

ORAL TESTIMONY

ON

BILL NO. 194

DATE: FEB 24, 1993

GOOD AFTERNOON, I AM ARLENE AGUON CASTRO, I AM EMPLOYED WITH GUMA' MAMI, INC. AS THE PROGRAM COORDINATOR FOR THE INDEPENDENT LIVING SKILLS TRAINING CENTER. MY TESTIMONY HAS A DUAL-PURPOSE AND FUNCTION, NOT ONLY HAS THE LACK OF RESPITE CARE AFFECTED MY PROFESSIONAL SERVICE DELIVERY, BUT I TOO AM A FAMILY MEMBER DEALING WITH NOT ONE BUT TWO FAMILY MEMBERS REQUIRING LONG-TERM MEDICAL CARE AND REQUIRED RESPITE.

PROFESSIONALLY, THROUGH THE ILSTC, GUMA' MAMI PROVIDES A DAY CURRICULUM PROGRAM FOR TWELVE DEVELOPMENTALLY DISABLED ADULTS. DAILY LIVING SKILLS INCLUDE:

- A. SELF HELP SKILLS
- B. SOCIALIZATION SKILLS
- C. HOUSEHOLD MANAGEMENT, AND
- D. PRE-VOCATIONAL WORK SKILLS.

THROUGH THESE CLIENTS WE NETWORK INTO THE PARENTAL AND FAMILY SUPPORT SYSTEM. OUR TREATMENT GOALS ARE THE SAME; TO ALLOW A MENTALLY RETARDED ADULT ACCESS TO SERVICES WHICH WOULD MAXIMIZE INDEPENDENT LIVING SKILLS TO THE GREATEST EXTENT POSSIBLE.

THE ILSTC IS A COMMUNITY INTEGRATED PROGRAM OPERATING ON THE PHILOSOPHY THAT WE PROVIDE INSTRUCTION IN THE "LEAST RESTRICTIVE ENVIRONMENT". IN OTHER WORDS, GUMA' MAMI CLIENTS ARE A VIABLE CONTRIBUTION TO OUR COMMUNITY, AND ~~GUAM NEEDS TO~~ ACKNOWLEDGE,

ENDORSE AND PROVIDE SERVICES NOT ONLY TO THE CLIENT BUT SUPPORTIVE SERVICES TO THE FAMILY CAREGIVERS.

OUR CULTURE IS SO FAMILY FOCUSED, IS THERE A CHAMORRO WORD THAT COMPLIMENTS THE TERM "RESPITE". I LEFT THE ISLAND IN 1980, THE STIGMA OF A GERIATRIC NURSING CARE FACILITY HAS BEEN ELIMINATED. SAINT DOMINIC'S NURSING FACILITY IS OUR PRIMARY EXAMPLE. ALSO THE CREATION OF GUMA TRANKILADAT IN TUMON IS ANOTHER EXAMPLE. BUT BOTH FACILITIES ARE PRESENTLY FULL AND FAMILIES ARE ON A WAITING LIST.

GUMA MAMI BEING UNIQUE IN PROVIDING RESIDENTIAL PLACEMENT IN TWO GROUP HOMES PRESENTLY ALSO HAS A WAITING LIST. PROVIDING SHORT TERM 24 HOUR RESPITE CARE NOW IS NOT POSSIBLE IN THE MARY CLARE HOME AND LIMITED AT THE INDEPENDENT GROUP HOME.

THE ILSTC DAY PROGRAM OFFERS DAY CARE RESPITE FOR THREE SUPPORT SERVICE CLIENTS AND THEIR FAMILIES. THE ILSTC PROGRAM ALSO HAS AN EXTENSIVE WAITING LIST OF APPLICANTS THAT FIT THE ELIGIBILITY CRITERIA. UNFORTUNATELY DUE TO LIMITED FUNDING, STAFF CAPABILITIES AND LACK OF PHYSICAL SPACE, GUMA' MAMI CANNOT PRESENTLY PROVIDE RESPITE SERVICES TO CLIENTS AND FAMILIES IN NEED. PLEASE HELP, ACKNOWLEDGE THE PROBLEMS AND NEEDS SO GUMA' MAMI AND OTHER DIRECT CARE AGENCIES MAY PROVIDE RESPITE SERVICES.

MY I ALSO APPEAL TO YOU AS A FAMILY MEMBER WHO RECENTLY HAD BOTH MY PARENTS HOSPITALIZED DUE TO A CAR ACCIDENT.

MY MOTHER IS NOW IN A MOTORIZED WHEELCHAIR AND IS PERMANENTLY DISABLED IN BOTH THE USE OF HER LEGS BUT ALSO HER RIGHT ARM. THANK GOD SHE HAS THIS ARM, IT WAS SEVERED IN THE ACCIDENT. THE ARM WAS REATTACHED AND IS HEALING SLOWLY. THE SKILLS OF FEEDING, DRESSING AND EVEN TOILETING HERSELF IS NOW SOMETHING THAT SHE NEEDS HELP WITH. MY MOTHER'S CHALLENGE IS NOT PHYSICAL BUT EMOTIONAL; SHE WORRIES ABOUT HER FAMILY "THINKING THAT SHE IS A BURDEN", HOW DO YOU TELL A CHAMORRO MOTHER THAT IS NOT TRUE. HER WHOLE LIFE SHE HAS BEEN THE HANDS AND CAREGIVER TO HER HUSBAND, CHILDREN AND GRANDCHILDREN.

