

# PROTECTION PLAN

Comprehensive Strategy for Council Preservation

*Preparing for the 2027 Legislative Session*

January 2026

## PART I: EXECUTIVE SUMMARY

### Background

The Nevada Rare Disease Advisory Council (NV-RDAC) was established by SB 315 in 2019 to advise state agencies and the legislature on policies affecting the estimated 310,000 Nevadans living with rare diseases. In 2025, NV-RDAC faced an existential threat when Governor Lombardo's SB 78 proposed consolidating numerous advisory councils, including potentially dissolving NV-RDAC into a general "Wellness and Prevention Advisory Council."

CRITICAL CONTEXT: While NV-RDAC was ultimately removed from SB 78, the Bureau of Boards & Commissions explicitly stated that advisory bodies would be "addressed in the 2027 legislative session." **The threat has been deferred, not eliminated.**

### Plan Purpose

This comprehensive plan outlines proactive steps to protect NV-RDAC and strengthen relationships with key legislators, state agencies, and coalition partners—ensuring we are fully prepared when the 2027 session begins.

### Key Strategic Objectives

1. Build strong relationships with key legislators before the 2027 session
2. Document and quantify NV-RDAC's value to the state
3. Establish early warning systems for legislative threats
4. Build a coalition of allies prepared to mobilize rapidly
5. Develop crisis response protocols for rapid deployment
6. Create administrative protection options as contingencies

## PART II: SITUATION ANALYSIS

### What Happened in 2025

Governor Lombardo introduced SB 78 as part of a government efficiency initiative to consolidate Nevada's boards and commissions. The original bill provisions could have dissolved NV-RDAC and transferred its responsibilities to a general wellness advisory council.

#### Timeline of Events

- January 2025: SB 78 introduced with broad consolidation language
- February 2025: NORD and national rare disease community mobilized opposition
- March 2025: Bureau of B&I narrowed bill scope, removing specific councils
- April 2025: SB 78 passed without NV-RDAC consolidation provisions
- Ongoing: B&I stated advisory bodies will be "addressed in 2027"

**Key Takeaway:** The removal of advisory councils from SB 78 was a tactical decision based on capacity—not a policy change. **The threat has been deferred, not eliminated.**

#### What Happened

NV-RDAC was included among the 200+ advisory bodies initially subject to SB 78's consolidation provisions. In March 2025, B&I amended the bill to remove all advisory bodies, citing limited staff capacity to address them during the 2025 session. The department explicitly stated these bodies would be "addressed in the 2027 legislative session."

#### What This Means

The deferral was administrative, not a policy victory. We cannot assume that opposition efforts or recognition of NV-RDAC's value drove this decision. The underlying efficiency initiative remains active, and advisory councils remain on B&I's agenda for 2027.

### Current Vulnerabilities

#### Structural Vulnerabilities

- Small operating budget makes RDAC appear dispensable
- Limited public awareness of rare disease issues
- Advisory-only status (no regulatory or enforcement authority)
- Dependent on volunteer council members' availability
- Reliance on DPBH for administrative support—if agency priorities shift, RDAC could lose staffing

#### Political Vulnerabilities

- 2027 session will revisit advisory body consolidation
- New administration priorities could emerge
- Budget pressures may drive further efficiency measures

- Limited institutionalized relationships with current legislators
- B&I leadership is actively driving the consolidation agenda—and NV-RDAC has no established relationship with that office

### Perception Vulnerabilities

- May be viewed as duplicating work of other health advisory bodies
- "Rare disease" seen as niche versus population health priorities
- Volunteer council could be perceived as less essential than paid staff functions

### External Vulnerabilities

- Federal funding instability affecting state health programs broadly
- Competing priorities in 2027 session (healthcare workforce, Medicaid, etc.) may overshadow advisory body discussions—or accelerate efficiency measures

### Strengths to Leverage

- Sen. Cannizzaro's co-sponsorship of founding legislation (SB 315)
- Proven track record: SB 348 (newborn screening), SB 189 (genetic counselor licensure)
- 643 patient cases in state reporting system (210 childhood cancer, 433 rare disease)
- 100% compliance with state reporting requirements
- Zero missed reporting deadlines
- Research-ready registry platform operational
- Strong national network (NORD, EveryLife Foundation, 33 peer state RDACs)
- Specialized expertise not available in general wellness councils

### Key Strategic Assets

**Legislative Champions** The Senate Majority Leader was a co-sponsor of SB 315 (2019), the legislation that created NV-RDAC. This founding connection represents our strongest legislative relationship and should be prioritized for ongoing engagement. Additionally, members of the Senate and Assembly Health Committees who supported rare disease legislation (SB 348, SB 189) have demonstrated commitment to our mission.

**Executive Branch Relationships** The Governor's health policy advisors and Department of Health and Human Services leadership influence how advisory bodies are viewed within the administration. Building relationships at this level provides early insight into efficiency initiatives and ensures NV-RDAC's value is understood before consolidation discussions occur.

**Agency Partnerships** DPBH leadership and the Office of State Epidemiology are our primary agency partners. Their support—or silence—during legislative discussions can significantly

impact our standing. Maintaining strong working relationships ensures they can speak to NV-RDAC's operational value if asked.

**National Network** Our partnerships with NORD, EveryLife Foundation, and peer RDACs in 33 states provide rapid mobilization capacity, model legislation examples, and national credibility that reinforces Nevada's commitment to rare disease patients.

**Critical Gap: Department of Business & Industry** B&I is the agency driving the consolidation initiative and will shape whatever advisory body reforms come to the 2027 session. Currently, NV-RDAC has no established relationship with B&I leadership. Before 2027, we must:

- Identify key contacts at B&I's Office of Nevada Boards, Commissions and Councils Standards
- Request an introductory meeting to understand their criteria for evaluating advisory bodies
- Provide B&I with NV-RDAC's value documentation proactively—before they begin their 2027 review
- Understand what metrics or outcomes B&I uses when recommending retention versus consolidation
- Position NV-RDAC as a cooperative partner in good governance, not a resistant entity

**Goal:** Ensure B&I understands NV-RDAC's unique value and specialized function *before* drafting 2027 legislation—not after.

