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Department of Public Health HB 966

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HEALTH

Department of Public Health: Amend Chapter 2A of Title 31 of the Official Code of Georgia Annotated, Relating to the Department of Public Health, so as to Establish Within the Department of Public Health the Alzheimer's Disease Registry; Provide for the Purpose of the Registry; Provide for Promulgation and Criteria of Rules; Provide for Confidentiality of Data; Provide for Compliance with P.L. 104-191, the Federal Health Insurance Portability and Accountability Act of 1996; Provide for Related Matters; Repeal Conflicting Laws; and for Other Purposes

CODE SECTIONS:	O.C.G.A. § 31-2A-17 (new)
BILL NUMBER:	HB 966
ACT NUMBER:	646
GEORGIA LAWS:	2014 Ga. Laws 822
SUMMARY:	The Act establishes an Alzheimer's Disease Registry within Georgia's Department of Public Health and grants the Department of Public Health authority to create procedures, rules, and regulations to establish and operate the Alzheimer's Disease Registry. The Act also ensures that any collected data contained in the Alzheimer's Disease Registry will be confidential and that the Alzheimer's Registry will comply with the federal Health Insurance Portability and Accountability Act.
EFFECTIVE DATE:	July 1, 2014

History

Georgia is an aging state. This is partly because Georgia's warm weather draws the elderly from colder climates, but it is also because more people are living well into their eighties and nineties.¹ Due to

1. See Telephone Interview with Rep. Sharon Cooper (R-43rd) (Apr. 21, 2014) [hereinafter Cooper

the high prevalence of Alzheimer's disease (Alzheimer's) among the elderly,² Georgia will likely see more of its population become afflicted with Alzheimer's as well.³ Some lawmakers believe that as the prevalence of Alzheimer's increases, so will the financial burden on the state.⁴ Individuals with Alzheimer's will likely exhaust the entirety of their resources combatting the disease; and Georgia is therefore likely see an increase in individuals depending on state-funded programs for their health care.⁵ Despite the imminent increase in Alzheimer's prevalence within the state, Georgia does not currently have a statewide Alzheimer's plan.⁶ House Bill (HB) 966 sought to address this issue.⁷

The bill's supporters focused on the increased prevalence of Alzheimer's in Georgia and the absence of a statewide Alzheimer's plan, whereas its opponents were concerned with breaches of confidentiality that could affect a person's right to obtain state licenses.⁸ Furthermore, there were concerns regarding the deference given to the Department of Public Health (DPH).⁹

Interview]; U.S. ADMIN. ON AGING, POLICY ACADEMY STATE PROFILE: GEORGIA 1(Dec. 2012), available at http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Behavioral/docs2/Georgia%20Epi%20Profile%20Final.pdf.

2. ALZHEIMER'S ASS'N, *2014 Alzheimer's Disease Facts and Figures*, 10 ALZHEIMER'S & DEMENTIA 2, at 9, http://www.alz.org/downloads/facts_figures_2014.pdf.

3. See Cooper Interview, *supra* note 1.

4. See Video Recording of House Human Relations and Aging Committee Meeting, Feb. 17, 2014 at 6 min., 30 sec. (remarks by Sen. Renee Unterman (R-45th)) [hereinafter House Committee Video Feb. 17], http://media.legis.ga.gov/hav/13_14/2014/committees/human/human021714EDITED.wmv. One factor increasing healthcare costs is many individuals with Alzheimer's disease live in nursing homes, which cost more than \$40,000 a year. *Id.*; METLIFE MATURE MKT. INST, MARKET SURVEY OF LONG-TERM CARE COSTS 21(2012), available at <https://www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf> (stating that in 2012 the lowest cost of a semi-private room in a Georgia nursing home is \$130 per day, which comes out to be \$47,450 per year, and the average cost is \$181 per day, making the average cost per year \$66,065).

5. METLIFE MATURE MKT, *supra* note 4.

6. House Committee Video Feb. 17, *supra* note 4, at 16 min., 25 sec. (remarks by Sen. Renee Unterman (R-45th)).

7. 2014 Ga. Laws 822.

8. House Committee Video Feb. 17, *supra* note 4, at 9 min., 42 sec. (remarks by Sen. Renee Unterman (R-45th)).

9. O.C.G.A. § 31-2A-17 (Supp. 2014) ("[DPH] shall establish procedures and promulgate rules and regulations for the establishment and operation of the registry."); See also, Telephone Interview with Sen. Mike Crane (R-28th) (May 12, 2014) [hereinafter Crane Interview] (expressing concern that the information stored in the Alzheimer's Registry could be used for purposes not originally intended, such as denying a gun license).