MY FATHER SUFFERS FROM A CLOSED HEAD INJURY. THE SIMPLE TASK OF THE BRAIN TELLING THE LUNGS TO BREATHE HAS BEEN INJURED IN HIS BRAIN STEM. HE WILL BE OXYGEN DEPENDENT AND BI-PAP VENTILATOR DEPENDENT THE REST OF HIS LIFE. HIS OXYGEN HOSE IS HIS LIFE LINE. MY DAD ALSO WAS AN ACTIVE PERSON, HE IS AN OUTDOORS PERSON: HUNTING, FISHING, CAMPING, HIKING AND GARDENING.

THEY NOW HAVE MATCHING HOSPITAL BEDS, NURSING STAFF THAT COME INTO THE HOME DAILY. MY BROTHERS AND SISTERS IN COLORADO MAKE ME FEEL GUILTY, I AM BACK TO GUAM EXPLORING OPTIONS TO BRING MY PARENTS HOME TO GUAM. THE LACK OF RESPITE CARE AND THE LACK OF COORDINATED HOME CARE ON GUAM RULES THAT OPTION OUT.

1993 WAS A YEAR THAT THE SABLAN/AGUON FAMILIES WOULD HAVE HAD OUR FAMILY REUNIONS ALONG WITH OUR PARENTS (50TH) GOLDEN WEDDING ANNIVERSARY CELEBRATION. **RESPITE CARE PROVISIONS WOULD GUARANTEE QUALITY CARE AND LIFE ENRICHMENT FOR MY ENTIRE FAMILY.**

ASG Autism Society of Guam

P.O. BOX 7502 • AGAT, GUAM 96928 • Tel. (671) 565-4459; 646-1416

February 24, 1993

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

Dear Senator Shimizu and Committee Members:

On behalf of the Autism Society of Guam, I, Jelly N. Flores, Founder and President, DDPC Legislative Committee Member, Autism Consultant for the Department of Education, Division of Special Education, and parent of a child with autism, thank you for the 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 Autism Society of Guam was first organized in 1989. It is a non-profit organization chartered by the Autism Society of America in Washington D. C. Our organization serves to promote and advocate for the general welfare of persons with autism.

Autism, for your information, is a lifelong developmental disability in which individuals may experience difficulty in language and communication, social development and behavioral responses to their environment.

Autism occurs along a spectrum from mild to severe. Autism in its mildest form may resemble a learning disability. However, the communication and social difficulties of autism still result in a need for individualized planning. Of persons with autism, according to a recent survey taken by the Autism Society of America, two to three percent have very severe behavior difficulties, such as intense self-injury or aggression. Autism may also be associated with other disabilities such as epilepsy and mental retardation.

Families who have a child with autism often experience ongoing 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 additional care required by a child with autism, families identify RESPITE CARE as a basic need, with the need increasing as the child gets older. Families who report less stress usually are the recipients of formal support services such as Respite Care. Respite Care for families who have a child with autism helps maintain family stability and may provide opportunities for the child to participate in special activities.



I had the opportunity to experience the effectiveness of a respite care program in Massachusetts during the school year 1990-91 when I was on sabbatical leave to attend graduate school in Boston. My studies required intensive research in the field of autism, and I often had to spend extra time on weekends, going to the library, reviewing the research, and then developing and writing up innovative intervention strategies for educating children with autism. My son, who has autism, attended a residential school in Boston, and usually came home on weekends to stay with me. The Respite Care Program in Massachusetts was essential for my survival during that time. It helped me to complete my studies successfully, and also helped to maintain my lifestyle and to release some strain and stress that resulted from the intense studies and the demands of caring for my child on weekends. In the Respite Care Program, I could select the care provider. The one I chose to be with my son was excellent; he was able to "connect"--to communicate with my son, which is an important aspect when working with an autistic child. They related well with each other, and it was such a relief to know that my child was happy and had the best of care. It truly was an excellent respite care program for it afforded me time to do my studies as well as opportunities to see some friends or attend meetings with the parents' organization. As a parent and a community leader, I was appreciative of the program because it met my needs as well as those of my son.

The Autism Society of Guam upholds and commends Senator David Shimuzu and the committee members involved in the development of Bill 194. ~~This~~ bill meets an essential, critical need for the families who have children with autism.

