2025 SENATE HUMAN SERVICES

SB 2305

2025 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2305
1/27/2025
9:57 a.m.

Relating to the family paid caregiver service program and the cross-disability advisory council.

9:57 a.m. Chairman Lee opened the hearing.

Members Present: Chairman Lee, Vice-Chairman Weston, Senator Clearly, Senator Van Oosting, Senator Hogan, Senator Roers.

Discussion Topics:
- Issues with self-assessment
- Status of applications
- Evidence based evaluation
- Previous program success
- Staffing challenges

9:58 a.m. Senator Hogan introduced the bill.

10:02 a.m. Tina Bay, Director of ND Health and Human Services, testified in neutral and submitted testimony #31609, #31610 and #31611.

10:11 a.m. Toby Lunstad, testified in favor and submitted testimony #31396 and #31397.

10:21 a.m. Roxane Romanick, Designer Genes of ND, testified in favor and submitted testimony #31650.

10:29 a.m. Katynka Morrissette, testified in favor and submitted testimony #31638.

10:41 a.m. Vicki Peterson, Family Consultant for Family Voices of ND, testified in favor and submitted testimony #31491.

10:44 a.m. Sarah Carlson, testified in favor and submitted testimony #31680.

Additional written testimony:

Brenda Schmid submitted testimony in favor #31283.

Amanda D. Burner submitted testimony in favor #31320.

Julianne Horntvedt, ND DD Council, submitted testimony in favor #31325.

Trevor Vannett submitted testimony in favor #31331.

Latecia Memeti submitted testimony in favor #31404.

Adrienne Montonye submitted testimony in favor # 31440.

Lucus Burner submitted testimony in favor #31441.

Kristy Rose submitted testimony in favor #31477.

Kristen Dvorak, Executive Director of The Arc of ND, submitted testimony in favor #31480.

Kara Geiger submitted testimony in favor #31548.

Allison Goetz submitted testimony in favor #31608.

Sarah Aker, Executive Director for ND Department of Health and Human services, submitted testimony in neutral #32298, #32299 and #32300.

10:59 a.m. Chairman lee closed the hearing.

Andrew Ficek, Committee Clerk

Testimony in Support of SB2305
2025 Legislative Session
January 23, 2025

Senator Lee and Members of the Senate Human Services Committee,

My name is Brenda Schmid. I live in Fargo in District 46 along with my husband and daughter.

I am providing this testimony in support of SB2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and cross-disability advisory council. We have a beautiful daughter who is 27 years old who has significant physical and intellectual disabilities along with complex medical needs (extra ordinary care needs). She lives at home with us and will do so as long as we are on this earth together. For 27 years I have been her primary caregiver, and my husband has taken the role of sole financial provider.

Our daughter uses a wheelchair (spastic quadriparesis), has epilepsy, neurogenic bowel/bladder, GJ tube (tube fed), scoliosis and kyphoscoliosis, cyclic vomiting and migraines, congenital tracheomalacia, nephrolithiasis, reflux disease, is nonverbal and has severe intellectual disabilities and has insomnia. She relies on others 100% to live.

I have been participating in the Pilot Program since Spring 2024. It has been life changing. I have attempted to work outside of the home many times over the past 27 years, only to have to resign as our daughter needs me. My husband travels for his work (same company for 33 years) he needs me to take care of our daughter and our home so he can do his job and focus on it to ensure financial support for our family.

My husband and I are in our mid and late 50's. As we enter this chapter of our lives we worry about retirement. When can we afford for my husband to retire? As our daughter will always live with us in our/her accessible home that meets all of her needs, she has her own personal van that enables her to access her community, she has me her Mom who not only takes cares of her, I manage all her medical appointments, medications, therapies, socialization, volunteering opportunities, recreation, leisure I make sure she has a beautiful, inclusive life that is meaningful, purposeful and dignified.

My husband and I financially do the heavy lift by providing housing (there is lack of affordable accessible housing), transportation (lack of transportation is a huge barrier for individuals living with disabilities), medical management (countless hours spent managing her care and no one knows her needs better than me) AND quality caregiving (there is a workforce crisis).

I keep a bank statement from the year our daughter was 1 year old, and I was unable to work outside of the home due to our daughter's extraordinary care needs and complex medical needs. We had 11 cents to our name. We never filed bankruptcy, we owned a little house built in 1921, 1 car, we never were on any state or federal funded assistance programs….we made it, through literally, blood, sweat, tears and the good Lord above we made it.

The Family Paid Caregiver Service Program is life changing. First and foremost, for the individual living with significant disabilities (extraordinary care needs) as they can be cared for by their family in their own home. Second, the financial impact. In today's economy dual incomes are necessary for families to pay for the basic necessities. Single parents who are unable to work due to their child's extraordinary care needs need a source of income.

In closing I want to thank you for your time and consideration and am respectfully requesting a "Do Pass" from the committee.

Brenda Schmid
701-866-8687

Testimony in Support of SB 2305
2025 Legislative Session

Dear Senator Lee and Members of the Senate Human Services Committee,

My name is Amanda Burner (I am a caregiver/parent to my son Kaden who is 22). I live in Minot ND and am part of district 5.

I am writing this testimony in support of SB 2305 for an act to amend and reenact section 50-24.1-47 of the ND Century Code, related to the paid caregiver service program and the cross disability advisory council.

The reasons I believe this bill (SB 2305) is so important are many, but I will try and keep it brief. I have had the privilege to be a part of the paid caregiver pilot program. It has been a true life altering program for my family. Our adult son Kaden has a rare disease called Leukodystrophy. This disease has come with so many challenges including profound cognitive disability (he cannot talk, do any of his own cares, feed himself, or walk), seizures, and being immune compromised. Due to all of these factors I have only been able to work minimum and sometimes not all leaving all the financial responsibility on my husband. We have done it and made it work, but it has been mentally exhausting. Once we became a part of the pilot program things changed drastically for the better. We were able to breath a little. It took the heaviness of financial issues off the table and allowed for some peace in that area. I even had my son's social worker and others comment to me that I seemed much less stressed and more at peace. It made me realize that just having the program made such a positive difference in our lives. For that we are so grateful. The mental load on parents and families of profoundly disabled children is something so hard to describe. We do the job because we love our child and want his quality of life to be the best it can be, but it is a heavy job. It has been so wonderful to get the recognition for doing this intense job from the start through this program. It has made me and my family feel less invisible and created less stress, thus improving the quality of all of our lives. For that I thank you! I respectfully request a Do Pass from the committee. From my family to you all thank you for helping us to improve the quality of our lives.

Respectfully
Amanda Burner

Minot ND

Testimony
Senate Bill 2305
January 24, 2025

Senator Lee and Members of the Senate Human Services Committee, my name is Julianne Horntvedt, and I serve as the Executive Director of the North Dakota State Council on Developmental Disabilities. I am submitting testimony on behalf of our Advocacy Committee.

For many families, caring for a loved one with disabilities is a full-time responsibility that requires immense time, energy, and commitment. This caregiving often comes without pay, forcing family members to make difficult decisions between their financial stability and their loved one's well-being. Parents, siblings, and other relatives frequently reduce their working hours, take unpaid leave, or leave their jobs altogether to provide the necessary care. This financial sacrifice can be devastating for families who are already struggling with the costs of medical treatment, therapies, and specialized care equipment.

By supporting this family-paid caregiver program, we give families the support they need to continue providing high-quality care in the home. Families are often the most qualified to provide this care because they understand their loved one's needs, preferences, and medical history better than anyone else. Allowing them to be compensated for this important work means families can continue providing that care without risking their financial futures.

This program also has profound benefits for people with disabilities. People with disabilities thrive in familiar, supportive environments. Home-based care is often preferable to institutional care, not only because it allows for a greater sense of comfort and dignity, but also because it is more personalized and aligned with the individual's unique needs. The consistent presence of a family member can help individuals with disabilities feel safe, stable, and empowered, which contributes to better health and emotional outcomes.

On a larger scale, this program benefits our state by helping reduce the need for more expensive institutional care and emergency medical interventions. When family caregivers are supported, families can keep their loved ones at home longer, resulting in reduced healthcare and housing costs for the state. This approach is both cost-effective and compassionate. By investing in the well-being of caregivers, the state would be making a long-term investment in the health, dignity, and independence of individuals with disabilities.

Sincerely,

Julianne Horntvedt

701-328-4847

jhorntvedt@nd.gov

Testimony in Support of SB2305
2025 Legislative Session
January 24, 2025

Senator Lee and Members of the Senate Human Services Committee,

My name is Trevor Vannett and I live in Bismarck.

I am in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and the cross-disability advisory council.

This bill is important because it lessens the impact of institutionalizing individuals with disabilities, a cost that far exceeds the cost of supporting caregivers in their homes. Studies have shown that family caregiving is not only more affordable, but it can also improve the quality of life for the individuals being cared for. Children, adults, and elderly individuals with disabilities are more likely to thrive in a familiar environment, benefiting from the emotional stability and personal connection that only a family member can provide.

Furthermore, a paid family caregiver program can help families sustain their own health and well-being. Many caregivers suffer from physical and emotional exhaustion due to the overwhelming demands placed on them, and financial compensation could reduce stress and burnout, making it easier for caregivers to provide better, more consistent care. This, in turn, benefits the individuals receiving care, who are more likely to experience positive outcomes when their caregivers are physically and emotionally healthy.

Finally, this program would send a powerful message that our state values and recognizes the critical role that family caregivers play. It acknowledges that caregiving is work and that it deserves compensation. It is an investment in the health and well-being of families, communities, and the state as a whole.

For all these reasons, I strongly support the paid family caregiver program. It is an investment in families, in individuals with exceptional needs, and in the overall well-being of our state. I urge you to act in favor of this program and to make a meaningful difference in the lives of those who are providing essential care to their loved ones.

Sincerely,
Trevor Vannett
701-955-0000

Testimony in Support of SB2305

2025 Legislative Session

January 24, 2025

Senator Lee and Members of the Senate Human Services Committee,

My name is Toby Lunstad and I live in Mandan – District 31. I am writing testimony in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the Paid Family Caregiver Service Option and the Cross-Disability Advisory Council.

I am writing in support of SB 2305 because I am the primary caregiver to my daughter, Addilynn, who requires extraordinary care to live a healthy and happy life. Addilynn is 10 years old and loves music, dancing, Mickey Mouse Clubhouse, and going fast in just about anything. She has a cheerful and sometimes mischievous personality and has blessed my life beyond measure.

Addilynn has a rare genetic disorder called CACNA1A, which has resulted in developmental delays in all areas, Lennox-Gastaut Syndrome (a medication-resistant form of epilepsy), hemiplegic migraines, and the need for specialized care and equipment. Addilynn is currently on the IID/DD Waiver.

In 2020, I was forced to leave my full-time employment as a manager and occupational therapist because her needs were so specialized that we could not find qualified staff to care for her while I worked. As a result, our family lost income, employer-paid health insurance, and other benefits. My husband now works longer hours in an effort to fill the financial gap created by my inability to work outside the home.

Addilynn and I are participating in the Paid Family Caregiver Pilot Program developed through SB 2276 during the 2023 Legislative Session. Participating in this program has reduced the emotional and financial strain on our family. It has provided Addilynn with a consistent, fully qualified caregiver who is deeply invested in her health and happiness.

I support SB 2305 and the provision for family caregiver payments to be set at rates comparable to self-directed direct support professionals. Under the pilot program, caregivers for individuals under 18 years old, like Addilynn, are paid only half the rate of caregivers for adults. Payment rates should be equal regardless of the individual's age and should reflect the skilled care being provided. This recommendation aligns with guidance from the **American Academy of Pediatrics Advocacy Action Guide on Paid Family Caregiving** released in late 2024.

AAP Advocacy Guide on Paid Family Caregiving

I also support the bill's language requiring the assessment process to be evidence-based and focused on the unique needs of the individual. As an occupational therapist, I understand that performing daily tasks, such as using the bathroom, involves multiple areas of need. Completing this single task requires consideration of:

- **Transferring**: Is the individual able to transfer to and from the toilet safely?
- **Balance**: Is the individual able to maintain sitting balance while completing toileting? Are they able to maintain standing balance during clothing management?
- **Clothing Management**: Are they able to donn and doff clothing or incontinence products?

- **Hygiene Completion**: Can the individual thoroughly complete hygiene to maintain skin integrity and reduce the spread of germs? Are they able to properly dispose of incontinence products?
- **Safety**: Can the individual complete these activities without risk of falling? What equipment is needed for safety and independence? If left unsupervised, does the individual have potential to cause damage to the home?
- **Cognition**: Do they understand and sequence the steps required to use the bathroom? Do they recognize the need to use the bathroom? Are they able to wait if necessary? Can they generalize using the bathroom in places other than their home?

An assessment focused on functional areas of need, rather than skills unrelated to daily care (such as the ability to throw a ball overhead), will more accurately identify individuals who require extraordinary care from their family caregivers.

I also support the inclusion of the Cross-Disability Advisory Council in providing feedback to the department regarding the planning, design, and implementation of the Paid Family Caregiver Service Option. Stakeholder input is essential to ensure the program meets the needs of eligible individuals. As long as the Cross-Disability Advisory Council represents individuals with a broad range of disabilities from across the state and provides opportunities for public comment, it will serve as an effective mechanism for stakeholder participation.

Thank you for the opportunity to express my support for SB 2305 and for your service to our state. I respectfully request a “Do Pass” recommendation from the committee on SB 2305. I am happy to answer any questions you may have.

Sincerely,

Toby Lunstad

tobylunstad@gmail.com

701-595-4386

PAID FAMILY CAREGIVING

STATE MEDICAID PATHWAYS FOR PAYMENT

Advocacy Action Guide for AAP Chapters

Overview

Children and youth with special health care needs (CYSHCN), including children with medical complexity (CMC), have high levels of health care utilization as well as unmet needs. Ongoing national shortages of home care services for such children, including private duty nursing, personal care, respite care, and therapists are drivers of such unmet needs. Without straightforward and consistent access to these essential services, CYSHCN are at increased risk for unnecessary hospitalization, institutionalization, and worsened health outcomes. Further, parents and caregivers often end up performing skilled tasks in the absence of home care services, which can increase stress, burnout, and financial hardship. One piece of the solution to the complex issue of home care workforce shortages and family burden is to enable parents and caregivers of CYSHCN to be paid for providing *personal care* and/or *home health* services. There are several potential pathways to paid family caregiving, involving a combination of assorted Medicaid *state plan authorities*, *waivers*, and changes to *state law and regulation*. This American Academy of Pediatrics (AAP) Advocacy Action Guide is intended as an introductory primer for AAP chapters on the need for and viability of these payment models, and considerations to address when advocating for coverage. Included in this resource are discussions of: *home health services vs personal care services; state plan benefits vs HCBS pathways; and state policy considerations*.

Background

Over the last few decades, care for CYSHCN has been shifting from institutions to the home or a community-based setting, thanks in large part to policy changes such as the Katie Beckett/Tax Equality and Fiscal Responsibility Act (TEFRA), the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, Home and Community-Based Services (HCBS) waivers, Section 504 of the Rehabilitation Act, and caselaw such as Olmstead v L.C.[1] Today, approximately half of all CYSHCN receive care at home from a family member.[2] This proportion increases when children have more than one special health care need, including CMC.[3] While medical literature demonstrates this shift to home and community-based care improves health outcomes, there is a growing number of CYSHCN reporting unmet home care needs.[4]

The most prominent barrier to accessing quality home care services is a shortage of workforce, a hurdle that can be even higher when considering home care services that specialize in pediatrics. Home care workforce shortages are driven by difficult hiring practices, variable training requirements, and most significantly, inadequate payment.[5] Research demonstrates that a lack of access to home care services drives increased risk of prolonged hospitalization and increased costs.[6] When these gaps exist, families are increasingly called upon to deliver specialized care for their children at home and at considerable personal cost. These issues can lead to family members forgoing employment to care for their children, which in turn can drive financial instability, unsafe workloads, and family stress.[7]

Family caregivers of CYSHCN in the United States provide about 1.5 billion hours of health care to approximately 5.6 million children annually.[8] The cost of these services, if provided by a home health agency, would total anywhere between $11.6 and $35.7 billion annually.[9] Further, while CMC make up just 0.4% of children in the US, the number of hours their families spend caring for them at home is exponentially more than even other CYSHCN.[10] Unsurprisingly, the issues of stress, burnout, and financial instability are more common for parents of CMC, even compared to parents of children with other chronic conditions.[11]

However, research shows that when states enable parents and caregivers of CYSHCN to be paid for the extraordinary care they provide to their children, there can be numerous potential benefits to the parents, child, and state, including:

- Parents being able to maintain their "emotional and moral commitment" to care for their child;
- Stable access to high quality care, which drives continuity of care;
- Increased options and flexibility for parents of CYSHCN;
- Betterment of the child's health and wellbeing;
- Enhanced family financial stability; and
- Acquisition and development of skills that are transferable, including to elder care, which can help parents find employment and boost the provider network when their children age out to adult care.[12]

During the COVID-19 pandemic, states had the option to adopt temporary policies to pay family caregivers for providing personal care services.[13] But with the expiration of these temporary flexibilities, states wishing to continue or expand paid family caregiving will need to make changes to their Medicaid programs, which can entail additional, and often confusing, legislative or regulatory action. Most states already enable paid family caregiving for seniors and adults with disabilities through an array of HCBS options, though to date only a small number of states have done so for children.[14] However, in recent years, a handful of states have crafted innovative policies enabling parents of CYSHCN to be paid family caregivers, *either by obtaining skilled licensure types and performing services through a home health agency*, or through *HCBS pathways enabling self-directed services, which doesn't require licensure*.

AAP has created this Advocacy Action Guide to serve as an introductory primer for AAP chapters of the various pathways likely available in their states to unlock Medicaid payment for family caregiving of CYSHCN, including a discussion of the various policy considerations that should be taken into account when working with the state to advance these programs.

State Pathways for Medicaid Payment to Family Caregivers

Broadly speaking, models for paid family caregiving can be categorized one of two ways: *models that require licensure and home health agency employment,*[i] *and models that do not*. CMS refers to these two options as the "agency service delivery model" and the "self-directed service delivery model."[15] There are several potential Medicaid pathways available to states to unlock these models, which can involve combination of Medicaid state plan authorities, waivers, and changes to state law and regulation. Within Medicaid, pathways can include the state plan home health benefit, HCBS waivers and state plan amendments, and 1115 waivers, all of which interplay with Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. In addition to identifying one or more Medicaid pathways, states will also likely need to analyze state law and regulations to either remove barriers or expressly authorize family caregivers to be paid. In particular, *home health services* are generally required to be provided by a home health agency and with the provider meeting some level of training, certification, or licensure, and are subject to rules about delegation, as determined by the state. Conversely, paid *personal care services* cannot normally be performed by a "legally responsible relative," unless through an HCBS pathway, which have their own policy and procedural safeguards states must meet.

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[i] *Note: There have been a small number of state models allow non-licensed individuals to provide services through a home health agency. Likewise, there have been a small number of states waivers allowing for self-direction of delegated skilled nursing tasks. However, these are largely exceptions to the rule.*

There are potential advantages and drawbacks to each pathway and service delivery model for the individual, the caregiver, and the state. As such, the model(s) and pathway(s) selected will likely be a state-by-state determination based on a number of policy considerations, which are discussed below.

1905(a)(7) Home Health Services

Home health, as defined in federal regulation, includes nursing and home health aide services through a home health agency, physical or occupational therapy, and the provision of medical supplies, all of which are 1905(a) services in and of themselves.[16] While these positions are able to perform skilled nursing tasks, they may also in the course of their duties provide services typically associated with personal care, as described below.[17] Home health is a mandatory state plan benefit when provided to an individual entitled to receive nursing facility services and for children is covered through EPSDT when medically necessary.[18] While there are no restrictions on a legally responsible relative's ability to be paid for providing home health services, these services generally have to be provided by a qualified provider through a home health agency, rather than be self-directed.[19] As such, states have enabled family caregivers to be paid for providing home health services if the family member (1) becomes employed by a home health agency, typically as some form of home health aide, and (2) meets state licensure and credentialing requirements – typically, LPN/RN, CNA, or newly-created parent caregiver licensure types (with a wide range of names, discussed below). Home health agencies need to meet federal Medicare standards, but states have flexibility to determine requirements for home health aides or these newly created licensure types, which can help lower barriers to entry for family caregivers.

1905(a)(24) Personal Care Services via HCBS

Personal care services include activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as cooking, cleaning, and shopping. Personal care is an optional state plan benefit; it nonetheless must be covered for children through EPSDT when determined to be medically necessary.[20] However, inconsistent application of EPSDT, compounded by provider shortages and the assumption parents are responsible for these tasks, can mean few eligible children actually receive this service. States set criteria for who can perform personal care services, including training requirements, supervision requirements, and whether personal care providers can operate independently or through an agency.[21] However, federal law prohibits "legally responsible relatives" from being paid for providing personal care services for minors under age 18, as the statue and regulations view these tasks as those a parent or guardian would otherwise be legally obligated to provide to a child.[22] Nevertheless, payment to a legally responsible relative for personal care services may be covered when included as part of a HCBS pathway, if the state demonstrates that performing these tasks for CYSHCN would be considered an "extraordinary" level of care.[23]

A Note on EPSDT

ESPDT is the Medicaid program's mandatory benefit for children, designed to ensure that any enrolled child can receive the care they need, when they need it, in the setting they need it. Through EPSDT, eligible children under 21 can receive any Section 1905 service necessary to "correct or ameliorate" a condition, regardless of whether the service is covered under the state plan. As home health is a mandatory benefit and personal care is an optional benefit under Section 1905, both are covered for children via EPSDT when determined to be medically necessary. Conversely, HCBS falls under Section 1915; as such, those services do not fall within EPSDT, but rather "wrap around" EPSDT to create a comprehensive benefit for children with disabilities. Therefore, while states may have CYSHCN enrolled in a HCBS program, this does not limit children's entitlement to receive services through EPSDT as well.

Nevertheless, longstanding inconsistencies in state implementation of EPSDT have posed significant barriers to CYSHCN accessing the care they are entitled to. The policy pathways described within represent ways to work around barriers to family members providing these services – the need for home health services to be furnished by a qualified provider, and a prohibition on "legally responsible relative" providing paid personal care services.

For a robust discussion of EPSDT requirements, see the recent CMS guidance, SHO # 24-005.

HCBS

HCBS is a patchwork of Medicaid waivers and state options that enable eligible individuals to receive institutional facility levels of care in their home or homelike setting in their community, rather than an institution. These programs enable coverage for services that are otherwise not available through Medicaid because they do not fit in a category listed in 1905(a), or can extend 1905(a) services beyond their normal amount, duration or scope.[24] As such, through HCBS pathways, states can enable a legally responsible relative to be paid for providing personal care services, either through becoming a qualified provider employed by a home health agency – similar to home health care state plan services – or through an option known as *participant-directed* or *self-directed care*, where the Medicaid enrollee essentially sets their own provider qualifications and "hires" their own provider.

While HCBS pathways can enable payment for personal care, there are hurdles the state must clear to overcome the federal limitation on paying legally responsible relatives for providing personal care.[ii] The state must establish that the care being provided is "extraordinary care" and develop a criteria for determining as much.[25] The state must also establish other safeguards, including: demonstrating the delivery of personal care by a legally responsible relative is in the child's best interest and will not hinder their ability to engage in meaningful community activities; implementation of appropriate oversight mechanisms to ensure the individual receives the services being paid for; and procedures to ensure payments are made for services rendered.[26]

There are several varying HCBS waivers and state plan pathways states can leverage to enable payment for family caregivers. States will need to asses the costs and benefits of pursuing paid family caregiving models through a waiver or its state plan, or even through multiple pathways, as discussed below.

1915(c) Home and Community-Based Services waiver

- The most common HCBS pathway, 1915(c) waivers enable states to tailor a wide array of services to specific populations as an alternative to institutionalization.
- States can elect to allow enrollees to self-direct services and/or have legally responsible relatives be employed by a Medicaid-enrolled home healthcare agency.
- If personal care services are provided by a legally responsible relative, must establish "extraordinary care" and the safeguards as described above.
- Individuals provided services under 1915(c) *must require* an institutional level of care.

1915(i) Home and Community-Based State Plan Option

- Enables states to provide HCBS services akin to 1915(c) to individuals who require *less than* an institutional level of care.
- Commonly used to limit service to a carefully constructed population
- If personal care is provided by a legally responsible relative, must establish "extraordinary care" and other safeguards

1915(j) Self-Directed Personal Assistance Services State Plan Option

- Enables participants to directly hire and self-direct personal care services and/or other 1915(c) HCBS services, including defining their own provider qualifications and managing their own personal care budget.
- States can elect to allow enrollees to hire a legally responsible relative, or other family member.

[ii] See Elizabeth Edwards' excellent National Health Law Program (NHeLP) resource, *Paid Family Caregivers: State Options, Limitations, and Policy Considerations*, for a more detailed discussion of the procedural and technical requirements of an HCBS waiver for paid family caregiving. https://healthlaw.org/wp-content/uploads/2023/12/Paid-Family-Caregivers-NHeLP-2023.pdf

1915(k) Community First Choice State Plan Option

- ACA-created option that enables higher FMAP percentage for community-based attendant services and supports.
- States can elect to allow enrollees to set their own provider qualifications and self-direct services and/or have legally responsible relatives employed by a Medicaid-enrolled home health agency.
- Can't have waiting lists.

Nearly all states have active HCBS waivers, if not multiple. Research by KFF indicated that in FY2020 there were 267 HCBS waivers in place across 47 states + DC, with a large majority (255) of these waivers being 1915(c) waivers.[27] In 2022, KFF identified eighteen (18) 1915(c) waivers focusing exclusively on children who are medically fragile or technology dependent (other states may address children with medical fragility through other non-exclusive programs).[28] As of 2022, 32 states had HCBS waivers allowing legally responsible relatives to be paid for certain services; however, only 11 states had used a 1915(c) waiver to enable a legally responsible relative to be paid for personal care services (though this number is likely larger now).[29] Similarly, a 2023 survey of states by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) found that nearly all states allow payment for HCBS services delivered by a *non*-legally responsible relative, but only 12 at the time allowed payment to legally responsible relatives for personal care services, though most focus on parents of adults with disabilities who have guardianship.[30]

While the above HCBS pathways give states significant flexibility to craft programs that encompass payment for caregivers, there can also be limitations. Most notably, most HCBS options do not have a prohibition on enrollment caps or waitlists. As of 2020, the average wait time for HCBS waiver services for medically fragile or technology dependent children was 23 months (no data exists for children in waivers co-mingled with other populations).[31] That said, HCBS may be the most-favorable pathway for the state because the flexibility inherent in the program allows states to control costs by limiting the scope of services, number of recipients, and geographic area.

