

House Bill 996

By: Representatives Dempsey of the 13<sup>th</sup>, Powell of the 171<sup>st</sup>, Houston of the 170<sup>th</sup>, Nimmer of the 178<sup>th</sup>, Welch of the 110<sup>th</sup>, and others

A BILL TO BE ENTITLED  
AN ACT

1 To amend Chapter 25 of Title 50 of the Official Code of Georgia Annotated, relating to the  
2 Georgia Technology Authority, so as to establish the Strategic Integrated Data System; to  
3 create a governing board and provide for its membership and terms; to provide for oversight  
4 of the project; to provide for board responsibilities; to provide for reporting; to provide for  
5 funding; to provide for data sharing; to provide for immunity; to provide for open records  
6 and meetings; to provide for related matters; to repeal conflicting laws; and for other  
7 purposes.

8 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

9 **SECTION 1.**

10 Chapter 25 of Title 50 of the Official Code of Georgia Annotated, relating to the Georgia  
11 Technology Authority, is amended by designating the existing provisions of Chapter 25 as  
12 Article 1.

13 **SECTION 2.**

14 Said chapter is further amended by adding a new article to read as follows:

15 "ARTICLE 2

16 50-25-30.

17 As used in this article, the term:

18 (1) 'Aggregated data' means information that has been combined into groups showing  
19 averages or other summary statistics and that is not individually identifiable information.

20 (2) 'De-identified data' means information that does not identify an individual, and for  
21 which there is no reasonable basis to believe that the information can be used to identify  
22 an individual, and that meets the requirements for de-identification of protected health  
23 information as defined under HIPAA.

24 (3) 'Governing board' or 'board' means the board established pursuant to Code Section  
 25 50-25-31 charged with responsibility for governing the Strategic Integrated Data System  
 26 established pursuant to this article.

27 (4) 'Health data' means information that is created or received by a governmental agency  
 28 or department that relates to the past, present, or future physical or mental health or  
 29 condition of an individual or the past, present, or future payment for the provision of  
 30 health care services to an individual.

31 (5) 'HIPAA' means the federal Health Insurance Portability and Accountability Act of  
 32 1996, P.L. 104-191, and any regulations promulgated thereunder by the Secretary of the  
 33 United States Department of Health and Human Services.

34 (6) 'Individually identifiable information' means information that identifies an individual,  
 35 or for which there is a reasonable basis to believe that the information can be used to  
 36 identify an individual.

37 (7) 'IRB' means an institutional review board designated by the governing board and  
 38 established pursuant to federal regulations (45 C.F.R. Section 46) with a federal-wide  
 39 assurance for the protection of human subjects approved by the United States Department  
 40 of Health and Human Services, Office for Human Research Protections, to review and  
 41 monitor research involving human subjects to ensure that such subjects are protected  
 42 from harm and that the rights of such subjects are adequately protected.

43 (8) 'Protected health information' has the same meaning as defined under HIPAA.

44 (9) 'Research' means a systematic investigation, including research development, testing,  
 45 and evaluation, which is designed to develop or contribute to generalizable knowledge  
 46 as defined pursuant to 45 C.F.R. Section 46.102(d).

47 (10) 'Researcher' means a public or private entity that conducts research under the review  
 48 and monitoring of an IRB and has received approval from the data steward for the  
 49 purpose of requested data elements.

50 (11) 'SIDS Project' means the Strategic Integrated Data System established pursuant to  
 51 this article.

52 50-25-31.

53 (a) The Strategic Integrated Data System governing board is established in the Georgia  
 54 Technology Authority.

55 (b)(1) The governing board shall consist of nine members, as follows:

56 (A) One member shall be the director of the SIDS Project, who shall serve as a  
 57 nonvoting, ex officio member;

58 (B) One member of the Senate appointed by the President of the Senate;

59 (C) One member of the House of Representatives appointed by the Speaker of the  
60 House of Representatives; and

61 (D) Two members shall be public members appointed by the Governor, as follows:  
62 (i) An individual with legal expertise in protecting the privacy and security of  
63 individually identifiable information; and  
64 (ii) An individual with technical expertise in the creation and maintenance of large  
65 data systems and data security.

66 (2) The four remaining members shall be voting, ex officio members consisting of the  
67 commissioner of public health or his or her designee, who shall serve as chairperson of  
68 the board; the commissioner of community health or his or her designee; the executive  
69 director of the Georgia Technology Authority or his or her designee; and the state auditor  
70 or his or her designee.

71 (c) Of the public members first appointed to the governing board, one shall be appointed  
72 to a term of three years and one shall be appointed to a term of two years. Following the  
73 expiration of the initial terms, public members of the board shall be appointed for terms of  
74 three years. The voting, ex officio members of the board shall serve during their respective  
75 terms of office. Any vacancy occurring in the membership of the board shall be filled in  
76 the same manner as the original appointment but for the unexpired term only. The board  
77 shall meet at least quarterly and at such other times as it determines, in its judgment, to be  
78 necessary. The appointed members of the board shall serve without compensation but may  
79 be reimbursed for necessary expenses incurred in the performance of their duties. In  
80 addition, the board shall be entitled to and avail itself of the assistance and services of the  
81 staff of the Georgia Technology Authority and of the employees of any other state  
82 department, board, bureau, commission, or agency, as it may require and as may be  
83 available for its purposes.