In view of this endorsement and support of the bill, the Autism Society of Guam respectfully recommends:

1. That there be a number of providers of respite care available and that parents be given their choice of respite care providers.
2. That providers be trained about the characteristics of children with autism and how to care for them.
3. That respite care programs incorporate an educational component so that providers can learn how to assist children with activities of daily living.
4. That the Autism Society of Guam be included in the planning and development of the respite care programs.

The Autism Society of Guam looks forward to the passage of this bill and to actively participating in the planning process as the respite care program is developed, particularly as the needs of autistic children and their families are addressed.

Thank you very much.

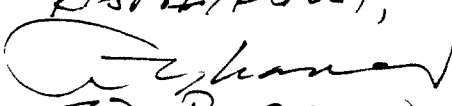
Sincerely yours,

Jelly N. Flores
Jelly N. Flores
President
Autism Society of Guam

EDUARDO REYES CHANCO
P.O. BOX 117
AGUINIGUA 96910

RE: RESPITE CARE PROGRAM
BILL NO. 194

I, EDUARDO R. CHANCO, HAVE READ BILL NO. 194 AND UNDERSTAND ITS INTENT. I'M IN COMPLETE SUPPORT OF THE BILL. HOWEVER, I WOULD LIKE TO RECOMMEND THAT OTHER PROFESSIONALS IN THE GOVGUAM PAYROLL BE MADE AVAILABLE TO THE DESIGNATED AGENCIES, DEPT OF PUBLIC HEALTH AND SOCIAL SERVICES (LEAD), ~~STATE~~ GOVERNOR'S COMMISSION ON PERSONS WITH DISABILITIES, GUAM DEVELOPMENTAL DISABILITIES PLANNING COUNCIL WHEN DEEMED NECESSARY. LASTLY, I WOULD LIKE TO SUGGEST A COMPLETION DATE OF RESPITE CARE PROGRAM

RESPECTFULLY,

ED R. CHANCO

February 24, 1994

The Honorable Dr. David L.G. Shimizu
Senator, Twenty-Second Guam Legislature
324 West Soledad Avenue, Suite 202
Agaña, Guam 96910

Dear Senator Shimizu,

This is to provide written testimony ~~in~~ support of Bill No. 194 relative to developing a Respite care program for individuals with chronic illnesses and disabilities and to appropriate funds for such purpose.

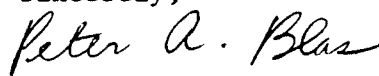
Based on both personal and professional experience, I ~~am~~ the sponsor of this proposed legislation. I have a brother who is profoundly mentally retarded. Although Guma' Mami provides some services through a pilot program having been fortunate to be involved, there is still room for expanded services. My family has borne the bulk care-giving responsibilities at home and we are sincerely appreciative of Guma' Mami's sharing the financial and emotional burden. Needless to say, caring for our brother is not an intrinsic burden but, nevertheless, any help is welcome.

From a professional viewpoint, as a service provider/case manager for Guma' Mami, I am constantly asked by families of clients for such a program that is being proposed in Bill No. 194. It is critical that the nuclear family be maintained moreso if a member of the family has a chronic illness or severe disability program. Personal interaction is crucial towards sustaining the well being of the individual. But the financial and emotional hardships can be staggering thus detracting from the crux of the matter, i.e., the care of the disabled individual.

In light of the above, Bill No. 194 is a good start towards assisting those families with disabled individuals requiring constant care. I would only hope that the plan be open for public hearing prior to adoption for further input.

Thank you for this opportunity to submit written testimony.

Sincerely,



PETER A. BLAS

Mr. Dury

RESPIRE CARE FACILITY

We, the families with disabled children would like the Legislature to response to our need for a Respite Care Facility. I for one have nine children, three of them adopted and two of the nine disabled. Our lives have been centered around our disabled children, as much as we all love the kids, we do have to leave the house for food shopping, funerals, medical appointments etc., which makes it hard having to depend on our healthy children. When they were going to school, I would have to have one of them stay home, from school, to watch my disabled kids. My children couldn't even join any after school activities, I had to make sure they come home right after school, in case an emergency comes up, to this day all my normal kids are living away from home, married with children and I would have to call them up to come and watch my kids while I go to a medical appointment, I am diabetic.

I think it is time the Legislature look into the needs of the families with disabled children. Having a Respite Care Facility will help eliminate the tension that go on in the families. Having to call one house after another to find a sitter to watch our children when an emergency comes up. Thinking that I have no one to turn to when I need to just get out. ~~It~~ is a hard life, having a disabled child, having our life centered around them, not having a life of your own, living your life to their needs. Don't get us wrong, we love our disabled children, but we also need whatever help we can get. Having the Respite Care Facility would at least give us time, even if just for an hour to shop, go to an appointment, ~~the~~ the headache of finding a sitter,

If anything is needed now for the disabled and the families it would be a Respite Care Facility. So if only we the families, can at least see that there is someone out there who cares and is willing to help, it would also lift alot of tension and anguish in our lives.

My name is Margaret Artero

I would like to thank Senator Shimizu
for the sponsorship of Bill 194.

