

AARTimes

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AARTimes presents the proceedings of the
Surgeon General's Regional Workshop on Home Care

Home Care Savings Potential Draws National Attention

Al Kemp Addresses Community-Oriented Home Care

The disabled comprise the fastest growing segment of our population, and the most vulnerable within these groupings are the children and the elderly. Here in the St. Louis area, as is the case in the rest of the country, we find probably the fastest growing segment of our population by age category — those over 65. This is the top region of the country as far as the proportion of percentage of elderly over 65.

Medical, surgical and technical advances have saved the lives of children and adults who would have died in past years. Children and adults with multiple disabilities now live longer and have more productive lives. The ramifications for health care needs of these disabled children and adults dependent upon technology for daily living are far reaching and complex. Pioneering efforts of doctors and nurses, allied health professionals, state agency officials, insurance, hospital administrators, social workers and parents' advocacy groups have made it possible for ventilator-dependent children to live in the community with significant savings. Yet now, this growing population needs regional coordinating organizations to maintain and refine current strategies providing community-based health care to guide and support parent groups and to educate the professional and private sector about the dynamics of community-oriented home care. For these reasons, we are gathered here today. ●

Sam Giordano Says Communication Vital To Home Care Success

This country's method of providing health care is undergoing a great deal of scrutiny and revision. The problem is in achieving a balance between cost efficient medical care and quality care. One possible and popular solution to the problem is the "unbundling" of medical services. Simply stated, this means that efforts should be made to effect an appropriate match of health care resources to patient needs. This results in a more cost effective way of rendering care with assurances that the patient will receive necessary medical care.

A key element in the unbundling process is home care. The Surgeon General, C. Everett Koop, MD, recognized that a significant benefit could be derived if certain patients not requiring hospitalization could be supported in their home environments. Pursuant to that goal, Dr. Koop convened a workshop on the plight of the ventilator-dependent child in late 1982. Several important recommendations were generated at the workshop. Not the least of those was to hold future workshops to identify problems and barriers confronting the home care patient, and to establish a network of that first follow-up workshop. Held Dec. 13, 1983, in St. Louis, MO, health care providers and ventilator-dependent patients from across the country convened to share their stories and to develop an understanding of the problems with home care under our present health system. I am sure that after reviewing this issue, you will find that there is a great deal of support for the home care patient, however, that aid is lacking central coordination and consistency.

It is our hope to continue to present the latest information on ideas, problems and methods, for indeed the first step in establishing an adequate structure to support home care must be communication — two-way communication. This issue satisfies only a part of that request. I invite you to satisfy the second part: please give us the benefit of your thinking. Please share with us ideas that may not be presented in this issue, and certainly send us comments on the subjects as they are presented here. This exchange will eventually result in an efficient and effective home care support network throughout this country. ●

Al Kemp is Director of Region VII Department of Health and Human Services

Sam Giordano, RRT, is executive director of the American Association for Respiratory Therapy.

What Is A Waiver?

Many of the articles in this special report on the Surgeon General's Workshop refer to the waivers available to ventilator-dependent patients. If you are unfamiliar with the waiver process, it is important to note that there are different kinds of waivers.

In 1981, as part of the Budget Reconciliation Act, Congress gave the states greater flexibility to establish home and community-based long term delivery systems for Medicaid individuals at risk of institutionalization. These waivers, known as Section 2176 waivers are quite different in their scopes, with some states targeting solely on the aged and physically disabled population, while others focus on the developmentally disabled. Each state requests its own range of services, and some do include respiratory therapy home care.

There is a second kind of waiver permitted under the 2176 program. The "model waivers" permit a state to target a specific group of no more than 50 blind or disabled individuals for Medicaid eligibility and community-based long term care services who, without the waiver, would be eligible for Medicaid benefits only if institutionalized.

Further, there are the Katie Beckett waivers, established by Section 134 of PL 97-248. These waivers give the states the option of extending coverage to disabled children living at home or in the community provided that the cost of the care does not exceed the cost of institutional care. Interestingly, and this is the basis of part of the AART's arguments, only one state, Idaho, has chosen the Section 134 Katie Beckett waiver option.

A very important fact to note about the waiver system is that it is exactly that — a system which waives existing rules. It becomes the exception rather than the rule. The AART firmly believes that respiratory care for ventilator dependent individuals ought to be the rule rather than the exception.