Bill Tracking

Because much of the text of HB 966, as passed, originated from Senate Bill (SB) 292, tracking the process of SB 292 is necessary to follow the path HB 966 took to become law.¹⁰

Consideration and Passage of SB 292 by the Senate

Senators Renee Unterman (R-45th), John Wilkinson (R-50th), Judson Hill (R-32nd), Mike Dugan (R-30th), Jack Hill (R-4th), and Jack Murphy (R-27th) sponsored SB 292.¹¹ The Senate read the bill for the first time on January 16, 2014.¹² Lieutenant Governor Casey Cagle (R) then referred the bill to the Senate Committee on Health and Human Services, which favorably reported the bill.¹³ The Senate read the bill for a second time on January 27, 2014.¹⁴ Finally, on February 3, 2014, the Senate read the bill for the third time and passed the bill by a vote of 45 to 6.¹⁵

Consideration and Passage of SB 292 by the House

Representative Tommy Benton (R-31st) sponsored the bill in the House.¹⁶ The House read the bill for the first time on February 4, 2014, and for the second time on February 5, 2014.¹⁷ On February 18, 2014, the House Committee on Human Relations and Aging reported favorably on the bill.¹⁸ On March 13, 2014, the House read the bill for the third time.¹⁹ The House then amended the bill by adding language from what later became the Georgia Health Care

10. See Aaron Gould Sheinin & Kristina Torres, *What Bills Made the Cut in Georgia's 2014 Legislative Session*, ATLANTA J.-CONST. (March 22, 2014), <http://www.ajc.com/news/news/state-regional-govt-politics/what-bills-made-the-cut-in-georgias-2014-legislative-session/nfJKj/>.

11. See Georgia General Assembly, SB 292, Bill Tracking, <http://www.legis.ga.gov/legislation/en-US/Display/20132014/SB/292>.

12. State of Georgia Final Composite Sheet, SB 292, May 1, 2014.

13. *Id.*

14. *Id.*

15. *Id.*; Georgia Senate Voting Record, SB 292 (Feb. 3, 2014).

16. Georgia General Assembly, HB 966, Bill Tracking, <http://www.legis.ga.gov/legislation/en-US/Display/20132014/SB/292>.

17. State of Georgia Final Composite Sheet, SB 292, May 1, 2014.

18. *Id.*

19. *Id.*

Freedom Act²⁰ to the bill,²¹ and passed the amended version on March 13, 2014 by 113 to 59.²² This amendment sought to ensure that the “the federal government . . . implement . . . and enforce [the Affordable Care Act]” so that Georgia does not have to expend its own resources in doing so.²³ The Senate never passed this version of the bill, but amended HB 966 to include the Alzheimer’s Disease Registry (the Registry) text of SB 292.²⁴

Consideration and Passage of HB 966 in the House

The original version of HB 966 was sponsored in the House by Representatives Sharon Cooper (R-43rd), Mary Margaret Oliver (D-82nd), Dale Rutledge (R-109th), Ben Watson (R-166th), Tom Weldon (R-3rd), and Margaret Kaiser (D-59th).²⁵ The House read the bill for the first time on February 10, 2014 and for the second time on February 11, 2014.²⁶ On February 21, 2014, the House Committee on Health and Human Services favorably reported the bill by substitute.²⁷ On February 25, 2014, the House read the bill for the third time and passed the substitute version 163 votes to 0.²⁸

20. O.C.G.A. § 31-1-40 (Supp. 2014).

21. *Anti-Obamacare Bill Close to Passage*, ATL. J. CONST. (Mar. 14, 2014), <http://www.myajc.com/news/news/state-regional-govt-politics/anti-obamacare-bill-close-to-passage/nfCbS/> (“[T]he House on Thursday attached language from [the Georgia Helath Care Freedom Act] to Senate Bill 292 . . . that would create a statewide Alzheimer’s registry.”).

22. State of Georgia Final Composite Sheet, SB 292, May 1, 2014; Georgia House of Representatives Voting Record, SB 292 (Mar. 13, 2014).

23. Video Recording of House Proceedings, Mar. 13, 2014 at 2 hr., 28 min., 20 sec. (remarks by Rep. Ed Lindsey (R-54th)), [hereinafter House Video, Mar. 13, 2014] <http://gpb.org/lawmakers/2014/day-38>.

