

Medical Access Barriers for Disabled Residents in Western Nebraska

Survey Findings on Travel, Cost, Insurance, and Specialty Care Access

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This report summarizes survey responses from Western Nebraska families affected by long-distance specialty care requirements, documenting the financial, logistical, and medical risks created when closer regional care options are unavailable or denied.

Key Focus: Equitable access to medically necessary specialty care for rural Medicaid recipients, disabled residents, medically complex children, and caregivers across Western Nebraska.

Families across Western Nebraska face severe barriers accessing specialized medical care. Survey responses from 43 households reveal overwhelming financial strain, extreme travel distances, frequent appointment delays, and significant health risks associated with long-distance travel to Omaha or Lincoln. Nearly all respondents report that closer access to Colorado, Wyoming, or South Dakota specialists would dramatically reduce travel time, cost, and medical risk.

Key findings include:

81% of families have delayed or skipped specialized care because travel was too difficult or expensive.

Average round-trip travel time to Omaha/Lincoln ranges from **12–48 hours**, often requiring **2–4 days** away from home.

Typical trip cost ranges from **\$400–\$1,000+**, with some reporting **\$2,500** or more.

77% of households have a child requiring specialized care; many have multiple medically complex family members.

Diagnoses include **SMA, cerebral palsy, epilepsy, Down syndrome, EDS, diabetes, Parkinson's, stroke, dementia, autism, ADHD**, and numerous rare disorders.

Families consistently report that access to Colorado, Rapid City, or Wyoming specialists would save **8–14 hours** of travel time and eliminate overnight stays.

The data demonstrates a clear pattern: **Western Nebraska families are medically, financially, and logistically disadvantaged under the current system**, and closer regional access is essential for equitable healthcare.

Methodology

Survey period: Start date 4th 2025

Respondents: 42 households across Western Nebraska

Data type: ZIP codes, diagnoses, travel frequency, cost estimates, and narrative accounts

Geographic coverage reached so far with more to cover: ZIP codes spanning 69129–69361

Population: Medicaid recipients, families with medically complex children, caregivers, and adults with disabilities

ZIP Code Distribution (42 responses)

Most respondents reside in rural ZIP codes across the Panhandle. Highest concentrations:

69162 (Scottsbluff): 10 responses

69341 (Gering area): 6 responses

69361 (Scottsbluff): 6 responses Other ZIPs represented include 69129, 69133, 69146, 69337, 69339, 69343, 69347, 69358, and others.

Who Requires Specialized Care?

- **Child:** 32 households (76.2%)
- **Self:** 6 households (14.3%)
- **Senior:** 5 households (11.9%)
- **Spouse:** 2 households

Additional: foster youth, adult children, grandchildren, and one in-home care agency.

Diagnoses Reported

Respondents reported **over 40 distinct diagnoses**, including:

- **Spinal Muscular Atrophy (SMA)**
- **Cerebral Palsy (multiple forms)**
- **Epilepsy**
- **Bilateral Perisylvian Polymicrogyria**
- **Down Syndrome**
- **Ehlers-Danlos Syndrome (EDS)**
- **Diabetes (Type 1 & Type 2)**
- **Parkinson's Disease**
- **Stroke & Hemiparesis**
- **Autism, ADHD, learning delays**
- **POTS, dementia, ulcerative colitis**
- **Rare genetic disorders (EBS, Galactosemia, Agenesis of Corpus Callosum)**
- **Severe asthma, visual impairment, speech apraxia**

This reflects a population with **high medical complexity** requiring multidisciplinary specialty care.

Findings

1. Travel Frequency to Omaha/Lincoln

In the past two years:

- **9 families** made **0 trips** (often because they *could not* travel).
- **4 families** made **2 trips**.
- **4 families** made **3 trips**.
- **4 families** made **4 trips**.

Several reported **6–30+ trips**, especially caregivers serving multiple clients.

Many noted they **refused care, lost appointments, or went without treatment** due to travel barriers.

2. Appointment Delays Due to Travel Difficulty

- **81% (34 families)** reported skipping or delaying specialized care because:

Travel was too expensive, was too long and weather often made it travel unsafe. For care givers work schedules made multi-day trips impossible and for the children some could not physically tolerate long car rides. This is one of the strongest indicators of systemic access failure.

