Needs Assessment & Data Summary

2025 Edition

Nevada Rare Disease Advisory Council

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NEVADA RARE DISEASE ADVISORY COUNCIL

At a Glance: 2025 Needs Assessment & Data Summary

2025 Edition · Published 2026 · Updated May 2026 · Observational Findings

SIGNATURE FINDING

Medicaid-insured Nevadans with rare disease report provider unfamiliarity at more than twice the rate reported by privately insured Nevadans — 36% versus 14%.

Wait times: 31% versus 16%. Privately insured respondents reported care coordination challenges at twice the rate of Medicaid respondents (20% vs 10%). The data describes different failure modes by payer type, not a uniform difference. Half of the Year Two cohort is Medicaid-insured.

BY THE NUMBERS

4,302
Unique Nevadans with rare disease diagnoses documented in 2025 clinical data, across 19 diagnostic categories

508
Patient and family responses across two years of the Council's Needs Assessment

69
Nevada healthcare professionals providing substantive responses to Year One of the Provider Survey

WHAT THE DATA SHOWS

- **Diagnostic delay is widespread.** 37% of respondents reported diagnostic timelines over one year; 14% over five years — in a cohort whose mean age is under four. 39% reported being misdiagnosed.
- **Authorization burden is quantified.** Nevada providers report only 40.6% of rare disease prior authorization requests are initially approved. 25.7% are ultimately denied.
- **Mental health is the most consistently reported impact.** Five of eight mental health items were selected by more than 30% of respondents. The most-selected item reached 55%.
- **Specialty care availability is below the midpoint across every category.** All seven specialties measured were rated below "available" by Nevada providers. 72% of providers report wait times of 3+ months.
- **Care coordination consumes the workforce.** 56% of Nevada providers report spending more than half of their clinical time on care coordination for rare disease patients; 44% report more than 75%.
- **Provider alignment on a coordinated solution is unusual and documented.** 82% of Nevada providers who answered support a comprehensive Center of Excellence; only one opposed.

WHAT IS AT STAKE

FOR PATIENTS
Continued diagnostic odysseys exceeding children's lifetimes. Continued out-of-state travel for care comparable populations receive locally. Continued financial impact on family stability documented at 50% on family-impact items.

FOR PROVIDERS
Continued case management at office-visit reimbursement. Continued risk that providers leave rare disease care, leave Nevada, or leave clinical practice. The workforce gap is not static.

FOR NEVADA
Continued documentation that the system is held together by personal effort. The 84th legislative session convenes February 2027. The evidence base is now established. What is built upon it is the work ahead.

Nevada Rare Disease Advisory Council · Annette Logan-Parker, Chair · Established by SB 315 (2019) · Created within the Nevada Department of Health and Human Services

The full report is observational. Recommendations and policy priorities are developed through separate Council work.

From the Chair

This report is the second annual edition of the Nevada Rare Disease Advisory Council's Needs Assessment and Data Summary, and the first edition that combines patient and family voices with provider voices and statewide clinical data in a single document.

Until now, Nevada's documented rare disease landscape has consisted of disease-specific registries for sickle cell disease and lupus maintained by the Nevada Office of State Epidemiology, four annual NV-RDAC reports to the Governor and Legislature summarizing Council activities and policy recommendations, the Year One While You Wait Needs Assessment, and clinical data contributed by Cure 4 The Kids Foundation. National-scale policy assessments such as the NORD State Report Card have placed Nevada in the middle tier of states for rare disease support. What has been absent is a Nevada-specific document that brings the experience of patients, families, and providers together with statewide clinical data in a single observational frame.

Five hundred and eight Nevadans living with rare disease and their families have participated in the Council's Patient and Family Needs Assessment over two years of collection. Sixty-nine Nevada healthcare professionals provided substantive responses to the inaugural year of the Council's Provider Survey. Statewide clinical data documents four thousand three hundred and two unique Nevadans with rare disease diagnoses in 2025.

Together, these voices form the most complete documented account of rare disease care in Nevada that has been assembled to date.

The report is observational. It documents what was reported, what was measured, and what the data shows. It does not recommend policy. Recommendations are developed through separate Council work.

Nevada's eighty-fourth legislative session will convene in February 2027, approximately nine months from this report's publication. Within that window, this report and its successors will continue to be available to the Council, the Legislature, the Department of Health and Human Services, and the partner organizations across the state who have built and sustained rare disease care in Nevada through institutional gaps the data now describes. What this report establishes is the evidence base. What is built upon it remains the work ahead.

Annette Logan-Parker

Chair, Nevada Rare Disease Advisory Council

A note on this edition: This document was first published in early 2026. A small number of additional Provider Survey responses received in May 2026 are reflected in this updated edition through an expanded subsection of provider open-text voices in Section 1.5. The quantitative findings reported throughout this edition are unchanged from the first published edition.

Executive Summary

Medicaid-insured Nevadans with rare disease report provider unfamiliarity with their condition at more than twice the rate reported by privately insured Nevadans.

36% of Medicaid-insured Year Two respondents identified provider unfamiliarity as an access barrier, compared to 14% of privately insured respondents. Wait times were reported as a barrier at 31% versus 16%. In a Year Two cohort that is half Medicaid-insured, this disparity describes the access experience of approximately half of the population the report represents.

This report is the second annual edition of the Nevada Rare Disease Advisory Council's Needs Assessment and Data Summary. It draws on three sources of evidence:

- 508 cumulative responses from Nevadans with rare disease and their families across two years of the NV-RDAC Patient and Family Needs Assessment, including 164 engaged Year Two respondents reporting on their experience under the v2 instrument.
- 69 Nevada healthcare professionals who provided substantive responses to Year One of the NV-RDAC Provider Survey, with 35 also completing the extended survey.
- Statewide clinical data documenting 4,302 unique Nevadans with rare disease diagnoses in 2025.

Findings are observational. Recommendations and policy priorities are developed through separate Council work.

Key findings

Patient, family, and provider voices converged on six system-level observations about rare disease care in Nevada:

1. The access experience is significantly different by payer type.

Medicaid-insured Year Two respondents reported provider unfamiliarity with rare disease as an access barrier at more than twice the rate reported by privately insured respondents (36% vs 14%) and long wait times at nearly twice the rate (31% vs 16%). Privately insured respondents reported care coordination challenges at twice the rate of Medicaid-insured respondents (20% vs 10%). The data describes different failure modes by payer type — Medicaid families face provider unfamiliarity and wait times; privately insured families face care coordination breakdowns. Both are documented in this report. Half of the Year Two cohort is Medicaid-insured.

2. Diagnostic delay is widespread, and not because patients failed to seek care.

Among Year Two patient and family respondents, 37% reported diagnostic timelines of more than one year and 14% reported more than five years — in a cohort whose mean age is under four. Misdiagnosis was reported by 39% of respondents who answered, and these respondents had seen an average of 2.24 physicians before reaching their final diagnosis (compared to 1.58 for those never misdiagnosed). Provider Survey respondents independently reported low confidence in recognizing rare disease symptoms (mean 2.12 of 5, n=41) and identified limited rare disease education in medical training, symptoms mimicking common conditions, and insurance barriers to testing as the three most-frequently cited causes of diagnostic delay.

