

**CENTER FOR HEALTH
INFORMATION AND ANALYSIS**

**MANDATED BENEFIT REVIEW OF HOUSE BILL 956:
AN ACT CONCERNING THE SAFETY OF
AUTISTIC AND ALZHEIMER INDIVIDUALS**

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BENEFIT MANDATE OVERVIEW: H.B. 956: AN ACT CONCERNING THE SAFETY OF AUTISTIC AND ALZHEIMER INDIVIDUALS

HISTORY OF THE BILL

The Joint Committee on Financial Services referred House Bill (H.B.) 956, “An Act concerning the safety of autistic and alzheimer individuals,” sponsored by Rep. Michlewitz of Boston (and submitted as H.B. 913 in the 189th General Court), to the Center for Health Information and Analysis (CHIA) for review.¹ Massachusetts General Laws, chapter 3, section 38C requires CHIA to review and evaluate the potential fiscal impact of each mandated benefit bill referred to the agency by a legislative committee.

WHAT DOES THE BILL PROPOSE?

H.B. 956 requires health insurance plans to provide coverage “for insured individuals who are diagnosed by a license [sic] physician with dementia, Alzheimer’s disease, or Autism spectrum Disorder, to obtain a Technology-Assisted Tracking Device if they or their guardian choose.” Many types of prevention and notification programs, public alerts, passive products, and active locator devices aim to reduce the risk and hazards of wandering; the bill as currently drafted limits required coverage to technology-assisted tracking devices meeting specific criteria, including that they function underwater, work indoors or under cover, do not depend on third-party public communication networks, are tamper-resistant but changeable by a caregiver, avoid false alarms, and are coded for specific users.

MEDICAL EFFICACY OF ACTIVE LOCATOR DEVICES

Individuals with dementia, Alzheimer’s disease, or an autism spectrum disorder (ASD) are at greater risk for wandering and its resulting hazards than individuals without those conditions. H.B. 956 requires insurers to cover radio-frequency active locator devices for such individuals which can shorten search and recovery time when a user wanders, thereby reducing the risk of harm. This review uncovered no research on the impact or medical efficacy of the use of such devices on the health outcomes of individuals with dementia, Alzheimer’s disease, or ASD. However, there is evidence these devices enable caregivers and law enforcement to find individuals who wander as a result of the disease more often and more quickly than without the devices.

This review found no formal or peer-reviewed studies on the efficacy or comparative effectiveness of passive or active locator devices. The bill’s specific requirements, as currently drafted, for devices that enable underwater and obstructed site location, as well as the involvement of law enforcement assistance in location efforts, may render these devices more effective than other anti-wandering tools. According to companies offering tracking devices that meet the bill’s criteria, since 2004, 175 individuals wearing these devices have been reported missing, and all have been found. However, each technology has specific advantages and limitations. Given these considerations, national advocacy groups, as well as a report by the U.S. Department of Justice, have not formally recommended any one locator technology over another.

¹ The 188th General Court of the Commonwealth of Massachusetts, House Bill 956, “An Act concerning the safety of autistic and alzheimer individuals.” Accessed 17 February 2015: <https://malegislature.gov/Bills/188/House/H956>. In the 189th General Court of the Commonwealth of Massachusetts, House Bill 913; accessed 16 March 2015: <https://malegislature.gov/Bills/189/House/H913>.

CURRENT COVERAGE

In a survey conducted for this review, of ten of the largest insurance carriers in Massachusetts, none report coverage for active locator devices. One large carrier indicated active locator devices were not specifically excluded from coverage, but analysis of Massachusetts claim data showed no evidence any carrier had covered any such claims through 2012.

COST OF IMPLEMENTING THE BILL

Requiring coverage for this benefit by fully-insured commercial health plans for members under age 65 would result in an average annual increase, over five years, to the typical member's monthly health insurance premiums of between \$0.003 (0.001%) and \$0.024 (0.005%). Requiring coverage for this benefit by fully-insured commercial Medicare supplement plans would result in an increase to the typical Medicare supplement member's monthly premiums of between \$0.16 and \$0.31.

The Massachusetts Division of Insurance and the Health Connector are responsible for determining any potential state liability associated with the proposed mandate under Section 1311 of the Affordable Care Act (ACA).

PLANS AFFECTED BY THE PROPOSED BENEFIT MANDATE

The bill as currently drafted amends the statutes that regulate the Commonwealth's medical assistance programs. However, this review addresses instead benefit plans most often covered in proposed mandates, including accident and sickness insurance policies, corporate group insurance policies, and HMO coverage issued pursuant to Massachusetts General Laws; plans, self- and fully-insured, provided by the Group Insurance Commission (GIC) for public employees and their dependents; and fully-insured Medicare supplement policies to the extent they are governed by state law. This review of the proposed mandate's impact is valid only if the Legislature amends the bill so that it applies to the commercial insurance statutes. The proposed benefit mandate is assumed to apply to members covered under the relevant plans, regardless of whether they reside within the Commonwealth.

PLANS NOT AFFECTED BY THE PROPOSED BENEFIT MANDATE

Self-insured plans (i.e., where the employer or policyholder retains the risk for medical expenses and uses a third party administrator or insurer only to provide administrative functions), except for those managed under the GIC, are not subject to state-level health insurance benefit mandates. State health benefit mandates do not apply to Medicare and Medicare Advantage plans, the benefits of which are qualified by Medicare. These mandates also do not apply to federally-funded plans including TRICARE (covering military personnel and dependents), the Veterans Administration, and the Federal Employee's Health Benefit Plan. Finally, the scope of this review does not include Medicaid/MassHealth.

MEDICAL EFFICACY ASSESSMENT: ACTIVE LOCATOR DEVICES FOR PEOPLE WITH DEMENTIA, ALZHEIMER'S DISEASE, OR AUTISM SPECTRUM DISORDER

Massachusetts House Bill (H.B.) 956 (submitted as H.B. 913 in the 189th General Court) requires health insurance plans to “provide full coverage... for insured individuals who are diagnosed by a license [sic] physician with dementia, Alzheimer’s disease, or Autism spectrum Disorder, to obtain a Technology-Assisted Tracking Device if they or their guardian choose.”¹ The mandate requires the devices to comply with specific requirements, including that they: are waterproof and function underwater; work indoors or under cover; do not depend on third-party public communication networks; are tamper-resistant but changeable by a direct caregiver; avoid false alarms; and are coded for specific users.²

M.G.L. c. 3 § 38C charges the Massachusetts Center for Health Information and Analysis (CHIA) with reviewing the medical efficacy of proposed mandated health insurance benefits. Medical efficacy reviews summarize current literature on the effectiveness and use of the mandated treatment or service, and describe the potential impact of a mandated benefit on the quality of patient care and the health status of the population.

DEMENTIA, ALZHEIMER'S DISEASE, AND AUTISM SPECTRUM DISORDERS

As defined by the National Institute on Aging of the U.S. National Institutes of Health, dementia is a general term for the loss of behavioral abilities and cognitive functioning, including reasoning and memory, “to such an extent that it interferes with a person’s daily life and activities.”³ Dementia can be caused by a variety of conditions, the two most common of which are Alzheimer’s disease and vascular dementia, which changes a person’s blood supply to the brain.⁴ It is estimated that almost 14 percent of people age 71 or older suffer from some form of dementia.⁵

Alzheimer’s disease is the most common form of dementia in older people, with symptoms most often first appearing after age 65.⁶ It is currently incurable, progressive, and irreversible, destroying the memory and thinking skills of patients, and eventually preventing them from carrying out activities of daily living.⁷ By current estimates, the disease affects 5.2 million Americans, including some 200,000 younger than age 65.^{8,9} One study estimated that approximately 120,000 Massachusetts residents over age 65 suffered from Alzheimer’s in 2014, a number that is expected to grow by 25 percent by 2025.¹⁰ Alzheimer’s disease was the sixth leading cause of death nationally and in Massachusetts in 2013.^{11,12} In 2010, approximately 1,773 patients in Massachusetts died due to Alzheimer’s disease.¹³

Autism spectrum disorders (ASD) describe “a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior.”¹⁴ The disorder varies significantly both in terms of individual severity and characteristics.¹⁵ The causes of ASD are currently unknown; according to the National Institute of Child Health and Human Development (NICHD), “[b]ecause the disorder is so complex and no two people with autism are exactly alike, there are probably many causes for autism.”¹⁶ A recent report from the U.S. Centers for Disease Control and Prevention (CDC), which focused specifically on children 8 years of age, estimated a prevalence rate that one in every 68 children has an ASD.¹⁷

WANDERING AND ITS DANGERS

Wandering is leaving a safe setting or responsible caregiver. It can be goal-directed (getting to or away from something), non-goal directed, or other (e.g. due to disorientation or confusion), and can include bolting or fleeing.¹⁸ It can be a side effect of medications.¹⁹ In most cases, wandering, referred to in some contexts as “elopement,” is defined for individuals ages four and over, beyond the toddler years when such behavior is considered normal.²⁰

