Listening to Caregivers
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NMCC 2023 Rural New Mexico Listening Tour

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Mission and Purpose of this Report

The New Mexico Caregivers Coalition (NMCC) advocates for paid professional caregivers as well as paid and unpaid family caregivers. We advocate for caregivers’ education, training, benefits, wages and professional development so they may better serve those who are elderly and those with disabilities.

This report focuses on results of the ten “Listening to Caregivers” sessions that were held in rural New Mexico in 2023. This report is intended for legislators and other elected officials; state agency staff; and for advocates as a Call to Action.

We thank the elected officials who attended these sessions (see Appendix 3). At their request, we have detailed the complex issues we learned about from caregivers, provider agencies (employers) and care recipients/consumers.¹

We have made recommendations as specific as possible to help elected officials understand these complicated issues and act on behalf of their communities. This report focuses on caregivers within the Personal Care Services (PCS) program and the Developmental Disabilities (DD) Waiver program because these are New Mexico’s publicly-funded Medicaid programs through NM Department of Human Services (HSD). Thus, elected officials are central to how these public funds are appropriated and then used.

We welcome your comments.
And we welcome your involvement too!

Adrienne Smith, President and CEO, NMCC

Listening Sessions are Central to Our Work

In 2008, New Mexico Caregivers Coalition was not yet formally organized. A small planning grant from Developmental Disabilities Council was provided to host a series of “Listening to Caregivers” sessions to be held in regions throughout New Mexico to give caregivers a “voice.” Our charge to caregivers was that they share challenges and solutions to the thorny issues of providing care to a care recipient or consumer. These early listening sessions served as the basis for obtaining valuable information across all parts of our state as well as the basis for establishing the foundational programs of NMCC. Travelling to locations throughout New Mexico was important so that caregivers could feel supported in sharing both their difficulties and solutions.

We have continued to conduct listening sessions since our inception. We hosted listening sessions in 2010, 2012, 2014 and, most recently, in 2018. Over time, NMCC has become an advocacy organization dedicated to the voice of the New Mexico caregiver. We welcome and support all individuals and organizations that also support caregivers.

We believe we do our best work when we work with caregivers, care recipients/consumers, provider agencies, advocates and the general public. For example, SB 85 (2019) and HB 395 (2023) were passed and signed into law because multiple stakeholders participated with us to lead passage of these bills.

¹ We use care recipients and consumers interchangeably. “Care recipient” is the preferred term within the Personal Care Services (PCS) environment. “Consumer” is the preferred term within the Developmental Disabilities (DD) Waiver environment.
“We [family caregivers] really don’t have the training we need to do the 24/7 job required to take care of a loved one. I am having trouble deciding if I made the right decision [for my son to be in the DD Waiver program].”

FARMINGTON PARENT OF A CHILD WITH DISABILITY

2023 “Listening to Caregivers” Sessions

NMCC organized the “Listening to Caregivers” sessions during the summer of 2023 in order to validate what we know about caregivers, and to learn more about our own, developing 2024 legislative priorities. The 2023 “Listening to Caregivers” sessions were held in Alamogordo, Hobbs, Roswell, Portales and Farmington, New Mexico. Two sessions were scheduled for each location (morning and evening) and participants had the choice of attending in-person or online via Zoom. Elected officials were invited to welcome his/her constituents and to listen to the challenges and solutions that caregivers presented. Elected officials, including state legislators, mayors and even one county commissioner, all attended (see Appendix 3).

What We Learned from “Listening to Caregivers” Sessions

We heard from paid, professional caregivers as well as paid and unpaid family caregivers. We also heard from Personal Care Services (PCS) and Developmental Disabilities (DD) Waiver program provider agencies. Note, the PCS and DD Waiver-funded programs are Medicaid-financed. Again, this report is centered on caregivers working within these environments.

A. Direct Care Workforce Crisis

Employers, care recipients/consumers and caregivers themselves frequently told us that the current direct care workforce shortages affect them. Paid, professional caregivers are overworked, stressed and underpaid, while family caregivers providing care to a loved one under a PCS- or DD-Waiver-funded self-directed program earn a pittance for a job that requires 24 hour-a-day care, seven days per week.

