



Territory of Guam
Territorio Guam

OFFICE OF THE GOVERNOR
UFISINAN I MAGA'LAHI
AGANA, GUAM 96910 U.S.A.

MAR 25 1993

REFER TO
LEGISLATIVE SECRETARY

The Honorable Joe T. San Agustin
Speaker, Twenty-Second Guam Legislature
155 Hesler Street
Agana, Guam 96910

A handwritten mark, possibly initials, in dark ink.

Dear Mr. Speaker:

Transmitted herewith is Bill No. 194 which I have signed into law this date as
Public Law 22-01.

Sincerely yours,

A handwritten signature in dark ink, appearing to read "Joseph F. Ada".

JOSEPH F. ADA
Governor of Guam

220118

Attachment

RECEIVED
OFFICE OF THE SPEAKER
DATE: 3/25/93
TIME: 2:30
RECD BY: [Signature]

TWENTY-SECOND GUAM LEGISLATURE
1993 (FIRST) Regular Session


CERTIFICATION OF PASSAGE OF AN ACT TO THE GOVERNOR

This is to certify that Substitute Bill No. 194 (LS), "AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES," was on the 16th day of March, 1993, duly and regularly passed.



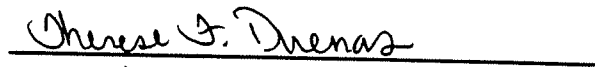
JOE T. SAN AGUSTIN
Speaker

Attested:



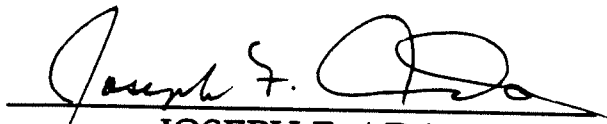
PILAR C. LUJAN
Senator and Legislative Secretary

This Act was received by the Governor this 17th day of March
1993, at 4:30 o'clock P.M.



Cheresse S. Duenas
Assistant Staff Officer
Governor's Office

APPROVED:



JOSEPH F. ADA
Governor of Guam

Date: MAR 25 1993

Public Law No. 22-01

TWENTY-SECOND GUAM LEGISLATURE
1993 (FIRST) Regular Session

Bill No. 194 (LS)

As substituted by its author and
as amended by the Committee on Rules

Introduced by:

D. L. G. Shimizu
E. P. Arriola
J. P. Aguon
C. T. C. Gutierrez
M. Z. Bordallo
M. D. A. Manibusan
D. F. Brooks
F. P. Camacho
T. S. Nelson
T. C. Ada
H. D. Dierking
P. C. Lujan
V. C. Pangelinan
D. Parkinson
E. D. Reyes
J. T. San Agustin
F. R. Santos
J. G. Bamba
A. C. Blaz
T. V. C. Tanaka
A. R. Unpingco

AN ACT TO DEVELOP A RESPITE CARE PROGRAM
FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND
DISABILITIES.

1 BE IT ENACTED BY THE PEOPLE OF THE TERRITORY OF GUAM:

2 Section 1. Findings and purpose. The Legislature finds that thousands
3 of families on Guam have children and adult members who require long-term
4 care because of a chronic or terminal illness or a major disability. Families

1 are the greatest resource available to those members who have a chronic
2 illness or disability and are the major providers of such persons' support,
3 care, and training. Such families often experience considerable physical,
4 emotional and financial stress associated with their care-giving
5 responsibilities. They must be supported on an on-going basis to assist them
6 in meeting such responsibilities while providing for continued care in the
7 home.

8 Persons with chronic or terminal illness or disability present medical,
9 economic and legal issues of extreme importance that have a substantial
10 impact on the lives of their families and on the whole community. Respite
11 care is one approach and response to the territory's need for effective,
12 accessible and affordable temporary care to help maintain and support
13 families and care-givers, while recognizing the critical importance of family
14 support to a family's ability to care for and nurture at home a member with a
15 chronic illness or disability.

16 The Legislature recognizes that although there are programs operating
17 to provide support to families who provide home care for members who are
18 chronically ill or disabled, those services do not comprise a comprehensive
19 system. Various approaches are needed to better support these families.

20 Finally, the Legislature finds that it is in the best interest of the territory
21 to preserve, strengthen, and maintain the family unit through the provision
22 of necessary support to families who have members with chronic illnesses or
23 disabilities. Failure to provide such support can precipitate abuse, major
24 family disruptions, or premature and inappropriate placement of these
25 individuals in costly institutions, nursing homes, or foster care settings.
26 Additionally, assistance and support in their care-giving roles enhance a

1 family's capacity to provide care and improve the quality of life for the entire
2 family, including the member with the disability or chronic illness.

3 **Section 2. Development of Respite Care Program.** The Department of
4 Public Health and Social Services, serving as the lead agency, the Governor's
5 Commission on Persons With Disabilities, and the Guam Developmental
6 Disabilities Planning Council are hereby directed to jointly and cooperatively
7 develop a Respite Care Program (the "Program") with corresponding quality
8 standards for individuals with chronic illnesses or disabilities, which Program
9 shall be family and consumer focused and directed, and shall include jointly
10 conducted on-going monitoring and evaluation activities of its operations.

11 **Section 3. Definition of respite care.** "Respite care" means in-home or
12 out-of-home temporary, non-medical care for families who have children or
13 adult members with chronic or terminal illnesses or disabilities. "Disability"
14 means (i) a physical or mental impairment which substantially limits one (1)
15 or more major life activities, or (ii) having a record of such an impairment, or
16 (iii) being regarded as having such an impairment.

17 **Section 4. Scope of respite care services.** Respite care services shall be
18 designed to:

- 19 A. Assist family members in maintaining the member with a
20 chronic illness or disability at home.
- 21 B. Provide temporary appropriate care and supervision to ensure
22 the individual's safety in the absence of family members.
- 23 C. Temporarily relieve family members from the constantly
24 demanding responsibility of caring for the individual with a
25 chronic illness or disability.
- 26 D. Attend to the individual's basic self-help needs and other
27 activities of daily living, including interaction, socialization

1 and continuation of the usual daily routine which would
2 ordinarily be performed by family members.

