REPORT OF THE
JOINT SUBCOMMITTEE STUDYING

The Needs of Machine-Dependent Individuals

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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Joint Subcommittee Studying the
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To
The Governor and the General Assembly of Virginia
Richmond, Virginia
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To: The Honorable Gerald L. Baliles, Governor of Virginia,
and
The General Assembly of Virginia

I. ORIGIN OF THE STUDY

The impetus for this study originally came from the University of Virginia Hospital because of experiences with ventilator-dependent patients who "live" in the hospital for extended periods of time. The primary example of these patients at the University of Virginia is a twelve-year-old quadraplegic who has been residing in the University of Virginia Hospital for a number of years. This child was injured when struck by two cars and was transferred to UVA following a substantial period of hospitalization in a local hospital. This child is unable to return home and, at this time, placement in a long-term care facility is virtually impossible, because there are no facilities in Virginia which are both capable of handling the ventilator-dependent adolescent and providing the education and social services needed by this type of child.

As a result of becoming familiar with this case and others like it, Senator Thomas J. Michie introduced Senate Joint Resolution No. 99, which created this study. SJR No. 99 called for a study of the needs of machine-dependent individuals to be conducted by a joint subcommittee consisting of members of the Senate Committees on Education and Health and on Finance and the House Committees on Health, Welfare and Institutions and on Appropriations. The resolution directed the Joint Subcommittee to address the following issues:

1. What should the policy of the Commonwealth's teaching institutions and indigent programs, including Medicaid, be in relationship to these machine-dependent individuals?

2. Do the Commonwealth's criteria for Medicaid eligibility discriminate against providing care for these individuals in a less restrictive environment such as the home or community? And, if so, how can this problem be remedied without substantially increasing the cost of Medicaid to the Commonwealth?

3. Should the Commonwealth apply to the Health Care Finance Administration for a model waiver under Medicaid to provide care in the home and community for up to fifty machine-dependent individuals?

4. Can appropriate delivery systems, other than acute care hospitals, be developed for these machine-dependent individuals, especially children, which would be less costly to the Commonwealth and less restrictive for the individual?

Senate Joint Resolution No. 99 required that the Joint Subcommittee complete its work in time to submit its recommendations to the 1986 Session of the General Assembly.

II. THE SCOPE OF THE STUDY

Although the resolution addressed the needs of machine-dependent individuals, the Joint Subcommittee decided to limit its deliberations to the needs of ventilator-dependent patients. The Subcommittee noted that there are a number of other classes of machine-dependent patients with needs similar to those of the ventilator-dependent patient, such as oxygen-dependent patients, patients requiring parenteral nutrients, and end stage renal disease patients who require renal dialysis. However, the task of investigating the problems related to care of every class of machine-dependent patient appeared to be formidable and too comprehensive for a one-year study. Further, this study was initiated to address the specific needs of the ventilator-dependent patient. The Joint Subcommittee believes that if the problems related to care of the ventilator-dependent patient can be solved, these solutions will benefit other machine-dependent individuals.

III. BACKGROUND OF THE STUDY

In recent years, it has become clear that the population of ventilator-dependent patients in all age groups from birth to old age has increased. It is incorrect to assume that the majority of these patients are the victims of trauma as in the case already described. Although an increasing number of small, premature infants are included in this category of patients, there has also been an increase in the number of chronically ill adolescents and adults of every age.

The reasons for the apparent growth in this population appear to be improved medical technology and trauma care resulting in longer life expectancies for individuals who, in the past, may have died very quickly; improved diagnostic capabilities; and changes in patient, family and societal attitudes which have resulted in increased use of ventilation and intubation.

Ventilator-dependent patients appear to fall into approximately four categories of disease pathology: 1. nervous system disorders including quadriplegics who are trauma victims and victims of progressive neurological diseases such as amyotrophic lateral sclerosis; 2. intrinsic muscle diseases such as patients with muscular dystrophy; 3. chest wall conditions (deformities or disabilities such as kyphoscoliosis); and 4. pulmonary disorders such as emphysema and other chronic obstructive pulmonary diseases and cystic fibrosis.

In terms of prognosis and quality of life, ventilator-dependent patients appear to fall into the following classes: 1. the long-term ventilator-dependent patient with a good prognosis and an expected good quality of life, who would definitely benefit from a flexible environment; 2. the patient with progressive disease which will result in death, who is not dying immediately and who would benefit from being outside of an acute care facility; 3. the terminally ill patient with a short-term life expectancy, who should not be in an acute care facility; and 4. the infant/child/adult patient with a long-term prognosis for length of life, but a poor prognosis for a good quality of life.

There is no data on how much this population has increased or at what rate it is growing. However, it is obvious that planning has not kept pace with this change in patient population. In Virginia, as in most other states, adequate and cost effective services are not available for these patients.

A. Issues related to long-term and home-based care: the dilemma of the ventilator-dependent patient

1. Inadequacy of long-term care services

A number of the ventilator-dependent patients should be eligible for nursing home placement or, under some specialized circumstances, placement in a home for adults or for appropriate services in their homes and rehabilititative services. However, many of these patients are being maintained in acute care hospitals because of the lack of facilities willing or able to accept these patients, especially the children, and a lack of adequate support services for home care.

Regardless of specialized needs, the Virginia Medicaid program reimburses nursing homes on the basis of regional, prospectively established rates according to the level of required care, i.e., skilled care or intermediate care. Therefore, part of the reason for the unwillingness or inability of nursing homes to accept the adult ventilator-dependent patient appears to be the level of care required for many ventilator-dependent patients. Some facility administrators undoubtedly prefer to accept less labor intensive patients, who require less costly, time consuming care. Many of the ventilator-dependent patients require skilled nursing supervision and respiratory therapy as well as assistance in eating and bodily functions. Even the growing number of ambulatory patients (both adult and pediatric) require periodic suctioning, maintenance services for the equipment and hospitalization during acute episodes.

Recently, the Medicaid program has negotiated with the nursing homes, and the program administrators believe that nursing homes in Virginia are now more willing to take ventilator-dependent patients. Medicaid will now pay the cost of the machine, while the nursing homes pay for the specialized staff such as the respiratory therapists. There is some indication that the cost of the rental of the machine may now include the services of a therapist. If this is taking place, it is the result of agreements between the nursing homes and the leasing companies. This situation appears to represent a sharing between the public and the private sector of the costs of care for a few patients.

In spite of this arrangement, many of the adult patients continue to reside in acute care facilities and hospital staffs report frustrating and unproductive efforts to place patients in less costly and more appropriate environments. For example, an elderly man has resided in the Intensvie Care Unit at MCV for months. It has been alleged that patients die in hospitals while waiting for nursing home placement.

There is an acute problem related to placement of children because there are few long-term care facilities in Virginia dedicated to the care of any pediatric patients and not all of these facilities accept ventilator-dependent children. Although there are young people, even teenagers, in nursing homes, at this time, placements of children in nursing home facilities providing care for elderly and disabled adults are not appropriate even when the facilities are willing to admit them.

2. Inadequacy of reimbursement for support services for home care

Hospital staff members and home health professionals believe that some of these patients could receive less costly care in their homes. However, the Virginia Medicaid Program does not reimburse for the services necessary for home care of these patients and many insurance plans still do not cover these services. Therefore, the patient often remains in the hospital while the insurance company pays for much more costly care or the hospital incurs a loss because of Medicaid reimbursement limitations (Virginia Medicaid reimburses for twenty-one days of acute care for one episode).

