NV-RDAC 2026–2027 Strategic Plan Survey Summary Report

Overview

Number of Respondents: 9
Survey Period: June 2025
Purpose: To inform priorities for NV-RDAC's 2026–2027 Strategic Plan based on internal council feedback.

Note on Participation: Although the response count was limited, this input provides valuable guidance. Open meeting laws continue to limit informal engagement and feedback collection, contributing to challenges in Council-wide participation.

1. Strategic Priorities – Ranked Focus Areas

- Respondents ranked the following six strategic areas from 1 (highest priority) to 6:
- Top-Ranked Areas (most commonly ranked 1–3):
- - Awareness & Education
- - Research & Data
- - Access to Diagnostics & Treatment
- Lower-ranked priorities:
- - Care & Support
- - Policy & Legislative Advocacy
- - Healthcare Provider Training & Workforce Development

2. Expansion Areas for the Next Plan

- Most frequently selected (multi-select):
- - Rare Disease Awareness Campaigns
- - Improved Data Collection & Utilization
- - Healthcare Provider Education & Training
- - Patient Navigation & Support Services
- - Partnerships with Research Institutions

3. Perceived Effectiveness of the Current Plan

- 5 respondents (56%): Current plan is effective
- 4 respondents (44%): Plan is somewhat effective
- 0 respondents: Plan is not effective

4. Areas Needing Improvement

- - Expansion of the Rare Disease Needs Assessment
- - Enhancing Medicaid and insurance coverage
- - Increasing legislative engagement
- - Inclusion of adult and aging rare disease populations

5. Additional Initiatives or Programs Suggested

- - Developing continuing education for providers
- - Expansion of rare disease registry
- - Creating strategic partnerships with local providers
- - Offering professional and peer support services
- - Building systems for coordinated care

6. Legislative Priorities

- - Support for mandatory newborn screening expansion
- - Improved Medicaid coverage and reimbursement
- - Legislative support for rare disease research and data collection
- - Protection of out-of-pocket caps for prescription drugs

7. Willingness to Participate in Advocacy

- 6 of 9 respondents (67%) expressed willingness to participate in:
- - Legislative meetings
- - Public testimony
- - Awareness campaigns

8. Effectiveness in Meeting Past Strategic Goals

- Responses were mixed:
- - Progress in visibility and awareness
- - Need for more measurable impact
- - One noted accomplishments were 'limited by capacity and volunteer bandwidth'

9. Suggestions to Improve Engagement & Participation

- - Create clearer roles/responsibilities for council members
- - Assign tasks through structured workgroups
- - Provide education on how members can contribute
- - Facilitate regular networking sessions or office hours

10. Support Needed for Member Engagement

- - More opportunities for direct advocacy
- - Training on rare disease issues and council structure
- - Peer networking with other rare disease stakeholders
- - Educational materials to support outreach

11. Should NV-RDAC Broaden Its Focus?

- 8 of 9 respondents (89%) supported expanding beyond the current scope
- 1 respondent felt the current focus was sufficient

12. Preferred Strategies for Expanding Focus

- - Shift from diagnosis-specific focus to systemic issues (e.g., access, equity)

- - Strengthen research and data infrastructure
- - Focus on care coordination and public health integration
- - Partner with academic and clinical institutions

13. Perceived Barriers to Broader Focus

- - Lack of sustainable funding
- - Limited administrative support and staffing
- - Pediatric-focused legacy bias
- - Lack of clear state-level engagement and buy-in
- - Volunteer limitations

14. Additional Thoughts on Strategic Evolution

- - Network with other state RDACs
- - Build on existing community relationships
- - Develop internal systems for project management
- - Include adult rare disease voices more prominently

15. Strategies to Strengthen DHHS & Stakeholder Engagement

- - Regular meetings with DHHS leadership
- - Deeper collaboration with Medicaid
- - Shared accountability with state agencies
- - Partnerships with hospitals, research centers, and managed care organizations

16. Expanding Member Responsibilities

- - Assign tasks or rotating duties
- - Form formal workgroups with deliverables
- - Provide accountability mechanisms (check-ins, updates)
- - Acknowledge time constraints of volunteer roles

17. Suggested Partnerships or Collaborations

- - National organizations: NORD, EveryLife, Global Genes
- - Federal research entities: NIH/NCATS, GARD
- - State-level partners: Medicaid, DHHS
- - Healthcare systems: Hospitals, insurers, provider networks
- - Peer RDACs in other states

18. License Plate Revenue – Recommended Uses

- - Continuing Medical Education (CME) for providers
- - Legislative advocacy
- - Patient navigation and support programs
- - Public awareness campaigns
- - Statewide rare disease meetings

19. Additional Suggestions for License Plate Fund Use

- - Build a network of rare disease provider champions
- - Host an annual summit for providers and advocates
- - Increase funding for patient assistance and travel
- - Use funds to amplify legislative priorities via public engagement

Final Observations

- This survey demonstrates a strong desire to evolve the NV-RDAC's role into a more inclusive, systems-based, and action-oriented advisory body. Respondents widely support strategic growth in advocacy, education, research, and partnerships—while calling for more infrastructure, accountability, and funding to support execution.