

# CROSS-DISABILITIES ADVISORY COUNCIL

## Virtual Meeting

Thursday, MAR 26, 2026

1:02 p.m. – 4:01 p.m.

**Cross-Disability Advisory Council Members Present:** Darcy Andahl, Kirsten Dvorak, Kyle Erickson, Andrea Hansen, Julianne Horntvedt, Kayla Johnson, Paul Kolstoe, Heather Lundeen, Kevin Miiller, Jonathan O'Konek, Vicki Peterson, Lorena Poppe, Danielle Robbins, Kendra Vander Wal

**Cross-Disability State Agency Representatives Present:** Jackie Adusimilli, Kathy Barchenger, Kayla Fender, Karla Kalanek

**Guests Present:** Erin Leveton, Kathy Miiller, Erin Moore, Jillian Salmon

## WELCOME and ADMINISTRATIVE MATTERS

- The meeting was called to order at 1:02.

## GENERAL BUSINESS

- Role Call
- APPROVAL OF CDAC February Minutes
  - Kevin Miiller opened the floor for discussion on the “ND-CDAC Minutes 19FEB26 DRAFT”
  - Motion: It was moved by Kayla Johnson and seconded by Kirsten Dvorak to approve the 19FEB26 Minutes
  - Vote (Yes): Kirsten Dvorak, Kyle Erickson, Andrea Hansen, Kayla Johnson, Paul Kolstoe, Heather Lundeen, Jonathan O'Konek, Vicki Peterson, Kendra Vander Wal
  - Vote (No): none
  - Motion carried
- APPROVAL OF CDAC Paid Family Caregiver: Guiding Principles
  - After discussion during the meeting and changes to the DRAFT “Paid Family Caregiver: Guiding Principles – CDAC Feedback / Recommendation”
  - Kevin Miiller opened the floor for discussion on the “Paid Family Caregiver: Guiding Principles – CDAC Feedback / Recommendation”
  - Motion: It was moved by Kirsten Dvorak and seconded by Andrea Hansen to approve the “Paid Family Caregiver: Guiding Principles – CDAC Feedback / Recommendation”
  - Vote (Yes): Darcy Andahl, Kirsten Dvorak, Kyle Erickson, Andrea Hansen, Julianne Horntvedt, Kayla Johnson, Paul Kolstoe, Heather Lundeen, Jonathan O'Konek, Vicki Peterson, Danielle Robbins, Kendra Vander Wal,
  - Vote (No): none
  - Motion carried

## Paid Family Caregiving (PFCG) as a Waiver Service Modality

- Members walked through an example of using a Charting the LifeCourse framework – The All Triangle – to think about paid family caregiving.
- Members discussed recent activity from the federal administration that may impact all states’ PFCG in the future.
  - Members discussed options for advocating for PFCG, including the opportunity to advocate outside of their role as a CDAC member.
- Members discussed some final case studies of PFCG in other states.

## PFCG Guiding Principles

- Members reviewed the updated guiding principles that reflected their feedback from February.
- Members shared some additional feedback on final changes to make, then voted to formalize these guiding principles and share them with HHS.

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


DRAFT

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

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

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

**31**



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


DRAFT

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

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

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

**3**



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

DRAFT

## CDAC Feedback / Recommendation

## A&M Notes

ND's PFCG pilot is set to expire on June 30<sup>th</sup>, 2027. This could be disruptive for families who are currently involved in the pilot.

In the upcoming legislative session, CDAC recommends that the ND Legislature:

- Fund the PFCG state pilot for another biennium.
- Allocate funds for a PFCG waiver service modality in the Cross-Disability Waiver.
- Allocate funds for a PFCG waiver service modality in the other existing children's waivers (IID/DD, ASD, MF).

Extending ND's PFCG pilot depends on the availability of state dollars. A state pilot allows for flexibility in the PFCG program but doesn't secure a federal match.

The Governor's Office will release its proposed budget for the 2027-2029 biennium this year (2026). HHS must align its budget – including PFCG options – to the priorities set by the Governor's Office. The ND Legislature will then decide how to appropriate funds for the 2027-2029 biennium next year (2027).

Given the well-documented examples of PFCG risks in other states (uncontrollable costs and participant isolation), we recommend starting small with PFCG as a waiver service modality with overlapping safeguards only in the capped CDW. Starting small in this way allows ND to study the impacts of PFCG and use lessons learned to potentially expand it in the CDW and possibly other waivers in more favorable budget years.

Federal regulations prevent "waivers within a waiver." Adding PFCG to the IID/DD Waiver would mean it had to be an option to all families, which would not be in line with starting small to reduce risks and protect the program.

### Terms:

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

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

33



## Cross-Disability Waiver (CDW) Service Array and Guiding Principles

- The feedback that members have shared in recent CDAC meetings about the CDW's service array and modalities was captured in draft guiding principles that will be shared with HHS.
  - Members reviewed an initial draft of these guiding principles.
- Members provided initial suggestions on revisions to the guiding principles to better reflect their feedback from the last few months.
- In upcoming CDAC meetings, members will continue to review and revise these guiding principles before voting to finalize and formally share them with HHS.

## ADJOURNMENT

- The meeting was adjourned at 3:57 p.m.