

SHB 1622 - S COMM AMD

By Committee on Health & Long-Term Care

1 Strike everything after the enacting clause and insert the
2 following:

3 "Sec. 1. RCW 42.48.010 and 1989 1st ex.s. c 9 s 207 are each
4 amended to read as follows:

5 For the purposes of this chapter, the following definitions apply:

6 (1) "Individually identifiable" means that a record contains
7 information which reveals or can likely be associated with the identity
8 of the person or persons to whom the record pertains.

9 (2) "Legally authorized representative" means a person legally
10 authorized to give consent for the disclosure of personal records on
11 behalf of a minor or a legally incompetent adult.

12 (3) "Personal record" means any information obtained or maintained
13 by a state agency which refers to a person and which is declared exempt
14 from public disclosure, confidential, or privileged under state or
15 federal law.

16 (4) "Research" means a planned and systematic sociological,
17 psychological, epidemiological, biomedical, or other scientific
18 investigation carried out by a state agency, by a scientific research
19 professional associated with a bona fide scientific research
20 organization, or by a graduate student currently enrolled in an
21 advanced academic degree curriculum, with an objective to contribute to
22 scientific knowledge, the solution of social and health problems, or
23 the evaluation of public benefit and service programs. This definition
24 excludes methods of record analysis and data collection that are
25 subjective, do not permit replication, and are not designed to yield
26 reliable and valid results.

27 (5) "Research in the jurisdiction of a state agency" means: (a)
28 Research conducted by an employee or a contractor of a state agency;
29 (b) research sponsored by a state agency; or (c) research that involves

1 access to or disclosure of identifiable personal records obtained or
2 maintained by a state agency.

3 (6) "Research record" means an item or grouping of information
4 obtained for the purpose of research from or about a person or
5 extracted for the purpose of research from a personal record.

6 ~~((+6+))~~ (7) "State agency" means: (a) The department of social and
7 health services; (b) the department of corrections; (c) an institution
8 of higher education as defined in RCW 28B.10.016; ~~((or))~~ (d) the
9 department of health; or (e) the department of labor and industries.

10 **Sec. 2.** RCW 42.48.020 and 1985 c 334 s 2 are each amended to read
11 as follows:

12 (1) A state agency may authorize or provide access to or provide
13 copies of an individually identifiable personal record for research
14 purposes if informed written consent for the disclosure has been given
15 to the appropriate department secretary, or the president of the
16 institution, as applicable, or his or her designee, by the person to
17 whom the record pertains or, in the case of minors and legally
18 incompetent adults, the person's legally authorized representative.

19 (2) A state agency may authorize or provide access to or provide
20 copies of an individually identifiable personal record for research
21 purposes without the informed consent of the person to whom the record
22 pertains or the person's legally authorized representative, only if:

23 (a) The state agency adopts research review and approval rules
24 including, but not limited to, the requirement that the appropriate
25 department secretary, or the president of the institution, as
26 applicable, ~~((appoint a standing human research))~~ designate a
27 registered institutional review board competent to review research
28 proposals as to ethical and scientific soundness; and the review board
29 determines that the disclosure request has scientific merit and is of
30 importance in terms of the agency's program concerns, that the research
31 purposes cannot be reasonably accomplished without disclosure of the
32 information in individually identifiable form and without waiver of the
33 informed consent of the person to whom the record pertains or the
34 person's legally authorized representative, that disclosure risks have
35 been minimized, and that remaining risks are outweighed by anticipated
36 health, safety, or scientific benefits; and

1 (b) The disclosure does not violate federal law or regulations; and

2 (c) The state agency negotiates with the research professional
3 receiving the records or record information a written and legally
4 binding confidentiality agreement prior to disclosure. The agreement
5 shall:

6 (i) Establish specific safeguards to assure the continued
7 confidentiality and security of individually identifiable records or
8 record information;

9 (ii) Ensure that the research professional will report or publish
10 research findings and conclusions in a manner that does not permit
11 identification of the person whose record was used for the research.
12 Final research reports or publications shall not include photographs or
13 other visual representations contained in personal records;

14 (iii) Establish that the research professional will destroy the
15 individual identifiers associated with the records or record
16 information as soon as the purposes of the research project have been
17 accomplished and notify the agency to this effect in writing;

18 (iv) Prohibit any subsequent disclosure of the records or record
19 information in individually identifiable form except as provided in RCW
20 42.48.040; and

21 (v) Provide for the signature of the research professional, of any
22 of the research professional's team members who require access to the
23 information in identified form, and of the agency official authorized
24 to approve disclosure of identifiable records or record information for
25 research purposes.

26 **Sec. 3.** RCW 42.48.040 and 1985 c 334 s 4 are each amended to read
27 as follows:

28 No research professional who conducts research in the jurisdiction
29 of a state agency and who has established an individually identifiable
30 research record from personal record information pursuant to RCW
31 42.48.020(2), or who has established a research record from data or
32 information voluntarily provided by (~~(an agency client or employee)~~) a
33 research subject under ((a)) an oral or written confidentiality
34 assurance for the explicit purpose of research, may disclose such a
35 record in individually identifiable form unless:

1 (1) The person to whom the research record pertains or the person's
2 legally authorized representative has given prior informed written
3 consent for the disclosure; or
4 (2) The research professional reasonably believes that disclosure
5 will prevent or minimize injury to a person and the disclosure is
6 limited to information necessary to protect the person who has been or
7 may be injured, and the research professional reports the disclosure
8 only to the person involved or the person's guardian, the person's
9 physician, and the agency; or
10 (3)(a) The research record is disclosed in individually
11 identifiable form for the purposes of auditing or evaluating a research
12 program; and
13 (b) The audit or evaluation is authorized or required by federal or
14 state law or regulation or is based upon an explicit provision in a
15 research contract, grant, or other written research agreement; and
16 (c) No subsequent disclosure of the research record in individually
17 identifiable form will be made by the auditor or evaluator except as
18 provided in this section; or
19 (4) The research record is furnished in compliance with a search
20 warrant or court order: PROVIDED, That:
21 (a) The court issues the search warrant or judicial subpoena
22 concerning the research record solely for the purpose of facilitating
23 inquiry into an alleged violation of law by the research professional
24 using the record for a research purpose or by the agency; and
25 (b) Any research record obtained pursuant to (a) of this subsection
26 and any information directly or indirectly derived from the research
27 record shall remain confidential to the extent possible and shall not
28 be used as evidence in an administrative, judicial, or legislative
29 proceeding except against the research professional using the record
30 for a research purpose or against the state agency."

SHB 1622 - S COMM AMD
By Committee on Health & Long-Term Care

1 On page 1, line 1 of the title, after "agency;" strike the
2 remainder of the title and insert "and amending RCW 42.48.010,
3 42.48.020, and 42.48.040."

--- END ---