B. How the Caregiver Workforce Crisis Affects Quality of Care

There are more than 62,000 paid, professional caregivers in New Mexico. Caregivers are also known as home care workers, homemakers, residential care aides, personal care assistants, nursing assistants (in nursing homes), direct support professionals (in DD Waiver programs) and respite workers. Caregivers work in a variety of settings: in homes, community-based settings such as adult day care centers, group homes, assisted living, memory care centers and nursing homes (see Appendix 1 – Definition of Terms).

The Bureau of Labor Statistics documents the average wage of a New Mexico home care worker was $10.90 in 2009; astonishingly, in 2019 it was $10.92!

In our state, 83% of paid, professional caregivers are women; 82% are people of color and 64% of all caregivers live at or below the federal poverty level. These statistics describe the people who are working. A young man who works as a caregiver for a DD Waiver agency said, “I work 10 hours a day, five days a week and I’m still poor!”
For paid, professional caregivers in both the nation and New Mexico, the workforce crisis is the result of low wages, few or no benefits and years of national and state policies sidelining this workforce.

**Inadequate DD Waiver and PCS Reimbursement Rates**

The “Listening to Caregivers” sessions shed new light on inadequate reimbursement rates paid to PCS and DD Waiver providers. The comments we heard in 2023 have been voiced for many years and show how care recipients/consumers are adversely affected as well. One PCS agency provider stated that turnover at his agency is currently 48 percent. He has been in business for 21 years, pays better than most employers and has always been able to find good workers – until now. This provider agency executive told listeners in Roswell: “We have a 48% caregiver turnover rate because of very low state reimbursement rates. We cannot retain caregivers because we do not have other ‘cost centers’ to make up the losses paid in wages.”

We learned how DD Waiver self-directed programs such as Mi Via are characterized by woefully inadequate Medicaid reimbursement rates. The Mi Via program will pay a family member (or any person chosen by the care recipient/consumer) for care. But just barely. A 2023 Public Consulting Group rate study detailed that the Mi Via caregiver (“Homemaker”) rates are as low as $7.50/hour, 62% lower than State minimum wage! Rates for Respite Care are equivalent to these. Family members are often the only ones able to serve in these roles, so programs like Mi Via and Respite Care can keep entire families in poverty.

**Employee Benefits Accompany Caregiver Wages? Few to None**

Both paid, professional caregivers and paid and unpaid family caregivers stated they receive little or no training on-the-job. The jobs themselves are isolating, with few or no employment supports while on the clock. In one of the Farmington sessions, a woman caring for an adult sister under the DD Waiver Mi Via program said she had a “24/7 job but little to show for it.” She shared that the rate she is paid is so low that it qualifies her for Medicaid. Another woman (also attending a Farmington session) said that the third-party provider agency that pays her offers no training and that family caregivers like her just have to “figure it out.”

One family caregiver shared that she is unable to take care of her own emotional and mental health needs because she cannot find Respite Care to get the personal counseling she herself desperately needs. AARP reports that more than a quarter of older adults in the U.S. said they have mental health needs, defined as either a diagnosed condition, such as anxiety or depression, or self-reported emotional distress. These needs most often go unaddressed because the caregiver does not have time away from the care recipient/consumer to get help.

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2 As of this writing, state minimum wage for 2023 is $12.00 per hour.
A PCS provider agency executive from Portales related how she went to meet an employee (caregiver) the previous week at a gas station to pay for sufficient fuel for that employee to drive to care recipients’ homes that day. That PCS executive informed listeners that her company paid out of pocket for caregivers’ mileage/travel time between care recipients/consumers.

While the federal Fair Labor Standards Act and SB 85 (2019) require that providers pay minimum wage, overtime and travel time between clients (not to get to the worksite itself), this PCS agency provider noted that the state does not reimburse providers for travel/mileage for caregivers traveling between clients during work hours.