1115 Waiver

Section 1115 waivers are the most flexible waiver option for states to innovate. This option, which is not specific to HCBS services, gives states broad authority to test out new models of services and payments that advance the goals of the Medicaid program (within the constraints of budget neutrality). While HCBS services are usually delivered through a HCBS waiver, there are a handful of states (AZ, DE, HI, NJ, NY, RI, VT, WA) that deliver HCBS services through 1115 waivers, though not specifically for purposes of paid family caregiving.[32, 33] This is usually done to streamline eligibility processes and provide faster access to services.

Policy Considerations

As indicated above, identification of a viable pathway for paid family caregiving for CYSHCN will be a state-by-state determination based on a number of factors, including the needs of the state's CYSCHN Medicaid population, fiscal and administrative costs to the state, the state's current utilization of HCBS pathways, and barriers located in state law and regulation. When assessing these pathways there are several policy considerations advocates and the state should take into account. Likewise, program evaluations such as those mentioned in the section below indicate a number of benefits that states can work to enhance, and some perceived drawbacks states can work to reduce.

Employment through agency or direct payment – When crafting a paid family caregiving policy, the state will need to weigh whether it will allow the Medicaid enrollee to self-direct their own care and hire a family member or guardian to provide personal care services, or whether family caregivers will need to be employed by a home health agency. As previously stated, home health services must be performed by a qualified provider through a home health agency. The provider types that typically perform home health aide services and their associated licensure, training, and certification requirements are prescribed by state law and nursing regulations, which may need to be amended to include parent caregivers. Self-direction options may reduce costs to the state, but can also be associated with increased administrative burden, including state oversight of the paid care giver and quality assurance processes.[34] Conversely, employment through a home health agency can enable the caregiver to be paid for providing low acuity tasks, which in turn can free up RNs to focus on higher acuity tasks and can boost the home health care workforce in the longer term, but may be associated with higher fiscal costs to the state.

Delegation – States may have nursing statutes or regulations that either enable or restrict delegation of skilled nursing tasks from a RN to a nursing assistant/aide. Assistants/aides are typically only permitted to provide low acuity tasks. While families of CMC may be highly familiar with complex care such as tracheostomy care and feeding tubes, in order to be paid for providing these home health services, it may be necessary to ensure delegation of these tasks is allowable under state law.

Nomenclature – State laws/regulations often have differing professional titles for the role that would be carried out by a family member providing paid home health services. Depending on the title, there could be associated certification and training requirements. For example, the term "Home Health Aide" is used in FL, IN, PN, and NJ, while the term "Complex Care Assistant" is used in MA and MT. Other states expressly indicate certification in the use of the titles "Certified Home Health Aide" (CA), "Certified Nursing Assistant" (CO), and "Certified Health Aide" (TX). Meanwhile, others expressly indicate licensure through the state nursing board, such as "Licensed Health Aide" (AZ) and "Licensed Nurse Aide" (NH). States will need to examine their own laws and regulations to determine which title will best fit within existing schemes.

Training, credentialing, fees – For states that require caregivers to go through training and hold a certificate or license, states should subsidize the cost of training to minimize barriers to entry and financial burden to family members participating in the program. If it is required that the caregiver be employed by a home healthcare agency, the state should work with the agencies operating in their jurisdiction to cover the cost of training for the parent caregivers they will be employing. For example, in Colorado, participants take a 4-week course through the hiring home healthcare agency, which is designed specifically for parents to become certified nursing assistants, including scheduling around family-friendly hours, with only fees to the parent for testing and licensure.[35] It may also be possible for states to exempt family caregivers from licensure requirements under a showing of competency or supervision by a registered nurse.[36] If such exemptions already exist in state law/regulations, policymakers should carefully weave a new paid family caregiving program into those definitions/exemptions.

Optional vs mandatory participation – When working with the state to craft paid family caregiver policies, advocates should ensure that the state makes explicit that participation in paid family caregiving by eligible individuals is entirely optional and not a mandate. For many families of CYSHCN, it is appropriate and desirable for family members to serve as paid family caregivers. However, not all families of CYSHCN prefer that caregiving arrangement, and policies allowing paid family caregiving should not supplant coverage of the same services through other means, as available. Just as receipt of private duty nursing should not be conditioned on family availability, parents of eligible CYSHCN similarly should not be compelled to go through the steps to become a paid family caregiver.[37]

Who can provide – State policymakers should be deliberate when defining which persons are eligible to be a paid family caregiver. As mentioned above, federal Medicaid law restricts "legally responsible relatives" from being paid for providing personal care services through the personal care state plan benefit, but no such prohibition exists for the home health state plan benefit. States may have a variety of terms already codified that could have legal implications vis-à-vis this federal restriction, including "legally responsible person," "legally liable relative," "legal guardian," "relative," and "legal representative."[38]

Number of hours – States may set limits on the number of hours in a week that a legally responsible relative can be paid for providing home care services, whether it be personal care or home health. Per NASDDDS, many states that allow for payment of a legally responsible relative limit the hours to 40 per week.[39] Others, such as North Carolina, use 40 hours as the base, but may allow up to 56 hours/week if there are extenuating circumstances.[40] Other states, such as Colorado, do not cap the number of hours that a parent can serve as a paid caregiver.[41]

Preventing burnout – Related to limits on hours, it is essential that when states craft these policies they consider options for respite care. A large percentage of parents of CMC want to care for their children at home, but the experience can be both exhausting and isolating.[42] Building care for the caregiver into the program can help protect against caregiver burnout, which in turn helps preserve quality of care and longevity of employment in the home health care workforce. Potential options for preventing caregiver burnout include prescribed respite hours, community-integration programs, support services, and ensuring that paid family caregiving services are appropriately supplemented with options delivered by non-relatives.[43]

Appropriate payment and eligibility considerations – One of the most frequently cited contributors to the home health care workforce shortage is the lack of adequate payment. Rates for personal care and home health services can vary widely by state, provider type, and service. Some states pay for home health services by visit, while others have an hourly rate. The average rate for a home health aide is around $36/hr, but can range from $15/hr to $60/hr**.**[44] Likewise, the average hourly rate for a provider of personal care services is about $22/hr, but can range from as low as $9/hr to $86/hr.[45] States should take care to craft their paid family caregiving program so as to support family stability and workforce development, but should also ensure that additional income from paid family caregiving does not impact the child's eligibility.[46] Likewise, states should take care to monitor the pass-through wages from agencies to families. To note, chapters should also monitor implementation of the HCBS provisions of CMS's recently released Access Rule, which could ultimately have the effect of increasing Medicaid payment for these services (See, AAP's Advocacy Action Guide on Access Rule and Managed Care Rule for a more robust discussion of these provisions).

Implementation through multiple pathways – Given the differences between HCBS pathways, or even within the same pathway, with respect to eligibility requirements, the ability to target specific populations, set different service limits, or enable participant self-direction, states may want to consider implementing paid family caregiving across multiple authorities. Likewise, in practice, there can be significant overlap between personal care tasks and home health tasks, with home health tasks often encompassing personal care tasks. Leveraging multiple state plan and waiver authorities can help enable "a comprehensive set of options that allow CYSHCN with varying needs and conditions to receive services from paid family caregivers."[47]

Conclusion

Creating paid family caregiving programs for CYSHCN can be complicated given the various state plan and waiver pathways, state law and regulation barriers, and various policy considerations. However, as can be seen above, there is a great need to create better support for the family members who are already doing this work at great personal cost, and there are likely available pathways in each state for enabling some form of payment for either personal care or home health services. Enabling paid family caregiving is but one piece of the puzzle for ensuring adequate access to care and strong provider networks, but for those caregivers who desire to provide the services for their child, states should aid them in that choice. Furthermore, while paid family caregiving is one piece of the solution to improve the home care workforce shortage and ensure CYSHCN and CMC continue to receive supports in the community, states must also work to address the overarching barriers of difficult hiring practices, variable training requirements, and inadequate payment. AAP stands ready to assist chapters wishing to explore these policies in their home states. Contact AAP State Advocacy at stgov@aap.org for consultation and technical assistance.

Addendum: Examples of Recently Passed State Legislation*+

*This following list does not purport to be exhaustive of the number of active paid family caregiving programs or those in development, but rather is illustrative of the type of legislation that has recently advanced in state legislatures. It likewise does not include programs established exclusively through a waiver or state plan amendment. A recent presentation by the Lucile Packard Foundation, in collaboration with Team Select (a home health agency), indicated that **as of March 2023 programs were operating in CA (limited), AZ (full), CO (full), IN (limited), PA (limited), MA (partial), and New Hampshire (full)**. (see, Paid Family Caregiving for Children with Medical Complexity and Disabilities - Lucile Packard Foundation for Children's Health (lpfch.org))

+At the time of publication, there is active legislation pending in Illinois, Oklahoma, and Rhode Island. Likewise, in recent years legislation has been introduced, but not advanced, in New Mexico, Washington, Texas and Connecticut.

State	Year Passed	Bill Number(s)	Title Used	Summary
Arizona	2021	HB 2521	License Health Aide	• Creates position of "licensed health aide" – parent or guardian of a member of the Arizona long term care system currently receiving service. Licensed only to provide services to that eligible member. Same scope of practice as a "licensed nursing assistant," but may also provide medication administration, tracheostomy care, enteral care and therapy, and other tasks approved by the Board of Nursing. Services must be ordered by physician. • Add's licensed health aide services to definition of HCBS • Licensed Health Aide must submit application to Board of Nursing, including: proof the licensed health aide is a parent/guardian/family member of an individual <21 years of age eligible to receive continuous skilled nursing or skilled nursing respite care services; completion of basic curriculum and certificate from a training program prescribed the Board that must include medication administration, tracheostomy care, enteral care and therapy, and any other tasks required by the Board; completion of competency exam approved by Board. • License fee: $50 • Director shall request CMS approval no later than 60 days after promulgation of rules to implement;
Montana	2023	HB 449	Pediatric Complex Care Assistant	• Creates position of "Pediatric complex care assistant" • Must complete a training curriculum to be created by the Department and pass a hands-on examination. Training must include medication administration, airway clearance therapies, tracheostomy care, enteral care and therapy for persons <21. • Can only provide care to person < 21 for whom the assistant is a parent, guardian, other family member, or kinship care or foster care provider. • Services must be ordered by physician and consistent with plan of care • Duties limited to: Duties considered by the department equivalent to those of a certified nursing assistant; medication administration; tracheostomy care and enteral care and therapy; airway clearance therapies; other services as allowed by the department by rule • Department shall adopt rules to implement
Florida	2023	SB 452	Home Health Aide for Medically Fragile Children	• Creates the Home Health Aide for Medically Fragile Children Program (HHAMFC), allowing a family caregiver to be paid by Medicaid, through employment with a home health agency, for care provided to a relative < 21 with an underlying physical, mental, or cognitive impairment, eligible to receive skilled care or respite care services through Medicaid

				• Reimbursement rate: $25/hr, up to 8 hours/day • Directs the Department to file any state plan amendments or waivers necessary to implement • Authorizes HHAMFC to perform tasks delegated by a registered nurse, such as medication administration, tasks associated with activities of daily living, maintaining mobility, nutrition and hydration, and safety and cleanliness. • Requires services provided by HHAMFC to result in a reduction in the number of private duty nursing service hours provided to an eligible recipient. • Prohibits services provided by a HHAMFC from duplicating private duty nursing services provided to an eligible recipient • Requires AHCA, in consultation with the Board of Nursing, to approve a training program • Establishes civil liability protection for a home health agency • Requires AHCA to conduct annual assessment of program and report the findings to Governor and Legislature
New Jersey	2023	S 1307	Homemaker -home health aide	• Directs the State Medicaid agency to establish a program in which family members of Medicaid enrollees can seek certification through the Board of Nursing to become a "homemaker-home health aide" and provide certified nursing assistant services through a home health agency. • Enrollee must be <21 and entitled to receive private duty nursing services through Medicaid • Requires family member to complete any training and certification required by state or federal law and requires the employing home health agency to cover all costs of training and certification • Tasks delegated to homemaker-home health aides shall be consistent with those consistent to ones allowed by the Board of Nursing to be delegated to certified nursing assistants • Reimbursement rate: no less than $30/hr • Provides Department and Board of Nursing with rulemaking authority • Requires Department to issue report to the governor and legislature 3 years after implementation on the viability of the program
Maine	2023	HP 163	Home health aide	• Directs Maine Dept of HHS to file a state plan amendment by 7/1/24 enabling qualifying parents of children and youth with in-home personal care needs eligible for MaineCare program to be reimbursed for providing home health aide services under the Medicaid home health benefit • Department to promulgate rules to establish and implement the program

Additional Recommended Resources

- National Health Law Program – Paid Family Caregivers: State Options, Limitation, and Policy Considerations (2023)
- National Association of State Directors of Developmental Disability Services – Caring Families: Paying Family Caregivers Topic Brief (2023)
- Lucile Packard Foundation – Medicaid Paid Family Caregiving for Children (2023)
- National Academy for State Health Policy – State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs Through Medicaid (2021)

Endnotes

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[9] Ibid.

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[13] During the pandemic there were 14 states used 1135 waivers to allow personal care services to be provided by a legally responsible relative (AK, GA, IA, MD, MN, MT, ND, NH, NJ, NM, OK, OR, PA, VT). Likewise there were 39 states that used an Appendix K amendment to an existing 1915(c) waiver to temporarily permit payment for services rendered by family caregivers, including legally responsible relatives (AK, AL, AZ, CA, CO, CT, DC, DE, FL, GA, HI, ID, IL, IN, KS, LA, MD, ME, MN, MO, MS, MT, NC, ND, NH, NJ, NM, NV, OH, OK, PA, RI, SC, SD, UT, VA, VT, WI, WV). KFF. (2021). *Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19*. KFF. https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/

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[15] Centers for Medicare and Medicaid Services. (2023). All-State Medicaid and CHIP Call, June 6, 2023. Centers for Medicare and Medicaid Services. https://www.medicaid.gov/resources-for-states/downloads/covid19allstatecall06062023.pdf

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[18] 42 CFR 440.70 and 42 CFR 441.15

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[20] 42 CFR 440.167

[21] CMS, Preventing Medicaid Improper Payment for Personal Care Services.

[22] *"[P]ersonal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the [individuals with intellectual disabilities], or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such service and* ***who is not a member of the individual's family****, and (C) furnished in a home or other location."* Social Security Act § 1905(a)(24)

[23] CMS, All-State Medicaid and CHIP Call, June 6, 2023.

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[25] Centers for Medicare and Medicaid Services. (2019). Application for a §1915(c) Home and Community-Based Services Waiver: Instructions, Technical Guide, and Review Criteria. https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

[26] Ibid.

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[27] O'Malley Watts, M., Musumeci, M., Ahmula, M. (2022). *State Policy Choices About Medicad Home and Community-Based Services Amid the Pandemic*. KFF. https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-appendix/#table1

[28] States with 1915(c) waivers for medically fragile or technology dependent children: AK, CA, CO, CT, FL, IL, KS, MD, MN, NM, NY, NC, ND, OK, OR, SC, TX, UT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[29] Per KFF, as of 2022 there were 32 states that allowed legally responsible relatives to be paid providers for HCBS waiver services: AL, AK, AR, CO, DE, FL, HI, ID, IL, IN, KS, KY, ME, MD, MN, MO, MT, NH, NM, NC, ND, OH, OK, PA, SD, TN, UT, VT, VA, WV, WI, and WY. However, there were only 11 states that allowed legally responsible relatives to be paid providers for personal care state plan services: AK, AR, CA, ID, IN, IA, MN, MT, NJ, OR, and VT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[30] Of the 27 states that responded to the NASDDDS survey, the following states indicated that they allow payment of a legally responsible relative for the provision of personal care services: CT, CO, DC, GA, IA, LA, MD, MN, NM, OH, PA, WV. National Association of State Directors of Developmental Disability Services. (2023). *NASDDS Topic Brief: Caring Families: Paying Family Caregivers Topic Brief*. National Association of State Directors of Developmental Disability Services. https://www.nasddds.org/wp-content/uploads/2023/07/Caring-Families_final-0713.2023tss.pdf

[31] O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[32] Guth, M., Musumeci, M. (2021). *State Options to Expand Medicaid HCBS: Examples and Evaluations of Section 1115 Waivers*. KFF. https://www.kff.org/medicaid/issue-brief/state-options-to-expand-medicaid-hcbs-examples-evaluations-of-section-1115-waivers/

[33] O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[34] Randi, Girmash, Honsberger, *State Approaches to Reimbursing Family Caregivers*.

[35] Carter, Blakely, Zuk, Brittan, Foster, Employing Family Caregivers.

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[37] Coleman, C., Grusin, S.L., & Foster, C.C. (2023). *Providing Equitable Medical Care for Children at Home: Federal law and State Policy*. Lucile Packard Foundation. https://lpfch.org/wp-content/uploads/2024/05/Coleman-Grusin-Foster-Regulatory-Review-Final.pdf

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[43] Edwards, *Paid Family Caregivers*.

[44] O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[45] Ibid.

[46] Edwards, *Paid Family Caregivers*.

[47] Randi, Girmash, Honsberger, *State Approaches to Reimbursing Family Caregivers*.

#31404

To Whom it May Concern

Good morning I am writing this letter in regards to Senate Bill #2305 Family Paid Service Program. My name is Latecia Memet. 60yr old grandma that is a guardian of a 4yr old grandson with tramatic brain injury. He requries around the clock care. From changing his diapers, dressing bathing, feeding taking to & from his appointments such as OT, PT, Speech Feeding and where ever else he may need to go. He is the light of my world & I love him beyond words but bottom line if his care & needs were not met he would die. When this program 1st came out I was probably one of the 1st one to summit my application. My issue was I was denied because I didn't fill out the assessment correctly I really didn't know what I was doing & I answered the questions to what I thought best fit my grandson it would of helped if there was a NA box to mark or a box to explain more about him. I even got legal assistance but still was denied. I was really angry & upset & disappointed about this but life goes on. I think you need to make this a permanent program and so I can apply again and more families can benefit from this program. After all nobody knows what someone goes through until you walk in there shoes

God Bless

Thank you for
listening
Latecia Maneti

Adrienne Montonye
Regarding SB 2305
1/25/2024

My name is Adrienne Montonye. Today I speak as the sister of Amanda Burner who received benefits by participating in the pilot program that is up for vote: SB 2305. I am testifying in favor of continuation of this program as I have seen the gift of the program transform the household of my sister and her family as caregivers to my 22-year-old nephew, Kaden. The program does something unique for the hard-working families dedicated to giving the best possible care to our community of profound special needs men and women. It is an extreme point of pride of this North Dakota citizen that there is a program offered in our state to benefit the community of people who often do the hardest and kindest work for our fellow citizens.

I want to testify about what this program is already doing for my sister and her family. The program gives support and acknowledgement of their lifelong dedication to caregiving. The unmatched quality of care for my nephew Kaden and citizens with special needs comes best from a family that has spent every day caring for and being active in his treatment. My nephew, who has Leukodystrophy, has spent his life in the loving care of his family. When I asked my sister what specifically about this program was helpful she said, “It just brings so much peace to not have to think about finances. The house just feels more peaceful, and I feel more at ease.” This program takes the worry of money away and allows her to free her mind and focus on Kaden’s cares entirely. She no longer has to split her mind into work life and home cares. Where before this program she could only be employed with places that could work with an unpredictable home situation, she now can excel in her role as caregiver because she is employed as caregiver to her son and she can put her efforts fully into the work she is fully invested in and an expert in.

Please vote yes. Make North Dakotans proud of what our State does for our most profound special needs citizens!

Thank you for hearing this testimony. I appreciate your thought and care in deciding your vote on this issue.

Subject: Urge Support for SB 2305 - A Bill to Provide Vital Support to Families of Citizens with Special Needs

Dear Senator Lee and Members of the Senate Human Services Committee,

I hope this message finds you well. I am writing to express my strong support for SB 2305, a bill that will provide much-needed monetary support to families of citizens with special needs. As you may know, these families face unique and often overwhelming challenges, both financially and emotionally.

This bill represents a vital step toward easing the burden on these families and ensuring they have the resources they need to provide the best care and opportunities for their loved ones. By voting YES on SB 2305, you will help create a more equitable and supportive environment for all families in our community.

I urge you to stand with families of special needs citizens and prioritize their well-being by voting in favor of this important legislation. Your support would make a significant, positive impact.

Thank you for your time and consideration. I look forward to your support on this critical issue.

Sincerely,
Lucas Burner
803 3rd st sw,
Minot, ND 58701
701-214-0133
Luke.burner@outlook.com

Kristy Rose
701-202-2001
kristywrose@gmail.com

North Dakota Legislature
69th Assembly

RE: SB 2305

I write to you today in support of Senate Bill 2305 relating to the family paid caregiver service program.

While I do not have a child who requires extraordinary care, I know several families who do, some of whom were part of the family paid caregiver pilot program which has eased their financial, mental and emotional burdens when it comes to the care of their children.

We are all familiar with the workforce shortage issues facing our state. These shortages are even more profound for the families who need specialized, qualified, caring and reliable help. It's hard to find someone to fill orders at McDonald's, imagine how much harder it is to find someone who will not expose an immune-sensitive child to illness, to manage a GI tube or medication port, or to recognize that despite their challenges, that child is a whole person who deserves loving care, thoughtful interaction and professional assistance. These impossible-to-find caregivers are real-world angels and become a very real part of these families.

But they are few and far between.

Nobody loves a child, nobody knows the child better, than his or her own family. And if a family member is willing to quit their job – or forced to because of the lack of help – and care for the extraordinary needs presented, then their sacrifice should be honored, their work should be supported and they should be paid just as a non-related caregiver would be paid.

I know some of these moms and dads. I've heard their stories. They need help. Help we can give them by paying them for the service they provide to their children.

Please pass SB 2305.

Thank you,
Kristy Rose

#31480

The Arc
North Dakota

Senate Health and Human Services
SB 23052193
January 23, 2023

Chairwoman Lee and Members of the Senate Human Services Committee, I am Kirsten Dvorak, Executive Director of The Arc of North Dakota, supporting individuals with intellectual and developmental disabilities since 1958. We empower families and foster inclusive communities throughout the state. I stand in support of Senate Bill No. 2305.

The 2023 FINDS (Family and Individual Needs for Disability Supports) Community Report, conducted by the Institute on Community Integration at the University of Minnesota in collaboration with The Arc of the United States, highlights significant challenges faced by families across the nation:

- Financial Strain: 41% have left their jobs to provide care. Many families struggle to afford the long-term caregiving required.

- Service Availability: Many individuals with disabilities are on waiting lists for essential services. This situation dramatically strains families, often leading to substantial personal expenses.

- Caregiving Responsibilities: Family caregivers dedicate over 40 hours each week to care, profoundly impacting their health and capacity to maintain employment.

At The Arc of North Dakota, we recognize the significance of lifelong care for individuals with intellectual and developmental disabilities. However, we also understand that not all families possess the resources to meet these needs. While compensating family caregivers is essential, it should not replace comprehensive support systems. Therefore, we are dedicated to advocating for policies that provide financial assistance, home-based services, and respite care. Additionally, investing in community support is crucial to strengthen the overall network available to families. These initiatives empower families to deliver high-quality care while safeguarding their overall well-being.

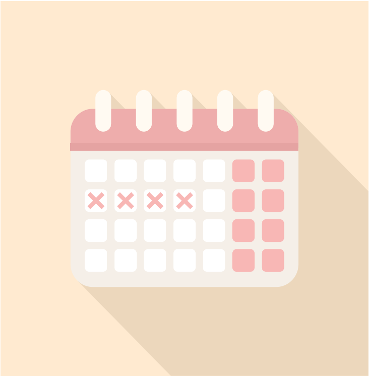
Helping families is important for enabling individuals with disabilities to receive the necessary care and support. Approving this bill offers families a vital choice to guarantee their loved ones get consistent and compassionate care. On behalf of The Arc of North Dakota and the families we assist, I encourage you to support Senate Bill No. 2305.

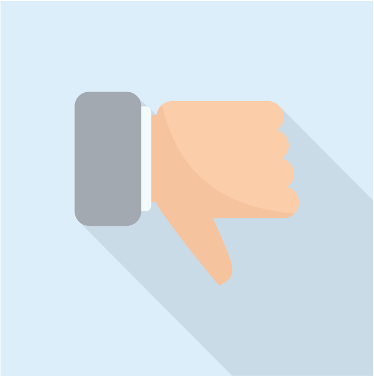
An infographic from The Arc of North Dakota's 2025 Data Book is also included for your reference

I am available for any questions.

The full FINDS Community Report can be accessed HERE https://thearc.org/resource/finds-community-report-2023-family-individual-needs-for-disability-supports/

Sincerely,
Kirsten Dvorak
Executive Director, The Arc of North Dakota

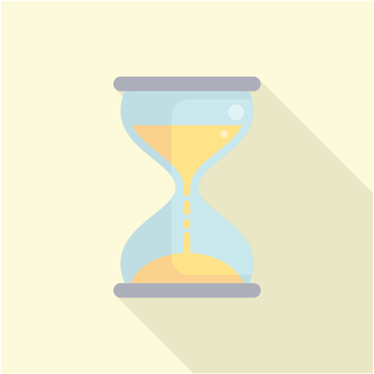


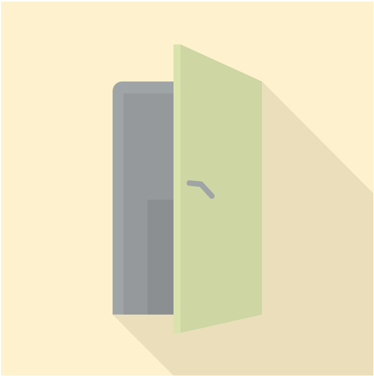


47%
Taking a leve of
absence

17%
Turning down a
promotion

77%
Going to work late
or leaving early





59%
Cutting back
their hours

36%
Warnings about
attendance

48%
Giving up work
entirely

59%
Purposely
Underemployed

The Arc of the United States,
2023

SB 2305

Senate Human Services Committee

January 27th, 2025

Madam Chair Lee and Members of the Senate Human Services Committee.

My name is Vicki Peterson, I am a Family Consultant for Family Voices of ND. Family Voices of ND is the statewide Family to Family Health Information and Education Center in ND. My role as a consultant is to support families who have children and youth with chronic health conditions, disabilities, and special health care needs. Family Voices of ND connects families to resources, application assistance, navigate systems of care, education, training, and emotional support.

I am here today to give my testimony in favor of SB2305 that would establish the Family Paid Caregiver Service Program in the ND 1915c Medicaid Waivers and serve as a modality choice of caring for a child with extraordinary needs, these needs go beyond a typical care in both medical or behavioral on which a legally responsible person would typically provide. These needs would involve complex medical or behavioral care that surpass the standard of care that is not considered normal parenting responsibilities that may require extra training or expertise. If passed this bill would make the option available in a Medicaid Waiver program that many other states have implemented in some form. ND currently has not and only created a pilot program outside of a 1915c Medicaid Waiver.