3. Specialty care is rated below the midpoint of available across every category measured.

Provider Survey respondents rated availability of all seven categories of rare disease specialty care below the midpoint of the 1–5 scale. Pediatric hematology and oncology was rated lowest at 2.19, followed by immunology/rheumatology (2.57), pediatric neurology (2.71), genetic counselors (2.88), metabolic specialists (2.89), medical geneticists (2.96), and adult rare disease specialists (3.19). Patient and family respondents identified specialist scarcity as the most-cited access challenge (34%). Of providers reporting on Nevada wait times, 18 of 25 (72%) reported waits of three months or more for rare disease specialty care.

4. The insurance authorization burden is quantified, not theoretical.

Providers who completed the extended Provider Survey reported that, on average, only 40.6% of their rare disease prior authorization requests are initially approved (n=16). An additional 45.0% are approved only after appeal, and 25.7% are ultimately denied (n=15). Reported individual estimates ranged from 0% to 95% across all three categories, reflecting variation in patient population, payer mix, and disease type.

5. The burden of care coordination falls on families and on the providers who serve them.

Of 27 Provider Survey respondents who answered the time-allocation question, 12 (44%) reported spending more than 75% of their clinical time on care coordination for rare disease patients. Combined with respondents reporting 51–75% of time, 56% of responding providers reported that more than half of their clinical time is consumed by care coordination. Patient and family respondents in v1 qualitative data described coordinating their own care across multiple specialties and serving as the principal information conduit between providers.

6. Mental health is the most consistently reported impact area in the v2 instrument.

Five of eight mental health impact items in the v2 instrument were selected by more than 30% of all engaged respondents. The most-selected mental health item was reported by 90 of 164 (55%) of engaged respondents. Of respondents who rated mental health challenge severity on a 1–5 scale (n=91), the modal rating was '4,' reported by 43% of those rating, indicating substantial mental health burden.

Family-level impacts were also widespread: the most-selected family financial impact item was reported by 50% of all engaged respondents.

A note on the payer disparity finding

Finding 1 above is presented as the report's signature observation because it is one of the few Nevada-specific quantitative findings on rare disease and payer equity that is documented in this dataset, and because it describes an experience that affects approximately half of the Year Two cohort. The finding describes different failure modes by payer type, not that one payer type is uniformly worse than the other. The report does not attribute responsibility for the disparity to any specific actor, system, or policy. Providers, payers, regulators, and policymakers will reasonably disagree about its causes; the report documents the pattern and leaves attribution to that conversation.

On provider alignment

Of 40 Provider Survey respondents who answered the question, 33 (82%) supported or strongly supported establishing a comprehensive rare disease Center of Excellence in Nevada, with 30 selecting 'strongly support' and only 1 opposing. Establishing a Center of Excellence was the improvement priority most-frequently ranked first by providers (n=17). When patient and family respondents were asked, in open-text responses, what they most wanted Nevada policymakers to hear, themes consistent with a multidisciplinary care center model recurred — more accessible specialty care, reduced need for out-of-state travel, and continuity across specialties. This level of alignment among Nevada providers across primary care, specialty care, nursing, pharmacy, genetics, social work, and care coordination is unusual and is documented here.

Geographic findings

Year Two patient and family participation was concentrated in Southern Nevada. Of 155 classified respondents, 146 (94%) were Southern and 9 (6%) were Northern. Read against Nevada's 2024 population distribution (75% Southern, 25% Northern), Southern Nevada participated at approximately 1.25 times its population share, while Northern Nevada participated at approximately 0.23 times its population share — roughly one-fifth of proportional participation. On a per-capita basis, Southern Nevadans participated at approximately 5.3 times the rate of Northern Nevadans (5.86 vs 1.10 responses per 100,000 population).

With small Northern n, statistical comparison is not appropriate. The directional pattern in the Year Two data suggests two distinct experiences of rare disease care in Nevada. Northern Nevada respondents disproportionately cited workforce-and-access barriers (long wait times, travel/distance, and provider unfamiliarity, each reported by 44%). Southern Nevada respondents were more likely to cite system-and-affordability barriers (insurance/coverage, cost, and care coordination). If confirmed in subsequent collection cycles, this pattern has implications for the design of any statewide rare disease strategy. Targeted Northern Nevada outreach is recommended for Year Three of collection.

Limitations of this edition

The Year Two patient and family cohort is, on the available evidence, exclusively pediatric. Of 163 engaged respondents who reported patient age, the mean was 3.9 years and all reported ages were under 15. The Year Two cohort therefore represents pediatric rare disease experience as reported by parents, family members, and caregivers.

This limitation produces what may be the report's most important methodological observation: even within a cohort whose mean age is under four years, 14% of families reported diagnostic timelines exceeding five years and 5% reported more than ten years. These children have not yet had time to accumulate longer odysseys. The full diagnostic burden among older Nevadans with rare disease — adults who have lived with these conditions for decades, AYAs aging out of pediatric care, families who have been navigating the system longer — is not yet captured in this report and is almost certainly greater than what these findings show. This is the visible portion of a larger phenomenon. A deliberate adult and AYA outreach strategy is recommended for Year Three of collection.

The Provider Survey's geographic field uses an urban/suburban/rural/frontier coding rather than a north/south regional coding. Provider data is therefore not directly comparable to patient and family data on a north/south basis. A methodology improvement is recommended for Year Two of Provider Survey collection.

What this report does and does not do

This report summarizes what was reported, what was measured, and what the data shows. It does not present recommendations or policy priorities; those are developed through separate Council work. The report is structured to support careful reading by clinicians, policymakers, advocacy partners, and members of the rare disease community in Nevada. Findings throughout the report are reported with response counts (n) so that readers can independently evaluate the strength of the underlying evidence.

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PART 1

Needs Assessment

1.1 Introduction and Methodology

Part 1 presents findings from two surveys conducted by the Nevada Rare Disease Advisory Council: the Patient and Family Needs Assessment, in collection since 2024, and the Provider Survey, which launched in August 2025.

Patient and Family Needs Assessment

Since 2024, 508 Nevadans have participated in the Needs Assessment. A Version 1 (v1) instrument collected 211 participant responses in 2024. A Version 2 (v2) instrument was deployed beginning in 2025 and has collected 297 responses through Q1 2026, of which 164 were engaged respondents who answered substantive sections.

The v2 instrument retained the core domains of v1 but simplified demographic and access questions, added a dedicated Mental Health Impact section, and reframed the policy priorities question. Where results in this report draw from a specific instrument version, the version is noted.

Distribution channels included NV-RDAC public meetings, Council member networks, partner organizations, the Cure 4 The Kids Foundation patient and family network, social media, and direct outreach.

Provider Survey

The NV-RDAC Provider Survey launched in August 2025. Of 99 records initiated, 69 respondents provided substantive engagement, and 35 of those completed the extended survey covering authorization outcomes, specialty availability, care coordination time, and pediatric-to-adult transitions. This report includes data from all 69 engaged respondents, with per-item response counts (n) provided throughout.

The Provider Survey was distributed through the Nevada State Medical Association, specialty society networks, hospital-based provider listservs, the Cure 4 The Kids Foundation clinical network, and direct outreach. Participation was voluntary and anonymous.

Limitations

Findings reflect those who chose to participate and may not represent the full Nevada rare disease community. Patient and family participation was concentrated in Southern Nevada (see Section 1.4). The Year Two patient and family dataset is, on the available evidence, exclusively pediatric (mean age 3.9 years; 100% under age 15 among engaged respondents). Adult and AYA voices are absent from the Year Two cohort. Pediatric voices are over-represented in the v1 cohort as well.