3 **Section 5. Rules and regulations.** The Director of Public Health and
4 Social Services, in accordance with the Administrative Adjudication Law, and
5 in consultation with the Governor's Commission on Persons With
6 Disabilities, and with the Guam Developmental Disabilities Planning
7 Council, shall adopt rules and regulations for the efficient and effective
8 implementation of the Respite Care Program authorized by this Act.

9 **Section 6. Program development: report to the Legislature.** Not more
10 than sixty (60) days after the enactment of this Act, the agencies required
11 under Section 2 of this Act to jointly develop an appropriate Respite Care
12 Program shall do so, including a program budget by categories, a report of
13 which shall be transmitted to the Legislature within thirty (30) days
14 thereafter.

15 **Section 7. Budget.** The budget for salaries, contracts, operations,
16 planning, development, and implementation of the program as provided in
17 this Act shall be submitted annually by the Department of Public Health and
18 Social Services (the "Department"), via the Bureau of Budget and
19 Management Research, for approval by the Legislature. The Legislature
20 shall appropriate funds to the Department, which shall disburse the same
21 pursuant to its directives and policies. Unexpended funds shall be maintained
22 in a continuing budget appropriation for use by the Department in succeeding
23 budget cycles.

TWENTY-SECOND GUAM LEGISLATURE

1993 (FIRST) Regular Session

Date: 3/16/93

VOTING SHEET

Bill No. 194

Resolution No. _____

Question: _____

NAME	AYE	NO	NOT VOTING/ ABSTAN	ABSENT/ OUT DURING ROLL CALL
ADA, Thomas C.	✓			
AGUON, John P.				✓
ARRIOLA, Elizabeth P.	✓			
BAMBA, J. George	✓			
BLAZ, Anthony C.	✓			
BORDALLO, Madeleine Z.	✓			
BROOKS, Doris F.	✓			
CAMACHO, Felix P.	✓			
DIERKING, Herminia D.	✓			
GUTIERREZ, Carl T. C.	✓			
LUJAN, Pilar C.	✓			
MANIBUSAN, Marilyn D. A.	✓			
NELSON, Ted S.	✓			
PANGELINAN, Vicente C.	✓			
PARKINSON, Don				✓
REYES, Edward D.	✓			
SAN AGUSTIN, Joe T.	✓			
SANTOS, Francisco R.	✓			
SHIMIZU, David L. G.	✓			
TANAKA, Thomas V. C.			✓	
UNPINGCO, Antonio R.	✓			

TOTAL

18 1 2

March 5, 1993

The Honorable
Joe T. San Agustin
Speaker, 22nd Guam Legislature
Agana, Guam



TWENTY SECOND
GUAM LEGISLATURE

via: Committee on Rules

Dear Mr. Speaker:

The Committee on Health, Ecology & Welfare, to which was referred BILL NO. 194: AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE, herein reports back and recommends that **Bill No.194 be passed as substituted by Author.**

Dr. DAVID L.G. SHIMIZU
Senator

CHAIRMAN:	<u> 9 </u> _____	To Pass
Committee on	<u> 0 </u> _____	Not To Pass
Health,	<u> 0 </u> _____	To The Inactive File
Ecology	<u> 0 </u> _____	Abstained
and	<u> 0 </u> _____	Off-Island
Welfare	<u> 0 </u> _____	Not Available

324 West Soledad Ave.
Suite 202,
Agaña, Guam
96910

Telephone:
(671)472-3543/44/45

Facsimile:
(671)472-3832

Sincerely,


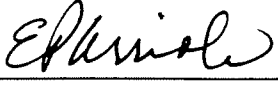
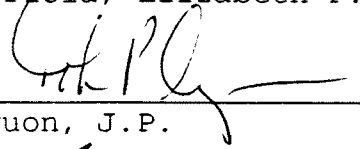
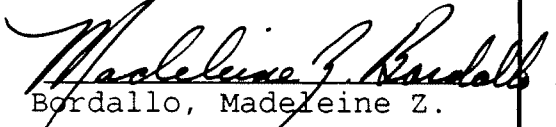

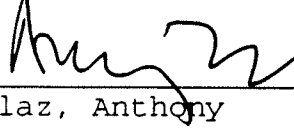
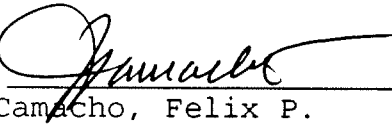
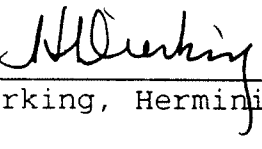

Dr. David L.G.
Shimizu

Attachments



VOTE SHEET
Committee on Health, Ecology & Welfare

Substitute Bill 194: AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE.

SENATOR	TO PASS	TO PASS	ABSTAIN	FILE
 Shimizu, David G.G.	✓			
 Arriola, Elizabeth P.	✓			
 Aguon, J.P.	✓			
 Bordallo, Madeleine Z.	✓			
 Brooks, Doris F.	✓			
 Blaz, Anthony	✓			
 Camacho, Felix P.	✓			
 Dierking, Herminia	✓			
 Manibusan, Marilyn D.A.	✓			

COMMITTEE ON HEALTH, ECOLOGY AND WELFARE

COMMITTEE REPORT ON BILL NO.194

AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE

BACKGROUND

Bill No. 194 (Attachment I) was referred to the Committee on Health, Ecology and Welfare on January 21, 1993 (Attachment II). The Bill was introduced by Senator David L. G. Shimizu. A Fiscal Note was requested from the Bureau of Budget and Management Research on February 16, 1993 (Attachment III). The Bureau advised that "Bill No. 194 would require an operating budget with personnel. At this time the fiscal impact is not available" (Attachment IV).