## PART III: QUANTIFIED VALUE PROPOSITION

### Nevada Rare Disease Impact

Metric	Value
Estimated Nevadans with rare diseases	~310,000 (10% of population)
Number of known rare diseases	7,000+
Average time to diagnosis	4-7 years
Patients seeing 7+ specialists before diagnosis	~50%
Rare diseases affecting children	~50%

### NV-RDAC Accomplishments

#### Legislative Impact

Achievement	Impact
SB 348 - Newborn Screening expansion	Passed 2023; modernized and enhanced Nevada's screening panel

<b>Achievement</b>	<b>Impact</b>
SB 189 - Genetic Counselor licensure	Passed 2023; established professional standards statewide
Genetic counselor regulations development	Collaborating with Nevada Board of Medical Examiners to draft implementing regulations

## **Data Infrastructure & Registry**

<b>Achievement</b>	<b>Impact</b>
Research-ready registry platform	Fully operational at Cure 4 The Kids Foundation; first rare disease registry infrastructure of its kind in Nevada. 100% compliance with state requirements
CNExT software platform	Fully operational; enables automated data collection, standardized reporting, and multi-condition integration capabilities
State Rare Disease Dashboard	Expanded list of conditions tracked through collaboration with Office of State Epidemiology, improving visibility into prevalence and trends statewide
Direct partnership with Nevada Central Cancer Registry	Established formal data-sharing relationship with state public health officials to ensure alignment and interoperability

## **Statewide Assessments**

<b>Achievement</b>	<b>Impact</b>
Patient/Family Needs Assessment	Launched January 2024; ongoing data collection via "While You Wait" campaign (bilingual)
Healthcare Provider Needs Assessment	Soft launch Q4 2025; full statewide rollout planned Q1 2026
Board of Medical Examiners	Agreed to share the NVRDAC Provider survey within their 3/2026 Newsletter to all licensed MDs in NV

## **Awareness & Visibility**

<b>Achievement</b>	<b>Impact</b>
NV-RDAC website	Functional platform serving patients and providers
"While You Wait" campaign	Bilingual outreach successfully driving needs assessment participation
Legislative recognition	Council recognized among legislators and healthcare stakeholders
National RDAC network	Active participation with 33 peer state councils

## **Council Effectiveness**

<b>Achievement</b>	<b>Impact</b>
Council member strategic plan satisfaction	100% rated plan effective or somewhat effective
Meeting schedule	12 meetings annually (6 full council, 6 subcommittee)
Strategic shift endorsed	89% of members supported expanding beyond diagnosis-specific focus to systemic issues

## **Key Findings from Needs Assessment**

The statewide assessment revealed consistent barriers across all rare disease categories:

- Insurance coverage challenges and high out-of-pocket costs
- Limited access to rare disease specialists
- Significant diagnostic delays
- Care coordination gaps across systems
- Insufficient provider knowledge about rare conditions

## **Why Consolidation Would Harm Nevada**

Here's the expanded section based on what NV-RDAC has actually built and accomplished:

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### **Why Consolidation Would Harm Nevada**

#### **Loss of Specialized Expertise**

- NV-RDAC members include physicians, nurses, geneticists, hospital administrators, and patients/families with rare disease expertise—a composition required by Nevada statute to ensure balanced, specialized representation
- This expertise cannot be replicated by a general wellness council; rare diseases require clinical knowledge spanning 7,000+ conditions affecting an estimated 310,000 Nevadans

#### **Destruction of Data Infrastructure Investments**

- NV-RDAC has built Nevada's first research-ready rare disease registry platform in partnership with Cure 4 The Kids Foundation
- The CNExT software platform is fully operational with automated data collection and multi-condition integration capabilities
- Direct partnership established with Nevada Central Cancer Registry and Office of State Epidemiology to expand the State Rare Disease Dashboard
- 100% reporting compliance with zero missed deadlines—this operational track record would be lost

- These data systems are specifically designed for rare disease surveillance and are incompatible with general wellness tracking

### **Severed Legislative Momentum**

- NV-RDAC successfully advocated for passage of SB 348 (newborn screening expansion) and SB 189 (genetic counselor licensure)
- Currently collaborating with Nevada Board of Medical Examiners on implementing regulations for genetic counselor licensure
- A general council would lack the specialized focus to advance rare disease-specific legislation

### **Loss of National Network & Federal Alignment**

- NV-RDAC maintains formal partnerships with NORD, EveryLife Foundation, and Global Genes
- Active member of the national RDAC network across 33 states—providing rapid mobilization capacity, model legislation, and shared advocacy tools
- These relationships provide Nevada access to national policy expertise, opposition letter support, and testimony coordination that a general wellness council would not have

### **Destruction of Needs Assessment Infrastructure**

- Patient/Family Needs Assessment launched January 2024 with bilingual "While You Wait" campaign actively collecting data on barriers to care
- Healthcare Provider Needs Assessment in soft launch with full statewide rollout planned Q1 2026
- This dual-perspective assessment—the first of its kind in Nevada—positions the state to make evidence-based policy decisions; consolidation would abandon this investment

### **Loss of Care Coordination Focus**

- NV-RDAC's 2026-2028 Strategic Plan prioritizes development of a Comprehensive Rare Disease Plan for Nevada addressing insurance coverage, specialist access, care coordination, and diagnostic delays
- Rare disease patients face unique "diagnostic odyssey" challenges—averaging 4-7 years to diagnosis, with 50% seeing 7+ specialists before receiving answers
- A general wellness council cannot address these specialized navigation and coordination needs

### **Undermining Nevada's National Leadership Position**

- Nevada was the 10th state to establish an RDAC; since 2019, there has been a 200% increase in RDACs nationally
- NV-RDAC is positioned to become a national model for data-driven rare disease policy



- Consolidation would signal retreat from a commitment that 33 states have recognized as essential

## Cost-Effectiveness Argument

### Cost-Effectiveness Argument

NV-RDAC operates with minimal state resources while delivering specialized policy expertise that would cost significantly more to replicate through paid staff or consultants. The council's volunteer members bring clinical, research, and lived experience expertise that cannot be purchased.