According to the U.S. Centers for Disease Control and Prevention, wandering is a serious safety issue for people with developmental and cognitive disabilities.²¹ These individuals have special challenges with communication, social interaction, attention and learning, and may not understand safety issues, placing themselves at increased risk for becoming lost or injured.²² The dangers of wandering include exposure, hypothermia, dehydration, drowning, traffic injuries, falls, physical restraint, and encounters with strangers and/or law enforcement.²³

According to the Alzheimer’s and Dementia Caregiver Center of the national Alzheimer’s Association, “[w]andering and getting lost is common among people with dementia and can happen during any stage of the disease.”²⁴ Approximately 60 percent of dementia patients will wander, resulting from the memory problems and disorientation that are symptoms of the condition. A widely-cited 1995 study examined the outcomes of lost patients with dementia who were involved in search and rescue efforts in the state of Virginia.²⁵ This study found that 19 percent of these patients died from hypothermia, dehydration or drowning as a result of their wandering; for patients not located within 24 hours, the mortality rate was 46 percent.²⁶

In one of the largest surveys of families whose children have ASD, researchers found that 49 percent had attempted to elope (wander) at least once after age 4, a significantly higher rate than for siblings who did not have ASD, with about one-quarter of these children “missing long enough to cause concern.”²⁷ Of this group, 65 percent were in danger of traffic injury and 24 percent were in danger of drowning.²⁸ Further results from this survey found that of children who wander, 35 percent are never or rarely able to communicate their name, address, or phone number by any means.²⁹ Studies of the autism population found that the mortality rate for individuals with ASD is twice as high as that of the general population,³⁰ and that drowning is one of the leading causes of death for this population.³¹

This review briefly describes programs and products aimed at reducing the risks of wandering, and then turns to devices covered under the proposed mandate.

PASSIVE PRODUCTS, PREVENTION AND NOTIFICATION PROGRAMS, AND PUBLIC ALERTS

Numerous programs and products aim to prevent and/or respond to wandering, including close caregiver supervision, home security measures, and passive identification techniques, or non-electrical items used for identifying persons with dementia, Alzheimer’s disease, or ASD that can be worn or carried by the individual.³² Bracelets, identification cards, tagged clothing and jewelry, some of which are attached to USB (universal serial bus) drives, can display contact and other information.³³

For example, the Alzheimer’s Association has partnered with the Medic Alert company nationally to create the Safe Return program, a 24-hour nationwide emergency response system for those with dementia who wander or have a medical emergency.³⁴ The program is based on a community support network that includes local law enforcement officials, as well as an identification bracelet and phone number that can be used when the individual who wandered is found.³⁵

When an individual is discovered to be missing, law enforcement or public safety agencies are often the first to be notified.³⁶ Following established protocols, public alert systems are sometimes activated where available.³⁷ These programs can include digital road signs, social media alerts, and automated mass notification.³⁸ The Massachusetts state government manages a Silver Alert community response system in twelve municipalities across the state.³⁹ Based on a state law enacted in August 2010,^{40,41} the program “provides a set of procedures and communication protocols among participating state and local public safety and human service agencies to identify people who are likely to wander from home and become lost, and return them to their homes.”⁴² This program is open to adults ages 18 and older with cognitive disabilities or adults with serious memory impairment who can be pre-registered in these localities.⁴³

No specific program exists for children aged 17 and under who wander, as they may not be included in the Silver Alert system. While the Amber Alert system is in place in Massachusetts, that system is designed for child abduction cases.⁴⁴ Most often, an Amber Alert is only issued if the situation meets five strict criteria, the first of which is that law enforcement reasonably believes that the child has been abducted.⁴⁵ For this reason, the Amber Alert system does not provide support for children who wander.

TECHNOLOGY-ASSISTED TRACKING DEVICES

Beyond the tools previously described are technology-assisted tracking devices, or active locator devices, that can prevent individuals from wandering, and assist in quickly locating them if it occurs. Active locator technology refers to devices that require a source of power and wireless system technology.⁴⁶

Various types of devices, most often worn on the wrist or ankle, use different technologies, including:^{47,48}

- RF: Radio frequency
- GPS: Global positioning system
- Cellular triangulation
- RFID: Active radio frequency identification

Each system has advantages and limitations. Table 1 summarizes the technologies and their advantages and limitations. Table 2 provides a sample of active locator devices currently available.

Federal funding is available to local law enforcement agencies for the purchase of these technologies for vulnerable populations through the U.S. Department of Justice (DOJ) Edward Byrne Memorial Justice Assistance Grant (JAG) Program.⁴⁹ In 2014, 40 agencies in Massachusetts were eligible for grants through the JAG program, which can be used for a wide variety of law enforcement programs.⁵⁰ According to the DOJ, “[p]otential applicants for this funding must work through their State Administering Agency and/or local police department to determine if funding is available within existing resources.”⁵¹

USE OF RADIO FREQUENCY TECHNOLOGY

H.B. 956 requires that technology-assisted tracking devices comply with several specific characteristics, including that they:⁵²

- Are waterproof, can function underwater, and are compliant with IP66 and IP68 standard
- Do not require a direct line of sight to the sky and can work indoors
- Do not depend on third-party communication networks, such as cellular, GSM, GPRS, or RFID
- Use tamper-resistant wrist or ankle straps that can be directly changed by a caregiver
- Use user-specific codes to avoid cases of mistaken identities, and avoid false alarms

While H.B. 956 does not explicitly require the use of RF technology, as currently drafted its specifications regarding a sky-direct sight line and requiring indoor functionality eliminate the use of GPS-based technology in devices that would be covered under the proposed mandate. Its prohibition of the use of third-party communication networks also eliminates location devices that use cellular triangulation or a wireless computer network (“Wi-Fi”) connection (necessary for RFID devices).

Two qualifying RF programs currently exist in Massachusetts, and 145 municipalities and seven county sheriff departments possess receiver equipment.^{53,54} Likewise, the Massachusetts State Police also have the equipment available statewide through their Special Emergency Response Team (SERT).⁵⁵ This specially trained field force is available to any requesting law enforcement agency throughout Massachusetts and New England for a variety of situations, including lost person searches.⁵⁶ The SERT has both vehicle and helicopter-mounted equipment available for searches.⁵⁷

Program administration varies by the local law enforcement agency (LEA) rules, with residents either enrolling through their local LEA, or directly with the national program or supplier.^{58,59} Eligibility depends on a clinical diagnosis that a patient either has a history of wandering or is at-risk to do so, and that the patient is under the supervision of a responsible caregiver 24 hours per day, 7 days per week.^{60,61} One program further requires that patients also no longer have access to a vehicle.⁶² Costs to individuals vary by program and municipality, with some devices purchased on a one-time basis, and others requiring an initial purchase and monthly enrollment fees.^{63,64} Both programs use waterproof, tamper-resistant devices and bands that can be directly changed by the caregiver, although some LEAs prefer to perform this function directly to ensure correct functioning and patient compliance and familiarity with law enforcement personnel.^{65,66}

In either program, a caregiver calls 911 when an individual is found to be missing.^{67,68,69} Law enforcement then either dispatches its own equipment, or contacts SERT or another agency that can deploy appropriate equipment and personnel to locate the individual.^{70,71} Both programs state that once the receiver equipment is in place, the time to locate an individual who has wandered averages 30 minutes or less.^{72,73} Since 2004, 175 residents in Massachusetts with these devices have been reported to a LEA as wandering or missing. All were found and no program participant has died from wandering while wearing one of these active locator devices.^{74,75}

EFFICACY OF TECHNOLOGY-ASSISTED TRACKING DEVICES

In summary, this analysis uncovered no published, peer-reviewed research on the impact or medical efficacy of the use of technology-assisted tracking devices on the health outcomes of individuals with dementia, Alzheimer’s disease, or autism spectrum disorders. However, there is evidence these devices enable caregivers and law enforcement to find individuals who wander as a result of the disease more often and more quickly than without the devices. The speed with which the individual is found has been associated with less severe injuries and fewer deaths.

More generally, this review found no formal or peer-reviewed studies on the efficacy or comparative effectiveness of passive or active locator devices. The bill’s specific requirements, as currently drafted, for devices that enable underwater and obstructed site location, as well as the involvement of law enforcement assistance in location efforts, may render these devices more effective than other anti-wandering options to which this review refers. However, each technology has specific advantages and limitations, as outlined in Table 1. Given these considerations, national advocacy groups including the Autism Wandering Awareness Alerts Response and Education Collaboration (AWAARE) and the Alzheimer’s Foundation of America, as well as a report by the U.S. Department of Justice, have not formally recommended any one locator technology solution over another.

TABLE 1: ACTIVE LOCATOR TECHNOLOGY COMPARISON⁷⁶

Technology	Locating Technology Description	Advantages	Disadvantages
RF: Radio Frequency	Signal transmitted from device to locating antenna	On-ground accuracy of signal, detectable from air	Sensitivity of the receiver
RFID: Active Radio Frequency Identification Device	Wireless access points functioning as readers to active tags	No additional cost for network, as device is implemented on a currently used [radio tower] infrastructure	Inability to locate a wanderer without an available Wi-Fi hotspot
GPS: Global Positioning System	GPS signals transmitted directly to device	Locates within 15 feet of wandering individual	Clear path to satellites needed. Time needed for a GPS receiver to acquire satellite signals and calculate a position
Cellular triangulation	Cellular module included in device to allow device to connect to network	Using cellular towers in close proximity to determine device location operating device in lower power mode	Cellular network (the network specific to the device) availability/reliability
A-GPS: Assisted Global Positioning System	Satellite-to-cellular base station to locating device	Clear path to satellites with regards to buildings. Shorter time to receive coordinates than with standalone GPS.	Positioning data may not be available in low cellular coverage
GSM: Global System for Mobile Communications	Satellite-to-cellular base station to locating device	Worldwide mature network	2G network phase-out to begin in 2016
W-CDMA: Wideband-Code Division Multiplexing Access	Satellite-to-cellular base station to locating device	3G network is newer technology compared to 2G	3G network phase-out to end by 2021

Radio frequency (RF) technology relies on radio wave transmission between a transponder, antenna, and receiver, providing location information.⁷⁷ The devices themselves are waterproof and often use small watch batteries which require less frequent replacement than other devices that require frequent recharging and can last up to 60 days.⁷⁸ While these devices are more reliable indoors and are not impacted by obstructed sight lines, they are limited in signal range.⁷⁹

Currently, there are two RF systems available. The first is a manually-activated system used by law enforcement agencies.⁸⁰ This system depends wholly on local law enforcement technology systems.⁸¹ These agencies must purchase and install equipment and obtain training in their use to support such a program.⁸² Devices in this system use a person-unique pre-set frequency.⁸³ When a caregiver contacts a law enforcement agency about a wandering individual, a vehicle equipped with a receiver or antenna is dispatched to the area until the receiver detects the strongest signal possible.⁸⁴ Rescuers then deploy on foot using hand-held devices and use the strength of the signal to locate the individual. Examples of these programs include Project Lifesaver, CareTrak and LoJack SafetyNet. Reported average rescue time using the Project Lifesaver and LoJack SafetyNet technologies, both of which are used in Massachusetts, is approximately 30 minutes.^{85,86}

The second system that uses RF technology does not involve direct connection to law enforcement, but uses the concept of geo-fencing.⁸⁷ A locating device transmits a signal to a mobile receiver which is programmed for a preset distance.⁸⁸ If an individual leaves this range, an alert is sent to a caregiver using email or texts over a cellular network but does not provide location information.⁸⁹

Radio frequency identification programs (RFID) use a global system of four widespread radio frequency bands.⁹⁰ Passive RFID is often used in medical and residential settings where an RFID tag in a transponder interfaces with an RFID through application software.⁹¹ An individual's data is transmitted when a person passes a stationary or handheld reader.⁹² While no power source is required for the system, and little to no maintenance is required, the range of the signal is only 3 to 30 feet, making it impractical for use with wandering individuals outside of a more secure environment.⁹³

However, new technology similar to RFID is currently under development.⁹⁴ Active RFID systems use battery-powered tags and Wi-Fi hotspots in place of stationary readers, thereby increasing the range of detection to within 300 feet of any Wi-Fi hotspot.⁹⁵ The advantage of this system is that it can be implemented on a currently available infrastructure which lowers system implementation costs.⁹⁶ However, Wi-Fi spots are not consistent and do not provide complete coverage, and active RFID tags are more expensive than passive technologies.⁹⁷

GPS systems depend on satellites which provide very accurate positioning and navigation information.⁹⁸ Activated by a caregiver, the technology is not dependent on a cellular network, and there are a variety of programs and applications that utilize this system.⁹⁹ The advantage of GPS is the accuracy of the location information that is transmitted.¹⁰⁰ However, GPS receivers rely on clear sight lines to the satellites, and do not reliably work indoors or anywhere there are barriers or obstructions.¹⁰¹ Likewise, standalone GPS systems often need more time to establish an initial location.¹⁰² Units are generally not waterproof and the devices require frequent charging, such as with cell phones, leaving users unprotected during the recharge period.¹⁰³ Examples of a GPS-based system include various geofencing applications¹⁰⁴ and programs such as the Alzheimer's Association ComfortZone.¹⁰⁵

GPS technology can be further enhanced with the use of network assisted GPS systems (A-GPS), a handset-based system which augments satellite coverage, most often through the use of cell towers.¹⁰⁶ Information can be accessed via computer or smart phone.¹⁰⁷ However, while this caregiver-activated technology attempts to compensate for GPS limitations in obstructed areas, it utilizes cellular network coverage which can itself be unreliable or incomplete.¹⁰⁸ And as with other GPS devices, these are not generally waterproof and require frequent charging.¹⁰⁹

Global System for Mobile Communications (GSM) technology is based on second-generation (2G) cellular networks, and can be either network or handset based.¹¹⁰ One example is the handset-based Enhanced Observed Time Difference (E-OTD) which can accurately locate a device within 50 to 500 feet.¹¹¹ Another example is Uplink Time Difference of Arrival (U-TDOA) technology that provides position location based on receivers placed on cellular base stations, or Location Measurement Units (LMUs). This network-based technology uses devices that are small and single-purpose, and link directly to emergency responders through local E-911 systems.¹¹² However, the major limitation of these devices is that someone must call 911 and open a local missing person's case before the system is activated and emergency response personnel are given the signal.¹¹³ This time lapse may be critical in safely locating a wandering individual. Moreover, while GSM network technology is mature and widely used, it is based on 2G technology that will be phased out beginning in 2016.¹¹⁴

Wideband Code Division Multiple Access (W-CDMA) technologies are handheld systems based on third generation (3G) technology.¹¹⁵ The system relies on a different navigation technique to determine location, known as Observed Time Difference of Arrival (O-TDOA).¹¹⁶ The advantage of using the more up-to-date 3G technology is mitigated by the estimated phase out of this network by 2021.¹¹⁷

TABLE 2: SAMPLE OF CURRENTLY AVAILABLE ACTIVE LOCATOR DEVICES¹¹⁸

Company/ Program	Technology	Product Type	Law Enforcement Involvement	Battery Life	Cost	Notes
Project Lifesaver	Radio Frequency locating device (216 MHz)	Location band	Yes	30-60 days	Varies ¹¹⁹	<ul style="list-style-type: none"> ■ Secure database for clients ■ Lightweight YAGI antenna for location ■ Car mount Omni antenna for location
Safety Net by LoJack	Radio Frequency locating device (216 MHz)	Location band	Yes	30-60 days	\$149 enrollment plus \$35/month ¹²⁰	
Project Lifesaver PAL	Radio Frequency invisible boundary (433 MHz), cellular and GPS	Digital watch and portable receiver	No	30-60 days	\$46/month ¹²¹	<ul style="list-style-type: none"> ■ Notification email and/or text ■ Mapping tracking
Keruve	GPS	Location band and GPS receiver	No	3.5 days	\$1499 one-time ¹²²	<ul style="list-style-type: none"> ■ No cellular fee
GPS Smart Shoe, GTX Corp. (Aetrex)	A-GPS (Geo-fence based)	A-GPS in shoe	No	Unknown	\$300 shoes plus \$20/month ¹²³	<ul style="list-style-type: none"> ■ Notification email and/or text ■ Mapping tracking
Comfort Zone	Cellular service based	Small, stand-alone device	No	Unknown	\$45 activation plus \$43/month ¹²⁴	<ul style="list-style-type: none"> ■ Requires cellular service ■ Alerts via text and email ■ Includes care consultation and call center access
Tracking System Direct	GPS (Geo-fence based)	GPS in wristwatch	No	Unknown	\$30/month ¹²⁵	<ul style="list-style-type: none"> ■ Panic button safety feature ■ Real-time tracking ■ Two-way voice communications available to wanderer

ENDNOTES

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**CENTER FOR HEALTH
INFORMATION AND ANALYSIS**

APPENDIX

**Actuarial Assessment of House Bill 956
Submitted to the 188th General Court:
“An act concerning the safety of
autistic and alzheimer individuals”**

Prepared for
Commonwealth of Massachusetts
Center for Health Information and Analysis

May 2015

Prepared by
Compass Health Analytics, Inc.



Actuarial Assessment of House Bill 956
Submitted to the 188th General Court:
“An act concerning the safety of autistic and alzheimer individuals”
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Actuarial Assessment of House Bill 956: “An act concerning the safety of autistic and alzheimer individuals”

Executive Summary

Massachusetts House Bill 956 (H.B. 956), as drafted for the 188th General Court (and submitted as House Bill 913 in the 189th General Court), requires health insurance plans to “provide full coverage, subject to all applicable co-payments, coinsurance, deductibles, and out-of-pocket limits, for insured individuals who are diagnosed by a license [sic] physician with dementia, Alzheimer’s disease, or Autism spectrum Disorder, to obtain a Technology-Assisted Tracking Device if they or their guardian choose.”¹

Massachusetts General Laws (M.G.L.) c.3 §38C charges the Massachusetts Center for Health Information and Analysis (CHIA) with, among other duties, reviewing the potential impact of proposed mandated health insurance benefits on the premiums paid by businesses and consumers. CHIA has engaged Compass Health Analytics, Inc. (Compass) to provide an actuarial estimate of the effect enactment of the bill would have on the cost of health insurance in Massachusetts.