The Provider Survey's geographic field uses an urban/suburban/rural/frontier coding rather than a north/south regional coding. Provider data is therefore not directly comparable to patient and family data on a north/south basis. A methodology improvement is recommended for Year Two of Provider Survey collection.

1.2 What the Voices Say Together

This section presents convergence findings — observations on which patient and family participants and Nevada healthcare professionals reported similar realities about rare disease care.

Convergence on diagnostic delay

Patient and family participants reported extended diagnostic timelines. Among Year Two respondents, 37% reported diagnostic timelines of more than one year, with 14% reporting more than five years and 5% reporting more than ten years. The mean number of physicians consulted before diagnosis was 1.84 (range 1–4). Misdiagnosis was reported by 39% of engaged respondents (49 of 125 who answered).

Provider Survey respondents independently reported low confidence in recognizing rare disease symptoms, with a Year One mean confidence rating of 2.12 of 5 (n=41). The most-frequently identified causes of diagnostic delay among providers were limited rare disease education in medical training (n=20), symptoms mimicking common conditions (n=19), and insurance barriers to testing (n=19).

Convergence on specialist availability

Patient and family participants identified specialist scarcity as the most-cited access barrier (34% of respondents). Provider Survey respondents rated availability of every category of rare disease specialist below the midpoint of the 1–5 scale, with pediatric hematology and oncology lowest at 2.19, followed by immunology/rheumatology (2.57), pediatric neurology (2.71), genetic counselors (2.88), metabolic specialists (2.89), medical geneticists (2.96), and adult rare disease specialists (3.19). All seven specialty categories were rated below 'available.'

Convergence on insurance and authorization barriers

Patient and family participants identified insurance/coverage as a top access challenge (26% overall). The pattern differed by insurance type: among Medicaid-insured respondents, the top three challenges were specialist scarcity, provider unfamiliarity with rare disease, and long wait times — each cited at higher rates than by privately insured respondents.

Provider Survey respondents identified authorization delays/denials as one of two co-equal top barriers (n=24 in top three; n=14 ranking it #1). Providers who completed the extended survey reported a mean initial approval rate of 40.6% (n=16), with 45.0% requiring appeal and 25.7% ultimately denied (n=15).

Convergence on the burden of care coordination

Patient and family participants described coordinating their own care across multiple specialties. Provider Survey respondents who answered the time-allocation question reported that 12 of 27 (44%) spend more than 75% of their clinical time on care coordination for rare disease patients. Combined with respondents reporting 51–75%, 56% of responding providers spend more than half of their clinical time on care coordination.

Convergence on a comprehensive Center of Excellence

When asked directly whether Nevada should establish a comprehensive rare disease center of excellence, 33 of 40 responding providers (82%) selected 'support' or 'strongly support,' with 30 selecting 'strongly support' and only 1 opposing. Establishing a center of excellence was the improvement priority most often ranked #1 by providers (n=17).

1.3 The Patient and Family Voice

This section consolidates findings across the diagnosis, access, financial, mental health, and policy domains of the Patient and Family Needs Assessment. Findings reflect 508 cumulative participants across the v1 and v2 instruments and 164 engaged Year Two (v2) respondents.

Throughout this section, quantitative findings are accompanied by selected open-text responses from participants. These passages are presented in participants' own words. They have been edited only to remove specific names, locations, and other potentially identifying details. They are presented to illustrate findings, not to substitute for them.

Participant profile

The Year Two v2 dataset is, on the available evidence, exclusively pediatric. Of 163 engaged respondents who reported patient age, the mean age was 3.9 years (median 4) and all reported ages were under 15. The largest age cluster was ages 1–4 (82% of respondents). The Year Two cohort therefore represents pediatric rare disease experience as reported by parents, family members, and caregivers — not adult or adolescent and young adult (AYA) experience.

Of 162 engaged respondents who identified the person completing the survey, 73% were family members of the patient, 20% were patients self-reporting (consistent with older pediatric patients reporting their own experience), and the remainder were caregivers and others.

Insurance distribution among Year Two respondents who reported insurance type:

- Medicaid: 78 (50%)
- Private/commercial: 49 (31%)
- Medicare: 11 (7%)
- Multiple/dual coverage: 9 (6%)
- Tricare/military: 7 (4%)
- Other or self-pay: 3 (2%)

Half of the Year Two cohort is Medicaid-insured. This is a meaningful operational detail: any policy or program serving this population must work within Medicaid constraints.

Diagnosis

Year Two respondents reported diagnostic timelines as follows (n=130 reporting):

- Less than one month: 4 (3%)
- 1–6 months: 50 (38%)
- 6–12 months: 28 (22%)
- 1–2 years: 21 (16%)
- 2–5 years: 9 (7%)
- 5–10 years: 12 (9%)

- More than 10 years: 6 (5%)

In total, 37% of respondents reported diagnostic timelines of more than one year, 21% reported more than two years, and 14% reported more than five years. Six respondents (5%) reported diagnostic timelines exceeding ten years.

These figures merit careful reading. The Year Two cohort has a mean age of 3.9 years and 100% of reported ages are under 15. The 5% of respondents reporting diagnostic delays exceeding ten years are, by definition, families whose children's diagnostic odyssey has taken longer than the children themselves have lived. The 14% reporting more than five years includes children whose families spent the majority of their child's life seeking a diagnosis. These are not the longest possible diagnostic delays in Nevada's rare disease population — they are the longest delays observable in a cohort that has not yet had time to accumulate longer ones. The full distribution of diagnostic delay among older Nevadans, AYAs aging out of pediatric care, and adults who have lived with rare disease for decades is not yet captured in this report and is almost certainly longer.

Misdiagnosis was reported by 39% of respondents who answered (49 of 125). Respondents who reported being misdiagnosed at some point also reported having seen more physicians before reaching their final diagnosis (mean 2.24 versus 1.58 for those never misdiagnosed).

Of respondents who reported on whether their diagnosis was confirmed by genetic testing (n=127), 40% reported yes, 32% reported no, 20% reported uncertain, and 7% reported they were still pursuing testing. The relatively high proportion of 'no' and 'uncertain' responses, in a population with a substantial proportion of conditions believed to be genetic in origin, is consistent with provider reports of insurance barriers to genetic testing.

> *"Various infections of multiple areas led to delay in diagnosis. Ear infections were treated by ENT, respiratory infections were treated by pulmonologist, sinus infections were treated by pediatrician. Due to lack of cohesiveness and communication between specialists, there was a delay in diagnosis and treatment."*
>
> — A Nevada parent describing a multi-year diagnostic journey

> *"I started having musculoskeletal symptoms at a very young age. This quickly progressed to dislocations every day as well as psychosocial difficulties. I visited countless providers, who all said I was just very flexible and that my pain was psychosomatic. This progressed to severe stomach problems, anemia, and underweight. I was admitted to hospitals several times."*
>
> — A Nevada patient with a connective tissue disorder, reflecting on years of misdiagnosis

> *"He was treated as if he had warts for years. I had to demand another doctor because they kept saying it was warts and that means he is dirty. They prescribed over-the-counter wart freeze that burned his skin. Once I got a new dermatologist he finally took it, sent it to lab, and it was a rare metabolic skin condition. We are finally on a treatment plan."*
>
> — A Nevada parent describing a years-long misdiagnosis

Access to care

Participants rated access to care in Nevada at a mean of 3.29 on a 1–5 scale (n=119), with very few participants rating access as easy. The most-frequently selected access challenges:

- Specialist not available: 55 (34%)
- Travel/distance: 46 (28%)
- Insurance/coverage barriers: 43 (26%)
- Provider unfamiliarity with rare disease: 43 (26%)
- Long wait times: 42 (26%)
- Care coordination: 21 (13%)
- Cost/out-of-pocket: 15 (9%)

Access challenges differed by insurance type. Comparing Medicaid-insured respondents (n=78) to privately insured respondents (n=49):

- Specialist not available: 37% (Medicaid) vs 31% (private)
- Long wait times: 31% vs 16%
- Provider unfamiliarity with rare disease: 36% vs 14%
- Care coordination: 10% vs 20%

Medicaid-insured respondents reported provider unfamiliarity with rare disease at more than twice the rate reported by privately insured respondents (36% vs 14%) and longer wait times at nearly twice the rate (31% vs 16%). Privately insured respondents reported care coordination as a challenge at twice the rate of Medicaid respondents (20% vs 10%).