84 (d) A member of the governing board shall not, by reason of the member's performance  
85 of any duty, function, or activity required of, or authorized to be undertaken by, the board,  
86 be liable in an action for damages to any person for any action taken or recommendation  
87 made by the member within the scope of the member's duty, function, or activity as a  
88 member of the board, if the action or recommendation was taken or made without malice.  
89 The members of the board shall be indemnified and their defense of any action provided  
90 for in the same manner and to the same extent as employees of this state on the basis of acts  
91 or omissions in the scope of their service.

92 (e) A member of the governing board shall not participate in deliberations or vote on any  
93 matter before the board concerning an individual with whom or entity with which the  
94 member has, or within the previous 12 months has had, any substantial ownership,  
95 employment, medical staff, fiduciary, contractual, creditor, or consultative relationship.

96 A member who has or who has had such a relationship with an individual or entity  
 97 involved in any matter before the board shall make a written disclosure before any action  
 98 is taken by the board with respect to the matter and shall make the relationship public at  
 99 any meeting in which action on the matter is to be taken.

100 (f) The governing board shall be a public body for the purposes of Chapter 14 of Title 50,  
 101 relating to open and public meetings, and shall conduct its business in accordance with the  
 102 provisions of said chapter. All proceedings of the governing board shall be subject to  
 103 Article 4 of Chapter 18 of Title 50, relating to inspection of public records.

104 50-25-32.

105 (a) No later than January 1, 2019, the Georgia Technology Authority shall establish an  
 106 operational Strategic Integrated Data System capable of securely receiving, maintaining,  
 107 and transmitting data in accordance with this article and with the HIPAA privacy and  
 108 security standards applicable to this article. The Georgia Technology Authority shall  
 109 employ a director of the SIDS project and may employ staff to assist with carrying out the  
 110 functions associated with the establishment and maintenance of the SIDS Project.

111 (b) The Georgia Technology Authority shall ensure the procurement of hardware,  
 112 software, and a data base system capable of performing analytics to the extent required to  
 113 carry out the purpose of the SIDS Project pursuant to this article. Further, the Georgia  
 114 Technology Authority shall procure sufficient management services to develop and  
 115 maintain the system.

116 (c) Notwithstanding any provision of this article to the contrary, the SIDS Project shall  
 117 seek to receive, maintain, and transmit de-identified data wherever possible and shall only  
 118 receive, maintain, and transmit individually identifiable information if permitted by this  
 119 Code section and other applicable law and if the information is in a form and format that  
 120 is secured to prevent disclosure of individually identifiable information.

121 50-25-33.

122 Oversight of the operation of the SIDS Project established pursuant to this article shall be  
 123 vested in the governing board. The SIDS Project shall receive, maintain, and transmit data  
 124 only as permitted by this article and as approved by the governing board and the agency  
 125 or department whose data are requested. The governing board's responsibilities shall  
 126 include:

127 (1) Identification of data that have been created, received, or maintained by agencies that  
 128 may be appropriate for receipt, maintenance, and transmission by the SIDS Project in  
 129 furtherance of the purposes of this article;

- 130 (2) Prior to the receipt of data by the SIDS Project, review and approval of the  
131 appropriateness of such receipt, including consideration of the following factors:
- 132 (A) Whether the transmitting agency or department has authority to collect the data  
133 proposed to be received by the SIDS Project, particularly if the data include  
134 individually identifiable information;
- 135 (B) Whether collection of the data proposed to be received by the SIDS Project is  
136 expected to further the purposes of this article, namely, the improvement of public  
137 health and the safety, security, and well-being of Georgia residents; and
- 138 (C) Whether reasonable efforts have been made to ensure that the SIDS Project will  
139 receive only the appropriate data needed to accomplish the purposes of this article;
- 140 (3) Prior to the receipt or transmission of data by the SIDS Project, review and approval  
141 of any necessary data use agreements or business associate agreements with any person  
142 or entity from which or to which information is received or transmitted in compliance  
143 with all applicable privacy and security standards, including, but not limited to, HIPAA,  
144 when such data include individually identifiable information that is protected health  
145 information;
- 146 (4) Adopting and publishing policies and procedures for the efficient and transparent  
147 operation of the SIDS Project, including, but not limited to, the following:
- 148 (A) Privacy and data security policies and procedures that comply with the applicable  
149 federal and state privacy and security statutes and regulations, including HIPAA;
- 150 (B) Data access policies and procedures that allow access by a public or private entity,  
151 including a researcher, only when such access request meets the standards set forth in  
152 the data access policies and procedures and has been approved by the governing board  
153 and the appropriate agency or department. When data access is requested by any public  
154 or private entity, including a researcher, for the purpose of conducting research, the  
155 governing board shall only approve access to data after review and approval by an IRB,  
156 and such access shall be limited to data identified in approved IRB research protocols  
157 and only for the period of the approval. In no event shall the governing board approve  
158 access to health data that identifies, or that may be used to identify, rates of payment  
159 by a private entity for the provision of health care services to an individual unless the  
160 entity seeking access agrees to keep such information confidential and to prevent public  
161 disclosure of such data or the rates of payment derived from such data;
- 162 (C) Data retention policies requiring that data shall be returned to transmitting agencies  
163 or departments or destroyed when it is no longer in the state's interest to promote  
164 analysis of such data and in accordance with applicable HIPAA regulations, data use  
165 agreements, and provisions of IRB approvals;