Background

The bill requires coverage for technology-assisted tracking devices, or active locator devices, for members with a diagnosis of dementia, Alzheimer’s disease,ⁱ or an autism spectrum disorder (ASD) at the request of the member or the member’s guardian.² It explicitly requires that the devices: are waterproof and function underwater; work indoors or under cover; do not depend on third-party public communication networks; are tamper-resistant but changeable by a direct caregiver; avoid false alarms; and are coded for specific users.³

The bill as currently drafted amends the statutes that regulate the Commonwealth’s medical assistance programs. This review assesses instead the effect of the proposed mandate on the types of commercial fully-insured coverage usually addressed in mandate legislation. This assessment will hold only if the Legislature amends the bill so that it applies to the commercial insurance statutes.

Analysis

Compass estimated the impact (for fully-insured commercial plans) of H.B. 956, as drafted for the 188th General Court, with the following steps. Additionally, Compass estimated a PMPM cost range for fully-insured Medicare supplement policies.

- Estimate the number of Massachusetts individuals aged less than 65 with a diagnosis of dementia, Alzheimer’s disease, or ASD.

ⁱ Alzheimer’s disease is the most common form of dementia.

- Estimate the fully-insured Massachusetts population under age 65, projected for the next five years.
- Estimate the number of fully commercially insured individuals aged less than 65 with a diagnosis of dementia, Alzheimer’s disease, or ASD.
- Estimate the number of individuals with dementia, Alzheimer’s disease, or ASD and at risk of wandering who are covered by fully-insured commercial policies.
- Estimate the number of individuals using an active locator device under the proposed mandate in each of the years 2016 to 2020.
- Research and establish the current cost per user per year of active locator devices in Massachusetts.
- Estimate cost per user per year of active locator devices for each year in the projection period.
- Calculate the proposed mandate’s incremental effect on medical expenses over the projection period.
- Apply an estimated cost-sharing factor based on carrier claim experience.
- Estimate the impact of insurer’s retention (administrative costs and profit).
- Calculate the estimated per member per month (PMPM) cost of the proposed mandate over the next five years.

The analysis requires assumptions about the prevalence of dementia, Alzheimer’s disease, and ASD, current and future levels of demand for active locator devices, and the extent and effect of carrier coverage limits. To adjust for these sources of uncertainty, the analysis produces a range of incremental impact estimates based on varying these parameters.

Summary results

Table ES-1 summarizes the estimated effect of H.B. 956, as drafted for the 188th General Court, on premiums for fully-insured commercial plans (other than Medicare supplement plans; Medicare supplement cost is presented separately) over five years. This analysis estimates that the mandate, if enacted, would increase premiums by as much as \$0.02 PMPM, or 0.005 percent, on average over the next five years; a more likely increase is in the range of \$0.01 PMPM, or 0.003 percent, equivalent to an average annual expenditure of approximately \$375,000 over the period 2016 to 2020.

Compass also estimated an annual PMPM premium increase range for the fully-insured Medicare supplement market of \$0.16 to \$0.31. The prevalence rate of dementia and Alzheimer’s disease in the Medicare supplement membership is much higher than it is among the under-65 commercially-insured population.

The impact of the bill on any one individual, employer-group, or carrier may vary from the overall results depending on the current level of benefits each receives or provides and on how the benefits will change under the proposed mandate.

**Table ES-1:
Summary Results for Members Aged 0 to 64
with Fully-Insured Commercial Policies**

	2016	2017	2018	2019	2020	Weighted Average	5 Yr Total
Members (000s)	2,329	2,305	2,279	2,253	2,226		
Medical Expense Low (\$000s)	\$49	\$81	\$75	\$74	\$74	\$75	\$353
Medical Expense Mid (\$000s)	\$220	\$365	\$339	\$335	\$331	\$338	\$1,590
Medical Expense High (\$000s)	\$391	\$649	\$603	\$596	\$589	\$601	\$2,827
Premium Low (\$000s)	\$54	\$90	\$83	\$83	\$82	\$83	\$392
Premium Mid (\$000s)	\$244	\$404	\$376	\$371	\$367	\$375	\$1,762
Premium High (\$000s)	\$434	\$718	\$668	\$660	\$652	\$666	\$3,132
PMPM Premium Low	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003
PMPM Premium Mid	\$0.012	\$0.015	\$0.014	\$0.014	\$0.014	\$0.014	\$0.014
PMPM Premium High	\$0.022	\$0.026	\$0.024	\$0.024	\$0.024	\$0.024	\$0.024
Estimated Monthly Premium	\$475	\$489	\$503	\$518	\$533	\$489	\$489
Premium % Rise Low	0.001%	0.001%	0.001%	0.001%	0.001%	0.001%	0.001%
Premium % Rise Mid	0.003%	0.003%	0.003%	0.003%	0.003%	0.003%	0.003%
Premium % Rise High	0.005%	0.005%	0.005%	0.005%	0.005%	0.005%	0.005%

Executive Summary Endnotes

¹ The 188th General Court of the Commonwealth of Massachusetts, House Bill 956: An act concerning the safety of autistic and alzheimer individuals. Accessed 10 March 2015: <https://malegislature.gov/Bills/188/House/H956>. The 189th General Court of the Commonwealth of Massachusetts House Bill 913: An act concerning the safety of autistic and alzheimer individuals. Accessed 18 March 2015: <https://malegislature.gov/Bills/189/House/H913>.

² *Ibid.*

³ *Ibid.*

Actuarial Assessment of House Bill 956: “An act concerning the safety of autistic and alzheimer individuals”

1. Introduction

Massachusetts House Bill 956 (H.B. 956), as drafted for the 188th General Court (and submitted as House Bill 913 in the 189th General Court), requires health insurance plans to “provide full coverage, subject to all applicable co-payments, coinsurance, deductibles, and out-of-pocket limits, for insured individuals who are diagnosed by a license [sic] physician with dementia, Alzheimer’s disease, or Autism spectrum Disorder, to obtain a Technology-Assisted Tracking Device if they or their guardian choose.”¹

Massachusetts General Laws (M.G.L.) c.3 §38C charges the Massachusetts Center for Health Information and Analysis (CHIA) with, among other duties, reviewing the potential impact of proposed mandated health insurance benefits on the premiums paid by businesses and consumers. CHIA has engaged Compass Health Analytics, Inc. (Compass) to provide an actuarial estimate of the effect enactment of the bill would have on the cost of health insurance in Massachusetts.

Assessing the impact of this bill on premiums entails analyzing its incremental effect on spending by insurance plans. This in turn requires comparing spending under the provisions of the proposed law to spending under current statutes and current benefit plans for the relevant services.

Section 2 of this analysis outlines the relevant provisions of the bill. Section 3 summarizes the methodology used for the estimate. Section 4 describes the calculations; results are presented in Section 5.

2. Interpretation of the bill

The following subsections describe the relevant provisions of H.B. 956 as drafted for the 188th General Court.

2.1. Plans affected by the proposed mandate

The bill as currently drafted amends the statutes (M.G.L. c. 118E) that regulate the Commonwealth’s medical assistance programs. CHIA requested that Compass assess instead the effect of the proposed mandate on the types of commercial fully-insured coverage usually addressed in mandate legislation:

- Accident and sickness insurance policies regulated by M.G.L. c.175
- Contracts with non-profit hospital service corporations regulated by M.G.L. c.176A
- Certificates under medical service agreements regulated by M.G.L. c.176B
- Health maintenance contracts regulated by M.G.L. c.176G

- Medicare supplement policies regulated by M.G.L. c.175

This analysis is valid only if the Legislature amends the bill so that it applies to the commercial insurance statutes.

This analysis also assumes the bill was intended to apply to all plans, fully-insured and self-insured, offered by the Group Insurance Commission (GIC) for the benefit of state and local employees and their dependents. The bill requires coverage for members under the relevant Massachusetts-licensed plans regardless of whether they reside within the Commonwealth or merely have their principal place of employment in the Commonwealth.

Self-insured plans, except for those managed by the GIC, are not subject to state-level health insurance benefit mandates. State mandates do not apply to Medicare or to Medicare Advantage plans, the benefits of which are qualified by Medicare. Finally, this analysis does not apply to Medicaid/MassHealth.