24. See HB 966 (AM 37 0259), 2014 Ga. Gen. Assem.; Sheinin & Torres, *supra* note 10.

25. Georgia General Assembly, HB 966, Bill Tracking, <http://www.legis.ga.gov/legislation/en-us/display/20132014/hb/966>. The original version of HB 966 sought to ensure that emergency medical services personnel had access to the opioid antagonist Naloxone, which can be used to “counter the effects of opiate overdose.” HB 966, as introduced, 2014 Ga. Gen. Assem.

26. State of Georgia Final Composite Sheet, HB 966, May 1, 2014.

27. *Id.* The only difference between the two versions of the bill was a change in the date that the bill would become effective if passed. Compare HB 966, as introduced, 2014 Ga. Gen. Assem., with HB 966, (LC 33 5585S), 2014 Ga. Gen. Assem.

28. State of Georgia Final Composite Sheet, HB 966, May 1, 2014; Georgia House of Representatives Voting Record, HB 966 (Feb. 25, 2014).

Consideration and Passage of HB 966 in the Senate

Senator Renee Unterman sponsored HB 966 in the Senate.²⁹ Originally, HB 966 would have allowed licensed health practitioners to administer Naloxone, an opioid antagonist, to individuals who have overdosed on opiates.³⁰ On February 26, 2014, the Senate read the original version of HB 966 for the first time, and Lieutenant Governor Cagle referred the bill to the Senate Health and Human Services Committee.³¹ On March 13, 2014, the Committee favorably reported the bill by substitute, and the Senate read the bill for a second time.³² This substitute version HB 966 would have created the Georgia Adult and Aging Services Board, which would have replaced the Division of Aging Services.³³ However, on March 18, 2014, the Senate tabled that version of HB 966.³⁴ Finally, on March 20, 2014, the Senate substituted the Registry text from SB 292 into HB 966, read HB 966 for the third time, and passed the amended version of HB 966.³⁵ The House passed the Senate substitute to the bill on March 26, 2014 and sent the bill to the Governor.³⁶ On April 29, 2014, the Governor signed HB 966 into law.³⁷

The Act

The Act amends Chapter 2A of Title 31 of the Official Code of Georgia Annotated, relating to DPH and creates the Registry.³⁸ Section One establishes the Registry and states its purpose “to assist in the development of public policy and planning” regarding Alzheimer’s disease and related disorders, and to “provide a central

29. Georgia General Assembly, HB 966 Bill Tracking, <http://www.legis.ga.gov/legislation/en-us/display/20132014/hb/966>.

30. *Id.*

31. State of Georgia Final Composite Sheet, HB 966, May 1, 2014.

32. *Id.*

33. Georgia General Assembly, HB 966 Bill Tracking, <http://www.legis.ga.gov/legislation/en-us/display/20132014/hb/966>.

34. *Id.*; State of Georgia Final Composite Sheet, HB 966, May 1, 2014.

35. State of Georgia Final Composite Sheet, HB 966, May 1, 2014. The bill passed by a vote of 46 to 4. Georgia Senate Voting Record, HB 966 (Mar. 20, 2014).

36. State of Georgia Final Composite Sheet, HB 966, May 1, 2014.

37. *Id.*

38. O.C.G.A. § 31-2A-17 (Supp. 2014).

data base of individuals” with those disorders.³⁹ Section One also delegates authority to the DPH to “establish procedures and promulgate rules and regulations” to create and operate the registry.⁴⁰ These procedures, rules, and regulations provide for: (1) data collection and evaluation regarding the prevalence of Alzheimer’s and related disorders, “including who shall report the data to the registry;” (2) what information will be in the registry and the length of time the data shall be available; (3) “[s]haring of data for policy planning purposes;” (4) disclosure of non-identifying data to support Alzheimer’s and related disorder research; (5) the methods “by which families and physicians of persons who are reported to the registry shall be contacted to gather additional data;” and (6) “[i]nformation about public and private resources.”⁴¹

Moreover, Section One requires that all the collected data in the Registry remain confidential, and all persons receiving the data maintain patient confidentiality.⁴² It further prohibits any publication of the information, research, or medical data from the Registry “that identifies any patient by name.”⁴³ Finally, Section One provides that the Registry shall be established and regulated according to the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements.⁴⁴

Analysis

Research Benefits

The Registry helps several aspects of research for Alzheimer’s. First, the Registry will assist in Alzheimer’s prevalence in Georgia,