3. Travel Time Burden

Round-trip travel time to Omaha/Lincoln ranged from:

- **12–17 hours** (strict driving time)
- **2–4 days** including appointments, lodging, feeding, medical care, and rest
- **Up to 48 hours** for medically fragile children requiring frequent stops

Families repeatedly emphasized:

Children with SMA, CP, EDS, diabetes, ventilator dependence, or seizure disorders **cannot safely tolerate** 12–16 hours in a vehicle.

Winter travel across Nebraska **life-threatening** for medically fragile children.

4. Financial Burden

Reported costs per trip:

- **Typical:** \$400–\$800
- **Common:** \$500–\$1,000
- **High-end:** \$1,300–\$2,500

Includes: gas, lodging, meals, lost wages, childcare, medical supplies

One respondent wrote:

“Going that far just isn't an option so we try to doctor ourselves.”

Another:

“We have forgone care due to time and money.”

5. Impact on Family Stability

- Lost wages and job instability
- Children missing multiple days of school
- Parents forced to travel with all children due to lack of childcare
- Single parents unable to make multi-day trips
- Families considering **moving out of Nebraska** to access care
- Emotional strain, exhaustion, and worsening medical conditions

One parent reported moving to Colorado entirely because Nebraska Medicaid would not allow her daughter's care in Denver.

Extreme Medical Risk

- Respiratory decline
- Pressure sores
- Joint contractures
- Increased seizure activity
- Mental strain
- Danger of winter travel
- Ventilator-dependent children requiring oxygen tanks and emergency supplies

Systemic Denials & Insurance Barriers

Many families report

- Denials
- “In-network provider closer” claims that are factually incorrect
- Months-long waits for multidisciplinary clinics
- Inability to schedule multiple specialists in one day in Omaha

Colorado Is Significantly Closer and Safer

- Nearly every respondent states:
- Denver is **3–5 hours**, not 12–16
- Rapid City is **2–4 hours**
- Cheyenne is **same-day travel**
- Colorado offers multidisciplinary clinics in one visit
- Families have existing medical relationships in Colorado

Families Are Being Forced to Choose Between Care and Survival

Quotes include:

“Trying to keep your kid alive is hard enough. We shouldn’t have the added stress of unnecessary travel.”

“We end up not getting the care when needed because the trip would mean missing work for multiple days.”

“I moved to Colorado because Nebraska Medicaid would not allow her care. I had to sell my home that was accessible for my daughter and move away from all my support to allow her the care she needed as I was a single mom to 3. I didn’t have the ability or the funds to go to Omaha every month”

Projected Time Savings if Allowed to Use Colorado/Rapid/Wyoming Specialists

Respondents report saving:

- **8–14 hours** of driving
- **1–3 days** of missed work
- **Elimination of hotel stays**
- **Hundreds of dollars per trip**
- **Reduced medical risk** for fragile children
- Many could complete appointments **same-day** instead of multi-day travel.

Conclusion

Western Nebraska families face profound barriers to accessing specialized care. The current system forces medically fragile children and adults to travel extreme distances, endure significant financial hardship, and often forgo essential care. Allowing access to closer regional specialists particularly in Colorado would dramatically improve health outcomes, reduce costs, and restore equity for rural Medicaid recipients.

The survey data clearly demonstrates that **the status quo is not medically safe, financially sustainable, or ethically defensible.**

Statements from Western Nebraska Families and the Burdens they face.