High Turnover Risks Quality of Care

Turnover rates in the direct care field are already higher than most other sectors – this was the case even prior to COVID-19. Due to worker shortages now, however, we observe that provider agencies have already lowered their acceptance rates, turning away Medicaid-eligible elders and those with disabilities, and even including those able to pay for care out-of-pocket.

Comments from a PCS provider agency executive attending a Roswell session parallel data from the national level: More than half (54%) of assisted living homes surveyed in 2022 reported they were forced to limit new care recipient admissions due to staffing shortages. In fact, home health agency (i.e., PCS provider agency) acceptance rates fell from 48% in June 2019 to 36% in 2022. All due to the workforce crisis.

One paid, professional caregiver attending a Farmington session said she and her co-workers are unwilling to leave a care recipient/consumer alone at those times when the next caregiver is due on shift but has not yet arrived. Yet, that caregiver stated her employer discourages overtime, leaving the care recipient/consumer and the caregiver herself in a very difficult position. Such a situation also places the provider agency at risk.

The two preceding examples should be of concern to our state’s executive and legislative branches because acceptance of federal funds presume that the state can adequately and safely serve persons who are elderly and those with disabilities.
The Direct Care Workforce Crisis Will Further Strain Systems of Care

The aging demographics of New Mexico and the nation will make for larger and more dire consequences. The direct care workforce crisis currently straining care recipients will further strain family caregivers too.

AARP estimated in 2021 that 38 million unpaid family caregivers nationally provided care to an adult who needed assistance with daily living activities (Hartoonian et. al. 2023). Our very own Aging and Long-Term Services Department reports that 419,000 New Mexicans provide more than 274 million hours of unpaid family care each year (NM State Plan for Family Caregiving). By the year 2030, one in five US adults age 65 or older will need care, including assistance with personal care activities such as bathing, dressing or other daily living tasks (AARP, 2019). However, the supply of direct care workers will fall far short of projected demand by nearly 7.9 million jobs from 2020 to 2030 (PHI, 2023).

Just one way in which the direct care workforce crisis affects family caregivers is that he/she cannot find a paid professional caregiver (respite) to fill in for even a few hours. Indeed, one woman caring for her daughter in hospice joined the Alamogordo session via Zoom and shared through her tears that she could not find a respite caregiver which she desperately needed just to get a break to care for herself. Sadly, we learned just three days later that this woman’s daughter died.

New Mexico Caregivers Coalition speculated in 2022 that paid professional caregivers may have left the field for good to seek better-paying jobs, with the intention of never returning (“Employers are Struggling to Find Caregivers,” Oct. 31, 2021). And now we know that to be true. Nationally, hourly wage growth was strongest for the lowest-wage workers (i.e., at the 10th percentile of all wage earners) between 2019 and 2022. This growth was more robust than at any time since 1979 (EPI, 2023).

New Mexico’s executive and legislative leadership in raising the state’s minimum wage in 2019 had a great deal to do even with lifting the average hourly wage of the nation’s low-wage workers. New Mexico’s minimum wage at the outset of 2022 was set by law at 11.50.

However, low-wage workers nationally and in New Mexico are predominantly women, Hispanic, Native-American and Black workers. And these are the very workers who make up New Mexico’s caregiver workforce who continue to suffer from grossly inadequate wages. NMCC is learning that state policy has a central role in resolving problems of poverty for the lowest-wage workers—and especially for those who are paid for with state and federal funds.
New Mexicans Need Robust Long-Term Care Program

We heard numerous times during the “Listening to Caregivers” sessions about New Mexicans whose income was too high to qualify for Medicaid Home and Community-Based Services yet not sufficient to pay out-of-pocket for much-needed care. Moreover, the nation’s demographics are changing—growing older—and New Mexico’s population is as well.

Washington State has established WA Cares Fund, a public long-term care insurance program. California is considering a similar plan. Minnesota and several other states are studying options. As reported in a New York Times article, 49% of Americans aged 40 and older expect Medicare to pay for their long-term care (Miller, 2023). In fact, Medicare covers only 100 days in a skilled nursing facility after a hospital stay.

