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SB 303 Testimony

Chair Nosse, Vice-Chairs Goodwin & Nelson, Members of the House Behavioral Health & Healthcare Committee,

Everyone seems aligned on a common goal to measure this program's efficacy and safety, while protecting Oregonians' data privacy and equitable access and minimizing OHA costs.

We heard from the bill's supporters that it now only involves aggregate data, no individual-level data will leave the service center, and clients will be able to provide true informed consent. The main difference of opinions is that the bill's supporters believe the bill adequately protects data privacy and health equity, while those actually risking their livelihood (and criminal prosecution) believe it doesn't. We appreciate Senator Steiner's commitment to this program, and we support her goal to measure safety and efficacy.

This testimony explains the bill's limitations and how our Data Privacy Amendment overcomes them to ensure the bill truly protects data privacy in a manner that aligns with Oregon's upcoming data privacy law (SB 619).

Limit to Aggregate Data

SB 303 has changed from being a bill that collected and shared a massive amount of individual-level data with OHSU and its partners. Backers now say the s2 amendment ensures this is only aggregate data, meaning no individual-level data of any kind. However, there is nothing that affirms this is only aggregated data. The data collection language is identical to what it was when this bill involved massive troves of individual records. Our Data Privacy Amendment makes changes to reflect their intent by using language that aligns with common data privacy terms including making it compatible with SB 619 definitions, principles and spirit.

Ensuring the program is truly limited to aggregate data is important for two key reasons. First, from a data privacy perspective, it is much safer to be sharing only aggregate data, i.e. mathematical totals, percentages, and averages than having service centers sending massive troves of individual de-identified records to OHA. It's also safer for service center operators if OHA is aggregating across all service centers the data that it shares with OHSU and publishes on the website. And second, it is much lower cost and effort for OHA to only deal in service center level aggregated data and not possess individual-level data.

Require Informed Consent

The backers have advised that the current language ensures that all clients will have an opportunity to understand and discuss this data sharing and have the opportunity to not participate. Under the current bill, however, all client data will be submitted to OHA unless a client specifically requests. This “opt-out” language means that service centers don’t have any need or obligation to have a conversation with the client about this data sharing and in fact. Our amendment requires the client to elect to participate (i.e. affirmative consent), which is the only way to make sure service centers discuss this data sharing with every client.

Limit Data to What’s in the Bill

Under the current bill, OHA can freely add whatever data it wants and that could include individual data. After all the community concern about the specific data covered here, it’s inappropriate to provide this data collection blank check to OHA. If they want to collect more data, that should require statutory change to ensure elected representatives and not appointed administrators decide what additional data gets shared. Our amendment ensures this sensitive data collection is limited to what’s enumerated. If there is other data needed, it should be included in this bill or revisited in a future bill.

We recognize the importance of data collection to measure this program’s success and defend it against detractors. Our Data Privacy Amendment makes small changes that will significantly improve the bill by better protecting data privacy, reducing fear of this data collection in marginalized communities, while reducing risk and cost for OHA to implement this program. We urge you to adopt our Data Privacy Amendment.

Sincerely,

A handwritten signature in black ink, appearing to read 'AY', written over a light blue horizontal line.

Andrew Yorra