THE WHITE HOUSE
WASHINGTON

December 12, 1983

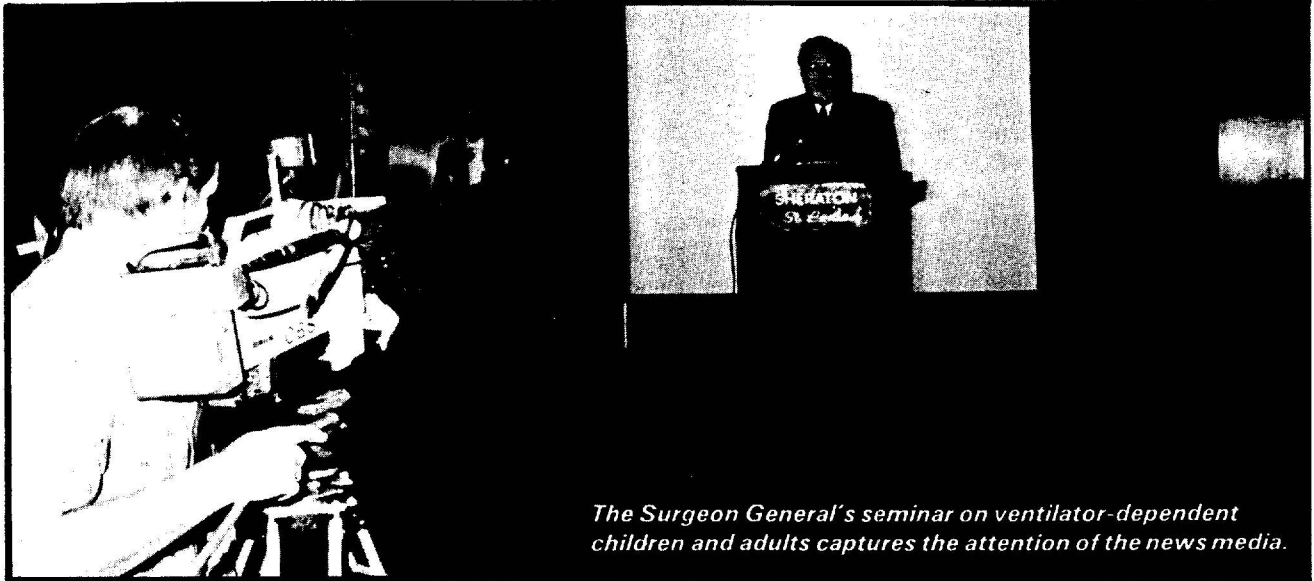
I am very pleased to extend my warm congratulations on the observance of the First Anniversary of the Surgeon General's Conference on Children with Handicaps and Their Families.

Because of your efforts, many children and their families have new hope and encouragement. Your willingness to tackle a difficult challenge has enabled children who live within the confines of institutions to encounter and enjoy a normal life as they now participate in their families, schools, and houses of worship. No longer is it acceptable to assume that a technology-dependent child must remain in an institution.

Your commitment to excellence has established new vistas of opportunity for those who have needed a helping hand. Let me encourage you to continue your good works. The spirit of cooperation that Americans bring to problem-solving is bound to result in significant achievement in the development of positive and realistic strategies for action in your states and communities.

On behalf of untold thousands of Americans, I thank you for your leadership, innovation, and commitment to change. Nancy joins me in sending every good wish for continued success in your efforts.

Ronald Reagan



The Surgeon General's seminar on ventilator-dependent children and adults captures the attention of the news media.

Surgeon General Appeals To Society To Share Problems Of The Handicapped

by **C. Everett Koop, MD**

This meeting is a natural follow-up to the Surgeon General's Workshop on Children with Handicaps and Their Families, which we held a year ago in Philadelphia. At that time, in my charge to the workshop participants I said, "The way we deal with problems like these reveals just what kind of society we are."

I think the record of the past 12 months is clear enough. It shows that we are still a caring and compassionate society — concerned about the health of children, sympathetic to the families who face enormous challenges in the course of accepting and raising a handicapped child, and innovative in the way we bend the political and economic environment to make it serve the human needs of our families, rather than the reverse.

But those are generalities. Actually, I have two specific reasons for being especially pleased to

open this conference this morning. First, I can't tell you how proud I am to be in the government, to have held a conference, and then, a year later, to be able to look back and see the results of that conference.