Most workers living in Washington State started paying a 0.58 percent payroll tax on their wages this July to fund their state-sponsored long-term care insurance program. Starting in 2026, participating residents will be able to claim a benefit if they have a demonstrated need for assistance with three or more activities of daily living. The maximum lifetime benefit of $36,500 will be adjusted annually for inflation. The benefit is designed to cover approximately one year of care at home. California and Minnesota are studying versions of this programs for their own residents (Miller, 2023).

State Policy Implementation Frustrates Agencies and Family Caregivers

State policies and directives are often announced without input from the field, according to both PCS and DD Waiver provider agencies and caregivers. Provider agencies are sometimes “in the dark” just like caregivers, left to fend for themselves because they lack information. One DD Waiver provider executive in Farmington gave this example:

New Mexico’s DD Waiver provider agencies were expecting a $10.2 million allocation that was to begin July 1, 2023. Yet, the Acting Secretary stated in a public forum in June that those raises would not be implemented.
until January 2024. The DD Waiver provider agency attending the Farmington session wondered aloud (and assuming the above characterization is correct), who or which agency and when was it decided that the public funds planned for July 1, 2023 would not be released.

Similarly, a PCS provider of one of the Farmington sessions stated, “We were told [by Human Services Department] that a reimbursement rate increase had been included in the FY 23 budget [for PCS provider agencies], but we have not seen those funds released, nor have we received any information as to when those funds may be forthcoming.”

In short, PCS and DD Waiver provider agencies stated that they, too, often operate without support, information or even sufficient funding to serve persons who are elderly and those with disabilities. When providers are in the dark, caregivers feel that pain as well.

Developmental Disabilities Waiver agency providers and advocates stated that the home visits mandated in Spring 2023 and conducted by Department of Health-Developmental Disabilities Supports Division (DDSD) and NM Aging and Long-Term Services (ALTSD) were one example of how not to conduct health and safety visits. More than one DD Waiver Family Living provider said she felt an invasion of privacy.

Another example of how input from the field could have been obtained prior to state implementation was the change in criminal background checks’ processing. The State of New Mexico changed background check vendors but did not notify PCS or DD Waiver provider agencies before doing so. As a result, fewer locations were immediately available to provider agencies, forcing them at times to drive long distances to have a potential new hires fingerprinted in advance of starting a new job. In various cases over a two-week time period, one PCS provider agency said he lost two new hires to area employers who do not require a background check.

“We want to put people to work but need a fair [business] environment to do so.”

ROSWELL PROVIDER AGENCY PARTICIPANT

“The mistaken notion that Americans don’t want to work can now be put to rest. Nearly 81% of Americans ages 25-54 are working, the highest since 2001.”

HEATHER LONG, 2023
Legislative Call to Action

New Mexico Caregivers Coalition has advocated since 2009 for higher wages, benefits, trainings and supports for this workforce—the single fastest-growing workforce in New Mexico.

As a result of the 2023 “Listening to Caregivers” sessions, we recommend:

• **Create a publicly-funded long-term care insurance program** for New Mexicans with incomes too high to qualify for Medicaid but not sufficient to pay for care out-of-pocket. Senator Gay Kernan introduced such a memorial (SM 26) in 2022 that we believe is a good starting point and should be re-introduced. See https://nmlegis.gov/Sessions/22%20Regular/memorials/senate/SM026.pdf.

• **Create a publicly-funded Respite Care system** that serves paid professionals and paid and unpaid family caregivers in giving them the time off they need for physical, emotional and mental well-being. Twenty-nine other states have a Lifespan Respite Care system and New Mexico should create such a system that serves caregivers across the lifespan in ways that are independent of geography, setting or disability.

• **Create a state ombuds-person within the new Health Care Authority Department** to help workers resolve grievances. The office should take a proactive role to help resolve issues between caregivers and provider agencies to avoid litigation. New Mexico Caregivers Coalition called for creation of such a function in 2018 (see https://www.nmdcc.org/wp-content/uploads/2023/07/Senate-Joint-Memorial-6-Task-Force-Phase-2-Final.pdf) as an important step in helping family caregivers resolve issues with and between state agencies and to help paid professional caregivers resolve issues with provider agencies in order to avoid litigation.