The Medicaid patient may be eligible for personal care services, which is a program of home-based, nonmedical services. In order to become eligible for the personal care services program, the patient must be processed through the preadmissions screening program for nursing home placement and found to be eligible for nursing home placement. The rationale for this requirement is that since the personal care services program is intended to avoid institutionalization of individuals who can be adequately served in their homes at less cost, the individual so served should need skilled nursing or intermediate care.

The Personal Care Services, which do not include medical treatment, are briefly: assistance with care of teeth, mouth, hair, skin, nails and face (shaving); assistance with bathing, toileting, walking, eating, and dressing, assistance with preparing and serving meals; monitoring of vital signs (pulse); assistance with self-administered medication; observation of client's general condition so that professional medical attention can be obtained appropriately; housekeeping for the client only such as washing dishes, cleaning kitchen, dusting, etc.; shopping for the client and washing personal laundry of client, if no other family member is available to do so.

It is difficult, if not impossible, for the ventilator-dependent patient to qualify for the personal care services program. The reason for this is two-fold: 1. The personal care services program is conducted as a special waiver authority as approved by the Health Care Finance Administration and the services allowed are specific and inflexible and do not include suctioning or skilled nursing; and 2. The plan of care for the individual under personal care services must take into consideration all of the services the individual requires and assure that the individual is not lacking in services during the hours not served by the plan.

The preadmissions screening teams frequently do not take into consideration the possibility of qualifying the ventilator-dependent for the Personal Care Services Program because of the nonmedical nature of the services and the need to assure that the patient will receive services when not served by the plan. In some cases, a combination of personal care services and home health services would be adequate to supplement the services of the caretaker family.

In order to obtain a waiver for personal care services, a state Medicaid program must assure that there will be financial accountability, that the program will be cost-effective and that the health, safety and welfare of the patients will be protected. Since the purpose of the personal care services program is to provide the critical services needed to keep recipients out of nursing homes, it was specifically designed to assist the elderly and disabled in staying in their homes. These services were never intended to be a substitute for family care or a means of providing respite care. Because the Medicaid personal care services program was not originally intended or designed to provide long-term care for children and infants, the division of responsibility between the personal care services aide and the parents becomes an issue. The line must be carefully drawn in order to avoid a situation in which the aide's services supplant family care.

There is a growing movement to provide care for such children in their homes. This movement can best be demonstrated by the phenomenal growth of an organization know as SKIP - Sick Kids (need) Involved People. SKIP was founded in Maryland primarily through the efforts of Mrs. Karen Shannon and her family, who have successfully cared for their child with severe respiratory failure at home since 1980. The child's development and physical progress have been excellent. This organization now has approximately twenty-five chapters and its influence has been felt throughout the nation as a result of the "Surgeon General's Workshop on Children with Handicaps and Their Families," which was held in 1982. At this time, Mrs. Cindi

Cline of Petersburg is spearheading an effort to organize a chapter of SKIP in Virginia.

In some jurisdictions in other states, policies encouraging and even requiring discharge of infants and young children to their homes have developed. Much controversy surrounds this type of policy because of the potential liability of the discharging hospital and concerns about the quality of the care delivered in some marginal families. However, if flexible discharge planning, training for the caretaker parent(s) and adequate community support services are available, the best place for such children may be the home. The hospital atmosphere is not conducive to development and socialization. In addition, the child may be subject to frequent and occasionally dangerous secondary infections in the acute care environment. The Surgeon General has been quoted as saying: "...it will be the family that will provide the long-term help required by the disabled infant. The family's daily decisions, routines, and relationships will translate into the support, the therapy, the special education, the recreational efforts, and all the other aspects of the best possible quality of life for the disabled child."

B. Medicaid waivers and the Katie Beckett option

Until very recently, states did not have the option to provide home and community-based care under Medicaid. This was changed by certain parts of the Omnibus Budget Reconciliation Act of 1981 which authorized the approval of waivers to the states to offer home and community-based services in order to avoid institutionalization where appropriate. These changes were intended to provide less costly and less restrictive alternatives to institutional care.

In most states, including Virginia, Medicaid eligibility is frequently tied to eligibility for SSI. In the case of children, the income of the parents is "deemed" to the children if they are living in the same household and the children are frequently not eligible for Medicaid benefits because of the "deeming." This means that if the child is institutionalized, the "deeming" rules do not apply and the child becomes eligible for Medicaid benefits.

As a result of the Katie Beckett case, the federal law (Tax Equity and Fiscal Responsibility Act of 1982) was changed so that states may furnish home or community-based services under Medicaid to children who would be Medicaid-eligible if they were placed in an institution. In other words, the state may waive the "deeming" rules and furnish Medicaid coverage to these children in their homes.

Through the intervention of President Reagan for Katie Beckett, the Health Care Finance Administration initially agreed to consider waiving the "deeming" rules on a case-by-case basis and later promulgated regulations pursuant to federal amendments for the consideration of model waiver applications for the care of up to fifty such patients in their homes. The federal government phased out the applications for the individual waivers at the end of 1984. However, prior to this phasing out, to be qualified for an individual Katie Beckett waiver in Virginia, the applicant must have met the following criteria:

1. under 18 years old;
2. disabled as determined by the Social Security regulations;
3. currently institutionalized at Medicaid expense;
4. suitable for care outside an institution; and
5. require care which could be provided at less cost outside an institution than it could be provided in an institution.

Although several inquiries were made about the Katie Beckett waiver, the Virginia Medicaid Program never submitted an application to HCFA because none of the cases would have qualified for cost effective care in the home. Criterion number 5 limited the applications for this waiver in the case of machine-dependent children. These children require care that frequently costs more in the home or community than it would in a long-term care facility. The Katie Beckett waiver did not work for patients requiring very expensive care in their homes because a comparison had to be made between the costs of care in the home and the costs of a skilled nursing facility or an intermediate care facility.

Virginia Medicaid pays approximately $1,400 per month for care in a skilled nursing facility and approximately $1,200 for care in an intermediate care facility. Home care of a ventilator-dependent child can cost in excess of $10,000 per month; therefore, viable cost comparisons were not possible. Theoretically, it could have been argued that Medicaid would have been paying for care in the acute care facility; therefore, in applying for the individual Katie Beckett waiver, a comparison of the cost in the acute care facility to the cost of the home-based care should have been made. However, Medicaid in Virginia will only pay for twenty-one days of care per admission in an acute care facility; therefore, acute care cost data could not be used in a Virginia application for a waiver. For these reasons, applications for the case-by-case Katie Beckett waivers for ventilator-dependent children presented a Catch 22.

In addition to the phased-out individual waiver, Medicaid programs were given the option of waiving the "deeming" rules for institutionalized children or those who would be eligible if they were institutionalized. Virginia has not chosen to cover all of these persons, because the federal law mandates that state Medicaid coverage be "statewide" and "comparable" in application, and the adoption of this Katie Beckett option would require Medicaid coverage for thousands of mentally retarded (and other handicapped or sick children) who are presently being cared for in their homes without danger of being institutionalized. Such coverage could be fiscally overwhelming for Virginia.

Another viable approach to assisting the ventilator-dependent patient in returning home would be for the Virginia Medicaid Program to apply for a model waiver for home-based care for up to fifty ventilator-dependent patients in their homes pursuant to the provisions of the Tax Equity and Fiscal Responsibility Act (TEFRA). Maryland has recently received approval for such a model waiver from the Health Care Finance Administration. Unfortunately, the same Catch 22 that thwarted the applications for the individual Katie Beckett waivers makes it impossible to develop cost comparison data to prove a savings for the model home-based care waiver for the ventilator-dependent patients in Virginia. Further, it appears that obtaining such a waiver takes a long time (Maryland's waiver was pending for almost two years) and careful planning to avoid excessively costly and inappropriate interim solutions. It must always be borne in mind that programs such as Medicaid and the Crippled Children's Program were founded to provide the best care affordable for the greatest number of those in need.