> *"Nevada has horrible care, even for general health care. My daughter's condition took too many ER visits and doctors to diagnose. We have been to Utah and California for over fifteen procedures."*
>
> — A Nevada parent describing repeated out-of-state travel for specialty care

> *"I spend nearly forty hours a month on the phone with insurance and providers to get the bills paid accurately and pre-authorizations approved. It has turned into a part-time job for me, which already includes being the main caregiver to my very ill child."*
>
> — A Nevada parent on the administrative burden of rare disease care

Financial impact

v1 qualitative findings indicated that annual healthcare costs for many participants exceeded $5,000, with some participants reporting catastrophic expenses exceeding $20,000. Year Two structured financial impact data show how broadly that financial strain reaches into household decisions:

On the family financial impact items, the most-selected single item was reported by 50% of all engaged Year Two respondents. Three of seven family impact items were reported by more than one in three

respondents. On the financial strain items, four of ten items were reported by more than 30% of all engaged respondents.

v1 qualitative findings identified medical travel, genetic testing, specialized therapies, and uncovered medications as the principal out-of-pocket cost drivers. Insurance denials were commonly reported for off-label medications, investigational treatments, and advanced diagnostic testing. Participants described fundraising, savings depletion, household debt, modifications to home purchase and family planning decisions, and reduced or modified employment among parents of children with rare disease.

> *"We had to use credit cards to pay hospital bills, and now our credit is bad. We are drowning financially."*
>
> — A Nevada parent on the cumulative financial impact of rare disease care

> *"I have transitioned from a full time employee to a per diem employee to help care for our daughter, which impacted our annual income. We have had to use all of our savings that we had for emergencies and savings we had for our first family vacation. We have had to borrow money from family members."*
>
> — A Nevada parent describing the employment and savings impact of caregiving

> *"I cannot keep a job to provide for my kids. I cannot function for most things in life. I can barely get them to school."*
>
> — A Nevada caregiver describing the daily impact of rare disease on a family

Mental health impact

Mental health was introduced as a dedicated domain in the v2 instrument. Mental health impact items were the most-selected items in the v2 instrument:

- Most-selected mental health item: 90 of 164 (55%)
- Second-most-selected: 70 of 164 (43%)
- Third-most-selected: 68 of 164 (41%)
- Fourth-most-selected: 64 of 164 (39%)
- Fifth-most-selected: 52 of 164 (32%)

Five of eight mental health impact items were reported by more than 30% of respondents. Of respondents who rated mental health challenges on a severity scale (n=91), the most-selected severity rating was '4' on a 1–5 scale (43% of those rating), indicating substantial mental health burden.

When asked what form of mental health support had been most helpful, participants described counseling and therapy for the individual with rare disease, counseling and therapy for family members (including parents and siblings), condition-specific support groups, patient care coordination to reduce caregiver burden, telehealth-delivered mental health services, and access to affordable mental health care.

> *"It has slowly damaged my family, leading to my mother and father barely getting along, and leading to my brother feeling a bit alone and forgotten."*

— A Nevada patient describing family impact

> *"Everyone has sought therapy to help cope with the stress and anxiety this condition inflicts upon all of us. Unfortunately our family is also experiencing a divorce; the stress of medical care decisions and disagreements was a contributing factor."*
>
> — A Nevada parent on the toll of rare disease on family stability

Policy priorities

Participants were asked what actions they believed Nevada policymakers should prioritize for the rare disease community. The top-ranked policy priority was selected by nearly three-quarters of participants who answered. Five of eleven policy priorities were selected by more than 60% of participants, indicating a broad cluster of legislative priorities rather than a single dominant concern.

When asked in open-text responses what message they most wanted Nevada policymakers to hear, participants described the cumulative effect of rare disease on household finances, family relationships, mental health, and children's education; frustration with insurance prior authorization requirements and denial processes; the need for expanded state support for families navigating the gap between Medicaid eligibility and affordable private coverage; concern that advances in rare disease research and care infrastructure not be dismantled or scaled back; and requests for more accessible specialty care, particularly for families required to travel out of state.

> *"I wish doctors knew that there is more to providing care than just the office visit with the patient. If they do not have a good administrative staff to back up their care plan and work with insurance to get it paid for, the patient will not receive the care ordered, and the patient will remain ill. It took nearly six months across two providers to get treatment approved."*
>
> — A Nevada parent on the gap between care ordered and care delivered

> *"I wish people would understand how it affects the whole family. Siblings and parents."*
>
> — A Nevada parent on what is missing from the public conversation about rare disease

1.4 Geographic Findings — Northern vs Southern Nevada

Geographic methodology

Regional classification was assigned using participant home zip code where provided, with treatment facility location and urban/rural Nevada county fields used as fallbacks. Southern Nevada includes Clark, Lincoln, Nye, and Esmeralda counties (zip codes 89000–89199). Northern Nevada includes Washoe, Storey, Carson City, Douglas, Lyon, Churchill, Pershing, Mineral, Humboldt, Lander, Eureka, White Pine, and Elko counties.

Population context

Nevada's population is heavily concentrated in the south. Based on 2024 Census estimates, Southern Nevada accounts for approximately 75% of the state's population (2,492,245 residents), while Northern Nevada accounts for approximately 25% (819,434 residents). Any analysis of participation distribution must be read against this population distribution rather than expecting equal representation.