Kissick Family- “Molina denying everything at the last minute when we have waited MONTHS for appointments and scheduling is out 3-6 months for specialties, AND multidisciplinary clinics are only held every so often. They CANNOT be missed or rescheduled”

Barker Family- “I fought and advocated with everything to continue care at Children’s Hospital Colorado for my daughter with Spinal Muscular atrophy. It takes us two days to make a trip to children’s Colorado, because her body cannot physically handle more than four hours in the car at a time. Children’s Hospital in Omaha we would not be able to see our whole team in one day. We would be lucky to be able to schedule at least two of the specialist back to back in one day, which would mean being in Omaha for more than one day or making several trips

to see neurology, muscle clinic, physical therapy, nutritionist, and pulmonology, Dentis because they will not do more than a cleaning here, eye doctor because the eye doctors her will not see her with her condition. Then add on the appointments every three months for her spinal injection for the medication that keeps her alive and with us today. This is not a trip that could be taken with one adult. It takes two adults, so somebody is in the back seat, taking care of her medically. We also would have to bring our son along, who is autistic and cannot handle the overstimulation of the long car ride. When we go to Children's Hospital in Colorado, it's all in one day. It is proven by the CDC and the National Health Institute that these long trips cause extreme strain, not only on the family physically and mentally, but on the child with physical or mental disabilities. it actually worsens their Respiratory system, Circulation, Causes pressure sores, Joint Contractions and mental strain. You are at higher risk of a car accidents and trying to drive from Western Nebraska eight hours Eastern Nebraska in the winter Is life-threatening on its own. Imagine being a little girl having spinal surgery and being told you now have to drive eight hours home From Omaha, Nebraska. My daughter is already a very weak little girl, and these constant trips to Omaha would weaken her body even more. We are lucky every day to wake up to see her alive still. But if Nebraska does not push for at least one Medicaid provider to be in network with Children's Hospital Colorado, we are a threat of losing care there and my daughter is a threat of losing her life. We as her parents would have to make the trip and face exhaustion and health decline ourselves, but that's what we would do for our kids. But why are we doing that to children? Please don't allow our children to face this in the future just because of where we live".

Anonymous "Availability, time, expenses"

Anonymous 69162- "My dad lost his job and is now on Medicaid. My mom has diabetes. They don't go to the dentist because there aren't any locally that accept Medicaid. When trying to schedule in Lincoln they aren't ever called back".

Lively 69361- "Multiple specialists and scheduling all in one day

Dillion K 69361- Traveling across NE is 10 hours, going to Cheyenne or Denver is crossing state lines so SNAP or other services aren't available"

Koch 69162- Having to travel so far for my child to see the nearest pediatric GI Dr. When traveling to Children's in Denver, Colorado is ALOT closer and would save so much time, money, wear and tear on my vehicle if Nebraska Medicaid would be accepted at Children's in Denver, Colorado.

Melissa S 69337- We are so much closer to Colorado Children's. The state has said they are "tracking" my son therefore he has to be seen by NE specialist. The blood work he has to have done must go to Mayo. I was told that doctors out here can not get the blood delivered before it's not testable."

69301- Traveling the long distance is the hardest for us.

Harris Family 69341-“Very lucky we've been able to go to Denver or Rapid I don't know what it would be like to have to travel so far and take two or three days”

Rebbeca P 69162 - “Usually, the trips we take to Omaha are time consuming. Since it's over a 6 hour drive from us we try to get as many appointments as possible for our son so that we don't have to make another trip. Usually, our appointments last 2-3 days with all of the care he needs. We make this trip 1-2 times a year if possible. We have had to cancel in the past due to the trip being time consuming and unable to get off of work that long or the cost.”

69162 “Long distance travel, easily accessible Medicaid benefits”

Bogert Family 69133 “.Finding time when we can make the trip and when the doctor is available. It's hard for the student to miss school and the parent to miss work” .

Broderick Family 69129- “My daughter is actually no longer alive. However my story was I actually moved to Colorado because Medicaid of Nebraska did not allow my daughter to attend doctors in Denver and I was even stuck with a helicopter ride expense years ago due to them not wanting to pay as airlin would not fly her to Omaha but rather to Denver as it was an emergency. I had to sell my home that was accessible for my daughter and move away from all my support to allow her the care she needed as I was a single mom to 3. I didn't have the ability or the funds to go to Omaha every month. I needed care closer. Many don't realize that we are closer to Colorado or even Wyoming or South Dakota than Omaha. It's not easy traveling with children who have needs. Denver was a day trip for us”.

Anonymous 69162 - “Work requirements do not allow us to leave for extended periods. Our son does not travel well and the stress on him makes it insanely difficult and stressful for us parents.”