Any consideration of home-based care for ventilator-dependent patients must emphasize the impact on the caretaker family. Families must be trained to perform suctioning, resuscitation and other services. When it is understood that many of these patients require constant attention such as hourly or more frequent suctioning twenty-four hours a day, it becomes apparent that only understanding, patient, caring persons with great stamina and commitment are capable of handling the home care of such patient. Some families are psychologically unable to cope with the emotional, social and physical strain of constant care for an adult patient, much less the fragile young child or infant. The desires and capabilities of the family of the patient must be considered when the potential for successful home care is evaluated.

IV. THE WORK OF THE JOINT SUBCOMMITTEE

The Joint Subcommittee held five meetings to receive data and hear testimony on the needs of ventilator-dependent patients. Staff prepared and presented an initial staff briefing paper on the issues related to these patients based on data collected through interviews with Medicaid officials and health care professionals and information obtained from attending a conference on ventilator-dependent children and other sources. Presentations were given to the Joint Subcommittee by physicians, social workers, home health nurses, representatives of the American Lung Association of Virginia, nursing home administrators, respiratory therapists, hospital nurses, Medicaid officials, Blue Cross/Blue Shield, and the parents of ventilator-dependent children.

Immediately following the first meeting, the Joint Subcommittee toured the MCV facilities to experience first hand the problems related to the care of ventilator-dependent patients. A ventilator-dependent child who is being cared for at home was present at two of the meetings. The presence of this child, who is developing rapidly now that he is at home, graphically demonstrated the difficulties encountered by families caring for such children.

An Ad Hoc Committee of the American Lung Association of Virginia, which was addressing the problems of obtaining appropriate care for ventilator-dependent patients, conducted a survey of the number of ventilator-dependent patients who are or have been in the last five years inpatients in Virginia hospitals. This Ad Hoc Committee volunteered its cooperation with the Joint Subcommittee and shared the results of this survey with the Joint Subcommittee. A copy of a summary of this survey is included in Appendix A. It should be understood that less than half of the hospitals in Virginia responded to the request for data; therefore, it appears the numbers of ventilator-dependent patients are substantially higher than the numbers which were reported.

During the third meeting, the Joint Subcommittee determined that the assistance of experts in medical and health care was necessary in order to develop any credible solutions to these problems. Two advisory groups were established, one to address the issues related to the care of pediatric patients and one to address the issues related to the care of adult patients. All individuals interested in working with the Subcommittee were eligible for membership on these groups. Staff was directed to hold meetings with the advisory groups and to prepare the recommendations of these groups for the Subcommittee's consideration.

V. THE WORK OF THE ADVISORY GROUPS

The Pediatric Advisory Group met for the first time on September 19, 1985, in the Legislative Services Conference Room at 11:00 A.M. Those present were: Jennifer Washington, R.N., Quality Care, Richmond, Virginia; Beverley Butler, Department of Social Work, University of Virginia; Sharon Hostler, M.D., Children's Rehabilitation Center, University of Virginia; Eric Bodin, Respiratory Therapist, Medical College of Virginia; Kathy Benner, Division for Children; William Jolly, Administrator, St. Mary's Infant Home; Diane Goode, Neonatal Intensive Care Unit, Roanoke Memorial Hospital; Kathy Webb, R.N., Department of Nursing, University of Virginia; John Mickell, M.D., Department of Pediatrics, Medical College of Virginia; and Ann Cook, Department of Medical Assistance Services.

Following intensive discussion, the Pediatric Advisory Group made recommendations for the ideal approach to meeting the needs of ventilator-dependent children and an approach believed to be practical for resolving the problems related to providing care for such children.

A. The Ideal Solution (as developed during the first meeting of the Pediatric Advisory Group).

The most generous and appealing solution to the present problems related to care of ventilator-dependent children would be to establish a thirty-bed, state-supported, centrally located facility with good transportation services available to all areas of the State. This facility, which would offer medical, rehabilitative, educational and social services, would serve as the base for care and services to ventilator-dependent children of all levels of functioning and all categories of disease pathology.

The facility would provide Virginia with an elite site for the development of expertise and research in all aspects of handling the ventilator-dependent child. As such, its services would include total medical care for dischargeable and nondischargeable patients, including step-down units, out-patient care and custodial care for comatose or nonfunctioning patients; training for parents of patients with potential for discharge; outreach services; various levels of educational, training, and enrichment programs for the children according to their ages and abilities; rehabilitative services for all functioning levels; respite care services in order to lessen the burden on the family; case management services for discharged patients and other social services as well as expert medical, educational, social services and rehabilitation consultation.

The programs of the facility would be flexible to facilitate movement from one level of care to another and capable of adapting to changes in technology and expertise in order to provide quality care and services for both the nontransient, custodial patient and the transient patient. Discharge to the home and community would not sever the relationship of the patient or family with the facility because the outpatient services, discharge management and outreach functions would provide a link for the patient/family to the facility for necessary readmissions, medical services, respite care, training, etc.

Such a facilty might eliminate the need for retaining ventilator-dependent children at total state expense in expensive tertiary facilities while still involving the staffs of the three medical schools in cooperative activities in the training of professionals and provision of care. This facility could receive Medicaid reimbursement for acute care, SNF and ICF beds (as certified) as well as reimbursement from private, third party payors.

B. The Practical Solution (as developed in the first meeting of the Pediatric Advisory Group).

The Pediatric Advisory Group recommended a budget amendment requiring the Department of Health to purchase a study of the feasibility of contracting with nonprofit facilities to provide appropriate care for the children at reasonable cost. The proposed language was:

Out of the appropriation for Crippled Children's Services, $ — shall be designated in the first year of the biennium for the Department to contract for a study to determine the feasibility of the Commonwealth contracting with nonprofit patient care facilities to provide a complete range of services to ventilator-dependent individuals under the age of twenty-one. The Request for Proposals shall address the feasibility of providing the following services for one unit of ten beds in each of three regions of the State: intermittent acute care, respite care, home care planning, rehabilitative services, caretaker training, educational programs, social services and counseling. In preparing the request for proposals, the Department shall consult with the experts who served on the Pediatric Advisory Group to the Joint Subcommittee Studying the Needs of Machine-Dependent Individuals pursuant to SJR No. 99 of 1985.

The Adult Advisory Group met for the first time on September 27, 1985, in the Legislative Services Conference Room at 11:00 A.M. Those present were James P. Baker, M.D., Norfolk General Hospital; Pat Baker, R.N., Norfolk General Hospital; Dudley Rochester, M.D., Department of Pulmonary Medicine, University of Virginia; Ann Cook, Department of Medical

Assistance Services; AnneMarie Robichaud, R.N., Medical College of Virginia; Virginia Bloch, American Lung Association of Virginia; Doug Hansell, Respiratory Therapy, Medical College of Virginia; Walter C. Wilson, Woodrow Wilson Rehabilitation Center; Donna Forsyth, Quality Care, Richmond, Virginia; Bill Peterson, Department for the Aging; Trina Vecchiolla, R.N., Department of Nursing, University of Virginia Hospital; Paul Fairman, M.D., General Medical Respiratory Intensive Care Unit, Medical College of Virginia; Tim Rossman, Respiratory Therapist, and Beverley Butler, Department of Social Work, University of Virginia.

