senior Supports
Iowa	Self-Directed	All Comprehensive waiver services
Kansas	Self-Directed	Personal Care
Kentucky	Self-Directed	Personal Care
Louisiana	Self-Directed and Traditional	All Comprehensive waiver services
Maryland	Self-Directed and Traditional	Community Development and Personal Supports
Minnesota	Self-Directed and Traditional	Extended Community First Services and Supports
Montana	Self-Directed and Traditional	Residential services, Day and Employment services, Personal and Companion Care
New York	Self-Directed and Traditional	Residential Habilitation in Family Care Homes; Community Habilitation; Habilitative Supports; and Respite
Ohio	Self-Directed and Traditional	Homemaker/Personal Care and Waiver Nursing Services
Pennsylvania	Self-Directed and Traditional	In-Home and Community Support and Life Sharing
Utah	Self-Directed	Supported Living
Virginia	Self-Directed and Traditional	Personal Assistance
West Virginia	Self-Directed	All Comprehensive Waiver Services ¹
Wisconsin	Self-Directed and Traditional	Personal Care, Employment Supports, Respite, or Skilled Nursing
Wyoming	Traditional	Personal Care

Peer State Approaches to Paid Family Caregiving in HCBS I/DD and ASD Waivers (1 of 2)

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 Population	Age	Payments to LRI Allowed?
Idaho	ID Adult DD Waiver	ASD, ID, DD	Adult (18+)	No (Previously allowed for children and adults via State Plan)
Iowa	IA HCBS ID Waiver	ID	Lifespan (0+)	Yes, all comprehensive waiver services
Kansas	KS HCBS I/DD Waiver	ASD, DD, ID	Ages 5+	Yes, personal care only
Kansas	KS Autism Waiver	ASD	Youth (0-5)	No
Minnesota	MN DD Waiver	DD, ID	Lifespan (0+)	Yes, extended community first services and supports
Montana	MT HCBS Waiver for DD	ID, DD	Lifespan (0+)	Yes, residential, day, employment, personal and companion
Nebraska	NE Comprehensive DD Services	ASD, DD, ID	Lifespan (0+)	No
Nebraska	NE DD Day Services for Adults	ASD, DD, ID	Adult (21+)	No
South Dakota	SD CHOICES Waiver	DD, ID	Lifespan (0+)	No (allowed in adult waiver only)
South Dakota	SD Family Support Waiver	DD, ID	Lifespan (0+)	No (allowed in adult waiver only)
Wyoming	WY Comprehensive Waiver	TBI, DD, ID	Lifespan (0+, unless TBI 21+)	Yes, personal care only
Wyoming	WY Supports Waiver	TBI, DD, ID	Lifespan (0+, unless TBI 21+)	Yes, personal care only

Minnesota: Basic Structure of Paid Family Caregiving in HCBS (Case Study #1)

LRI 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 intellectual disabilities or developmental disabilities 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's Approach to Determining Age-Appropriate Dependencies, Part 1 (Case Study #1)

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

Note: Minnesota's assessment scores dependencies across a variety of ADL's. 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?	
			<input type="checkbox"/>	<input type="checkbox"/>

Minnesota: Safeguards for Paid Family Caregiving in HCBS (Case Study #1)

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

Idaho: The Initiation of Paid Family Caregiving (Case Study #2)

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 Paid Family Caregiving (Case Study #2)

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 #2)

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 #2)

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."