This bill came about because of the
concerns raised by parents at last years
Special Education Conference for the need
of respite care.

I am here to express my support for
Bill 194 and hope that the department and
organizations that are assigned to develop this
program take into consideration the
different needs and concerns of persons
~~with concern~~ with disabilities and their
families.

Thank you
Margaret Artero

A WRITTEN TESTIMONY IN FAVOR OF BILL 194 - An act to develop a RESPITE CARE PROGRAM for individuals with chronic illness and disabilities and to appropriate funds for such purpose.

My name is AURELIO Z. DELOS REYES, father of a 4 year old girl and a new member of Autism Society of Guam, currently residing at 159 - J Bonito Street, Dededo, Guam.

I came here today not because of my 4 year old girl who was dianosed of having a very rare illness secondary to 'TUBEROUS SCLEROSIS' but to express my support of others who have the same predicaments and no time to come just because they rather want to stay to care for their ill kids who needs constant attention to prevent accidents. Should there be a place or somebody who could look into their kids temporarily, they would not think twice but to testify in favor of this bill.

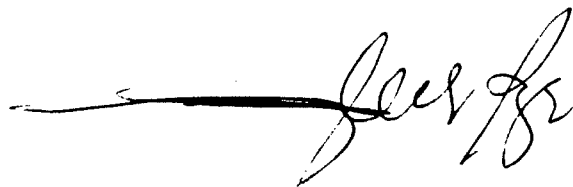
As a father, I experienced a very tight and stressful situation wherein I keep thinking everyday whether my 4 year old daughter have a seisure or hurt herself because nobody was watching her.

The bill if passed into law is a big relief not only to individuals with chronic illness 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, eventhough in a short period of time.

A first and foremost, this bill will encourage others to come out and exposed themselves feeling that they could be socially accepted eventhough they are less fortunate, physically and mentally.

Today's hearing has a far reaching effect not only to the parents of today but to our kids who might have off-spring having disabilities.

Lastly, I would like to express my thanks to the chairman of this committee and its members who feel that individuals with chronic illness and disabilities are not left behind with a needed services they are entitled.



RESPITE CARE

My wife and I have two children. Our son PAUL is 6 years old and our daughter RACQUEL is 19 months.

Paul is Autistic, the diagnosis was made this past year after he was seen by a team of specialist at Tripler Army Medical Center in Hawaii.

He is in the first grade at PC LUJAN and receives special services through DOE special education because of his disability.

PAUL his a very handsome healthy 6 yrs old. However he is very active to the point of hyperactivity due to his AUTISIM. He also has a history of SIEZURES.

Due to this fact PAUL obviously needs constant watching and someone to be able to see to his special needs.

Paul is unable to talk. He only says a few words therefore communication can be extremely difficult at times. He understands a lot of things well but when he wants something he must pull you to it or point. When you don understand what he wants he cries and screams. He also has little patience and a very short attention span.

Going out to dinner, shopping at the mall, grocery store and just about any social situation is extremely trying. PAUL's reaction to these situations are almost always screaming, crying and flailing himself on the floor. It is a stressful situation for both PAUL and ourselves. Don't get me wrong, we will continue to take PAUL to these places, because he does have to learn to deal with it. However a ~~break would be most welcome~~, once in a while, such as this program could provide. My wife and I don't go out as a couple. If we do it is separately with our friends, which is seldom, I might add this way one of us is always there to watch our kids.

We have tried a babysitter twice. They were close friends and knew of PAUL's situation. Both times we returned to find our friends well spent. Even though they wouldn't say anything we felt we were putting them out to much to ask them again to sit our kids. You see with AUTISTIC children or any child with special needs you have to live with them to really know how to deal with them or be someone with training and experience to be with them without being "Drained" after a few hours.

without a doubt ~~our~~ 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.

Thank you,

Respectfully,



L. E. WILLIAMS



STEVE SPENCER, Ed.D.
Associate Superintendent

**DEPARTMENT OF EDUCATION
SPECIAL EDUCATION DIVISION**

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February 24, 1993

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

Dear Senator Shimizu and Committee Members:

I am Dr. Faye Mata. I supervise Guam's family-centered early intervention and preschool programs, which provide services to children birth to five years who are developmentally delayed or have other disabilities.

Although an array of services are already available to these children and their parents, ~~respite care is an important service which currently is not available to our families.~~ With modern medical technology, we have a larger number of children surviving today, being able to live at home instead of the hospital, but who also need a great deal of nursing, special feeding, and intensive care from parents. For these families, ~~respite care could be the supportive service which enables them to cope with all the many responsibilities and stresses of caring for a child with disabilities.~~

Impact of Available Respite Care on the Family

All parents need time away from their children. Often it is difficult or impossible for parents of disabled sons or daughters to find willing and competent caretakers for their children. This can result in parents becoming isolated from the mainstream of life. ~~Respite care could provide a temporary rest from the daily challenge of caring for a child who has a disability. It can serve and strengthen the family as a unit rather than only the single child identified as disabled. It can relieve families of the constant responsibility of caring for their child for a few hours, a weekend, or longer to allow parents and other family members to rest, relax, go out for an evening, take a vacation, tend to necessities of life, or deal with stress such as illness, hospitalization, job transfer, or moving.~~ Respite care is not a frill. Time-off is essential to everyone's well-being and can prevent parents from becoming so stressed and fatigued that they can no longer cope with the needs of the disabled son or daughter.