Participation against population — the per-capita view

Among 155 classified Year Two respondents (146 Southern, 9 Northern, with 6 unclassified and 3 out-of-state):

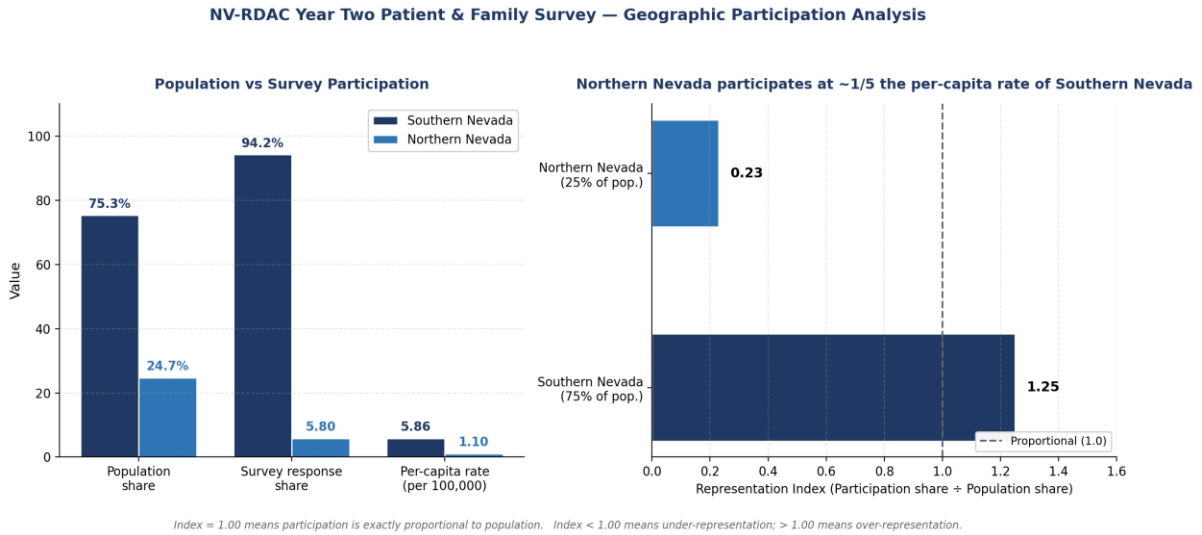
Measure	Southern NV	Northern NV
Population (2024 est.)	2,492,245	819,434
% of state population	75.3%	24.7%
Survey respondents	146	9
% of classified respondents	94.2%	5.8%
Responses per 100,000 population	5.86	1.10
Representation index*	**1.25**	**0.23**

**Representation index = participation share ÷ population share. An index of 1.00 indicates exactly proportional participation. Greater than 1.00 indicates over-representation; less than 1.00 indicates under-representation.*

Southern Nevada participation in the Year Two cohort exceeded its population share by approximately 25% (representation index 1.25). Northern Nevada participation was approximately 77% below proportional (representation index 0.23). On a per-capita basis, Southern Nevadans participated at approximately 5.3 times the rate of Northern Nevadans (5.86 vs 1.10 per 100,000 population).

If the 155 classified Year Two respondents had participated in exactly population-proportional numbers, Southern Nevada would have produced 117 responses and Northern Nevada would have produced 38. The actual figures were 146 and 9. The Northern Nevada gap of approximately 29 responses represents the additional engagement that proportional participation would have produced.

Population vs participation — visual summary



These findings should be read as a statement about NV-RDAC's distribution channels rather than a statement about Northern Nevada's rare disease prevalence. NV-RDAC's outreach mechanisms — including the Cure 4 The Kids Foundation patient and family network, which is geographically concentrated in Southern Nevada — reach the Southern Nevada community more effectively than the Northern Nevada community. Targeted Northern Nevada engagement is recommended for Year Three of collection.

Diagnostic experience by region

With the small Northern Nevada sample (n=9), no statistical comparison is appropriate. The directional patterns observed in the Year Two data are presented for transparency:

Measure	Southern NV	Northern NV
Mean access to care rating (1=easy, 5=hard)	3.29 (n=112)	3.29 (n=7)
Ever misdiagnosed	38% (n=117)	60% (n=5)
Mean # of physicians before diagnosis	1.84 (n=120)	1.83 (n=6)
Diagnosis confirmed by genetic testing	40% (n=118)	33% (n=6)
Reported treatment out of state	12%	11%

Access challenges by region

Southern and Northern respondents reported the same overall mean access rating, but emphasized different barriers underneath that rating:

Access Challenge	Southern NV	Northern NV
Specialist not available	34%	33%
Insurance / coverage barriers	28%	11%
Long wait times	25%	44%
Travel / distance	28%	44%
Provider unfamiliarity with rare disease	27%	44%
Cost / out-of-pocket	10%	0%
Care coordination	14%	0%

Even with small Northern n, the directional pattern suggests two distinct experiences of rare disease care in Nevada: Northern Nevada respondents disproportionately cited workforce-and-access barriers (wait times, travel, provider unfamiliarity), while Southern Nevada respondents were more likely to cite system-and-affordability barriers (insurance, cost, care coordination). If confirmed in subsequent collection cycles, this pattern has implications for the design of any statewide rare disease strategy.

1.5 The Provider Voice

This section presents findings from Year One of the NV-RDAC Provider Survey. Findings reflect 69 Nevada healthcare professionals who provided substantive responses between August 2025 and the end of Q1 2026, with 35 of those respondents also completing the extended survey instrument.

Respondent profile

Year One Provider Survey respondents represented:

- Primary care physicians: 18
- Nurse practitioners / physician assistants / nurses: 17
- Pediatric specialists: 7
- Adult specialists: 7
- Genetic counselors: 3
- Pharmacists: 2
- Social workers / care coordinators: 1
- Other healthcare professionals: 9

Provider confidence

Providers rated their confidence across five domains of rare disease care on a 1–5 scale. Year One mean ratings:

Confidence Domain	Mean (1–5)	n
Coordinating care	2.00	41
Recognizing rare disease symptoms	2.12	41
Initiating diagnostic workup	2.22	41
Managing treatment	2.33	39
Navigating insurance	2.52	40

All five confidence domains were rated below the midpoint of the 1–5 scale. Coordinating care was rated lowest, at exactly 2.00 of 5.

Specialty availability

Providers rated availability of seven categories of specialty care in Nevada on a 1–5 scale:

Specialty	Mean (1–5)	n
Pediatric hematology / oncology	2.19	27
Immunology / rheumatology	2.57	28

Specialty	Mean (1–5)	n
Pediatric neurology	2.71	28
Genetic counselors	2.88	26
Metabolic specialists	2.89	27
Medical geneticists	2.96	28
Adult rare disease specialists	3.19	26

Top barriers

Limited specialist access and authorization delays/denials were tied as the most-frequently identified barriers:

Barrier	In top 3	Ranked #1
Limited specialist access	25	16
Authorization delays / denials	24	14
Lack of provider knowledge / training	19	7
Poor care coordination	15	2
Long wait times	15	2
Inadequate reimbursement	8	5

Insurance authorization outcomes

Providers who completed the extended survey estimated, in actual percentages, the proportion of their rare disease prior authorization requests that were initially approved, approved after appeal, or ultimately denied:

Authorization Outcome	Mean	Median	n
Initially approved	40.6%	45%	16
Approved after appeal	45.0%	40%	16
Ultimately denied	25.7%	20%	15

Reported individual estimates ranged from 0% to 95% across all three categories. Less than half of rare disease prior authorization requests were reported as initially approved, with a substantial proportion requiring appeal or ultimately denied.

Care coordination time

Of 27 responding providers, 12 (44%) reported spending more than 75% of their clinical time on care coordination for rare disease patients. Combined with the 3 reporting 51–75%, 56% of responding providers reported spending more than half of their clinical time on care coordination.

Improvement priorities

Improvement Priority	In top 3	Ranked #1
Insurance authorization reform	25	12
Establish a comprehensive Center of Excellence	21	17
Specialist access / wait times	18	6
Rare disease education	18	3
Care coordinators	16	5
Clinical decision tools	12	0

Establishing a comprehensive Center of Excellence was selected as the #1 priority more frequently than any other option (n=17). When asked directly whether Nevada should establish such a center, 33 of 40 responding providers (82%) supported or strongly supported it.