### Volunteer Expertise at No Cost to the State

- Council members include physicians, nurses, geneticists, hospital administrators, rare disease patients, and parents of children with rare diseases—all serving without compensation
- This expertise would cost hundreds of thousands of dollars annually if the state hired consultants with equivalent clinical, policy, and lived experience knowledge
- Members meet 12 times per year (6 full council meetings, 6 subcommittee meetings), contributing significant professional time to advance Nevada's rare disease agenda

### Leveraging External Resources

- NV-RDAC's partnership with Cure 4 The Kids Foundation provides operational infrastructure for the rare disease registry—at no direct cost to the state general fund
- National partnerships with NORD, EveryLife Foundation, and Global Genes provide Nevada access to policy expertise, advocacy support, and rapid mobilization capacity that would otherwise require paid lobbyists or consultants
- Collaboration with the 33-state RDAC network provides shared toolkits, model legislation, and best practices—reducing duplication and accelerating Nevada's progress

### Infrastructure Built Without Dedicated Funding

- Despite having no sustainable funding source, NV-RDAC has delivered:
  - A fully operational research-ready registry platform
  - Successful passage of two significant pieces of legislation (SB 348, SB 189)
  - A statewide patient/family needs assessment with bilingual outreach
  - A healthcare provider needs assessment launching statewide in 2026
  - Expansion of the State Rare Disease Dashboard in collaboration with the Office of State Epidemiology
- Council members identified "limited by capacity and volunteer bandwidth" as the primary constraint—yet still achieved 100% strategic plan effectiveness ratings

## Return on Minimal Investment

- The estimated 310,000 Nevadans living with rare diseases represent approximately 10% of the state's population
- Rare diseases generate disproportionate healthcare costs due to diagnostic delays, complex care needs, and high-cost therapies
- NV-RDAC's policy work—improving newborn screening, establishing genetic counselor licensure, advocating for Medicaid coverage improvements—reduces long-term costs by enabling earlier diagnosis and appropriate treatment
- Dissolving the council would not eliminate the need for rare disease policy expertise; it would simply shift that burden to paid staff or leave it unaddressed entirely

## What Consolidation Would Actually Cost

- A general wellness council would lack the specialized knowledge to advance rare disease policy, requiring the state to either:
  - Hire dedicated rare disease staff or consultants, or
  - Abandon rare disease policy work entirely—leaving 310,000 Nevadans without representation
- Either outcome costs more than maintaining the volunteer-driven NV-RDAC
- Here's the expanded section:
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## PART IV: LEGISLATIVE RELATIONSHIP STRATEGY

- **Strategic Context**
- NV-RDAC has demonstrated its ability to influence state policy through focused, data-informed advocacy. The passage of SB 348 (newborn screening expansion) and SB 189 (genetic counselor licensure) during the 2023 session proves that targeted legislative engagement works. Building on this momentum—while preparing for the 2027 consolidation threat—requires deepening existing relationships and expanding our legislative network.
- **Priority Legislators**
- **Tier 1: Critical Champions**

Position	Role/Importance	Engagement Strategy
Senate Majority Leader	Co-sponsor of SB 315 (2019), the legislation that created NV-RDAC; most important legislative relationship	Maintain champion relationship; quarterly briefings; Rare Disease Day recognition; ensure early awareness of any consolidation discussions
Senate Health Committee Leadership	Jurisdiction over health policy; key gatekeeper for rare disease legislation	Build personal relationship; invite to RDAC events and Carson City legislative education event; provide policy briefings with needs assessment data

Position	Role/Importance	Engagement Strategy
Assembly Health Committee Leadership	Critical for bill passage in Assembly; healthcare policy focus	Healthcare focus alignment; connect with patient families; provide testimony opportunities for council members

- **Tier 2: Key Influencers**

Category	Why They Matter	Engagement Approach
Health Committee members (both chambers)	Vote on health-related legislation including any consolidation proposals	Legislative briefing packages; invite to Rare Disease Day events; connect with constituent families affected by rare diseases
Appropriations Committee members	Control funding decisions; influence budget-related consolidation arguments	Present cost-effectiveness data; demonstrate return on minimal state investment
Rural legislators	Geographic coverage for rare disease services; understand access barriers	Highlight telehealth expansion priorities; share needs assessment data on rural access gaps; emphasize that consolidation would worsen rural patient outcomes
Legislators with personal rare disease connections	Natural champions with lived experience understanding	Identify through outreach; offer council briefings; invite to share their stories at RDAC events

- **Tier 3: Strategic Awareness**

Category	Why They Matter	Engagement Approach
Government Affairs Committee members	Jurisdiction over boards and commissions legislation; will handle any consolidation bills	Proactive education on NV-RDAC's unique value; differentiate from general advisory bodies
Senate and Assembly Leadership	Control floor votes and legislative priorities	Ensure leadership offices receive annual reports and impact summaries
Freshman legislators (2027 class)	New members may lack awareness of rare disease issues or RDAC history	Early education and relationship building; orientation briefings

## Engagement Timeline

### Engagement Timeline

Timeframe	Action	Owner
Q1 2026	Senate Majority Leader briefing and relationship renewal	Chair
Q1 2026	Disseminate NV-RDAC 2026-2028 Strategic Plan and Annual Report to Nevada Health Authority, DHS leadership, and Governor's Office	Chair/DPBH Liaison
Q1 2026	Identify B&I leadership contacts (Office of Nevada Boards, Commissions and Councils Standards)	DPBH Liaison
Q1 2026	Conduct council member survey on session engagement capacity and role interest	Chair
Q1 2026	NORD coordination call—confirm rapid response commitment and update contact protocols	Chair
Feb 2026	Rare Disease Day email campaign—Chair distributes Strategic Plan and Annual Report to all lawmakers with recognition message	Chair
Feb 2026	Launch 2026 NV-RDAC Blog Post Series to build ongoing awareness and visibility	Communications Lead
Mar 2026	Carson City legislative education event	Events Committee
Q2 2026	Request introductory meeting with B&I leadership	Chair
Q2 2026	All Tier 1 and Tier 2 legislators receive briefing packages	DPBH Liaison
Q2 2026	Government Affairs Committee member outreach begins	Chair/Vice Chair
Q2 2026	Document backup leadership chain; ensure Vice Chair has access to all materials and contacts	Chair/Vice Chair
Q2 2026	Identify and prepare 3-5 families willing to serve as public spokespeople if needed	Chair
Q2 2026	Establish media contacts at Las Vegas Review-Journal, Nevada Independent, Reno Gazette-Journal	Communications Lead
Q2 2026	Connect with Ohio RDAC leadership to learn from their successful defense against consolidation	Chair
Q3 2026	Provide B&I with NV-RDAC value documentation	Chair
Q3 2026	Governor's Office briefing	Chair