Impact on the Child

~~Respite care on a regular basis allows the child with a disability to develop relationships outside the family unit. This extension of social contact beyond the family is healthy and essential for normal development.~~

Respite Care Services, the Provider, and the Community

Respite care can also have a very positive impact on the respite providers themselves. Besides the opportunity to earn some income, many experience great satisfaction and personal growth through their work. Many providers feel that it is important for their own children to get to know children with special abilities and needs. Frequently, the developmentally disabled child's relationship with the provider extends to the friends, families, and neighbors of the provider. **This personal contact increases the community's awareness and acceptance of persons with disabilities.**

Respite Care and Residential or Institutional Care

Our children are young and residential or institutional care is usually not a consideration. However, we know that a number of our children as they became older have needed to be placed in on-island group homes or even in residential centers off-island. **Respite services can reduce the need for long-term services (group homes, institutions) in two related ways. First, the mere availability of respite services reduces the likelihood that a person with a temporary need will be placed into a long-term program. Second, the provision of respite services to any individual or family over an extended period of time reduces the probability of that family's ever needing long-term services. Over time, these dynamics will lead to a reduced demand for long-term service.**

Respite Care as Part of a Comprehensive Array of Family Support Services

Respite care is often the support services most often identified as a priority by families. However, **it should not be viewed as a panacea or as a substitute for other necessary services. It is important that all other services available to families with children with disabilities continue and that respite care be provided in coordination with these services.**

Summary and Recommendations

In summary, adding respite care to the support services currently available to the parents of young children with disabilities should accomplish the following:

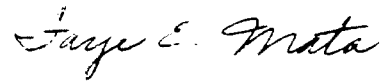
1. Reduce stress within the family.
2. Allow parents and family members to "normalize" their lives by being able to participate in recreational and community activities or to pursue activities which will give them personal satisfaction, relaxation, and enjoyment.
3. Reduce social isolation of families.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

In addition, this respite care program, if effective, will also create additional benefits, such as:

1. Increasing public awareness and acceptance of children with disabilities, and
2. Offering persons in the community an opportunity to share and grow with young people with disabilities through their work as respite providers.

On behalf of the personnel and parents of children with disabilities in our program, I fully endorse this legislation and recommend that it receive the highest consideration by the Legislature. As providers and consumers, we pledge our support and assistance in developing a quality respite care program for Guam.

Sincerely yours,



Faye E. Mata, Ed. D.

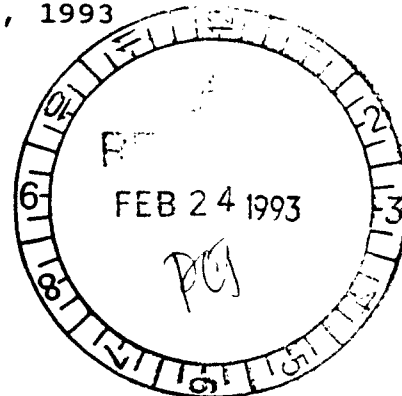
Guam Association of Retired Persons

Servicio Para I ManAmko
P. O. Box 3057 - Agana, GU 96910
Retirement Bldg, Maite, Guam
(671) 472-2188 477-9014/1156 472-6632 Fax: 477-9015



February 24, 1993

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



Dear Senator Shimizu:

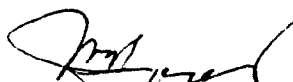
Bill No. 194, Twenty-Second Guam Legislature, 1993 (First) Regular Session, an "Act to Develop a Respite Care Program for Individuals with Chronic Illnesses and Disabilities and to appropriate funds for such purposes", is fully endorsed by the Guam Association of Retired Persons (GARP).

GARP, an advocate of Senior Citizens endorses any programs that would be beneficial to them; also most of our current members are Senior Citizens and some probably have some sort of chronic illness.

SPIMA's records of Senior Citizens Center Participants show that about 415 have been identified as having some chronic illness.

GARP would give its full cooperation to the Agency or Commission which will be implementing the provision of Bill No. 194 when its enacted into law.

Sincerely yours,


JUAN T.M. TOVES
President, GARP

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Grace G. Santos

February 23, 1993

VIA FAX

Dr. David L.G. Shimizu, Chairman
Health, Ecology and Welfare Committee
324 W. Soledad Avenue, Suite 202
Agana, Guam 96910

RE: Bill 194, Respite Care

Dear Senator Shimizu:

I am responding to your recent request to Guam Legal Services Corporation for input regarding the above Bill.

