

Below are the survey results about the Paid Family Care Giver concept and program by the 15 CDAC voting members. In this Biennium the composition of CDAC was mainly focused on generating feedback for the Children's Cross-Disability Waiver development work with Alvarez & Marsal (A&M).

In your opinion, how important is a Paid Family Care Giver program for the Cross-Disability Children's Waiver?
1 = Not important at all 3 = Average importance 5 = Vitally important

4.67 Average Score

Why do you feel that a Paid Family Care Giver program is needed? How will it help?
93% 14 Survey Respondents Answered This Question

71% 10 Workforce: Lack Of - Turnover - Not Able To Access Services

36% 5 Care Best: Parents Know Needs - Compassionate Support - Personalized - Choice - Stable

21% 3 Care Issues: Extraordinary Needs Not Being Met - Not Understanding Needs - Not Consistent - Lack Of Continuity - Safety
14% 2 Financial Burden
14% 2 Burnout: Decreases (Job & Care)
7% 1 Medicaid's Goals: Cost-Effectiveness and Community-Based Care by Reducing Reliance on Expensive Institutional Settings
7% 1 Potential: Lacking Care Keeps From Achieving Full Potential
7% 1 Remaining In Home
7% 1 Dignity: Recognizing Caregivers As A Cornerstone Of Our Health Care Infrastructure

What existing problem would a Paid Family Care Giver program solve?
100% 15 Survey Respondents Answered This Question

60% 9 Workforce: Shortage - Turnover - Rural - Flexibility

40% 6 Care: Consistent - Compassionate - Good - Improved - Choice - Trained
27% 4 Finances: Stability - Working Just To Pay Another - Just Scrapping By Due To Caring For Child

13% 2 Communities: Keeping People In Communities, Keeping Child In Home
7% 1 Service: Not Able To Utilize It
7% 1 Burnout: Decrease Job & Care
7% 1 Communication: Understanding Child
7% 1 Medicaid's Goals: Cost-Effectiveness and Community-Based Care by Reducing Reliance on Expensive Institutional Settings
7% 1 Dignity: Recognizing Caregivers As A Cornerstone Of Our Health Care Infrastructure

How would it benefit a child with a disability?
100% 15 Survey Respondents Answered This Question

80% 12 Care Quality: Consistent (Stability), Personalized, Tailored Care, Continuity Of Care, Families Know Child's Needs The Best, Parental Expertise

33% 5 Emotional: Child Needs (Consistency)

20% 3 Workforce Shortage: Care Availability - Child Cared For (Safe & Healthy) When No Other Options Available
7% 1 Safety: Reduces Risk Of Medication Error or Untrained Staff - Sickneses Brought Into House
7% 1 Finances: Of Family
7% 1 Medicaid's Goals: Cost-Effectiveness and Community-Based Care by Reducing Reliance on Expensive Institutional Settings
7% 1 Dignity: Recognizing Caregivers As A Cornerstone Of Our Health Care Infrastructure

How would it benefit the family of a child with a disability?

93% 14 Survey Respondents Answered This Question

73% 11 Security For Family: Income From Care Verses Loss Of Employment Due To Need To Care For Child - Parents Not Able To Work And Care - Focus On Child - Can Stay Home

47% 7 Psychological Benefits Parents: Decreased Stress - Child Getting Best Care - Having Care - Not Relying On Others - Financial Stress

27% 4 Care Quality: Consistant & Reliable Care - Best Care (Know Their Needs Best) - Deal With Their Anxiety

13% 2 Workforce: Get Required Services - Allows LRI To Be Considered An Employee - Join Workforce

7% 1 Medicaid's Goals: Cost-Effectiveness and Community-Based Care by Reducing Reliance on Expensive Institutional Settings

7% 1 Dignity: Recognizing Caregivers As A Cornerstone Of Our Health Care Infrastructure

What risks / drawbacks / challenges might paid family caregiving present for a child with a disability?

87% 13 Survey Respondents Answered This Question

33% 5 Burn-Out: Parents

33% 5 Care: Not Being Met or Decreased Quality or Not Best Solution - Generalized or Reduction of Skill

27% 4 Isolation: or Social Interactions Lacking

7% 1 Accountability

7% 1 Abuse, Neglect, And Explotation: Possibility

7% 1 Dependence: On Caregiver

7% 1 Resentment: Kids Resenting Mom

7% 1 When Family Is Not The Most Stable/Reliable Caregiver

What risks / drawbacks / challenges might paid family caregiving present for the family of a child with a disability?

93% 14 Survey Respondents Answered This Question

73% 11 Burn Out: Parents

13% 2 Technology: Veridian, Payment Structure, New Technology

13% 2 Care: Limited Training For Caregivers, Not Best

7% 1 Decision Making: Could Be Scrutinized Financial or Best For Child

7% 1 Finances: A Struggle

7% 1 Isolation:

7% 1 Quality Of Life Parents: Quit Personally Fulfilling Jobs

7% 1 Tension or Conflict: In Relationship Caused By Wearing Two Hats

**Below are example safeguards for LRI service provision that states have used. Please select the options that you feel North Dakota should explore potentially using to protect children and families and ensure good stewardship of funds.
Select all options to explore.**

93% 14 Quarterly face-to-face visits with case managers and participant
87% 13 Care plan documentation regarding how they will ensure care is delivered in the best interest of the participant
80% 12 Quarterly reviews of participant health, safety, and welfare status

67% 10 Background check for LRIs
60% 9 Complete necessary trainings
53% 8 Annual case manager discussion with participant without LRI to ensure best interests are met

40% 6 Participant verification of worker time documentation
40% 6 Annual physical examinations
33% 5 Requirement to utilize EVV to track service provision
33% 5 Quarterly review of expenditures
27% 4 Opportunity for unannounced visits

20% 3 LRI must watch informational video with detailed instructions and sign attestation
13% 2 LRI cannot be both employer and employee (in the case of self-direction)
13% 2 Must demonstrate participants have attempted to find a direct care worker who is not a LRI / live-in relative
13% 2 Requirement for LRI to be employed through provider agency
7% 1 Other Comment

How can ND help ensure individuals receiving paid family caregiving services remain integrated in the community and not isolated?

Select all of the below options that you feel ND should explore as possibilities:

80% 12 Care plan goals surrounding community integration

60% 9 Participation in non-waiver community opportunities such as school, clubs, teams
60% 9 Peer supports in the community
53% 8 Participation in community-based waiver services
47% 7 Written documentation of best interest / community integration in application

0% 0 "Other"