NEVADA RARE DISEASE ADVISORY COUNCIL

2027 Legislative Priorities

Three Legislative Priorities and the 2027 Council Anchor Event

Discussion Brief Prepared for the NV-RDAC Council Meeting · May 2026

This brief presents three candidate legislative priorities for the Council's 2027 session work, together with the Council's planned anchor event for that work — Rare Disease Awareness Day at the Legislature in February 2027. The recommendations are derived from two evidence sources, both new and both Nevada-specific: the 2025 NV-RDAC Needs Assessment and Data Summary, and a spring 2026 stakeholder consultation with eight Nevada policy and healthcare leaders working in pediatric and rare disease care.

The Council is asked to discuss the three priorities, provide direction on what each requires to succeed, consider whether the Council is prepared to formally adopt them as 2027 legislative priorities, and provide initial direction on the planning of Rare Disease Awareness Day at the Legislature. Items not included in the 2027 slate but pursued through the Council's longer workplan are summarized at the end of this brief.

AT A GLANCE

Priority 1 · Foundational

Protect NV-RDAC as a standalone advisory body in the 2027 Bureau of Boards and Commissions review.

Priority 2 · Reimbursement

Establish a Nevada Medicaid rare disease complexity add-on billing code.

Priority 3 · Diagnostic Access

Expand Nevada Medicaid coverage for genetic counseling services.

Anchor Event · Public-Facing

Rare Disease Awareness Day at the Legislature · February 2027 · Plan to be determined.

The 84th Nevada Legislative Session convenes February 1, 2027. The window for sponsor identification, fiscal note preparation, and pre-session stakeholder coordination is approximately nine months.

The Evidence Base

These priorities rest on two complementary data sources, both new and both Nevada-specific.

The 2025 Needs Assessment and Data Summary

The Council's second annual Needs Assessment, completed in spring 2026, documents the experience of 508 Nevadans living with rare disease and their families, 69 substantive responses from Nevada healthcare professionals, and statewide clinical data documenting 4,302 unique Nevadans with rare disease diagnoses across 19 diagnostic categories. Findings are observational; the Needs Assessment does not recommend policy. Recommendations are developed through this Council process.

Findings most relevant to the 2027 slate:

- Medicaid-insured Nevadans report provider unfamiliarity with rare disease at more than twice the rate reported by privately insured Nevadans (36% vs 14%); wait time barriers at nearly twice the rate (31% vs 16%). Half of the cohort is Medicaid-insured.
- 56% of responding providers report spending more than half of their clinical time on care coordination for rare disease patients; 44% report more than 75%.
- Of 127 patient and family respondents reporting on genetic testing status, 32% reported their diagnosis was not confirmed by genetic testing and 20% reported uncertain — in a population where genetic confirmation has direct clinical relevance.
- All seven categories of rare disease specialty care were rated below the midpoint of 'available' by Nevada providers; 72% of responding providers report wait times of three months or longer.

Spring 2026 Stakeholder Consultation

In spring 2026, NV-RDAC conducted a stakeholder consultation with eight Nevada policy and healthcare leaders working in pediatric and rare disease care. The response count is small but the depth of engagement is unusually high: every respondent completed at least 100 of 134 substantive fields, and the open-text responses reflect detailed institutional knowledge of Nevada's policy landscape. The consultation should be read as informative, not statistically generalizable.

The three priorities below were named by stakeholder respondents in their own language as the most concrete, highest-impact 2027 policy levers available.

Why both data sources matter

These three priorities are supported by the convergence of population-level evidence from the Needs Assessment and policy-mechanism specificity from the stakeholder consultation. The Needs Assessment establishes that the underlying problem exists at scale. The stakeholder consultation translates each problem into a specific policy mechanism that Nevada is positioned to implement. That dual anchoring — population evidence plus implementation specificity — is the foundation for each of the recommendations that follow.