The development of a respite program to bring relief to overstressed caregivers is needed on Guam. Persons who are stressed out and burned out sometimes take out their frustrations on others. This increases the instances of violence within the family.

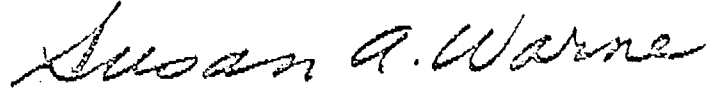
The whole community would benefit from a program under which all caregivers could be given relief time. This would help reduce the stress level within the family. We regularly see an increase in household violence (people coming to us for restraining orders) during holidays, after typhoons, and during other stressful times. Any relief given to family members who are caregivers might well serve to reduce the incidences of abuse against family members.

On a more personal note, I am a member of the Guam Council on Senior Citizens. At a recent meeting of the Council's Legislative Committee, it was agreed that a program of this sort could benefit senior citizens in two ways. First, it would give some relief to those seniors who provide care to others. Second, it would assist those seniors receiving care because the care giver could be given a much needed rest thus improving the quality of care the senior receives from the regular care giver.

Every program must be built on a strong foundation in order to succeed. The foundation for this program should include training for those who relieve the regular care giver.

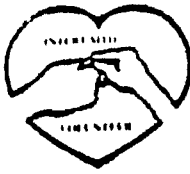
Thank you for including Guam Legal Services Corporation in your request for response to this proposed Bill.

Sincerely,



SUSAN A. WARNE
Acting Executive Director

SAW/tbm



● INTERFAITH VOLUNTEER CAREGIVERS, INC.

A Coalition Serving the Elderly & Handicapped

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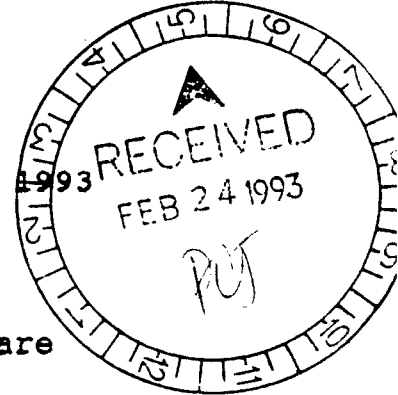
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February 24, 1993



Senator David L.G. Shimizu
Chairman
Committee on Health, Ecology and Welfare

Re: Bill 194 - To Develop Respite Care Program

Dear Senator and Committee Members,

As the Project Director of Interfaith Volunteer Caregivers, Inc. I would like to voice out my personal approval and support of the respite care program planned for our community. Attached is a brief essay of IVC's purpose in caregiving.

We are experiencing difficulty in finding volunteers to provide respite care services, as often times this requires long-term commitment.

The adoption of the respite care program is an essential means of support for our elderly, handicapped and family and friends of those in need of this service.

Please be assured of my support and will contribute my utmost in this undertaking.

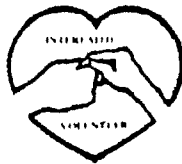
Sincerely,

Lenore C. Cabot
Lenore C. Cabot

Attachment

cc: Frances Limtiaco Standing Soldier
Executive Director, Dev. Disabilities
Planning Council

(671) 477-CARE (2273)
472-2944
653-0982/3



INTERFAITH VOLUNTEER CAREGIVERS, INC.

A Coalition Serving the Elderly & Handicapped

INTERFAITH VOLUNTEER CAREGIVERS, INC.

PURPOSE IN CAREGIVING

Purpose

The purpose of the Interfaith Volunteer Caregivers, Inc. is to enable the elderly and disabled who are at risk of institutionalization to remain in their homes by strengthening and complimenting the care they presently receive, or by providing support to those without care arrangements.

Assistance in essential daily activities such as feeding, bathing, toileting and dressing is provided to elderly patients, disabled adults and children. Included among the latter are persons with disorders such as autism, cerebral palsy, paralysis and mental retardation. For these individuals, institutionalization can only be avoided by having some source of support for their personal care in addition to spouses, children, relatives and friends. Because family and friends often undergo great sacrifice in order to keep and care for individuals at home, these informal sources of support can be tenuous. Studies have shown that a breakdown in physical or emotional health of a caregiver can precipitate institutionalization for an impaired individual as well as deterioration of caregivers.

It is clear that multiple arrangements for serving the needs of the health impaired must be explored. The traditional commitment of churches and synagogues to the welfare of the infirm provides a strong basis for their collaboration in organizing and delivering volunteer care services. The Interfaith Volunteer Caregivers, Inc. of Guam seeks to advance this concept.

INTERFAITH VOLUNTEER CAREGIVERS PROJECT

Interfaith caregiving is a faith ministry which welcomes everyone who believes they are their brother's keeper.

There is always a need for more volunteers. If you have at least one free hour during the week and are interested in a meaningful involvement, call 477-CARE or 653-0982.

RECOGNITION:

There is no way to adequately thank our Volunteers for the time they give. Our Volunteers answer the calls for help so that someone less fortunate than themselves may be a little bit more comfortable.