Why is this important for ND families caring for their child with those extraordinary needs? This service would be a win for everyone. It will allow family member, legally responsible adult, to be compensated for the remarkable time, care, and effort for their child with complexity in care. The service could alleviate financial strain on a family as well as the financial strain a state may have by providing those services in a nursing home care or other type of institutionalized care. Can also reduce a family having to seek out other programs if this service modality was in our 1915c Medicaid Waivers (excluding Aged and Disabled which already offers a similar option). This option in a service could allow a legally responsible adult who would be compensated at a wage that would allow to maintain financial stability and promote comprehensive well-being when considering the demanding nature of care. A fair wage, in proportion to a professional self-directed support staff would receive, would be the right choice to make. Beyond reducing financial burden, a

fair wage can improve the quality of care by dedicating more time and energy to providing exceptional care, more personalized care by meeting emotional needs as having the deep understanding of their child. Consistent and personalized care is a key importance which is beneficial for the care recipient and keeping the family unit together.

During a ND Cross Disability Advisory Council (CDAC) it was reported that there were 444 applications with a waitlist of 182 for varied reasons, on the pilot for family paid caregiver program. Many states have created this new modality of service or modifying their program that was created during the public health emergency. The workforce shortage has made this program essential for filling the gaps to ensure necessary care.

I receive many calls from families who are desperately seeking help. You heard many remarkable stories during the 2021-2023 Legislative session that provided you with the day to day lives these families lead with children that require this service to exist. There are more.

I encourage you to have a DO Pass on SB 2305 for the children with complex and extraordinary needs along with their families to be able to utilize this service.

Thank you for your time and consideration.

Vicki L Peterson

Family Voices of ND

vicki@fvnd.org

701-258-2237

Lobbyist #293

Statement of Support for Senate Bill 2305 1/26/2025

Dear Members of the Senate Human Services Committee

I strongly support Senate Bill 2305 because it recognizes the incredible sacrifices family caregivers make every day to support their loved ones. Caring for someone with extraordinary medical or behavioral needs can be exhausting and financially draining, but this bill offers meaningful relief.

By compensating family caregivers, we're helping people stay in their homes, where they feel safe and loved, rather than forcing them into institutions. This bill also ensures caregivers are supported based on their loved one's unique needs and brings in voices from the Cross-Disability Advisory Council to help shape a thoughtful and effective program.

This is a compassionate and practical step to support families in North Dakota who are doing some of the hardest, most important work there is. I urge the Committee to give this bill a Do Pass and show caregivers they're not alone.

Sincerely,

Kara L. Geiger
Mandan

Testimony in Support of SB2305
2025 Legislative Session
01/26/2025

Senator Lee and Members of the Senate Human Services Committee,

Allison Goetz,Sterling, North Dakota.

I am writing in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and the cross-disability advisory council.

This bill is a huge opportunity to help all those families with special needs children. Our son who was diagnosed with Cask Gene Mutation will be starting school next year and we are concerned for how it is going to go. There is really no support for him after school or before. My daughter goes to blast and that would not be a good program for him. He needs more one on one support and he would not get that there. It is just high school students who would not be used to watching someone like that, especially with all the other kids there. With school hours changing now, it is making it harder for parents with children who have special needs to be able to hold a job. I will most likely need to leave my job and also take a pay cut to be able to support my child. We do have respite, but that is not something we can count on. We have one good person and that is it. No one is wanting to work in respite and if they do, it is most likely someone you can not trust. It is younger high school kids who do not want to actually play with our son or they are unable to come out to our house in Sterling or it is someone who is out of high school just looking for money. They could be on drugs or someone who we could not trust. With respite they do not do drug tests. We have had multiple people try and take care of our son through respite who were not a good fit. We had a younger girl who just sat on her phone while Easton was in the back room playing and not being supervised, we had some who showed up for one hour and then claimed she was sick and left. So we had to leave our job and go home to be with our son and when we contacted her again, she kept saying she was sick and ended up quitting. That same girl ended up being on drugs. We had actually asked the program manager after she became a parent if she would trust the people they have hired to watch her child and she actually said absolutely not. If she is unable to trust those people with a "normal" child, how are we supposed to trust them with our children who are unable to speak for themselves or know what is right from wrong. With my son I have had leave my job during the middle of the day due to him being in Becep and needing to take him to daycare afterwards. I have had to leave my job at random hours due to him being in therapy multiple days a week. It is very hard to find a job to be flexible with a schedule like that. This would be a huge impact on all those families out there who have to take care of their children, when others are unable to.

In conclusion, I am asking the committee to vote to pass this bill.

Allison Goetz
701-426-2913

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Testimony
Senate Bill No. 2305
Senate Human Services Committee
Senator Judy Lee, Chairman
January 27, 2025

Chairman Lee, and members of the Senate Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Section with the Department of Health and Human Services (Department). I appear before you to offer an update on the pilot project that was funded by SB 2276 in the 2023 legislative session. Please note that this program is not included in the Executive Budget Recommendation this is being heard in Appropriations.

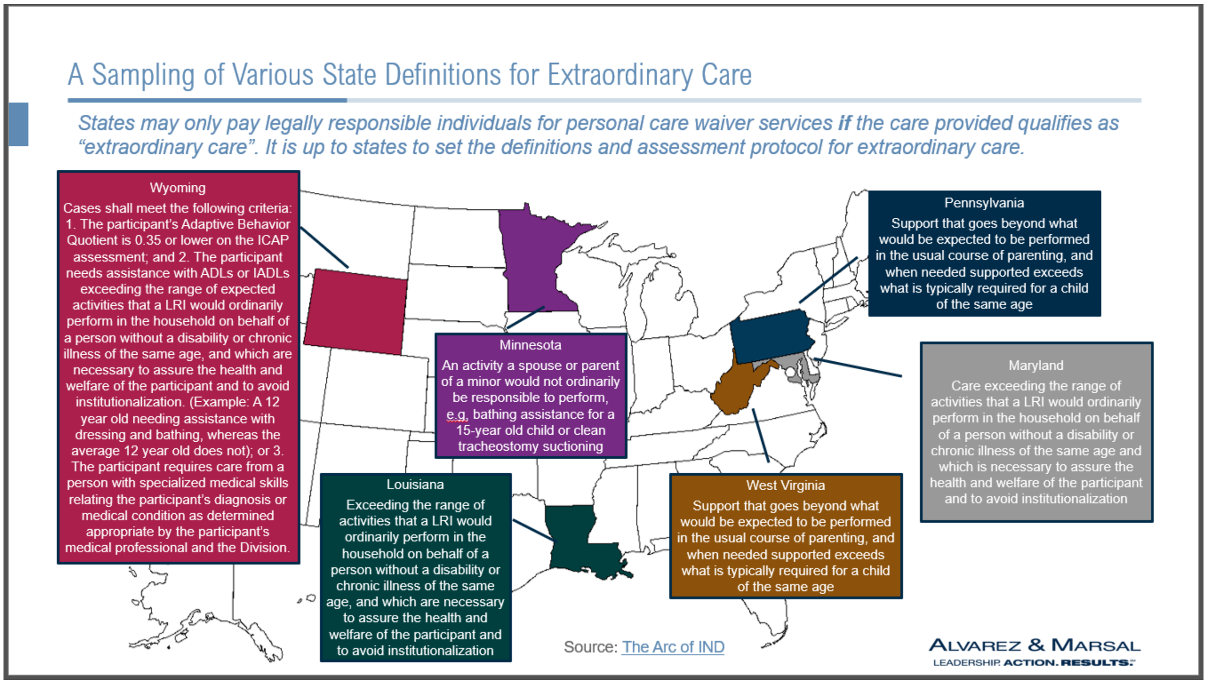
SB 2276 directed the Department to develop a family caregiver service pilot program to provide payments to legally responsible individuals offering extraordinary care to eligible individuals. This involved creating administrative rules, an assessment tool, and a payment portal, all to be implemented by April 1, 2024.

While the pilot program is funded by state general funds, our ultimate goal was to ensure the program's structure would align with Medicaid rules. If the state decided to move the family caregiver service beyond a pilot, this alignment would help pave the way for a smoother transition to Medicaid funding in the future. In accordance with the Centers for Medicare and Medicaid Services requirements, when compensating legally responsible individuals for providing care to children under 18, it is essential to demonstrate that the care provided is extraordinary, not ordinary. To meet this requirement, the Department needed to define and assess extraordinary care.

We conducted a national scan and found that no existing evidence-based assessments adequately addressed the evaluation of extraordinary care. Instead, states have developed their own assessment tools, including North Dakota, which followed a similar approach. After drafting our assessment, we worked with several families to test the tool; these families represented children, adults, and individuals with complex medical and behavioral needs. Based on their feedback, we made adjustments to the assessment, and the scoring methodology was finalized.

North Dakota’s assessment includes categories and questions that may not apply to all age groups. While every child receives points, the tool does not assign points for “ordinary” care, as determined by the age of the recipient of services.

In December, representatives from Alvarez & Marsal shared the information below with the Cross Disability Advisory Council. This provides a snapshot of how other states have defined extraordinary care.



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.

Minnesota
An activity a spouse or parent of a minor would not ordinarily be responsible to perform, e.g. bathing assistance for a 15-year old child or clean tracheostomy suctioning

Louisiana
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 are necessary to assure the health and welfare of the participant and to avoid institutionalization

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

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

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

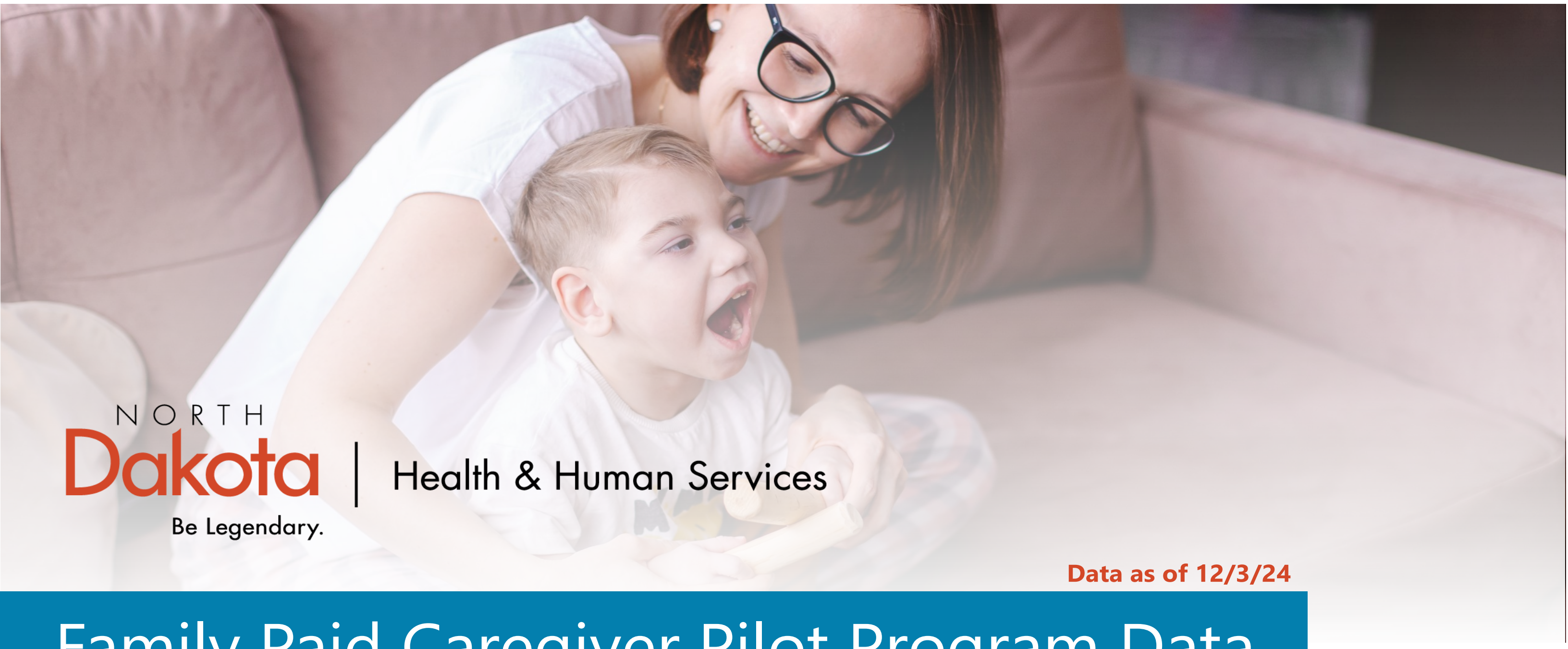
Source: The Arc of IND

ALVAREZ & MARSAL
LEADERSHIP. ACTION. RESULTS.

Families expressed a strong desire to keep the process simple and avoid complicating the application procedure. In response, the Department created a process that allowed families to complete the assessment themselves, rather than requiring a third-party professional such as a physician. Families often have the most intimate understanding of an individual's needs, strengths, and challenges. However, we recognize that a self-assessment methodology creates a risk that families may unintentionally overstate or understate certain issues, which could lead to less objective evaluations.

Additionally, some families requested the inclusion of a narrative section in the assessment. While narratives can provide valuable context, not all family members are comfortable or able to convey detailed, clear, or accurate information in this format. Given the limited nature of the pilot, it was critical to ensure the assessment remained as objective as possible.

This concludes my testimony. I would be happy to try to answer any questions the committee may have. Thank you.



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Data as of 12/3/24

Family Paid Caregiver Pilot Program Data

Pilot program start date: 4/1/24

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 Service: **$2,200,000**

Total Funds Authorized: **$1,252,245.67**

Held for Appeals: **$609,131.25**

Held for Pending Applications: **$338,623.08**

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

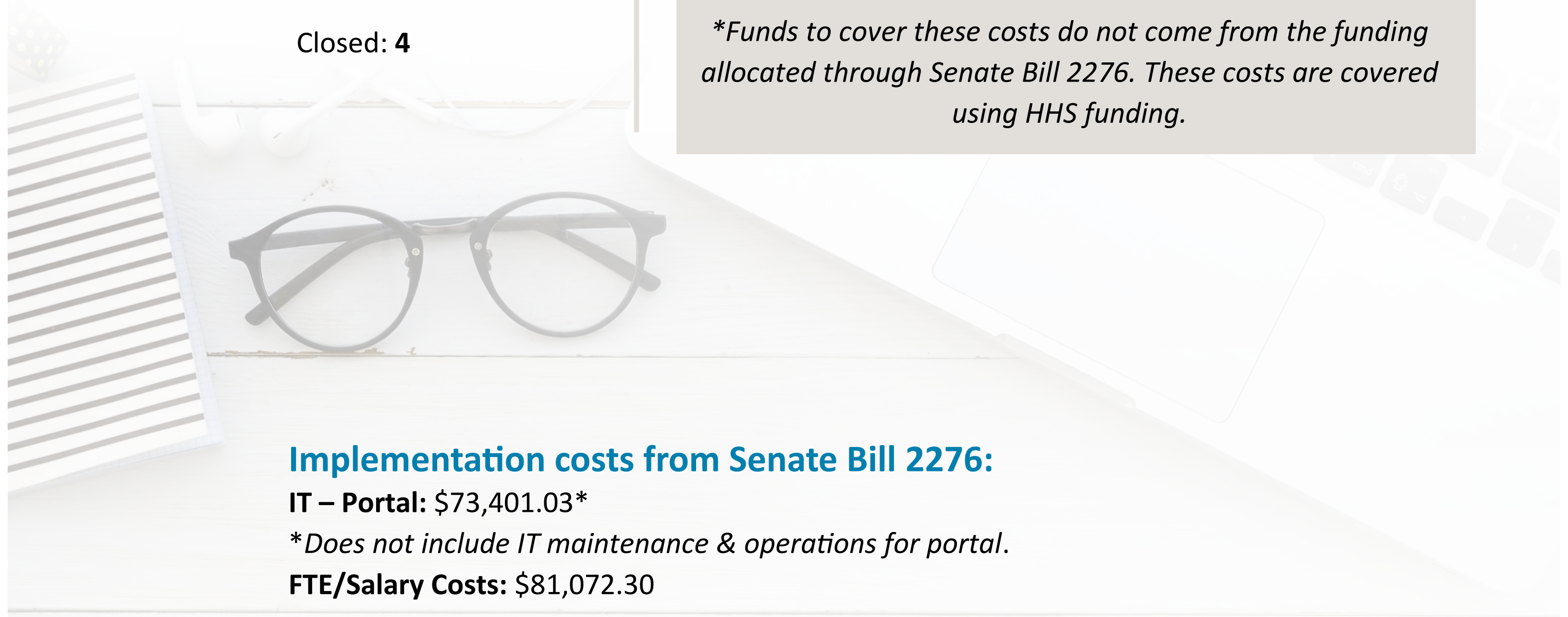
**Anyone who has been denied for an appealable reason would have appeal rights where the funding is held until 30 days after the decision date (unless appealed further, then the funding continues to be held)*

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.*



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

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Family Paid Caregiver Pilot Program

Frequently Asked Questions

Program Criteria:

Q1. What is the family paid caregiver pilot program?

A. A state funded pilot program that will provide payments to family caregivers who provide extraordinary care to eligible individuals enrolled in a Medicaid 1915 (c) waiver.

Q2. When does the pilot program start?

A. April 1st, 2024

Q3. Who is eligible for this pilot program?

A. Participants must meet all the following criteria:

- enrolled in a Medicaid 1915c waiver (Autism Spectrum Disorder Waiver, Medically Fragile Waiver, Children's Hospice Waiver, Developmental Disabilities Traditional IID/DD Waiver);
- support needs are not otherwise compensated though other services available in a 1915c waiver or Medicaid State Plan; and,
- assessed needs meet extraordinary care.

Q4. Is there an age requirement for participants?

A. No. This pilot program is available to all participants enrolled in one of the qualifying 1915c waivers.

Q5. What is extraordinary care?

A. Extraordinary care means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of the applicant or eligible participant without extraordinary medical or behavioral needs and is necessary to assure the health and welfare and to avoid institutionalization of the applicant or eligible participant in need of care.

Q6. Who is a family caregiver?

A. A legally responsible individual who lives with and provides daily care(s) to the applicant. This may include, but not limited to a biological or adoptive parent, non-entity custodian, guardian, or spouse.

Q7. Can the family caregiver still have employment outside of this pilot program?

A. Yes, the family caregiver would be able to be employed and also partake in this pilot program if found eligible.

Q8. Will this affect other waivered services I may be receiving?

A. Those who are found eligible for this pilot program will still be able to receive the waivered services they are currently receiving. Hours within the waivered service will not automatically decrease but will continue to be discussed as a team on how the service(s) is meeting the needs of the individual or if any changes are needed.

Application:

Q9. Who can apply and what is the process for applying?

A. The applicant or legally responsible individual may submit an application within the Family Caregiver Portal. Once the application is reviewed, the applicant or legally responsible individual will receive an assessment to complete. This self-assessment will aid in identifying the extraordinary needs of the applicant. This application is valid for 1 year.

Q10. If the eligible participant lives in more than one household can both family caregivers enroll in this pilot program?

A. Yes. Both family caregivers are eligible as long as the pilot program requirements are met.

Q11. Will a background check be required?

A. The family paid caregiver will be required to submit the Child Abuse & Neglect Background Inquiry (SFN 433), however no criminal background check is required.

Q12. If I am providing care to more than one person in my household, am I able to receive payment for each?

A. No. This program is limited to one per household.

Q13. Is there a deadline to apply for this pilot program?

A. There is no specific deadline as applications will be reviewed as they are received. The number of participants and funding is limited and once those limits have been exhausted, applications will no longer be approved.

Q14. Will I need to reapply for this pilot program?

A. Yes. The initial application and assessment are valid for 1 year. If the eligible participant and legal decision maker wish to continue past the initial year, they

will need to reapply prior to the expiration of the approved application and assessment.

Q15. How will I know if I am approved?

A. A letter of determination will be sent to applicant.

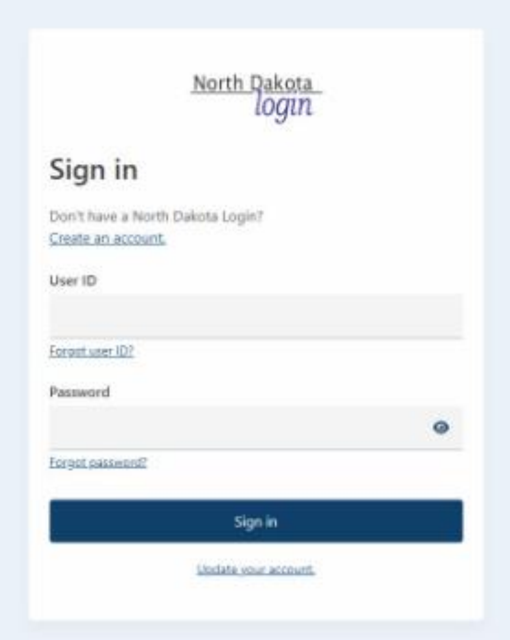
Portal:

Q16. What is the Family Caregiver Portal?

A. A secure web-based system that will provide the applicant or legally responsible individual access to the application, communication, authorizations, and payment requests.

Q17. How do I access the Family Caregiver Portal?

A. The portal will be available on April 1st, 2024, and the link will be available on our website hhs.nd.gov/family-paid-caregiver-pilot-program. If you already have a North Dakota Login account (*pictured below*), you will be able to use that User ID and password to access the portal. A new account can be created if you do not wish to use the same account, however, a different email address will need to be used.



Don't have a North Dakota Login?

Payment:

Q18. What is the rate of payment?

A. Eligible participants ages 0 through 17 will receive an authorization for $77.45 per day and participants ages 18 and older for $154.89 per day. This is a daily rate.

Q19. How do payments work?

A. Once an authorization has been created, the family caregiver will be able to submit a request for payment twice a month in the Family Caregiver Portal. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm). The authorization will be valid for up to six months and may be reissued for an additional six months.

Guidance for requesting payments will be included via email once a payee account has been successfully created.

Payments will be issued two times a month according to the defined payment schedule:

Time Period	Request for Payment Due to State	Payment Date
April 16-30	5/5/2024	5/15/2024
May 1-15	5/20/2024	5/31/2024
May 16-31	6/5/2024	6/14/2024
June 1-15	6/20/2024	6/28/2024
June 16-30	7/5/2024	7/15/2024
July 1-15	7/20/2024	7/31/2024
July 16-31	8/5/2024	8/15/2024
August 1-15	8/20/2024	8/30/2024
August 16-31	9/5/2024	9/13/2024
September 1-15	9/20/2024	9/30/2024
September 16-30	10/5/2024	10/15/2024
October 1-15	10/20/2024	10/31/2024
October 16-31	11/5/2024	11/15/2024
November 1-15	11/20/2024	11/29/2024
November 16-30	12/5/2024	12/13/2024
December 1-15	12/20/2024	12/31/2024
December 16-31	1/5/2025	1/15/2025

Q20. How do I know what days I am able to request payment for?

A. If the eligible participant was in your care that day, you are eligible to submit a request for payment within the program guidelines. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm).

Q21. If more than one family caregiver is authorized to provide care, how do payments work?

A. The maximum number of days that can be claimed between all approved caregivers for the eligible participant is five days per week (Sunday 12:00am – Saturday 11:59pm). If the family caregivers both provided care on the same day,

they will need to decide which family caregiver requests payment for that day. If there are duplicate requests for payments on the same day, both will be denied.

Q22. What happens if I missed the due date for requesting a payment according to the payment schedule?

A. A request for payment may be submitted after the missed due date and payment will be issued on the next scheduled payment date.

Q23. Is this considered income for the family caregiver?

A. Yes, you will receive a 1099 and this income may impact other benefits you may be receiving. It is the family caregiver's responsibility to report this income as appropriate.

Q24. What happens if I don't request payment?

A. If a request for payment is not submitted for thirty calendar days, the family caregiver will be notified. If an additional thirty calendar days pass without a request for payment, the service may be terminated due to inactivity.

Q25. Will I be required to pay this back at any point?

A. If it is discovered that there is intentional deception or misrepresentation made by the applicant or family caregiver, the funds may be required to be paid back.

Q26. If the pilot program ends or the participant/family caregiver has been terminated, how long do I have to request payment?

A. You would have 15 calendar days to submit that final request for payment.

Quality Assurance:

Q27. How will the Department monitor services?

A. Face-to-face visits will be completed by your current waiver case manager at a minimum of every six months. These visits may coincide with already occurring face-to-face visits. This will ensure that the plan of care/plan for supports is monitored adequately, and the participant's needs are met by the family caregiver.

Q28. If a denial, revocation, or termination is received can the decision be appealed?

A. Yes. However, it is not appealable if one of the following reasons has been given:

- Funding has been exhausted for the pilot program.
- The applicant is no longer eligible for a Medicaid 1915c waiver.
- The application has been withdrawn.

Q29. Who can appeal?

A. The applicant, eligible participant, or family caregiver have the right to timely appeal.

Q30. How do I appeal?

A. A request for an appeal must be submitted in writing within thirty (30) calendar days of the notice issued. You may represent yourself in an appeal hearing or may use legal counsel, a friend, or other spokesperson.

Appeals Supervisor
North Dakota Department of Human Services
600 East Blvd Ave Dept 325
Bismarck ND 58505-0250
Phone: (701) 328-2311
Toll Free: (800) 472-2622
ND Relay TTY: 711
Fax: (701) 328-2173
dhslau@nd.gov

Q31. Who do I contact if I have questions?

A. Any questions can be submitted to familycaregiver@nd.gov.

Senate Human Services
SB 2305
January 26th, 2025

Chairman Lee and members of the Senate Human Services committee,

My name is Katynka Morrissette and I live in Bismarck, ND with my husband and our 3 young children. I am here today in support of Senate Bill 2305, pertaining to the family paid caregiver service program and the Cross-Disability Advisory Council.

I am here today to give testimony on why I support SB 2305 and share with you how it impacts our family. I am the primary caregiver to our three children Joey (age 9), Medrick (age 8), and Eleanor (age 7), who are on the Medically Fragile Waiver. They require extraordinary care due to their metabolic condition and other complexities.

Daily they require multiple doses of medications and nutritional support administered through their G or G/J tube, a complex feeding schedule and diet, glucose and ketone checks, breathing treatments, care for their medical ports, and assistance with home therapy treatment plans and daily living activities. Due to their high level of need and how specialized some of these cares are, we have been unable to find appropriately trained staff to provide support for them.

