



RE: [UES4410-2](#) Article 7 Sec 6 Lines 369.5-370.2  
Unrestricted Access to Services for the Diagnosis, Monitoring, & Treatment of Rare Disease  
ATTN: Health & Human Services Conference Committee  
DATE: May 10<sup>th</sup>, 2022

Dear Conference Committee Members,

The Minnesota Council on Disability urges you to retain the provisions in the Omnibus Health & Human Services bill [UES4410-2](#) Article 7 Sec 6 Lines 369.5-370.2 regarding the unrestricted access to services for the diagnosis, monitoring, & treatment of rare disease. We believe these provisions not only improve the lives of those living with rare diseases, but also streamlines and provides costs savings to our healthcare system by reducing the time and money it takes to diagnose, monitor, and treat a person with a rare disease.

Under most Minnesota-based health insurance policies, Minnesotans with rare diseases must first see doctors and specialists within their insurance network before being referred to see a specialist that is out-of-network. Due to the nature of rare diseases there are likely few doctors who may be aware of the disease, much less able to treat the condition. This requires a person with a rare disease to see many doctors and can be both a time and financial burden on a person with a rare disease. In many cases, a person with a rare disease knows exactly which specialist they need to see, especially if there are a limited number of specialists who can accurately diagnose and treat the disease. Updating Minnesota law to require health insurance plans to allow people with rare diseases to see rare disease specialists right away, regardless if they are in-network or not, would save time and reduce the financial burden on the person with the rare disease.

Many disabilities are manifestations of rare diseases. Rare disease patients often have diagnostic odysseys, waiting an average of 6 years from onset of symptoms for an accurate diagnosis. Misdiagnosis and incorrect treatment are frequent in rare diseases. During the diagnostic odyssey patients suffer from loss of quality of life, disease progression, incorrect treatment and complications that are sometimes irreversible. At the same time, unnecessary consultations cause substantial costs for the individual and for healthcare systems. Before the correct diagnosis is made, patients see an average of 7.3 physicians. Therefore, there is an urgent need to improve rare disease diagnosis.

A wide range of disabilities are caused by rare disease so these provisions which seek to improve access to diagnosis and treatment of rare disease would have a major impact on the quality of life of many Minnesotans with disabilities.

Thank you

Trevor Turner  
Public Policy Director