The Committee on Health, Ecology and Welfare conducted a public hearing on Wednesday, February 24, 1993, 3:00 p.m., in the Legislative Public Hearing Room. The committee members present include: Senator David L. G. Shimizu, Chairman; Senator Elizabeth P. Arriola, Vice Chairperson; Senator Doris Flores Brooks; Senator Marilyn D.A. Manibusan; and Senator Felix P. Camacho. The hearing was very well attended by both service providers and consumers.

TESTIMONY

The Committee heard and received written testimony from Dr. Leticia V, Espaldon, Director of Public Health and Social Services; Dr. Steve Spencer, 2nd Vice Chairperson, Developmental Disabilities Planning Council; Mrs. Frances Limitaco Standing Soldier, Executive Director, Developmental Disabilities Planning Council; Mr. Benito S. Servino, Executive Director, Commission on Persons with Disabilities; Ms. Lola C. Rojas, Executive Director, Guma' Mami, Inc.; Mr. Jose S. Perez, Chairperson, Guam Council on Senior Citizens, and District Director of Guam AARP, Inc.; Mr. Danny Aurgon, Disabled American Trade Enterprise; Ms. Arlene Aguon Castro, program coordinator with Guam' Mami and a family member dealing with two (2) family members requiring respite; Ms. Jelly N. Flores, President, Autism society of Guam; Mr. Eduardo R. Chanco, a private citizen; Mr. Peter

A. Blas, case manager from Guma' Mami; Mr. Gerald M. Day, Autism Society of Guam; Ms. Anita Lujan Manglona, a private citizen; Ms. Margaret Artero; Ms. Erin Powers, a private citizen; Mr. Aurelio Z. Delos Reyes, Autism Society of Guam; Mr. Lawrence E. Williams, Autism Society of Guam; Dr. Faye E. Mata, Department of Education, Division of Special Education; Ms. Susan A. Warne, Acting Executive Director, Guam Legal Services Corporation; Mr. Juan T. M. Toves, President, Guam Association of Retired Persons; Mrs. Lenore C. Cabot, Project Director, Interfaith Volunteer Caregivers, Inc.; and Mrs. Cerila M. Rapadas, Executive Director, Catholic Social Services.

The following is a synopsis of the testimonies presented.

1. Dr. Leticia V. Espaldon, Director of Public Health and Social Services, aside from submitting a written testimony (Attachment V), appeared at the hearing along with a staff member of the Division of Senior Citizens, Mr. Robert R. Kelly. She started her testimony by stating that, aside from the many valid findings incorporated within Bill No. 194, respite support to caregivers is also an integral part of a program to attempt to alleviate the occurrence and/or reoccurrence of abuse. She went on and said the Department of Public Health and Social Services welcomes the opportunity to, along with the Commission of Persons with Disabilities and the Developmental Disabilities Planning Council, define the eligibility standards and to develop a flexible respite care program to assist as great a number of individuals as possible. Finally, she recommended some change in the language of Section 3, to prevent and confusion regarding the appropriation.

2. Dr. Steve Spencer and Mrs. Frances Limitaco Standing Soldier of the Developmental Disabilities Planning Council appeared together at the hearing and submitted a joint testimony (Attachment VI) on Bill No. 194, which was presented by Mrs. Standing Soldier. The Council strongly supports the measure because the bill will provide support to families caring for members with disabilities and chronic illnesses. The Council noted that there are approximately 2,520 individuals with developmental disabilities on Guam. Some families that have a member with a developmental disability cope with extraordinary circumstances and needs, emotional stress, time demands, and financial costs. The development of a respite care program for families on Guam as proposed by Bill No. 194 is urgently needed and a progressive step in the development of territorial policy.

3. Mr. Benito S. Servino of the Commission on Persons with Disabilities appeared and presented a written testimony in behalf of the Chairperson, Mr. Roland L.G. Taimanglo, and the commission members (Attachment VII). Mr. Servino testified that "the Commission fully supports Bill No. 194 as it represents an important step forward in our Territory's effort to improve the availability of adequate services to meet the needs of persons with disabilities and their families." He went on and said that the Respite

Care Program to be established by Bill No. 194, will enable families to access and choose temporary care arrangements that best meets their needs and preferences in view of the fact that it has become increasingly evident that the traditional access to traditional extended family supports have diminished due to the necessity of employment and other demands on the primary care givers. He also recommended that the definition be amended to reflect the severity of the individual's impairment.

4. Ms. Maria San Nicolas, a staff from Guma' Mami, Inc., appeared and presented the written testimony of Ms. Lola C. Rojas, Executive Director, (Attachment VIII) who was ill. Ms. Rojas' testimony noted that "... it is not only my responsibility but a pleasure to provide ... testimony in support of Bill No. 194. She said that Guma' Mami, Inc., is grateful and welcome the opportunity to continue to support any endeavor which would alleviate the hardships encountered by persons with disabilities and their families, which Bill No. 194 proposes to do.

5. Mr. Jose S. Perez of the Council on Senior Citizens testified that he wanted to be put on record as favoring of Bill No. 194, and wanted to commend the Committee on Health, Ecology and Welfare for introducing the Bill. In his written testimony (Attachment IX), Mr. Perez said that Bill No. 194 "... is most needed on Guam to relieve the caregivers, temporarily, a much needed rest thus improving the quality care for persons with chronic illnesses or disabilities."

6. Mr. Aurgon did not present any written testimony but made an oral one. He said that he came to the hearing "... to manifest his wholehearted support of Bill No. 194, because it is a necessity for the island and an investment in the future."

7. Ms. Arlene Aguon Castro's testimony (Attachment X) was presented from (1) as a program coordinator for the Independent Living Skills Training Center of Guma' Mami, Inc., wherein respite care is lacking in the delivery of professional service and (2) as family member dealing with not one but family member requiring long-term medical care required respite. She said that "... Guam needs to acknowledge, endorse and provide services not only to the client but support services to the family caregivers ... [as] respite care provisions would guarantee quality care and life enrichment"

8. Ms. Jelly N. Flores presented her written testimony (Attachment XI) from the standpoint of founder and president of the Autism Society of Guam, member of the Developmental Disability Planning Council, Autism Consultant for the Department of Education and a parent of a child with autism. She said that autism is a lifelong developmental disability in which individuals may experience difficulty in language and communication, social development and behavioral responses to their environment. "Families

who have a child with autism often experience on-going stress. Aspects of the family that may be impacted by a family member with autism include: family recreation, finances, social relations with friends relatives, spouses and neighbors and the emotional, physical and well-being of parents and siblings." Because of the care needed by a child with autism, respite care has been identified as a basic need, with the need increasing as the child get older. Bill No. 194, therefore, meets an essential, critical need for the families who have children with autism and she looks forward to the passage of the bill and to actively participating in the planning process as the respite care program is developed.

9. Mr. Eduardo R. Chanco, a Federal Civil Service employee, presented a written testimony (Attachment XII) wherein he said that he read Bill No. 194, understand its intent and completely support it. However, he recommended that other professionals in the Government of Guam be made available to the lead agencies in the development of the respite care program.

10. Mr. Peter A. Blas of Guma' Mami, Inc., and a caregiver of a profoundly mentally retarded brother presented a written testimony (Attachment XIII) in support of Bill No. 194, and lauded the sponsor of the proposed legislation. He said the Bill is a good start towards assisting those families with disabled individuals requiring constant care.

11. Mr. Gerald N. Day, parent of two disabled children, testified (Attachment XIV) that the respite care program proposed under Bill No. 194, would " ... held eliminate the tension that go on in the families" and provide the needed relief for shopping, funerals, medical appointments, etc.

12. Ms. Anita Lujan Manglona testified orally in support of Bill No. 194, from the standpoint of a professional working with persons with disabilities and a caregiver to a disabled brother. She said that the Bill is long overdue and provides needed relief to caregiving families under stress and tension.

13. Ms. Margaret Artero presented a written testimony (Attachment XV), wherein she noted that Bill No. 194 came about as a result of concerns raised by parents during the 1992 Special Education Conference. She also said that supports the passage of the Bill and hopes "... that the department and organizations that are assigned to develop this program take into consideration the different needs and concerns of persons with disabilities and their families."

14. Ms. Erin Powers, a private citizen with experience working with the disabled community for the past six years, testified orally. She said one of the most frustrating and haunting experience working with persons with disabilities was to encounter individuals whose time, energy and finances are

taxed beyond bearing and realize that there is no service on the island that could relieve them even for a day. The family home life was taxed, stressed and impoverished due to the serious commitment to take care of a family member. The passage of Bill No. 194, into law and implementation would be an answer of desperate prayers to these individuals and family members.

15. Mr. Aurelio Z. Delos Reyes, Autism Society of Guam member, submitted a written testimony (Attachment XVI) in favor of Bill No. 194. He said the bill, if passed into law, will be "... a big relief not only to individuals with chronic illnesses and disabilities but to those who cares for them as they feel safe and could attend to other family matters that entails time thinking that their kids are in good caring hands, even though in a short period of time."

16. Mr. Lawrence E. Williams, Autism Society of Guam member, submitted a written testimony (Attachment XVII) in favor of Bill No. 194, because "... this bill would enable parents like ourselves to be able to enjoy a rare evening out or to go when something important came up, and know our children will be taken care of by someone with the understanding and capabilities to do so." The measure would a break that is most welcomed.

17. Dr. Faye E. Mata of the Department of Education, Division of Special Education, submitted a written testimony (Attachment XVIII) noting that respite care to the support services currently available would:

- a. Reduce stress within the family
- b. Allow parents and family members to "normalize" their lives by being able to participate in recreational and community activities or to pursue activities which will give them personal satisfaction, relaxation and enjoyment.
- c. Reduce social isolation of families.
- d. Assist families through periods of stress and crisis such as illness, divorce, job transfer, moving, birth of a new baby, etc.
- e. Reduce the probability that a child with a disability would be placed outside of his or her own home.
- f. Increase long-term family stability.
- g. Reduce demand for group homes and long-term residential services.

18. Mr. Juan T.M. Toves, President, Guam Association of Retired Persons, submitted a written testimony (Attachment XIX) wherein his association fully endorsed Bill No. 194, as the respite care program would be beneficial to his membership.

19. Ms. Susan A. Warne, Acting Executive Director, Guam Legal Services Corporation, submitted a written testimony (Attachment XX) in favor of Bill No. 194, since a respite program would provide a relief to overstressed caregivers and help reduce the stress level within the family.

The program might well serve to reduce the incidence of abuse against family members.

20. Mrs. Lenore C. Cabot, Project Director of Interfaith Volunteer Caregivers, Inc., submitted a written testimony (Attachment XXI) voicing her personal approval and support of the respite care program planned under Bill No. 194, since its adoption "... is an essential means of support for our elderly, handicapped and family and friends of those in of this service."

21. Mrs. Cerila M. Rapadas, Executive Director, Catholic Social Services, submitted a written testimony (Attachment XXII) noting the importance of the respite care program to be developed under Bill No. 194 and the necessity of this kind of support to patients and families. She went on and said that "the bill is written in a fairly general way, so that there can be some creativity in the programs."

FINDINGS

The Committee finds that thousands of families on Guam have children and adult members who require long-term care because of a chronic or terminal illness or a disability. Families are the greatest resource available to their members with a chronic illness or disability and are the major providers of support, care and training. These families often experience additional physical, emotional and financial stress associated with their caregiving responsibilities. They must supported on an on-going basis to assist them in meeting their caregiving responsibilities while providing for continued care in the home.

Respite care, defined as in-home or out-of-home temporary, non-medical care for families who have children or adult members with chronic or terminal illnesses or disabilities, is one approach and response to the Territory's need for effective accessible and affordable temporary care to help maintain and support families and caregivers, while acknowledging the critical importance of family support to a family's ability to care for and nurture a member with a chronic illness and/or disability at home. Persons with chronic or terminal illness and /or disability present medical, economic and legal issues of extreme importance that impact on the lives of their families and the whole community.