In 2023 legislation was passed (SB 2276) that developed the Paid Family Caregiver Pilot Program in North Dakota. Our family has been able to participate in the program and see firsthand the benefits that have resulted. This has reduced some of the financial burden of my previously lost income, we saw a further reduction in hospital admissions this past year, and it has improved the overall health of our children. Last week, Joey told me he was “happy I was his worker because he never had to worry someone gave him the wrong food and was going to make him sick.” I did not foresee the positive mental impact this program would provide, but the fear I had as a mother in leaving my children with an unqualified caregiver is nothing in comparison to the fear and anxiety my child was feeling.

I support SB 2305 requiring the caregiver payments to be comparable to the rate for self-directed support staff, because I am a qualified and trained caregiver who wants to continue to be seen as part of the workforce. The payment rate should not be decreased due the age of the participant (as we saw in the pilot program) but should be based on the rate we are authorized to pay a direct support professional that we hire off the street.

I also support the amendment to ensure the extraordinary care assessment fully encompasses the support needs of the participant, considering assistance with daily living tasks, emotional and behavioral health, and medical cares. The assessment should be balanced and ensure that kids of all ages are able to access this service option if their needs and cares are extraordinary.
Thank you for your time today and allowing me to share with you the impact your past legislative work has had on our family. I am asking for a “Do Pass” recommendation on Senate Bill 2305 so that more families in our state can access this service option with improvements learned through the pilot program and fill the caregiver shortage that so many have experienced. I will now answer any questions you may have for me.

Thank you again for your time and consideration.

Katynka Morrissette

Katynka Morrissette
jkmorr@icloud.com
701-301-1541

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2305

Senate Human Services
Monday, January 20, 2025
Senator Judy Lee, Chair

Chair Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I'm writing as the representative for Designer Genes of ND, Inc. Designer Genes' membership represents individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

First off, I'd like to thank you for your work and investment in the concept of paid family caregiving during the 68th legislative session and help to kickstart the current pilot program. I'd also like to thank the Department for their dedicated work to "go live" and make the program a reality for 50 North Dakota caregivers. (Per 12-11-24 Cross Disability Advisory Council Meeting).

Designer Genes is in support of SB 2305 and asks for a "do pass" from this committee. We are asking your consideration of an amendment in Section 1.4 (on page 2), lines 18 – 19 to include the words "developmentally accurate and include a family statement of need". We are also open to a discussion about Section 1.4, lines 19 – 21 because we are still unclear how this affects a family's ability to use other waiver services, such as respite, if they are being paid a daily rate. This language exists in the current law from SB 2276 that you passed last session. When the paid family caregiving option is woven into the Medicaid waivers and being paid for with a Medicaid match, this will become a more critical consideration.

We estimate that there are about 600 individuals with Down syndrome that live in North Dakota and a majority of those individuals are screened to the Individuals with Intellectual Disabilities/Developmental Disabilities 1915c Medicaid Waiver. Quality waiver service options are one of our advocacy priorities and having the paid family caregiver option in our Medicaid waivers is important to our families across the lifespan. Individuals with Down syndrome and their families are able to achieve quality lives in their communities with the formal supports of the Medicaid waivers and State Plan

Medicaid. One thing that is important to note is that families who have children eligible for our Medicaid waivers depend on the service options within the waivers, but also depend on having access to State Plan Medicaid for their children. When they can't use waiver services due to a lack of workforce or quality providers, they run the risk of losing both the waiver service options and State Plan Medicaid. This option can help provide some confidence for families of children with exceptional need that they will not lose coverage.

We are concerned about the current assessment as it does not offer enough information to the Developmental Disabilities Section for children under 8. As you will probably hear in other testimony, the younger a child is, the less items that can be completed on the current assessment. For children with Down syndrome, this is especially concerning as many conditions such as congenital heart defects, gastro-intestinal defects, and childhood leukemias may present themselves at birth. These conditions to name a few can cause lengthened hospitalizations, an inability to use typical child care, increased care coordination efforts, trips out of state for medical care, and missed work for parents. While an infant needs total care, the care for an infant with failure to thrive or who is post-surgical looks much different. We've got to figure out a way to "measure" this to assist our families during this time of increased pressure.

We understand the SB 2113 made changes to the Cross Disability Advisory Council (CDAC). Even with those changes, we continue to support Section 1.6 and think that CDAC is an effective method of assuring stakeholder involvement on the paid family caregiver service option.

Please consider the passage of SB 2305 with our suggested amendment considerations. I'm available for any questions.

Roxane Romanick
Designer Genes of ND, Inc.
701-391-7421
info@designergenesnd.com

Testimony on SB 2305
January 27, 2025
Senate Human Services Committee

Good day, Madam Chair Lee and members of the Senate Human Services committee. My name is Sarah Carlson. I live in Dickinson, ND and I am writing this, representing my own thoughts and not on behalf of my employers. I am in support of SB 2305.

I have a 12-year-old son, Beckett, who has severe multiple disabilities. He has had these since birth and they are lifelong conditions.
SB2305 allows families, specifically members who reside with the person with the disability to be paid caregivers. For the sake of this letter, I will refer to the dominate role as 'parents,' but this would also include older siblings, multigenerational families, etc.

As a parent to Beckett, every week I must decide how I will juggle his appointments, medical needs, and my work life. I direct services for adults with disabilities and am a critical part of our organization. Not only do I provide leadership to my team of about 75+ staff, I also fill in for staff shortages and work 50+ hours weekly. Leaving my job will only increase the strain on community providers with workforce shortages. This has been something I have needed to consider, though, because of my son's needs and the lack of workforce available to support him. I am grateful that my husband, with a less-demanding full-time job, can be counted on to be home every day after work and adjust to be home if Beckett is ill and I am counted on for my job. He also has not pursued leadership within his vocation because of Beckett's needs and my own leadership role. We make decisions like this daily.

As a parent, I will always be dedicated to my child. But Beckett's needs are extraordinary and the work that I do for him is simply beyond that of typical parents. I will always be "mom," but there are many days that reading, making meals, and monitoring his tablet usage would be simpler. I juggle additional honorary roles of physical, occupational and speech therapist, special education teacher, social worker, medical specialist, pharmacist, etc. A peak year, he had over 200 appointments in a year. As a twelve-year old, the department of human services says that not only can he be left alone, he can babysit and be responsible for other children. Beckett's supervision needs are far beyond that—with his seizure disorder and support needs, he is in our line of sight almost always, and leaving him alone for any period of time does not happen, nor is that likely in the future. I sleep in the same room as him to monitor for seizures and apneic episodes, relying on my light sleep patterns to wake if I hear him starting a seizure or pauses in breathing. Beckett weighs about 100lbs—we lift and reposition him several times a day as he relies on full support for all movement. These are all adjustments that our lives have adapted to, but speak to the extraordinary hours and dedication families commit to.

The workforce shortage does not meet our needs. We have hours available for Beckett to receive support through self-directed service, but there are not workers available. The last person that we interviewed was a nursing student currently working as a CNA at a long term care setting. He declined the job: it was too much work. Supporting Beckett is challenging, but rewarding work. The economy is an employee's arena. Providing self-directed support is not enticing for some staff, as I am unable to provide benefits or a competitive wage. I understand that there are fiscal impacts to commit to provide this for families, but downstream, if we don't do something, we are looking at other fiscal impacts, like children needing to be institutionalized so families can work outside the home.
Thank you for your time and consideration. Please vote in favor of SB 2305.

Sarah Carlson
Cell: 515.450.7378

Displaying title 42, up to date as of 1/23/2025. Title 42 was last amended 1/23/2025.

Title 42 —Public Health
Chapter IV —Centers for Medicare & Medicaid Services, Department of Health and Human Services
Subchapter C —Medical Assistance Programs
Part 440 —Services: General Provisions
Subpart A —Definitions

§ 440.167 Personal care services.

Unless defined differently by a State agency for purposes of a waiver granted under part 441, subpart G of this chapter—

(a) *Personal care services* means services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for individuals with intellectual disabilities, or institution for mental disease that are—

(1) Authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State;

(2) Provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and

(3) Furnished in a home, and at the State's option, in another location.

(b) For purposes of this section, *family member* means a legally responsible relative.

[42 FR 47902, Sept. 11, 1997]

#32299

North Dakota Medicaid Waivers

1915(c) Home and Community Based Services (HCBS) Waivers

- Autism Spectrum Disorder Waiver
- Children's Hospice Waiver
- Waiver for Medically Fragile Children
- Waiver for Home and Community Based Services
- Traditional Intellectual Disabilities and Developmental Disabilities HCBS Waiver

- 1915(c) waivers have two components of eligibility:
  - Functional Need
    - Assessments are used to measure an individual's needs. The assessment helps shape the care plan in addition to verifying eligibility.
  - Financial
    - For waivers, only the income of the individual applying for the waiver's income is used to determine financial eligibility.
    - Allows coverage of disabled individuals at incomes higher than those that would traditionally qualify for Medicaid.

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HCBS Programs and Populations

	Intellectual and Developmental Disabilities	Physical Disabilities	Behavioral Health	
Adults	Medicaid State Plan			
	Traditional Intellectual Disabilities and Developmental Disabilities HCBS Waiver	Waiver for Home and Community Based Services Programs for All Inclusive Care for the Elderly (PACE)	1915(i)	
Children	Medicaid State Plan			
	Traditional Intellectual Disabilities and Developmental Disabilities HCBS Waiver Autism Spectrum Disorder Waiver	Waiver for Medically Fragile Children	1915(i)	Children's Hospice Waiver

Money Follows the Person →

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Medicaid Children Waiver Service Comparison

Developmental Disabilities

- Residential Habilitation
- Extended Home Health Care
- Behavioral Consultation
- Environmental Modifications
  - $40K for 5 years
- Equipment And Supplies
  - $5K per year
- Family Care Option
- In-home Supports
  - 300 hours per month
- Infant Development
- Respite
  - 600 hours per year

Medically Fragile

- Program cap of $25,300.00 to be used towards all waiver services except Case Management per fiscal year
- Case Management
- Institutional Respite
- Dietary Supplements
- Environmental Modifications
- Equipment & Supplies
- Individual and Family Counseling
- Transportation Services

Autism

- Respite
  - 40 hours per month
- Service Management
  - 16 hours per month
- Assistive Technology
  - $5K duration of waiver
- Community Connector
- Remote Monitoring

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Serving Children with Disabilities

2021

SB 2256: Legislative Management Study of Developmental Disability Services and Autism Spectrum Disorder Waiver and Voucher Programs

2022

North Dakota Developmental Disabilities Study
Recommended Children's Cross Disability Waiver to provide individual and family supports.

2023

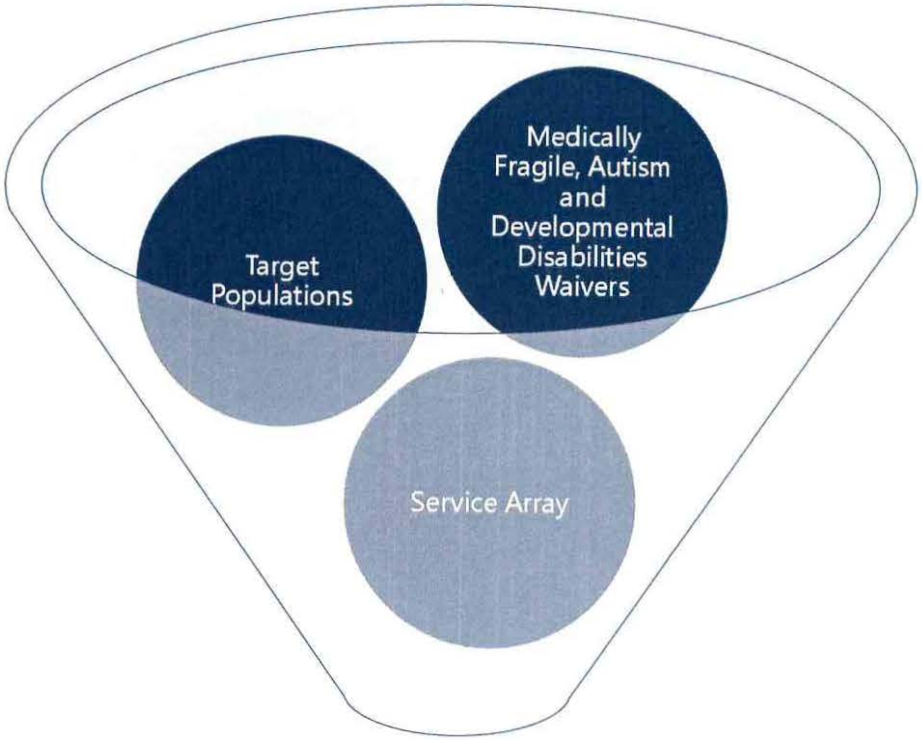
SB 2276: Established Cross Disability Advisory Council

Cross Disability Advisory Council met monthly from December 2023 – May 2024 to provide input regarding design of new cross disability waiver.

2024

Cross Disability Advisory Council compiled detailed recommendations in design of a potential new cross-disability children's waiver.

2025



Cross Disability Children's Waiver
helps children and families gain independence, self-determination, social capital, economic sufficiency, and community inclusion.

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To summarize, when a state provides for payment to legally responsible individuals for the provision of personal care or similar services, the services will be equivalent to services supplied by other types of providers. The waiver must also specify:

- The types of legally responsible individual (as defined in state law or regulations) to whom payment may be made;
- The waiver personal care or similar services for which payment will be made;
- How the state distinguishes extraordinary care from ordinary care;
- The state policies to determine that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant;
- When the legally responsible individual has decision-making authority over the selection of providers of waiver services, the state's process for ensuring that the legally responsible individual uses substituted judgement on behalf of the individual;
- Any limitations of the circumstances under which payment will be authorized;
- Any limitations on the amount of services for which payment will be made;
- Any additional safeguards not specified above the state implements when legally responsible individuals provide personal care or similar services;
- How the state implements required oversight, such as determining that payments are made only for services rendered.

CMS Review Criteria

When the waiver provides for the payment for personal care or similar services to legally responsible individuals for extraordinary care, the waiver specifies:

- The types of legally responsible individuals to whom payment may be made;
- The waiver personal care or similar services for which payment may be made;
- The method for determining that the amount of personal care or similar services provided by legally responsible individual is "extraordinary care," exceeding the ordinary care that would be provided to 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;
- The state policies to determine that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant;
- When the legally responsible individual has decision-making authority over the selection of providers of waiver services, the state's process for ensuring that the legally responsible individual uses substituted judgement on behalf of the individual;
- Any limitations on the circumstances under which payment will be authorized or the amount of personal care or similar services for which payment may be made;
- Any additional safeguards the state implements when legally responsible individuals provide personal care or similar services; and
- The procedures that are used to implement required state oversight, such as ensuring that payments are made only for services rendered.

Item C-2-e: State Policies Concerning Payment for Waiver Services Furnished by Relatives/ Legal Guardians

Instructions

This item concerns state policies regarding payment for waiver services rendered by relatives and/or legal guardians that do not fall within the scope of Item C-2-d. Select whether the state makes payments to relatives or legal guardians for any waiver service (besides personal care or a similar service furnished by a legally responsible individual as described in C-2-d). If the state makes payments to relatives and/or legal guardians for waiver services, select one of the next three choices and provide the additional information under the selected choice.

Technical Guidance

At the option of the state, waiver services may be provided by a relative and/or legal guardian of the participant. When responding to this item, keep in mind that Item C-2-d addresses extraordinary care payments to legally responsible individuals who furnish personal care or similar services to a waiver participant. **For the purposes of this item, legally responsible individuals are considered to be a type of "relative" with respect to payments for the provision of waiver services other than personal care or similar services.** When a relative or legal guardian may be paid to provide waiver services, the relative or legal guardian must meet the provider qualifications that have been specified for the service. Services must be monitored as provided in Appendix D-2 and there must be a properly executed provider agreement.

When relative/legal guardians deliver services, all required statutory and regulatory components of 1915(c) waivers must continue to be met, including, but not limited to, an individual's free choice of providers, adherence to person-centered service planning, health and welfare oversight, and ensuring community integration consistent with the home and community-based settings regulations.

This item presents four response choices as follows:

- **No Payments**. A state may elect not to make payments to relatives or legal guardians for the provision of any waiver services.
- **Specific Circumstances**. A state may elect to pay relatives or legal guardians for the provision of specified waiver services only in *specific circumstances*. Such circumstances must be specified by the state. Specific circumstances might include: (a) the lack of a qualified provider in remote areas of the state; (b) the lack of a qualified provider who can furnish services at necessary times and places; (c) the unique ability of a relative or legal guardian to meet the needs of a person; and/or, (d) other circumstances specified by the state.

  When this choice is selected, the waiver must specify the following:

  - The types of relatives or legal guardians that may be paid to furnish waiver services. For example, a state may specify that relatives may be paid to furnish services but not legal guardians. The state may specify that only relatives who do not live in the same household as the participant may be paid to furnish services. A state may specify that certain types of relatives may be paid to furnish services (e.g., grandparents of the participant) but others may not (e.g., legally responsible individuals). A state may provide that legally responsible individuals may be paid to furnish services (other than personal care or similar services, which have been addressed in Item C-2-d) that require specialized skills (e.g., nursing or physical therapy), provided that the legally responsible individual is not legally obligated to furnish such services.

- The types of waiver services, and any limitations on the amount of waiver services, for which payment may be made to a relative or legal guardian. Non-legally responsible individuals may be permitted to furnish personal care or similar services.
- The specific circumstances when payment may be made to a relative or legal guardian. The waiver also must describe the method for determining when these circumstances apply.
- When payment may be made to a relative/legal guardian, the waiver should include the state policies for determining that the provision of waiver services by a legal guardian is in the best interests of the waiver participant.
- When the relative/legal guardian has decision-making authority over the selection of providers of waiver services, the state's process for ensuring that the legally responsible individual uses substituted judgement on behalf of the individual;
- Any additional safeguards the state implements when relatives/legal guardians provide waiver services; and
- The procedures that are followed to ensure that payment is made only for services rendered.

In Appendix C-3, there is the opportunity to select whether a waiver service may be provided by a legally responsible individual or a relative/legal guardian. When this choice has been selected, the selection in Appendix C-3 is qualified by the response to this item (i.e., "relative/legal guardian" means the types that are specified in this item). It is not necessary to repeat the information provided in response to this item in the service specifications.

- **Specific Circumstances Do Not Apply**. A state may provide that relatives or legal guardians are permitted to be paid for rendering waiver services but <u>not</u> limit payment for such services to specific circumstances. That is, provided that the relative otherwise meets the qualifications to provide a service, the state will make payment to the relative or legal guardian. When this selection is made:
    - Specify any limitations on the types of relatives or legal guardians who may furnish services (e.g., whether legally responsible individuals are excluded).
    - In Appendix C-3, for each waiver service that a relative or legal guardian may furnish, check off relative/legal guardian as a provider type. When relative/legal guardian is not checked off in Appendix C-3, the state does not allow relatives or legal guardians to be paid to furnish the service. For example, if this selection has been made in Item C-2-e and transportation is the only service that has been checked off in Appendix C-3, then only the relatives or legal guardians specified here may be paid to furnish transportation and they may not be paid to provide any other waiver services.
    - Specify the state policies to determine that the provision of waiver services by a relative/legal guardian is in the best interests of the participant.

  - When the relative/legal guardian has decision-making authority over the selection of providers of waiver services, the state's process for ensuring that the legally responsible individual uses substituted judgement on behalf of the individual.
  - Specify the procedures that have been established to ensure that payment is made only for services rendered.
- **Other Policy**. Select this choice when either of the foregoing two choices does not accommodate the state's policies. For example, the state may restrict payment for waiver services to specific circumstances in the case of some services or certain types of relatives or legal guardians but not in the case of other services or other types of relatives or legal guardians. When this choice is selected, the information provided in the text field should parallel that required in the foregoing choices, depending on whether specific or extraordinary circumstance are involved.

CMS Review Criteria

When the waiver provides for the payment of services furnished by relatives or legal guardians:

- The types of relatives or legal guardians to whom payment may be made are specified.
- The waiver services for which payment may be made to relatives or legal guardians are specified.
- When relatives or legal guardians may be paid to furnish waiver services only in specific circumstances, the waiver specifies the circumstances and the method of determining that such circumstances apply.
- Limitations on the amount of services that may be furnished by a relative or legal guardian are specified.
- The state policies to determine that the provision of waiver services by a relative/legal guardian is in the best interests of the participant are specified.
- When the relative/legal guardian has decision-making authority over the selection of providers of waiver services, the state has a process in place for ensuring that the relative/legal guardian uses substituted judgement on behalf of the individual.
- Any additional safeguards the state implements when relatives/legal guardians provide waiver services are specified.
- The waiver specifies the procedures that are employed to ensure that payment is made only for services rendered.

Item C-2-f: Open Enrollment of Providers

Instructions

In the text field, specify the processes that are employed to assure that all willing and qualified providers have the opportunity to enroll as waiver service providers.

Technical Guidance

Except when a section 1915(c) waiver operates concurrently with a waiver granted under section 1915(b) of the Act waiving section 1902(a)(23) with respect to Medicaid beneficiary free choice of provider, any willing and qualified provider must be afforded the opportunity to enroll as a Medicaid provider. A willing provider is an individual or entity that executes a Medicaid provider agreement and accepts the state's payment for services rendered as payment in full. A qualified provider is a provider that meets the provider qualifications set forth in the approved waiver. In accordance with 42 CFR § 431.51. the state must provide for the ***continuous, open enrollment*** of waiver service providers.

2025 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2305
1/27/2025
2:30 p.m.

Relating to the family paid caregiver service program and the cross-disability advisory council.

2:33 p.m. Chairman Lee opened the hearing.

Members Present: Chairman Lee, Vice-Chairman Weston, Senator Van Oosting, Senator Clemens, Senator Hogan, Senator Roers.

Discussion Topics:

- Waiver eligibility
- Parental rights
- Cross Disability Advisory Council
- Fraud waste and abuse potential
- Qualified Service Providers

2:34 p.m. Sarah Aker, Executive Director of ND Department of Health and Human Services, answered committee questions.

3:06 p.m. Chairman Lee closed the hearing.

Andrew Ficek, Committee Clerk

2025 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2305
2/4/2025

Relating to the family paid caregiver service program and the cross-disability advisory council.

2:33 p.m. Chairman Lee opened the hearing.

Members Present: Chairman Lee, Vice-Chairman Weston, Senator Van Oosting, Senator Clemens, Senator Hogan, Senator Roers.

Discussion Topics:
- Current enrollment
- Family caregiver payment option
- Medicaid 1915 (c) waiver

2:35 p.m. Sarah Aker, Executive Director of ND Department of Health and Human Services, testified in neutral and submitted testimony #34711.

2:50 p.m. Roxane Romanick, Designer Genes of ND, testified in favor.

3:00 p.m. Kirsten Dvorak, Executive Director at The Arc of Bismarck, answered committee questions.

3:02 p.m. Senator Hogan moved Amendment LC#25.0909.02001.

3:02 p.m. Senator Weston seconded the motion.

Senators	Vote
Senator Judy Lee	Y
Senator Kent Weston	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Kristin Roers	Y
Senator Desiree Van Oosting	Y

Motion passed 6-0-0.

3:05 p.m. Senator Hogan moved Do Pass as Amended and rerefer to Appropriations.

3:05 p.m. Senator Weston seconded the motion.

Senators	Vote
Senator Judy Lee	Y

Senator Kent Weston	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Kristin Roers	Y
Senator Desiree Van Oosting	Y

Motion passed 6-0-0.

Senator Hogan will carry the bill.

3:06 p.m. Chairman Lee closed the hearing.

Andrew Ficek, Committee Clerk

RS 2/4/25

1 of 3

25.0909.02001
Title.03000

Adopted by the Human Services
Committee
February 4, 2025

Sixty-ninth
Legislative Assembly
of North Dakota

PROPOSED AMENDMENTS TO

SENATE BILL NO. 2305

Introduced by

Senators Hogan, Cleary, Lee, Weston

Representative Dobervich

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service ~~program~~pilot project and the cross-disability advisory council; and to provide an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 50-24.1-47 of the North Dakota Century Code is amended and reenacted as follows:

50-24.1-47. Family paid caregiver service pilot project~~services program - Report~~. (Contingent expiration date - See note)

1. The department shall ~~establish~~ manage and operate the family caregiver service pilot project to ~~assist in making payments~~~~submit an amendment to all current Medicaid 1915(c) waivers and those to be developed to provide payment for family caregiver services. The payment must be made~~make 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 paid caregiver service pilot project ~~may~~~~program~~ must 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

RS
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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 paid caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall manage and operate the family paid caregiver pilot project in accordance with the adopted rules and within the limits of legislative appropriation for the family paid caregiver pilot project. The department shall utilize an assessment of an eligible individual to determine the need for extraordinary care which must consider the unique needs and circumstances of applicants including age, activities of daily living, medical needs, and social emotional needs. The department may not make payments to a legally responsible individual which duplicate~~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 service or assistance provided, administered, or supervised by the department, including Medicaid 1915(c) waiver or the Medicaid state plan. A legally responsible individual shall attest on an annual basis that the legally responsible individual agrees not to seek reimbursement for extraordinary care through the family paid caregiver service pilot project on days when other 1915(c) waiver services are paid by the department.

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~~A payment under this section to a legally responsible individual must be commensurate with the ~~current self-directed support professional hourly wage~~rate for family caregiving in the home and community-based services aged and disabled waiver.

R5

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~~4. When a family paid caregiver service program is available through a Medicaid-approved home and community-based services waiver, the department shall use an assessment to determine the level of care authorized which must consider the unique needs and circumstances of all applicants including age, activities of daily living, medical needs, and social emotional needs. The assessment must be evidence-based. The family paid caregiver service program may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.~~

~~5. 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 paid caregiver service program administered by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family paid caregiver service program.~~

6. The cross-disability advisory council under section 50-06-46 shall participate with and provide feedback to the department on the planning, design, and ongoing implementation of the family paid caregiver service ~~program~~pilot project and future centers for Medicare and Medicaid services children's cross-disability 1915(c) waiver. The council shall provide input into the development of the assessment method used to determine the ~~level of care authorized for an individual~~need for extraordinary care.

SECTION 2. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY 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 $9,000,000, 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.

REPORT OF STANDING COMMITTEE
SB 2305

Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS (25.0909.02001)** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2305 was placed on the Sixth order on the calendar. This bill does not affect workforce development.

#34711

PROPOSED AMENDMENT TO SENATE BILL NO. 2305

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and the cross-disability advisory council; to provide an appropriation; and to provide an expiration date.