• **Raise PCS and DD Waiver provider agency reimbursement rates** in ways that caregivers can see those increases, which, in turn, would help 1) employers retain current caregivers, and 2) encourage caregivers who have left the sector to return to the field.

• **Create a Department of Workforce Solutions state policy directive** to require that all employers pay travel time to caregivers when traveling between care recipients/consumers.

Fair Labor Standards Act revisions in 2015 and state law Senate Bill SB 85 (2019)) brought all NM caregivers under full protection of Fair Labor Standards Act. The State of New Mexico must enforce caregiver reimbursement for travel between care recipients/consumers. If a
mileage reimbursement does not already exist within the PCS program, one should be created. By law, Department of Workforce Solutions must enforce that these travel reimbursements make their way to caregivers.

**State policy reform should include enhanced funding to organizations providing training and support** to caregivers and potential caregivers. There are numerous agencies throughout New Mexico serving urban, rural, immigrant and tribal job seekers, including youth seeking to be of service. In addition to job training and advocacy organizations, high schools can offer dual credit and/or caregiver competency programs so graduating seniors may be hired immediately upon graduation.

Current state policy requires that a caregiver to be at least 18 years old to serve a person receiving PCS and DD Waiver services. This is an antiquated policy given the current workforce crisis. Many young people have both the desire and motivation to earn the skills to work – at the very least – as Respite caregivers.

**Policies already in place should be fully enforced.** Besides full enforcement of FLSA and SB85 by Department of Workforce Solutions, the State of New Mexico requires a minimum of 12 hours training of all caregivers working in any home health agency.

This requirement should be enforced by Human Services Department. We learned from numerous caregivers that, not only are career ladders absent from the direct care field in our state, caregivers are rarely trained on key competencies that could make them feel safer, better supported, more knowledgeable and more confident.

**The Career Ladder Identifier and Financial Forecaster (CLIFF),** is a practical tool developed by the Federal Reserve Bank of Atlanta, for use in counseling individuals on career choices that can move them to self-sufficiency. The tool looks at the impact of public benefits like SNAP and childcare subsidies on career mobility and how ‘benefit cliffs’ may be addressed through program design. It is a perfect tool for considering how caregivers can lose public assistance benefits as they move "up the wage ladder."

CLIFF has already been adapted to local and regional economies of New Mexico, using our own state and local data, disaggregated by county by the Federal Reserve Bank of Atlanta. It is available now, publicly and at no charge at https://www.nmdcc.org/public-assistance-benefits-test/.

State policymakers should be using CLIFF to 1) model the effects of wage increases on caregivers’ loss of public benefits at the regional/county workforce level, and then to 2) respond to those scenarios at the state and regional workforce levels.

“Unlivable wages are the main reason for huge turnover and poor retention…no matter much Centers for Medicare and Medicaid Services (CMS) raises reimbursement rates, as long as CMS allows agencies to pay workers minimum wage, nothing will change.”

DEMING, NM PROVIDER AGENCY


Appendix 1 – Definition of Terms

Caregiver – A professional care provider and/or an unpaid individual/family member who provides person-centered, quality assistance or support with daily activities, so that each care recipient/consumer may lead the most independent life possible.1

Developmental Disabilities (DD) Waiver – Medicaid-funded program designed to provide services and supports that assist eligible children and adults with Intellectual and Developmental Disabilities (IDD) to participate as active members of their communities. This program serves as an alternative to institutional care. The New Mexico Department of Health-Developmental Disabilities Supports Division administers the DD Waiver program.5

Centennial Care Community Benefit – Long-term care services and supports for Medicaid beneficiaries choosing to remain at home or in a community setting, rather than in institutional settings like assisted living and nursing homes. Services include help with Activities of Daily Living such as bathing, dressing, grooming and also include home (environmental) modifications to make living at home safer and more accessible.

