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Nevada Rare Disease Advisory Council

State of Nevada Governor's Advisory Council on Rare Disease

2021 Annual Report

On behalf of the Council:

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Introduction

The formation of the Nevada Rare Disease Advisory Council (“the Council”) in 2019 heralded increased awareness of the need to identify and support Nevadans with rare disease. The National Organization of Rare Disorders (NORD) reported Nevada's report card on rare disease in November of 2020 as follows:

Medicaid Eligibility: A

Medicaid Eligibility (% FPL) for Childless Adults: A
Medicaid Eligibility (% FPL) for Parents of Dependent Child: A
Medicaid Eligibility (% FPL) for Pregnant Women: C
Medicaid Eligibility (% FPL) for Children: B

Medical Nutrition: B

Private Insurance Coverage Requirements: B
Private Insurance Covered Disorders: C
State Coverage Requirements: B
State Covered Disorders: A

Newborn Screening: B

Screening for Recommended Uniform Screening panel (RUSP)Core Conditions: C
Adding Screens: B
Funding: B
Dried Blood Spot (DBS) Use: D
Advisory Committee: A

Prescription Drug Out-of-Pocket Costs: F

Protecting Patients in the State Medicaid Program: PassProtecting
Patients in State-Regulated Insurance: C Step Therapy: F
Categories of Exceptions: F
Exceptions Process: F
Process Based Off Clinical Practice: F
Timeline in Status: F

Although delayed due to COVID-19, the Council began meeting and developed two subcommittees, the Legislative subcommittee and Educational subcommittee, to analyze Nevada's approach in meeting each of the 11 legislative objectives. Further, the Council has formalized and approved bylaws. This report will summarize the work and recommendations of the council over the 2021 reporting year.¹

¹ Objectives may appear out of numerical order, as certain activities and recommendations apply to more than one objective.

Status Report on Legislative Objectives and Council Recommendations

Objective #1 & #11:

Objective #1 – Perform a statistical and qualitative examination of the incidence, causes and economic burden of rare diseases in Nevada.

Objective #1.1 – Develop a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such rare diseases

1. Activities:

- a. Discussions revealed that due to ICD-10 coding and lack of specific rare disease ICD taxonomy, it is currently not possible to know the true incidence or economic burden of rare disease in the state which limits the analysis of the scarce data available. Ability to conduct a statistical analysis and parse out specific rare disease codes is also currently limited by available funding.
- b. Concurrently, the Patient Protection Committee had submitted SB40, an act to create an all-payer claims database which was passed during the 81st Legislative Session. The Council reached out to discuss rare disease elements and submitted a letter of support to assist in passage.
- c. The Council currently has a small registry of two entities who have submitted numbers regarding pediatric cancer, inherited bleeding and clotting conditions, and newborn screening.

2. Recommendations:

- a. The Council recommends that the Nevada Department of Health and Human Services (DHHS) include Council input when establishing regulations and an advisory committee for SB40. Approaches could include presentation of tentative regulations for Council meeting review or the inclusion of Council members in the advisory committee itself. This approach would better facilitate the appropriate inclusion and categorization of rare diseases to facilitate a potential future statistical analysis.
- b. The Council requests consideration to proceed with presenting at least one Bill Draft Request (BDR) each legislative session.

Objective #2:

Objective # 2 – Receive and consider reports and testimony concerning rare diseases from persons, the division, community-based organizations, providers of health care and other local and national organizations whose work relates to

rare disease.

1. Activities: The Council has received both personal and professional testimony of experiences with rare disease. Additionally, the Council has collaborated with the Patient Protection Committee and built professional relationships with the National Organization for Rare Disorders, inclusive of regional presentations and one national presentation.
2. Recommendations:
 - a. The Council Educational Subcommittee will continue to foster additional partnerships to continue to receive testimony. The Educational Subcommittee is currently building a Nevada rare disease website which aims to include contact information of medical, community, and national resources searchable by diagnosed condition. Additionally, the Educational Subcommittee is inviting community clinicians to provide a more comprehensive directory of available rare disease clinicians in the state.

Objective #3 & #7:

Objective # 3 - Increase awareness of the burden caused by rare disease in Nevada.

Objective #7 - Increase awareness among providers of health care of the symptoms of and care for patients with rare disease.

1. Activities: The Council Educational Subcommittee continues to develop educational content for all levels of rare disease involvement from community support resources, clinicians, and patients. Currently, the Educational Subcommittee is working on uploading diagnosis specific information to be included in the Council website. This content will connect consumers to clinicians and community support by name of diagnosis as opposed to specialty which has delayed appropriate connections.
2. Recommendations:
 - a. The Council seeks assistance from DHHS to compile a more complete directory of state clinicians under a taxonomy which more clearly identifies their skill in rare disease. It is too common for insurance directories to overlap community providers obfuscating the reality of the state's shortage and mandating patients see preferred clinicians regardless of the panel's skill in rare disease.
 - b. The Council will continue to provide and seek testimony on the burden of rare disease at state and national meetings.

- c. The Council requests a meeting with the DHHS to improve reimbursement for rare disease care.
- d. The Council will continue to work hand in hand with NORD and websites such as FindZebra to improve information in the state.

Objective #4 & #9:

Objective # 4 - Identify evidence-based strategies to prevent and control rare disease

Objective # 9 - Determine the effective methods of collecting data concerning cases of rare diseases in Nevada for the purpose of conducting epidemiological studies of rare disease.