Wait times and pediatric-to-adult transition

Of 25 providers reporting on Nevada wait times, 18 (72%) reported wait times of 3 months or longer for rare disease specialty care, including 6 reporting wait times exceeding 6 months.

On pediatric-to-adult transitions, 9 of 28 responding providers reported transitions as 'difficult,' 9 as 'variable,' 3 as 'somewhat smooth,' and 7 as 'very smooth.' The most-frequently identified transition challenges were insurance coverage changes (n=21), loss of pediatric specialist relationship (n=16), and adult providers' lack of rare disease expertise (n=14).

Single most important change

Of 36 open-text responses, the most-frequently identified themes for the single most important change that would improve rare disease care in Nevada:

- Specialist recruitment to Nevada and expanded specialty care access — approximately 18 of 36 responses (50%)
- Genetic testing access and insurance coverage of genetic services — 7 responses
- Insurance authorization reform — 6 responses
- Reimbursement reform reflecting time and complexity of rare disease care — 4 responses
- A pediatric multidisciplinary rare disease clinic or center of excellence — 4 responses
- Care coordination support, particularly for primary care practices — 3 responses

Additional provider voices (May 2026 update)

Three additional Nevada healthcare professionals completed the Provider Survey on May 5, 2026, shortly after the publication of the initial edition of this report. Their quantitative responses are consistent with the patterns documented in this section and do not change any of the findings reported above. Their open-text responses, presented below, are added to this edition because they articulate, with unusual directness, the financial dysfunction and referral-cycle breakdown that the broader Provider Survey data describes more abstractly. They are presented in respondents' own words, edited only to remove identifying details.

> *"We need to accept that these patients are challenging to care for — they take more time, pose more risk, they cost providers money out of their limited profits because insurances are not required to pay the cost of actual care. It is no wonder no one wants to treat them in primary care — they need specialists, we (PCPs) should refer and let go — but they keep coming back to us because they have no options. It really is dysfunctional. Payors — specifically Medicaid — needs to pay us better."*
>
> — A Nevada primary care provider, hospital-based urban practice, 21+ years in practice

> *"The good outcomes I have are because I am willing to do the extra work without adequate reimbursement."*
>
> — A Nevada primary care provider, hospital-based urban practice, on what makes good outcomes possible

> *"Either bring in the specialists or accept that we have to send them out — do not just do nothing about it."*
>
> — A Nevada primary care provider on the cycle that returns rare disease patients to primary care

> *"We need the tools required to make a diagnosis — the payers stand in the way of making this easy for anyone, providers and patients alike."*
>
> — A Nevada adult specialist, hospital-based urban practice, 11–20 years in practice

> *"Improved Medicaid reimbursement, more specialists, organized care coordination."*
>
> — A Nevada primary care provider, hospital-based suburban practice, on the single most important change for rare disease care in Nevada

These voices reinforce findings reported elsewhere in this section — below-midpoint specialty availability, authorization burden, and the consumption of provider time by care coordination — and articulate a structural observation made implicitly throughout the Provider Survey: that the rare disease care system in Nevada returns patients to primary care providers because there is nowhere else for them to go, and that the providers who absorb that return do so largely on personal time and without commensurate reimbursement. This pattern is documented here.

1.6 Part 1 Observations

Part 1 has presented findings from 508 cumulative Nevada patient and family participants and 69 Nevada healthcare professionals. The two voices, captured through separate instruments and distribution channels, identified consistent observations across diagnostic delay, specialty access, insurance and authorization barriers, the burden of care coordination, and support for a comprehensive Center of Excellence.

Geographic findings indicate that Year Two patient and family participation was concentrated in Southern Nevada at approximately 1.25 times its population share, while Northern Nevada participated at approximately one-fifth its proportional share. NV-RDAC's distribution channels reach Southern Nevada more effectively than Northern Nevada in the current collection cycle. Targeted Northern Nevada engagement is recommended.

Year Two patient and family findings reflect a cohort that is, on the available evidence, exclusively pediatric. Adult and AYA voices are absent from the Year Two cohort and would require dedicated outreach in subsequent collection cycles. Adult experience captured in v1 (2024) is preserved in the cumulative dataset where applicable.

Patterns in the Year Two data suggest that the access experience differs by insurance type. Medicaid-insured respondents reported higher rates of specialist scarcity, longer wait times, and provider unfamiliarity with rare disease than privately insured respondents. Privately insured respondents reported care coordination challenges at higher rates than Medicaid respondents. These differences will be examined further in subsequent collection cycles.

Year One Provider Survey findings should be read as preliminary. The Provider Survey will be repeated annually; multi-year findings will be reported in subsequent editions of this report. A methodology improvement to align provider geographic coding with the patient and family geographic framework is recommended for Year Two of Provider Survey collection.

Recommendations and policy priorities arising from these findings are developed through separate Council work and are not presented in this document.

PART 2

2025 Data Summary

2.1 Introduction and Methodology

Part 2 presents a summary of statewide clinical data on rare disease in Nevada for calendar year 2025. Data reflect unique patients identified by ICD-10 diagnosis codes corresponding to recognized rare disease classifications, as reported by clinical sites serving Nevada's rare disease population. The principal data source is the Cure 4 The Kids Foundation.

Patients may appear in multiple diagnostic categories or subcategories where multiple rare conditions are present; the sum of subcategory counts may therefore not equal category totals.

2.2 2025 Statewide Patient Volume

In 2025, the contributing clinical dataset documented 4,302 unique Nevadans with rare disease diagnoses across 19 diagnostic categories.

2.3 Rare Diseases by Diagnostic Category

Diagnostic Category	Unique Patients
Hematologic (Blood) Disorders	1,765
C4K Unique (other rare conditions)	1,124
Rare Genetic Disorders	416
Leukemia	273
Immune Deficiency Disorders	252
Neurological & Neuromuscular Disorders	230
Metabolic & Mitochondrial Disorders	192
Other Rare Pediatric Cancers	156
Endocrine Disorders	154
Central Nervous System (CNS) Tumors	128
Lymphomas	80
Rare Connective Tissue & Skeletal Disorders	51
Bone and Soft Tissue Sarcomas	39

Diagnostic Category	Unique Patients
Renal and Liver Tumors	36
Rare Autoimmune	31
Retinoblastoma and Germ Cell Tumors	27
Hearing & Vision Screening	17
Lysosomal Storage Disorders	17
Cystic Fibrosis & Pulmonary Disorders	5
Peroxisomal Disorders	1
Total unique patients	**4,302**

The 19 diagnostic categories above are aggregations of more granular subcategories. The top three categories — Hematologic (Blood) Disorders, the C4K Unique grouping (which captures rare conditions outside the principal pediatric oncology and hematology categories), and Rare Genetic Disorders — together account for 3,305 of the 4,302 unique patients (77%). Sections 2.4 and 2.5 disaggregate this further.