Q3 2026	Conduct crisis response tabletop exercise to test 72-hour protocol	Chair/Vice Chair
Q3 2026	Finalize pre-written op-ed for Nevada newspapers	Chair/Communications Lead
Q4 2026	Pre-session briefings with all key legislators	Chair + Members
Q4 2026	Identify and engage incoming freshman legislators	Legislative Liaison
Q4 2026	Distribute updated Annual Report to all legislators and executive branch contacts	Chair/DPBH Liaison
Jan 2027	Final pre-session outreach and coordination	Full Council
Jan 2027	Pre-identify council members and families available for testimony on short notice	Chair
Jan 2027	Confirm NORD/national partner communication chain for rapid mobilization	Chair
Feb 2027	Session begins—daily NELIS monitoring activated	Legislative Liaison
Feb 2027	Rare Disease Day Community Event (Las Vegas)—in partnership with NORD	Events Committee
Feb 2027	Rare Disease Day Legislative Awareness Event (Carson City)—early session visibility; NORD invited to participate	Events Committee/Chair

## Council Member Legislative Assignments

Each council member should be assigned 2-3 legislators based on:

- Geographic proximity (legislators representing their district)
- Professional expertise alignment (clinicians to Health Committee members, etc.)
- Personal connections or relationships

Assignments ensure every priority legislator has a designated NV-RDAC contact and that outreach is distributed across the council rather than concentrated in leadership.

Note: A council member survey will be conducted in Q1 2026 to assess availability and interest in session engagement roles. Assignments will be made based on survey results.

## Key Messages for Legislative Engagement

1. NV-RDAC delivers results: SB 348, SB 189, research-ready registry, 100% reporting compliance
2. We represent 310,000 Nevadans: 10% of the state's population lives with a rare disease
3. We operate at minimal cost: Volunteer council leverages external partnerships and national networks
4. Consolidation would destroy infrastructure: Registry platform, data partnerships, national relationships cannot be replicated by a general wellness council
5. 33 states have RDACs: Nevada was an early leader; consolidation would signal retreat from a national best practice

Here's the expanded Governor's Office Strategy:

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## Governor's Office Strategy

Ohio's RDAC survived only through gubernatorial intervention after legislative dissolution. This precedent underscores the critical importance of building executive branch relationships—not just legislative ones. If legislative protection efforts fail, a strong relationship with the Governor's office could provide an alternative pathway to preservation or restoration.

## Nevada Context

Governor Lombardo's administration has demonstrated a clear focus on government efficiency, as evidenced by SB 78's consolidation initiative. However, the administration has also shown commitment to healthcare priorities—the November 2025 special session included SB 5, which created the Statewide Health Care Access and Recruitment Program to address Nevada's healthcare workforce shortage. This signals that healthcare remains a priority, even within an efficiency-focused agenda.

Additionally, the July 2025 restructuring of Nevada's Department of Health and Human Services into two distinct entities—the Nevada Health Authority (NVHA) and the Department of Human Services (DHS)—reflects the administration's interest in streamlining health-related functions. NV-RDAC must position itself as aligned with these efficiency and healthcare goals, not as a bureaucratic obstacle to reform.

The Chair's existing strong relationship with the Governor's Office of Economic Development (GOED) provides a valuable foundation for building broader executive branch connections. This relationship should be leveraged strategically to open doors to health policy advisors and other key administration contacts.

## Current Asset: GOED Relationship

The Chair maintains a strong existing relationship with the Governor's Office of Economic Development (GOED). This connection provides a foundation for broader executive branch engagement and should be leveraged to open doors to other offices within the administration.

## Executive Branch Engagement Plan

Office	Strategy	Timeframe	Owner
Governor's Health Policy Advisor	Leverage GOED relationship to secure introductory meeting; position NV-RDAC as a data-driven	Q2 2026	Chair

Office	Strategy	Timeframe	Owner
Lieutenant Governor's Office	partner supporting administration efficiency goals Connect on health initiatives; explore alignment with any rural health or community wellness priorities	Q3 2026	Chair
First Lady's Office	Explore interest in children's health causes—50% of rare diseases affect children; potential champion for pediatric rare disease awareness	Q3 2026	Chair
Governor's Communications	Ensure Governor's office is aware of Rare Disease Day activities and positive media opportunities	Feb 2026, Feb 2027	Chair/Communications Lead

## Key Actions

1. **Leverage Existing GOED Relationship**
  - Request introduction from GOED contact to Governor's Health Policy Advisor
  - Frame NV-RDAC's work as supporting Nevada's healthcare infrastructure and economic competitiveness
  - Highlight rare disease patients who travel out of state for care—economic impact on Nevada families and healthcare system
2. **Connect with Lieutenant Governor's Office**
  - Research current health initiatives or priorities
  - Identify alignment with NV-RDAC's rural access and telehealth expansion goals
  - Request briefing opportunity on rare disease access challenges in rural Nevada
3. **Explore First Lady's Office Partnership**
  - Research First Lady's current philanthropic focus areas
  - If children's health or family support is a priority, present pediatric rare disease as a natural alignment
  - Offer patient family stories that humanize the issue
  - Potential opportunity: First Lady participation in Rare Disease Day event
4. **Ensure Governor Receives Impact Documentation**
  - Include Governor's office on distribution of Strategic Plan and Annual Report (Q1 2026)
  - Provide quarterly impact summaries to Health Policy Advisor
  - Frame all communications around data, outcomes, and efficiency—aligning with administration priorities
5. **Frame NV-RDAC as Supporting Administration Goals**
  - Emphasize that NV-RDAC supports efficiency through data-driven policy, not bureaucratic expansion
  - Highlight cost-effectiveness: volunteer council leveraging external partnerships at minimal state cost

- Position registry and needs assessment work as providing actionable data that improves state decision-making
- Connect rare disease policy to broader administration priorities: healthcare workforce, Medicaid sustainability, children's health

### **Messaging for Executive Branch**

- "NV-RDAC helps the state make smarter, data-driven decisions about healthcare policy for 310,000 Nevadans."
- "Our volunteer council delivers specialized expertise at minimal cost—the kind of efficient governance this administration values."
- "Rare disease patients who can access care in Nevada don't have to travel out of state, keeping healthcare dollars in our economy."
- "Early diagnosis through newborn screening and genetic counseling reduces long-term Medicaid costs."

