

The Data Justice Act (HB 3159)

The Need

Oregon does not have the information it needs to tackle the many severe health issues disproportionately impacting BIPOC, LGBTQ+ people, people with disabilities, and other underserved populations.

Why? Because we are collecting little to no data on the identities affecting patients' health. It wasn't until more than six months into the COVID-19 pandemic, for example, that OHA began receiving information from healthcare providers on the race and ethnicity of COVID-19 patients, despite the disparate impact of the disease on communities of color.



The management expert Peter Drucker famously said, "What gets measured, gets managed." How can Oregon "manage" institutional racism in healthcare or social determinants of LGBTQ+ health when we don't measure even the most basic characteristics of this population? We cannot achieve health equity without achieving data justice.

The Act

The Data Justice Act will empower our state to effectively address health disparities by asking providers to gather and share data with the Oregon Health Authority (OHA) on patients' race, ethnicity, language, disability, sexual orientation, and gender identity. Providers will have to report this data once a year. Currently, healthcare providers are only required to collect race, ethnicity, language, and disability (REAL-D) data from COVID-19 patients, and are not required by law to collect any sexual orientation and gender identity (SOGI) data.

The bill directs OHA to build a data system that will allow providers to report patients' REAL-D and SOGI data through electronic health record systems, and allow patients to self-report their data via an online portal. This data will be considered confidential and not subject to disclosure under public-record laws, may only be released if it is anonymized and aggregated, and may not be considered by health insurers.

Supporters

The chief sponsors of the Data Justice Act are Rep. Rob Nosse and Sen. Kate Lieber. Advocates are working closely with OHA on developing this legislation, with input from providers. On the



recommendation of the Racial Justice Council, Governor Kate Brown proposed in her recommended budget an investment of more than \$7 million to implement REAL-D and SOGI data collection. Lastly, the bill has been endorsed by a broad coalition of healthcare providers and advocacy organizations working to advance health equity for marginalized communities across Oregon.

(cont.)

For more information, contact Jonathan Frochtzwaig at CAP: jfrochtzwaig@capnw.org

The following organizations have endorsed the Data Justice Act:

