

LEGISLATIVE COMMITTEE MINUTES

SB414

Bill as Introduced

SB 414-FN-A - AS INTRODUCED

2022 SESSION

22-2882
05/04

SENATE BILL ***414-FN-A***

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

SPONSORS: Sen. Avard, Dist 12; Sen. French, Dist 7; Sen. Gannon, Dist 23; Sen. Reagan, Dist 17; Sen. Carson, Dist 14; Sen. Rosenwald, Dist 13; Sen. Hennessey, Dist 1; Sen. Whitley, Dist 15; Sen. Watters, Dist 4; Sen. Soucy, Dist 18; Sen. Birdsell, Dist 19; Sen. Prentiss, Dist 5; Rep. Burt, Hills. 39; Rep. Ammon, Hills. 40; Rep. Hunt, Ches. 11; Rep. Knirk, Carr. 3

COMMITTEE: Health and Human Services

ANALYSIS

This bill revises the definition of ADRD, Alzheimer's disease and related disorders, and makes a \$1 appropriation to the department of health and human services for respite care services for persons caring for individuals with ADRD.

Explanation: Matter added to current law appears in ***bold italics***.
Matter removed from current law appears ~~[in brackets and struck through]~~
Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twenty Two

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 1 Alzheimer's Disease and Related Disorders. Amend RSA 161-F:66, I to read as follows:

2 I. "ADRD", Alzheimer's disease and related disorders, means ~~[a condition which]~~ **conditions**
3 **for which an individual** receives a differential diagnosis of Alzheimer's disease or a similar
4 irreversible dementia, **or for which an individual demonstrates symptoms of Alzheimer's**
5 **disease or a similar irreversible dementia to an extent such symptoms interfere with**
6 **activities of daily living.**

7 2 Appropriation. There is hereby appropriated to the department of health and human services
8 the sum of \$1 for the biennium ending June 30, 2023 for the purpose of providing respite care
9 services for caregivers of individuals with ADRD pursuant to RSA 161-F:66 -161-F:70. The governor
10 is authorized to draw a warrant for said sum out of any money in the treasury not otherwise
11 appropriated. Funds appropriated in this section shall be nonlapsing.

12 3 Effective Date. This act shall take effect July 1, 2022.

LBA
22-2882
12/23/21

**SB 414-FN-A- FISCAL NOTE
AS INTRODUCED**

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

FISCAL IMPACT:

Due to time constraints, the Office of Legislative Budget Assistant is unable to provide a fiscal note for this bill, as introduced, at this time. When completed, the fiscal note will be forwarded to the Senate Clerk's Office.

AGENCIES CONTACTED:

Department of Health and Human Services

**SB 414-FN-A FISCAL NOTE
AS INTRODUCED**

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

FISCAL IMPACT: State County Local None

STATE:	Estimated Increase / (Decrease)			
	FY 2022	FY 2023	FY 2024	FY 2025
Appropriation	\$0	\$1	\$0	\$0
Revenue	\$0	\$0	\$0	\$0
Expenditures	\$0	Indeterminable Increase	Indeterminable Increase	Indeterminable Increase
<i>Funding Source:</i>	<input checked="" type="checkbox"/> General	<input type="checkbox"/> Education	<input type="checkbox"/> Highway	<input type="checkbox"/> Other

METHODOLOGY:

This bill revises the definition of Alzheimer's disease and related disorders to include circumstances in which "an individual demonstrates symptoms of Alzheimer's disease or a similar irreversible dementia to an extent such symptoms interfere with activities of daily living." The Department of Health and Human Services states that the change is intended to capture situations in which individuals become symptomatic well before receiving a formal diagnosis, or in which individuals display symptoms but do not go to a doctor out of fear of a diagnosis. RSA 167-F:66 currently requires the Department to provide statewide respite care services to individuals, including those with Alzheimer's disease. The Department notes that it received \$327,000 in FY 2021 and \$302,508 each year of the FY 2022/23 biennium for the administration of respite care services. The Department further notes that 234 caregivers utilized respite funds in FY 2020, and 227 caregivers utilized such funds in FY 2021. The Department states that while it is unable to determine the number of additional caregivers who will seek funds as a result of the change contained in the bill, it expects that budgeted appropriations will be insufficient to fund care for all newly-eligible individuals.

This bill contains a nonlapsing appropriation of \$1 for the biennium ending June 30, 2023. The bill has an effective date of July 1, 2022, so any fiscal impact will begin in FY 2023.

AGENCIES CONTACTED:

Department of Health and Human Services

SB 414-FN-A - AS AMENDED BY THE SENATE

02/03/2022 0316s

2022 SESSION

22-2882

05/04

SENATE BILL

414-FN-A

AN ACT

relative to the definition of Alzheimer's disease and related disorders.

SPONSORS:

Sen. Avard, Dist 12; Sen. French, Dist 7; Sen. Gannon, Dist 23; Sen. Reagan, Dist 17; Sen. Carson, Dist 14; Sen. Rosenwald, Dist 13; Sen. Hennessey, Dist 1; Sen. Whitley, Dist 15; Sen. Watters, Dist 4; Sen. Soucy, Dist 18; Sen. Birdsell, Dist 19; Sen. Prentiss, Dist 5; Rep. Burt, Hills. 39; Rep. Ammon, Hills. 40; Rep. Hunt, Ches. 11; Rep. Knirk, Carr. 3

COMMITTEE:

Health and Human Services

AMENDED ANALYSIS

This bill revises the definition of ADRD, Alzheimer's disease and related disorders.