The Adult Advisory Group discussed methods of delivering care which would be ideal and also sought a practical solution to the problem of the inadequacy of long-term care for the adult ventilator-dependent patient. The Advisory Group was in agreement that an immediate solution should be found to provide the needed institutional long-term care beds for the ten adult patients who had been residing for long periods at the Medical College of Virginia, Norfolk General, and the University of Virginia Hospitals because the plight of these patients is serious. The Adult Advisory Group recommended several steps for immediately remedying the plight of the adult ventilator-dependent patient as well as a model concept of care.

C. The Model Concept (as developed during the first meeting of the Adult Advisory Group).

The best system of care for the adult ventilator-dependent patient would be a multifacility network which would be capable of providing acute care, intermediate care, vocational rehabilitation, custodial long-term care and residential care allowing psychological independence. The structure of such a model would be:

1. Acute care -

University of Virginia

Eastern Virginia Medical School

Medical College of Virginia

The three tertiary facilities would continue to provide the expert, acute care for the adult ventilator-dependent patient during those periods when such care is indicated such as episodic illness, initial injuries, treatment of chronic diseases, etc.

2. Exigent Care Facility - A new kind of intermediate facility which would not be a nursing home or an acute care facility, but would be between these two levels of care. This facility would provide the patient with medical education (how to handle his condition, necessary self-care, etc.), physical rehabilitation services and rehabilitative education as well as care. Depending on the circumstances and the condition of the individual patient, the patient would be discharged from this facility to:

a. The Woodrow Wilson Rehabilitation Center for vocational evaluation and rehabilitation, or

b. a nursing home for long-term custodial care, or

c. his home.

3. Woodrow Wilson Rehabilitation Center - WWRC could provide the ventilator-dependent patient with vocational evaluation and depending on the vocational potential of the individual with vocational rehabilitation. Depending on the circumstances, the patients would be discharged from WWRC to:

a. a nursing homes, or

b. his home, or

c. a residential care facility (see step four below).

4. Residential Care Facility - This facility would be structured similarly to a home for adults and would not be a nursing home. The Residential Care Facility would provide the patient with a sheltered environment from which he could be transported to educational institutions, work and other activities or from which he could conduct his work and other activities. The patient would be able to achieve psychological independence while still receiving appropriate care and conducting an active, high quality life.

The primary design of the model concept was suggested by Mr. Walter Wilson of Woodrow Wilson Rehabilitation Center as a result of his and Commissioner Altamont Dickerson's work in

developing a system to care for and rehabilitate head-injured patients.
D. Practical approaches to remedying the inadequacies in long-term care alternatives for adult ventilator-dependent patients (as developed during the first meeting of the Adult Advisory Group).

The Adult Advisory Group recommended:

1. The adoption by the Virginia Medicaid Program of a revised reimbursement formula providing for reimbursement on the basis of the intensity of the services in intermediate care facilities.

2. That state-owned and state-operated acute care facilities be encouraged to contract with nursing homes for the long-term care of adult ventilator-dependent patients.

3. That the Department of Medical Assistance Services provide education to the individuals serving on preadmissions screening teams in the services available for home-based care of the adult ventilator-dependent patient.

4. That six specialized, long-term care facilities for adult ventilator-dependent patients be developed to be located in various geographical areas of the Commonwealth near population centers which would be reimbursed on the basis of the intensity of the services by the Virginia Medicaid Program. These facilities would provide custodial and support services and would group patients appropriately according to their ages and disabilities in order to facilitate peer support among individuals of the same age and circumstances.

5. That adequate funds be appropriated in the 1986-1988 Biennium Budget to fund a demonstration project administered by the Department of Health or the Department of Medical Assistance Services. This project would be in the form of a grant of state general funds to the chosen department to contract with a hospital to provide care for the patients now housed at the three medical school hospitals. The chosen department would be required to develop a Request for Proposals by May and be ready to contract by July 1, 1986. In developing the Request for Proposals, the chosen department would be required to consult with the experts who served on the Adult Advisory Group to the Joint Subcommittee Studying the Needs of Machine-Dependent Individuals pursuant to SJR No. 99 of 1985.

These proposals were presented to the joint subcommittee at its October meeting. Following discussion of the proposals of both advisory groups, the joint subcommittee requested these groups to reexamine their proposals to determine if less costly actions could be developed.

The Pediatric Advisory Group met for the second time on November 4, 1985, in the Legislative Services Conference Room at 1:30 P.M. Those present were Jennifer Washington, R.N., Quality Care, Richmond, Virginia; Beverley Butler, Department of Social Work, University of Virginia; Sharon Hostler, M.D., Children's Rehabilitation Center, University of Virginia; Eric Bodin, Respiratory Therapist, Medical College of Virginia; Kathy Webb, R.N., Department of Nursing, University of Virginia; and Ann Cook, Department of Medical Assistance Services.

The Pediatric Advisory Group revised its recommendations for meeting the needs of ventilator-dependent children and devised a practical approach to resolving the problems related to providing care for such children.

The Adult Advisory Group met for the second time on November 4, 1985, in the Legislative Services Conference Room at 10:00 A.M. Those present were AnneMarie Robichaud, R.N., Medical College of Virginia; Virginia Bloch, American Lung Association of Virginia; Walter C. Wilson, Woodrow Wilson Rehabilitation Center; Donna Forsyth, Quality Care; and Beverley Butler, Department of Social Work, University of Virginia.

The Adult Advisory Group determined that only a practical approach which includes the minimum of expansion in the present service delivery systems would be an acceptable recommendation to the Joint Legislative Subcommittee because of the many demands on the Commonwealth's resources at this time. Therefore, even though the Model Concept was still considered a proper, ideal goal for the Commonwealth, it was abandoned as a definitive recommendation in view of the present fiscal constraints.

Summary of the concluding discussions of the Pediatric and Adult Advisory Groups.

Any system for handling the ventilator-dependent patient must take into consideration the needs of dischargeable and nondischargeable patients, including step-down units; out-patient care and custodial care for comatose or nonfunctioning patients; training for families of patients with potential for discharge; outreach services; various levels of educational, training, and enrichment programs, especially for the children, according to the age and abilities of the patient; and social and rehabilitative services for all ages and functioning levels. Many of the elements of this system, which are being delivered in or from the medical school hospitals, appear to be working well. Therefore, the expert, acute care should continue to be delivered by the tertiary institutions at the University of Virginia, the Medical College of Virginia and Eastern Virginia Medical School. However, these acute care facilities should not become warehouses of patients in need of long-term care.

The provision of home and community-based care is difficult to accomplish in Virginia for many of these adults and children because of lack of third party support. Even though home care should be a less costly alternative, care in the hospital continues to be the norm and care in the home the exception.

In addition, long-term care placements for those who can not be returned to the family or community are almost nonexistent; rehabilitaion services for such adults and children are critically inadequate and access to higher education is not readily available.

The Advisory Groups concluded that it is crucial for these conditions to be changed and that these changes can be facilitated within the existing system with some revisions in Medicaid reimbursement, more flexibility on the part of private insurance carriers, state agencies and educational institutions and some additional funds for expanding existing services.