2.2. Requirements of the proposed mandate

H.B. 956, as drafted for the 188th General Court, requires coverage for technology-assisted tracking devices, or active locator devices, for members with a diagnosis of dementia, Alzheimer’s disease, or an autism spectrum disorder (ASD) at the request of the member or the member’s guardian.² The mandate explicitly requires that the devices: are waterproof and function underwater; work indoors or under cover; do not depend on third-party public communication networks; are tamper-resistant but changeable by a direct caregiver; avoid false alarms; and are coded for specific users.³

Dementia, Alzheimer’s disease, and autism spectrum disorders

As defined by the National Institute on Aging of the U.S. National Institutes of Health, dementia is a general term for the loss of behavioral abilities and cognitive functioning, including reasoning and memory, “to such an extent that it interferes with a person’s daily life and activities.”⁴ Dementia can be caused by a variety of conditions, the two most common of which are Alzheimer’s disease and vascular dementia, which changes a person’s blood supply to the brain.⁵ It is estimated that almost 14 percent of people age 71 or older suffer from some form of dementia.⁶

Alzheimer’s disease is the most common form of dementia in older people, with symptoms most often first appearing after age 65.⁷ By current estimates, the disease affects 5.2 million Americans, including some 200,000 younger than age 65.^{8,9} One study estimated that approximately 120,000 Massachusetts residents over age 65 suffered from Alzheimer’s in 2014, a number that is expected to grow by 25 percent by 2025.¹⁰

Autism spectrum disorders (ASD) describe “a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior.”¹¹ The disorder varies significantly both in terms of individual severity and characteristics.¹² *The Massachusetts Autism Commission Report* published in March 2013 used a benchmark ASD prevalence estimate of 1.1 percent statewide for people of all ages.¹³

Wandering

Wandering (sometimes called “elopement”) is leaving a safe setting or responsible caregiver. According to the U.S. Centers for Disease Control and Prevention, wandering is a serious safety issue for people with developmental and cognitive disabilities.¹⁴ These individuals have special challenges with communication, social interaction, attention and learning, and often do not understand safety issues, placing themselves at increased risk for becoming lost or injured.¹⁵ The dangers of wandering include exposure, hypothermia, dehydration, drowning, traffic injuries, falls, physical restraint, and encounters with strangers and/or law enforcement.¹⁶

Individuals with dementia, Alzheimer’s disease, or ASD are at greater risk for wandering and its resulting hazards than individuals without those conditions. In one of the largest surveys of families whose children have ASD, researchers found that 49 percent had attempted to elope at least once after age four, a significantly higher rate than for siblings who did not have ASD, with about one-quarter of these children “missing long enough to cause concern.”¹⁷ According to the Alzheimer’s and Dementia Caregiver Center of the national Alzheimer’s Association™, “[w]andering and getting lost is common among people with dementia and can happen during any stage of the disease.”¹⁸ Approximately 60% of dementia and Alzheimer’s disease patients will wander, resulting from the memory problems and disorientation that are symptoms of the condition.

H.B. 956 as currently drafted would require insurers to cover radio-frequency active locator devices for individuals with dementia, Alzheimer’s disease, or ASD. Such devices are used to shorten search and recovery time when a user wanders, reducing the risk of harm. There is evidence these devices enable caregivers and law enforcement to find patients, wandering as a result of their disease, more often and more quickly than without the devices. See CHIA’s review of the medical efficacy of H.B. 956 for more detail.

2.3. Existing laws affecting the cost of H.B. 956

Massachusetts Chapter 207 of the Acts of 2010, “An Act Relative to Insurance Coverage for Autism,” (ARICA), requires all commercial health insurance policies regulated by the state and written or renewed on or after January 1, 2011 to provide coverage for the diagnosis and treatment of ASDs.¹⁹ However, coverage for devices or durable medical equipment (DME) such as active locator devices is not required.²⁰

This analysis has uncovered no current Massachusetts insurance mandates regarding insurance coverage for active locator devices. No existing federal mandates related to the specific subject matter of this bill have been identified.

3. Methodology

3.1. Steps in the analysis

Compass estimated the impact of the bill on commercial fully-insured coverage for individuals without primary Medicare coverage (i.e., individuals under age 65) with the following steps. Additionally, Compass estimated a single-year PMPM cost range for fully-insured Medicare supplement policies.

- Estimate the number of Massachusetts individuals aged less than 65 years with a diagnosis of dementia, Alzheimer's disease, or ASD.
- Estimate the fully-insured Massachusetts population under age 65, projected for the next five years.
- Estimate the number of fully commercially insured individuals aged less than 65 years with a diagnosis of dementia, Alzheimer's disease, or ASD.
- Estimate the number of individuals with dementia, Alzheimer's disease, or ASD and at risk of wandering who are covered by fully-insured commercial policies.
- Estimate the number of individuals using active locator device under the proposed mandate in each of the years 2016 to 2020.
- Research and establish the current cost per user per year of active locator devices in Massachusetts.
- Estimate cost per user per year of active locator devices for each year in the projection period.
- Calculate the proposed mandate's incremental effect on carrier medical expenses over the projection period.
- Apply an estimated cost-sharing factor based on carrier claim experience.
- Estimate the impact of insurer's retention (administrative costs and profit).
- Calculate the estimated per member per month (PMPM) cost of the proposed mandate over the next five years.

3.2. Data sources

The primary data sources used in the analysis were:

- Information from device makers, cited as appropriate
- Information from a written survey administered by Compass to private health insurance carriers in Massachusetts
- Academic literature and government reports, including population data, cited as appropriate

- Massachusetts insurer claim and eligibility data from CHIA’s Massachusetts All Payer Claim Database (APCD) for calendar years 2009 to 2012 submitted by plans covering the majority of the Medicare supplement and under-65 insured populations²¹

The following subsection and the step-by-step description of the estimation process address limitations in some of these sources and the uncertainties they contribute to the cost estimate.

3.3. Limitations

This analysis relies primarily on an assessment of the demand for active locator devices and their associated costs in the dementia, Alzheimer’s disease, and ASD communities. The estimates draw on medical research regarding the prevalence of the covered conditions and dangerous wandering among people with the conditions, device cost information from manufacturers, and 2011 and 2012 statewide data on condition prevalence and DME cost sharing. The estimates of incremental costs for the proposed mandate for 2016 to 2020 require assumptions about:

- The prevalence of dementia, Alzheimer’s disease, and ASD in Massachusetts among the commercial fully-insured population under age 65 for the period 2016 to 2020, and among the fully-insured Medicare supplement population
- The current and future levels of demand for active locator devices based on individual need (i.e., the frequency and riskiness of wandering behaviors)
- The extent and effect of carrier medical necessity criteria, cost sharing, and coverage limits

These uncertainties are addressed by modeling a reasonable range of assumptions based on informed judgment.

4. Analysis

Compass executed the following calculations to estimate the impact of the proposed legislation. Simplified somewhat, the baseline cost calculation is:

	Number of Massachusetts commercial fully-insured plan members with dementia, Alzheimer’s disease, or ASD
x	Percent of members with dementia, Alzheimer’s disease, or ASD acquiring an active locator device
x	Annual device and monitoring cost
x	Cost-sharing factor
=	Estimated total incremental annual carrier claim expense

The components are multiplied together to estimate a total annual incremental carrier claim expense which is then divided by commercial fully-insured enrollment (member months), yielding a per-member per-month (PMPM) cost estimate. This claim cost estimate is the starting point for calculating the final five year (2016 to 2020) premium cost projection.

By varying the percent of members assumed to opt for a device, the analysis includes development of a best estimate “middle-cost” scenario, a low-cost scenario using a lower utilization assumption, and a high-cost scenario using a more conservative utilization assumption that produced a higher estimated impact.

4.1. Prevalence of dementia, Alzheimer’s disease, and ASD

Estimating the cost of the proposed mandate requires estimating the number of Massachusetts individuals less than 65 years old with dementia, Alzheimer’s disease, and autism spectrum disorders covered by fully-insured commercial policies.

The Massachusetts Autism Commission Report published in March 2013 used a benchmark estimate of 1.1 percent (or 1 in 88) of all Massachusetts citizens living with ASD in 2012.²² To estimate the fully-insured commercial population in Massachusetts less than 65 years of age with ASD in each of the study years, Compass first multiplied 1.1 percent by Census Bureau estimates of the total Massachusetts population, yielding an average of approximately 77,600 individuals in each year of the period 2016 to 2020. These totals were then multiplied by the ratio of the estimated commercial fully-insured population less than 65 years of age to the estimated total population. This calculation yielded an annual average of about 25,900 members with ASD.

Dementia and Alzheimer’s disease among those younger than 65, known as early-onset dementia, is comparatively rare: a 2006 report by the Alzheimer’s Association™ cites a range of 220,000 to 640,000 Americans with early-onset dementia,²³ or 0.09 to 0.25 percent of the U.S. population aged 0 to 64 in 2006.²⁴ Compass’s research did not find any state or regional estimates of the prevalence of early-onset dementia. The population of Massachusetts individuals in the fully-insured commercial market with early-onset dementia was therefore estimated by averaging the two population percentages above and multiplying the resulting prevalence rate (0.17 percent) by the estimate of total Massachusetts individuals under 65 with fully-insured commercial coverage for each year in the projection period. This calculation yielded an annual average of about 3,800 individuals with early-onset dementia.