SECTION 1. AMENDMENT. Section 50-24.1-47 of the North Dakota Century Code is amended and reenacted as follows:

50-24.1-47. Family paid caregiver service pilot project~~services program - Report~~. (Contingent expiration date - See note)

1. The department shall ~~establish~~continue to manage and operate the family paid caregiver service pilot project to ~~assist in making payments~~~~submit an amendment to all current Medicaid 1915(c) waivers and those to be developed to provide payment for family caregiver services. The payment must be made~~make 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 paid caregiver service pilot project ~~may~~~~program~~ must 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 paid caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall manage and operate the family paid caregiver pilot project pursuant to the adopted rules and within the limits of legislative appropriation for the family paid caregiver 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~~need for extraordinary care which must consider the unique needs and circumstances of applicants including age, activities of daily living, medical needs, and social emotional needs. Payments made by the department to a legally responsible individual may not duplicate any care that is otherwise compensated through a service or assistance provided, administered, or supervised by the department, including Medicaid 1915(c) waiver or the Medicaid state plan. A legally responsible individual shall attest on an annual basis that they agree not to seek reimbursement for extraordinary care through the family paid caregiver pilot project on days where other 1915(c) waiver services are paid by the department.

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~~A payment under this section to a legally responsible individual must be commensurate with the ~~current self-directed support professional hourly wage~~rate for family caregiving in the home and community-based services aged and disabled waiver.

~~4.~~ ~~When a family paid caregiver service program is available through a Medicaid-approved home and community-based services waiver, the department shall use an assessment to determine the level of care authorized which must consider the unique needs and circumstances of all applicants including age, activities of daily living, medical needs, and social emotional needs. The assessment must be evidence-based. The~~

~~family paid caregiver service program may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.~~

~~5.~~ ~~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 paid caregiver service program administered by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family paid caregiver service program.~~

6. The cross-disability advisory council under section 50-06-46 shall participate with and provide feedback to the department on the planning, design, and ongoing implementation of the family paid caregiver service ~~program~~pilot project and future centers for Medicare and Medicaid services children's cross-disability 1915(c) waiver. The council shall provide input into the development of the assessment method used to determine the ~~level of care authorized for an individual~~need for extraordinary care.

SECTION 2. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY 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 $, 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 paid caregiver service pilot project, for the biennium beginning July 1, 2025, and ending June 30, 2027. Participation in this service pilot project is capped at individuals.

SECTION 3. EXPIRATION DATE. Section 1 of this Act is effective until the date the commissioner of the department of health and human services certifies to the legislative council that a family paid caregiver services program is available through a centers for Medicare and Medicaid services approved children's cross-disability 1915(c) waiver.

2025 SENATE APPROPRIATIONS

SB 2305

2025 SENATE STANDING COMMITTEE MINUTES

Appropriations - Human Resources Division

Harvest Room, State Capitol

SB 2305
2/12/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

8:32 a.m. Chairman Dever opened the hearing.

Members Present: Chairman Dever, Senators Cleary, Davison, Magrum, and Mathern

Discussion Topics:

- Paid Family Caregiver Pilot Program
- Extraordinary Care
- Medicaid Waivers
- Patient Assessment
- Cross-Disability Waivers

8:33 a.m. Senator Hogan, District 21, introduced the bill and submitted testimony #37051, #37052, and #37053.

8:47 a.m. Senator Hogan introduced amendment LC#25.0909.02001 and submitted testimony #37321.

8:50 a.m. Sarah Aker, Executive Director, ND Department of Health & Human Services (DHHS), testified neutral.

8:56 a.m. Tina Bay, Director of Developmental Disabilities Section (DHHS), testified in favor.

9:10 a.m. Toby Lundstad, Parent Advocate, testified in favor and submitted testimony #37361 and #37361

9:26 a.m. Katynka Morissette, Parent Advocate, testified in favor and submitted testimony #37363.

9:49 a.m. Senator Dever closed the hearing.

Joan Bares, Committee Clerk

Testimony
SB 2305
Senate Appropriations Committee
February 12, 2025
Kathy Hogan

Chairman Bekkedahl for the record, my name is Kathy Hogan. I represent District 21 which is central Fargo and a portion of West Fargo.

During the 68th Legislative Session, the ND Legislature established a Paid Family Caregiver Pilot Program to provide needed support to families who have members with serious illnesses or disability, both children and adults, who need extraordinary support to remain out of institutional care. Recognizing that these extraordinary supports need to be blended with other Medicaid waiver funding for in-home care services, this concept was challenging from the beginning for many reasons.

Your Senate Human Services Committee received a summary of the guidelines for the pilot project and data on utilization that are uploaded in the testimony for this hearing. We also heard testimony from families on the amazing impacts this model had made for families with very seriously disabled members.

Paralleling the work on the Family Paid Caregiver Pilot Program is the effort to improve coordination and access for children and adults with disabilities through other waivered services, including the DD and HCBS waiver by moving toward a Cross Disabilities Waiver concept that is still being designed. This effort will improve flexibility for people being supported and their families by allowing greater service options so that you do not need to change waivers to get some services. It is anticipated that by June 30, 2027, the cross-disability waivers will be ready for implementation and that this program will be integrated into those services.

Because this was a unique pilot project funded with state dollars, the program design was put on a fast track with limited by funding. The pilot project is not included in the Governor's 2025-2027 budget.

I need to thank a small working group that reviewed all the data that is uploaded in the testimony on the FAQ on the program, the program data and spending pattern. The group included DHHS staff, advocates and family members and reviewed several funding recommendation options. The materials we looked at are attached to this testimony. The group recommended that we request $9 million to continue services to those already enrolled, those in appeals and pending applications. We did not recommend that all those on the wait list be funded because of the fiscal note. We chose the middle ground.

Your Senate Human Services Committee unanimously recommended do pass on this request because of its success. Thank you for considering SB 2305 and I am more than willing to answer any questions.

People	1	70	120	150
Daily Rate:	$159.54			
Inflation SFY 2026:	1.50%			
Cost SFY2026:	$ 42,102.61	$ 2,947,182.42	$ 5,052,312.72	$ 6,315,390.90
Inflation SFY 2027:	1.50%			
Cost SFY 2027:	$ 42,111.94	$ 2,947,835.74	$ 5,053,432.69	$ 6,316,790.86
Total Cost for 2025-2027 Biennium:	**$ 84,214.55**	**$ 5,895,018.16**	**$ 10,105,745.41**	**$ 12,632,181.76**

#37052

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Data as of 12/3/24

Family Paid Caregiver Pilot Program Data

Pilot program start date: 4/1/24

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 Service: **$2,200,000**
Total Funds Authorized: **$1,252,245.67**
Held for Appeals: **$609,131.25**
Held for Pending Applications: **$338,623.08**

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

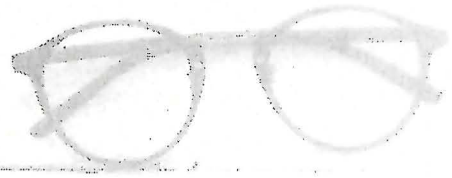
**Anyone who has been denied for an appealable reason would have appeal rights where the funding is held until 30 days after the decision date (unless appealed further, then the funding continues to be held)*

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.*



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

#37053

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Family Paid Caregiver Pilot Program

Frequently Asked Questions

***Program Criteria*:**

Q1. What is the family paid caregiver pilot program?

A. A state funded pilot program that will provide payments to family caregivers who provide extraordinary care to eligible individuals enrolled in a Medicaid 1915 (c) waiver.

Q2. When does the pilot program start?

A. April 1st, 2024

Q3. Who is eligible for this pilot program?

A. Participants must meet all the following criteria:

- enrolled in a Medicaid 1915c waiver (Autism Spectrum Disorder Waiver, Medically Fragile Waiver, Children's Hospice Waiver, Developmental Disabilities Traditional IID/DD Waiver);
- support needs are not otherwise compensated though other services available in a 1915c waiver or Medicaid State Plan; and,
- assessed needs meet extraordinary care.

Q4. Is there an age requirement for participants?

A. No. This pilot program is available to all participants enrolled in one of the qualifying 1915c waivers.

Q5. What is extraordinary care?

A. Extraordinary care means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of the applicant or eligible participant without extraordinary medical or behavioral needs and is necessary to assure the health and welfare and to avoid institutionalization of the applicant or eligible participant in need of care.

Q6. Who is a family caregiver?

A. A legally responsible individual who lives with and provides daily care(s) to the applicant. This may include, but not limited to a biological or adoptive parent, non-entity custodian, guardian, or spouse.

Q7. Can the family caregiver still have employment outside of this pilot program?

A. Yes, the family caregiver would be able to be employed and also partake in this pilot program if found eligible.

Q8. Will this affect other waivered services I may be receiving?

A. Those who are found eligible for this pilot program will still be able to receive the waivered services they are currently receiving. Hours within the waivered service will not automatically decrease but will continue to be discussed as a team on how the service(s) is meeting the needs of the individual or if any changes are needed.

Application:

Q9. Who can apply and what is the process for applying?

A. The applicant or legally responsible individual may submit an application within the Family Caregiver Portal. Once the application is reviewed, the applicant or legally responsible individual will receive an assessment to complete. This self-assessment will aid in identifying the extraordinary needs of the applicant. This application is valid for 1 year.

Q10. If the eligible participant lives in more than one household can both family caregivers enroll in this pilot program?

A. Yes. Both family caregivers are eligible as long as the pilot program requirements are met.

Q11. Will a background check be required?

A. The family paid caregiver will be required to submit the Child Abuse & Neglect Background Inquiry (SFN 433), however no criminal background check is required.

Q12. If I am providing care to more than one person in my household, am I able to receive payment for each?

A. No. This program is limited to one per household.

Q13. Is there a deadline to apply for this pilot program?

A. There is no specific deadline as applications will be reviewed as they are received. The number of participants and funding is limited and once those limits have been exhausted, applications will no longer be approved.

Q14. Will I need to reapply for this pilot program?

A. Yes. The initial application and assessment are valid for 1 year. If the eligible participant and legal decision maker wish to continue past the initial year, they

will need to reapply prior to the expiration of the approved application and assessment.

Q15. How will I know if I am approved?

A. A letter of determination will be sent to applicant.

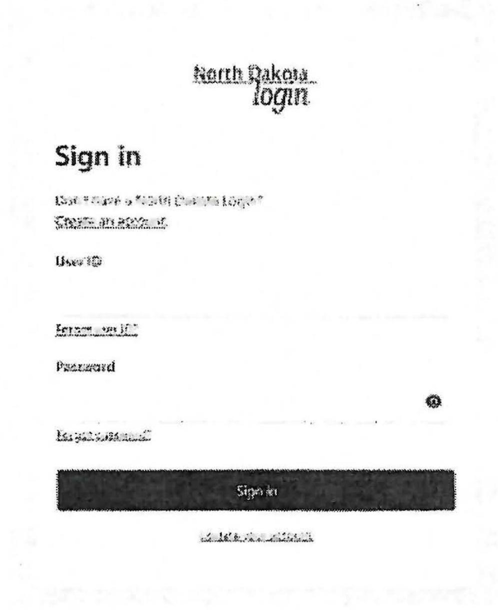
Portal:

Q16. What is the Family Caregiver Portal?

A. A secure web-based system that will provide the applicant or legally responsible individual access to the application, communication, authorizations, and payment requests.

Q17. How do I access the Family Caregiver Portal?

A. The portal will be available on April 1st, 2024, and the link will be available on our website hhs.nd.gov/family-paid-caregiver-pilot-program. If you already have a North Dakota Login account (*pictured below*), you will be able to use that User ID and password to access the portal. A new account can be created if you do not wish to use the same account, however, a different email address will need to be used.



Payment:

Q18. What is the rate of payment?

A. Eligible participants ages 0 through 17 will receive an authorization for $77.45 per day and participants ages 18 and older for $154.89 per day. This is a daily rate.

Q19. How do payments work?

A. Once an authorization has been created, the family caregiver will be able to submit a request for payment twice a month in the Family Caregiver Portal. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm). The authorization will be valid for up to six months and may be reissued for an additional six months.

Guidance for requesting payments will be included via email once a payee account has been successfully created.

Payments will be issued two times a month according to the defined payment schedule:

Time Period	Request for Payment Due to State	Payment Date
April 16-30	5/5/2024	5/15/2024
May 1-15	5/20/2024	5/31/2024
May 16-31	6/5/2024	6/14/2024
June 1-15	6/20/2024	6/28/2024
June 16-30	7/5/2024	7/15/2024
July 1-15	7/20/2024	7/31/2024
July 16-31	8/5/2024	8/15/2024
August 1-15	8/20/2024	8/30/2024
August 16-31	9/5/2024	9/13/2024
September 1-15	9/20/2024	9/30/2024
September 16-30	10/5/2024	10/15/2024
October 1-15	10/20/2024	10/31/2024
October 16-31	11/5/2024	11/15/2024
November 1-15	11/20/2024	11/29/2024
November 16-30	12/5/2024	12/13/2024
December 1-15	12/20/2024	12/31/2024
December 16-31	1/5/2025	1/15/2025

Q20. How do I know what days I am able to request payment for?

A. If the eligible participant was in your care that day, you are eligible to submit a request for payment within the program guidelines. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm).

Q21. If more than one family caregiver is authorized to provide care, how do payments work?

A. The maximum number of days that can be claimed between all approved caregivers for the eligible participant is five days per week (Sunday 12:00am – Saturday 11:59pm). If the family caregivers both provided care on the same day,

they will need to decide which family caregiver requests payment for that day. If there are duplicate requests for payments on the same day, both will be denied.

Q22. What happens if I missed the due date for requesting a payment according to the payment schedule?

A. A request for payment may be submitted after the missed due date and payment will be issued on the next scheduled payment date.

Q23. Is this considered income for the family caregiver?

A. Yes, you will receive a 1099 and this income may impact other benefits you may be receiving. It is the family caregiver's responsibility to report this income as appropriate.

Q24. What happens if I don't request payment?

A. If a request for payment is not submitted for thirty calendar days, the family caregiver will be notified. If an additional thirty calendar days pass without a request for payment, the service may be terminated due to inactivity.

Q25. Will I be required to pay this back at any point?

A. If it is discovered that there is intentional deception or misrepresentation made by the applicant or family caregiver, the funds may be required to be paid back.

Q26. If the pilot program ends or the participant/family caregiver has been terminated, how long do I have to request payment?

A. You would have 15 calendar days to submit that final request for payment.

Quality Assurance:

Q27. How will the Department monitor services?

A. Face-to-face visits will be completed by your current waiver case manager at a minimum of every six months. These visits may coincide with already occurring face-to-face visits. This will ensure that the plan of care/plan for supports is monitored adequately, and the participant's needs are met by the family caregiver.

Q28. If a denial, revocation, or termination is received can the decision be appealed?

A. Yes. However, it is not appealable if one of the following reasons has been given:

- Funding has been exhausted for the pilot program.
- The applicant is no longer eligible for a Medicaid 1915c waiver.
- The application has been withdrawn.

Q29. Who can appeal?

A. The applicant, eligible participant, or family caregiver have the right to timely appeal.

Q30. How do I appeal?

A. A request for an appeal must be submitted in writing within thirty (30) calendar days of the notice issued. You may represent yourself in an appeal hearing or may use legal counsel, a friend, or other spokesperson.

Appeals Supervisor
North Dakota Department of Human Services
600 East Blvd Ave Dept 325
Bismarck ND 58505-0250
Phone: (701) 328-2311
Toll Free: (800) 472-2622
ND Relay TTY: 711
Fax: (701) 328-2173
dhslau@nd.gov

Q31. Who do I contact if I have questions?

A. Any questions can be submitted to familycaregiver@nd.gov.

#37321

25.0909.02001
Title.03000

Adopted by the Human Services
Committee
February 4, 2025

Sixty-ninth
Legislative Assembly
of North Dakota

PROPOSED AMENDMENTS TO

SENATE BILL NO. 2305

Introduced by

Senators Hogan, Cleary, Lee, Weston

Representative Dobervich

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service ~~program~~pilot project and the cross-disability advisory council; and to provide an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 50-24.1-47 of the North Dakota Century Code is amended and reenacted as follows:

50-24.1-47. Family paid caregiver service pilot project~~services program - Report~~. (Contingent expiration date - See note)

1. The department shall ~~establish~~ manage and operate the family caregiver service pilot project to ~~assist in making payments~~~~submit an amendment to all current Medicaid 1915(c) waivers and those to be developed to provide payment for family caregiver services. The payment must be made~~make 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 paid caregiver service pilot project ~~may~~~~program~~ must 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 paid caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall manage and operate the family paid caregiver pilot project in accordance with the adopted rules and within the limits of legislative appropriation for the family paid caregiver pilot project. The department shall utilize an assessment of an eligible individual to determine the need for extraordinary care which must consider the unique needs and circumstances of applicants including age, activities of daily living, medical needs, and social emotional needs. The department may not make payments to a legally responsible individual which duplicate~~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 service or assistance provided, administered, or supervised by the department, including Medicaid 1915(c) waiver or the Medicaid state plan. A legally responsible individual shall attest on an annual basis that the legally responsible individual agrees not to seek reimbursement for extraordinary care through the family paid caregiver service pilot project on days when other 1915(c) waiver services are paid by the department.

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~~A payment under this section to a legally responsible individual must be commensurate with the ~~current self-directed support professional hourly wage~~rate for family caregiving in the home and community-based services aged and disabled waiver.

~~4. When a family paid caregiver service program is available through a Medicaid-approved home and community-based services waiver, the department shall use an assessment to determine the level of care authorized which must consider the unique needs and circumstances of all applicants including age, activities of daily living, medical needs, and social emotional needs. The assessment must be evidence-based. The family paid caregiver service program may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.~~

~~5. 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 paid caregiver service program administered by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family paid caregiver service program.~~

6. The cross-disability advisory council under section 50-06-46 shall participate with and provide feedback to the department on the planning, design, and ongoing implementation of the family paid caregiver service ~~program~~pilot project and future centers for Medicare and Medicaid services children's cross-disability 1915(c) waiver. The council shall provide input into the development of the assessment method used to determine the ~~level of care authorized for an individual~~need for extraordinary care.

SECTION 2. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY 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 $9,000,000, 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.

SB 2305
2-12-25

Testimony in Support of SB 2305

2025 Legislative Session

February 12, 2025

Chairman Dever and Members of the Senate Appropriations – Human Resources Division,

My name is Toby Lunstad and I live in Mandan – District 31. I am writing testimony in support of SB 2305 relating to the Paid Family Caregiver Pilot Program.

I am writing in support of SB 2305 because I am the primary caregiver to my daughter, Addilynn, who requires extraordinary care to live a healthy and happy life. Addilynn is 10 years old and loves music, dancing, Mickey Mouse Clubhouse, and going fast in just about anything. She has a cheerful and sometimes mischievous personality and has blessed my life beyond measure.

Addilynn has a rare genetic disorder called CACNA1A, which has resulted in developmental delays in all areas, Lennox-Gastaut Syndrome (a medication-resistant form of epilepsy), hemiplegic migraines, and the need for specialized care and equipment. Addilynn is currently on the IID/DD Waiver.

In 2020, I was forced to leave my full-time employment as a manager and occupational therapist because her needs were so specialized that we could not find qualified staff to care for her while I worked. As a result, our family lost income, employer-paid health insurance, and other benefits. My husband now works longer hours to fill the financial gap created by my inability to work outside the home.

Addilynn and I are participating in the Paid Family Caregiver Pilot Program developed through SB 2276 during the 2023 Legislative Session. Participating in this program has reduced the emotional and financial strain on our family. It has provided Addilynn with a consistent, fully qualified caregiver who is deeply invested in her health and happiness.

My testimony highlights the critical difference between typical parental care and the extraordinary caregiving that family caregivers provide. To illustrate this, I want to compare the care my sister provides for her son—who is two months younger than my daughter, Addilynn—to the care I provide for Addilynn in daily activities of eating, bathing, and dressing.

At mealtime, my nephew comes to the table, serves himself, ensures his food is a safe temperature to eat, eats independently, and drinks as needed. In contrast, when Addilynn eats, I transfer her into her wheelchair, make sure the meal is a texture she can safely eat, cut her food to a safe size, and monitor the temperature. She is unable to bring a utensil to her mouth, so I assist with every bite. I also monitor and provide cues so she does not choke or aspirate. Since she cannot reach for her drink, I offer fluids throughout the meal, using the only type of water bottle she can safely drink from.

When it's time to bathe and dress, my nephew needs only a verbal reminder. He completes the routine independently. For Addilynn, I transfer her to the bathroom, regulate the water and room temperature due to her difficulties with temperature control, and complete every aspect of her bathing and dressing. This process is time-consuming and physically taxing for Addilynn, so I have to factor in a time for rest after these routines are completed.

These are just two parts of a typical day, but they illustrate the profound difference between ordinary parental care and the extraordinary care provided by family caregivers.

The impact of family caregivers extends beyond daily tasks. Data from Arizona, where family caregivers are paid, shows that individuals receiving care from a family member have significantly lower hospitalization rates—0.7% compared to 7.7% for those with outside caregivers. This means better health outcomes, less medical trauma, and cost savings for the Medicaid system.

Funding the Paid Family Caregiver Pilot Program is an investment in health, well-being, and financial responsibility. I respectfully request a "Do Pass" on SB 2305 and welcome any questions.

Thank you for your time and service to our state.

Sincerely,

Toby Lunstad
tobylunstad@gmail.com
701-595-4386

B 2305
2-12-25

EXTRAORDINARY CARE EXAMPLES
Compiled by North Dakota Family Caregivers who provide extraordinary care

Extraordinary care is defined as “exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of a same aged individual without extraordinary medical or behavioral needs.” An assessment method that accurately captures extraordinary care, particularly for children, is needed to insure the correct individuals are participating in the program. Capturing the extraordinary needs of children is difficult because extraordinary care for a 1 year old vs for a 10 year old is very different based on the developmental levels across the age span. Therefore an assessment that is developmentally accurate and assesses activities of daily living, medical needs, and social-emotional needs is needed.

As family caregivers, we have all been trained to meet our child’s extraordinary needs by physical therapists, occupational therapists, speech therapists, respiratory therapists, nurses, different medical specialists, pharmacists, and dieticians. If someone is hired to provide Medicaid covered services to our children, this is what we train them to do. However, some of these extraordinary cares cannot be delivered by anyone except the primary caregiver who has been trained by medical personnel.

We have in-home support service hours authorized under the ND waivers that are not being utilized both because of the quality of staff available and because of the workforce shortage. The work is exactly the same, the only difference is that a non-legally responsible individual is paid to complete these tasks and we are not. The American Academy of Pediatrics recommends that family caregivers should be paid to reflect the skilled care being provided as stated in the **American Academy of Pediatrics Advocacy Action Guide on Paid Family Caregiving** released in late 2024. (Document has been uploaded in 2305 testimony for January 27, 2025 hearing with Senate Human Services Committee).

This list is not an all-inclusive list as every individual has different diagnoses and needs. However, we wanted to provide you with examples in order to provide a clearer picture of what extraordinary care is being provided by family caregivers.

Thank you for your time and dedication to our state.

