

Senate Human Services SB 2031 January 16th, 2023

Senator Lee and committee members. I am Kirsten Dvorak, Executive Director of The Arc of North Dakota.

On behalf of our organizations representing people with disabilities across the state, we are here to express concern with SB 2031. This legislation would import discriminatory value metrics from Canada into North Dakota.

Last session, we were delighted that the 67th legislative session threw out a similar bill that included the use of quality-adjusted life years. (QUALYs) that import value metrics from Canada that devalue the lives of people with disabilities in assessing the cost-effectiveness of treatments.

SB 2031 would still reference the prescription drug prices from a third party that actively relies on the QALY, the Canadian Patented Medicine Prices Review Board (PMPRB). The PMPRB establishes a fee-based cost-utility analysis model in which health outcomes are expressed as QALYs. The result of this in Canada is that many individuals living with disabilities are unable to receive the treatments and care they need. We understand and share the state's concern about affordable medicines, but we cannot support discriminatory legislation.

In 2019, the National Council on Disability reported that using QALY would be contrary to United States civil rights and disability law. The information directly recommended that the United States refrain from reference prices

¹ https://www.canada.ca/en/patented-medicine-prices-review/services/legislation/about-guidelines/guidelines.html

² https://valueourhealth.org/wp-content/uploads/2020/04/Canada.pdf

established in other countries that rely on using QALY. ³ Because of these clear discriminatory implications, the public and policymakers within the United States have generally opposed using the QALY.

The Affordable Care Act of 2010 (ACA) included a ban on using the QALY and similar metrics in Medicare.⁴ In 1992, the George H.W. Bush administration established that Oregon's efforts to utilize cost–effectiveness standards in Medicaid would violate the Americans with Disabilities Act.⁵

With this background, we hope the North Dakota Senate Human Services committee will recommend a Do Not Pass and work on finding solutions to healthcare affordability.

Kirsten Dvorak 222-1854

³https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf

⁴ 111th Congress of the United States of America. (2010). H.R. 3590 The Patient Protection and Affordable Care Act. *Section 1182*. Washington, DC.

 $^{^{5}\} https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html$