Barrett Family 69358- “Getting the help we need”

Stark Family 69162- “Travel and motel”

Anonymous 69343- “Finding resources in our small community.”

Karashinski Family 69162- “My girls were born raised and diagnosed in Colorado. We chose to move here after researching and being told that we would still be able to maintain our care through childrens in Denver only to move here and find out that that was not the case. Being on the spectrum my girls struggle with change so to hear that they would have to find all new doctors was a huge stress for us. If we could travel to Denver for their care that would be a huge relief in so many ways. This is one of many factors that has been thought about when

we wonder if moving here was the right choice and often consider moving back to Colorado just to maintain care.”

Anonymous Zip 69131- “We used to be able to get referrals to Denver area for specialists. Fort Collins we only had to drive 2 hrs and now it's a 5+ hr trip one way with 5 kids. So we usually do less apts.”

Lee Family 69162- “With my diabetic child who uses Medicaid as secondary insurance we have be able to go to children's Colorado for years which has save so much time and money and most importantly STRESS. Trying to keep your kid alive is hard enough, we shouldn't have the added stress of unnecessary travel which is also extremely hard on her body. Being trapped in a car for that many hours causes physical harm to her body. With our EDS kids we will have to pay out of pocket to see the more qualified staff at the EDS specialty clinic at children's Colorado. That clinic has a 2-year wait list so if you can even get on it, you don't turn it down over insurance.”

Halligan Family 69156 – “We end up not getting the care when needed because the trip would mean me missing work for multiple days as a single parent, having to take all 4 of my kids because I couldn't just leave the ones that don't have the appointment for multiple days, as well as financial strain. Plus one of my kids has a doctor who knows his case well due to being at the hospital we were sent to when he was flighted out but because they are In Colorado (only a 2 hour drive there for us) instead of Nebraska our insurance is constantly denied because of a "in network provider closer" when it is not the case. The providers we try seeing are the closest ones and are the ones constantly recommended to us.”

Anonymous 69145- “ Our biggest challenge that we face out here in Western Nebraska is the lack of resources we need desperately. Currently, an ABA therapist is needed yet no one is here and no one is willing to drive more than 30 minutes away. In order to access physical therapy or occupational therapy that is specialized for our child we have to drive at least an hour. Thankfully, we have found a neurologist in the children's hospital in Denver that is able to see my son because driving to Omaha was out of the picture. When we do have to go to Denver, we can usually do that in one day trip on the rare occasions that they need him to stay longer. They put us up in the Ronald McDonald house in Denver”.

Gilber Family 69361- “The cost is a huge factor and not only that but we have to take multiple days off work. We have to pay for fuel to drive 12 + hours. We have had to do that a few times and now trying to figure out how we will make another trip here shortly to see a pediatric neurologist.

My son has numerous appointments as does my daughter trying to line up care all in the same trip is extremely hard”.

Jacob Family 69347- “So, my family does not have any special needs at this time that cannot be taken care of locally. But the diagnoses that are in place currently are very minimal.

However, if something were to come up where we needed Specialized Care for either of my children, we would have to travel and I am a single mom and cannot afford to be traveling all the time and be taking days off of work. Driving to someplace closer would mean less time and money for me. Also, my oldest is in school so that would also affect his education."

27.Cleanaboutu1@hotmail.com **69361**- "Milage to a specialist and transportation, weather meds will hold at the correct temp"

Garrett Family 69131- "Having to travel so far doesn't just cost our family thousands of dollars but it takes a toll on our mental health. The stress of traveling so far and the stress it cause our son. Our son in on a ventilator so we need to travel with tons of supplies including oxygen tanks. Our worry also is our son having a emergency and not having the help we need in quick timely matter. We doctor at Children's in Omaha so why is it not possible to doctor at another Children's hospital that is MUCH closer!"

Richards Family 69341- "At the moment it's getting to Lincoln or Omaha"

Sanders Family 69341- " My daughter had apraxia and needs specialized private speech therapy. There is no one locally who offers this so we drive every week and pay out of pocket for all of her speech therapy. If we lived in Colorado, we would have access to speech therapy that is needed and could go through insurance. We are trying to move out of Nebraska for this very reason."