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"

South Dakota: Paid Family Caregiving for Adult Waiver Services Only (Case Study #3)

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



Population: South Dakota 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 provide 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 service coordinator
- At least annual physical examination
- Quarterly reviews of health, safety, and welfare status of the client
- Opportunity for unannounced visits
- Quarterly reviews of expenditures

Ohio: Approach to Paid Family Caregiving for Children on HCBS Waivers (Case Study #4)

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. This waiver provides 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:

- Personal care
- Participant-directed homemaker / personal care
- Waiver nursing



Assessment: 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's Approach to Determining Age-Appropriate Dependencies, Part 1 (Case Study #4)

- 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) <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>	Requires Assistive Device (1) <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) <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>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>	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 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>

Ohio's Approach to Determining Age-Appropriate Dependencies, Part 2 (Case Study #4)

Ohio Extraordinary Care Instrument			
Individual's Name: _____		Assessor's Name: _____	
Date of Birth: _____		Date Completed: _____	
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 <u>at least three</u> 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>
Dressing <i>Completing all steps necessary to put on and remove clothing items and shoes. This includes using zippers, buttons, snaps, shoestrings, Velcro, and/or other means to secure clothing to the individual's body. This also includes choosing clothes, protective weather gear, and shoes appropriate to the individual's environment and physical needs.</i>	Toileting <i>Completing all steps required to manage bowel and/or bladder functions when needed. This includes cleaning after elimination. This does not include transfers, which are addressed in Transfer Assistance.</i> <i>If the individual is incontinent, then score based on their ability to manage their incontinence needs.</i>

Ohio: Safeguards for Paid Family Caregiving in HCBS (Case Study #4)

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 as a participant directed service
- Services must be needed from the parent / spouse while a willing and 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

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

Appendix

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: 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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LEADERSHIP. ACTION. RESULTS.™

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?

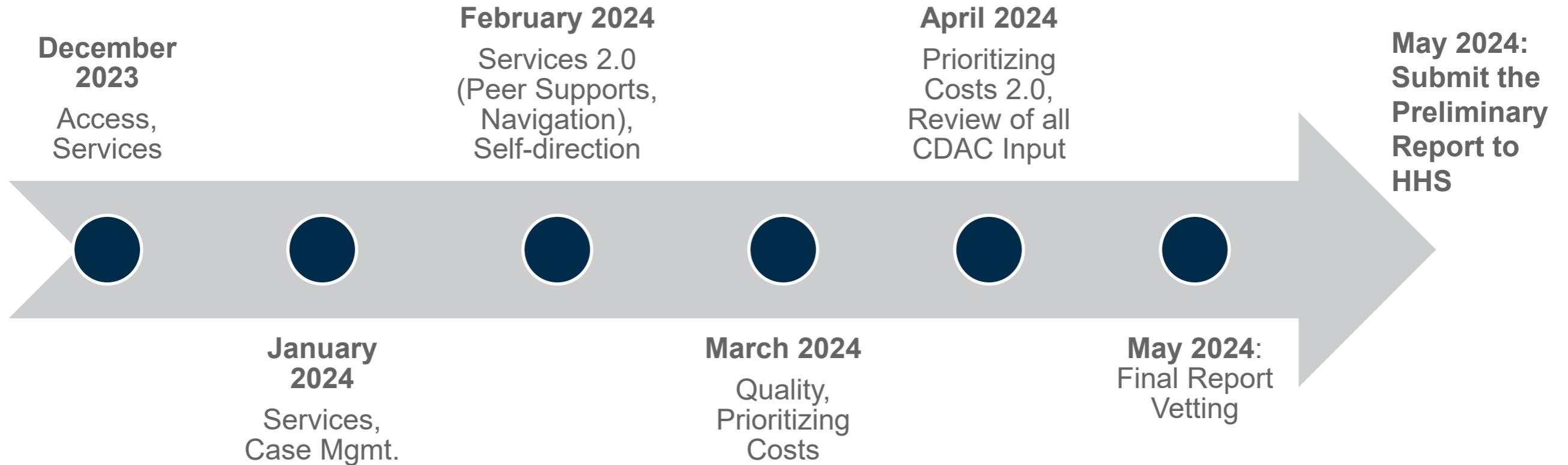
Quality 
What does quality look like?



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



May 2024:
Submit the Preliminary Report to HHS



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.