Even after two-plus years in this position, I still consider myself to be the new kid on the block in the Public Health Service. Many of my colleagues and friends in the Public Health Service have been fighting the battle of inertia for much longer than I. As the new kid, I haven't had the years of triumph and uncertainty that usually come with the territory of public service. But we've been very fortunate. In this highly complex and emotionally charged area of service to handicapped children and adults and their families, we've been able to make significant, measurable progress. I'm very proud of that — as a public servant and as your Surgeon General — and I hope you feel

the same way. In a single year, we may have made a difference in the lives of many hundreds of children and their families.

My second reason is a little different. Over the past year, we've been devoting our time to an issue that brooks no obstruction, that admits of no pettiness — an issue that inspires people to offer the best that is in them in order to plan and implement such a worthwhile program. The problems faced by ventilator-dependent patients and their families can be staggering. They are among the most complex problems to appear within the environment of medicine. They require innovative, careful relationships between medicine and community social services. These are also costly problems, requiring the help of accountants with the souls of saints. And the problems are also inextricably linked to a cluster of profound mys-

teries — the mystery of the human infant, the mystery of parenthood, the mystery of personal courage, and the mystery of family love.

As formidable a task as we set for ourselves, I have to nevertheless say that it was the right task. For too many years we had talked about this problem and we sympathized and commiserated and had come up with a number of steps to somehow lighten the burden for both the ventilator-dependent patient and his or her family. But clearly we were not doing enough.

Also, the way we were going about it said quite a bit about our intentions, generally in regard to the solving of many other serious socio-medical issues. The fact is, if we could pull together our resources in such a coherent and effective way that we could make good things happen for ventilator-dependent children, then we could do good things for many, many other disabled and handicapped children and adults.

You remember the words of Cassius to Brutus in Shakespeare's *Julius Caesar*. "The fault, dear Brutus, is not in our stars but in ourselves, that we are underlings." We so often defer to circumstance, as the Romans deferred to Caesar, and we become, in effect, the "underlings" of circumstance. That need not always be so. It is not written anywhere in the stars that disabled children, attached to machinery for the vital air of life, must go without any other help from their society. Nor is it written anywhere that other disabled and handicapped individuals, very young ones to very old ones, should be left outside the pale of assistance. That's just not the way we want our society to be.

So, with this project, addressing the needs of ventilator-dependent children and their families, we

declared our intention to blame the stars no longer, but rather to look to ourselves for what could be done. And I can tell you it worked.

At the close of last December's workshop, we affirmed our commitment to turn into reality as many of the workshop recommendations as possible. With us today are a number of the same people



C. Everett Koop

who had taken part in last year's program. And they have stories to tell us — stories of hope, professionalism, character, and I'm pleased to say, of success.

As an introduction to their contributions, let me briefly report on the status of the seven recommendations and how we're doing on them. As the top of the list last year was the need to get as clear a *definition of the problem* as we could. And by that, I don't mean to narrow down the problem and thus, in a sense, trivialize many of its aspects — quite the reverse. It was felt that the public as well as the medical and social service professions needed to appreciate the scope of the problem of care for

handicapped children and their families. We did not feel — and rightly so — that such appreciation was current.

I believe that the publication and distribution of the proceedings of the December workshop has contributed to this task of clarifying what the problem is. The workshop report does provide a common base of understanding for all persons with an interest in this problem.

Stimulated by this first recommendation regarding the definition of the problem, the Crippled Children's Program at the University of Illinois surveyed the status of ventilator therapy and support among children in Illinois. This makes Illinois the second state to obtain this kind of information. Pennsylvania was the first and has been updating its information base.

A similar study was also begun at the University of California at San Francisco. The health policy program at the university is investigating, for example, the increase in the last 25 years of the number of days of limited activity among children.

Additional efforts have included a "National Conference on Chronic Illnesses in Children," conducted last April by Vanderbilt University. This conference has helped us in a number of ways, but I'll mention in particular the attention it paid to the issue of research priorities regarding chronic illness among children.