VI. FINDINGS AND RECOMMENDATIONS OF THE JOINT SUBCOMMITTEE

The scaled-down recommendations of the advisory groups were received by the Joint Subcommittee, revised and adopted. Staff was directed to draft such resolutions, bills or budget amendments as would be necessary to implement the Subcommittee's recommendations. The Subcommittee's recommendations are as follows:

<u>RECOMMENDATION NUMBER 1.</u> The Joint Subcommittee recommends that the Virginia Department of Medical Assistance Services revise the State Plan to include reimbursement for more than twenty-one days of acute care services provided to Medicaid recipients up to the age of twenty-one.

<u>RATIONALE:</u>

The Virginia Medicaid Program does not reimburse for more than twenty-one days of acute care per episode. Children, particularly premature infants, frequently require long periods of hospitalization before they can be stabilized. Technology has resulted in incredible advances in the ability of physicians to keep such children alive and to assist in them becoming healthy adults. However, no discharge can take place until the child is medically stable; therefore, often the child who is a Medicaid recipient remains in a teaching institution's tertiary care facility beyond the twenty-one-day limitation at total state expense or in a private, acute care facility as a charity case or as a recipient of uncompensated care. This has resulted in several embarrassing situations. One private, nonprofit facility in Washington, D.C., recently considered a proposal not to accept Virginia Medicaid children. Several private, non-profit facilities in the Commonwealth have been financially impacted because of the medical necessity of keeping such children.

Since the numbers of children who are ventilator-dependent are increasing and a substantial increase in the population of ventilator-dependent pediatric patients may occur because of the federal "Baby Doe" Regulations, which hospital staffs frequently believe require ventilation and intubation of patients that would not have received such care heretofore, the financial impact of the twenty-one-day limitation on hospitals may result in a future fiscal crisis unless some relief is provided now.

The Joint Subcommittee believes that lifting the twenty-one-day limitation for children would be equitable for three reasons: 1. The Commonwealth should not be expecting private hospitals to shoulder the cost of care beyond twenty-one days for its chronically ill children; 2. The State should not be funding the entire cost of care beyond the twenty-one days for Medicaid children in its teaching facilities (Medicaid reimbursement would include 53% federal money); and 3. lifting the twenty-one-day limitation would provide an opportunity for the Virginia Medicaid Program to compile the necessary cost data for acute care stays of ventilator-dependent children to compare with the cost of home care in order to apply for a model waiver.

<u>RECOMMENDATION NUMBER 2.</u> The Joint Subcommittee endorses the concept of Medicaid

reimbursement based on the intensity of nursing services for heavy care ICF patients in order to create an incentive for nursing homes to accept the ventilator-dependent patient.

RATIONALE:

A number of the ventilator-dependent patients should be eligible for nursing home placement. However, many of them are being maintained in acute care hospitals because of the lack of facilities willing or able to accept these patients.

There is an acute problem related to placement in long-term care facilities of ventilator-dependent children because there are only a few long-term care facilities in Virginia willing to accept any pediatric patients. Therefore, long-term care of the ventilator-dependent child in Virginia almost always occurs in the isolation and unrealistic environment of an acute care facility. This problem is exacerbated because children need services that most nursing homes are not staffed or equipped to deliver, such as education, and the nursing home industry has been traditionally focused on the needs of the adult disabled and elderly population.

The reason for the unwillingness or inability of nursing homes to accept the adult patient appears to be that regardless of specialized needs, the Virginia Medicaid Program reimburses on the basis of regional, prospectively established rates according to the level of care, i.e., skilled care or intermediate care. This reimbursement system has been alleged to create an incentive to reject labor-intensive, heavy-care patients.

Currently, the Department of Medical Assistance Services has been mandated to study the nursing home reimbursement system and a contract has been issued to the Center on Aging and the Department of Health Administration at MCV for this study. This study is focused on developing a case mix reimbursement methodology to reimburse nursing homes appropriately based on the intensity of nursing services for heavy care ICF patients.

The Joint Subcommittee believes that the adoption by the Virginia Medicaid Program of a methodology for reimbursement on the basis of the intensity of the services might provide an incentive for nursing homes to accept the adult ventilator-dependent patient; that more homes may be willing to accept the ventilator-dependent child patient and that educational services can be delivered to such children in long-term care facilities appropriately within the existing, state-funded hospital and visiting teacher programs.

RECOMMENDATION NUMBER 3. The Joint Subcommittee supports the expansion of intermediate rehabilitation facilities in order to provide services to the pediatric and adult ventilator-dependent patients in Virginia.

RATIONALE:

Although the needs are critical, rehabilitative services are sorely lacking in Virginia for the ventilator-dependent adult and pediatric patients. The primary reason for this situation is that rehabilitative engineering for the ventilator-dependent patient is just beginning to develop. However, programs are being implemented in other states, notably Texas, and the technology appears to be advancing and becoming more affordable rapidly. The Joint Subcommittee believes that additional rehabilitative services are crucial in order to improve the plight of the ventilator-dependent patient and that these services can be provided through expansion of present programs.

For example, the existing adult rehabilitation unit at MCV might be provided adequate appropriations to expand its services to include centralized, comprehensive, statewide, intermediate rehabilitation services. This facility could provide the patient with medical and nursing education (evaluation and fitting of equipment, how to handle his condition, necessary self-care, etc.), physical rehabilitation services, education and counseling. Any appropriations requested would initiate a change in direction for an existing program which would provide much-needed services.

In order to improve the plight of the young ventilator-dependent patient, intermediate services can be provided through expansion of present services in the Children's Rehabilitation Center at the University of Virginia. For example, the existing rehabilitation unit at UVA would need appropriations of $1,764,000 to expand its services to ventilator-dependent patients between the ages of one and twenty-one. This facility would provide the patient and his parents with medical and nursing education (how to handle his condition, necessary self-care, etc.), physical rehabilitation services, education and counseling. Further, the University of Virginia has made a commitment to this project and agreed to aggressively seek its implementation.

The Joint Subcommittee wishes to emphasize that no new programs are being proposed. No long-term care or warehousing unit would be established with these expansions. The Joint Subcommittee strongly supports limiting admission to the expanded units to <u>those patients with prior discharge planning for nursing home admission, home care or some other facility.</u> In the opinion of the Joint Subcommittee, patients should be fed into these intermediate rehabilitation facilities from all over the state for short term evaluation, training and counseling, but only after obtaining appropriate discharge planning.

In addition, the initiation of services to ventilator-dependent patients at Woodrow Wilson Rehabilitation Center would provide these patients, particularly young people, with an appropriate setting for receiving vocational rehabilitation.

<u>RECOMMENDATION NUMBER 4.</u> The Joint Subcommittee supports the initiation of services to ventilator-dependent patients at Woodrow Wilson Rehabilitation Center through requesting additional appropriations for the establishment of a four-bed unit for ventilator-dependent patients.

<u>RATIONALE:</u>

Woodrow Wilson Rehabilitation Center could provide the ventilator-dependent patient with vocational evaluation and, depending on the vocational potential of the individual, with vocational rehabilitation. At present, some ventilator-dependent patients are employed in their professions or occupations and performing well. However, the vocational potential of the quadriplegic, ventilator-dependent patient may be limited at present. As already stated, engineering technology in rehabilitaion is only just beginning according to the experts, but is progressing quickly. In the future, the vocational potential and rehabilitaion of the immobile, ventilator-dependent patient will, undoubtedly, be expanded. The Woodrow Wilson Rehabilitation Center administrators are willing to establish a four-bed unit to accommodate the ventilator-dependent patient with vocational potential and are currently investigating programs in other states to determine the appropriate direction for this program.