COMMUNICATION

- Interpret body language and vocal cues to determine how individual is feeling (feeling good, pain, illness, emotional upset, etc)
- Encourage use of assistive communication device activated with eyes
- Encourage use of assistive communication device activated with finger

MEDICATION PREPARATION & ADMINISTRATION

- **Oral medications:** accurate measurement of meds, mixing meds with food due to taste or flavor aversions, prompts and encouragement to prevent individual from spitting meds out
- **Meds given through feeding tube:** accurate measurement of liquid medications in syringes, crushing and dissolving medications in syringes, administration of medications via feeding tube
- **Med passes per day:** 2 - 7 or more depending on diagnosis
- Constant monitoring for side effects from medications

NEUROLOGICAL DAILY CARE OR EMERGENCY (Epilepsy, hemiplegic migraines)

- Insure seizure medications are given as prescribed at the same times daily
- Administer emergency medications, monitor vital signs, and give oxygen during a neurological emergency
- Prevention/reduced exposure to neurological event triggers such as illness, lack of sleep, stress, pain, sensory overstimulation
- Monitor 24 hours a day, 7 days a week because a neurological emergency can occur at any time, without warning
- 1:1 care so we can assess and intervene at a moment's notice

RESPIRATORY DAILY CARE OR EMERGENCY

- Use emergency inhaler or nebulizer along with monitoring vital signs
- Use of a tracheal tube and cares required
- In need of a ventilator for part or all of the day
- 1:1 care so we can assess and intervene intervene at a moment's notice

METABOLIC DAILY CARE OR EMERGENCY

- Multiple blood sugar and ketone checks throughout the day and night
- Management of nutrition and hydration orally and via feeding tube throughout the day and night to maintain metabolic stability
- Increase of above cares if metabolic stability decreases in an effort to prevent a prolonged hospital stay
- 1:1 care and constant monitoring so we can assess and intervene at a moment's notice

OVERNIGHT MONITORING AND CARE

- Monitor and provide care overnight if alarms sound indicating the need for assistance with feeding tube, trach, or a neurological, metabolic, or respiratory emergency.
- Reposition for safety and skin integrity
- Monitor individual for safety and flight risk concerns

EMOTIONAL AND SAFETY DAILY CARE OR EMERGENCY

- Constant monitoring due to flight risk
- Interpret body language and cues to determine emotional triggers, prevent emotional emergencies and maintain safety
- Provide support during an emotional emergency to maintain safety of child and others Prepare and insure access to many positive activities throughout the day as attention span is short and when left to guide their own activities the individual's safety is at risk

BATHING

- Transfer into and out of bath/shower and complete all washing, drying, and skin care tasks
- Provide emotional support and encouragement to allow bathing to occur due to sensory issues and/or fear

TOILETING

- Manage bowel and bladder incontinence
- Transfer onto and off of toilet
- Supervise for safety and assist with hygiene and clothing management
- Provide emotional support and encouragement to allow toileting and hygiene to occur due to sensory issues and/or fear

DRESSING

- Obtain clothing, complete all dressing tasks
- Provide emotional support and encouragement if clothing color or feel is not something that feels safe for the sensory system that day

GROOMING & HYGIENE

- Hair brushing, teeth brushing etc all completed for her
- Wound care

MOVING FROM PLACE TO PLACE (WHEELCHAIR OR WALKING)

- Ceiling lift or physical transfer
- Complete position changes throughout the day and night for skin integrity and comfort
- 1:1 assist with gait belt for balance, safety, fall and injury prevention
- Properly apply orthosis devices and set up adaptive equipment such as stander or gait trainer

PULMONARY CARE/TRACH CARE

- Needing to suction as needed 24/7
- Change trach for cleaning as prescribed
- Keeping the area clean

FEEDING TUBE CARE

- Wound care of feeding tube site
- Change feeding tube every 3 months

EATING

- Physically feed due to being unable
- Prepare, weigh, and calculate food to be eating orally and food to be given via feeding tube
- Prepare and measure out food to be given strictly via feeding tube, refill as needed throughout the day, constantly monitor for appropriate temperature of food/formula
- Meals often have goals to increase oral motor skills, decrease food aversions, and meet calorie needs
- Provide encouragement and prompts throughout meal to insure meal is eaten

DRINKING

- Physically hold water bottle if unable
- Calculate fluids to meet hydration goals
- Provide encouragement, prompts, and assistance throughout day to insure individual stays hydrated

PORT CARE

- Properly caring for port and surrounding area
- Adding heparin in the correct dosage for port care
- Accurate measurement and preparation of medications administered through the port
- Monitor for side effects and infection

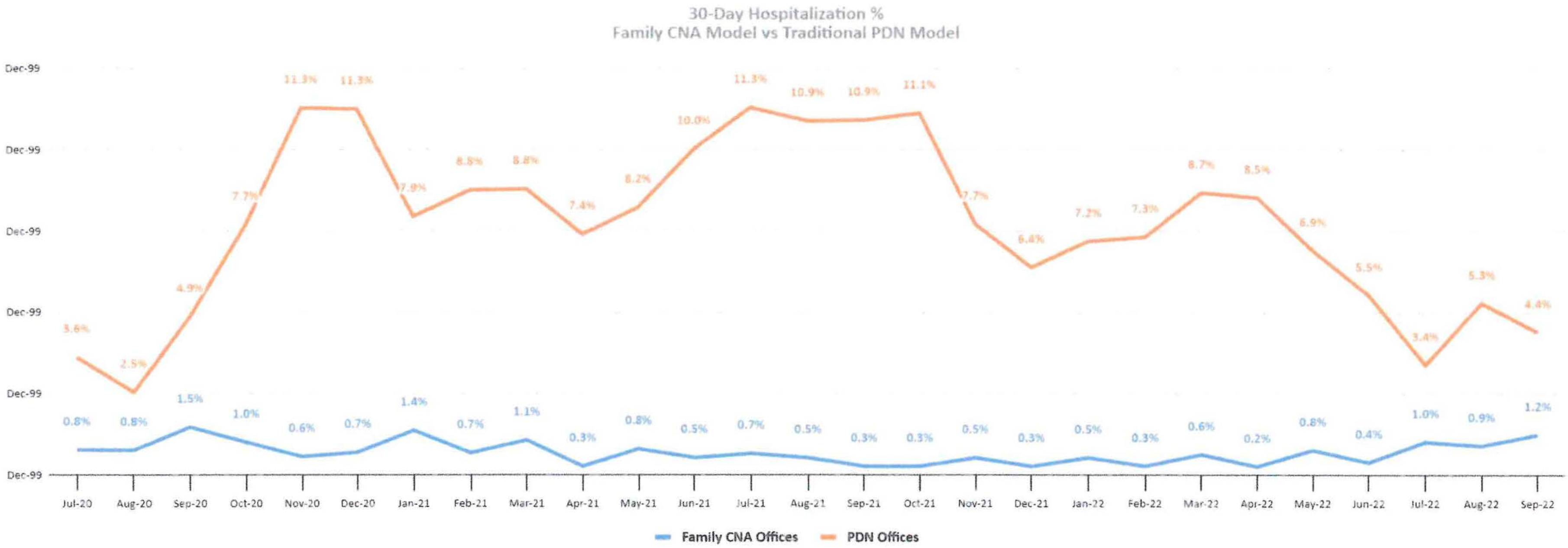
HOME PROGRAMMING

- Home exercise programs as prescribed by physical therapy and occupational therapy
- Home sensory programs as prescribed by occupational therapy
- Home feeding and speech programs as prescribed by speech therapy
- Home programming as prescribed by ABA specialists
- Adaptation of leisure and play activities

SB2305
2-12-25

Participant Hospitalizations 24 Month Comparison of Family Caregivers vs Outside Caregivers

Participants utilizing family caregivers in Team Select's Family CNA program had an average hospitalization rate of 0.7% over 24 months, while participants relying on outside caregivers had an average hospitalization rate of 7.7% over the same period. This 7% decrease in hospitalization rates is a tremendous savings to the state's medicaid system.



Active Census	Jul-20	Aug-20	Sep-20	Oct-20	Nov-20	Dec-20	Jan-21	Feb-21	Mar-21	Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22
Family CNA Offices	652	661	681	700	716	722	730	741	751	758	756	759	764	768	766	769	770	765	764	760	804	802	796	787	793	785	810
PDN Offices	415	394	391	390	390	391	390	388	398	392	401	419	407	395	440	755	765	768	779	779	772	938	942	978	1,005	1,042	1,140
30 Day Hosp %	Jul-20	Aug-20	Sep-20	Oct-20	Nov-20	Dec-20	Jan-21	Feb-21	Mar-21	Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22
Family CNA Offices	0.8%	0.8%	1.5%	1.0%	0.6%	0.7%	1.4%	0.7%	1.1%	0.3%	0.8%	0.5%	0.7%	0.5%	0.3%	0.3%	0.5%	0.3%	0.5%	0.3%	0.6%	0.2%	0.8%	0.4%	1.0%	0.9%	1.2%
PDN Offices	3.6%	2.5%	4.9%	7.7%	11.3%	11.3%	7.9%	8.8%	8.8%	7.4%	8.2%	10.0%	11.3%	10.9%	10.9%	11.1%	7.7%	6.4%	7.2%	7.3%	8.7%	8.5%	6.9%	5.5%	3.4%	5.3%	4.4%

SB 2305
2-12-24

Senate Appropriations-Human Resources Division
SB 2305
February 12th, 2025

Chairman Dever and members of the Senate Appropriations Committee,

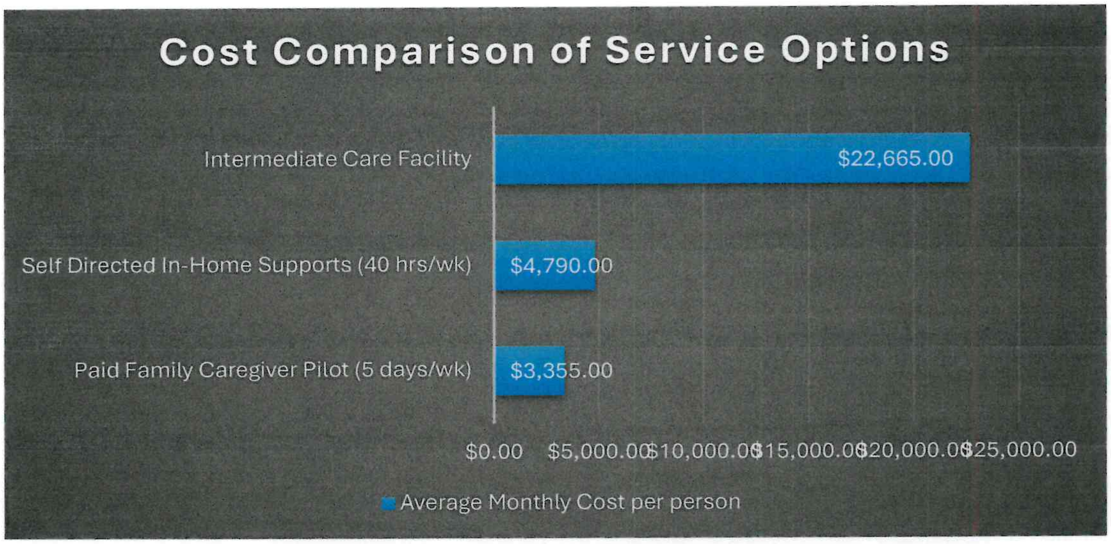
My name is Katynka Morrissette and I live in Bismarck, ND with my husband and our 3 young children. I am here today to give testimony on why I support SB 2305 and share with you how it impacts our family. I am the primary caregiver to our three young children Joey (age 9), Medrick (age 8), and Eleanor (age 7), who are on the Medically Fragile Waiver. They require extraordinary care due to their metabolic condition and other complexities.

Daily they require multiple doses of medications and nutritional support administered through their G or G/J tube, a complex feeding schedule and diet, glucose and ketone checks, breathing treatments, care for their medical ports, and assistance with home therapy treatment plans and daily living activities. Due to their high level of need and how specialized some of these cares are, we have been unable to find appropriately trained staff to provide support for them.

In 2023 legislation was passed (SB 2276) that developed the Paid Family Caregiver Pilot Program in North Dakota. Our family has been able to participate in the program and see firsthand the benefits that have resulted, like decreased hospital stays and improved mental health.

But today I wanted to touch on a few of the cost benefits of allowing legally responsible individuals to be part of the workforce to provide our already authorized services.

To be on a 1915c Medicaid Home and Community Based Services waiver, the participant must meet an institutional level of care. Below is a chart comparing the costs of a participant being institutionalized in an Intermediate Care Facility (ICF), Self Directed In-Home Supports and the cost of the Paid Family Caregiver Pilot.



While I could never put a dollar amount on the health and wellbeing of a child, and no parent ever wants to be faced with the possibility of placing their child in a care facility, this unfortunately is the reality many in our state have faced and will continue to if we don't work to provide the services these children need. With caregiver turnover and workforce shortages across the state, many people are going without the services they are assessed for and authorized to receive.

We as caregivers know our children best and have training to provide these specialized cares, and it is crucial for this pilot to continue as the department works to get it implemented into the current waivers as a service option so that we can be a part of that workforce.

Thank you for your time today and allowing me to share with you some of the impact this pilot has had on our family, I am asking for a "Do Pass" recommendation on Senate Bill 2305 so that families in our state can access this service option with the improvements learned through the pilot program and fill the caregiver shortage that so many have experienced. I will now answer any questions you may have for me.

Thank you again for your time and consideration.

Katynka Morrissette

jkmorr@icloud.com

701-301-1541

2025 SENATE STANDING COMMITTEE MINUTES

Appropriations - Human Resources Division

Harvest Room, State Capitol

SB 2305 11:02 a.m.
2/12/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

11:02 a.m. Chairman Dever opened the hearing.

Members Present: Chairman Dever, Senators Cleary, Davison, Magrum, and Mathern

Discussion Topics:

- Appropriation Reduction

11:02 a.m. Senator Davison moved to amend the appropriation to 5 million.

11:04 a.m. Senator Magrum seconded the motion.

Senators	Vote
Senator Dick Dever	N
Senator Sean Cleary	N
Senator Kyle Davison	Y
Senator Jeffery J. Magrum	Y
Senator Tim Mathern	N

Motion failed 2-3-0.

11:11 a.m. Senator Cleary moved a Do Pass.

11:12 a.m. Senator Mathern seconded the motion.

Senators	Vote
Senator Dick Dever	Y
Senator Sean Cleary	Y
Senator Kyle Davison	N
Senator Jeffery J. Magrum	N
Senator Tim Mathern	Y

Motion passed 3-2-0.

Senator Cleary will carry the bill.

11:12 a.m. Chairman Dever closed the hearing.

Joan Bares, Committee Clerk

2025 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Harvest Room, State Capitol

SB 2305
2/13/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

3:24 p.m. Chairman Bekkedahl opened the hearing.

Members Present: Chairman Bekkedahl, Senators Burckhard, Cleary, Conley, Davison, Dever, Dwyer, Magrum, Mathern, Meyer, Schaible, Sickler, Sorvaag, Thomas, Wanzek.
Members Absent: Vice-Chairman Erbele.

Discussion Topics:

- Benefits of Family Caregiving
- Hospital Care Reduction with Family Caregivers

3:25 p.m. Senator Cleary introduced the bill.

3:28 p.m. Senator Davison moved to amend by reducing appropriation amount from 9 million to 7.3 million with LC #25.0909.03001.

3:30 p.m. Senator Dever seconded the motion.

Senators	Vote
Senator Brad Bekkedahl	Y
Senator Robert Erbele	A
Senator Randy A. Burckhard	Y
Senator Sean Cleary	N
Senator Cole Conley	Y
Senator Kyle Davison	Y
Senator Dick Dever	Y
Senator Michael Dwyer	Y
Senator Jeffery J. Magrum	Y
Senator Tim Mathern	N
Senator Scott Meyer	Y
Senator Donald Schaible	Y
Senator Jonathan Sickler	Y
Senator Ronald Sorvaag	Y
Senator Paul J. Thomas	Y
Senator Terry M. Wanzek	Y

Motion Passed 13-2-1.

3:39 p.m. Senator Cleary moved a Do Pass as Amended.

3:39 p.m. Senator Mathern seconded the motion.

Senators	Vote
Senator Brad Bekkedahl	Y
Senator Robert Erbele	A
Senator Randy A. Burckhard	Y
Senator Sean Cleary	Y
Senator Cole Conley	Y
Senator Kyle Davison	Y
Senator Dick Dever	Y
Senator Michael Dwyer	Y
Senator Jeffery J. Magrum	Y
Senator Tim Mathern	Y
Senator Scott Meyer	Y
Senator Donald Schaible	Y
Senator Jonathan Sickler	Y
Senator Ronald Sorvaag	Y
Senator Paul J. Thomas	Y
Senator Terry M. Wanzek	Y

Motion Passed 15-0-1.

Senator Hogan will carry the bill.

3:41 p.m. Chairman Bekkedahl closed the hearing.

Elizabeth Reiten, Committee Clerk

25.0909.03001
Title.04000

Prepared by the Legislative Council
staff for Senate Appropriations
Committee
February 13, 2025

2-14-25
1 of 3

Sixty-ninth
Legislative Assembly
of North Dakota

PROPOSED AMENDMENTS TO FIRST ENGROSSMENT

ENGROSSED SENATE BILL NO. 2305

Introduced by

Senators Hogan, Cleary, Lee, Weston

Representative Dobervich

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 50-24.1-47 of the North Dakota Century Code is amended and reenacted as follows:

50-24.1-47. Family paid caregiver service pilot project ~~- Report~~. (Contingent expiration date - See note)

1. The department shall ~~establish~~manage and operate the family caregiver service pilot project to ~~assist in making payments~~make 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 paid caregiver service pilot project ~~may~~must 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.

2 of 3

3. The department may adopt rules addressing management of the family paid caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall manage and operate the family paid caregiver pilot project in accordance with the adopted rules and within the limits of legislative appropriation for the family paid caregiver 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~~need for extraordinary care which must consider the unique needs and circumstances of applicants including age, activities of daily living, medical needs, and social emotional needs. The department may not make payments to a legally responsible individual which duplicate any care that is otherwise compensated through a service or assistance provided, administered, or supervised by the department, including Medicaid 1915(c) waiver or the Medicaid state plan. A legally responsible individual shall attest on an annual basis that the legally responsible individual agrees not to seek reimbursement for extraordinary care through the family paid caregiver service pilot project on days when other 1915(c) waiver services are paid by the department.

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~~A payment under this section to a legally responsible individual must be commensurate with the rate for family caregiving in the home and community-based services aged and disabled waiver.

6. The cross-disability advisory council under section 50-06-46 shall participate with and provide feedback to the department on the planning, design, and ongoing implementation of the family paid caregiver service pilot project and future centers for

3 of 3

Medicare and Medicaid services children's cross-disability 1915(c) waiver. The council shall provide input into the development of the assessment method used to determine the need for extraordinary care.

SECTION 2. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY 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 ~~$9,000,000~~$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.

REPORT OF STANDING COMMITTEE
ENGROSSED SB 2305

Appropriations Committee (Sen. Bekkedahl, Chairman) recommends **AMENDMENTS (25.0909.03001)** and when so amended, recommends **DO PASS** (15 YEAS, 0 NAYS, 1 ABSENT OR EXCUSED AND NOT VOTING). SB 2305 was placed on the Sixth order on the calendar. This bill does not affect workforce development.

2025 HOUSE HUMAN SERVICES

SB 2305

2025 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

SB 2305
3/12/2025

Relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

2:59 p.m. Chairman M. Ruby opened the hearing.

Members Present: Chairman M. Ruby, Vice-Chairman Frelich, Representatives K. Anderson, Beltz, Bolinske, Davis, Dobervich, Fegley, Hendrix, Holle, Kiefert, Rios, Rohr

Discussion Topics:

- Equal treatment
- Issues finding staff
- Essential care

2:59 p.m. Senator Hogan, District 21, introduced the bill and submitted testimony, #40461, #40462, #40463.

3:15 p.m. Roxane Romanick, Representative/Lobbyist of Designer Genes of ND, Inc., testified in favor and submitted testimony, #40921.

3:24 p.m. Senator Cleary, District 35, testified in favor.

3:27 p.m. Brittany Zapone, Private Citizen, testified in favor and submitted testimony, #40690.

3:36 p.m. Toby Lunstad, Private Citizen, testified in favor and submitted testimony, #40426, #40427, #40428.

3:41 p.m. Katynka Morrissette, Private Citizen, testified in favor and submitted testimony, #41041.

3:44 p.m. Kristen Dvorak, Executive Director of The Arc of North Dakota, testified in favor and submitted testimony, #40611.

Additional written testimony:
Jennifer Restemayer, Private Citizen, submitted testimony in favor, #39642.
Julianne Horntvedt, Executive Director of ND DD Council, submitted testimony in favor, #39914.
Trevor Vannett, Private Citizen, submitted testimony in favor, #40072.
Brenda Schmid, Private Citizen, submitted testimony in favor, #40490.

3:45 p.m. Vice Chairman Frelich adjourned the meeting.

Jackson Toman, Committee Clerk

Testimony in Support of S.B. 2305

2025 Legislative Session

March 8, 2025

Chairman Ruby and members of the House Human Services Committee,

My name is Jennifer Restemayer and I live in West Fargo, ND. My husband Jim and I are the primary caregivers to our young adult daughter Allison who just celebrated her 24th birthday. I am writing to you in support of SB 2305 and to share with you how being able to participate in the Paid Family Caregiver Pilot Program has been a benefit to our daughter and to our family.

Allison was diagnosed at the age of 2 with a rare genetic disorder called Mucopolysaccharidosis type 1. Allison requires daily meds as well as a 6 hour weekly I.V. infusion of an enzyme replacement therapy (ERT), and she also has multiple therapies throughout the week. Allisons disorder is progressive and degenerative, when she was diagnosed we were told that she would be bedridden by 8 and dead by the age of 10 without treatment. Allison has now had 1133 weeks of her ERT infusions. The progression of Allison's disorder has led to her currently being unable to walk or stand on her own, she is legally blind and has a profound hearing loss. Her ability to verbally communicate is her greatest strength, however she needs someone with her constantly to narrate the environment in a way that she can hear and understand. Allison's anxiety level is high due to her impairments.

Our ability to participate in the Family Paid Caregiver Pilot program has allowed us to provide the care that Allison needs without the revolving door of respite staff that we have had in the past. Our family has utilized respite staff, but when COVID shut things down, our respite staff who were all college students at the time, left the area. Since Covid, Allison's needs have intensified, and we have not been able to find suitable staff to train and hire. I know that being able to provide the care for Allison has been a huge benefit to her health as there have been fewer hospitalizations for her, fewer major illnesses, and her mental health has shown improvement.

My husband and I have had to adjust our work schedules to accommodate Allison's needs. This is nothing new as I have needed to do this since Allison was 2 years old and newly diagnosed. The pressure my husband has felt to be the primary breadwinner, maintain our health insurance and continue to assist with Allison's care has been overwhelming at times. I have always had to find a way to continue to be part of the workforce in taking very flexible part time jobs that would allow me to drop everything if needed to be there for Allison. The shortage in the workforce of qualified caregivers with the willingness and knowledge of how to care for a medically fragile child/ young adult has been something our family has had to navigate for years. The Family Paid Caregiver pilot project allows me to continue to be a part of the workforce and be there for Allison in a way that benefits my whole family.

Thank you for taking the time to read the impacts this pilot project has had on my family and for considering a “do pass” recommendation on SB 2305 so more families in our state are able to contribute to our workforce as paid caregivers to our most precious resource, our children.

Jennifer Restemayer

630 23rd Ave W

West Fargo, ND

Jennifer_restemayer@yahoo.com

701-471-8714

Testimony
Senate Bill 2305
March 10, 2025

Chairman Ruby and members of the House Human Services Committee, my name is Julianne Horntvedt, and I serve as the Executive Director of the North Dakota State Council on Developmental Disabilities. I am submitting testimony on behalf of our Advocacy Committee.

Our previous testimony speaks to the need of this program to exist in our state and the recent changes to the language of the bill help the bill read clearer and outline a path to providing this benefit to families who need it.

This approach is both cost-effective and compassionate. By investing in the well-being of caregivers, the state would be making a long-term investment in the health, dignity, and independence of individuals with disabilities.

Sincerely,

Julianne Horntvedt

701-328-4847

jhorntvedt@nd.gov

Testimony in Support of SB2305
2025 Legislative Session
March 10, 2025

Chairman Ruby and Members of the House Human Services Committee,

My name is Trevor Vannett and I live in Bismarck.

I am in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and the cross-disability advisory council. I support this bill because it allows family choice and it lets families have an option to stay home and support their loved one.

This bill is important because it lessens the impact of institutionalizing individuals with disabilities, a cost that far exceeds the cost of supporting caregivers in their homes. Studies have shown that family caregiving is not only more affordable, but it can also improve the quality of life for the individuals being cared for. Children, adults, and elderly individuals with disabilities are more likely to thrive in a familiar environment, benefiting from the emotional stability and personal connection that only a family member can provide.

Furthermore, a paid family caregiver program can help families sustain their own health and well-being. Many caregivers suffer from physical and emotional exhaustion due to the overwhelming demands placed on them, and financial compensation could reduce stress and burnout, making it easier for caregivers to provide better, more consistent care. This, in turn, benefits the individuals receiving care, who are more likely to experience positive outcomes when their caregivers are physically and emotionally healthy.

Finally, this program would send a powerful message that our state values and recognizes the critical role that family caregivers play. It acknowledges that caregiving is work and that it deserves compensation. It is an investment in the health and well-being of families, communities, and the state as a whole.

For all these reasons, I strongly support the paid family caregiver program. It is an investment in families, in individuals with exceptional needs, and in the overall well-being of our state. I urge you to act in favor of this program and to make a meaningful difference in the lives of those who are providing essential care to their loved ones.

Sincerely,
Trevor Vannett
701-955-0000

EXTRAORDINARY CARE EXAMPLES

Compiled by North Dakota Family Caregivers who provide extraordinary care

Extraordinary care is defined as “exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of a same aged individual without extraordinary medical or behavioral needs.” An assessment method that accurately captures extraordinary care, particularly for children, is needed to insure the correct individuals are participating in the program. Capturing the extraordinary needs of children is difficult because extraordinary care for a 1 year old vs for a 10 year old is very different based on the developmental levels across the age span. Therefore an assessment that is developmentally accurate and assesses activities of daily living, medical needs, and social-emotional needs is needed.

As family caregivers, we have all been trained to meet our child’s extraordinary needs by physical therapists, occupational therapists, speech therapists, respiratory therapists, nurses, different medical specialists, pharmacists, and dieticians. If someone is hired to provide Medicaid covered services to our children, this is what we train them to do. However, some of these extraordinary cares cannot be delivered by anyone except the primary caregiver who has been trained by medical personnel.

We have in-home support service hours authorized under the ND waivers that are not being utilized both because of the quality of staff available and because of the workforce shortage. The work is exactly the same, the only difference is that a non-legally responsible individual is paid to complete these tasks and we are not. The American Academy of Pediatrics recommends that family caregivers should be paid to reflect the skilled care being provided as stated in the **American Academy of Pediatrics Advocacy Action Guide on Paid Family Caregiving** released in late 2024. (Document has been uploaded in 2305 testimony for January 27, 2025 hearing with Senate Human Services Committee).

This list is not an all-inclusive list as every individual has different diagnoses and needs. However, we wanted to provide you with examples in order to provide a clearer picture of what extraordinary care is being provided by family caregivers.

Thank you for your time and dedication to our state.

COMMUNICATION

- Interpret body language and vocal cues to determine how individual is feeling (feeling good, pain, illness, emotional upset, etc)
- Encourage use of assistive communication device activated with eyes
- Encourage use of assistive communication device activated with finger

MEDICATION PREPARATION & ADMINISTRATION

- **Oral medications:** accurate measurement of meds, mixing meds with food due to taste or flavor aversions, prompts and encouragement to prevent individual from spitting meds out
- **Meds given through feeding tube:** accurate measurement of liquid medications in syringes, crushing and dissolving medications in syringes, administration of medications via feeding tube
- **Med passes per day:** 2 - 7 or more depending on diagnosis
- Constant monitoring for side effects from medications

NEUROLOGICAL DAILY CARE OR EMERGENCY (Epilepsy, hemiplegic migraines)

- Insure seizure medications are given as prescribed at the same times daily
- Administer emergency medications, monitor vital signs, and give oxygen during a neurological emergency
- Prevention/reduced exposure to neurological event triggers such as illness, lack of sleep, stress, pain, sensory overstimulation
- Monitor 24 hours a day, 7 days a week because a neurological emergency can occur at any time, without warning
- 1:1 care so we can assess and intervene at a moment's notice

RESPIRATORY DAILY CARE OR EMERGENCY

- Use emergency inhaler or nebulizer along with monitoring vital signs
- Use of a tracheal tube and cares required
- In need of a ventilator for part or all of the day
- 1:1 care so we can assess and intervene intervene at a moment's notice

METABOLIC DAILY CARE OR EMERGENCY

- Multiple blood sugar and ketone checks throughout the day and night
- Management of nutrition and hydration orally and via feeding tube throughout the day and night to maintain metabolic stability
- Increase of above cares if metabolic stability decreases in an effort to prevent a prolonged hospital stay
- 1:1 care and constant monitoring so we can assess and intervene at a moment's notice

OVERNIGHT MONITORING AND CARE

- Monitor and provide care overnight if alarms sound indicating the need for assistance with feeding tube, trach, or a neurological, metabolic, or respiratory emergency.
- Reposition for safety and skin integrity
- Monitor individual for safety and flight risk concerns

EMOTIONAL AND SAFETY DAILY CARE OR EMERGENCY

- Constant monitoring due to flight risk
- Interpret body language and cues to determine emotional triggers, prevent emotional emergencies and maintain safety
- Provide support during an emotional emergency to maintain safety of child and others Prepare and insure access to many positive activities throughout the day as attention span is short and when left to guide their own activities the individual's safety is at risk

BATHING

- Transfer into and out of bath/shower and complete all washing, drying, and skin care tasks
- Provide emotional support and encouragement to allow bathing to occur due to sensory issues and/or fear

TOILETING

- Manage bowel and bladder incontinence
- Transfer onto and off of toilet
- Supervise for safety and assist with hygiene and clothing management
- Provide emotional support and encouragement to allow toileting and hygiene to occur due to sensory issues and/or fear

DRESSING

- Obtain clothing, complete all dressing tasks
- Provide emotional support and encouragement if clothing color or feel is not something that feels safe for the sensory system that day

GROOMING & HYGIENE

- Hair brushing, teeth brushing etc all completed for her
- Wound care

MOVING FROM PLACE TO PLACE (WHEELCHAIR OR WALKING)

- Ceiling lift or physical transfer
- Complete position changes throughout the day and night for skin integrity and comfort
- 1:1 assist with gait belt for balance, safety, fall and injury prevention
- Properly apply orthosis devices and set up adaptive equipment such as stander or gait trainer

PULMONARY CARE/TRACH CARE

- Needing to suction as needed 24/7
- Change trach for cleaning as prescribed
- Keeping the area clean

FEEDING TUBE CARE

- Wound care of feeding tube site
- Change feeding tube every 3 months

EATING

- Physically feed due to being unable
- Prepare, weigh, and calculate food to be eating orally and food to be given via feeding tube
- Prepare and measure out food to be given strictly via feeding tube, refill as needed throughout the day, constantly monitor for appropriate temperature of food/formula
- Meals often have goals to increase oral motor skills, decrease food aversions, and meet calorie needs
- Provide encouragement and prompts throughout meal to insure meal is eaten

DRINKING

- Physically hold water bottle if unable
- Calculate fluids to meet hydration goals
- Provide encouragement, prompts, and assistance throughout day to insure individual stays hydrated

PORT CARE

- Properly caring for port and surrounding area
- Adding heparin in the correct dosage for port care
- Accurate measurement and preparation of medications administered through the port
- Monitor for side effects and infection

HOME PROGRAMMING

- Home exercise programs as prescribed by physical therapy and occupational therapy
- Home sensory programs as prescribed by occupational therapy
- Home feeding and speech programs as prescribed by speech therapy
- Home programming as prescribed by ABA specialists
- Adaptation of leisure and play activities

Testimony in support of SB 2305

2025 Legislative Session

March 11, 2025

Chairman Ruby and Members of the House Human Services Committee

My name is Toby Lunstad, and I live in Mandan in District 31. I am here today testifying in support of SB 2305 for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the Paid Family Caregiver Service Option and the Cross-Disability Advisory Council.