The Legislature recognizes that although there are programs operating to provide support to families who provide home care for members who are chronically ill or disabled, those services do not comprise a comprehensive system. Various approaches are needed to better support these families. It is, therefore, in the best interest of the Territory to preserve, strengthen and maintain the family unit through the provision of necessary supports to families who have members with chronic illnesses and/or disabilities.

Failure to provide such supports precipitates abuse, major family disruptions, or premature and inappropriate placement of these individuals in costly institutions, nursing homes or foster care settings. Additionally, assistance and support in their caregiving roles enhances a family's capacity to provide care and improves the quality of life for the entire family including the member with disability or chronic illness.

RECOMMENDATION

The Health, Ecology and Welfare Committee, having heard and received testimonies on Bill No. 194, recommends that subject bill **TO DO PASS AS SUBSTITUTED BY THE AUTHOR** (Attachment XXIII).

TWENTY-SECOND GUAM LEGISLATURE
1993 (FIRST) REGULAR SESSION

Bill No. 194
Introduced by:

D.L.G. Shimizu *Shizu*

AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR
INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES
AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE.

BE IT ENACTED BY THE PEOPLE OF THE TERRITORY OF GUAM:

Section 1. Findings and Purpose. The Legislature finds that thousands of families on Guam have children and adult members who require long-term care because of a chronic or terminal illness or a disability. Families are the greatest resource available to their members with a chronic illness or disability and are the major providers of support, care, and training. These families often experience additional physical, emotional and financial stress associated with their caregiving responsibilities. They must be supported on an on-going basis to assist them in meeting their caregiving responsibilities while providing for continued care in the home.

Respite care, defined as in-home or out-of-home temporary, non-medical care for families who have children or adult members with chronic illnesses or disabilities, is one approach and response to the Territory's need for effective accessible and affordable temporary care to help maintain and support families and caregivers, while acknowledging the critical importance of family support to a family's ability to care for and nurture a member with a chronic illness and/or disability at home. Persons with chronic or terminal illness and/or disability present medical, economic and legal issues of extreme importance that impact on the lives of their families and the whole community.

The Legislature recognizes that although there are programs operating to provide support to families who provide home care for members who are chronically ill or disabled, those services do not comprise a comprehensive system. Various approaches are needed to better support these families.

Finally, the Legislature finds that it is in the best interest of the Territory to preserve, strengthen, and maintain the family unit through the provision of necessary supports to families who have members with chronic illnesses and/or disabilities. Failure to provide such supports precipitates abuse, major family disruptions, or premature and inappropriate placement of these individuals in costly institutions, nursing homes, or foster care settings. Additionally assistance and support in their caregiving roles enhances a family's capacity to provide care and improves the quality of life for the entire family including the member with disability or chronic illness.'

Section 2. The Department of Public Health and Social Services, serving as the lead agency, the Governor's Commission on Persons With Disabilities, and Guam Developmental Disabilities Planning Council are hereby directed to jointly and cooperatively develop a Respite Care Program with corresponding quality standards for individuals with chronic illnesses and/or disabilities which is family/consumer focused and directed and jointly conduct on-going monitoring and evaluation activities of the Program. Respite Care services shall be designed to:

1. Assist family members in maintaining the member with a chronic illness and/or disability at home.
2. Provide temporary appropriate care and supervision to ensure the individual's safety in the absence of family members.
3. Temporarily relieve family members from the constantly demanding responsibility of caring for the individual with a chronic illness and/or disability.

4. Attend to the individual's basic self-help needs and other activities of daily living including interaction, socialization and continuation of usual daily routine which would ordinarily be performed by family members.

Section 3. There is hereby appropriated from the General Fund Three Hundred Thousand Dollars (\$300,000) to be utilized for the planning, development, and implementation of the Respite Care Program mandated under Section 2, the service of which may be contracted out. The Department of Public Health and Social Services shall include the Respite Care Program within future budgetary processes and plans.

Section 4. Not more than sixty (60) days after the enactment of this bill into law, the department and organizations enumerated under Section 2 shall have developed an appropriate Respite Care Program, a report of which shall be transmitted to the Legislature within thirty (30) days thereafter.



Perminia D. Dierking

Chairperson, Committee on Rules ~ 22nd Guam Legislature

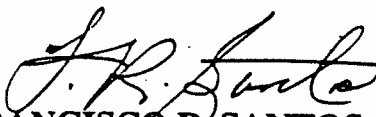


January 21, 1993

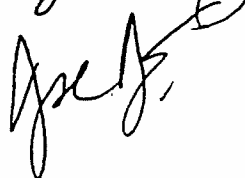
MEMORANDUM

TO: Chairperson, Committee on Health, Ecology and Welfare
FROM: Chairperson, Committee on Rules
SUBJ: Referrals - Bills No. 192 and 194

The above Bills are referred to your Committee. Please note that the referrals are subject to ratification by the Committee on Rules at its next meeting. It is recommended you schedule a public hearing at your earliest convenience.


FRANCISCO R. SANTOS
Acting

Attachments

Received 1-25-93


February 16, 1993

Mr. Giovanni Sgambelluri
Director
Bureau of Budget & Management Research
P.O. Box 2950
Agana, Guam 96910



TWENTY SECOND
GUAM LEGISLATURE

Dear Mr. Sgambelluri:

The Health, Ecology & Welfare Committee will hold a public hearing at the Legislative Hearing Room on Wednesday, February 24, 1993 from 3 p.m. on

Dr. DAVID L.G. SHIMIZU
Senator

Bill 192: AN ACT TO AMEND, REPEAL AND REENACT CERTAIN SECTIONS OF, AND ENACT A NEW ARTICLE AND SUBSECTIONS TO, CHAPTER 34, TITLE 10, GUAM CODE ANNOTATED RELATIVE TO CONTROL AND LICENSING OF PETS, PERMITS FOR ANIMAL FACILITIES AND HUMANE ANIMAL CARE AND QUARANTINE.