Explanation:

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Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twenty Two

AN ACT relative to the definition of Alzheimer's disease and related disorders.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 1 Alzheimer's Disease and Related Disorders. Amend RSA 161-F:66, I to read as follows:

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6 ***activities of daily living.***

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SB 414-FN-A- FISCAL NOTE
AS INTRODUCED

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

FISCAL IMPACT: State County Local None

STATE:	Estimated Increase / (Decrease)			
	FY 2022	FY 2023	FY 2024	FY 2025
Appropriation	\$0	\$1	\$0	\$0
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Funding Source:	<input checked="" type="checkbox"/> General	<input type="checkbox"/> Education	<input type="checkbox"/> Highway	<input type="checkbox"/> Other

METHODOLOGY:

This bill revises the definition of Alzheimer's disease and related disorders to include circumstances in which "an individual demonstrates symptoms of Alzheimer's disease or a similar irreversible dementia to an extent such symptoms interfere with activities of daily living." The Department of Health and Human Services states that the change is intended to capture situations in which individuals become symptomatic well before receiving a formal diagnosis, or in which individuals display symptoms but do not go to a doctor out of fear of a diagnosis. RSA 167-F:66 currently requires the Department to provide statewide respite care services to individuals, including those with Alzheimer's disease. The Department notes that it received \$327,000 in FY 2021 and \$302,508 each year of the FY 2022/23 biennium for the administration of respite care services. The Department further notes that 234 caregivers utilized respite funds in FY 2020, and 227 caregivers utilized such funds in FY 2021. The Department states that while it is unable to determine the number of additional caregivers who will seek funds as a result of the change contained in the bill, it expects that budgeted appropriations will be insufficient to fund care for all newly-eligible individuals.

This bill contains a nonlapsing appropriation of \$1 for the biennium ending June 30, 2023. The bill has an effective date of July 1, 2022, so any fiscal impact will begin in FY 2023.

AGENCIES CONTACTED:

Department of Health and Human Services

CHAPTER 98
SB 414-FN-A - FINAL VERSION

02/03/2022 0316s

2022 SESSION

22-2882
05/04

SENATE BILL

414-FN-A

AN ACT

relative to the definition of Alzheimer's disease and related disorders.

SPONSORS:

Sen. Avard, Dist 12; Sen. French, Dist 7; Sen. Gannon, Dist 23; Sen. Reagan, Dist 17; Sen. Carson, Dist 14; Sen. Rosenwald, Dist 13; Sen. Hennessey, Dist 1; Sen. Whitley, Dist 15; Sen. Watters, Dist 4; Sen. Soucy, Dist 18; Sen. Birdsell, Dist 19; Sen. Prentiss, Dist 5; Rep. Burt, Hills. 39; Rep. Ammon, Hills. 40; Rep. Hunt, Ches. 11; Rep. Knirk, Carr. 3

COMMITTEE:

Health and Human Services

AMENDED ANALYSIS

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CHAPTER 98
SB 414-FN-A - FINAL VERSION

02/03/2022 0316s

22-2882
05/04

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twenty Two

AN ACT relative to the definition of Alzheimer's disease and related disorders.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 98:1 Alzheimer's Disease and Related Disorders. Amend RSA 161-F:66, I to read as follows:

2 I. "ADRD", Alzheimer's disease and related disorders, means ~~[a condition which]~~ **conditions for**
3 **which an individual** receives a differential diagnosis of Alzheimer's disease or a similar irreversible
4 dementia, **or for which an individual demonstrates symptoms of Alzheimer's disease or a similar**
5 **irreversible dementia to an extent such symptoms interfere with activities of daily living.**

6 98:2 Effective Date. This act shall take effect July 1, 2022.

Approved: May 20, 2022
Effective Date: July 01, 2022

Committee Minutes

SENATE CALENDAR NOTICE
Health and Human Services

Sen Jeb Bradley, Chair
Sen James Gray, Vice Chair
Sen Kevin Avard, Member
Sen Tom Sherman, Member
Sen Rebecca Whitley, Member

Date: January 5, 2022

HEARINGS

Wednesday	01/26/2022	
(Day)	(Date)	
Health and Human Services	Legislative Office Building 101	9:00 a.m.
(Name of Committee)	(Place)	(Time)
9:00 a.m.	SB 401-FN	relative to Medicaid reimbursement rates for hospital birthing services.
9:15 a.m.	SB 403-FN-A	re-establishing the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Farmers Market Nutrition Program.
9:30 a.m.	SB 404-FN	establishing a supplemental nutrition assistance program.
9:45 a.m.	SB 416-FN	relative to behavioral health assessment and treatment for children in out-of-home placements.
10:00 a.m.	SB 414-FN-A	relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.
10:15 a.m.	SB 439-FN	relative to the brain and spinal cord injury advisory council and community-based support program.

EXECUTIVE SESSION MAY FOLLOW

Sponsors:

SB 401-FN

Sen. Bradley
Sen. Sherman
Sen. D'Allesandro
Sen. Avar
Sen. Soucy

Sen. Hennessey
Sen. Carson
Sen. Perkins Kwoka
Sen. Gannon
Rep. Umberger

Sen. Watters
Sen. Gray
Sen. Ricciardi
Sen. Cavanaugh
Rep. Wallner

Sen. Rosenwald
Sen. Whitley
Sen. Prentiss
Sen. Kahn
Rep. Tucker

SB 403-FN-A

Sen. Whitley
Sen. Soucy
Sen. Perkins Kwoka
Sen. Prentiss
Rep. Deshaies

Sen. Bradley
Sen. Birdsell
Sen. Watters
Rep. Myler

Sen. Rosenwald
Sen. Sherman
Sen. Kahn
Rep. Wazir

Sen. Hennessey
Sen. Gannon
Sen. Cavanaugh
Rep. Luneau

SB 404-FN

Sen. Whitley
Sen. Watters
Sen. Sherman
Rep. Edwards
Rep. Deshaies

Sen. Hennessey
Sen. Bradley
Sen. Gannon
Rep. Rice

Sen. Rosenwald
Sen. Perkins Kwoka
Sen. Cavanaugh
Rep. Wallner

Sen. D'Allesandro
Sen. Soucy
Sen. Prentiss
Rep. Luneau

SB 416-FN

Sen. Whitley
Sen. Perkins Kwoka
Sen. Sherman
Rep. Wallner

Sen. Hennessey
Sen. Watters
Sen. Prentiss
Rep. Luneau

Sen. D'Allesandro
Sen. Soucy
Rep. Rice
Rep. Myler

Sen. Rosenwald
Sen. Carson
Rep. Rombeau

SB 414-FN-A

Sen. Avar
Sen. Carson
Sen. Watters
Rep. Burt

Sen. French
Sen. Rosenwald
Sen. Soucy
Rep. Ammon

Sen. Gannon
Sen. Hennessey
Sen. Birdsell
Rep. Hunt

Sen. Reagan
Sen. Whitley
Sen. Prentiss
Rep. Knirk

SB 439-FN

Sen. Giuda
Rep. Howard

Sen. Carson

Sen. Gannon

Rep. M. Pearson

Cameron Lapine 271-2104

Jeb Bradley
Chairman

Senate Health and Human Services Committee

Cameron Lapine 271-2104

SB 414-FN-A, relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

Hearing Date: January 26, 2022

Time Opened: 11:02 a.m.

Time Closed: 11:16 a.m.

Members of the Committee Present: Senators Bradley, Gray, Avard, Sherman and Whitley

Members of the Committee Absent: None

Bill Analysis: This bill revises the definition of ADRD, Alzheimer's disease and related disorders.

Sponsors:

Sen. Avard

Sen. French

Sen. Gannon

Sen. Reagan

Sen. Carson

Sen. Rosenwald

Sen. Hennessey

Sen. Whitley

Sen. Watters

Sen. Soucy

Sen. Birdsell

Sen. Prentiss

Rep. Burt

Rep. Ammon

Rep. Hunt

Rep. Knirk

Who supports the bill: Senator Kevin Avard (Senate District 12), Wendi Aultman and John Williams (DHHS), Mackenzie Nicholson (Alzheimer's Association), Senator David Watters (Senate District 4), Senator Sharon Carson (Senate District 14), Senator Harold French (Senate District 7), Senator Regina Birdsell (Senate District 19), Senator Erin Hennessey (Senate District 1), Senator Cindy Rosenwald (Senate District 13), Senator Bill Gannon (Senate District 23), David Sky, Bev Cotton, Richard Crocker, Jessica Wright, Nancy Brennan, Randy Hayers, Halie DesRosiers, Jim Isaak, Roger DesRosiers, Sharon Monroe, Jill Sinclair, Delores Perrotta, Jennifer Delaney (AARP New Hampshire), Ryan Donnelly (Granite State Independent Living), Michelle Wangerin (New Hampshire Legal Assistance), Merry Fortier, and Kathleen Hoey.

Who opposes the bill: Curtis Howland and William Domenico.

Who is neutral on the bill: None.

Summary of testimony presented in support:

Senator Kevin Avard

Senate District 12

- Senator Avard said that the content of SB 414-FN-A was originally passed unanimously in 2020, but, because of the COVID-19 pandemic, the bill fell through the cracks.
- Senator Avard said that the bill changes the definition of Alzheimer's to include people who are symptomatic but not diagnosed. He said that this will expand the population of people who are eligible for Alzheimer's Disease and Related Dementias (ADRD) respite grants.
- Senator Avard said that the ADRD program was written in 1989 and has since provided for respite care for individuals with the diagnosis. He said that this care is funded by the General Fund and administered by the Family Caregiver Supports and Consumer Directed Programs at the Department of Health and Human Services (DHHS) and only individuals with an ADRD diagnosis can access grant.
- Senator Avard said that many people may not have a formal diagnosis and these grants can provide a small amount of relief for their caregivers.
- Senator Avard described being a caregiver for someone suffering from ADRD as having a full-time job, which is emotionally and economically exhausting, since caregivers often have to cut back at work to provide care.
- Senator Avard described providing assistance for caregivers as a win-win for families so that they can spend ample time with their loved ones and get them the care they need.
- Senator Avard said that the appropriation in SB 414-FN-A is \$1. He said that DHHS has indicated they have American Rescue Plan (ARP) funds to cover the increase. He said that the appropriation in the 2020 bill was \$100,000.
- Senator Avard emphasized the bipartisan nature of SB 414-FN-A.

Mackenzie Nicholson

Public Policy Manager, Alzheimer's Association, Massachusetts/New Hampshire Chapter

- Ms. Nicholson said that New Hampshire has 26,000 individuals with Alzheimer's and 57,000 caregivers who take care of those people. She described how difficult the job of a caregiver is in assisting loved ones with many aspects of daily living.
- Ms. Nicholson said that 83% of help to these older adults comes from family and friends who are unpaid. She said that all of this assistance totals to 82 million hours of care.
- Ms. Nicholson explained that many caregivers have to cut back hours or take a leave of absence from their employment. She said that, in some cases, they may even have to leave the workforce. She said caregivers must also deal with depleted income from health care or other services for their loved ones.
- Ms. Nicholson said that the cost of care for someone with ADRD in 2020 was \$373,000, and 70% of this is borne by family caregivers. She said that examples of these costs included unpaid caregiving, medication, and food.
- Ms. Nicholson said that caregivers deal with increased emotional stress and 74% of caregivers report that they are somewhat-to-very concerned about maintaining their own health, as the stress of providing care increases their susceptibility to illness.

- Ms. Nicholson said that New Hampshire does have a respite grant which would allow family members of those with ADRD to take a break while knowing that their loved ones are being cared for safely. She said that the difficulty lies in the fact that one must be diagnosed with Alzheimer's or dementia in order to access the grant.
- Ms. Nicholson explained how some providers are hesitant to formally diagnose someone with Alzheimer's or dementia due to the stigma which surrounds those two diseases. She said that a definitive diagnosis is also very costly and time consuming since it includes scans, tests, and, potentially, a lumbar puncture.
- Ms. Nicholson described how transportation can be an issue for those who live in rural areas.
- Ms. Nicholson said that access to the respite grant will be beneficial because it will provide a better chance of helping caregivers so that they do not get burnt out.
- Ms. Nicholson described her personal experience with her 66-year-old mother whom she described as withdrawn along with barely being able to walk and having trouble with recalling words and actions. She said this is because her mother is struggling with the middle-to-late stages of dementia.
- Ms. Nicholson said that while she can help with care, she must balance taking care of her parents with taking care of her own children.
- Ms. Nicholson described her father, who is her mother's primary care giver, as being in-over-his head with respect to being a caregiver.
- Ms. Nicholson said she worries that if her father had to step away from caregiving in order to tend to another matter, her mother could stop taking her medication or stop eating. Ms. Nicholson said her parents simply cannot access respite care due to her mother lacking a formal diagnosis.
- Ms. Nicholson said that in 2025, the amount of New Hampshire citizens with this disease will be 32,000 and will increase as the population continues to get older.
- Ms. Nicholson said that ADRD are incurable and fatal diseases which are absolutely heartbreaking to witness.

John Williams and Wendi Aultman

Legislative Director, and Bureau Chief, Elderly and Adult Services, DHHS

- Mr. Williams said that DHHS supports SB 414-FN-A.
- Mr. Williams said that Senator Bradley was the sponsor of the similar bill in 2020 that died on the table due to the COVID-19 pandemic. He said that the only change in language is the addition of "which" on Line 3.
- Mr. Williams said that the Legislative Budget Assistant said in December that it did not have time to complete a fiscal note. He said that DHHS and the Bureau of Elderly and Adult Services has secured what it believes to be sufficient funds through ARP funds.
- Mr. Williams said the policy of SB 414-FN-A is wonderful.
- Senator Bradley asked, given the appropriation is \$1, what the actual cost will be.
 - Ms. Aultman said that it is estimated at \$117,000 per fiscal year. She said that she did not have the utilization figures for Fiscal Year 2022, but 227 caregivers were served through the grant and she anticipates that that number would

grow. She said that if the need is demonstrated, more funds can be requested in the next budget.

- Senator Bradley asked if, since DHHS is planning to use ARP funds, Ms. Aultman had gone to the Fiscal Committee.
 - Ms. Aultman cited the Older Americans Act Title III. She said that the value of the grant has been increased to \$2,000.
- Senator Bradley asked if Section 2 of SB 414-FN-A was necessary.
 - Ms. Aultman said that it was not and said that ARP funds go until September of 2023.
- Senator Bradley asked if the grants would be included in the next budget.
 - Ms. Aultman said that they would.

Summary of testimony presented in opposition: None.

Neutral Information Presented: None.

cml

Date Hearing Report completed: January 28, 2022

Speakers

Senate Health & Human Services Committee SIGN-IN SHEET

Date: Wednesday, January 26th, 2022 Time: 10:00 a.m.

SB 414- FN-A AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

Name/Representing (please print neatly)

Name/Representing (please print neatly)	Support	Neutral	Oppose	Speaking?	Yes	No
✓ Wendi Aultman & John Williams DHHS	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>		<input checked="" type="checkbox"/>	<input type="checkbox"/>
✓ Mackenzie Nicholson Alzheimer's Association	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input checked="" type="checkbox"/>	<input type="checkbox"/>
✓ Sen Assad	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input checked="" type="checkbox"/>	<input type="checkbox"/>
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Senate Remote Testify

Health and Human Services Committee Testify List for Bill SB414 on 2022-01- Support: 26 Oppose: 2

<u>Name</u>	<u>Title</u>	<u>Representing</u>	<u>Position</u>
Watters, Senator David	An Elected Official	Myself	Support
Carson, Senator Sharon	An Elected Official	Myself	Support
French, Senator Harold	An Elected Official	Senate District 7	Support
Birdsell, Senator Regina	An Elected Official	Senate District 19	Support
Hennessey, Sen. Erin	An Elected Official	Myself	Support
Rosenwald, Cindy	An Elected Official	SD 13	Support
Gannon, Senator Bill	An Elected Official	SD 23	Support
Sky, David	A Member of the Public	Myself	Support
Cotton, Bev	A Member of the Public	Myself	Support
Crocker, Richard	A Member of the Public	Myself	Support
Wright, Jessica	A Member of the Public	Myself	Support
Brennan, Nancy	A Member of the Public	Myself	Support
Hayes, Randy	A Member of the Public	Myself	Support
Hennessey, Erin	An Elected Official	Myself	Support
DesRosiers, Halie	A Member of the Public	Myself	Support
Isaak, Jim	A Member of the Public	Myself	Support
Lacroix, Marc	A Member of the Public	Myself	Support
DesRosiers, Roger	A Member of the Public	Myself	Support
Broe, Sharon	A Member of the Public	Myself	Support
Sinclair, Jill	A Member of the Public	Myself	Support
Perrotta, Delores	A Member of the Public	Myself	Support
Delaney, Jennifer	A Lobbyist	AARP New Hampshire	Support
Donnelly, Ryan	A Member of the Public	Granite State Independent Living	Support
Wangerin, Michelle	A Lobbyist	New Hampshire Legal Assistance	Support
Fortier, Merry	A Member of the Public	Myself	Support
Hoey, Kathleen	A Member of the Public	Myself	Support
Howland, Curtis	A Member of the Public	Myself	Oppose
Domenico, William	A Member of the Public	Myself	Oppose

Testimony

Sen. Avard Introductory Remarks SB414

SB414-FN-A: relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders and making an appropriation therefor.

Sponsors: (Prime) Avard (R), French (R), Gannon (R), Reagan (R), Carson (R), Rosenwald (D), Hennessey (R), Whitley (D), Watters (D), Donna Soucy (D), Birdsell (R), Prentiss (D), Burt (R), Ammon (R), Hunt (R), Knirk (D)

Status: Senate Health and Human Services

Hearing: Wednesday, 1/26/2022 at 10:00am in the Legislative Office Building

—

Thank you, Chairman Bradley and members of the committee. My name is Sen. Kevin Avard, representing New Hampshire Senate District 12. I come before you today asking for your support for SB414, an act relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders and making an appropriation therefor. At first glance this legislation may be familiar to some of you. In 2020, this same legislation was introduced as SB742-FN, and adopted by the Senate Health and Human Services committee unanimously, and on the floor by a voice vote. The bill came out of the Senate Finance Committee unanimously but was laid on the table with hundreds of other bills during the pandemic. I have provided you with a copy of the 2020 bill docket.

This bill changes the definition of Alzheimer's disease and related disorders to include people who are symptomatic of these diseases for the purposes of expanding the population of Granite Staters who would be eligible for an Alzheimer's Disease and Related Disorders Program (ADRD) respite grant. The ADRD program was written into New Hampshire state statutes in 1989 and provided for respite care services for individuals with a diagnosis of Alzheimer's disease or other related disorders. These respite care services

are funded by State General Funds and administered by Family Caregiver Supports and Consumer Directed Programs at the NH Department of Health and Human Services.

Under current law, only individuals with formal Alzheimer's or other dementia diagnoses may access the grant. There are many reasons why an individual may not seek or be given a formal diagnosis quickly which will be laid out before you today. These respite grants can provide a small amount of relief to caregivers who are caring for a loved one who experiences one of these conditions. Caring for a loved one with Alzheimer's or dementia is a full-time job and can be emotionally and economically exhausting, with many caregivers cutting back at work or leaving the workforce altogether to provide care for their loved ones at home.

Any assistance we can provide to the 57,000 caregivers in the Granite State helping a loved one with Alzheimer's or dementia stay in their homes for as long as possible is a win-win for families, the state, and the long-term care system in New Hampshire. For these reasons, I ask that you vote Ought to Pass on SB414. **One item to note is that the appropriation in the bill is set at \$1, and the Department has indicated they have ARPA funds to cover the increase.** In the 2020 legislation, the sum appropriated to cover the additional population was only \$100,000. Thank you.

alzheimer's association®

January 26, 2022

The Honorable Jeb Bradley
Chairman, Senate Health and Human Services

The Honorable James Gray
Vice-Chairman, Senate Health and Human Services

Thank you, Chairman Bradley and members of the committee. My name is MacKenzie Nicholson and I am the Public Policy Manager of the Alzheimer's Association, MA/NH chapter. I am here before you today asking for your support for SB414, an act relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

As Senator Avard mentioned, in New Hampshire, there are an estimated 26,000 individuals living with Alzheimer's or other dementia and an estimated 57,000 caregivers providing care to them. Caregivers of those living with Alzheimer's and dementia have incredibly difficult jobs and often assist their loved ones with one or more activities of daily living (ADLs), including bathing, dressing, and eating as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation.

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers and in 2020 alone, caregivers in New Hampshire provided more than 82 million hours of unpaid care to loved ones experiencing Alzheimer's or dementia at an estimated economic value of more than \$1.4 billion.

In order to provide this care to their loved one, many caregivers report needing to cut back hours, take a leave of absence or leave the workforce entirely. They also experience depleted income and finances due to paying for healthcare or other services for themselves and those living with dementia. The total lifetime cost of care for someone with dementia was estimated at \$373,527 in 2020. Seventy percent of the lifetime cost of care is borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses for items ranging from medications to food for the person with dementia.

In addition to the economic burden placed on these caregivers, as the person with dementia's symptoms worsen, caregivers often experience increased emotional stress, depression and new or exacerbated health problems. Seventy-four percent of caregivers of people with Alzheimer's or other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver. Evidence also suggests that the stress of providing dementia care increases caregivers' susceptibility to a multitude of disease and health complications.

All this to say that caregiving can be physically, emotionally and financially challenging.

To help reduce the burden on caregivers, New Hampshire has a respite grant which, when received, can assist a caregiver in acquiring alternative care for their loved one so that they can take a break while knowing that their loved one is safely cared for. However, current law states that in order to access the respite grant, you must have Alzheimer's or other dementia thus preventing access for those without a formal diagnosis.

There are many reasons why someone may not have a formal diagnosis. For example:

- Some medical providers are resistant, for one reason or another, to make an official diagnosis;
- There is still a stigma around dementia and it may be easier to discuss that the patient is exhibiting signs of dementia rather than exploring a full diagnosis;
- In some areas, transportation is an issue and even getting someone to the medical provider's office can be difficult;
- Family members can have a hard time exploring a diagnosis, so the medical provider takes baby steps with them and discusses how the patient has symptoms of dementia; and
- Lastly, testing for a definitive Alzheimer's or dementia diagnosis can be incredibly time consuming and costly. Often it can take multiple specialists visits, cognitive tests, scans and even a lumbar puncture to make a diagnosis.

We know that having access to respite is more beneficial when started as soon as possible, not when someone is in the later stages of the dementia process – as the caregiver may be already burnt out. If we can provide respite early on, we have a better chance of helping the caregiver care for their loved one in the home for a longer period of time. In order to do this, we need to change the definition of Alzheimer's disease and related disorders to include those who are symptomatic, which is what SB414 seeks to do.

The fight against Alzheimer's and dementia is personal for me. Growing up and even until a few short years ago my mom was an outgoing, active and happy woman who loved to bake pies with her grandkids and hand out candy at Halloween. Now, 66, she is withdrawn, can hardly walk, has trouble finding words and recalling even something as simple as what she had for lunch. I know in my heart that my mom is likely in the middle stages of dementia.

I'm lucky that I live close enough to help my dad with her care. In fact, approximately one-quarter of dementia caregivers are in my situation and a part of the "sandwich generation" — meaning that we not only care for an aging parent, but also for our children. Because my dad is my mom's primary caregiver, I don't have a good insight as to what happens during my mom's medical appointments. Either out of love, denial, or fear, my dad has not pushed doctors to determine a reason for why my mom has slowly gotten worse over the past few years. My dad is in over his head with her care, something he will freely admit and I worry about them night and

day. I worry that if something were to happen to my dad or if he needed to travel to attend to family elsewhere that my mom would forget to take medication or eat - something that has happened before! Unfortunately, my parents would not be eligible for an ADRD respite grant if they were to seek it because my mom lacks a formal diagnosis.

My mom's story is not unique, and although I have a personal connection, I know I am not alone. By 2025, the number of Granite Staters living with the disease is expected to increase to 32,000, and as our state continues to age, that number is only going to grow. Alzheimer's is an incurable, fatal disease that is incredibly heartbreaking to witness. I ask that you vote Ought to Pass on SB414 so that we can better support those living with Alzheimer's and other forms of dementia and their caregivers. Thank you.

Mackenzie Nicholson
Public Policy Manager
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Expand Access to Critical Respite Grant Funding for Caregivers

In recent years, family members and friends of those living with Alzheimer's or other related dementias have provided unpaid care worth nearly \$257 billion dollars, and around 15.3 billion hours throughout the United States. From 2006 to 2009 I was one of those unpaid caregivers. My grandmother Alberta started showing signs of Alzheimer's in 2008 and needed consistent care by early 2009. My aunts and I were Alberta's fulltime caregivers until we could secure an apartment in an assisted living facility where she spent the last few months of her life.

Eighty percent of older adults with dementia need help with personal care such as bathing, dressing, eating, and toileting. Often it is a family member that helps with these activities of daily living, and it can be embarrassing for both parties. My grandmother suffered so many UTIs because she was too embarrassed to ask for our help.

Two-thirds of unpaid caregivers expect to continue to provide this care for upwards of 5 years or more. Those 5 years or more can be very tolling on the caregiver, both mentally, and physically. They often have no experience or training, which makes it even more difficult.

After my grandmother passed, I decided on a career path as a licensed nurse assistant. It was during that time that I truly realized how straining caring for someone with dementia could be. Now that I have both this professional and personal experience under my belt, I can truly see why respite for these unpaid caregivers is desperately needed. During my time as an LNA I became injured due to the physical demands of the job and subsequently needed surgery. Just last week I was told last week that I am at maximum medical improvement and need to find another career path. This may be somewhat easy for me given my professional background, but family caregivers do not have the luxury of passing the baton to a coworker if they get injured, become ill, or just need a mental break from it all. Caregivers' health often deteriorates and is often put on the backburner because of their need and want to care for their loved one. Depression among caregivers of those with dementia is higher than caregivers of others. The physical and emotional impact of dementia caregiving is estimated to have resulted in \$11.8 billion in healthcare costs in the United States. That estimate is from 2018, can you imagine the cost now, 4 years later?

There are an estimated 57,000 caregivers providing care to a loved one with Alzheimer's or dementia in New Hampshire and that number is expected to increase as our state continues to age. Without adequate access to respite the strain on caregivers may become too much and affect their long-term health as well as how long those with the disease are able to remain at home. On

behalf of myself and the many other caregivers in our state, please vote Ought to Pass on SB414, an act relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders so that those of us who can and want to provide care to our loved ones are able to.

Sincerely,

Denika Jones

PO Box 2328

Salem, New Hampshire 03079



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January 26, 2022

Senate Health and Human Services Committee
New Hampshire Senate
State House
Concord, New Hampshire 03301

RE: AARP New Hampshire Testimony in Support of SB 414

Dear Chairman Bradley and Committee Members:

Thank you for your support on the issues most important to residents 50+ in the Granite State. AARP NH urges favorable passage of Senate Bill No. 414 relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders (ADRD) and making an appropriation therefor.

177,000 caregivers across the Granite state provide on average 148 hours of care per year, with a value of \$2,300,000 to the State. While Alzheimer's disease is the most common cause of dementia in older adults, other irreversible dementia related disorders interfere with daily living and require caregiving services. It is critical that all ADRD caregiver have access to respite care, and appropriations are made for this purpose.

Today, 42 million caregivers provide an invaluable resource in caring for friends and family at home — many on call 24 hours a day, seven days a week. Caring for a loved one with ADRD can be particularly taxing. This labor of love is worth more than \$450 billion in unpaid care each year. And because of family caregivers' commitment, millions of older people are able to live at home rather than in costly institutions such as nursing homes. Respite care provides caregivers a temporary rest from caregiving, while the person living with ADRD continues to receive care in a safe environment.

AARP is fighting to make sure respite care programs are available in the community to all caregivers and strongly urges the Health and Human Services Committee to favorably report out Senate Bill 414. Thank you.

Respectfully submitted,

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<https://www.aarp.org/content/dam/aarp/ppi/2019/11/family-caregivers-data-by-state.pdf>



Complete Document

Can Be Viewed

In Bill Folder

2020 Report

Caregiving in the U.S.



Conducted by

AARP

Family Caregiving™

naac
National Alliance for Caregiving

Acknowledgments

The National Alliance for Caregiving (NAC) and AARP are proud to present *Caregiving in the U.S. 2020*. Many people played important roles throughout the research process, including:

- | | |
|--|---|
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| Patrice A. Heinz , Vice President, Strategy & Operations, National Alliance for Caregiving | Lynn Friss Feinberg , MSW, Senior Strategic Policy Advisor, AARP Public Policy Institute |
| Gabriela Prudencio , MBA, Hunt Research Director, National Alliance for Caregiving | Laura Skufca , MA, Senior Research Advisor, AARP |
| Michael R. Wittke , BSW, MPA, Senior Director, Public Policy and Advocacy, National Alliance for Caregiving | Robert Stephen , MBA, Vice President, Health & Caregiving, AARP Programs |
| | Rita Choula , MA, Director, Caregiving Projects, AARP Public Policy Institute |

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- Carol Levine, MA, Senior Fellow, United Hospital Fund, New York City (former Director of UHF Families and Health Care Project)
- Feylyn Lewis, PhD, Research Fellow, University of Sussex
- David Lindeman, PhD, Director Health, Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley; Director, Center for Technology and Aging (CTA)
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- Steve Schwab, CEO, Elizabeth Dole Foundation (with special thanks to Laurel Rodewald)
- Regina A. Shih, PhD, Senior Policy Researcher, RAND Corporation

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- | | |
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| Home Instead Senior Care® | UnitedHealthcare |
| TechWerks | |

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I. Introduction

This study presents a portrait of unpaid family caregivers¹ today. The National Alliance for Caregiving (NAC) and AARP are proud to present *Caregiving in the U.S. 2020*, based on data collected in 2019.

A national profile of family caregivers first emerged from the 1997 *Caregiving in the U.S.* study. Related studies were conducted in 2004, 2009, and 2015 by NAC in collaboration with AARP. This study builds on those prior efforts and replicates the new methodology implemented in 2015, allowing for examination of changes to caregiving since the last data collection effort in 2015.

The core areas we examined in this study include the following:

- The prevalence of caregivers in the United States
- Demographic characteristics of caregivers and care recipients
- The caregiver's situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregiving affects caregiver stress, strain, and health
- Financial impact on caregivers
- Impacts on and supports provided to working caregivers
- Information needs and resources
- Technology and role of online supports

Because adult caregivers' circumstances can vary markedly depending on the age of their care recipient, NAC and AARP will be publishing two companion reports in the coming months that separately explore the experiences of caregivers whose recipient is (a) age 18 to 49, with trend comparisons to the 2015 study; and (b) age 50 or older, with trend comparisons to the 2015 study.

OVERVIEW OF METHODOLOGY

This report is based on nationally representative quantitative online surveys with 1,392 caregivers ages 18 and older. Caregivers of adults are defined as those who provide unpaid care, as described in the following question:

At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

¹ Family caregivers are not exclusively related to the person they are providing care to; they include any adult who provides unpaid care or support to a family member or friend.

Caregivers of younger adults less often report having health insurance (80 percent vs. 88 percent of those caring for someone age 50 or older). They less often report their younger recipient is a veteran (6 percent), as compared to those caring for an older recipient (16 percent of recipients are veterans).

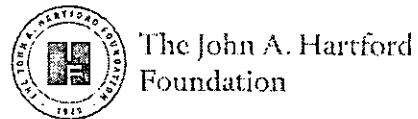
Figure 89 (continued). Demographic Summary by Care Recipient Age

	Total (n = 1,392)	Caregivers of Younger Adults 18-49 (n = 188) A	Caregivers of Older Adults 50+ (n = 1,204) B
Caregiver Has Health Insurance			
Yes	87%	80%	88% ^A
No	13%	20% ^B	11%
Caregiver Source of Health Insurance			
Employer-sponsored	56%	53%	57%
Medicare	20%	18%	21%
Medicaid	9%	11%	9%
Direct purchase	8%	10%	7%
Military/Veterans	4%	5%	4%
Caregiver Service in Armed Forces			
Served on active duty	9%	8%	10%
Did not ever serve	91%	92%	90%
Caregiver LGBTQ Status			
Yes	8%	10%	7%
No	91%	87%	92%
Care Recipient Living Location			
Urban/Suburban	69%	64%	69%
Rural	31%	36%	30%
Care Recipient Service in Armed Forces			
Served on active duty	14%	6%	16% ^A
Did not ever serve	83%	90% ^B	82%

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020.
<https://doi.org/10.26419/ppi.00103.001>