This program will soon be known as “Turquoise Care” by New Mexico Department of Human Services.

Home and Community-Based Services (HCBS) – These Medicaid-funded programs serve a variety of targeted populations groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.8

Agency-Based Community Benefit (ABCB) – Services delivered by a provider agency that is contracted with Managed Care Organizations (MCO). “Care Coordinators” negotiate and then manage services based on member needs.9

Self-Directed Community Benefit (SDCB) – Services in which a “Member” (care recipient/consumer) is himself/herself responsible for managing the care plan and budget. The Member is responsible for hiring, firing and training of the caregiver, ensuring background checks are completed, submitting timesheets and invoices for payment to caregivers, arranging for Respite Care workers.10

Family Living – Medicaid-funded program intended for individuals who are assessed to need residential habilitation to ensure health and safety while providing the opportunity to live in a typical family setting. Individuals live on their own in a non-residential setting, furnished by a natural or host family member, or companion, who meets the requirements and is approved to provide these services in the individual’s home or the home of the Family Living direct support provider.6

Health Care Authority Department – Created as a result of the 2023 legislative session, this new department will replace New Mexico Human Services Department’s services and benefits to 1,046,816 New Mexicans through several programs including Medicaid, Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP), Child Support and several Behavioral Health Services.7


New Mexico Caregivers Coalition. (June 2019). Customized Training for New Mexico Caregivers [PowerPoint slides].


New Mexico Human Services Department (March 2023). Medical Assistance Division Long-term Services and Supports Bureau [PowerPoint slides].

New Mexico Human Services Department (March 2023). Medical Assistance Division Long-term Services and Supports Bureau [PowerPoint slides].
**Long-Term Care** – Public- or private-pay insurance that helps a care recipient/consumer pay for skilled, intermediate and/or care in a nursing home, in-home care, adult day care or assisted living facility. A policy typically pays a fixed amount per day while a person is receiving care.¹¹

**Medicaid** – A state- and federally-funded program that pays for and provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. This program is administered by states, according to federal requirements.¹²

**Centennial Care** – This is the name of New Mexico’s Medicaid program. The program began January 1, 2014 with services provided by four managed care organizations (MCOs) to Medicaid-eligible “Members.” Services include physical health, behavioral health, long-term care and community benefits.¹³

**Medicare** – The federally-funded health insurance program for Americans 65 and older, certain younger people with disabilities and people with permanent kidney failure requiring dialysis or a transplant.

**Medicare Part A (Hospital Insurance)** covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.

**Medicare Part B (Medical Insurance)** covers certain doctors’ services, outpatient care, medical supplies, and preventative services.

**Medicare Part D (prescription drug coverage)** helps cover the cost of prescription drugs (including many recommended shots or vaccines).

**Mi Via** – A person-centered, community-oriented program approach to deliver services and supports that assist eligible children and adults with Intellectual and Developmental Disabilities (IDD) or Medically Fragile conditions to participate as active members of their communities.¹⁴

**Respite Care** – A term used for taking a short break from caregiving duties to allow the primary caregiver an opportunity to rest, refresh and recharge.¹⁵

**Respite Care Registry (NM)** – Online public listing of trained respite providers in the State of New Mexico. Providers listed must have completed the Respite Care Training developed by the New Mexico Caregivers Coalition.¹⁶

**Respite Care Training Portal (NM)** – An online, self-paced training program consisting of ten core competencies that any respite care worker ought to know/possess. This course is designed to deliver the ARCH National Network Respite Care Professionals Core Competencies that, in turn, serve as a baseline for entry-level respite care professionals. Additional training may be required by a NM payor, depending on the unique needs of the care recipient and their family.¹⁷

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¹³ Centennial Care Overview | New Mexico Human Services Department. (n.d.). Retrieved July 24, 2023, from https://www.hsd.state.nm.us/lookingforassistance/centennial-care-overview/
Appendix 2 – Additional References


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Appendix 3 – Acknowledgements

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