### **Contingency: Executive Order Pathway**

If legislative efforts fail, a strong relationship with the Governor's office provides the foundation for pursuing executive order reestablishment—the same pathway Ohio successfully used. Building these relationships now ensures we have options if the 2027 session does not go as planned.

## **PART V: EARLY WARNING SYSTEM**

Here's the fully rebuilt Legislative Monitoring section:

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### **PART V: EARLY WARNING SYSTEM**

#### **Purpose**

The early warning system is designed to identify potential threats to NV-RDAC as early as possible, allowing maximum time for relationship activation and response coordination. The 2025 experience demonstrated that consolidation language can appear in broad omnibus bills with little advance notice—we cannot rely on being directly notified.

#### **Nevada Consolidation History & Context**

Understanding the trajectory of Nevada's consolidation initiative is essential for effective monitoring:



## 2023: Foundation Laid

- SB 431 passed unanimously, creating the Office of Nevada Boards, Commissions and Councils Standards within the Department of Business & Industry
- This office was given purview over 37 professional and occupational licensing boards
- B&I was tasked with establishing "centralized administration, uniform standards, transparency and consumer protection, and ensuring efficacy and efficiency"
- This legislation opened the door for future reforms

## 2025: Consolidation Attempted

- Governor Lombardo stated in his State of the State address that the board system should be "smart, lean and productive"
- SB 78 proposed consolidating 20 occupational licensing boards into 6 new bodies
- Original bill included provisions affecting advisory councils, including a "Wellness and Prevention Advisory Council" that would have absorbed health-related advisory bodies
- B&I characterized the 300+ boards and commissions as a "de facto fourth branch of government, operating with minimal oversight"
- In March 2025, B&I amended SB 78 to remove all advisory body provisions, citing "limited staff capacity"
- B&I explicitly stated that "Executive Branch advisory boards, commissions, councils will be removed from SB78 and addressed in the 2027 legislative session"

## 2027: Expected Threat

- A separate bill or provision specifically targeting advisory bodies should be anticipated
- B&I has had two years to build capacity and develop recommendations for advisory council consolidation
- NV-RDAC must be prepared for inclusion in any advisory body reform legislation

## Legislative Monitoring

### NELIS Monitoring Protocol

Phase	Frequency	Responsibility	Focus Areas
Interim (2026)	Weekly	Chair	Interim committee agendas, BDR filings, study committee reports, B&I publications
Pre-Session (Dec 2026-Jan 2027)	Daily	Chair	Bill draft releases, committee assignments, leadership announcements, Governor's recommended bills
Session (Feb-June 2027)	Daily (multiple times)	Chair	Floor calendars, committee agendas, amendments, vote schedules, conference committee reports
Post-Session	Weekly	Chair	Veto messages, implementation timelines, interim study assignments

## Alert Thresholds

Alert Level	Trigger	Immediate Action
GREEN - Routine	General health policy bills without RDAC impact	Log and monitor; no immediate action
YELLOW - Monitor	Any bill mentioning advisory councils, boards, commissions, or government efficiency	Vice Chair notification within 24 hours; increase monitoring frequency
ORANGE - Prepare	Bill language that could apply to health advisory bodies; B&I testimony scheduled	Full council notification; activate communications toolkit; contact NORD
RED - Activate	Direct reference to NV-RDAC, rare disease council, or consolidation of health advisory bodies	Vice Chair notification immediately; 72-hour crisis protocol activated

## Key Search Terms

Nevada's consolidation initiative has a specific history and vocabulary that should guide monitoring efforts. The following search terms are organized based on actual language used in SB 431 (2023), SB 78 (2025), Governor Lombardo's State of the State addresses, and B&I policy documents.

### Primary Terms - Direct Threat Indicators

Term	Why It Matters
"advisory council"	Direct reference to bodies like NV-RDAC
"boards and commissions"	Umbrella term used in all consolidation discussions
"consolidation"	Core action term in SB 78 and B&I policy papers
"termination"	SB 78 authorizes B&I to recommend termination of boards
"Office of Nevada Boards, Commissions and Councils Standards"	The B&I office driving the consolidation initiative (created by SB 431 in 2023)
"SB 78" or "SB78"	The 2025 consolidation bill; similar bill numbers may appear in 2027
"BDR 18"	Bill Draft Request category used for boards/commissions legislation

### Secondary Terms - Administration Language

Term	Why It Matters
"smart, lean and productive"	Governor Lombardo's exact phrase from 2025 State of the State describing desired board system

<b>Term</b>	<b>Why It Matters</b>
"fourth branch of government"	B&I's characterization of boards/commissions operating with "minimal oversight"
"de facto fourth branch"	Variation used in B&I policy documents
"centralized administration"	Key goal stated in SB 431 and SB 78
"uniform standards"	B&I objective for all boards under its purview
"periodic review"	SB 78 authorizes B&I to periodically review each board
"sunset"	Legislative mechanism for automatically terminating bodies

### **Efficiency & Reform Language**

<b>Term</b>	<b>Why It Matters</b>
"efficiency"	Core justification for consolidation
"streamline"	Frequently used in Governor's statements
"government reform"	Broader category that includes board consolidation
"administrative efficiency"	B&I's stated goal
"reduce barriers"	Language used to justify licensing board changes
"modernization"	Framing used to make consolidation sound positive
"reorganization"	Alternative term for consolidation
"oversight"	B&I argues boards operate with "minimal oversight"
"accountability"	Key justification in B&I policy papers
"transparency"	Another B&I stated objective

### **Action Terms - Specific Threat Language**

<b>Term</b>	<b>Why It Matters</b>
"eliminate"	Direct action term used in SB 78
"merge"	SB 78 proposes merging multiple boards
"transfer"	Functions may be "transferred" rather than eliminated
"abolish"	Stronger term used in sunset reviews
"restructure"	May indicate organizational changes affecting RDAC
"combine"	Alternative to "merge"
"integrate"	B&I language for combining similar functions

