

HOUSE BILL REPORT

2E2SHB 1541

As Passed Legislature

Title: An act relating to increasing access and representation in policy-making processes for people with direct lived experience.

Brief Description: Establishing the nothing about us without us act.

Sponsors: House Committee on Appropriations (originally sponsored by Representatives Farivar, Couture, Mena, Pollet, Taylor, Ortiz-Self, Street, Thai, Reed, Waters, Fosse, Caldier, Simmons, Davis, Alvarado, Schmidt, Ryu, Griffey, Ramel, Barnard, Orwall, Hackney, Bergquist, Walen, Berry, Tharinger, Peterson, Goodman, Volz, Eslick, Stonier, Gregerson, Riccelli, Ormsby, Kloba, Doglio, Bateman, Macri and Duerr).

Brief History:

Committee Activity:

State Government & Tribal Relations: 2/3/23, 2/10/23 [DPS];
Appropriations: 2/22/23, 2/24/23 [DP2S(w/o sub SGOV)].

Floor Activity:

Passed House: 3/7/23, 83-12.
Passed House: 2/6/24, 83-14.
Passed Senate: 2/28/24, 40-9.
Passed Legislature.

Brief Summary of Second Engrossed Second Substitute Bill

- Implements certain membership requirements for statutory entities, defined as any multimember task force, work group, or advisory committee, that is: (1) temporary; (2) established by statute; (3) established for the specific purpose of examining a particular issue that directly and tangibly affects a particular underrepresented population; and (4) required to report to the Legislature on that issue.
- Requires various reports by statutory entities and the Office of Equity (Office) on the effectiveness of the membership requirements under the

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act, among other information.

- Requires the inclusion of the membership requirements under the act in the Bill Drafting Guide.

HOUSE COMMITTEE ON STATE GOVERNMENT & TRIBAL RELATIONS

Majority Report: The substitute bill be substituted therefor and the substitute bill do pass. Signed by 4 members: Representatives Ramos, Chair; Stearns, Vice Chair; Gregerson and Mena.

Minority Report: Do not pass. Signed by 1 member: Representative Christian, Assistant Ranking Minority Member.

Minority Report: Without recommendation. Signed by 2 members: Representatives Abbarno, Ranking Minority Member; Low.

Staff: Connor Schiff (786-7093).

HOUSE COMMITTEE ON APPROPRIATIONS

Majority Report: The second substitute bill be substituted therefor and the second substitute bill do pass and do not pass the substitute bill by Committee on State Government & Tribal Relations. Signed by 28 members: Representatives Ormsby, Chair; Bergquist, Vice Chair; Gregerson, Vice Chair; Macri, Vice Chair; Stokesbary, Ranking Minority Member; Corry, Assistant Ranking Minority Member; Berg, Chandler, Chopp, Connors, Couture, Davis, Dye, Fitzgibbon, Harris, Lekanoff, Pollet, Riccelli, Ryu, Sandlin, Schmick, Senn, Simmons, Slatter, Springer, Steele, Stonier and Tharinger.

Minority Report: Without recommendation. Signed by 2 members: Representatives Chambers, Assistant Ranking Minority Member; Rude.

Staff: Emily Stephens (786-7157).

Background:

The phrase "nothing about us without us" is a mantra that has historically resonated with the disability rights community in advocating for full and direct participation in all decisions that impact their lives.

Various state entities encourage the participation of, or require the inclusion of, people with direct lived experience, individuals from underrepresented communities, and those from vulnerable populations. For example, the Strategic Plan Advisory Group established by the

Children and Youth Behavioral Health Work Group must include in its membership individuals with lived experience receiving behavioral health services or whose family members have received such services. Additionally, Community Health Advisory Boards (Board) are required to be broadly representative of the character of the community, with the Board's composition consisting of community members with lived experience in areas such as health care access and quality, health care inequities, and social and economic sectors. Also, the Utility Wildland Fire Prevention Advisory Committee must include two members representing historically marginalized or underrepresented communities. Further, the Governor is required to appoint to the Criminal Justice Training Commission at least three members from historically underrepresented communities.

In 2023 legislation was enacted that requires the Office of Equity to:

- consult with certain state boards and commissions to identify issues related to access and meaningful participation in stakeholder engagement, and
- develop a toolkit on best practices for supporting meaningful engagement of underrepresented individuals with direct lived experience participating on statutory entities.