I am the primary caregiver to my daughter, Addilynn. She is 10 years old and loves music, dancing, Mickey Mouse Clubhouse, and anything that goes fast. Addilynn’s cheerful and sometimes mischievous personality brings immense joy to our lives. She receives waiver services via the IID/DD Waiver, and we are participating in the Paid Family Caregiver Pilot Program.

Addilynn has a rare genetic variant on a gene called CACNA1A, which has resulted in developmental delays, Lennox-Gastaut Syndrome (a medication-resistant form of epilepsy), hemiplegic migraines, and the need for specialized care and equipment. She is entirely dependent on others for all aspects of daily living.

Despite being authorized for in-home support services, we have been unable to consistently access them due to an ongoing workforce shortage. In 2020, I was forced to leave my career as a manager and occupational therapist because we could not find qualified staff to meet Addilynn’s complex needs, creating significant financial and emotional strain on our family. With the Paid Family Caregiver Pilot Program, families like mine can access the support they need without having to choose between financial stability and ensuring their loved one receives essential care.

It bridges a gap by providing Addilynn with a fully qualified, consistent caregiver who is deeply invested in her well-being. This program is not about paying parents to be parents—it is about ensuring individuals with significant disabilities receive the care they are authorized for, from caregivers who are both capable and committed. Without it, many North Dakotans, like Addilynn, would be left without essential services.

Extraordinary caregiving goes far beyond typical parenting. For example, while my nephew, who is two months younger than Addilynn, eats independently, mealtime for Addilynn requires transferring her to her wheelchair, preparing food to a safe texture and bite size, assisting with every bite, monitoring for choking, and offering fluids in the only bottle she can safely drink from. This is just one of many tasks that require constant vigilance and specialized care.

As a highly trained caregiver, I manage Addilynn's complex medical needs, recognize early signs of medical distress, and provide skilled care that cannot simply be replaced by outside providers. The Paid Family Caregiver Pilot Program ensures individuals receive the care they need from caregivers who are both qualified and committed. This program has helped ease the caregiver crisis by ensuring individuals receive the highly skilled, essential care they need to thrive, maintain their health, and actively participate in their communities.

There are benefits to this program that cannot be measured in dollars. The peace of mind that comes from knowing a loved one is in capable and compassionate hands is invaluable. The security of consistent, high-quality care reduces stress for both the caregiver and the individual receiving support.

Along with my testimony, I have provided a flyer detailing the benefits of paid family caregiving, including improved care quality, cost savings, and better health outcomes. I have also included a list of extraordinary cares compiled by ND Family Caregivers to further illustrate the realities of this level of caregiving.

Thank you for your time and consideration. I respectfully request a "Do Pass" recommendation on SB 2305. I am happy to answer any questions you may have.

Sincerely,
Toby Lunstad
701-595-4386
tobylunstad@gmail.com

#40428

FINANCIAL BENEFITS OF PAID FAMILY CAREGIVING

Lower Use of Institutional Care: Paying family caregivers reduces reliance on costly institutional care.

Cost Savings: Paying family caregivers is often more cost-effective.

Prevention of Hospital Readmissions: Family caregivers manage medical conditions at home, reducing emergency and hospitalization costs.

Sustainability of Care: Paying caregivers ensures that long-term care remains viable without financial hardship.

Income for Caregivers: Many family caregivers leave jobs to provide full-time care for a disabled child. Paying them ensures they receive financial compensation, alleviating financial strain.

Reduced Economic Burden: Compensation helps families afford medical care, therapy, and specialized equipment.

Economic Contribution: Paid caregivers can maintain financial stability and contribute to the economy.

Boosting Local Spending: Paid caregivers contribute to local economies by spending their earnings within the community.

Reduced Dependency on Public Assistance: Paid caregivers maintain financial independence, decreasing reliance on state aid.

Healthier Families: Supported caregivers experience less stress-related illness, reducing strain on public health systems.

Care for Vulnerable Populations: Family caregivers have extensive training from medical specialists and can prevent costly medical interventions.

FAMILY BENEFITS OF PAID FAMILY CAREGIVING

Sense of Fulfillment: Being paid for caregiving helps caregivers feel valued and appreciated, improving mental health.

Reduced Financial Stress: Compensation alleviates anxiety and provides financial security.

Less Stress and Fatigue: Caregiving is physically and emotionally demanding. Financial support acknowledges this effort and helps reduce stress.

Invested in Individual’s Well-Being: Family caregivers are deeply invested in their child’s well-being, ensuring care aligns with their values.

Recognition and Appreciation: Compensation validates caregivers' hard work, reducing resentment and strain.

Less Strain on Relationships: Financial support eases emotional burdens, helping families maintain strong relationships.

Reduced Social Isolation: Financial support allows caregivers to engage with their communities and access resources.

Encouraging Caregiving as a Recognized Role: Payment helps shift societal perceptions, increasing public support.

Developed by ND Family Advocates

#40461

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Data as of 12/3/24

Family Paid Caregiver Pilot Program Data

Pilot program start date: 4/1/24

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 Service: **$2,200,000**
Total Funds Authorized: **$1,252,245.67**
Held for Appeals: **$609,131.25**
Held for Pending Applications: **$338,623.08**

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

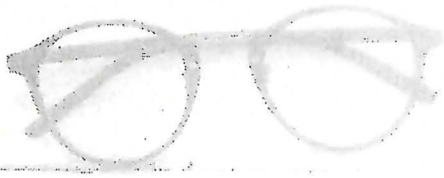
**Anyone who has been denied for an appealable reason would have appeal rights where the funding is held until 30 days after the decision date (unless appealed further, then the funding continues to be held)*

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.*



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

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Family Paid Caregiver Pilot Program

Frequently Asked Questions

Program Criteria:

Q1. What is the family paid caregiver pilot program?

A. A state funded pilot program that will provide payments to family caregivers who provide extraordinary care to eligible individuals enrolled in a Medicaid 1915 (c) waiver.

Q2. When does the pilot program start?

A. April 1st, 2024

Q3. Who is eligible for this pilot program?

A. Participants must meet all the following criteria:
- enrolled in a Medicaid 1915c waiver (Autism Spectrum Disorder Waiver, Medically Fragile Waiver, Children's Hospice Waiver, Developmental Disabilities Traditional IID/DD Waiver);
- support needs are not otherwise compensated though other services available in a 1915c waiver or Medicaid State Plan; and,
- assessed needs meet extraordinary care.

Q4. Is there an age requirement for participants?

A. No. This pilot program is available to all participants enrolled in one of the qualifying 1915c waivers.

Q5. What is extraordinary care?

A. Extraordinary care means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of the applicant or eligible participant without extraordinary medical or behavioral needs and is necessary to assure the health and welfare and to avoid institutionalization of the applicant or eligible participant in need of care.

Q6. Who is a family caregiver?

A. A legally responsible individual who lives with and provides daily care(s) to the applicant. This may include, but not limited to a biological or adoptive parent, non-entity custodian, guardian, or spouse.

Q7. Can the family caregiver still have employment outside of this pilot program?

A. Yes, the family caregiver would be able to be employed and also partake in this pilot program if found eligible.

Q8. Will this affect other waivered services I may be receiving?

A. Those who are found eligible for this pilot program will still be able to receive the waivered services they are currently receiving. Hours within the waivered service will not automatically decrease but will continue to be discussed as a team on how the service(s) is meeting the needs of the individual or if any changes are needed.

Application:

Q9. Who can apply and what is the process for applying?

A. The applicant or legally responsible individual may submit an application within the Family Caregiver Portal. Once the application is reviewed, the applicant or legally responsible individual will receive an assessment to complete. This self-assessment will aid in identifying the extraordinary needs of the applicant. This application is valid for 1 year.

Q10. If the eligible participant lives in more than one household can both family caregivers enroll in this pilot program?

A. Yes. Both family caregivers are eligible as long as the pilot program requirements are met.

Q11. Will a background check be required?

A. The family paid caregiver will be required to submit the Child Abuse & Neglect Background Inquiry (SFN 433), however no criminal background check is required.

Q12. If I am providing care to more than one person in my household, am I able to receive payment for each?

A. No. This program is limited to one per household.

Q13. Is there a deadline to apply for this pilot program?

A. There is no specific deadline as applications will be reviewed as they are received. The number of participants and funding is limited and once those limits have been exhausted, applications will no longer be approved.

Q14. Will I need to reapply for this pilot program?

A. Yes. The initial application and assessment are valid for 1 year. If the eligible participant and legal decision maker wish to continue past the initial year, they

will need to reapply prior to the expiration of the approved application and assessment.

Q15. How will I know if I am approved?

A. A letter of determination will be sent to applicant.

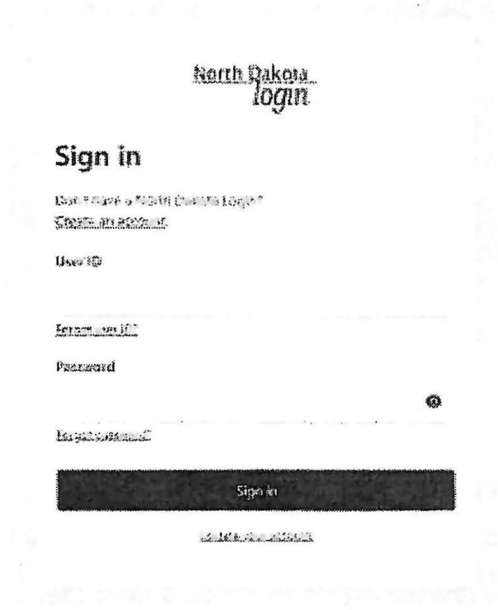
Portal:

Q16. What is the Family Caregiver Portal?

A. A secure web-based system that will provide the applicant or legally responsible individual access to the application, communication, authorizations, and payment requests.

Q17. How do I access the Family Caregiver Portal?

A. The portal will be available on April 1st, 2024, and the link will be available on our website hhs.nd.gov/family-paid-caregiver-pilot-program. If you already have a North Dakota Login account (*pictured below*), you will be able to use that User ID and password to access the portal. A new account can be created if you do not wish to use the same account, however, a different email address will need to be used.



Payment:

Q18. What is the rate of payment?

A. Eligible participants ages 0 through 17 will receive an authorization for $77.45 per day and participants ages 18 and older for $154.89 per day. This is a daily rate.

Q19. How do payments work?

A. Once an authorization has been created, the family caregiver will be able to submit a request for payment twice a month in the Family Caregiver Portal. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm). The authorization will be valid for up to six months and may be reissued for an additional six months.

Guidance for requesting payments will be included via email once a payee account has been successfully created.

Payments will be issued two times a month according to the defined payment schedule:

Time Period	Request for Payment Due to State	Payment Date
April 16-30	5/5/2024	5/15/2024
May 1-15	5/20/2024	5/31/2024
May 16-31	6/5/2024	6/14/2024
June 1-15	6/20/2024	6/28/2024
June 16-30	7/5/2024	7/15/2024
July 1-15	7/20/2024	7/31/2024
July 16-31	8/5/2024	8/15/2024
August 1-15	8/20/2024	8/30/2024
August 16-31	9/5/2024	9/13/2024
September 1-15	9/20/2024	9/30/2024
September 16-30	10/5/2024	10/15/2024
October 1-15	10/20/2024	10/31/2024
October 16-31	11/5/2024	11/15/2024
November 1-15	11/20/2024	11/29/2024
November 16-30	12/5/2024	12/13/2024
December 1-15	12/20/2024	12/31/2024
December 16-31	1/5/2025	1/15/2025

Q20. How do I know what days I am able to request payment for?

A. If the eligible participant was in your care that day, you are eligible to submit a request for payment within the program guidelines. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm).

Q21. If more than one family caregiver is authorized to provide care, how do payments work?

A. The maximum number of days that can be claimed between all approved caregivers for the eligible participant is five days per week (Sunday 12:00am – Saturday 11:59pm). If the family caregivers both provided care on the same day,

they will need to decide which family caregiver requests payment for that day. If there are duplicate requests for payments on the same day, both will be denied.

Q22. What happens if I missed the due date for requesting a payment according to the payment schedule?

A. A request for payment may be submitted after the missed due date and payment will be issued on the next scheduled payment date.

Q23. Is this considered income for the family caregiver?

A. Yes, you will receive a 1099 and this income may impact other benefits you may be receiving. It is the family caregiver's responsibility to report this income as appropriate.

Q24. What happens if I don't request payment?

A. If a request for payment is not submitted for thirty calendar days, the family caregiver will be notified. If an additional thirty calendar days pass without a request for payment, the service may be terminated due to inactivity.

Q25. Will I be required to pay this back at any point?

A. If it is discovered that there is intentional deception or misrepresentation made by the applicant or family caregiver, the funds may be required to be paid back.

Q26. If the pilot program ends or the participant/family caregiver has been terminated, how long do I have to request payment?

A. You would have 15 calendar days to submit that final request for payment.

Quality Assurance:

Q27. How will the Department monitor services?

A. Face-to-face visits will be completed by your current waiver case manager at a minimum of every six months. These visits may coincide with already occurring face-to-face visits. This will ensure that the plan of care/plan for supports is monitored adequately, and the participant's needs are met by the family caregiver.

Q28. If a denial, revocation, or termination is received can the decision be appealed?

A. Yes. However, it is not appealable if one of the following reasons has been given:

- Funding has been exhausted for the pilot program.
- The applicant is no longer eligible for a Medicaid 1915c waiver.
- The application has been withdrawn.

Q29. Who can appeal?

A. The applicant, eligible participant, or family caregiver have the right to timely appeal.

Q30. How do I appeal?

A. A request for an appeal must be submitted in writing within thirty (30) calendar days of the notice issued. You may represent yourself in an appeal hearing or may use legal counsel, a friend, or other spokesperson.

Appeals Supervisor
North Dakota Department of Human Services
600 East Blvd Ave Dept 325
Bismarck ND 58505-0250
Phone: (701) 328-2311
Toll Free: (800) 472-2622
ND Relay TTY: 711
Fax: (701) 328-2173
dhslau@nd.gov

Q31. Who do I contact if I have questions?

A. Any questions can be submitted to familycaregiver@nd.gov.

SB 2305 Testimony
House Human Services Committee
Senator Kathy Hogan
March 12, 2025

Chairman Ruby for the record, my name is Kathy Hogan. I represent District 21 which is central Fargo and a portion of West Fargo.

During the 68th Legislative Session, the ND Legislature established a paid family caregiver pilot program to provide needed support to families who have members with serious illnesses or disability, both children and adults, who need extraordinary support to remain out of institutional care. Recognizing that these extraordinary supports need to be blended with other Medicaid waiver funding for in-home care services, this concept was challenging from the beginning for many reasons.

Your Human Services Committee received a summary of the guidelines for the pilot project and data on utilization that are uploaded in the testimony for this hearing. We also heard testimony from families on the amazing impacts this model had made for families with very seriously disabled members.

Paralleling the work on the Family Caregiver Pilot project is the effort to improve coordinated and access for children and adults with disabilities through other waivered services, including the DD and HCBS waiver by moving toward a Cross Disabilities Waiver concept that is still being designed. This effort will improve flexibility for people being supported and their families by allowing greater service options so that you do not need to change waivers to get some services. It is anticipated that by June 30, 2027, the Cross Disability Waivers will be ready for implementation and that this program will be integrated into those services.

Because this was a unique pilot project funded with state dollars, the program design was both put on a fast track, with limited funding. The pilot project is not included in the Governor's 2025-2027 budget.

A small working group reviewed all the data that is uploaded in the testimony on the FAQ on the program, the program data and spending pattern. The group included DHHS staff, advocates and family members and reviewed several funding recommendation options. The materials we looked at are attached to this testimony. The group recommended that we request $9 million to continue services to those already enrolled, those in appeals and pending applications. We did not recommend that all those on the wait list be funded because of the fiscal note. We chose the middle ground.

Your Human Services Committee unanimously recommended to pass on this request because of its success. The Senate Appropriations Committee supported this bill and the funding.

Thank you for considering SB 2305 and I am more than willing to answer any questions.

Testimony in Support of SB2305

2025 Legislative Session March 12, 2025

Chairman Ruby and Members of the House Human Services Committee,

My name is Brenda Schmid. I live in Fargo in District 46 along with my husband and daughter, Hannah.

I am providing this testimony in support of SB2305 for an Act to amend and reenact section 50 24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service program and cross-disability advisory council.

We have a beautiful daughter, Hannah, who is 27 years old who has significant physical and intellectual disabilities along with complex medical needs (extra ordinary care needs). She lives at home with us and will do so as long as we are on this earth together. For 27 years I have been her primary caregiver, and my husband has taken the role of sole financial provider. Our daughter uses a wheelchair (spastic quadriparesis), has epilepsy, neurogenic bowel/bladder, GJ tube (tube fed), scoliosis and kyphoscoliosis, cyclic vomiting and migraines, congenital tracheomalacia, nephrolithiasis, reflux disease, is nonverbal and has insomnia. She relies on others 100% to live.

I have been participating in the Pilot Program since Spring 2024. A few words I would use to describe what the family paid caregiving pilot program means to me and my family are "relief, validation, valued **and** recognized as an asset that helps fills the void in the caregiver shortage crisis.

I have attempted to work outside of the home many times over the past 27 years, only to have to resign as Hannah needs me. My husband travels for his work (same company for 33 years) he needs me to take care of Hannah and our home so he can do his job and focus on it to ensure financial support for our family.

By being Hannah's primary caregiver for the past 27 years we have saved the state an astronomical amount of money and resources. Here are a few examples:

- When Hannah was in school (K-12) there were countless days, I had to pick her up early and bring her home due to medical reasons and behaviors. If I had been working outside of the home, I would have been unable to pick her up and the staff at school would have had to care for her consequently taking away from other students and staff.
- When Hannah is hospitalized, she is discharged in a timely manner as I can carry out her discharge plan with quality and precision versus her returning to a congregated living situation where staff may not be trained or instructed properly to care for her.

- When she has a medical situation, I get her the medical attention she needs and am equipped to take care of her at home versus unnecessary hospitalizations or ER visits.
- Her medical team makes different long term medical decisions based on her living situation. i.e. no colostomy bag or bladder port as I can monitor and manage her bowel and bladder regiment better than if she was in a congregated living situation and unable to receive the one-on-one care she needs.
- We provide an accessible home in a community of her choice; we provide an accessible van that enables her to be an active part of her community.
- And most importantly she is happy, healthy (all things considered) confident, secure and thriving in every aspect of her life because she is loved and cared for by me (us) in her home.

There has always been a "need" for a Family Paid Caregiver Program in ND. With that being said, I believe there has never been a "greater need" for this program than the here and now.

I am asking that you act in favor of this program, and I thank you for your time and consideration.

Sincerely,

Brenda Schmid (Hannah's proud Mom)

701-866-8687

The Arc
North Dakota

House Health and Human Services
SB 2305
March 12, 2025

Chairwoman Lee and Members of the Senate Human Services Committee, I am Kirsten Dvorak, Executive Director of The Arc of North Dakota, supporting individuals with intellectual and developmental disabilities since 1958. We empower families and foster inclusive communities throughout the state. I stand in support of Senate Bill No. 2305.

The 2023 FINDS (Family and Individual Needs for Disability Supports) Community Report, created by the Institute on Community Integration at the University of Minnesota in partnership with The Arc of the United States, reveals the significant challenges faced by families caring for individuals with disabilities. These families contend with substantial financial strains and difficulty accessing essential services needed for the care of their loved ones. The report highlights the pressing need for policy initiatives like Senate Bill No. 2305 to alleviate these issues and ensure families receive the support they need.

- **Financial Hardship**: 41% of family caregivers have quit their jobs to provide care. This issue isn't about compensating parents for staying home; it highlights that many have lost their jobs because of the extensive care requirements of their children. These families face significant financial pressure as they attempt to cover the long-term caregiving expenses needed for their loved ones.
- **Limited-Service Availability**: Many individuals with disabilities remain on waiting lists for essential services, such as in-home support, respite care, and specialized therapies, placing enormous pressure on families who must take on caregiving responsibilities with little to no external support.
- **Caregiving Demands**: Family caregivers often dedicate over 40 hours per week to providing care, impacting their health and ability to maintain employment. Research has shown that prolonged caregiving without support can lead to increased rates of stress, anxiety, and even physical health issues such as high blood pressure and chronic fatigue.
- **Cost of Institutionalization vs. Home Care**: Studies have shown that home-based care is significantly more cost-effective than institutional care. On average, institutionalization can cost two to three times more than providing care within the home. By supporting family caregivers, we can help individuals with disabilities remain in a stable and familiar environment while reducing the overall financial burden on the state.

Senate Bill No. 2305 presents vital assistance through the Family Paid Caregiver Service Pilot Project, designed to reward family caregivers who deliver outstanding care to qualified Medicaid 1915(c) waiver recipients. This legislation guarantees compensation for caregivers who provide care beyond typical daily living activities necessary to prevent institutionalization. The Department of Health and Human Services will oversee the program, ensuring accurate eligibility assessments and avoiding duplicate payments from other services. Moreover, the Cross-Disability Advisory Council will advise on the program's implementation and future Medicaid waiver initiatives. The legislature will receive ongoing reports on the program's effectiveness, utilization, and expenses to ensure transparency and effectiveness. Additionally, a one-time funding of $7.3 million from the general fund will support this initiative for the two years from July 1, 2025, to June 30, 2027.

At The Arc of North Dakota, we believe that while financial assistance to family caregivers is essential, it should not replace comprehensive support systems. Investments in home-based services, respite care, and community programs remain crucial to ensuring that individuals with disabilities receive high-quality care that supports them and their families.

This bill represents a step toward recognizing and alleviating the burden carried by countless families in our state. By supporting SB 2305, we can empower families with the resources they need to provide the best care possible while maintaining their well-being.

On behalf of The Arc of North Dakota and the families we serve, I urge you to support Senate Bill No. 2305. Thank you for your time and consideration. I am happy to answer any questions.

Sincerely,
Kirsten Dvorak
Executive Director, The Arc of North Dakota

Testimony in Support of SB2305
2025 Legislative Session
03/11/2025

Chairman Ruby and Members of the House Human Services Committee-

My name is Brittany Zappone, and I live in Bismarck, ND. I have two children, Kohner (10) and Kenadi (6). I am here today in support of SB2305 pertaining to the Family Paid Caregiver Service Pilot Project.

I come today with testimony that may be considered a rare example, but I assure you this is happening as we speak today. My family has not been a part of the pilot program as my son would not meet the criteria and my daughter, who was shaken at 2 months of age, passed away from her injuries in May 2023, shortly after the pilot program was established. She was medically complex and needed 24/7 care. We started with respite and quickly found the care provided was rarely quality.

Parents are expected to work to keep a roof over our family's heads and trust those who care for our children while we're away. However, I had caregivers that slept on the job, others that refused to care for her altogether, and she even incurred injuries on their watch. I, thankfully, kept cameras in my house so I was able to catch these things, but it shouldn't have happened to begin with.

If a respite provider we trusted was not available, we lost the hours. Essentially, someone else got them because I refused to place my daughter in harm's way. In the last year Kenadi was with us, we finally found one respite provider we trusted, and she stayed with us until my daughter passed away. We got lucky there.

Among other things, my daughter needed several medications administered daily, assistance with all ADLs, and she was visually impaired. She relied heavily on trusting a caregiver's voice to feel safe. She also had epilepsy and attended intense therapies 5 days a week. All in addition to a full school day. She was stubborn and determined to beat all the odds stacked against her. Her smile would brighten any room, and you knew when she felt safe.

I worked a job that was fairly flexible and very understanding; another area we got lucky. I went where my children needed me and my job knew that. If we had extended hospital stays, surgeries, appointments, etc. I attended them and did so without pay. It had a great financial impact, but my children are always my priority. I worked a lot of time after hours with my children nearby and often sacrificed family time because I needed to pay the bills. We made it because we had to. It is time we will never get back, but I will never regret putting them first.

My daughter transitioned to hospice, and I immediately put in leave, without pay. My daughter remained on hospice for 4 months and I spent every single moment with her, my son, and my family. My son is medically needy and has intense therapies as well, which have only gotten more intense since my daughter passed. He continues these today.

I realize many will think that we are just parents asking to be paid to be parents. We certainly are parents, but we are different. We do the extraordinary because, well, we aren't the ordinary. We don't fit in the box. We have many titles, and we do all of this for those that we love. For those who deserve to have someone care for them. Someone that truly cares.

These respite hours are already approved for these families. The workers are paid a good wage, ours was paid $24/hour to care for my daughter. We did not use all our hours, but the dollar amount was more than what is being offered here in this program. Families do this 24/7 because it is needed and without any hesitation. Families will never do it for the money, but they are also expected to keep the rest of the family afloat and a roof over their heads. It is impossible to do both. These cares are extraordinary and are above and beyond what someone would do in the home for a child with "ordinary" cares.