- 166 (D) Policies to require researchers to consult with subject matter experts in the data sets  
 167 being linked on a specific project. The purpose of such consultation shall be to help  
 168 researchers understand and interpret the data being linked to a specific project; and  
 169 (E) Policies that establish processes to engage researchers and academic institutions  
 170 across Georgia to help set research priorities and promote the use of the SIDS Project  
 171 to accelerate population health research in this state;
- 172 (5) Communicating to all state agencies and departments that each state agency or  
 173 department shall, upon request of the board, make available to the board through the  
 174 SIDS Project all data housed within their respective offices pursuant to policies  
 175 established pursuant to this Code section;
- 176 (6)(A) Establishing the process by which each state agency or department is required,  
 177 in consultation with the board, to identify and submit to the board a minimum of two  
 178 distinct policy concerns that may be studied in an integrated information environment  
 179 in order to identify evidence based solutions to such policy concerns; and
- 180 (B) Establishing procedures for ranking the submission and selection of those policy  
 181 concerns considered by the board to be of greatest concern to the health, safety,  
 182 security, and well-being of Georgia's citizens; and
- 183 (7) Establishing the process to set research priorities that utilize the SIDS Project to  
 184 provide effective and efficient policy management for the state.

185 50-25-34.

186 No later than July 1, 2019, upon the receipt of data by the SIDS Project pursuant to this  
 187 article, and on an annual basis thereafter, the Georgia Technology Authority, in  
 188 consultation with the board, shall publish a report that is made available and accessible to  
 189 the General Assembly consisting of:

- 190 (1) A description of the implementation of the SIDS Project, including identification of  
 191 the sources and types of data received and maintained by the SIDS Project over the  
 192 prior 12 months;
- 193 (2) A list of all aggregated data maintained by the SIDS Project;
- 194 (3) A description of each IRB approved disclosure of data or data sets by the SIDS  
 195 Project;
- 196 (4) A list of publications and other reports based on SIDS Project data;
- 197 (5) A strategic plan for achieving the purposes of this article during the successive 12  
 198 month period; and
- 199 (6) Any other information deemed appropriate by the governing board.

200 50-25-35.

201 (a) The governing board and the Georgia Technology Authority may apply for and receive  
202 funding in relation to the SIDS Project from the following sources:

203 (1) Grants from research or other private entities;

204 (2) Fees paid by persons or entities requesting access to SIDS Project data or the  
205 performance of analyses by the SIDS Project, which fees have been approved by the  
206 governing board to support the cost of preparing data for access or performing analyses;

207 (3) Federal grants; and

208 (4) Grants or other financial assistance from state or local departments, agencies,  
209 authorities, and organizations at the discretion of these entities, for specific projects of  
210 interest to these entities.

211 (b) Any and all appropriations made to the SIDS Project pursuant to the General  
212 Appropriations Act or a supplementary appropriations Act shall be directed through the  
213 Georgia Technology Authority. The governing board shall submit its budget to and  
214 through the Georgia Technology Authority.

215 50-25-36.

216 Any agency or department that creates, receives, or maintains publicly supported programs  
217 data or health data shall, only after execution of an enforceable data use, data sharing, or  
218 other similar agreement that is acceptable to the agency or department, transmit or allow  
219 access to such data as is necessary and appropriate to further the purposes of this article and  
220 shall cooperate with SIDS Project requests for receipt of or access to such data.  
221 Notwithstanding the foregoing, no agency or department shall be required to transmit data  
222 it creates, receives, or maintains to the SIDS Project, or to allow access to such data, if the  
223 Attorney General's review or the applicable agency's or department's review determines  
224 that such transmission or access would violate state or federal law. The Attorney General's  
225 review shall include consideration of an analysis from the agency or department whose data  
226 are being requested. This Code section shall not prohibit the Georgia Technology  
227 Authority or any agency or department from creating, receiving, maintaining, or  
228 transmitting data in data systems that are separate and distinct from the SIDS Project."

229 **SECTION 3.**

230 All laws and parts of laws in conflict with this Act are repealed.