### **Agency & Statute References**

<b>Term</b>	<b>Why It Matters</b>
"DPBH"	Division of Public and Behavioral Health—NV-RDAC's home agency

Term	Why It Matters
"NRS 439"	Nevada Revised Statutes chapter containing NV-RDAC's authorizing legislation
"NRS 232.8413" through "NRS 232.8415"	Statutes governing B&I's Office of Boards, Commissions and Councils Standards
"Department of Business and Industry" or "B&I"	Agency driving consolidation initiative
"Nevada Health Authority" or "NVHA"	New agency (July 2025) overseeing healthcare programs
"Division of Public and Behavioral Health"	Full name of DPBH
"health advisory"	Category that could include NV-RDAC
"rare disease"	Direct reference to NV-RDAC's mission

### Contextual Terms - Budget & Policy

Term	Why It Matters
"cost savings"	Justification for consolidation
"duplicative"	Argument that advisory bodies overlap
"budget reduction"	May drive consolidation pressure
"fee-based"	B&I notes many boards are fee-based; advisory councils are not
"minimal accountability"	B&I's critique of current board system
"workforce barriers"	B&I frames reform as reducing barriers

### Historical Context Terms

Term	Why It Matters
"SB 431" or "SB431"	2023 legislation that created B&I's oversight office—foundation for SB 78
"Sunset Subcommittee"	Legislative body that reviews boards for potential termination
"wellness advisory"	Proposed consolidated body in original SB 78 that would have absorbed health advisory councils
"Executive Branch advisory"	Category B&I stated would be "addressed in the 2027 legislative session"

### Search String Examples for NELIS

Purpose	Search String
Broad monitoring	"advisory council" OR "boards and commissions"
Direct threat	"rare disease" OR "RDAC" OR "NRS 439"

Purpose	Search String
B&I activity	"Business and Industry" AND ("consolidation" OR "termination" OR "review")
Budget impact	"DPBH" AND ("budget" OR "appropriation" OR "reduction")
Reform bills	"BDR 18" OR "boards and commissions"
Governor priorities	"smart lean productive" OR "fourth branch"

## Budget Bill Review Process

Budget and omnibus bills present particular risk because consolidation language can be buried in large, complex legislation. The 2025 SB 78 experience demonstrated this vulnerability—at 92 pages and 39,000+ words, consolidation provisions were not immediately apparent.

Action	Timing	Responsibility
Review Executive Budget for health agency changes	Upon release (typically January)	Chair
Monitor all omnibus health bills	Throughout session	Chair
Check bill amendments for last-minute additions	Within 24 hours of any amendment	Chair
Review committee amendments before floor votes	Day of scheduled vote	Chair
Track conference committee reports	Final weeks of session	Chair
Review any "skeleton form" bills	Immediately upon filing	Chair

**Note on "Skeleton Form" Bills:** SB 78 was introduced "in skeleton form," meaning specific details were added through amendments during the legislative process. Any bill filed in skeleton form related to boards, commissions, or advisory councils should be treated as a potential threat regardless of initial language.

## Interim Committee Monitoring

Threats often originate in interim study committees before formal legislation is drafted. Key committees to monitor:

Committee	Why It Matters	Monitoring Approach
Legislative Committee on Health Care	Jurisdiction over health policy; may study advisory body effectiveness	Review agendas; track study topics
Interim Finance Committee	Budget decisions affecting health agencies	Monitor for DPBH funding discussions

Committee	Why It Matters	Monitoring Approach
Government Affairs Interim	Boards and commissions oversight; primary source of consolidation discussions	Priority monitoring; this committee passed SB 78
Sunset Subcommittee	Reviews boards for potential termination; recommended termination of 35 boards from 2013-2023	Track all reviews and recommendations
B&I Advisory Committees	Agency-level planning for 2027	Request meeting notifications; track published reports

### Executive Branch Intelligence

Legislative threats may be preceded by executive branch signals. Monitor for:

Signal	Source	Implication	Timing
Governor's State of the State address	January 2027	May signal efficiency priorities for session; watch for "smart, lean, productive" language	Early January
Agency budget requests	Fall 2026	Cuts to DPBH may affect RDAC support; B&I budget increases may signal expanded consolidation capacity	September-November 2026
B&I public statements or reports	Ongoing	Will indicate 2027 advisory body plans	Monitor continuously
B&I policy papers	Pre-session	Similar to the policy paper released before SB 78 outlining consolidation rationale	Q4 2026
Executive orders related to government efficiency	Ongoing	May preview legislative priorities	Monitor continuously
Governor's recommended legislation	Pre-session	Direct signal of administration priorities	January 2027
B&I Director testimony or public comments	Committee hearings, press	May preview 2027 intentions	Monitor continuously

### Risk Indicators Dashboard

Indicator	Trigger	Response Level	Action Required
BDR filed mentioning advisory councils	Any filing	YELLOW	Vice Chair notification; monitor progression
B&I interim activity on advisory bodies	Efficiency discussions	YELLOW	Request meeting; provide value documentation
Budget pressure announcements	Cuts to health programs	YELLOW	Assess DPBH impact; increase executive outreach
Governor's office efficiency initiatives	New streamlining proposals	YELLOW	Brief Health Policy Advisor on RDAC value
B&I policy paper on advisory bodies	Publication	ORANGE	Full council notification; analyze recommendations; NORD alert
Bill draft names RDAC or health advisory bodies	Direct reference	ORANGE	Full council notification; NORD alert
Committee hearing scheduled with advisory bodies on agenda	Direct threat	RED	Activate 72-hour crisis protocol
Floor amendment adding consolidation language	Surprise addition	RED	Immediate mobilization; emergency testimony request
"Skeleton form" bill filed for boards/commissions	BDR 18 filing	ORANGE	Monitor closely; prepare for amendments

### Information Sources

Source	Access Method	Update Frequency	Priority
NELIS (Nevada Electronic Legislative Information System)	nelis.leg.state.nv.us	Real-time during session	PRIMARY
Legislative Counsel Bureau	Subscribe to notifications	As bills are drafted	PRIMARY
Committee agendas	NELIS calendar function	Posted 3+ days before hearings	PRIMARY
B&I website and publications	business.nv.gov/boards-and-commissions	Check weekly	HIGH
B&I press releases	business.nv.gov/news-media	As released	HIGH
DPBH internal communications	Through DPBH Liaison	Ongoing	HIGH
Nevada Independent legislative coverage	nevadaindependent.com	Daily during session	MEDIUM
Las Vegas Review-Journal state government coverage	reviewjournal.com	Daily during session	MEDIUM
Governor's Office press releases	gov.nv.gov	As released	MEDIUM