<u>RECOMMENDATION NUMBER 5.</u> The Joint Subcommittee recommends that health insurance plans adopt flexible options and initiate case-by-case evaluations of home care for the ventilator-dependent patient.

<u>RATIONALE:</u>

Although many private third party payors seem to be adopting flexible approaches to the reimbursement for care of these patients such as ombudsman programs, access to home care for the ventilator-dependent person covered by private insurance continues to be restricted in many cases. Frequently, because the plan does not include home-based care, the adult patient resides in an acute-care facility for long periods when he could be receiving less costly, more beneficial care at home. In spite of the fact that home and community-based care of the children is far more conducive to normal development than the acute care environment, such nontraditional care for chronically ill children has not yet received widespread acceptance. For these reasons, the Joint Subcommittee believes that flexibility on the part of the private, third party payors is essential. In the opinion of the Joint Subcommittee, every patient receiving care in a hospital and who is covered by private insurance should be carefully evaluated and, whenever appropriate, should be provided a home discharge plan.

<u>RECOMMENDATION NUMBER 6.</u> The Joint Subcommittee supports the provision of appropriations to fund a foster care payment differential for ventilator-dependent children.

<u>RATIONALE:</u>

Currently, foster care payments are the same regardless of the needs of the child. No differentials are provided for families willing to take children whose needs are physically and emotionally demanding. The Joint Subcommittee believes that providing a differential would be an incentive for foster care families to accept the ventilator-dependent child.

Further, since the population of ventilator-dependent children is undoubtedly growing and more of these children will be in foster care, the Joint Subcommittee believes that it is essential for Virginia to face this need now instead of waiting until a crisis occurs.

<u>RECOMMENDATION NUMBER 7.</u> The Joint Subcommittee recommends that the Virginia Medicaid Program study the feasibility of providing additional services to ventilator-dependent children in group homes.

RATIONALE:

Institutional settings are not ideal environments for children. There are several group homes which accept handicapped children; however, none accept the ventilator-dependent child. Some of the group homes provide good programs which would be more "home-like" than other types of institutions. Therefore, the Joint Subcommittee believes that the Virginia Medicaid program should consider providing addition services to ventilator-dependent children in group homes as an incentive for these homes to admit such children.

RECOMMENDATION NUMBER 8. The Joint Subcommittee recommends that the Commonwealth's institutions of higher education strive to provide access to education through programs specifically designed for the ventilator-dependent patient.

RATIONALE:

As rehabilitation engineering progresses, more ventilator-dependent young people will need access to higher education. There are no programs or institutions at present in Virginia which could readily provide access to higher education to the ventilator-dependent individual. Many of these young people are of normal or above-normal intelligence. Therefore, the Joint Subcommittee believes that institutions of higher education need to be informed of the potential need for access to a college education for the ventilator-dependent young person.

RECOMMENDATION NUMBER 9. The Joint Subcommittee strongly supports the proposal under consideration in Congress, which would allow state Medicaid programs to cover additional services in the home for ventilator-dependent patients.

RATIONALE:

Until very recently, states did not have the option to provide home and community-based care under Medicaid. This was changed by certain parts of the Omnibus Budget Reconciliation Act of 1981 by allowing waivers to the states to offer home and community-based services in order to avoid institutionalization where appropriate. These changes were intended to provide less costly and less restrictive alternatives to institutional care. However, in the case of ventilator-dependent patients, the personal care services waiver does not allow the kinds of services needed. Further, although the Medicaid patient may be eligible for both personal care services and home health services, in many cases, up to eight hours of skilled nursing services per day are necessary in order to keep the patient in the home. Therefore, many of these patients continue to reside in acute care facilities.

H.R. 3103, which would have amended the Medicare and Medicaid provisions of the Social Security Act, included a new state option to provide additional services to ventilator-dependent patients in their homes. Although the Joint Subcommittee is aware that H.R. 3103 did not pass and this option is still being reviewed by Congress, it is believed that support of some degree of skilled care to assist family members with home care of such patients would be appropriate. The option to cover such services would alleviate to a large degree the present difficulties encountered by Medicaid patients in returning to their homes.

RECOMMENDATION NUMBER 10. The Joint Subcommittee recommends that the Department of Health adopt a flexible policy for evaluation of applications of hospitals for certificates of need to provide skilled nursing services in order to increase the number of appropriate long-term care placements for the ventilator-dependent patient.

RATIONALE:

The Joint Subcommittee believes that development of residential, long-term care placements is crucial and that this development can be accomplished in the private sector if the appropriate incentives are provided. At present, as already stated, many nursing homes are unwilling to accept heavy-care patients; therefore, long-term care placements for the ventilator-dependent patient are limited. On the other hand, many community hospitals have empty beds at this time and might be willing to establish programs for these patients which would accomodate any special educational and social needs. In addition, this type of facility could initiate programs to encourage the adult ventilator-dependent patient in achieving a measure of independence, if appropriate, e.g., conducting work from his room, continuing his education, etc.

The Joint Subcommittee also believes that the Commonwealth should encourage hospitals to convert this excess bed capacity to the delivery of other much-needed services. Community hospitals appear to be more prepared to accept these patients due to existing medical, skilled nursing and therapy services and structural capacities. However, at present, in order to convert medical/surgical beds to SNF beds, hospitals are required to apply for and receive a certificate of need for (i) a new service regardless of whether a capital outlay is necessary or not or (ii) an increase in services, if the facility already has some SNF beds.

The Joint Subcommittee also believes that an increase in SNF capacity in Virginia would not impact Medicaid costs because of the checks provided by the Preadmissions Screening Program. In Virginia, Medicaid reimbursement for long-term care placement is tied to this program.

In the opinion of the Joint Subcommittee, allowing hospitals to implement SNF services would also increase access to skilled nursing care for other categories of patients. In addition to Medicaid recipients, increased SNF capacity would benefit Medicare and private pay patients in need of short term SNF care who are unable to obtain such care because of waiting lists in nursing homes. Further, the quality of such care as well as the continuum of long-term care in the State would be improved by this development.

The Joint Subcommittee wishes to express its appreciation to the many professionals and citizens who contributed their time and ideas to this study as well as to the personnel of the Department of Medical Assistance Services, the Department of Rehabilitative Services, the Department of Health, the Department of Education and the Woodrow Wilson Rehabilitative Center.

Respectfully submitted,

Thomas J. Michie, Jr., Chairman

Dorothy S. McDiarmid, Vice-Chairman

John C. Buchanan

Vincent F. Callahan, Jr.

Jay W. DeBoer

Yvonne B. Miller

Frank W. Nolen

APPENDIX A

Senate Joint Resolution No. 99 of 1985

Letter on Blue Cross/Blue Shield policy

Survey conducted by ad hoc committee of the American Lung Association of America

LD9128125

SENATE JOINT RESOLUTION NO. 99

Offered January 21, 1985

Requesting the Senate Committees on Education and Health and on Finance and House Committees on Health, Welfare and Institutions, and Appropriations to study the needs of machine-dependent individuals.