The Interfaith Board of Directors and Staff members meet and thank our Volunteers. A Volunteer recognition get-together is held each year to give us the opportunity to express that appreciation personally. This is a time of fellowship, to visit with other Volunteers as well as sharing experiences and passing along helpful suggestions to others.

TRANSPORTATION

The project provides transportation service to clients whenever possible. For this purpose we presently have a seven passenger van and we are in the process of procuring another which will be equipped with a wheelchair lift.

RE WE?

Interfaith Volunteer Caregivers is a non-profit ecumenical project offering volunteer support services to the elderly and disabled of Guam. There are currently more than 100 Volunteers and faith members. The Board of Directors includes representatives from different religions. Current members include: Catholic, Episcopal, Seventh Day Adventists, Jewish, Latter Day Saints, Bahá'í, and Baptist.

DO WE DO?

The goal of Interfaith is to assist the frail and disabled to live as independently as possible for as long as practical. Services include: respite care, transportation, escort, light housekeeping, light yard work, companionship, telephone reassurance, reading in private homes, in St. Dominic's Home, the Skilled Nursing Center, Life Skill Center. Interfaith's services complement existing programs. We in no way compete with other agencies providing similar services.

DID IT ALL BEGIN?

A group of concerned individuals of various faiths met and wrote to the Robert Wood Johnson Foundation and applied for one of 25 grants offered to assist Interfaith projects. We received a grant in the amount of \$10,000 to be disbursed over a three year period. After that time, the project was able to continue on its own. And it did.

WHERE ARE WE NOW?

February 1987 was the end of the Robert Wood Johnson grant for the Guam Interfaith Project. Since then interfaith has been depending on fundraisers, local donations, and contributions from the organization's member congregations. In 1990, the FHP Foundation enabled us to expand into the Northern sector of Guam and we also received matching funds from the 20th Guam Legislature, making this expansion possible.

HOW CAN SOMEONE HELP?

Anyone can help by visiting the Interfaith office on the third floor of the Agaña Cathedral-Basilica, or the Yigo office at Our Lady of Lourdes Church. Registration forms to become a Volunteer or to nominate a client are available. Another form of assistance would be a financial donation sent to: PO Box 21899, GMF GU 96921. A very important way to help would be to identify those needing assistance and to refer them to either the Agaña or Yigo office.

Do you know someone who is in need of help?

Please contact the Interfaith office!

For further information about services or to volunteer, please contact:

INTERFAITH VOLUNTEER CAREGIVERS
PO BOX 21899, GMF GU 96921

Phones: 477-CARE, 472-2944 (Agaña),
653-6982, 653-0983 (Yigo)

INTERFAITH VOLUNTEER CAREGIVERS



HELP THE RAIL, ELDERLY AND
DISABLED

477-CARE

OR

653-0982/3

P. O. Box 21899, GMF, Guam, GUAM 96921 • Tel. 477-CARE / 477-2944

INTERFAITH VOLUNTEER CAREGIVERS PROJECT

Our aim is to assist with basic home and personal maintenance so that older frail and disabled individuals will not be placed prematurely in a nursing home.

Through various churches working together, we are caring for many elderly and disabled persons in our community. Men and women of all ages are reaching out to the frail, alone and elderly who have no other means of assistance.

Although our focus is the frail elderly, we also give help to younger persons who lack family support or financial means and who are not eligible for other existing services.

This care and comfort is given in as little as one hour a week or a day and there is no limit to the grand total hours that may be extended by one individual. We are trying to ensure that the unmet needs of the community are addressed by this coalition.



AN ECUMENICAL NETWORK

SERVING:

- ✱ Families, friends, neighbors who are caring for an elder frail or health impaired individual.
- ✱ Isolated individuals who need a network of caregiving persons maintain their independence.

PROVIDING:

- ✓ CAREGIVERS... education and support to help make the responsibilities more manageable.
- ✓ ISOLATED INDIVIDUALS... volunteer support network trained to provide a variety of needed tasks.
- ✓ THE COMMUNITY... a unique resource for linking the formal and informal networks of caregivers of Guam.

SERVICES AVAILABLE

May be adapted to fit individual needs and

include:

- | | |
|-------------------|----------------|
| Respite care | Visiting |
| Yardwork | Grooming |
| Reading/writing | Feeding |
| Transportation | Escort Service |
| Workshop/training | Lite cleaning |



CATHOLIC SOCIAL SERVICE

Location: Farenholt Ave., Tamuning
P.O. Box EJ, Agana, Guam 96910
Fax No. 649-9224

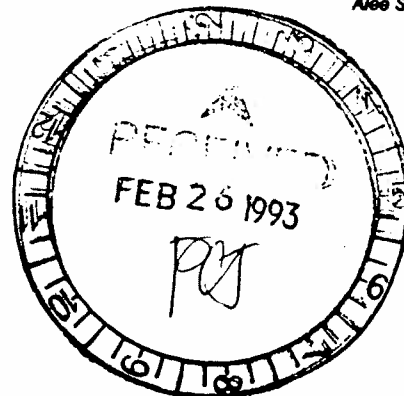
MAIN OFFICE: 649-5717
646-4974
646-1924
649-7377
KITCHEN: 646-6163
Also Shelter: 472-6729

Archbishop Anthony S. Apuron
OFM CAP D.D.
Chairman, Board of Directors

Cerila M. Rapadas
Executive Director

February 24, 1993

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



Dear Senator Shimizu:

This is in response to Bill #194, "An Act to Develop a Respite Care Program for Individuals with Chronic Illness and Disabilities and to Appropriate Funds for Such Purpose".