For the fully-insured Medicare supplement population (97 percent of which is age 65 or older), Compass first calculated prevalence of dementia and Alzheimer’s disease using Massachusetts APCD claim and eligibility data for fully-insured Medicare supplement products. For the years 2011 and 2012, the number of individuals with fully-insured Medicare supplement coverage who had at least one claim with a principal diagnosis of dementia or Alzheimer’s disease was divided by the average monthly membership reported in these same products, resulting in prevalence rates of 8.5 percent in 2011 and 6.6 percent in 2012. However, studies estimate that one in nine Americans 65 or older has Alzheimer’s disease²⁵ and almost 14 percent of people age 71 or older suffer from some form of dementia.²⁶ Investigating the differences between the APCD results and these widely-accepted figures (which may be due in part to a real difference in prevalence of dementia and Alzheimer’s disease among the population insured under Medicare supplement plans) is outside the scope of this study; Compass therefore estimated a PMPM incremental premium range using a

low-end prevalence rate of 7 percent based on the APCD results and a high-end prevalence rate of 14 percent.ⁱ

4.2. Projected fully-insured population in Massachusetts

Calculating prevalence for the covered conditions in the commercial fully-insured population in Massachusetts less than 65 years of age over the study period required estimating the total commercially fully insured population in Massachusetts less than 65 years of age for the next five years. Table 1 displays these values. Appendix A describes the sources of these values.

**Table 1:
Projected Fully-Insured Population in Massachusetts, Ages 0-64**

<u>Year</u>	<u>Total (0-64)</u>
2016	2,329,040
2017	2,304,658
2018	2,279,367
2019	2,253,405
2020	2,226,328

4.3. Percent of members opting for an active locator device

Estimating the demand for active locator devices under the proposed mandate requires three steps: (i) estimating the population with the covered conditions at risk of wandering, (ii) estimating the proportion of the at-risk population who would (or whose guardians would) opt to use an active locator device, and (iii) estimating a rate of utilization “ramp-up” during which members and/or their guardians would become aware of the benefit and undertake the process of obtaining and deploying the device.

Estimate population at risk for wandering

In one of the largest surveys of families whose children have an ASD, researchers found that 49 percent had attempted to elope at least once after age 4, a significantly higher rate than for siblings who did not have an ASD.²⁷ According to the Alzheimer’s and Dementia Caregiver Center of the national Alzheimer’s Association™, “[w]andering and getting lost is common among people with dementia and can happen during any stage of the disease.”²⁸ Approximately 60 percent of individuals with dementia or Alzheimer’s disease will wander, resulting from the memory problems

ⁱ Although this prevalence range was modeled for dementia and Alzheimer’s disease, it is reasonable to assume it adequately covers all three conditions. While assuming the benchmark prevalence rate for ASD from *The Massachusetts Autism Commission Report* would increase the Medicare supplement combined condition prevalence rate by 1 percent, note that the well-known dramatic rise in prevalence of ASD diagnoses in the past twenty years has occurred primarily in children, suggesting the (known) prevalence among the population aged 65 and over is lower, and in fact the APCD prevalence of ASD for the fully-insured Medicare supplement population was only 0.03 percent in both 2011 and 2012. In addition, the 14 percent high-end prevalence rate for dementia and Alzheimer’s disease is likely somewhat overstated, as dementia and Alzheimer’s disease are less prevalent in the population aged 65 to 70.

and disorientation that are symptoms of the condition. Multiplying the estimated ASD population prevalence of 1.1 percent by a 50 percentⁱⁱ wandering risk factor and the estimated 0.17 percent early-onset dementia population prevalence by the 60 percent wandering risk factor above yields the average annual population at risk for wandering among the fully-insured commercial population less than 65 years old shown in Table 2.

**Table 2:
Population with Dementia, Alzheimer’s disease, or ASD at Risk for Wandering**

<u>Condition</u>	<u>Avg. MA Comm. FI 0-64 Population, 2016-2020</u>	<u>Percent at Risk for Wandering</u>	<u>Avg. MA Comm. FI 0-64 Population At Risk</u>
ASD	25,893	50%	12,946
Dementia and Alzheimer’s	3,793	60%	2,276
Total	29,685	51%ⁱⁱⁱ	15,222

Estimate active locator utilization rate

Because members with ASD comprise 85 percent (12,946/15,222) of the at-risk population under age 65, relying primarily on data for people with an ASD to set the utilization range for this age group is reasonable. Observed utilization rates for active locator devices provide an obvious starting point for building such a range. These data are available for one Massachusetts county^{iv} comprising 10 percent of the Massachusetts population. The county sheriff testified in support of H.B. 956 that approximately 55 county residents with ASD currently use the devices.²⁹ At a population ASD prevalence rate of 1.1 percent and a 50 percent risk of wandering for individuals with ASD, 55 users implies a county utilization rate of 1.4 percent. Because survey responses from ten of the largest commercial health insurance carriers in Massachusetts indicated active locator devices are not covered medical benefits,^v this rate represents utilization in the absence of insurance coverage.

By defraying user costs, mandated insurance coverage is likely to significantly increase utilization. Compass therefore considered 1.4 percent a starting point for the lower bound of the utilization range, and modeled a low-cost scenario utilization factor of two percent (a 40 percent increase).

To estimate best estimate and upper bound utilization rates in the presence of the mandate, Compass relied on the survey discussed above in which parents reported that 49 percent of their children with ASD had wandered. Parents reported that about one-quarter of the children who wandered were “missing long enough to cause concern.”³⁰ Of the children missing long enough to cause concern, 35 percent (or 9 percent of all children with ASD who wandered) were never or

ⁱⁱ Rounded up from the 49 percent found in the survey of parents of children with ASD.

ⁱⁱⁱ The percent of total members with the two conditions at risk of wandering is the weighted average of the wandering risks for the two conditions.

^{iv} The availability of current utilization information is limited by privacy concerns.

^v One large carrier indicated active locator devices were not specifically excluded from coverage, but analysis of the Massachusetts APCD showed no evidence the carrier had covered any such claims through 2012.

rarely able to communicate their name, address or phone number by any means³¹ and 65 percent (or 16 percent of children who wandered) were reported to have been in danger of traffic injury while missing.³² These results combined with the experience of the Massachusetts county described above suggest the active locator device utilization range displayed in Table 3.

**Table 3:
Estimated Utilization Range for Members with
Dementia, Alzheimer’s disease, or ASD at Risk of Wandering**

Low Scenario	2%
Middle Scenario	9%
High Scenario	16%

The research on wandering upon which Compass relied to develop the 50 percent wandering risk factor for individuals with ASD in Table 2 and the utilization range in Table 3 focused on children with ASD; in the absence of comparable data regarding severity and riskiness of wandering behaviors among other populations, Compass applied the same range to all members of the 0 to 64 age group. The expected cost of the proposed mandate, if enacted, would be lower than the middle scenario to the extent that wandering behaviors are less common or less severe among adults with ASD.

A recent British study notes that about 5 percent of individuals with Alzheimer’s disease or dementia repeatedly get lost as a result of wandering.³³ Expressing this figure in terms of the 60 percent of individuals with dementia or Alzheimer’s disease considered at risk for wandering results in an estimate of 8.3 percent of at-risk individuals becoming lost repeatedly.

This similarity between the middle scenario estimate for children with ASD and the rate of getting lost repeatedly for at-risk adults with dementia or Alzheimer’s disease provides additional support for nine percent as the best estimate utilization factor.

Apply utilization “ramp-up”

These utilization rates would not be reached immediately upon implementation; there would be a period of “ramp-up” during which members and their guardians became aware of the benefit and undertook the process of obtaining and deploying the device.

This analysis assumed an implementation date of January 1, 2016 for the proposed benefit. Compass further assumed 75 percent of the expected users would receive the benefit in 2016, with full utilization beginning in 2017. Table 4 displays the estimated progression of utilization rates and fully-insured commercial user counts in each scenario.

**Table 4:
Utilization Ramp-up for Members with Dementia, Alzheimer’s disease or ASD and at risk of Wandering**

	2016	2017	2018	2019	2020	Average
Members at risk of wandering	15,559	15,396	15,227	15,054	14,873	15,222
Utilization Rate Low	2%	2%	2%	2%	2%	2%
Utilization Rate Mid	7%	9%	9%	9%	9%	9%
Utilization Rate High	12%	16%	16%	16%	16%	15%
Users Low	233	308	305	301	297	303
Users Mid	1,050	1,386	1,370	1,355	1,339	1,362
Users High	1,867	2,463	2,436	2,409	2,380	2,422

4.4. Annual device and monitoring costs

Two radio frequency active locator device programs meeting the bill’s requirements are currently available in Massachusetts. For one of the programs, costs to users vary based on law enforcement agency policy (some agencies are able to cover some or all costs of the device and monitoring under their budgets, while others cannot). The other, which provides statewide coverage through the Massachusetts state police Special Emergency Response Team (SERT), advertises current pricing of a one-time \$99 enrollment fee and an ongoing \$30 per month monitoring fee. A planned April 2015 price increase will increase the enrollment fee to \$149 and monthly monitoring to \$35, resulting in an annual price structure by the time the proposed mandate, if passed, would be implemented of \$569 for the first year and \$420 each year thereafter.