Source	Access Method	Update Frequency	Priority
Sunset Subcommittee reports	leg.state.nv.us	As published	MEDIUM

### Communication Protocol

When a threat is identified:

Alert Level	Who Is Notified	Timeframe	Method
YELLOW	Vice Chair	Within 24 hours	Email with assessment
ORANGE	Full council, NORD	Within 12 hours	Email + phone call to Vice Chair
RED	Full council, all national partners, key legislators	Within 4 hours	Phone tree activation; emergency meeting scheduled

### Monitoring Capacity Consideration

Currently, the Chair handles all NELIS monitoring responsibilities. The Q1 2026 council member survey will assess whether any members have capacity and interest in sharing monitoring duties during the intensive session period. If a council member is identified, monitoring responsibilities could be distributed to reduce Chair burden during critical periods.

### Key Dates for 2026-2027 Monitoring

Date	Event	Monitoring Action
September 2026	BDR filing period opens	Begin daily BDR monitoring
November 2026	Agency budget requests submitted	Review for DPBH and B&I changes
January 2027	Governor's State of the State	Analyze for efficiency/consolidation language
January 2027	Bill drafts released	Intensive daily monitoring begins
February 2027	Session begins	Multiple daily NELIS checks
April 2027	First committee deadline	Peak threat period for buried amendments
May-June 2027	Final weeks of session	Monitor conference committees; watch for last-minute additions

### Agency Intelligence Network



Early warning often comes through informal channels before formal legislative action. Building an intelligence network within state agencies provides advance notice.

### Key Agency Relationships

Contact	Intelligence Value	Engagement
DPBH Liaison	Advance notice of internal discussions; budget pressures	Ongoing
Nevada Health Authority Leadership	Health policy shifts; where rare disease fits in priorities	Quarterly check-ins
Department of Human Services Leadership	Human services policy affecting rare disease families	Quarterly check-ins
B&I Office of Boards, Commissions and Councils Standards	CRITICAL GAP - consolidation criteria, timeline, recommendations	Establish Q2 2026
Governor's Health Policy Advisor	Advance awareness of Governor's legislative agenda	Annual minimum
GOED Contact (existing)	Introduction to other executive branch contacts	Leverage as needed

### Legislative Staff Relationships

Contact	Intelligence Value
Senate Government Affairs Committee Staff	Advance notice of bill drafts; insight into committee priorities
Assembly Government Affairs Committee Staff	Same for Assembly side
Senate Health Committee Staff	Awareness of health legislation; how RDAC is perceived
Assembly Health Committee Staff	Same for Assembly side

### Intelligence Gathering Protocol

Action	Frequency	Owner	Purpose
DPBH Liaison check-in	Monthly (minimum)	Chair	Agency awareness
NVHA leadership meeting	Quarterly	Chair	Relationship building
DHS leadership meeting	Quarterly	Chair	Human services insight
B&I relationship building	Q2 2026, then quarterly	Chair	CRITICAL

Governor's Health Policy briefing	Q3 2026, then as needed	Chair	Executive insight
Legislative staff outreach	Q2 2026, then pre-session	Chair	Committee dynamics

### Intelligence Indicators to Watch

Signal	Source	What It Means
DPBH budget discussions mentioning "efficiency"	DPBH Liaison	Pressure to reduce costs
B&I requests for RDAC information	DPBH Liaison or direct	B&I evaluating for 2027
Governor's office inquiries about advisory bodies	Health Policy Advisor	Legislative priorities forming
Legislative staff questions about RDAC effectiveness	Committee staff	Committee considering action
Changes in DPBH staffing/support for RDAC	DPBH Liaison	Reduced commitment
Negative comments in interim hearings	Committee monitoring	Session priorities preview

## Risk Indicators Dashboard

Indicator	Trigger	Level	Action
BDR filed mentioning advisory councils	Any filing	YELLOW	Monitor
B&I interim activity on advisory bodies	Efficiency discussions	YELLOW	Request meeting
Budget pressure announcements	Cuts to health programs	YELLOW	Assess impact
B&I policy paper on advisory bodies	Publication	ORANGE	Full council + NORD
Bill names RDAC or health advisory bodies	Direct reference	ORANGE	Full council + NORD
"Skeleton form" bill for boards/commissions	BDR 18 filing	ORANGE	Close monitoring
Committee hearing with advisory bodies on agenda	Direct threat	RED	Crisis protocol
Floor amendment adding consolidation	Surprise addition	RED	Immediate mobilization

## Key Dates for 2026-2027 Monitoring

Date	Event	Monitoring Action
September 2026	BDR filing period opens	Begin daily BDR monitoring
November 2026	Agency budget requests submitted	Review for DPBH and B&I changes
January 2027	Governor's State of the State	Analyze for efficiency language
January 2027	Bill drafts released	Intensive daily monitoring
February 2027	Session begins	Multiple daily NELIS checks
April 2027	First committee deadline	Peak threat for buried amendments
May-June 2027	Final weeks of session	Conference committees; last-minute additions

## PART VI: COALITION & ALLY NETWORK

### National Partners

Organization	Resource Available	Contact Protocol
NORD	Opposition letters, national media, testimony	48-hour response commitment
EveryLife Foundation	Policy expertise, federal connections	Advance briefing on threats
Global Genes	Patient community mobilization	Social media activation
Childhood Cancer Int'l	Pediatric advocacy network	Coalition alignment

### Peer State RDACs

Contact established peer councils for support letters and testimony if needed:

- North Carolina Rare Disease Advisory Council (model legislation)
- Minnesota Rare Disease Advisory Council (strong track record)
- Pennsylvania Rare Disease Advisory Committee
- Ohio Commission on Rare Diseases (survived similar threat)

### Nevada Healthcare Coalition

- Cure 4 The Kids Foundation - registry partnership, pediatric expertise
- Renown Health - provider perspective
- UMC - Clark County health system support
- Nevada Hospital Association - institutional voice
- Nevada State Medical Association - physician community
- UNLV School of Medicine - academic partnership
- UNR School of Medicine - research collaboration

### Patient Advocacy Network

- Disease-specific organizations with Nevada members
- Parent/caregiver support groups
- Newborn screening advocacy community
- Childhood cancer family network
- Genetic counseling professional community



Here's the corrected version with Nevada Open Meeting Law considerations:

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## **PART VII: CRISIS RESPONSE PROTOCOL**

**ACTIVATION TRIGGER:** Any bill, amendment, or executive action that directly threatens NV-RDAC's existence, funding, or core mission.