CHAIRMAN:
Committee on
Health,
Ecology
and
Welfare

Bill 194: AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUND FOR SUCH PURPOSE.

Bill 140: AN ACT TO ADD A SUBSECTION (d) TO SECTION 2913.10, 10 GCA, TO PROVIDE CARE IN A NURSING HOME FACILITY FOR LYTICO OR BODIG (AMYOTROPHIC LATERAL SCLEROSIS OR PARKINSONISM-DEMENTIA) PATIENTS.

Bill 75: AN ACT RELATIVE TO ESTABLISHING A "HEMOPHILIA MEDICAL FUND PROGRAM" WITHIN THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES FOR THE SPECIFIC PURPOSE OF ASSISTING HEMOPHILIAC PATIENTS.

Please prepare a fiscal note on the above bills pursuant to §9101 2 GCA Chapter 8.

324 West Soledad Ave.
Suite 202,
Agaña, Guam
96910

Telephone:
(671)472-3543/44/45

Facsimile:
(671)472-3832

David L.G. Shimizu
2/16/93

Sincerely,

Dr. David L.G. Shimizu



(72-2825)
CARMEN SUBANKS

FISCAL NOTE
BUREAU OF BUDGET AND MANAGEMENT RESEARCH

BEMR-F7

Bill No. 194
 Amendatory Bill YES NO

Date Received 2-16-93
 Date Reviewed 2-23-93

Department/Agency Affected: Public Health and Social Services
 Department/Agency Head: Dr. Leticia V. Espaldon
 Total FY Appropriation to Date: \$51,881,487

Bill Title (preamble) : AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE.

Change in Law: Yes

Bill's Impact on Present Program Funding:
 Increase Decrease Reallocation No Change

Bill is for: Operations Capital Improvement Other (_____)

FINANCIAL/PROGRAM IMPACT

PROGRAM CATEGORY	<u>ESTIMATED SINGLE-YEAR FUND REQUIREMENTS (Per Bill)</u>		TOTAL
	GENERAL FUND	OTHER	

Health and Welfare _____

ESTIMATED MULTI-YEAR FUND REQUIREMENTS (Per Bill)

<u>FUND</u>	<u>1st</u>	<u>2nd</u>	<u>3rd</u>	<u>4th</u>	<u>5th</u>	<u>TOTAL</u>
GENERAL FUND	<u>See Footnotes</u>	_____	_____	_____	_____	_____
OTHER	_____	_____	_____	_____	_____	_____
TOTAL	_____	_____	_____	_____	_____	_____

FUNDS ADEQUATE TO COVER INTENT OF THE BILL? YES/NO-IF NO, ADD'L AMOUNT REQUIRED \$ _____
 AGENCY/PERSON/DATE CONTACTED: _____/_____/_____

ESTIMATED POTENTIAL MULTI-YEAR REVENUES

<u>FUND</u>	<u>1st</u>	<u>2nd</u>	<u>3rd</u>	<u>4th</u>	<u>5th</u>	<u>TOTAL</u>
GENERAL FUND	_____	_____	_____	_____	_____	_____
OTHER	_____	_____	_____	_____	_____	_____
TOTAL	_____	_____	_____	_____	_____	_____

ANALYST Paul O. Leon Guerrero DATE _____ DIRECTOR Giovanni T. Sgambelluri DATE FEB 24 1993

Bill #194 would require an operating budget with Personnel. At this time



DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES

GOVERNMENT OF GUAM
P. O. BOX 2816
AGANA, GUAM 96910



FEB 23 1993

Senator David L.G. Shimizu
Chairperson
Committee on Health, Ecology and Welfare
Twenty-Second Guam Legislature
Suite 202
324 West Soledad Avenue
Agana, Guam 96910

Dear Senator Shimizu:

On behalf of the Department of Public Health and Social Services, I would like to extend my appreciation to your Committee for your invitation to testify on Bill No. 194 (An Act to Develop a Respite Care Program for Individuals with Chronic Illnesses and Disabilities and to Appropriate Funds for such Purposes).

Upon review of Bill 194, the following comments are considered for your consideration:

In addition to the many valid findings incorporated within this Bill, respite support to caregivers is also an integral part of a program to attempt to alleviate the occurrence and or reoccurrence of abuse.

Unfortunately, to date, the Division of Senior Citizens has received 214 referrals of senior citizens abuse and 125 referrals of abuse to adults with disabilities. In addition to these two groups of individuals, we also add the untold number of children with chronic illnesses and disabilities. In essence, the passage of this legislation will alleviate the stress of and provide necessary support to the caregivers of individuals encompassing all age groups of our society.

The Department of Public Health and Social Services welcomes the opportunity to, along with the Governor's Commission on Persons with Disabilities and the Guam Developmental Disabilities Planning Council, define the eligibility standards and develop a flexible respite care program to assist as great a number of individuals as possible.



Commonwealth Now!

Ltr. to Senator Shimizu
Page 2
Re: Bill 194


Section 3. In order to preclude any confusion regarding the appropriation, we request that Section 3 read

"Section 3. There is hereby appropriated from the General Fund to the Department of Public Health and Social Services, Three Hundred Thousand Dollars (\$300,000) to be utilized for the planning, development, and implementation of the Respite Care Program mandated under Section 2, the service of which may be contracted out. The Department of Public Health and Social Services shall include the Respite Care Program within future budgetary processes and plans."

In closing, I would like to say that we, as a community, share concerns for the education of our children, the preservation of our resources, our economic growth, and we have planned for the future in all of these areas. Now, let us start with the passage of this legislation to initiate the planning of programs to assist the families of, and the individuals who suffer from, chronic illnesses and disabilities. This Bill should be considered an investment in the future of this segment of our society.

Thank you for the opportunity to testify on Bill No. 194. Should you require additional information, please feel free to contact me.