Priority 1: Protect NV-RDAC as a Standalone Advisory Body

Foundational · Required for all other priorities

The proposal

The Council adopts a formal position protecting NV-RDAC's standalone status in advance of the 2027 Bureau of Boards and Commissions advisory body review, develops a concise institutional case rooted in the Needs Assessment, and engages early and proactively with the Bureau, key legislators, and partner organizations.

Why this matters

The Bureau of Boards and Commissions will review Nevada's advisory bodies during the 2027 legislative session. Consolidation of NV-RDAC into a broader council was a live possibility in 2025 and remains a possibility in 2027. If NV-RDAC is dissolved or absorbed, Nevada loses the statewide needs assessment infrastructure, the Council's place in the 33-state RDAC network, and the legislative credibility built across multiple sessions. Every other priority on this slate depends on the Council surviving the 2027 review.

> *Stakeholder consultation: identified as a 'non-negotiable prerequisite' for advancing other priorities. Needs Assessment: documents that no Nevada-specific document combining patient, family, provider, and clinical data on rare disease existed prior to the Council's work. The 2025 edition is the most complete documented account of rare disease care in Nevada that has been assembled to date. Consolidation would dissolve the only state-level instrument capturing this evidence.*

Implementation considerations

The institutional case

The case for NV-RDAC's continued standalone status is rooted in the Needs Assessment itself. The Council should develop a concise document — likely two pages — that names what NV-RDAC has produced (the statewide needs assessment, the 2026–2027 strategic plan, the Nevada Rare Disease Dashboard with the Office of State Epidemiology, legislative engagement on SB 189 and SB 348), what would be lost if the Council were consolidated (the only state-level rare disease instrument; Nevada's place in the 33-state network), and why the rare disease population is structurally distinct from the populations served by adjacent advisory bodies.

Engagement timing

Engagement with the Bureau of Boards and Commissions and key legislators should begin in summer 2026, well before the formal 2027 review. Early engagement allows the Council's case to inform the framing of the review itself, rather than responding to consolidation proposals that have already gained momentum.

Council action requested

Adopt a formal position; designate Council members or staff to develop the institutional case; authorize Chair-led engagement with the Bureau and legislators.

Priority 2: Nevada Medicaid Rare Disease Complexity Add-On

Reimbursement · Workforce sustainability

The proposal

The Council formally supports a 2027 legislative or regulatory ask to establish a Nevada Medicaid rare disease complexity reimbursement add-on, modeled on the CMS G0545 framework for chronic condition management. The add-on would more accurately compensate providers for the time, multi-specialty consultation, and care coordination that rare disease encounters require.

Why this matters

Current Medicaid CPT coding does not adequately capture the time and cognitive load required for rare disease clinical encounters. A typical rare disease visit involves 60 to 90 minutes of care coordination, multi-specialty consultation, and family education — currently reimbursed at the same rate as a standard 15- to 20-minute visit. The result is that Nevada providers serving rare disease patients are subsidizing care with their own time, and the financial sustainability of the state's rare disease clinical infrastructure is at risk. The Needs Assessment quantifies this: 56% of responding providers spend more than half of their clinical time on care coordination, and 44% spend more than 75%.

> *Needs Assessment: 56% of providers spend more than half their clinical time on care coordination; 44% spend more than 75%. Medicaid-insured patients report provider unfamiliarity at twice the rate of privately insured patients (36% vs 14%), indicating the workforce gap falls disproportionately on Medicaid-insured Nevadans. Stakeholder consultation: named by multiple respondents as the most concrete policy lever available; G0545 cited as direct CMS precedent.*

Implementation considerations

Legislative or regulatory pathway

The complexity add-on may be advanced as a Medicaid State Plan Amendment, as a regulatory change through the Nevada Department of Health and Human Services, or as a legislative directive. Each pathway has different timing, different cost-offset analysis requirements, and different stakeholder engagement needs. The Council should identify in 2026 which pathway is most viable and proceed accordingly.