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Voting Sheets

Senate Health and Human Services Committee

EXECUTIVE SESSION RECORD

2021-2022 Session

Bill # SB 414 - FN-A

Hearing date: 1/26/22

Executive Session date: 1/26/22

Motion of: Committee Amendment to strike Section 2 Vote: 5-0

Committee Member	Present	Made by	Second	Yes	No
Sen. Bradley, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Gray, Vice Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Avard	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Sherman	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Whitley	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Motion of: OTPA Vote: 5-0

Committee Member	Present	Made by	Second	Yes	No
Sen. Bradley, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Gray, Vice Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Avard	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Sherman	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Whitley	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Motion of: Consent Vote: 5-0

Committee Member	Present	Made by	Second	Yes	No
Sen. Bradley, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Gray, Vice Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Avard	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Sherman	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Sen. Whitley	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Reported out by: Sen. Avard

Notes: _____

Committee Report

STATE OF NEW HAMPSHIRE

SENATE

REPORT OF THE COMMITTEE
FOR THE CONSENT CALENDAR

Wednesday, January 26, 2022

THE COMMITTEE ON Health and Human Services

to which was referred SB 414-FN-A

AN ACT

relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

Having considered the same, the committee recommends that the Bill

ought to pass with amendment

by a vote of: 5-0

Amendment # 0316s

Senator Kevin Avar
For the Committee

SB 414-FN-A revises the definition of ADRD (Alzheimer's disease and related disorders) and makes a \$1 appropriation to the Department of Health and Human Services for respite care services for persons caring for individuals with ADRD. There are many reasons why someone may not receive a formal diagnosis of ADRD, including travel circumstances, stigma-related family objections, or medical roadblocks, but the caregivers of those individuals are still being put in extremely difficult positions. Those caregivers should still be eligible for the ADRD respite care grants that are available. The Committee Amendment removes the appropriation, given that the Department is working with the Fiscal Committee to use American Rescue Plan Act funds for these grants.

Cameron Lapine 271-2104

FOR THE CONSENT CALENDAR

HEALTH AND HUMAN SERVICES

SB 414-FN-A, relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

Ought to Pass with Amendment, Vote 5-0.

Senator Kevin Avard for the committee.

SB 414-FN-A revises the definition of ADRD (Alzheimer's disease and related disorders) and makes a \$1 appropriation to the Department of Health and Human Services for respite care services for persons caring for individuals with ADRD. There are many reasons why someone may not receive a formal diagnosis of ADRD, including travel circumstances, stigma-related family objections, or medical roadblocks, but the caregivers of those individuals are still being put in extremely difficult positions. Those caregivers should still be eligible for the ADRD respite care grants that are available. The Committee Amendment removes the appropriation, given that the Department is working with the Fiscal Committee to use American Rescue Plan Act funds for these grants.

Docket of SB414

Docket Abbreviations

Bill Title: (New Title) relative to the definition of Alzheimer's disease and related disorders.**Official Docket of SB414.:**

Date	Body	Description
12/23/2021	S	To Be Introduced 01/05/2022 and Referred to Health and Human Services; SJ 1
1/6/2022	S	Hearing: 01/26/2022, Room 101, LOB, 10:00 am; SC 2
1/26/2022	S	Committee Report: Ought to Pass with Amendment #2022-0316s , 02/03/2022; Vote 5-0; CC; SC 5
2/3/2022	S	Committee Amendment #2022-0316s , AA, VV; 02/03/2022; SJ 2
2/3/2022	S	Ought to Pass with Amendment 2022-0316s, MA, VV; OT3rdg; 02/03/2022; SJ 2
3/23/2022	H	Introduced 03/17/2022 and referred to Health, Human Services and Elderly Affairs
3/29/2022	H	Public Hearing: 04/05/2022 11:25 am LOB 205-207
4/8/2022	H	Executive Session: 04/05/2022 10:00 am LOB 205-207
4/11/2022	H	Committee Report: Ought to Pass (Vote 21-0; CC) HC 15 P. 10
4/21/2022	H	Ought to Pass: MA VV 04/21/2022 HJ 10
5/13/2022	S	Enrolled Adopted, VV, (In recess 05/12/2022); SJ 13
5/13/2022	H	Enrolled (in recess of) 05/12/2022
5/24/2022	S	Signed by the Governor on 05/20/2022; Chapter 0098; Effective 07/01/2022

NH House

NH Senate

Other Referrals

Senate Inventory Checklist for Archives

Bill Number: SB 414-FV-A

Senate Committee: HHS

Please include all documents in the order listed below and indicate the documents which have been included with an "X" beside

Final docket found on Bill Status

Bill Hearing Documents: {Legislative Aides}

- Bill version as it came to the committee
- All Calendar Notices
- Hearing Sign-up sheet(s)
- Prepared testimony, presentations, & other submissions handed in at the public hearing
- Hearing Report
- Revised/Amended Fiscal Notes provided by the Senate Clerk's Office

Committee Action Documents: {Legislative Aides}

All amendments considered in committee (including those not adopted):

___ - amendment # _____ ___ - amendment # _____
___ - amendment # _____ ___ - amendment # _____

- Executive Session Sheet
- Committee Report

Floor Action Documents: {Clerk's Office}

All floor amendments considered by the body during session (only if they are offered to the senate):

___ - amendment # _____ ___ - amendment # _____
___ - amendment # _____ ___ - amendment # _____

Post Floor Action: (if applicable) {Clerk's Office}

- Committee of Conference Report (if signed off by all members. Include any new language proposed by the committee of conference):
- Enrolled Bill Amendment(s)
- Governor's Veto Message

All available versions of the bill: {Clerk's Office}

as amended by the senate ___ as amended by the house
 final version

Completed Committee Report File Delivered to the Senate Clerk's Office By:

Cameron M. Jofine
Committee Aide

7-18-02
Date

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