Sincerely,


LETICIA V. ESPALDON, M.D.
Director
Department of Public Health
and Social Services



Developmental Disabilities Planning Council

Member of the National Association Developmental Disabilities Councils

122 IT&E PLAZA, RM. B201, HARMON, GUAM 96911 • TEL: (671) 646-9468/9 • TDD (671) 649-3911 • FAX: (671) 649-7672

JOSEPH F. ADA
Governor

FRANK F. BLAS
Lt. Governor

LUIS S.N. REYES
Chairperson

FRANCES LIMTIACO
STANDING SOLDIER, M.P.H.
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Member

LAURETTA SOTTO
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MARY ANN TAITAGUE
Member

JUDITH ULLOA
Member

NORBERT UNGACTA
Member

MARILYN WINGFIELD, PH.D.
Member

February 24, 1993

Dr. David L.G. Shimizu

Senator

Chairperson, Committee on Health, Ecology, and Welfare

324 West Soledad Ave.

Suite 202

Agana, Guam 96910

Dear Chairperson Shimizu and Committee Members:

On behalf of the Guam Developmental Disabilities Planning Council, we would like to extend our appreciation for the invitation and opportunity to testify on Bill 194: An Act To Develop A Respite Care Program For Individuals With Chronic Illnesses And Disabilities And To Appropriate Funds For Such Purpose. **The DD Council strongly supports Bill 194 and gratefully acknowledges and commends Senator Shimizu and the Committee on its development and for your responsiveness and dedication to supporting families caring for members with disabilities and chronic illnesses.**

The DD Council serves as an advocate for persons with developmental disabilities through systemic change activities directed towards policies that are more likely to result in overall, sustained and significant change within the system of services for persons with developmental disabilities. Under the federal definition, a developmental disability is a long-term and persistent mental, cognitive, or physical impairment that occurs either at birth, in early childhood, or during adolescence up to age of 22, and which shall continue throughout the person's life. Developmental Disabilities limit an individual's mental, physical, or social abilities and functioning, with these functional impairments often resulting in the individual's need for extended or lifelong care, treatment, or other services which are individually planned and coordinated. On Guam, it is estimated that there are 2520 individuals with developmental disabilities (1.8% prevalence rate).

Some families that have a member with a developmental disability cope with extraordinary circumstances and needs, emotional stress, time demands, and financial costs. Increasingly, states are moving away from a traditional provider-driven service system that often separates children from their families, to a

system that empowers families to participate in the process and to choose services that best meets their needs. The development of a respite care program for families on Guam as proposed in Bill 194 is urgently needed and a progressive step in the development of territorial policy that incorporates the following critical keypoints:

1. Assistance with at-home care enhances a family's capacity to provide care and improves the quality of life for the entire family, including the member with a disability or chronic illness.
2. The development of responsive family support programs, such as respite services, provides for the building of a continuum of placement opportunities for families with a member with a disability or chronic illness, whether they be biological, foster, or adoptive.
3. The strengthening of the family structure may be less costly to Guam than funding expensive alternative residential options for children and adults with disabilities or chronic illnesses.

The DD Council is not only personally aware of many families on Guam in need of respite services, but, in 1990, conducted a consumer satisfaction survey and public forum, where it had been documented that the provision of respite services, to families with a member with a developmental disability, was an identified gap in the system of services and most urgently needed. Over the years, the DD Council has known of many families who want their members with a developmental disability to live at home and be a part of their families, however required assistance, including respite services, to do so. At a time when there is increased emphasis on maintaining children and adults with developmental disabilities in home settings, a responsive respite care program is imperative. The development of a program of respite care, defined as in-home or out-of-home temporary, non-medical care for families who have a member with a disability or chronic illness, represents a significant turning point in the Territory's provision of family supports that would improve the quality of life for these families and assist in the maintenance of members with developmental disabilities in a nurturing home environment.

Again, the DD Council extends its support of Bill 194 and is committed to jointly and cooperatively working with the Department of Public Health and Social Services, the Governor's Commission on Persons With Disabilities, and consumer members in the planning and development of a flexible and consumer-directed Respite Care Program including the development of corresponding quality standards, rules, and regulations for the efficient and successful implementation of the program so as to ensure that the program is responsive to the needs of families. The DD Council has also had opportunity to review models of "best practice" and innovative respite care programs implemented incorporating the

provision of "subsidies" and "allocated" respite care services, and stands ready to provide recommendations and technical assistance.

Again, we thank you for your dedication and efforts to support families on Guam in caring for their members with a disability or chronic illness at home and in furthering the establishment of family preservation and support as a territorial agenda.

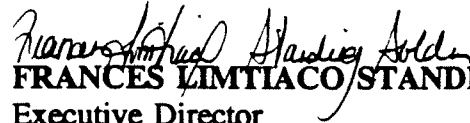
Sincerely,



STEVE SPENCER, ED.D.

2nd Vice Chairperson

Developmental Disabilities Planning Council



FRANCES LIMTIACO STANDING SOLDIER, M.P.H.

Executive Director

Developmental Disabilities Planning Council



GOVERNOR'S COMMISSION ON PERSONS WITH DISABILITIES

P.O. Box 2950 • Agana, Guam 96910 • (671) 472-8931 • Fax: (671) 477-4826 • TDD: 472-1106

February 24, 1993

Senator David L.G. Shimizu
Chairperson
Committee on Health,
Ecology and Welfare
Twenty-Second Guam Legislature
324 West Soledad Ave., Suite 202
Agana, Guam 96910

Dear Senator Shimizu:

On behalf of Mr. Roland L.G. Taimanglo, Chairperson, and the members of the Governor's Commission on Persons with Disabilities, I, Benito S. Servino, Executive Director, thank you for the invitation to testify on Bill No. 194: An Act To Develop A Respite Care Program For Individuals With Chronic Illness And Disabilities And To Appropriate Funds For Such Purpose.

The Commission fully supports Bill No. 194 as it represents an important step forward in our Territory's effort to improve the availability of adequate services to meet the needs of persons with disabilities and their families.