Then, just this past October in Kalamazoo, MI, a three-day "Invitational Symposium on Ventilator-Dependent Children" was held. I understand it was quite a success. A full report of that symposium will soon be published in *Pediatrics* magazine, and I urge you all to watch for it. The Kalamazoo Symposium dealt with a num-

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ber of issues such as the need for better data, the problems associated with the financing of care from both public and private sources, the research needs of this field, and the major task of education that has to be done among parents, patients, health and social service professionals, and our communities in general.

The second recommendation of the workshop last December concerned the need for *model standards*. The workshop participants felt we needed to spend much more time and effort in developing standards that reflected the needs of the family as well as the concern for the quality of life of each disabled child. To get this work started, our division of Maternal and Child Health awarded two grants for special projects of regional and national significance now known as “Sprans” grants. One of these is the project at the University of Iowa. It will explore the relationships that develop between disabled children and the health professionals who take care of them.

The other, at the University of Michigan, is looking at standards of care that may be applied to regionalized community health services for children with diabetes. Such a regionalized support network would involve health and social service professionals, private professional and voluntary organizations, and local and state governmental agencies. It's an ambitious and very worthwhile project.

And that brings up the third recommendation which was to develop *regionalized systems of*

care for ventilator-dependent children.

Three “Sprans” grants have been awarded for the development of regionalized systems that deal specifically with ventilator-dependent children. The accent is on ways to help move children out of institutional settings and get them back home, or at least to a home-like setting. Naturally, the role played by effective community-based support systems is crucial.

Six other “Sprans” grants have been awarded for the development of model systems to serve children with arthritis. In all, the Public Health Service has awarded close to \$750,000 for the development of regionalized systems of care for disabled children.

Among the most exciting efforts in this area is the contract awarded by the Office of Human Development Services to the John F. Kennedy Institute in Baltimore. What we hope to accomplish here is a model for a working nationwide referral network for the developmentally disabled. Using today's sophisticated technology, it should be possible for a developmentally disabled individual, or the physician, parents, or care-takers of such an individual, to query a single source for information about that disability and pinpoint the best or most appropriate places to get help for the person so disabled — help anywhere in the country or possibly even the world.

This is no longer the “blue-sky” thinking of visionaries. We know it can be done because it is being done here and there, albeit in piece-meal fashion. But we look to

the Kennedy Institute to pull some of these things together.

Under the terms of this award, the strong features of two important information systems are to be combined and regionalized. One is a data retrieval system for the particular use of practicing physicians, and the other is accessible by the general public.

The database for the physician-oriented system was developed by the Kennedy Institute in Baltimore, using data supplied by the 38 university-affiliated facilities around the country. As a matter of fact the American Medical Association itself has a contract with Kennedy to bring the institute's data in as the fifth offering of the AMA's Nationwide Medical Information Network, or “Minet.” It is available to every “Minet” subscriber who has a desk-top computer and a telephone.

This enterprise nicely pulls together government, the private non-profit sector, and organized medicine — in this case, the AMA — to make information available to physicians concerning access to specialized care for their patients and the presence of community support services.

The other and more consumer-oriented data system is now functioning out of the University of South Carolina to benefit citizens of that state. The system carries information on access to care and community support services within the state. However, any individual or family member can get into the system merely by dialing a toll free “800” number. It isn't open only to physicians, for ex-

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ample.

The Kennedy Institute has an excellent concept of just how such a network will function. By means of the Kennedy Award, we hope to expand the South Carolina model to cover all the states in federal Region IV, and they are, in addition to South Carolina, Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, and Tennessee. If that works — and I am very optimistic that it will — then the next step is to “go national” as it were, and thus make available to all our citizens the best information and the most appropriate resources relative to handicapping conditions.

I'd like to add one additional point. The Kennedy Grant is for \$95,000. It is probably the greatest bargain today in the entire field of health care and social service R & D. But it also illustrates that the size of the problem may not always determine the costliness of the solution. As professionals in this field, we need to keep our minds open to what can be done and then pay what's necessary.

I agree that such a sentiment is easier to say than to live, and for that reason, we have been moving on the fourth recommendation, the one that deals with the *financing of care* for children with disabilities. Last May, we held another kind of workshop in Washington, D.C. on this problem.

The cost of care is an important and continuing concern of the administration. I can tell you that the May workshop and a subsequent meeting in June with officials of the Health Care Financing Admin-

istration have served to throw some light on more and better ways — within existing law and regulation — to help pay for more and better service to handicapped children.