Fiscal note framing

The fiscal note will be the central political question. The complexity add-on creates new Medicaid expenditure in the short term but addresses a specific structural failure mode — providers leaving rare disease care due to inadequate reimbursement — that produces larger long-term costs (out-of-state referrals, emergency care utilization, workforce attrition). The case must be supported by rigorous cost-offset analysis. The Council should consider whether commissioning that analysis is part of summer 2026 preparation.

Sponsor identification

This priority requires a Senate or Assembly sponsor with health policy fluency and Medicaid committee positioning. Sponsor identification should begin in summer 2026.

Council action requested

Adopt as a 2027 priority; authorize Chair-led sponsor identification and engagement with DHHS and Nevada Medicaid leadership; consider what additional analysis the Council requires before formal support.

Priority 3: Genetic Counseling Coverage Under Nevada Medicaid

Diagnostic Access · High impact, low cost

The proposal

The Council formally supports 2027 legislative or regulatory action to formalize genetic counseling as a covered Nevada Medicaid service for rare disease diagnostic workup. This builds on SB 189 (2025), which established Nevada's licensure framework for genetic counselors, by ensuring the licensure investment translates into actual access for Medicaid-insured Nevadans.

Why this matters

Genetic counseling is the standard of care for diagnosing and managing most rare diseases. It guides clinical decision-making, helps families understand prognosis and inheritance, and informs family planning decisions. Nevada Medicaid currently provides inconsistent coverage of genetic counseling services, creating a meaningful barrier for families — particularly those in rural communities or with limited means. Without this coverage, the workforce that SB 189 enabled cannot reach the population that needs it most.

> *Needs Assessment: 32% of patient and family respondents reported their diagnosis was not confirmed by genetic testing; 20% reported uncertain — in a population where genetic confirmation has direct clinical relevance. Stakeholder consultation: named as 'one of the highest-impact, lowest-cost policy changes available.'*

Implementation considerations

Legislative or regulatory pathway

Genetic counseling coverage is most likely to advance as a Medicaid State Plan Amendment or DHHS regulatory action. A legislative vehicle may also be appropriate, particularly if positioned as completing the work begun by SB 189. The Council should evaluate the relative timing and political viability of each pathway.

Coordination with Priority 2

Priorities 2 and 3 are both Medicaid coverage actions. The Council should consider whether they are best advanced as a coordinated 2027 ask — a single legislative or regulatory package that addresses both reimbursement adequacy and diagnostic access — or as parallel but separate efforts. A coordinated approach allows the Council to present its 2027 work as a coherent whole rather than as multiple discrete asks.

Fiscal note framing

Genetic counseling coverage carries a smaller fiscal note than the complexity add-on. It also has a stronger long-term cost-offset case: confirmed genetic diagnoses reduce diagnostic odyssey costs (additional specialist visits, repeat imaging, inappropriate treatments) that currently fall on Medicaid. The cost-offset analysis should quantify this where possible.

Council action requested

Adopt as a 2027 priority; authorize coordination with Priority 2; engage with Nevada Medicaid and DHHS to determine the most viable pathway; consider whether to position this priority as the completion of the SB 189 framework or as a stand-alone coverage action.

Rare Disease Awareness Day at the Legislature

February 2027 · Public-facing anchor for the Council's 2027 session work

The commitment

The Council will hold Rare Disease Awareness Day at the Legislature in February 2027, in alignment with international Rare Disease Day observed on the last day of February. The Day will serve as the public-facing anchor for the Council's 2027 session work — the moment when the three legislative priorities adopted by the Council are presented directly to Nevada legislators, supported by patient and family voices, provider voices, and the evidence base of the Needs Assessment.

The plan for the Day is to be determined. The Council is asked to provide direction on format, partners, materials, and coordination at this meeting and at subsequent meetings as planning progresses through the second half of 2026.