39. O.C.G.A. § 31-2A-17(b) (Supp. 2014).

40. O.C.G.A. § 31-2A-17(c) (Supp. 2014).

41. *Id.*

42. O.C.G.A. § 31-2A-17(d) (Supp. 2014).

43. *Id.*

44. *Id.* HIPAA generally applies to covered entities, such as health care providers and health plans, and ensures that these covered entities keep protected health care information private and secure. U.S. DEP’T OF HEALTH AND HUMAN SERVICES, HEALTH INFORMATION PRIVACY, <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html> (last visited Sept. 11, 2014). For a more in-depth discussion of HIPAA, see Deborah F. Buckman, *Validity, Construction, and Application of Health Insurance Portability and Accountability Act of 1996 (HIPAA) and Regulations Promulgated Thereunder*, 194 A.L.R. Fed 133 (2004).

where it is most prevalent, and what kinds of services affected individuals need.⁴⁵ Additionally, the Registry will help determine how long affected individuals can be treated at home before requiring State resources for assistance.⁴⁶ Without the Registry, this information may not be available elsewhere for various reasons.⁴⁷ For example, because most Alzheimer's patients die from other causes, data from death certificates often do not include a person's Alzheimer's status.⁴⁸

The Registry could help prevent this problem by requiring doctors to provide more information on death certificates, working with families to communicate that interest to their doctors, or asking doctors to report Alzheimer's cases they diagnose.⁴⁹

Confidentiality Concerns

Much uncertainty remains about the Registry's methodology and effectiveness. The Act only created the Registry and delegated the regulation and rulemaking authority to DPH.⁵⁰ This broad rulemaking authority created concerns regarding confidentiality.⁵¹ For example, if DPH interprets the Act's confidentiality provisions too broadly, some fear that the Registry's resulting procedures could allow the information to spread in a way that affects individual rights.⁵² Would a person's placement on the Registry as having Alzheimer's or designation as "pre-Alzheimer's" preclude them from obtaining a gun or driver's license?⁵³ And what if the doctor's diagnosis of that person was incorrect? Such questions make the Act's opponents uneasy.⁵⁴

45. See Cooper Interview, *supra* note 1.

46. *Id.*

47. *Id.*

48. *Id.*

49. *Id.*

50. See generally, O.C.G.A. § 31-2A-17 (Supp. 2014).

51. See Cooper Interview, *supra* note 1 ("There were some questions on the floor about confidentiality."); see also Crane Interview, *supra* note 9 (noting skepticism regarding the bill's ability to ensure confidentiality from the Registry).

52. See Crane Interview, *supra* note 9 (expressing concern that a person who "shows early signs of Alzheimer's" in the Registry could lose the ability to obtain licenses such as a gun license).

53. *Id.*

54. *Id.*

The Alzheimer's Registry is not the first registry to operate in Georgia.⁵⁵ DPH currently requires reporting of all confirmed positive, non-anonymous, HIV tests, which is essentially the HIV equivalent of the Alzheimer's Registry.⁵⁶ However, DPH may disclose certain information pertaining to reported HIV cases to prevent further spread of HIV.⁵⁷ In fact, a bill passed during the 2014 legislative session allows DPH to disclose a person's HIV status to certain health care providers when the providers are consulted for medical treatment or advice.⁵⁸ The Alzheimer's Registry does not go so far; the information contained in the Registry is limited to research and resource allocation.⁵⁹ Furthermore, the Act's supporters stress the names of those on the Registry will be redacted.⁶⁰

Given these safeguards to breaches in confidentiality, the Act will likely only serve its purpose of disseminating non-identifiable health information for research purposes rather than result in the release of identifiable information that could affect the individual.

Keegan Gary & Edgar Neely

55. House Committee Video Feb. 17, *supra* note 4, at 11 min., 5 sec. (remarks by Rep. Terry Rogers (R-10th) and Sen. Renee Unterman (R-45th)) (referencing that Georgia currently has HIV and Tuberculosis registries); Cooper Interview, *supra* note 1.

56. *See generally*, O.C.G.A. § 24-12-21 (2013 & Supp. 2014); GA. COMP. R. & REGS. 511-2-5.10 (2013).

57. O.C.G.A. § 24-12-21(h)(3) (2013 & Supp. 2014).

58. O.C.G.A. § 24-12-21(h.1) (Supp. 2014).

59. House Committee Video Feb. 17, *supra* note 4, at 7 min., 45 sec. (remarks by Sen. Renee Unterman (R-45th)) (noting that Emory University, Georgia Regents University, and Mercer University are going to look for "pockets" of individuals with Alzheimer's Disease and try to determine why those "pockets" exist, and that these "pockets" will be useful in determining where to allocate community, and home-based care services).

60. *Id.* ("We're not interested in who they are, we are interested in their age because we'd like to know if they have early onset Alzheimer's and Dementia, but all their names are redacted.").