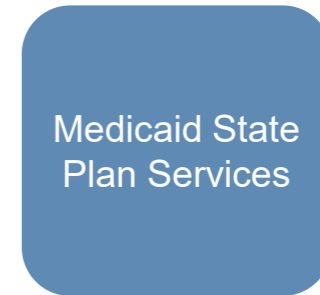
Upon department's request, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

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

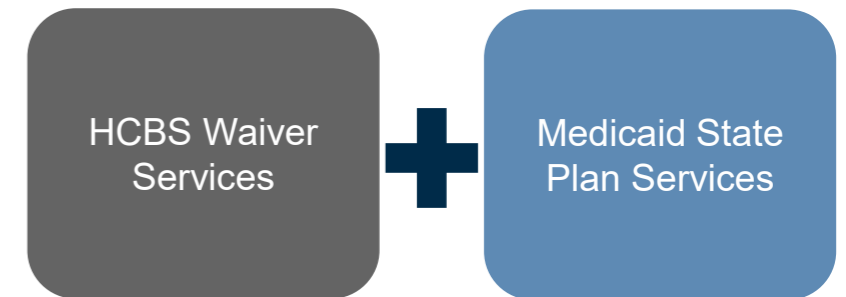
CDAC Scope

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

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

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:

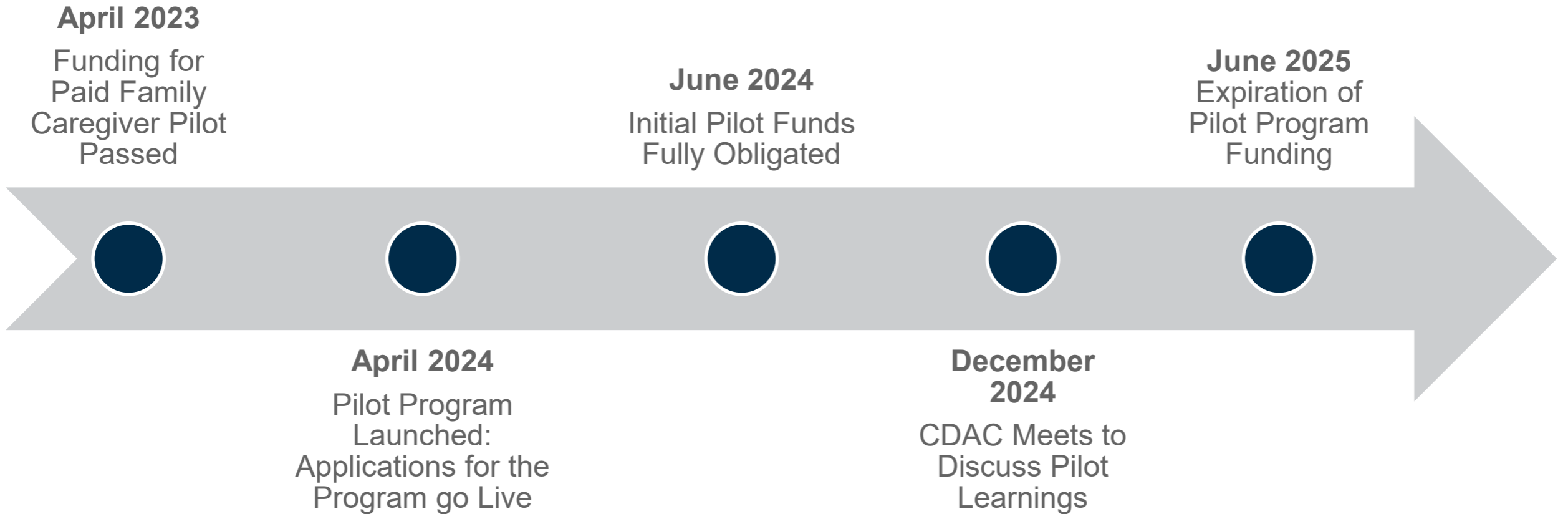
Families on CDAC stressed the importance of offering an option for Paid Family Caregiver in the new waiver. Use learnings from the pilot to define the parameters of Paid Family Caregiver for the Cross-Disability Children’s Waiver. Consider parity between self-directed, and paid family caregiver rates.

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.

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