### **Reality Check: NV-RDAC Capacity**

NV-RDAC is a volunteer advisory council without dedicated staff, budget, or communications infrastructure. This crisis response protocol is designed to be achievable within those constraints, leveraging national partners who do have professional capacity.

### **Important: Nevada Open Meeting Law Compliance**

NV-RDAC is subject to Nevada's Open Meeting Law (NRS Chapter 241). The council cannot convene or deliberate outside of properly noticed public meetings. This protocol is designed for individual actions by council leadership—not collective council action—until an emergency meeting can be scheduled.

### **What Can Be Done Without a Meeting:**

- Chair can take individual actions (make calls, send informational emails, provide testimony as an individual)
- Chair can notify council members of a threat (one-way information sharing)
- Individual council members can contact their own legislators
- Individual council members can provide testimony as individuals (not "on behalf of the council")
- Chair can coordinate with NORD and national partners

### **What Requires a Properly Noticed Meeting:**

- Any official council position or statement
- Approval of opposition letters sent "on behalf of NV-RDAC"
- Coordinated council testimony strategy
- Any collective decision-making or deliberation

## **72-Hour Response Protocol**

### **Hour 0-24: Initial Response (Chair Individual Actions)**

1. Chair verifies threat details and timeline (NELIS review, contact DPBH Liaison)
2. Chair notifies Vice Chair by phone (information sharing, not deliberation)

3. Chair alerts NORD State Policy Team (they have 48-hour response commitment and professional staff)
4. Chair sends brief email to full council with situation summary (one-way information; no reply-all discussion)
5. Chair contacts Senate Majority Leader's office to inform champion and request guidance
6. Chair requests DPBH Liaison initiate emergency meeting notice procedures

### **Emergency Meeting Procedures:**

- Contact DPBH Liaison immediately to initiate emergency meeting request
- Nevada Open Meeting Law requires 3 working days' notice for regular meetings
- Emergency meetings may be called with shorter notice if "an unforeseen circumstance requires immediate action"
- DPBH Liaison handles posting requirements (agenda, notice to public)
- Target: Schedule emergency meeting within 5-7 days if legislative timeline permits

### **Hour 24-48: Parallel Track Response**

#### *Track A: Individual Actions (No Meeting Required)*

7. Chair coordinates with NORD on messaging and talking points
8. Chair individually contacts prepared spokesperson families to alert them testimony may be needed
9. Vice Chair monitors NELIS for hearing schedule and updates
10. Individual council members may contact their own legislators to share personal concerns (not as official council position)

#### *Track B: Emergency Meeting Preparation*

11. DPBH Liaison posts emergency meeting notice per Open Meeting Law requirements
12. Chair prepares draft materials for council consideration (opposition letter, talking points, testimony coordination)
13. NORD prepares draft opposition letter for council review at emergency meeting

### **Hour 48-72 and Beyond: Emergency Meeting and Coordinated Response**

#### *Once Emergency Meeting Is Held:*

14. Council formally approves position statement and/or opposition letter
15. Council authorizes Chair to speak on behalf of NV-RDAC
16. Council coordinates testimony strategy (who will testify, key messages)
17. Council authorizes any communications materials

#### *If Legislative Hearing Occurs Before Emergency Meeting Can Be Held:*

- Chair may provide individual testimony (clearly stating personal capacity vs. council capacity)
- NORD may provide testimony and opposition on their own behalf
- Individual council members may provide individual testimony
- After emergency meeting, council can issue formal position for the record

### Communication Protocol

Type	Permitted Without Meeting	Requires Meeting
Chair notifying council of threat	YES (one-way information)	-
Council members discussing strategy via email	NO (constitutes deliberation)	YES
Chair coordinating with NORD	YES (external partner, not council deliberation)	-
Opposition letter "from NV-RDAC"	-	YES
Chair testimony "on behalf of NV-RDAC"	-	YES (authorization required)
Chair testimony as individual	YES	-
Council member testimony as individual	YES	-

### Pre-Drafted Materials (Maintain Current)

These materials should be drafted and reviewed at a regular council meeting (Q4 annually) so they are ready for rapid approval at an emergency meeting:

Material	Owner	Status
Template opposition letter (requires council approval to send)	Chair/NORD	
Testimony talking points—Chair	Chair	
Testimony talking points—Council Member (individual use)	Chair	
Testimony talking points—Patient/Family	Chair	
One-page fact sheet for legislators	Chair/DPBH Liaison	
Patient story summaries (2-3, with permission)	Chair	

### Spokesperson Protocol

Capacity	Who May Speak	Authorization Required
On behalf of NV-RDAC	Chair only	Council approval at meeting
As individual council member	Any member	None (but should clarify capacity)
On behalf of NORD	NORD staff	None (independent organization)
Patient/family story	Spokesperson families	Permission from family



## Rules:

- No council member may claim to speak "on behalf of NV-RDAC" without council authorization
- All testimony should clearly state capacity: "I am speaking as an individual member of..." vs. "On behalf of the Nevada Rare Disease Advisory Council..."
- Council members should avoid reply-all email discussions that could constitute deliberation
- When in doubt about Open Meeting Law compliance, consult DPBH Liaison

## What NV-RDAC Can Realistically Do

Action	Without Meeting	With Emergency Meeting
Monitor NELIS and identify threat	YES (Chair)	-
Alert national partners	YES (Chair)	-
Notify council members (one-way)	YES (Chair)	-
Individual testimony	YES (any member)	-
Coordinate with NORD	YES (Chair)	-
Official council position	NO	YES
Opposition letter from NV-RDAC	NO	YES
Coordinated testimony strategy	NO	YES
Authorize Chair as spokesperson	NO	YES