Patron—Michie

Referred to the Committee on Rules

WHEREAS, medical technology can preserve the lives of individuals with catastropic injuries and illnesses; and

WHEREAS, many of the individuals whose lives are saved by this high technology become dependent for their lifetime on machines for the maintenance of their vital functions; and

WHEREAS, young adults and children, some of whom are infants, constitute a sizeable group among these machine-dependent individuals and have potentially long lifespans; and

WHEREAS, many of these machine-dependent patients are presently receiving care in acute care hospitals at great cost to society; and

WHEREAS, pursuant to the Omnibus Budget Reconciliation Act of 1981, states are allowed to apply for waivers to offer home and community-based services for Medicaid recipients in order to avoid institutionalization and provide care in a less costly and restrictive environment; and

WHEREAS, however, in most states, including Virginia, Medicaid eligibility is frequently tied to eligibility for SSI and in the case of children, the income of the parents is "deemed" to the children if they are living in the same household; and

WHEREAS, this means that an institutionalized child is not "deemed" to have the income of the parents and can be eligible for Medicaid; and

WHEREAS, as a result of the publicity given to the plight of Katie Beckett, a little disabled girl who was institutionalized and unable to return home because she would lose Medicaid eligibility, the federal law was changed so that states may furnish home or community-based services under Medicaid to persons who would be Medicaid-eligible if they were placed in an institution; and

WHEREAS, Virginia has not chosen to cover all of those individuals who would be eligible under the optional provision of this federal Medicaid law, but has adopted a policy of applying to the federal Health Care Finance Administration for individual waivers in appropriate cases; and

WHEREAS, in order to qualify for a Katie Beckett waiver in Virginia, the applicant must be under eighteen years old, disabled, institutionalized at Medicaid expense as a medically-needy individual and suitable for outside care which can be provided at less than in an institution; and

WHEREAS, home, community-based and other less restrictive alternatives to expensive acute care facilities have been developed for the care of machine-dependent individuals in other states; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Senate Committees on Education and Health and on Finance and the House Committees on Health, Welfare and Institutions, and Appropriations are hereby requested to establish a joint subcommittee to study the needs of machine-dependent individuals, particularly young adults and children. The joint subcommittee shall consist of seven members as follows: two members of the Senate Committee on Education and Health and one member of the Senate Committee on Finance to be appointed by the Senate Committee on Privileges and Elections; and two members of the House Committee on Health, Welfare and Institutions and two members of the House Committee on Appropriations to be appointed by the Speaker of the House. In its deliberations, the joint subcommittee shall consider the following:

1. What should the policy of the Commonwealth's teaching institutions and indigent programs, including Medicaid, be in relationship to these machine-dependent individuals?

2. Does the Commonwealth's criteria for Medicaid eligibility discriminate against providing care for these individuals in a less restrictive environment such as the home or community? And, if so, how can this problem be remedied without substantially increasing the cost of Medicaid to the Commonwealth?

3. Should the Commonwealth apply to the Health Care Finance Administration for a model waiver under Medicaid to provide care in the home and community for up to fifty machine-dependent individuals?

4. Can appropriate delivery systems, other than acute care hospitals, be developed for these machine-dependent individuals, especially children, which would be less costly to the Commonwealth and less restrictive for the individual?

The joint subcommittee shall complete its work in time to submit its recommendations to the 1986 Session of the General Assembly.

All direct and indirect costs of this study are estimated to be $23,000.

Official Use By Clerks

Agreed to By The Senate	**Agreed to By The House of Delegates**
without amendment ☐	without amendment ☐
with amendment ☐	with amendment ☐
substitute ☐	substitute ☐
substitute w/amdt ☐	substitute w/amdt ☐
Date: ________	Date: ________
Clerk of the Senate	Clerk of the House of Delegates

Blue Cross®
Blue Shield®
of Virginia

Richardson Grinnan, M.D.
Vice President
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November 20, 1985

Norma Szakal
Staff Attorney
Division of Legislative Services
P O Box 3 - AG
Richmond, VA 23208

Dear Norma,

As follow-up to the Joint Subcommittee Hearings Studying the Needs of Machine-Dependent Individuals, the following is a detailed overview regarding coverage by Blue Cross and Blue Shield of Virginia.

Seventy-eight percent (78%) of Blue Cross and Blue Shield of Virginia managed contracts make provision for coverage of machine dependent individuals under the HOME HEALTH CARE benefit. A break down by Line of Business includes the following:

LINE OF BUSINESS	HOME HEALTH CARE	
Regular Non-Group	100%	
Small Business	100%	
Medicare Extended, Non-Group	100%	
Community	100%	
HMO +	100%	
State of Virginia	100%	
Local Experience Rated Groups	95%	
Control National and Par National Accounts	0%*	
FEP Option 1	100%	(40% of FEP)
Option 2	0%	(60% of FEP)

*Apparently, very few national control Blue Cross Plans have Home Health Care.

As I also pointed out in my testimony, the Board of Blue Cross and Blue Shield of Virginia passed a resolution which allows extra contractual coverage of lower levels of care in situations in which it is determined to be care and cost effective. However, for an individual to continue to receive such a benefit, the individual must meet the medical necessity guidelines which would otherwise qualify him/her for inpatient care.

If there are other questions regarding coverage in this area, I would be glad to serve as a resource to have them addressed.

Sincerely,

Richardson Grinnan, M.D.

RG:fp

cc: Senator Thomas J. Michie, Jr., Chairman

American Lung Association of Virginia
311 South Boulevard
P. O. Box 7065
Richmond, Virginia 23221

JOINT SUBCOMMITTEE STUDYING THE NEEDS OF MACHINE-DEPENDENT INDIVIDUALS

Mr. Chairman, and members of the Subcommittee.

The following is a summary of the report that was presented on behalf of the American Lung Association of Virginia at the subcommittee meeting that was held on Thursday, August 15, 1985.

The American Lung Association of Virginia and its medical section, the Virginia Thoracic Society, consider the problem of ventilator-dependent patients to be a major issue in the care of children and adults with pulmonary disease. An ad hoc committee chaired by Dr. Dudley F. Rochester, head, Pulmonary Division UVA School of Medicine, has been given the charge of obtaining information regarding ventilator-dependent patients in Virginia. This information has been saught in order to increase the accessibility and availability of outpatient care for this type of patient.

A survey has been completed of hospitals and home care providers to identify the number of ventilator-dependent patients. The results of the hospital survey with 53 of 109 hospitals responding are:

1.	4 children 18 adults	-	Currently in hospitals who could be discharged if outpatient resources were available.
	18 children 204 adults	-	Over the past five years who have been patients in hospitals but could have been discharged if outpatient resources had been available.
2.	5 children 27 adults	-	Discharged from hospitals to home in the past two years using mechanical ventilation.
	7 children 50 adults	-	Discharged from hospitals to home over the past five years with mechanical ventilation.
3.	17 adults	-	Discharged from hospitals to nursing homes in the past two years with mechanical ventilation.
	50 adults	-	Discharged to nursing homes over the past five years with mechanical ventilation.

Chronic obstructive pulmonary disease ranks the highest in the disease catagories for both children and adults using mechanical ventilation. Spinal cord injury is the second highest.

-continued-

The problems encountered by the hospitals rank as follows: inadequate reimbursement; outpatient nursing care; outpatient respiratory therapy; outpatient physician coverage; and availability of hospital personnel to facilitate multidisciplinary discharge planning.

The results of the survey of home care providers with 80 out of 146 providers responding are:

1. 11 children - Currently at home and using mechanical ventilation.
   59 adults

   27 children - Over the past five years at home using mechanical ventilation.
   150 adults

2. 11 adults - Currently followed in a nursing home with mechanical ventilation.
   33 adults - Over the past five years in a nursing home.

Problems associated with home ventilation are: inadequate reimbursement and availability of nursing home to accept adult ventilator patients.

Future plans of the ALAV are:

1. To develope a discharge planning guide and provide consultation services when requested for hospital personnel.

2. Provide training workshops for nursing home personnel.

3. Thank the hospitals and home care providers who responded to our survey and request they keep more accurate records for the next year regarding the number of ventilator-dependent patients. Another survey will be conducted at that time.

