



June 26, 2018

House Committees on General Investigating & Ethics Committee and Appropriations, Subcommittee on Article II  
State Capitol  
Box 2910  
Austin, TX 78768-2910

*Submitted via email to [bobbyjoe.dale@house.texas.gov](mailto:bobbyjoe.dale@house.texas.gov)*

**Re: Oversight of Medicaid Managed Care Contracts**

Dear Chairwoman Davis, and Members of the Committees:

On behalf of the 1-in-10 Texas residents with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes in regard to the Committees' oversight of the Texas Health & Human Services Commission's management of Medicaid managed care contracts.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. In Texas, NORD operates the "Rare TX" coalition, a network of volunteers and patient advocates seeking to improve public policy for the rare disease community.

Medicaid has long been a lifesaving source of health care coverage for rare disease patients in Texas who cannot access other forms of coverage. It is an especially critical source of care for children with rare diseases, as the onset for nearly 70 percent of all rare diseases is in childhood.<sup>1</sup>

With this in mind, we share the Committees' concerns over whether the Medicaid managed care organizations (MCOs) in Texas are inhibiting access to proper care and treatment for medically fragile children.

In particular, NORD has received multiple reports from patients and community organizations throughout the state regarding problems with the implementation of the STAR Kids program. According to these reports, families participating in STAR Kids have experienced life-threatening coverage delays or denials, difficulty gaining access to disease specialists and preferred providers, and a lack of proper care coordination among existing providers. Further, each of these issues has been exacerbated by a lack of transparency and communication with families about changes in their coverage.

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<sup>1</sup> Bavisetty, Supriya, Wayne W. Grody, and Shahram Yazdani. "Emergence of Pediatric Rare Diseases." *Rare Diseases*. January 28, 2013. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3932940/>.



NORD firmly believes that managed care can be an effective tool for states to lower Medicaid costs while maintaining essential health care services. However, in order to ensure proper care for people with severe and complex disorders, it is essential that managed care be flexible. Based on our experience, the gaps that often exist within managed care – securing timely access to disease specialists and disease-appropriate coverage – disproportionately impact rare disease patients.

In order to resolve these challenges in Texas, NORD and our partners are ready and willing to work with the Committees to identify practical solutions that can improve coverage for the most vulnerable families. To that end, we have identified the following potential reforms for the STAR Kids program:

1. Strengthen the appeals process for families to challenge coverage decisions, including allowing independent third parties to adjudicate appeals, rather than the plans themselves.
2. Implement “Critical Care Partners” protections that facilitate access to essential providers across all plans.
3. Eliminate geographic boundaries for certain essential services.
4. Implement pilot programs to test alternative delivery methods for essential services for medically fragile children.

Thank you for the opportunity to comment on this important matter. Please feel free to reach out to NORD and our partners in Texas to discuss any of the issues raised in this letter.

Sincerely,

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