2.4 Top Conditions Across the Dataset

The following are the most frequently observed specific rare disease conditions in the 2025 statewide clinical dataset, ranked by unique patient count across all diagnostic categories:

Condition	Diagnostic Category	Patients
Sickle Cell Disease	Hematologic	476
Misc. Congenital Disorders	C4K Unique	389
Von Willebrand Disease	Hematologic	306
Acute Lymphoblastic Leukemia (ALL)	Leukemia	238
Hemoglobin & Hemolytic Disorders	Hematologic	225
Thalassemia	Hematologic	201
GI Conditions (rare)	C4K Unique	150
Rare Neurological Disorders (C4K)	C4K Unique	147
Coagulation Disorders	Hematologic	128
Purpura & Platelet Disorders	Hematologic	120

Condition	Diagnostic Category	Patients
Primary Immunodeficiencies	Immune Deficiency	115
Immunologic/Autoimmune Disorders	Immune Deficiency	109
Metabolic/Endocrine Disorders	Endocrine	101
Newborn Screening (rare conditions)	C4K Unique	98
Autoimmune Blood Disorders	Hematologic	99
Neurodevelopmental Disorders	Neurological	88
Hematologic Disorders (general)	Hematologic	92
Malignant Neoplasm/Tumor (rare, C4K)	C4K Unique	80
Rare Chromosomal Anomalies	Rare Genetic	75
Genetic Disorders (general)	Rare Genetic	72

Several observations follow from this distribution:

- Sickle Cell Disease is the single most frequently observed rare disease condition in the 2025 statewide clinical dataset (476 unique patients). This is consistent with the State of Nevada Office of State Epidemiology maintaining a Sickle Cell Registry as one of two disease-specific rare disease registries in the state, established by Assembly Bill 254 during Nevada's 80th Legislative Session.
- Acute Lymphoblastic Leukemia (ALL) accounts for 238 of the 273 unique leukemia patients in the dataset (87%), making it by a substantial margin the most common pediatric cancer in the Nevada cohort.
- Five of the top ten conditions are hematologic (sickle cell, von Willebrand, hemoglobin and hemolytic disorders, thalassemia, and coagulation disorders), reflecting the concentration of pediatric hematology and oncology services in the contributing dataset.
- Three of the top ten conditions fall under the C4K Unique grouping, which captures rare conditions outside the principal pediatric oncology and hematology categories. This grouping in aggregate represents 1,124 unique patients across heterogeneous conditions, indicating that a substantial portion of Nevada's pediatric rare disease population presents with conditions less easily classified by standard rare disease taxonomies.

2.5 Subcategory Detail Within the Largest Categories

The 19 diagnostic categories presented in Section 2.3 each contain multiple subcategories of related conditions. The five largest categories — Hematologic Disorders, the C4K Unique grouping, Rare Genetic

Disorders, Leukemia, and Immune Deficiency Disorders — together account for 3,830 of the 4,302 unique patients (89%). Their composition is presented below.

Hematologic (Blood) Disorders — 1,765 unique patients

The largest single diagnostic category in the dataset. The principal subcategories are Sickle Cell Disease (476), Von Willebrand Disease (306), Hemoglobin & Hemolytic Disorders (225), Thalassemia (201), Coagulation Disorders (128), Purpura & Platelet Disorders (120), and Autoimmune Blood Disorders (99). An additional 18 hematologic subcategories each represent fewer than 100 patients, ranging from RBC Membrane Disorders (46) and Hemophilia A (40) to single-patient conditions including Paroxysmal Nocturnal Hemoglobinuria, Genetic Myelodysplastic Syndromes, and Plasma Cell/Gammopathy Disorder.

C4K Unique (Other Rare Conditions) — 1,124 unique patients

This grouping captures rare disease conditions that do not fall within the principal pediatric oncology or hematology categories. The principal subcategories are Miscellaneous Congenital Disorders (389), rare GI conditions (150), Rare Neurological Disorders (147), conditions identified through Newborn Screening (98), and rare Malignant and Benign Neoplasms (80 and 53 respectively). Additional subcategories include Rare Autoimmune Disorders (36), Rare Cardiovascular Disorders (29), and Rare Infectious Disease (26). The breadth of this grouping — more than 30 distinct subcategories — reflects the heterogeneity of the rare disease population presenting at Nevada's principal pediatric specialty site.

Rare Genetic Disorders — 416 unique patients

The principal subcategories are Rare Chromosomal Anomalies (75), general Genetic Disorders (72), Tumor Predisposition Syndromes (60), Vascular Anomalies (28), and a residual category of Rare Genetic Disorders (27). Subcategories below 25 patients include various inherited syndromes and conditions identified through expanded genetic testing. Genetic Counselors and Medical Geneticists were rated by Nevada providers at 2.88 and 2.96 respectively on a 1–5 availability scale (Section 1.2), indicating that the workforce serving this category specifically is below the midpoint of available.

Leukemia — 273 unique patients

Acute Lymphoblastic Leukemia (ALL) accounts for 238 of the 273 leukemia patients (87%). Acute Myeloid Leukemia (AML) accounts for 33 patients (12%). Smaller subcategories include Leukemias-Rare Cancer (12) and Juvenile Myelomonocytic Leukemia (JMML) (1). The concentration in ALL is consistent with national pediatric leukemia distribution; ALL is the most common cancer in children.

Immune Deficiency Disorders — 252 unique patients

The principal subcategories are Primary Immunodeficiencies (115), Immunologic/Autoimmune Disorders (109), Autoinflammatory Syndromes (10), and Common Variable Immune Deficiency (9). Smaller

subcategories include various inherited immune conditions. Immunology and Rheumatology was rated at 2.57 on the 1–5 availability scale by Nevada providers (Section 1.2).

Other observations

Beyond the five largest categories, the remaining 14 categories together represent 472 unique patients. Notable subcategory observations include: 62 of 128 CNS Tumor patients (48%) are classified as Ependymoma; 41 of 80 Lymphoma patients (51%) are classified as Hodgkin Lymphoma; 32 of 39 Bone and Soft Tissue Sarcoma patients (82%) are classified as Osteosarcoma or Ewing Sarcoma; and 23 of 36 Renal and Liver Tumor patients (64%) are classified as Wilms Tumor (Nephroblastoma). These concentrations are consistent with documented pediatric oncology epidemiology and reflect the contributing site's focus.

Why these distributions matter

Many of the most frequently observed conditions in this dataset — Sickle Cell Disease, Von Willebrand Disease, Hemophilia A and B, Thalassemia, ALL, AML, primary immunodeficiencies, Wilms Tumor, Osteosarcoma, Hodgkin Lymphoma, Retinoblastoma — have well-established treatment protocols and, in many cases, well-developed pediatric subspecialty workforces nationally. Their concentration in Nevada's clinical dataset indicates that, at the level of disease recognition, Nevada is treating the rare diseases that established systems are designed to treat. The provider survey findings (Section 1.2) — below-midpoint availability across all seven specialty categories, 72% of providers reporting wait times of three months or more, the documented payer disparity in provider familiarity — describe what happens after recognition: the structural conditions under which these diseases are treated.

2.6 Distribution by Age

Age Bracket	Unique Patients
Infants (<1 year)	473
12–24 months	225
25 months – 4 years	329
5–9 years	751
10–14 years	986
15–19 years	1,079
20–24 years	254
25 years	32

The single largest age bracket is 15–19 years (n=1,079), followed by 10–14 years (n=986) and 5–9 years (n=751). The 15–19 to 20–24 transition shows a substantial decrease in observed patient volume (1,079 to 254), consistent with the pediatric-to-adult care transition pattern documented in the Provider Survey.

2.7 Adolescent and Young Adult (AYA) Population

The Adolescent and Young Adult (AYA) population, defined per National Cancer Institute convention as ages 15–39, represents a substantial subset of the 2025 dataset. The 15–19 bracket alone represents 1,079 unique patients, the largest single age bracket in the dataset. The substantial decrease in observed patient volume between the 15–19 and 20–24 brackets is consistent with the pediatric-to-adult transition pattern documented in the Provider Survey, in which 9 of 28 responding providers rated transitions as 'difficult.'