The intent of Bill #194 is to provide relief to families who care for these children and other family members who have a chronic or terminal illness, or is disabled. The respite care intended to help these families could be an in-home or out-of-home temporary non-medical care. The bill also acknowledges the importance of keeping the family together and providing them support in the care of their loved one.

Catholic Social Service recognizes the importance of this type of support to patients and families, in pursuing the philosophy of respect for the dignity of the human person. Presently, there is a form of respite care provided to the Elderly in the In-Home Program, funded by the Division of Senior Citizens, Department of Public Health and Social Services. The In-Home Homemaker is assigned to a frail Elderly's home to provide such services that the caregiver usually gives to the Elderly, such as personal care, making the bed, cleaning the bedroom, cooking, etc. This is proving to be quite beneficial, especially if the caregiver is also an Elderly (spouse).

The bill is written in a fairly general way, so that there can be some creativity in the programs. For example, in assisting to maintain the patient at home, it could be in the form of a caregiver being provided a relief as in the In-Home Program, or in providing a group home where the patients can be cared for while the caregiver is given some time off.

Let us congratulate the Committee for hearing such a bill and for identifying a time element in getting the program off the ground.

Sincerely,


CERILA M. RAPADAS
Executive Director



Dedicated To The Dignity Of The Human Person



TWENTY-SECOND GUAM LEGISLATURE
1993 (FIRST) REGULAR SESSION

Bill No. 194
As substituted by Author

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.D. Camacho
H.D. Dickson

**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:

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

10 Persons with chronic or terminal illness and/or disability present
11 medical, economic and legal issues of extreme importance that impact on the
12 lives of their families and the whole community.

13 Respite care is one approach and response to the Territory's need for effective
14 accessible and affordable temporary care to help maintain and support
15 families and caregivers, while acknowledging the critical importance of
16 family support to a family's ability to care for and nurture a member with a
17 chronic illness and/or disability at home.

18 The Legislature recognizes that although there are programs operating
19 to provide support to families who provide home care for members who are

1 chronically ill or disabled, those services do not comprise a comprehensive
2 system. Various approaches are needed to better support these families.

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

12 Section 2. General Provision.

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

20 Section 3. Definition

21 Respite care is in-home or out-of-home temporary, non-medical care for
22 families who have children or adult members with chronic or terminal
23 illnesses or disabilities. Disability is defined as a physical or mental
24 impairment which substantially limits one or more major life activity, or
25 having a record of such an impairment or being regarded as having such an
26 impairment.

27 Section 4. Coverage

28 Respite Care services shall be designed to:

- 29 A. Assist family members in maintaining the member with a
30 chronic illness and/or disability at home.
31 B. Provide temporary appropriate care and supervision to
32 ensure the individual's safety in the absence of family members.
33 C. Temporarily relieve family members from the constantly
34 demanding responsibility of caring for the individual with a
35 chronic illness and/or disability.

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

5 5. Rule-Making Authority.

6 The Director of Public Health and Social Services, in accordance with the
7 Administrative Adjudication Law and in consultation with the Governor's
8 Commission on Persons With Disabilities and the Developmental Disabilities
9 Planning Council, shall adopt rules and regulations for the efficient and
10 successful implementation of the Respite Care Program.

11 Section 6. Program Development - Report to the Legislature

12 Not more than sixty (60) days after the enactment of this bill into law, the
13 department and organizations enumerated under Section 2 shall develop an
14 appropriate Respite Care Program and program budget by categories, a report
15 of which shall be transmitted to the Legislature within thirty (30) days
16 thereafter.

17 Section 7. Budget.

18 The budget for salaries, contracts, operations, planning, development, and
19 implementation of program as provided in this Chapter shall be submitted
20 annually by the Department of Public Health and Social services for approval
21 by the Legislature. The Legislature shall appropriate funds to the Department
22 of Public Health and Social Services, which shall disburse the funds pursuant
23 to its directives and policies. Unexpended funds shall be maintained in a
24 continuing budget appropriation for use by the Department of Public Health
25 and Social Services in succeeding budget cycles.

FEB 26 '93

TWENTY-SECOND GUAM LEGISLATURE
1993 (FIRST) REGULAR SESSION

Bill No. 194 (LS)
Introduced by:

D.L.G. Shimizu *Shimizu*

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.