SB 835 -1 STAFF MEASURE SUMMARY

Senate Committee On Health Care

Prepared By: Alexandra Kihn-Stang

Meeting Dates: 2/18, 3/27

WHAT THE MEASURE DOES:

The measure directs the Oregon Health Authority (OHA) and Oregon Department of Human Services (ODHS) to work with the nine federally recognized American Indian tribes in Oregon to adopt rules and standards pertaining to the collection, storage, and use of tribal affiliation data as part of the collection of the data on race, ethnicity, language, disability (REALD).

Detailed Summary

- Expands rules around the collection of REALD data to include tribal affiliation.
- Directs OHA, in collaboration with ODHS and the nine federally recognized American Indian tribes in Oregon, to adopt standards for collecting, storing, and using tribal affiliation data. Specifies that OHA and ODHS will adhere to the adopted standards in any data collection surveys and in all programs which engage with tribal data. Directs OHA and ODHS, in collaboration with the Tribes, to review and update the data standards no less than once every two years. Prohibits OHA and ODHS from collecting, storing, or using data on tribal affiliation until the standards have been adopted.
- Stipulates that a Tribe will retain the right to govern the collection, storage, and use of tribal data. Requires OHA to obtain a written data use agreement in order to release tribal data. Specifies that the data use agreement only applies to the specific tribe to which the data belong.
- Adds tribal affiliation to the Oregon data collection system and rules related to data collection for coordinated
 care organizations, health care providers, and health insurers. Directs OHA to collaborate with the nine Tribes
 to create rules regarding collection, storage, and use of tribal affiliation data. Clarifies that patients may opt
 out of providing data on their tribal affiliation.
- Stipulates that an advisory committee should include a representative of the Tribes.
- Declares an emergency, effective on passage.

Fiscal impact: May have fiscal impact, but no statement yet issued Revenue impact: May have revenue impact, but no statement yet issued

ISSUES DISCUSSED:

EFFECT OF AMENDMENT:

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- Prohibits OHA from collecting, storing, or using any tribal affiliation data until the authority, in collaboration with the nine federally recognized Indian tribes in Oregon, has adopted uniform standards for the collection, storage and use of such data.
- Prohibits OHA from releasing data collected under the section regarding tribal affiliation unless the release of that data is allowed by a written data use agreement entered into by the affected tribe.
- Gives OHA authority to make rules for collection, storage, and use of data that must protect the right of each tribe to govern.

BACKGROUND:

House Bill 2134 (2013) directed OHA and ODHS to standardize the collection of demographic data on race, ethnicity, language, and disability (REALD). REALD includes standardized data collection categories and survey

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questions. These standards support the collection of consistent data across all Oregon data systems and are used to measure and compare services and health disparities statewide. REALD data collection does not currently include questions about tribal affiliation.

Oregon is home to <u>nine</u> federally recognized American Indian tribes, including: the Burns Paiute Tribe; Confederated Tribes of the Coos, Lower Umpqua, and Siuslaw Indians; Confederated Tribes of Grand Ronde; Confederated Tribes of Siletz Indians; Confederated Tribes of the Umatilla Indian Reservation; Confederated Tribes of Warm Springs; the Cow Creek Band of Umpqua Tribe of Indians; the Coquille Tribe; and the Klamath Tribes of the Klamath, Modoc, and Yahooskin. These sovereign nations have powers to protect the health and safety of their members and to govern their own lands and maintain formal government-to-government relations with state and federal governments.

Senate Bill 835 directs OHA and ODHS to work with the nine federally recognized American Indian tribes in Oregon to adopt rules and standards pertaining to the collection, storage, and use of tribal affiliation data as part of the collection of REALD data.