2.8 Data Limitations

- The dataset reflects patients receiving care at contributing clinical sites and does not capture all Nevadans living with rare disease.
- Pediatric populations are over-represented due to the inclusion of pediatric-specialty contributing sites.
- Patients receiving care exclusively out of state are not represented.
- Undiagnosed patients and patients without ICD-10 codes corresponding to recognized rare disease classifications are not represented.
- Patients may appear in multiple diagnostic categories or subcategories; subcategory counts may therefore exceed category totals.

2.9 Part 2 Observations

Part 2 has presented a summary of 2025 statewide clinical data on rare disease in Nevada. The contributing clinical dataset documents 4,302 unique Nevadans with rare disease diagnoses, distributed across 19 diagnostic categories with hematologic disorders representing the single largest category, and across pediatric and adolescent age brackets with the 15–19 bracket representing the largest single group.

Findings should be read in light of the data limitations described in Section 2.8.

What Is at Stake

This section presents the findings of this report as a forward-looking observation. It does not recommend specific policies or programs; recommendations are developed through separate Council work. It does, however, name what the data describes is currently happening in Nevada — and what continuation of the documented trends would mean.

If the payer-based disparity in access documented in this report continues

Medicaid-insured Year Two respondents reported provider unfamiliarity with rare disease at more than twice the rate reported by privately insured respondents (36% vs 14%) and longer wait times at nearly twice the rate (31% vs 16%). Privately insured respondents reported care coordination challenges at twice the rate of Medicaid-insured respondents (20% vs 10%). The data describes different failure modes by payer type, not a uniform difference in care quality.

Half of the Year Two cohort is Medicaid-insured. Continuation of the documented pattern means Nevada's Medicaid-insured rare disease population — approximately half of the population captured in this report and a substantial share of the broader Nevada rare disease population — will continue to bear a disproportionate share of the workforce gap, with longer waits to be seen and a higher likelihood of being seen by a provider unfamiliar with their condition. It also means privately insured Nevada families will continue to navigate a more fragmented multi-specialty care experience without the coordination support that would reduce that fragmentation. The two failure modes will continue to coexist, and policy responses calibrated against only one will leave the other unaddressed.

If the diagnostic delays documented in this report continue

In 2024 and 2025, 14% of Year Two patient and family respondents reported diagnostic timelines exceeding five years, and 5% reported more than ten years — in a cohort whose mean age was under four. Continuation of these trends means more Nevada children will reach school age, and adulthood, without a confirmed diagnosis. It means more Nevada families will see more physicians, run more inconclusive tests, and accumulate more uncovered out-of-pocket costs in pursuit of an answer that the system is currently slow to provide. It means the children whose parents reported being misdiagnosed at rates of 39% will continue to be a substantial proportion of Nevada's pediatric rare disease population.

If the workforce gaps documented in this report continue

Nevada providers rated availability of every category of rare disease specialty care below the midpoint of 'available' in Year One of the Provider Survey. 72% of responding providers reported wait times of three months or longer for rare disease specialty care; 24% reported waits of more than six months. Continuation of these trends means Nevada families will continue to travel out of state for care that comparable populations in other states receive within their own borders. It means Nevada will continue

to lose patients to neighboring states' specialty centers, and providers caring for those patients will continue to compensate for institutional gaps with their own time.

56% of providers reported spending more than half of their clinical time on care coordination for rare disease patients, with 44% reporting more than 75%. Continuation of this trend has predictable consequences: providers performing case-management work at office-visit reimbursement rates are providers who are at risk of leaving rare disease care, leaving Nevada, or leaving clinical practice altogether. The workforce gap documented in this report is not static.

If the insurance authorization burden documented in this report continues

Providers reported that, on average, only 40.6% of rare disease prior authorization requests are initially approved. An additional 45.0% require appeal, and 25.7% are ultimately denied. These figures describe a system in which less than half of rare disease prior authorization requests are approved without dispute, and roughly one in four is denied entirely. Continuation of these trends means continued reliance on appeals processes that consume provider time without changing clinical decisions, and continued out-of-pocket spending or treatment delay for the patients whose authorizations are not ultimately approved.

If the geographic disparity in participation documented in this report continues

In Year Two, Northern Nevada participated in NV-RDAC's Patient and Family Needs Assessment at approximately one-fifth its proportional share. The directional pattern in the small Northern cohort suggests Northern Nevadans face a different cluster of barriers — workforce-and-access barriers including long wait times, travel, and provider unfamiliarity, each cited by 44% of Northern respondents. Continuation of the current outreach pattern means subsequent reports will continue to be heard primarily through a Southern Nevada lens, and policy responses will continue to be calibrated against the system-and-affordability barriers most visible to Southern respondents. The Northern Nevada cluster of barriers will remain less visible, less measured, and less addressed.

If the mental health burden documented in this report continues

Five of eight mental health impact items in the Year Two instrument were selected by more than 30% of all engaged respondents. The most-selected item was reported by 55%. The most-selected family financial impact item was reported by 50%. Open-text responses described family relationships under sustained strain, including parental separation and divorce identified as a contributing factor to family financial impact. Continuation of these trends means Nevada families managing rare disease will continue to absorb a mental health and family-stability burden that current systems are not consistently capturing or responding to. The siblings of children with rare disease, identified in qualitative responses as feeling forgotten or alone, will continue to grow up in households where their needs are deferred.

If the alignment documented in this report continues

82% of Nevada providers who answered the Provider Survey question supported establishing a comprehensive rare disease Center of Excellence in Nevada. 30 of 40 selected 'strongly support.' One opposed. This level of alignment among Nevada providers across primary care, specialty care, nursing, pharmacy, genetics, social work, and care coordination is unusual and is documented here. The corresponding alignment in patient and family open-text responses — describing needs consistent with the model of a comprehensive multidisciplinary care center — is also documented. Continuation of the current trajectory means this alignment will continue to exist, and the gap between it and the institutional structure available to the patients and providers it represents will continue to grow.

Closing observation

The findings in this report describe a Nevada rare disease care system that, in 2025, is held together substantially by the personal effort of providers, the financial sacrifice of families, and the resilience of patients. The data captured in this edition documents that effort, that sacrifice, and that resilience. It also documents the cost of leaving them as the structural response to a population the size of which — 4,302 unique Nevadans in 2025, in the contributing clinical dataset alone — exceeds what individual effort can sustain over time.

Nevada's eighty-fourth legislative session will convene in February 2027, approximately nine months from this report's publication. Within that window, the patient and family voices captured in this report, the provider voices captured for the first time in this edition, and the clinical data assembled here will continue to be available to inform the work of the Nevada Rare Disease Advisory Council, the Nevada Legislature, the Nevada Department of Health and Human Services, and partner organizations across the state. What this report does not do is recommend what should be done with this evidence. What it does do is name what is at stake if no action is taken.

About This Report

The Nevada Rare Disease Advisory Council (NV-RDAC) was established to advise the State of Nevada on matters affecting individuals and families living with rare disease. The Council is composed of patients, family members, clinicians, researchers, and representatives of state agencies and advocacy organizations.

This report is the second annual edition of the NV-RDAC Needs Assessment and Data Summary. Subsequent editions are anticipated annually.

Nevada Rare Disease Advisory Council

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