Summary of Second Engrossed Second Substitute Bill:

Membership Requirements for Statutory Entities.

The membership of each statutory entity created on or after January 1, 2025, must include at least three individuals from underrepresented populations who have direct lived experience with the issue that the statutory entity is tasked with examining. The entities must also reflect the diversity of people who have direct lived experience with the issue being examined.

A statutory entity is any multimember task force, work group, or advisory committee, that is temporarily established by statute for the specific purpose of examining policies directly and tangibly affecting a particular underrepresented population, and that is required to report to the Legislature on that issue.

An "underrepresented population" is defined as a population group that is more likely to be at higher risk for disenfranchisement due to adverse socioeconomic factors, such as unemployment, high housing and transportation costs relative to income, effects of environmental harms, limited access to nutritious food and adequate health care, linguistic isolation, and other factors that may be barriers to participation in policy decision making. A person with "direct lived experience" means a person with direct personal experience in the subject matter being addressed by the statutory entity.

If the membership requirements under the act require that additional members be appointed to statutory entities created on or after January 1, 2025, the identified appointing authority for that statutory entity must appoint the additional members. If there are multiple appointing authorities for the statutory entity, they may collectively choose one individual

among themselves to make the appointments for any additional members or they may defer to the Office of Equity (Office) or a state commission, board, or committee to make any necessary appointments. Except for appointing authorities from the legislative branch, appointing authorities must consult with relevant state entities identified by the Office when making appointments to the statutory entity. The additional members must have voting authority.

The Statute Law Committee must include information about membership requirements for statutory entities in the Bill Drafting Guide.

Reports.

Beginning January 1, 2025, each statutory entity must collect the following information:

- a brief description of the statutory entity's purpose; and
- information relating to the underrepresented populations directly and tangibly impacted by its work, including:
 - the number of members who are appointed to the statutory entity who have direct lived experience with the specific policy that the statutory entity is tasked with examining;
 - anonymous aggregate demographic information of statutory entity members related to disability status, age, race, gender, sexual orientation, ethnicity, and geographic representation;
 - an analysis of whether the membership requirements under the act reduced barriers to participation in policymaking decisions by members of underrepresented populations;
 - an analysis of how participation by members from underrepresented populations with direct lived experience affected the conduct and outcomes of the statutory entity as it accomplished its mission; and
 - the number of members from an underrepresented population who have direct lived experience and qualify for the existing statutory stipend of \$200 per day, the number of those who requested stipends, and the number who received the stipend.

The statutory entities must, by the date that its final report is due to the Legislature, report the collected information specified above to the Office, except that statutory entities administered by the Legislature must instead report the collected information to the Secretary of the Senate and the Chief Clerk of the House of Representatives.

By October 31, 2026, and each October 31 thereafter, the Office must analyze the information provided to it by statutory entities as of the end of the prior fiscal year and include in its annual report to the Legislature:

- an overall evaluation of the process relating to membership requirements for statutory entities;
- recommendations for improving the membership process;
- recommendations to further decrease barriers to participation; and

- recommendations to increase the diversity of statutory entity applicants.

By July 1, 2024, the Office must consult state boards and commissions that support the participation of underrepresented populations in policymaking processes, and may consult with other relevant state agencies or offices to identify and report to the Legislature on:

- barriers to access and meaningful participation in stakeholder engagement by people from underrepresented populations who have direct lived experience;
- tools to support access and meaningful participation in stakeholder engagement;
- modifications to the stakeholder engagement processes that would promote an increase in access and opportunities for participation in policymaking processes; and
- any recommended changes to rules or the law that would promote increased access and participation to the policymaking process.

Appropriation: None.

Fiscal Note: Available.

Effective Date: The bill contains multiple effective dates. Please see the bill.

Staff Summary of Public Testimony (State Government & Tribal Relations):

(In support) The conversation around this policy began three years ago and was led with self-advocates from the disability rights community who were left out of the decision-making process about a policy that directly impacted them. As the conversation continued, advocates realized that while this movement started as a disability rights issue, meaningful engagement is important to all populations with direct lived experience in all walks of life.

