February 10, 2025

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February 18, 2025

Senate Committee on Health and Human Services
Nevada State Legislature
401 S. Carson St.
Carson City, NV 89701

Re: Letter of Support and Recommended Amendments to SB185

Dear Chair Doñate, Vice Chair Taylor, and Members of the Committee,

On behalf of the Nevada Rare Disease Advisory Council (NV RDAC), I am writing to express our strong support for SB185, which expands Medicaid reimbursement for family caregivers of children with disabilities and chronic illnesses. This legislation represents a significant step forward in recognizing the essential role that family caregivers play in providing daily care for Nevada's most vulnerable children. However, we respectfully recommend the following amendments to further strengthen the bill and ensure it meets the needs of families affected by rare diseases.

Recommended Amendments to SB185

1. Expand Parental Reimbursement to Include Part-Time Caregiving

- Current Limitation: SB185 only reimburses parents/guardians when the child requires continuous assistance. This excludes children who need frequent but not 24/7 caregiving support. This also excludes families where the child needs frequent but not full-time support.
- Proposed Change: Expand reimbursement eligibility to include parents/guardians providing part-time caregiving for children who require regular assistance but not 24/7 care.
- Rationale: Many children with rare diseases do not need round-the-clock assistance but still require significant caregiving support that prevents parents from working full-time.

2. Include Non-Parent Family Members as Eligible Caregivers

- Current Limitation: The bill only allows parents and legal guardians to be reimbursed.

- Proposed Change: Expand eligibility to grandparents, adult siblings, and extended family members who serve as the primary caregiver for a Medicaid-eligible child.
- Rationale: Many children with rare diseases receive primary care from non-parent relatives due to parental work commitments, financial strain, or health limitations. Recognizing these caregivers ensures greater access to support and prevents families from having to seek institutional care.

We commend the Nevada Legislature for recognizing the critical role that family caregivers play in supporting children with disabilities and chronic illnesses. By adopting these amendments, SB185 will provide even stronger protections for Nevada's families, ensuring they receive the financial and structural support necessary to care for their loved ones.

We urge you to pass SB185 with these recommended improvements, as they will make a real difference for families navigating the challenges of rare and chronic diseases.

Thank you for your time and consideration.

Sincerely,

Annette Logan-Parker, Chair
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