Why this matters

The Council's 2027 legislative priorities require visibility, sponsor engagement, and broad community support to move through the session. Rare Disease Awareness Day at the Legislature is the most efficient mechanism the Council has to provide all three in a single coordinated event. It places the Council's evidence in front of legislators at the moment they are forming priorities for the session. It allows patient and family voices documented in the Needs Assessment to be heard directly rather than referenced. It demonstrates community alignment behind the Council's work — across patients, families, providers, and partner organizations — at a scale that written materials alone cannot achieve.

Other state Rare Disease Advisory Councils have used analogous events as the primary vehicle for legislative engagement during session years. The 33-state RDAC network includes well-developed models for these events that Nevada can draw on.

Elements to be developed

Format

Format options under consideration include a morning briefing with afternoon legislator visits; a half-day program combining patient and family voices, provider voices, and policy briefings; a press event combined with legislator engagement; or a hybrid approach. The format choice depends on the number of participating families, the legislative committee schedules during the chosen week, and the Council's resource and partner capacity. The Council should consider which format best serves the 2027 priorities as adopted.

Date

Late February 2027 places the Day in proximity to international Rare Disease Day. The 84th Nevada Legislative Session convenes February 1, 2027; selecting a date late in the session's first month places the Council's priorities in front of legislators while bills are still in early committee review and amendment is most feasible. The Council should consider the legislative calendar carefully when selecting a specific date.

Coordination

Planning will require a designated lead — the Chair, a Council working group, or a partner organization with event capacity. The Council should consider whether to designate the lead at this meeting or at a subsequent meeting, and whether the Day should be planned as a Council activity, a partner-led activity with Council sponsorship, or a coalition activity with multiple convening organizations.

Partners

Partner participation is essential. The National Organization for Rare Disorders (NORD), the EveryLife Foundation, individual disease advocacy organizations active in Nevada, the Pediatric and AYA Cancer Collaborative, and other partner organizations have established roles in similar state-level events. The Council should identify which partners to engage formally and at what stage of planning.

Materials

Materials likely to be developed for the Day include a legislator handout summarizing the Council's three 2027 priorities, the Needs Assessment at-a-glance, patient and family voice materials with consent for public use, and a Council briefing packet for legislators and staff. Material development should begin in fall 2026 to allow for review, partner input, and translation as appropriate.

Patient and family participation

The most powerful element of an Awareness Day is the direct presence of Nevadans living with rare disease. The Council should consider how families will be identified, invited, supported (including travel and accommodation if necessary), and prepared. Family participation must be consensual, age-appropriate, and supported throughout the event. Recruitment of family participants should begin in fall 2026.

Engagement targets

The Council should consider what engagement targets are appropriate for the Day — for example, briefings with all members of relevant committees (Health and Human Services committees in both chambers), individual visits with the Council's identified bill sponsors, and broader awareness across the full membership of both chambers. Specific targets help structure the day's logistics and allow the Council to evaluate the Day's success after the fact.

Connection to the 2027 Legislative Priorities

Rare Disease Awareness Day at the Legislature is not a separate Council initiative. It is the public-facing expression of the three priorities adopted in this brief. Each priority will be advanced at the Day:

- Priority 1 — protecting NV-RDAC as a standalone advisory body — is reinforced by the Day itself. A Council that organizes a substantive Legislative Awareness Day demonstrates the institutional capacity that the 2027 advisory body review will evaluate. The Day is, in part, the answer to the question of whether NV-RDAC should continue as a standalone body.
- Priority 2 — the Medicaid rare disease complexity add-on — is presented at the Day with provider voices documenting the time and complexity rare disease care requires, and with the Needs Assessment evidence on care coordination time burden.
- Priority 3 — Nevada Medicaid coverage for genetic counseling — is presented at the Day with family voices on the diagnostic odyssey, supported by the Needs Assessment evidence on genetic testing gaps.