Although entities may have the best intentions when it comes to finding solutions to problems, meaningful engagement doesn't always happen. At times participation is merely a box that is checked and resources necessary for proper access are not provided. Other times, people are left out of the conversation entirely. However, when those with direct lived experience are given proper access to participate in policy making decisions and the change to be involved in formalizing the recommendations of an entity rather than being limited to merely providing feedback, assumptions are challenged, myths are dispelled, others are better informed and more educated about the issue, and most of all, better and cheaper long-lasting solutions are found. Technical experience and knowledge learned from holding a higher education degree does not replace the experience, wisdom, and lessons learned of those who have direct experience with a particular issue. Marginalized communities are experts in their own lives and know what they need to thrive, whether that is in the areas of education, homelessness and housing, mental health, food security, transportation access, criminal justice, child support, government assistance programs, or other areas.

When people with direct lived experience are not involved in decisions that directly impact

their lives, it leads to policies or practices that do not actually do anything to solve the root cause of the problem and in some cases, it could lead to discriminatory policies or practices, making the situation worse. Involving people with direct lived experience in decisions that impact their lives is the only way policy makers will know whether their solutions work.

The requirements in this act are a cultural shift, and things are not perfect the first time around when there is such a big cultural shift, but this is a good place to start. This act is not meant to restrict the participation of members, but to increase participation from people who are the most marginalized in our communities. The government has a valuable resource at their fingertips—constituents with direct lived experience in the issues it is trying to solve. If the government took this human-centered approach and involved these constituents more in decision making, it would lead to a government that is more representative, accountable, and responsive to the citizens it serves. Democracy demands that those who are most impacted have a seat at the table. When people are engaged, they can achieve more success.

(Opposed) None.

(Other) Not all people with direct lived experiences can participate in the same way. A person with intellectual and developmental disabilities may not be able to adequately convey their experience. In this circumstance, caregivers often know the direct lived experiences of those they care for the best because they go through the barriers and obstacles with them, oftentimes giving caregivers direct lived experience in a particular issue. Legal representatives who support those with complex needs need a seat at the table.

Staff Summary of Public Testimony (Appropriations):

(In support) The bill is a culmination of three years of hard work. The goal of the bill is to include individuals who are directly impacted the most by government policies in the decision-making process, because people with direct lived experience can provide firsthand knowledge of what works and what does not work. The bill aligns with the Governor's commitment to ensure that those who have been historically and systematically excluded from policies that impact them the most are included. This act provides an avenue for holding agencies accountable for ensuring that inclusion and equity are woven into their work. The Office of Equity would be providing tools and resources to help state government to do this work well. Each Washington resident should have full access to opportunities and resources they need to live the best life possible. The original cost of the bill was \$3.5 million, and it has since been reduced to under \$1 million.

(Opposed) The bill is in violation of Article 1, section 12 of the state Constitution which prohibits special privileges and immunities. The act creates a special door that only certain people can use to gain access to decision-making bodies that consider important matters. This fosters more division in communities instead of building a better foundation for all Washingtonians.

Persons Testifying (State Government & Tribal Relations): (In support) Representative Darya Farivar, prime sponsor; Jessica Renner, Self Advocates in Leadership; Samantha Fogg, Seattle Council Parent Teacher Student Associations; Ivanova Smith, People First of Washington; Kyle Matheson; Shawn Latham, Allies in Advocacy; Eric Matthes, The Arc of King County; Jordan Landry; Amy Roark; Carol Sullivan, League of Women Voters of Washington; Kristin DiBiase, Governor's Committee on Disability Issues and Employment; Craig Sicilia and Mike Raymond, NorthStar Project; Michele Kauffman; Sunshine Cheng, Disability Rights Washington; William Kinyon; Duaa-Rahemaah Willams, Resident Action Project and the Washington Low Income Housing Alliance; Gabby Fitz, Communities for Our Colleges; Tracy Turner; and Robert M. Wardell.

(Other) Lloyd Baker, Action DD.

Persons Testifying (Appropriations): (In support) Representative Darya Farivar, prime sponsor; Carol Sullivan, League of Women Voters of Washington; Karen Johnson, Washington State Office of Equity; Kristin DiBiase, Governor's Committee on Disability Issues and Employment; and Terique Scott, League of Education Voters.

(Opposed) Eric Pratt.

Persons Signed In To Testify But Not Testifying (State Government & Tribal Relations): None.

Persons Signed In To Testify But Not Testifying (Appropriations): None.