I have friends that have their children in an institution as they cannot physically lift them any longer and there was no staff available to help them keep their loved one at home. Imagine being a child and being somewhere with strangers every day after spending so many years surrounded by a loving family. It breaks my heart every time I visit. The level of care is significantly worse than a loving parent would provide. People go there for a job, and unfortunately, not always because they love the kids. I have visited and provided care to some when I saw it was needed and not a single staff member would came to help. I would walk in and see children sitting in wheelchairs and having nothing but a screen to stare at with no caregiver in sight. It is truly heartbreaking and not a decision any of the families made easily. The care is not quality and, therefore, the children do not thrive.

Child caregivers are not asking for anything more than what adults are getting. I am also involved in a home health care business and see what services are provided to adults in their home. Why can adults receive this and not the children?

What people do not see is what these children must go through just to get on these lists. The number of doctors, therapists, and specialists the children need to see for support as well as the extra time and dedication from their caregivers shouldn't be overlooked.

I cannot stand here and tell you how this will affect my family as that opportunity is no longer an option. I can, however, tell you that I provided care for my children despite the challenges. I was the only one that knew my daughter and her needs in a way no one else could without spending the time with her and listening to her. I was there through all her medical appointments, emergency medical flights, therapies, her 27 surgeries and recovery, her time on hospice, and the only one with her as she took her last breath.

We as parents will always step up when needed. All we are asking here is that we are seen as an equal to the others and to be compensated. For others to truly know what it is like, they would have to experience it. I strongly believe no one would stand here and say that institutional care is best after that. Unfortunately, some had no other choice. I am positive everyone in this room has a story to tell. They all may be different, but they will all be tied together by the love and extraordinary care they provide for those who deserve it most.

I thank you for your time today and ask that you consider a do pass on this bill. The need is there, and it will be heard many times over today, we just need your help to get there.

Thank you for your time and consideration,
Brittany Zappone
Bismarck, ND
Brittany.Zappone1516@gmail.com

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2305

House Human Services
Wednesday, March 12, 2025
Representative Matt Ruby, Chair

Chair Ruby and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm here today as the representative for Designer Genes of ND, Inc. Designer Genes' membership represents individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

First off, I'd like to thank you for your work and investment in the concept of paid family caregiving during the 68th legislative session and your help to kickstart the current pilot program. I'd also like to thank the Department for their dedicated work to "go live" and make the program a reality for 50 North Dakota caregivers. (Per 12-11-24 Cross Disability Advisory Council Meeting).

Designer Genes is in support of SB 2305 and asks for a "do pass" from this committee. We'd like to thank Senator Hogan for including us in discussion on the amendments that were proposed and passed. We are in agreement with the amendments that were made in the Senate and the proposed appropriation.

We estimate that there are about 600 individuals with Down syndrome that live in North Dakota and a majority of those individuals are screened to the Individuals with Intellectual Disabilities/Developmental Disabilities 1915c Medicaid Waiver. Quality waiver service options are one of our advocacy priorities and having the family paid caregiver option in our Medicaid waivers is important to our families across the lifespan. Individuals with Down syndrome and their families are able to achieve quality lives in their communities with the formal supports of the Medicaid waivers and State Plan Medicaid. One thing that is important to note is that families who have children eligible for our Medicaid waivers depend on the service options within the waivers, but also depend on having access to State Plan Medicaid for their children. When they can't use waiver services due to a lack of workforce or quality providers, they run the risk of losing both the waiver service options and State Plan Medicaid. This option can help provide some stability for families of children with exceptional and extraordinary need so that they will not lose coverage.

While we acknowledge that we should not change the eligibility standards for the pilot program, we would like to make known that the current assessment does not offer enough information to the Department for children under 8. As you will probably hear in other testimony, the younger a child is, the less items that can be completed on the current assessment. For children with Down syndrome, this is especially concerning as many conditions such as congenital heart defects, gastro-intestinal defects, and childhood leukemias may present themselves at birth. These conditions to name a few can cause lengthened hospitalizations, an inability to use typical child care, increased care coordination efforts, trips out of state for medical care, and missed work for parents. While an infant needs total care, the care for an infant with failure to thrive or who is post-surgical looks much different. We hope that ongoing evaluation of the assessment process can happen with input from the Cross Disability Advisory Council (CDAC) so that families of younger children are not missed.

We understand the SB 2113 made changes to the Cross Disability Advisory Council (CDAC). Even with those changes, we continue to support Section 1.6 and think that CDAC is an effective method of assuring stakeholder involvement on the paid family caregiver service option.

Thank you for your time and I'm available for any questions.

Roxane Romanick
Designer Genes of ND, Inc.
701-391-7421
info@designergenesnd.com

House Human Services
SB 2305
March 12th, 2025

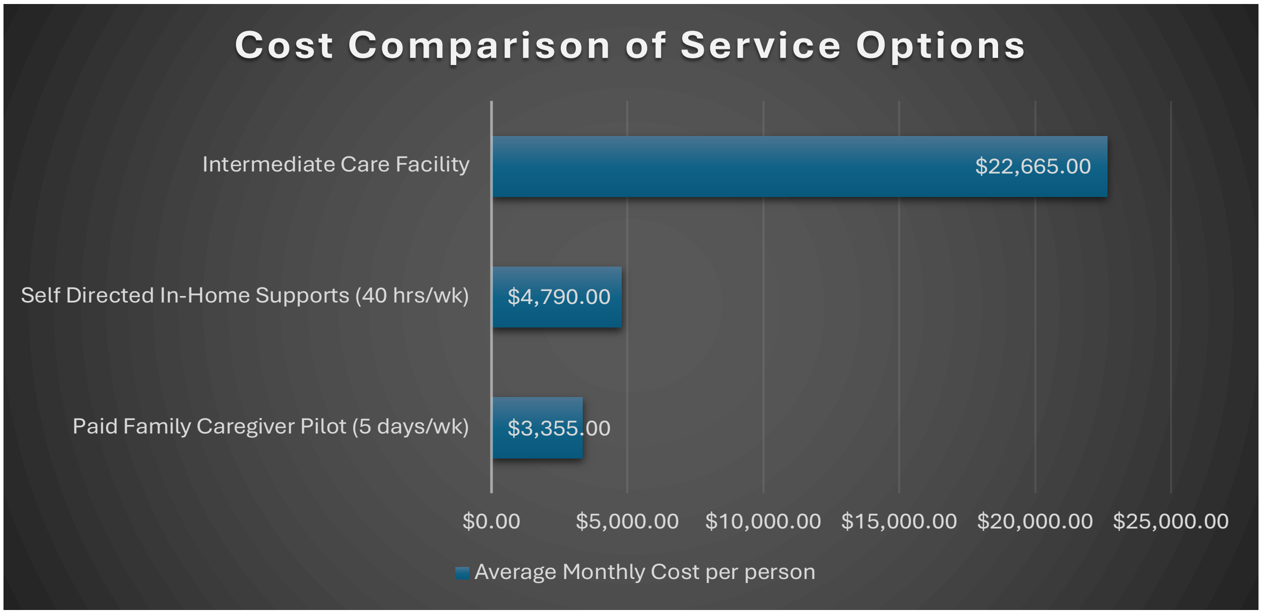
Chairman Ruby and members of the House Human Services Committee,

My name is Katynka Morrissette and I live in Bismarck, ND with my husband and our 3 young children. I am here today to give testimony on why I support SB 2305 and share with you how it impacts our family. I am the primary caregiver to our three young children Joey (age 9), Medrick (age 8), and Eleanor (age 7), who are on the Medically Fragile Waiver. They require extraordinary care due to their metabolic condition and other complexities.

Daily they require multiple doses of medications and nutritional support administered through their G or G/J tube, a complex feeding schedule and diet, glucose and ketone checks, breathing treatments, care for their medical ports, and assistance with home therapy treatment plans and daily living activities. Due to their high level of need and how specialized some of these cares are, we have been unable to find appropriately trained staff to provide support for them.

In 2023 legislation was passed (SB 2276) that developed the Paid Family Caregiver Pilot Program in North Dakota. Our family has been able to participate in the program and see firsthand the benefits that have resulted, like decreased hospital stays and improved mental health.

Paid family caregiving offers multiple clear benefits: it supports families, reduces reliance on institutional care facilities, and ensures individuals with disabilities can stay in their own communities with proper support. Reducing institutional care also has financial benefits, as shown in the chart below comparing service options for individuals.



While I could never put a dollar amount on the health and wellbeing of a child, and no parent ever wants to be faced with the possibility of placing their child in a care facility, this unfortunately is the reality many in our state have faced and will continue to if we don't work to provide the services these children need. With caregiver turnover and workforce shortages across the state, many people are going without the services they are assessed for and authorized to receive.

A while back our oldest son had commented about how he is no longer afraid of getting sick from food other people give him, because one mistake in his diet has many consequences for him. Today he is actually in bed with multiple symptoms and sores in his mouth, because of an emergency need to leave him with someone who accidentally gave him unsafe food. It only takes one slip up and oversight to have lasting consequence for individuals with extraordinary care needs. The years of experience and training from his care team have allowed me to be the best caregiver for him and Senate Bill 2305 places value and recognition on the care that I provide.

We as caregivers know our children best and have training to provide these specialized cares, and it is crucial for this pilot to continue as the department works to get it implemented into the current waivers as a service option so that we can be a part of that workforce.

Thank you for your time today and allowing me to share with you some of the impact this pilot has had on our family, I am asking for a "Do Pass" recommendation on Senate Bill 2305 so that families in our state can access this service option with the improvements learned through the pilot program and fill the caregiver shortage that so many have experienced. I will now answer any questions you may have for me.

Thank you again for your time and consideration.

Katynka Morrissette

jkmorr@icloud.com

701-301-1541

2025 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

SB 2305
3/19/2025

Relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

9:30 a.m. Chairman M. Ruby opened the meeting.

Members Present: Chairman M. Ruby, Vice-Chairman Frelich, Representatives K. Anderson, Beltz, Bolinske, Davis, Dobervich, Fegley, Hendrix, Holle, Kiefert, Rios, Rohr
Members Absent: Representatives

Discussion Topics:

- Committee action

9:31 a.m. Representative Rohr moved a Do Pass and rerefer to appropriations.

9:31 a.m. Representative Dobervich seconded the motion.

Representatives	Vote
Representative Matthew Ruby	Y
Representative Kathy Frelich	Y
Representative Karen Anderson	Y
Representative Mike Beltz	Y
Representative Macy Bolinske	Y
Representative Jayme Davis	AB
Representative Gretchen Dobervich	Y
Representative Cleyton Fegley	Y
Representative Jared Hendrix	AB
Representative Dawson Holle	Y
Representative Dwight Kiefert	Y
Representative Nico Rios	AB
Representative Karen Rohr	Y

9:34 a.m. Motion passed 10-0-3.

Representative Rohr will carry the bill.

9:34 a.m. Chairman M. Ruby closed the meeting.

Jackson Toman, Committee Clerk

REPORT OF STANDING COMMITTEE
REENGROSSED SB 2305 (25.0909.04000)

Human Services Committee (Rep. M. Ruby, Chairman) recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (10 YEAS, 0 NAYS, 3 ABSENT OR EXCUSED AND NOT VOTING). SB 2305 was rereferred to the **Appropriations Committee**.

2025 HOUSE APPROPRIATIONS

SB 2305

2025 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee
Roughrider Room, State Capitol

SB 2305
3/27/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

9:09 a.m. Chairman Vigesaa opened the meeting.

Members present: Chairman Vigesaa, Vice Chairman Kempenich, Representatives Anderson, Berg, Bosch, Brandenburg, Fisher, Hanson, Louser, Martinson, Meier, Mitskog, Monson, Murphy, Nathe, Nelson, O'Brien, Pyle, Richter, Sanford, Stemen, Swiontek, Wagner

Discussion Topics:

- Cross-Disability Waiver
- Extraordinary Care for Children

9:09 a.m. Representative M. Ruby introduced the bill.

9:15 a.m. Senator Kathy Hogan answered questions and testified In Favor #44293.

9:21 a.m. Sarah Aker, Medical Services Division Director, ND Department of Health and Human Services.

9:35 a.m. Chairman Vigesaa closed the meeting.

Krystal Eberle, Committee Clerk

SB 2305 Testimony
HOUSE APPROPRIATIONS COMMITTEE
Senator Kathy Hogan
March 27, 2025

Chairman Vigesaa for the record, my name is Kathy Hogan. I represent District 21 which is central Fargo and a portion of West Fargo.

During the 68th legislative session, the ND legislature established a paid family caregiver pilot program to provide needed support to families who have members with serious illnesses or disability, both children and adults, who need extraordinary support to remain out of institutional care. Recognizing that these extraordinary supports need to be blended with other Medicaid waiver funding for in-home care services, this concept was challenging from the beginning for many reasons.

The Senate Human Services Committee received a summary of the guidelines for the pilot project and data on utilization that are uploaded in the testimony for this hearing. We also heard testimony from families on the amazing impacts this model had made for families with very seriously disabled members.

Paralleling the work on the Family Caregiver Pilot project is the effort to improve coordinated and access for children and adults with disabilities through other waivered services, including the DD and HCBS waiver by moving toward a Cross Disabilities Waiver concept that is still being designed. This effort will improve flexibility for people being supported and their families by allowing greater service options so that you do not need to change waivers to get some services. It is anticipated that by June 30, 2027, the Cross-Disability Waivers will be ready for implementation and that this program will be integrated into those services.

Because this was a unique pilot project funded with state dollars, the program design was both put on a fast track with limited funding. What we learned very quickly was there was a much greater need than we anticipated. The pilot project was not included in the Governor's 2025-2027 budget.

After the first hearing in the Senate Human Service Committee, a small working group of various parties reviewed all the data that is uploaded in the testimony on the FAQ on the program, the program data and spending pattern. The group included DHHS staff, advocates and family members and reviewed several funding recommendation options. The materials we looked at are attached to this testimony.

In preparing the fiscal note we worked from a spreadsheet of funding options for your consideration. The first column reflects the estimated cost to continue the program for existing families, the second column reflects the costs for all those who have application appeals pending and the last column is the number of applications that are on the waiting list. The group recommended that we request $9 million to continue services to those already enrolled, and some of those with pending appeals. We did not recommend that all those on the wait list be funded because of the fiscal note. The Appropriations Committee changed the funding to $7.3 million to continue services to existing families and partially fund families when appeals have been finalized. If this bill is not funded, 70 seriously disabled individuals and their families will face an immediate crisis which could result in needing to move to institutional care such as Anne Carlsen or long-term care facilities.

Your Human Services Committee recommended to pass on this request because of its success. The Senate Appropriations Committee supported this bill and the funding. Your House Human Services Committee recommended do pass and so here we are.

Thank you for considering SB 2305 and I am more than willing to answer any questions.

NORTH
Dakota | Health & Human Services
Be Legendary.

Family Paid Caregiver Pilot Program

Frequently Asked Questions

Program Criteria:

Q1. What is the family paid caregiver pilot program?

A. A state funded pilot program that will provide payments to family caregivers who provide extraordinary care to eligible individuals enrolled in a Medicaid 1915 (c) waiver.

Q2. When does the pilot program start?

A. April 1st, 2024

Q3. Who is eligible for this pilot program?

A. Participants must meet all the following criteria:

- enrolled in a Medicaid 1915c waiver (Autism Spectrum Disorder Waiver, Medically Fragile Waiver, Children's Hospice Waiver, Developmental Disabilities Traditional IID/DD Waiver);
- support needs are not otherwise compensated though other services available in a 1915c waiver or Medicaid State Plan; and,
- assessed needs meet extraordinary care.

Q4. Is there an age requirement for participants?

A. No. This pilot program is available to all participants enrolled in one of the qualifying 1915c waivers.

Q5. What is extraordinary care?

A. Extraordinary care means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of the applicant or eligible participant without extraordinary medical or behavioral needs and is necessary to assure the health and welfare and to avoid institutionalization of the applicant or eligible participant in need of care.

Q6. Who is a family caregiver?

A. A legally responsible individual who lives with and provides daily care(s) to the applicant. This may include, but not limited to a biological or adoptive parent, non-entity custodian, guardian, or spouse.

Q7. Can the family caregiver still have employment outside of this pilot program?

A. Yes, the family caregiver would be able to be employed and also partake in this pilot program if found eligible.

Q8. Will this affect other waivered services I may be receiving?

A. Those who are found eligible for this pilot program will still be able to receive the waivered services they are currently receiving. Hours within the waivered service will not automatically decrease but will continue to be discussed as a team on how the service(s) is meeting the needs of the individual or if any changes are needed.

Application:

Q9. Who can apply and what is the process for applying?

A. The applicant or legally responsible individual may submit an application within the Family Caregiver Portal. Once the application is reviewed, the applicant or legally responsible individual will receive an assessment to complete. This self-assessment will aid in identifying the extraordinary needs of the applicant. This application is valid for 1 year.

Q10. If the eligible participant lives in more than one household can both family caregivers enroll in this pilot program?

A. Yes. Both family caregivers are eligible as long as the pilot program requirements are met.

Q11. Will a background check be required?

A. The family paid caregiver will be required to submit the Child Abuse & Neglect Background Inquiry (SFN 433), however no criminal background check is required.

Q12. If I am providing care to more than one person in my household, am I able to receive payment for each?

A. No. This program is limited to one per household.

Q13. Is there a deadline to apply for this pilot program?

A. There is no specific deadline as applications will be reviewed as they are received. The number of participants and funding is limited and once those limits have been exhausted, applications will no longer be approved.

Q14. Will I need to reapply for this pilot program?

A. Yes. The initial application and assessment are valid for 1 year. If the eligible participant and legal decision maker wish to continue past the initial year, they

will need to reapply prior to the expiration of the approved application and assessment.

Q15. How will I know if I am approved?

A. A letter of determination will be sent to applicant.

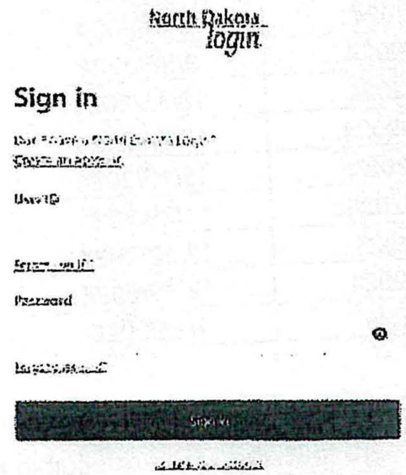
Portal:

Q16. What is the Family Caregiver Portal?

A. A secure web-based system that will provide the applicant or legally responsible individual access to the application, communication, authorizations, and payment requests.

Q17. How do I access the Family Caregiver Portal?

A. The portal will be available on April 1st, 2024, and the link will be available on our website hhs.nd.gov/family-paid-caregiver-pilot-program. If you already have a North Dakota Login account (*pictured below*), you will be able to use that User ID and password to access the portal. A new account can be created if you do not wish to use the same account, however, a different email address will need to be used.



Payment:

Q18. What is the rate of payment?

A. Eligible participants ages 0 through 17 will receive an authorization for $77.45 per day and participants ages 18 and older for $154.89 per day. This is a daily rate.

Q19. How do payments work?

A. Once an authorization has been created, the family caregiver will be able to submit a request for payment twice a month in the Family Caregiver Portal. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm). The authorization will be valid for up to six months and may be reissued for an additional six months.

Guidance for requesting payments will be included via email once a payee account has been successfully created.

Payments will be issued two times a month according to the defined payment schedule:

Time Period	Request for Payment Due to State	Payment Date
April 16-30	5/5/2024	5/15/2024
May 1-15	5/20/2024	5/31/2024
May 16-31	6/5/2024	6/14/2024
June 1-15	6/20/2024	6/28/2024
June 16-30	7/5/2024	7/15/2024
July 1-15	7/20/2024	7/31/2024
July 16-31	8/5/2024	8/15/2024
August 1-15	8/20/2024	8/30/2024
August 16-31	9/5/2024	9/13/2024
September 1-15	9/20/2024	9/30/2024
September 16-30	10/5/2024	10/15/2024
October 1-15	10/20/2024	10/31/2024
October 16-31	11/5/2024	11/15/2024
November 1-15	11/20/2024	11/29/2024
November 16-30	12/5/2024	12/13/2024
December 1-15	12/20/2024	12/31/2024
December 16-31	1/5/2025	1/15/2025

Q20. How do I know what days I am able to request payment for?

A. If the eligible participant was in your care that day, you are eligible to submit a request for payment within the program guidelines. The maximum number of days the family caregiver can claim is five days per week (Sunday 12:00am – Saturday 11:59pm).

Q21. If more than one family caregiver is authorized to provide care, how do payments work?

A. The maximum number of days that can be claimed between all approved caregivers for the eligible participant is five days per week (Sunday 12:00am – Saturday 11:59pm). If the family caregivers both provided care on the same day,

they will need to decide which family caregiver requests payment for that day. If there are duplicate requests for payments on the same day, both will be denied.

Q22. What happens if I missed the due date for requesting a payment according to the payment schedule?

A. A request for payment may be submitted after the missed due date and payment will be issued on the next scheduled payment date.

Q23. Is this considered income for the family caregiver?

A. Yes, you will receive a 1099 and this income may impact other benefits you may be receiving. It is the family caregiver's responsibility to report this income as appropriate.

Q24. What happens if I don't request payment?

A. If a request for payment is not submitted for thirty calendar days, the family caregiver will be notified. If an additional thirty calendar days pass without a request for payment, the service may be terminated due to inactivity.

Q25. Will I be required to pay this back at any point?

A. If it is discovered that there is intentional deception or misrepresentation made by the applicant or family caregiver, the funds may be required to be paid back.

Q26. If the pilot program ends or the participant/family caregiver has been terminated, how long do I have to request payment?

A. You would have 15 calendar days to submit that final request for payment.

Quality Assurance:

Q27. How will the Department monitor services?

A. Face-to-face visits will be completed by your current waiver case manager at a minimum of every six months. These visits may coincide with already occurring face-to-face visits. This will ensure that the plan of care/plan for supports is monitored adequately, and the participant's needs are met by the family caregiver.

Q28. If a denial, revocation, or termination is received can the decision be appealed?

A. Yes. However, it is not appealable if one of the following reasons has been given:

- Funding has been exhausted for the pilot program.
- The applicant is no longer eligible for a Medicaid 1915c waiver.
- The application has been withdrawn.

Q29. Who can appeal?

A. The applicant, eligible participant, or family caregiver have the right to timely appeal.

Q30. How do I appeal?

A. A request for an appeal must be submitted in writing within thirty (30) calendar days of the notice issued. You may represent yourself in an appeal hearing or may use legal counsel, a friend, or other spokesperson.

Appeals Supervisor
North Dakota Department of Human Services
600 East Blvd Ave Dept 325
Bismarck ND 58505-0250
Phone: (701) 328-2311
Toll Free: (800) 472-2622
ND Relay TTY: 711
Fax: (701) 328-2173
dhslau@nd.gov

Q31. Who do I contact if I have questions?

A. Any questions can be submitted to familycaregiver@nd.gov.

People	1	70	120	150
Daily Rate:	$159.54			
Inflation SFY 2026:	1.50%			
Cost SFY2026:	$ 42,102.61	$ 2,947,182.42	$ 5,052,312.72	$ 6,315,390.90
Inflation SFY 2027:	1.50%			
Cost SFY 2027:	$ 42,111.94	$ 2,947,835.74	$ 5,053,432.69	$ 6,316,790.86
Total Cost for 2025-2027 Biennium:	**$ 84,214.55**	**$ 5,895,018.16**	**$ 10,105,745.41**	**$ 12,632,181.76**

2025 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee

Roughrider Room, State Capitol

SB 2305
3/31/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

11:08 a.m. Chairman Vigesaa opened the meeting.

Members present: Chairman Vigesaa, Representatives Anderson, Berg, Bosch, Brandenburg, Fisher, Hanson, Louser, Martinson, Meier, Mitskog, Monson, Murphy, Nathe, Nelson, O'Brien, Pyle, Richter, Sanford, Stemen, Swiontek, Wagner

Member absent: Vice Chairman Kempenich

Discussion Topics:

- Cross-Disability Advisory Council
- Children Long Term Care
- Anne Carlson Specialty Charge

11:08 a.m. Representative Vigesaa initiated discussion on SB 2305.

11:24 a.m. Chairman Vigesaa adjourned the meeting.

Krystal Eberle, Committee Clerk

2025 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee

Roughrider Room, State Capitol

SB 2305
4/2/2025

A BILL for an Act to amend and reenact section 50-24.1-47 of the North Dakota Century Code, relating to the family paid caregiver service pilot project and the cross-disability advisory council; and to provide an appropriation.

9:10 a.m. Chairman Vigesaa opened the meeting.

Members present: Chairman Vigesaa, Representatives Anderson, Berg, Brandenburg, Fisher, Hanson, Louser, Martinson, Meier, Mitskog, Monson, Murphy, Nathe, Nelson, O'Brien, Pyle, Sanford, Stemen, Swiontek, Wagner

Members absent: Vice Chairman Kempenich, Representatives: Bosch, Richter

Discussion Topics:

- Committee Action

9:17 a.m. Representative Stemen moved Do Pass.

9:17 a.m. Representative Martinson seconded the motion.

9:20 a.m. Roll Call Vote

Representatives	Vote
Representative Don Vigesaa	Y
Representative Keith Kempenich	AB
Representative Bert Anderson	Y
Representative Mike Berg	Y
Representative Glenn Bosch	AB
Representative Mike Brandenburg	Y
Representative Jay Fisher	Y
Representative Karla Rose Hanson	Y
Representative Scott Louser	Y
Representative Bob Martinson	Y
Representative Lisa Meier	Y
Representative Alisa Mitskog	Y
Representative David Monson	Y
Representative Eric J. Murphy	Y
Representative Mike Nathe	Y
Representative Jon O. Nelson	Y
Representative Emily O'Brien	Y
Representative Brandy L. Pyle	Y
Representative David Richter	AB
Representative Mark Sanford	Y
Representative Gregory Stemen	Y

Representative Steve Swiontek	Y
Representative Scott Wagner	Y

9:20 a.m. Motion passed 20-0-3.

9:20 a.m. Representative Rohr will carry the bill.

9:21 a.m. Chairman Vigesaa closed the meeting.

Krystal Eberle, Committee Clerk

REPORT OF STANDING COMMITTEE
REENGROSSED SB 2305 (25.0909.04000)

Appropriations Committee (Rep. Vigesaa, Chairman) recommends **DO PASS** (20 YEAS, 0 NAYS, 3 ABSENT OR EXCUSED AND NOT VOTING). Reengrossed SB 2305 was placed on the Fourteenth order on the calendar.