Given that the above pricing is currently available to all residents of Massachusetts (and that some local news reports about an ongoing Massachusetts implementation of the former program indicated a similar pricing structure),³⁴ and assuming that under mandated health insurance coverage law enforcement agencies would pass on market costs of the devices and monitoring to commercial insurers when possible, this analysis assumed the April 2015 cost structure of the latter program for all years. Compass has assumed no price increases during the study period because the planned April 2015 price increase appears to be the first such increase for the program in more than five years.³⁵

Estimating average annual cost per user required developing an estimate of the number of more costly first-year users in each year of the study period. Given that the limited information available regarding current enrollment in radio frequency active locator programs suggests current enrollment is low, Compass assumed that 80 percent of users would be first-year users in 2016. In 2017, Compass assumed that all incremental users would be new, and applied a turnover rate of 20 percent to the 2016 user count (to account for users moving out of Massachusetts or out of the fully-insured commercial population under age 65 and those discontinuing use being replaced by new users), that is, 20 percent of those users were priced at the first year cost. The same 20 percent turnover rate was used for 2018 to 2020.

Table 5 displays the final weighted average annual cost per user for each year in the analysis period resulting from these calculations.

**Table 5:
Estimated Weighted Average Annual User Cost**

<u>Year</u>	<u>Avg. Ann. User Cost</u>
2016	\$539
2017	\$479
2018	\$450
2019	\$450
2020	\$450

4.5. Cost sharing

H.B. 956 as drafted for the 188th General Court makes the required coverage subject to the cost-sharing terms that generally apply in the affected policies. Carrier survey responses indicated that if the bill were passed active locator devices would in all likelihood be covered as durable medical equipment (DME). To estimate a cost-sharing factor for DME coverage, Compass used Massachusetts APCD claims for the years 2011 and 2012 to calculate annual average cost sharing for all paid DME claims in the period for all fully-insured commercial members aged 0 to 64 who had any adjudicated claim with a principal diagnosis of dementia, Alzheimer’s disease, or ASD during the period 2009 to 2012. This calculation resulted in an observed DME cost-sharing factor of 44 percent. Accordingly, Compass applied a cost-sharing factor of 45 percent in the cost model.

4.6. Net total annual increase in carrier medical expense

For each scenario, multiplying the annual number of users by the cost per user and the cost-sharing factor, dividing the result by the projected fully-insured commercial membership, and averaging the results over the period 2016 to 2020 yields the average annual medical expense per member per month (PMPM) displayed in Table 6.

**Table 6:
Estimate of Weighted Average Annual Increase in Carrier Medical Expense PMPM**

Low Scenario	\$0.003
Middle Scenario	\$0.012
High Scenario	\$0.022

The middle scenario increase in PMPM medical expense of \$0.012 is equivalent to average annual medical claim spending of approximately \$330,000.

4.7. Net increase in premium

Assuming an average retention rate of 9.7 percent based on CHIA’s analysis of administrative costs and profit in Massachusetts,³⁶ the increase in medical expense was adjusted upward to approximate the total impact on premiums. Table 7 shows the result.

**Table 7:
Estimate of Weighted Average Annual Increase in PMPM Premium**

Low Scenario	\$0.003
Middle Scenario	\$0.014
High Scenario	\$0.024

The middle scenario baseline PMPM premium of \$0.01 is equivalent to average annual spending of approximately \$375,000.

4.8. Projected final year cost for fully-insured Medicare supplement coverage

As described in subsection 4.1, Compass applied a prevalence range of 7 to 14 percent for the covered conditions to the fully-insured Medicare supplement population. Compass estimated an annual user count by reducing the population range estimate by the 60 percent wandering risk factor for individuals with dementia and Alzheimer’s disease and the best estimate utilization rate of nine percent.

Compass applied the estimated 2020 pricing structure of \$569 first-year cost for 20 percent of users and \$420 ongoing cost for 80 percent of users. As the primary purpose of Medicare supplement policies is to cover deductibles and cost sharing for Medicare members, this analysis applied no cost sharing to this estimate.

These calculations resulted in an estimated medical cost range of \$0.14 to \$0.28 PMPM. Applying carrier retention of 9.7 percent resulted in a total premium increase estimate of \$0.16 to \$0.31 PMPM.

5. Results

The estimated impact of the proposed mandate is outlined below. The analysis includes development of a best estimate “middle-cost” scenario, as well as a low-cost scenario using assumptions that produced a lower estimate, and a high-cost scenario using more conservative assumptions that produced a higher estimated impact.

5.1. Five-year estimated impact

For each year in the five-year analysis period, Table 8 displays the projected net impact of the proposed mandate on medical expense and premiums using a projection of Massachusetts fully-insured membership. The 2016 estimate is pro-rated to account for contract renewal dates after January 1. This analysis estimates that the mandate, if enacted as drafted for the 188th General Court, would increase premiums by as much as \$0.02 PMPM, or 0.005 percent, on average over the next five years; a more likely increase is in the range of \$0.01 PMPM, or 0.003 percent, equivalent to an average annual expenditure of approximately \$375,000 over the period 2016 to 2020.

The impact of the bill on any one individual, employer-group, or carrier may vary from the overall results depending on the current level of benefits each receives or provides and on how the benefits will change under the proposed mandate.

**Table 8:
Summary Results for Members Aged 0 to 64 with Fully-Insured Commercial Policies**

	2016	2017	2018	2019	2020	Weighted Average	5 Yr Total
Members (000s)	2,329	2,305	2,279	2,253	2,226		
Medical Expense Low (\$000s)	\$49	\$81	\$75	\$74	\$74	\$75	\$353
Medical Expense Mid (\$000s)	\$220	\$365	\$339	\$335	\$331	\$338	\$1,590
Medical Expense High (\$000s)	\$391	\$649	\$603	\$596	\$589	\$601	\$2,827
Premium Low (\$000s)	\$54	\$90	\$83	\$83	\$82	\$83	\$392
Premium Mid (\$000s)	\$244	\$404	\$376	\$371	\$367	\$375	\$1,762
Premium High (\$000s)	\$434	\$718	\$668	\$660	\$652	\$666	\$3,132
PMPM Premium Low	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003	\$0.003
PMPM Premium Mid	\$0.012	\$0.015	\$0.014	\$0.014	\$0.014	\$0.014	\$0.014
PMPM Premium High	\$0.022	\$0.026	\$0.024	\$0.024	\$0.024	\$0.024	\$0.024
Estimated Monthly Premium	\$475	\$489	\$503	\$518	\$533	\$489	\$489
Premium % Rise Low	0.001%	0.001%	0.001%	0.001%	0.001%	0.001%	0.001%
Premium % Rise Mid	0.003%	0.003%	0.003%	0.003%	0.003%	0.003%	0.003%
Premium % Rise High	0.005%	0.005%	0.005%	0.005%	0.005%	0.005%	0.005%

5.2. Impact on Medicare supplement plans

The extent to which the prevalence of dementia and Alzheimer’s disease among people with Medicare supplement plans differs from the prevalence in the general population over 64 is difficult to determine. But the APCD and available research suggest a range considerably higher than the prevalence for the conditions relevant to this bill (dementia, Alzheimer’s disease, and ASD) in the under-65 population, resulting in a considerably higher impact on PMPM premiums.

Compass estimated an annual PMPM premium increase range for the fully-insured Medicare supplement market of \$0.16 to \$0.31. As noted, this assumes no cost sharing on the part of the member.

5.3. Impact on the GIC

The proposed mandate is assumed to apply to both fully-insured and self-insured plans operated for state and local employees by the Group Insurance Commission (GIC), with an effective date for all GIC policies on July 1, 2016.

Because the benefit offerings of GIC plans are similar to most other commercial plans in Massachusetts, and likewise do not currently cover active locator devices, the estimated PMPM effect of the proposed mandate on GIC coverage is not expected to differ from that calculated for the other fully-insured plans in Massachusetts. To estimate the medical expense separately for the GIC,

the PMPM medical expense for the general fully-insured population was applied to the GIC membership starting in July of 2016.

Table 9 breaks out the GIC-only fully-insured membership and the GIC self-insured membership and the corresponding incremental medical expense and premium. Note that the total medical expense and premium values for the general fully-insured membership displayed in Table 8 also include the GIC fully-insured membership. Finally, the proposed mandate is assumed to require the GIC to implement the provisions on July 1, 2016; therefore, the results in 2016 represent approximately one half of an annual value.

