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SB 2170 IBL March 22, 2021

Chairman Lefor and members of the House Industry, Business and Labor Committee. My name is Kirsten Dvorak, and I am the executive director of The Arc of North Dakota, which includes all six chapters of The Arc in North Dakota: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve people's quality of life with intellectual and developmental disabilities and actively support their full inclusion and community participation.

The Arc of North Dakota supports the need for affordable health care. We encourage the state to manage health care that is person-centered on meeting our residents' needs with disabilities. We ask for a DO NOT PASS for SB 2170, as it is based on discriminatory metrics, the Quality-Adjusted Life Years (QALY). QALYs use measures based on the degree to which a drug or treatment extends life and improves the quality of life.

QALY-based assessments assign a financial value to health improvements provided by a treatment that does not account for outcomes that matter to people living with the relevant health condition and attribute a lower value to a life lived with a disability. When applied to health care decision-making, the results can mean that people with disabilities and chronic illnesses, including older adults, are deemed not worth the cost to treat. We encourage you to review the report from the National Council on Disability, an independent federal agency, recommending that policymakers avoid referencing or importing the QALY from other countries (such as Canada), clarifying that its use in public programs would be contrary to United States civil rights and disability policy.

SB 2170 would reference Canadian rates of prescription drugs. The bill directly references the process paid for drugs in five Canadian provinces. Before applying for coverage by the provinces, all medications must complete a Common Drug Review by Canadian Agency for Drugs and Technologies in Health (CADTH), which references QALYs. In Canada, the outcome is that many individuals living with disabilities are unable to receive the treatments and care they need.



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The 2019 National Council on Disability report was direct in recommending that the United States should not reference prices established in other countries that rely on QALY use. The Affordable Care Act of 2010 (ACA) included a ban on the use of QALY and similar metrics in Medicare, and in 1992 it established Oregon's efforts to utilize a cost-effectiveness standard in Medicaid, which would violate the Americans with Disabilities Act. Most recently, the US Department of Health and Human Services (HHS) reiterated in a final rule that it is a violation of Section 504 of Rehabilitation the Act (ADA), the Age of Discrimination Act, and Section 1557 of the ACA for state Medicaid agencies to use measures that would unlawfully discriminate based on disability or age.

Thank you for taking the time today to understand why The Arc recommends a DO NOT PASS for SB 2170.

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