4. Offer recommendations for changes in coverage to third party payers, carriers and agencies.

8/23/85:dj

APPENDIX B

Senate Bill No. 121

Senate Joint Resolution No. 27

Senate Joint Resolution No. 88

LD1236125

SENATE BILL NO. 121

Offered January 15, 1986

A BILL to amend and reenact § 32.1-325 of the Code of Virginia, relating to medical assistance plans.

Patron—Michie

Referred to Committee on Education and Health

Be it enacted by the General Assembly of Virginia:

1. That § 32.1-325 of the Code of Virginia is amended and reenacted as follows:

§ 32.1-325. Board to submit plan for medical assistance services to Secretary of Health and Human Services pursuant to federal law; administration of plan; contracts with health care providers.—A. The Board, subject to the approval of the Governor, is authorized to prepare, amend from time to time and submit to the Secretary of the United States Department of Health and Human Services a state plan for medical assistance services pursuant to Title XIX of the United States Social Security Act and any amendments thereto. The Board shall include in such plan:

(1) A provision for payment of medical assistance on behalf of individuals, up to the age of twenty-one, placed in foster homes or private institutions by private, nonprofit agencies licensed as child-placing agencies by the Department of Social Services;

(2) A provision for determining eligibility for benefits which disregards any transfer of assets into an irrevocable trust where such transfer has been designated solely for burial of the transferor or his spouse. The amount transferred into the irrevocable trust together with the face value of life insurance and any other irrevocable funeral arrangements shall not exceed $1,500; ~~and~~

(3) A requirement that, in determining eligibility, a home shall be disregarded. A home means the house and lot used as the principal residence and all contiguous property as long as the value of the land, exclusive of the lot occupied by the house, does not exceed $5,000 ~~.~~ *; and*

(4) A provision for payment of medical assistance on behalf of individuals up to the age of twenty-one, who are Medicaid eligible, for medically necessary stays in acute care facilities in excess of twenty-one days per admission.

In preparing the plan, the Board shall work cooperatively with the State Board of Health to ensure that quality patient care is provided. The Board may make, adopt, promulgate and enforce such regulations as may be necessary to carry out the provisions of this chapter.

B. The Director of Medical Assistance Services is authorized to administer such state plan and to receive and expend federal funds therefor in accordance with applicable federal and state laws and regulations.

C. The Director of Medical Assistance Services is authorized to enter into agreements and contracts with medical care facilities, physicians, dentists and other health care providers where necessary to carry out the provisions of such state plan. Any such agreement or contract shall terminate upon conviction of the provider of a felony. In the event such conviction is reversed upon appeal, the provider may apply to the Director of Medical Assistance Services for a new contract.

When the services provided for by such plan are services which a clinical psychologist is licensed to render in Virginia, the Director shall contract with any duly licensed clinical psychologist who makes application to be a provider of such services, and thereafter shall pay for covered services as provided in the state plan.

D. The Board shall prepare and submit to the Secretary of the United States Department of Health and Human Services such amendments to the state plan for medical assistance as may be permitted by federal law to establish a program of family assistance whereby children over the age of eighteen years shall make reasonable contributions, as determined by regulations of the Board, toward the cost of providing medical assistance under the plan to their parents.

LD1720125

SENATE JOINT RESOLUTION NO. 27

Offered January 20, 1986

Expressing the sense of the General Assembly in support of the recommendations of the Joint Subcommittee Studying the Needs of Machine-Dependent Individuals.

Patrons–Michie, Buchanan, and Nolen; Delegates: Miller, Y. B., DeBoer, McDiarmid, Callahan, and Van Yahres

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Referred to Committee on Rules

WHEREAS, the Joint Subcommittee Studying the Needs of Machine-dependent Individuals has limited its deliberations to the needs of ventilator-dependent patients; and

WHEREAS, the joint subcommittee has worked diligently, has obtained imput from Medicaid officials, representatives of health insurance plans, medical professionals and other health personnel working with ventilator-dependent patients; and

WHEREAS, the joint subcommittee has toured intensive care and other units and has witnessed the care of a ventilator-dependent child; and

WHEREAS, access to long-term care facilities and home-based care is severely limited for the ventilator-dependent patient in Virginia; and

WHEREAS, the population of ventilator-dependent patients in all age groups and disease pathologies is growing; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the General Assembly hereby expresses its support of the recommendations of the Joint Subcommittee Studying the needs of Machine-dependent Individuals. The joint subcommittee recommends:

1. Endorsement of the concept of Medicaid reimbursement based on the intensity of nursing services for heavy care ICF patients in order to create an incentive for nursing homes to accept the ventilator-dependent patient.

2. Revision by the Virginia Department of Medical Assistance Services of the State Plan to include reimbursement of acute care services provided to individuals up to the age to twenty-one, who are Medicaid recipients, in excess of twenty-one days.

3. Expansion of two intermediate rehabilitation facilities in order to provide services to the pediatric and adult ventilator-dependent patients in Virginia.

4. Initiation of services to ventilator-dependent patients at Woodrow Wilson Rehabilitation Center.

5. That health insurance plans adopt flexible options and initiate case-by-case evaluations of home care for the ventilator-dependent patient.

6. Provision of a foster care payment differential for ventilator-dependent children.

7. That the Virginia Medicaid Program study the feasibility of providing additional services to ventilator-dependent children in group homes.

8. That the Commonwealth's institutions of higher education strive to provide access to

education through programs specifically designed for the ventilator-dependent patient.

9. That Virginia demonstate support for the proposal recently considered by Congress, which would have allowed state Medicaid programs to cover additional services in the home for ventilator-dependent patients.

10. That the Department of Health adopt a flexible policy for evaluation of applications of hospitals for certificates of need to provide SNF services in order to increase the number of appropriate long-term care placements for the ventilator-dependent patient.

LD1723125

SENATE JOINT RESOLUTION NO. 88

Offered January 21, 1986

Memorializing Congress to approve a provision which authorizes services in the home for individuals who, but for the need for ventilator support, would require inpatient hospital care.

Patrons–Michie, Nolen, and Buchanan; Delegates: McDiarmid, Callahan, Miller, Y. B., and DeBoer

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Referred to Committee on Rules

WHEREAS,care of the ventilator-dependent patient in Virginia most frequently takes place in an acute care facility; and

WHEREAS, there are many reasons for this warehousing of ventilator-dependent children and adults in acute care facilities; and

WHEREAS, one of the primary reasons for this inappropriate situation is that third party payment systems, including Medicaid and health insurance plans, do not provide the kinds of services these patients require to receive home care; and

WHEREAS, Congress has recently considered provisions which would have allowed the state medicaid programs to cover additional services in the home for individuals who, but for the need for ventilator support, would require inpatient hospital care; and

WHEREAS, because of other, unrelated issues included in the same bill, the provisions allowing augmented services in the home for ventilator-dependent patients were not approved by Congress; and

WHEREAS, in many cases, allowing the adult ventilator-dependent patient to return home when his family is willing and able to care for him would be a more humane policy than insitutionalization; and

WHEREAS, home care of the ventilator-dependent child is much more conducive to physical and social development; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Congress of the United States is hereby memorialized to approve a provision authorizing services in the home for individuals who, but for the need for ventilator support, would require inpatient hospital care.

RESOLVED FURTHER, That the Clerk of the Senate is directed to prepare a copy of this resolution for transmittal to the Congress of the United States.