**Table 9:
GIC Summary Results**

	2016	2017	2018	2019	2020	Weighted Average	5 Yr Total
GIC Fully-Insured							
Members (000s)	59	59	59	59	59		
Medical Expense Low (\$000s)	\$1	\$2	\$2	\$2	\$2	\$2	\$9
Medical Expense Mid (\$000s)	\$4	\$9	\$9	\$9	\$9	\$9	\$40
Medical Expense High (\$000s)	\$7	\$17	\$16	\$16	\$16	\$16	\$70
Premium Low (\$000s)	\$1	\$2	\$2	\$2	\$2	\$2	\$10
Premium Mid (\$000s)	\$4	\$10	\$10	\$10	\$10	\$10	\$44
Premium High (\$000s)	\$8	\$18	\$17	\$17	\$17	\$17	\$78
GIC Self-Insured							
Members (000s)	263	263	263	262	262		
Medical Expense Low (\$000s)	\$4	\$9	\$9	\$9	\$9	\$9	\$39
Medical Expense Mid (\$000s)	\$18	\$42	\$39	\$39	\$39	\$39	\$176
Medical Expense High (\$000s)	\$31	\$74	\$69	\$69	\$69	\$70	\$313

Appendix A: Membership Affected by the Proposed Mandate

Membership potentially affected by a proposed mandate may include Massachusetts residents with fully-insured employer-sponsored health insurance issued by a Massachusetts licensed company (including through the GIC), non-residents with fully-insured employer-sponsored insurance issued in Massachusetts, Massachusetts residents with individual (direct) health insurance coverage, and, in some cases, lives covered by GIC self-insured coverage. Membership projections for 2016 to 2020 are derived from the following sources.

Total Massachusetts population estimates for 2012, 2013, and 2014 from U. S. Census Bureau data³⁷ form the base for the projections. Distributions by gender and age, also from the Census Bureau,³⁸ were applied to these totals. Projected growth rates for each gender/age category were estimated from Census Bureau population projections to 2030.³⁹ The resulting growth rates were then applied to the base amounts to project the total Massachusetts population for 2016 to 2020.

The number of Massachusetts residents with employer-sponsored or individual (direct) health insurance coverage was estimated using Census Bureau data on health insurance coverage status and type of coverage⁴⁰ applied to the population projections.

To estimate the number of Massachusetts residents with fully-insured employer-sponsored coverage, projected estimates of the percentage of employer-based coverage that is fully-insured were developed using historical data from the Medical Expenditure Panel Survey Insurance Component Tables.⁴¹

To estimate the number of non-residents covered by a Massachusetts policy – typically cases in which a non-resident works for a Massachusetts employer offering employer-sponsored coverage – the number of lives with fully-insured employer-sponsored coverage was increased by the ratio of the total number of individual tax returns filed in Massachusetts by residents⁴² and non-residents⁴³ to the total number of individual tax returns filed in Massachusetts by residents.

The number of residents with individual (direct) coverage was adjusted further to subtract the estimated number of people previously covered by Commonwealth Care who moved into MassHealth due to expanded Medicaid eligibility under the Affordable Care Act.⁴⁴

Projections for the GIC self-insured lives were developed using GIC base data for 2012,⁴⁵ 2013,⁴⁶ and 2014⁴⁷ and the same projected growth rates from the Census Bureau that were used for the Massachusetts population. Calculations of GIC self-insured lives used breakdowns of the population by gender and age based on Census Bureau distributions.

Endnotes

¹ The 188th General Court of the Commonwealth of Massachusetts, House Bill 956: An act concerning the safety of autistic and alzheimer individuals. Accessed 10 March 2015: <https://malegislature.gov/Bills/188/House/H956>. The 189th General Court of the Commonwealth of Massachusetts House Bill 913: An act concerning the safety of autistic and alzheimer individuals. Accessed 18 March 2015: <https://malegislature.gov/Bills/189/House/H913>.

² *Ibid.*

³ *Ibid.*

⁴ U.S. National Institutes of Health (NIH), National Institute on Aging (NIH-NIA), Alzheimer's Disease Education and Referral Center: About Alzheimer's Disease: Alzheimer's Basics. Accessed 17 February 2015: <http://www.nia.nih.gov/alzheimers/topics/alzheimers-basics>.

⁵ *Op. cit.* NIH-NIA: About Alzheimer's Disease: Alzheimer's Basics.

⁶ Plassman BL, Langa KM, Fisher GG, et. al. Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology*. 2007;29(1-2):125-32. Accessed 17 February 2015: <http://www.ncbi.nlm.nih.gov/pubmed/17975326>.

⁷ *Op. cit.* NIH-NIA: About Alzheimer's Disease: Alzheimer's Basics.

⁸ Hebert LE, Weuve J, Scherr PA, et. al. Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology* 2013;80(19):1778–83. Accessed 17 February 2015: <http://www.ncbi.nlm.nih.gov/pubmed/23390181>.

⁹ Alzheimer's Association. Early Onset Dementia: A National Challenge, A Future Crisis. Published 2006; accessed 17 February 2015: http://www.alz.org/national/documents/report_earlyonset_summary.pdf.

¹⁰ Alzheimer's Association. 2014 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, Volume 10, Issue 2. Accessed 17 February 2015: http://www.alz.org/downloads/Facts_Figures_2014.pdf.

State-by-state prevalence of Alzheimer's disease: These state-by-state prevalence numbers are based on an unpublished analysis of incidence data from the Chicago Health and Aging Project (CHAP), projected to each state's population, with adjustments for state-specific age, gender, years of education, race and mortality provided to the Alzheimer's Association in 2013 by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

¹¹ NIH National Institute of Neurological Disorders and Stroke (NIH-NINDS): Autism Fact Sheet. Updated 6 November 2014; accessed 18 February 2015: http://www.ninds.nih.gov/disorders/autism/detail_autism.htm.

¹² NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH-NICHHD): Autism Spectrum Disorder (ASD) Condition Information. Updated 16 January 2014; accessed 18 February 2015: <http://www.nichd.nih.gov/health/topics/autism/conditioninfo/Pages/default.aspx>.

¹³ *The Massachusetts Autism Commission Report*. Published March 2013. p. 9. Accessed 5 March 2015: www.mass.gov/hhs/autismcommission.

¹⁴ U.S. CDC: Safety and Children with Disabilities, Wandering (Elopement). Updated 1 August 2014; accessed 18 February 2015: <http://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html>.

¹⁵ *Op. cit.* U.S. CDC: Safety and Children with Disabilities, Wandering (Elopement).

¹⁶ AWAARE Collaboration: Wandering Dangers. Accessed 20 February 2015: <http://awaare.nationalautismassociation.org/>.

¹⁷ Anderson C, Law JK, Daniels A, et. al. Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics*. 2012 Nov;130(5):870-7.

¹⁸ Alzheimer's Association, Alzheimer's and Dementia Caregiver Center: Wandering and Getting Lost. Accessed 17 February 2015: <http://www.alz.org/care/alzheimers-dementia-wandering.asp#ixzz3S1oEiBdL>.

¹⁹ Massachusetts Acts of 2010, Chapter 207, “An Act Relative to Insurance Coverage for Autism.” Accessed 12 March 2015: <https://malegislature.gov/Laws/SessionLaws/Acts/2010/Chapter207>.

²⁰ Autism Insurance Resource Center at New England INDEX. The Massachusetts Autism Insurance Law (aka ARICA) Frequently Asked Questions. Waltham, MA; UMass Medical School, The Shriver Center. 2011. Accessed 4 March 2015: <http://www.mass.gov/eohhs/docs/eohhs/autism/arica-factsheet.pdf>.

What treatments are covered under ARICA?

The law covers the following care prescribed, provided, or ordered for an individual diagnosed with one of the Autism Spectrum Disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:

- *Habilitative or Rehabilitative Care* – this includes professional, counseling and guidance services and treatment programs, including but not limited to, applied behavior analysis supervised by a board certified behavior analyst, that are necessary to develop, maintain and restore, to the maximum extent practicable, the functioning of an individual .
- *Pharmacy care* -medications prescribed by a licensed physician and health -related services deemed medically necessary to determine the need or effectiveness of the medications, to the same extent that pharmacy care is provided by the insurance policy for other medical conditions.
- *Psychiatric care* - direct or consultative services provided by a psychiatrist licensed in the state in which the psychiatrist practices.
- *Psychological care* -direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices.
- *Therapeutic care* - services provided by licensed or certified speech therapists, occupational therapists, physical therapists or social workers.

²¹ More information can be found at <http://chiamass.gov/ma-apcd/>.

²² *Op. cit. The Massachusetts Autism Commission Report*. Published March 2013. p. 9.

²³ Alzheimer’s Association™. Early Onset Dementia: A National Challenge, A Future Crisis. June 2006. p. 10. Accessed 3 March 2015: https://www.alz.org/national/documents/report_earlyonset_full.pdf.

²⁴ U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement, 2006. Internet release date: August 1, 2007. Accessed 16 March 2015: https://www.census.gov/population/www/socdemo/men_women_2006.html.

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