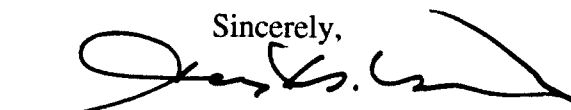
Respite Care will enable families to access and choose temporary care arrangements that best meets their needs and preferences. The need for Respite Care Services had been expressed in a past consumer survey which was conducted by the Developmental Disabilities Planning Council and at a Conference Forum Panel discussion sponsored by Parent Agencies Networking. It has become increasingly important as access to traditional extended family supports have diminished due to the necessity of employment and other demands on the primary care givers.

In almost all state-funded programs, eligibility is based on age, income and disability. With the passage of the Americans with Disabilities Act (ADA) the definition of disability focuses on a physical or mental impairment which substantially limits one or more major life activity, or having a record of such an impairment or being regarded as having such an impairment. This definition broadens the scope of the eligibility criteria when used independently. We recommend that the definition of disability be further clarified to reflect the severity of the individual's impairment.

The Commission looks forward to assisting in the cooperative development of a Respite Care Program and in jointly conducting on-going monitoring and evaluation activities of the Program.

Again, thank you for the opportunity to present input on this important proposed legislation.

Sincerely,



BENITO S. SERVINO



GUMA' MAMI, INC.

A NON-PROFIT CORPORATION

P.O. Box 2148 Agana, Guam 96910 • Office: 477-1505/1757
Independent Group Home: 734-1634 • Mary Clare Home: 477-1165

Board of Directors

February 23, 1993

Pat Mesa
President

Antonio Materne
Vice President

Dr. David L.G. Shimizu
Senator, 22nd Guam Legislature
324 West Soledad Ave.
Suite 202
Agana, Guam 96910

Martha Gogue
Secretary

Connie Duenas
Treasurer

Thank you for your invitation to provide testimony on Bill 194: An Act to Develop a Respite Care Program for individuals with chronic illnesses and disabilities and to appropriate funds for such purpose.

Ben Guerrero
Member

I regret that I will not be able to present this testimony myself because of illness but I would appreciate it if one of my staff will be allowed to read it in my behalf.

John Diaz
Member

GUMA' MAMI extends its gratitude for the interest and sensitivity to the needs of persons with disabilities and their families. You and your staff have established a track record of responsiveness and productivity when it comes to issues of disabilities. For this we are grateful and welcome the opportunity to continue to support any endeavor which would alleviate the hardships encountered by this population in our island community.

Julie Middleton
Member

Lola C. Rojas
Executive Director

Si Yu'os Ma'ase

Lola C. Rojas
LOLA C. ROJAS
Executive Director

TESTIMONY IN SUPPORT OF BILL NO. 194: AN ACT TO DEVELOP A RESPITE CARE PROGRAM FOR INDIVIDUALS WITH CHRONIC ILLNESSES AND DISABILITIES AND TO APPROPRIATE FUNDS FOR SUCH PURPOSE.

Good afternoon, Mr. Chairman and members of the Committee on Health, Ecology and Welfare. Because of illness I am not able to deliver this testimony personally but I am confident that a member of my staff will do a splendid job of presenting my testimony. As Executive Director of Guma' Mami and as a "home-grown" social worker, it is not only my responsibility but a pleasure to provide this testimony in support of Bill No. 194.

Guma' Mami is the only organization on Guam providing residential, community support and day-program services to the adult population with developmental disabilities and mental retardation. In residential services we currently operate two group homes: The Independent Group Home is funded by the Department of Public Health and Social Services and the Mary Clare Home is funded by the Department of Mental Health and Substance Abuse. Our contract with the Department of Public Health and Social Services for residential services includes the provision of respite care services for two clients at a time and long-term residential services for eight clients. The respite care component of residential services is rather limited in both scope and capability.

The Independent Group Home which is tasked with the responsibility for respite care services is already difficult to manage. The eight resident clients are predominantly in the severe to profound level of mental retardation. Their mental deficiencies are further compounded by multiple physical disabilities and exacerbated by self-abusive behavior patterns on the part of two clients. All this translates into life-long supervision and inability to be independently functioning at any point in their lifetime. Given the shortage of available housing and human resources it is a constant challenge to keep this home operational, let alone provide respite care services. In scope, the extent to which respite services is made available is extremely limited and dependent on adequate space and staff. This service is available to those adults with developmental disabilities and mental retardation, a mere fraction of the population of persons with disabilities and their families in need of respite care.

The parents and/or families of our clientele are generally not aggressive in pursuing respite care services and do so mainly in an emergent or crisis situation. The reasons for this hesitance are as varied as the number of persons, none of which is because they do not want or need the service. One which may be of concern is the idea of not making waves which could capsize the boat carrying what little is already available in services.

For the year 1992 Guma' Mami received three requests for respite services in anticipation of the caregiver or another family member requiring off-island medical treatment. Requests for respite care in its true sense are very rare. On a positive note, this may be an indication that our cultural values and beliefs remain intact. The extended family system is still a very much alive and valuable resource. The question that remains unanswered is "To what extent does our island community support and encourage the continued existence and functioning of this valuable resource?"

The recognition and appreciation of this system as a community resource in need of support in order to survive is long overdue. Bill No. 194 is a positive step in the right direction.

Si Yu'os Ma'ase.

Lola C. Rojas
LOLA C. ROJAS
Executive Director
GUMA' MAMI, INC.

When ~~the~~ ~~Committee~~ ~~on~~ ~~Health,~~ ~~Education,~~ ~~and~~ ~~Welfare~~ ~~continued~~ ~~for~~
introduced Bill No. 194, which is most needed
NAME —

~~the Committee~~

Thank you for giving me the
opportunity to testify on bill
no. 194, Respite Care.

I want to be put on record that
I am in favor of bill 194, which
would ~~benefit~~ ~~the~~ ~~for~~ this program
is needed in order to relieve the
caregivers temporarily, a much needed
rest thus improving the quality
care for persons with chronic illness
or disabilities.

Jose S. Perez