Misty B 69162- "Medicaid recipients in western Nebraska deserve the same reasonable access to specialized healthcare as anyone else. Requiring patients to travel more than 400 miles to Omaha, when equivalent specialists are available in Denver at less than half that distance, creates unnecessary financial, physical, and emotional burdens. For many families, taking additional time off work, paying for fuel, lodging, and meals, or enduring hours of travel while already managing serious medical conditions can become a barrier to receiving care altogether. Access to healthcare should be determined by medical need—not by an unreasonable driving distance when a closer, qualified option exists."

Anonymous 69146- "Travel time requires time away from work and razor thin PTO banks"

Bongard 69339- "At \$5 a gallon gas that is literally \$250 extra that in my budget that I typically don't count on. Especially when I only get \$300 a month in child support. Not to mention the amount of time I have to take off work. I could drive 90 miles to Rapid City for a VNS battery replacement out patient and be back home the same day. But no we have to travel to Omaha which is a bare minimum two day travel and one day in the hospital so then we are adding two extra days of missed work along with two nights in a motel. Our lives are already hard, this is adds an unnecessary burden on to it. And don't even get me started on trying to find an adult dentist that will put someone under anesthesia for a cleaning. We are VERY limited on neurologists because of his VNS, they have to be set up with LivaNova

(device manufacturer) so We see Dr. Barr in Rapid. Insurance pays for Dr. visits in Rapid but will not pay for anything at the hospital and to top it off I filed for an exemption one time and the hospital said they would refuse payment from Nebraska Medicaid which BLOWS MY MIND. Like how, why? Our old Neurologist was in Omaha and he was absolutely amazing. He would fly into Grand Island and see patients there. He wanted the ability to do that in Chadron, but the admin of the hospital wouldn't approve it, I haven't tried with the new admin as this was 4 years ago and that neurologist could be retired for all I know." **Updated story 7-10-26** Okay so Grady has a giant mass on his neck that keeps getting bigger and bigger. It is attached to the tube of a non functioning shunt. Thank goodness it's just a calcium deposit but it needs removed. His neurosurgeon that put it in recommended removing the shunt as well (this was in February), but has since retired. Now our only option is make two in person appointments to either Kearney or Omaha and then do the surgery down there. Yes you read that right we would have to do a minimum of 24 hours of driving just to get the surgery scheduled.... I'm so frustrated.

Neal Family 69146- "The financial aspect is really hard to travel that far away, as is the time it takes. My son does not travel well and I can't go alone with him so I have to get someone to travel with us. Normally resulting in lost wages and time for them as well."

Fitz Family 69357 "Not enough specialist within our area"

Some information I want to reference is that Congress agrees on accessible access. In February, Congress approved and the President signed into law a big funding package (Consolidated Appropriations Act of 2026). Included in that legislation was legislation (called the Accelerating Kids Access to Care Act) that would help to streamline the process that would allow out-of-state providers (i.e., Denver Children's Hospital) to access Medicaid payments from another state. The whole point of this legislation was to make sure that kids with disabilities and rare diseases can access the specialized care that they need.

I am including a press release on the legislation and a letter Cure SMA did in support of the legislation (the second section of the letter that contained other issues). The broader legislation (where this provision was included) was supported by both of our Nebraska Senators: Sen. Fischer and Sen. Ricketts.

Consolidated Appropriations Act, 2026

https://www.senate.gov/legislative/LIS/roll_call_votes/vote1192/vote_119_2_00020.htm

https://www.senate.gov/legislative/LIS/roll_call_votes/vote1192/vote_119_2_00020.htm#state

Accelerating Kids Access to Care Act (included in the above bill)

<https://www.grassley.senate.gov/news/news-releases/grassley-bennet-legislation-to-improve-kids-access-to-life-saving-medical-care-becomes-law>

<https://millermeeks.house.gov/media/press-releases/miller-meeks-grassley-bill-improve-kids-access-life-saving-medical-care>

<https://www.curesma.org/wp-content/uploads/2025/12/Cure-SMA-Urges-Congress-to-Finalize-2025-Priorities.pdf>

Other Information

<https://pubmed.ncbi.nlm.nih.gov/17761659/>