Council action requested

Confirm Rare Disease Awareness Day at the Legislature as the Council's 2027 anchor event; provide initial direction on format, coordination lead, and partner engagement; authorize the Chair or a Council working group to develop a planning document for review at a subsequent meeting; consider what resources and authority the Council requires to support the event through 2026 and into 2027.

Strategic Notes for the 2027 Slate

On the discipline of three priorities

Three legislative priorities is a deliberate number. A council with eight legislative priorities cannot meaningfully advance any of them in a single session; a council with one appears unambitious relative to its evidence base. Three allows the Council to enter the 2027 session with focused, coordinated asks: one foundational, two substantive. The foundational priority is required for the Council's continued existence; the two substantive priorities address documented Medicaid coverage gaps and produce coherent policy progress.

On legislative timing

The 84th Nevada Legislative Session convenes February 1, 2027 — approximately nine months from this meeting. Tier 1 priorities require operational decisions before the end of summer 2026: sponsor identification, fiscal note preparation, partner coordination, and pre-session stakeholder engagement. The Council should consider what authority and resources are needed to act within that timeline, and whether a small Council working group should be designated to manage 2027 session preparation.

On items not in the 2027 slate

Several findings from the Needs Assessment and stakeholder consultation are not represented in the 2027 legislative slate. They remain part of the Council's longer-term work. The Council pursues these through its own workplan, agency engagement, and partner coordination — not through 2027 legislation. They include:

- A standing interagency workgroup on pediatric specialty and rare disease care (Council activity, no legislation required).
- Coordination of Nevada's pediatric and rare disease patient navigation infrastructure (partner convening, no legislation required).
- Development of a Nevada AYA cancer and rare disease program framework (longer runway; targeted for 2029 session).
- Prior authorization reform for rare disease treatments (data supports it; political pathway requires further development).
- Pediatric subspecialty fellowship development (data supports it; operational and funding alignment requires further development).
- Establishment of a comprehensive rare disease Center of Excellence framework (82% provider support documented; institutional pathway requires further development before legislative proposal).

Each of these items is supported by data. None is dismissed. They are not proposed as 2027 legislative priorities because each requires additional development — political alignment, fiscal modeling, partner coordination, or institutional design — that should be completed before formal legislative engagement. The Council should consider whether any item should be elevated into the 2027 slate based on developments since this brief was prepared, or whether the workplan structure for these items is appropriate.

On the framing of the Council's 2027 voice

If the Council adopts these three priorities, it enters the 2027 session with a coherent identity: a Council that protects its institutional capacity, addresses Medicaid reimbursement adequacy for rare disease care, and completes the genetic counselor framework begun in SB 189. That identity is consistent with the observational, evidence-based positioning of the Needs Assessment. The Council does not appear in the 2027 session as an advocate for a specific institutional response; it appears as a Council that has surveyed the evidence and proposes targeted, well-supported actions Nevada is positioned to take.

Discussion Questions for the Council

The Council is asked to consider the following questions and provide direction:

- Are these the right three priorities for 2027? Are any items missing that should be elevated into the slate?
- Is the Council prepared to formally adopt these as 2027 legislative priorities at this meeting, or is a subsequent meeting required?
- Should Priorities 2 and 3 be advanced as a coordinated Medicaid coverage package, or as parallel separate efforts?
- For Priority 1: what authority does the Council require for the Chair to begin engagement with the Bureau of Boards and Commissions and key legislators over the summer of 2026?
- For Priorities 2 and 3: should the Council designate a small working group to manage sponsor identification, fiscal note preparation, and partner coordination through summer and fall 2026?
- For Rare Disease Awareness Day at the Legislature: who should lead planning, what format best serves the 2027 priorities as adopted, and what partner organizations should be engaged early?
- For items not in the 2027 slate: are the proposed workplan and longer-term commitments appropriate, or should any item be elevated into 2027?

Prepared by the Office of the Chair · Nevada Rare Disease Advisory Council · May 2026
This is a discussion brief. Council members are asked to review and respond.