But the problem will not go away with the conduct of one workshop or the scheduling of one meeting. For that reason, I am setting as a personal objective the need to keep track of all developments in the financing of care so that the potential for increased support is fully realized and every child who needs care will get it. I know that is clearly the feeling here in our host state of Missouri, and I want to recognize the leadership given to this complex issue by Governor Bond.

Three other recommendations are worth mentioning, although I would rather not take the time to comment on them right now. They are: *Identifying areas of potential abuse*. That is, controlling costs, eliminating duplicative services, monitoring care according to model standards, and so on. Another is *incorporating principles of care for children with disabilities into training programs for health professionals and parents* which is a straightforward enough recommendation. I can report that an Ad Hoc Committee dedicated to following up this training recommendation met last June, with representation from across a broad spectrum of health, social service and educational specialties.

The seventh recommendation from our first workshop has to do with *supporting research in the care of children with disabilities*. The Vanderbilt study that I men-

tioned earlier, has been helpful in giving us some direction in our research strategy.

I hope you feel as good as I do about this record of achievement over the past 12 months. It does demonstrate that concerned citizens — health and social service professionals, government officials, and lay citizens — can focus their interests and energies on a particular issue and make a difference in the outcome of the public debate, and that disabled children and adults will benefit.

In these remarks I have measured progress according to what's been accomplished on the recommendations of last year's workshop. But many other things have happened over the past year, and I would be remiss if I did not recognize that. In fact, I would like to pay special attention to an event that took place in Washington, D.C. on November 29.

On that day, representatives of nine national organizations came together at a press conference. They convened to announce their agreement on a joint statement entitled, “Principles of Treatment of Disabled Infants.” The nine participants included:

- The American Academy of Pediatrics
- The American Association of University-Affiliated Programs
- The American Association of Mental Deficiency
- The American Coalition of Citizens with Disabilities
- The Association for the Severely Handicapped

- The National Association of Children's Hospitals and Related Institutions
- The Association for Retarded Citizens — United States
- The National Down's Syndrome Congress
- The Spina Bifida Association of America

The first statement of their statement reflects a great deal of social, legal, and medical history of the past few decades. It says, "Discrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible."

The statement goes on to highlight the "need for information" which will "improve decision-making about disabled individuals,

especially newborns." Medical care and the role of both government and the community are also dealt with in this statement. If you have not read it, I urge you to get a copy by writing directly to any of the nine signatories.

At the beginning of this year, I doubt that more than two or three of these nine groups could have agreed on such a broad statement, although they all believe deeply in the issues as well as in the need to keep moving forward. As the debate over the "Baby Doe" cases unfolded, I think the need for accommodation and consensus became increasingly clear to everyone. Yes, principles are at stake, but they are not at risk.

Events have made this past year both hectic and crowded, but it

has been a gratifying year as well. I've not been gone that long from the Children's Hospital of Philadelphia that I've forgotten the enormous personal and family problems faced by a number of my former patients — little children who had to be hooked up to a ventilator to get through the first few months of life with a disability.

So the hard work of the past year does have its very precious rewards. More children and more adults are going to get a better break in life, as a result of what we've accomplished and what we intend to accomplish. It seems to me that getting deeply involved in this kind of issue is precisely what an office such as mine ought to do — or else — what are Surgeon Generals for? ●



Julie Beckett visits with Missouri governor Christopher Bond (left) and Al Kemp during one of the seminar breaks.

The Missouri Waiver: A Means Of Decreasing Costs And Improving Health Care

by Christopher S. Bond

We in Missouri are no strangers to the idea of home and community based services. Last year we worked for and signed legislation that will mark the beginning of a new era in providing for the needs of our frail elderly. This legislation provides for in-home and community care for elderly persons who wish to stay in their homes and who can do so only if they receive some very basic and very important in-home services. I believe that we have proven in Missouri that we can provide for a much better quality of life and at the same time do so at savings.

Likewise, we know that there are children in our state who face very

similar circumstances. As with the elderly, these children face a choice between the lifesaving care they find in an institution, or the love and warmth they so desperately need from their families in their own homes. Children with multiple and complex handicaps have a right to the best quality of life possible. Many of these children can realize the maximum in potential for health, education, self-fulfillment and self-support, only with extensive medical, physical, social and psychological support. Hospital intensive care units and nursing homes currently provide the bulk of these services; but now we must find new ways to

meet the needs of these children.