1. Activities: Data is required to develop evidence-based strategies. Currently, Nevada has no such centralized registry nor database from which to compile evidence-based strategies specific to Nevada. The Council has supported the endeavors of SB40 to attempt to obtain such data. The Council made efforts to obtain a first run of this data through Council members' own databases, which have only been successful for two entities.

2. Recommendations:

- a. As such expertise is housed in specific statewide centers of excellence, it is paramount that continuity of care for patients with rare disease be maintained.
- b. The council recommends that Medicaid Service Regulations be updated to include the following requirement:

All payers currently providing managed Medicaid services or exchange based plans to Nevada beneficiaries must include, at a minimum, the same provider network as fee-for-service Medicaid.

Objective #5:

Objective # 5 - Determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from rare disease and the economy of Nevada

1. Activities: As with all such committees, the exact monetary impact cannot be determined without appropriate funding. Current national research has historically been shared, but does not include the impact on local policies.

2. Recommendations:

- a. Without a mechanism to register patients with rare disease, the Council is unable to determine data which is specific to patients in Nevada. While barriers remain for ERISA specific plans, the Nevada Division of Insurance should require all payers seeking to provide rare disease care

maintain an open network which at minimum aligns with fee-for-service Medicaid. This will prevent the significant delays that patients with rare disease currently face when having to move between plans and reduce the disruption in therapy access.

Objective #6, #8, & #10:

Objective # 6 - Study the effect of early treatment for rare disease on the quality of life for patients suffering from rare disease; the provision of services to such patients and reimbursement for such services

Objective #8 - Evaluate the systems for delivery of treatment for rare diseases in place in Nevada and develop recommendations to increase the survival rates and quality of life of patients with rare disease.

Objective #10 - Establish a comprehensive plan for the management of rare diseases in Nevada which must include recommendations for the state and local health authorities, public and private organizations, businesses and potential sources of funding, and update the comprehensive plan as necessary.

1. Activities: The Council appreciates Governor Sisolak's support of this important goal. The Council has discussed the various systems and services currently in place through experiential dialogue.
2. Recommendations:
 - a. The Council is requesting assistance from DHHS to provide grant writing and submission assistance to community partners who otherwise may not have the resources to do so, to improve state funding for such programming and provide grant administration assistance with accounting and reporting.
 - b. The Council is requesting assistance from DHHS to develop a state disease specific reimbursement model to reduce administrative burdens and properly reimburse the complexity of the level of care. The current mechanisms for reimbursement which, for example, limit the use of the code 99215, increase the patient burden of having to come back for multiple lower-level visits and does not fully cover the complexity of the care provided.
 - c. The Council is requesting assistance from DHHS to develop an additional statewide reimbursement model to provide incentives for providers to provide rural care.
 - d. Although housed under DHHS, policies affecting rare disease are not currently presented before the Council to assess impact before implementation. The Council recommends that DHHS seek an impact statement from the council prior to changes especially as it relates to revisions of the Nevada Medicaid

Services Manual.

- e. The Council requests funding for a patient navigator who can assist Nevadans with accessing rare disease specific care. The Council could develop road map and transition and continuity of care algorithms and this role could be shared with the Patient Protection Commission patient navigator.
- f. The Council requests the funding of a study which would evaluate the development of a new specialty designation and curricula for physician residency programs, advanced nurse, and nursing programs with a specific focus on rare disease.
- g. The Council also requests a state level request to the American Board of Medical Specialties to provide a position statement on the possibility of acknowledging rare disease treaters who meet specialty outcomes who may not be board certified in that specialty.

Conclusion

As noted above, the Council's activities have been hindered by lack of adequate funding. At times, a lack of quorum has also hindered our ability to progress. Many state rare disease advisory councils are not subject to open meeting law, and are thus able to address issues more adequately in real-time. Furthermore, limited or varying insurance coverage of rare disease providers, as well as differences in reimbursement for services continue to be a significant barrier in making meaningful comparisons or data analysis in rare disease policies.

The Council members remain committed to assisting rare disease in Nevada, however, the lack of resources, inability to provide legislative input via BDR, and lack of department collaboration have proven to be immense barriers to make meaningful change. The Council recognizes the devastating budgetary impacts that COVID-19 has had on Nevada's budget and the reality that not all legislatively implemented councils can be funded. In the absence of any additional funding, the Council requests to be integrated into the Patient Protection Commission which is currently well-funded and would benefit immensely from the Council's input to preserve a commitment to patients. Many of the objectives of the Council and the Commission overlap and would serve both rare disease and non-rare disease patients alike in the progression of patient centered initiatives and policies. This integration could preserve the website and resources and encourage a more centralized place for patients to seek assistance.

The Council expresses their sincere gratitude to Governor Sisolak and the 2019 Legislature for the acknowledgement of the need to update and improve rare disease policies in Nevada. The Council has been honored to seek a path forward on behalf of patients, families, caregivers, and others who have fought to bring about this

public body. We also wish to express gratitude for the tireless efforts of the DHHS staff with agenda, meeting, and minute recording support.

We look forward to having DHHS review these recommendations for consideration and feedback. We wish for DHHS to approve the sharing of this report to the Nevada Division of Insurance and Network Adequacy Council. As always, the Council remains committed to progressing the care of Nevadans with rare disease in any way we can.

Respectfully submitted.

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