Missouri's waiver project is designed to demonstrate the cost-effectiveness of placing these children, who currently must stay in costly institutions, back into their own homes and communities. Our goal is to provide them an opportunity to grow and develop as normally as possible in their own homes as members of their own families. I believe that home and community based services can allow these children this kind of growth and development, while providing significant cost savings.

The Omnibus Budget Reconciliation Act approved by Congress in 1981, accelerated the transfer of

fiscal and managerial responsibilities for health programs from the federal government to the state. This allows the Secretary of the Department of Health and Human Services to approve, by waiver, any state plan that includes home and community based services as medical assistance. Missouri's waiver was proposed under these guidelines and had been sent to Secretary Heckler. We expect a positive response from the department in the very near future.

The second objective is even more important than the cost factor. Certainly we expect, and we think we can demonstrate, the project will be cost-effective. But most important of all, the waiver can and will improve the quality of life for children who can be returned to their homes. By expanding the number and scope of services covered in a home based setting, children can be discharged earlier and treated in much more comfortable and more familiar surroundings. As a result, children will be reunited with their families, and in many cases, recovery time can be shortened as their quality of life improves.

As the Surgeon General pointed out, very often children in hospitals may encounter other diseases and infections, but when they go back to their homes they are in an environment in which they can grow, not only because of the physical conditions, but because of the love and care that a family can give.

The specific services that will be offered under the Missouri waiver will apply to needy children who will be eligible for Medicaid services. Some of these services are already covered under the state plan. But current limitations render them inadequate for the extensive service requirements for these children. With this waiver, the state will pay for the medical trans-

portation for the children in need. For example, if the child needs to go back to the hospital, the state will pay for the ambulance. The state will also pay for the homemaker or chore services to help the family with homemaking services, medical equipment and supplies, physical therapy, and pharmacy costs.



Christopher S. Bond

These services represent a very sophisticated level of technology. Indeed, it's often called High Tech Home Health Care. They offer the essential life support systems these kids need to survive. They also include the highest level of skilled nursing care necessary to maintain the patient's quality of life.

The concept behind the waiver was developed while working very closely with children's hospitals and medical professionals. Cer-

tainly we in state government could not have done it on our own, and we owe thanks to a great many dedicated physicians and other health care professionals who helped us pull together the information and outline the standards we must follow. With their combined efforts, we developed the principles and data which are contained in the waiver. We think the idea of a group approach is extremely important, because the children and their families need the support of all care providers. Their combined efforts in bringing together the information is essential if we are to identify the children needing these services, provide the care, and monitor their progress to the highest achievement of their potential and welfare.

The extensive array of services made available through this waiver would enable the children to receive quality care in their own homes. They extend not only to the child, but to the entire family unit. This is a very important aspect of the waiver because it recognizes that not only does the patient have special needs, but that the entire family also must cope with these responsibilities. The waiver alone, however, does not make all of this happen. Many other services are needed if the programs are to be successful. We must have support from the medical community including hospitals, physicians, home health agencies, medical equipment providers and a whole host of medical personnel, as they try to adapt to the changed lifestyle that accompanies the presence of a handicapped child in the home.

Studies have shown that families of handicapped children appear to be particularly vulnerable to the experience of stress. In fact, in some cases, this stress factor is so great that some families have felt that

they have had no choice but to seek institutional care for their children. As a result, we must find new methods of returning these children to their own homes, which will alleviate the stress as much as possible. We believe and expect this is precisely what the Missouri waiver will do.

In addition, as I indicated earlier, the waiver will be a cost-effective mechanism for delivering alternative sources of care to these children. Implementation of the waiver provisions will save approximately \$3500 per child over a year's time. This translates into savings for the taxpayer, while clients are provided better services more efficiently in their home surroundings.

We speak of the waiver of being

the magic instrument which will save money and ensure quality. Obviously, it's a start, and when you're dealing with government, you're going to have paperwork. Still, it is what this paperwork represents that is important. It represents a unified approach for children and their parents to be successfully reunited so that each child can reach his or her full potential in an environment most conducive to recovery. Without the expertise of the physician, the medical needs of the child cannot be totally identified. Without the case manager, the various essential one-on-one support to the child and the family would be missing. Without the support and cooperation of the service providers, the

entire program would not be possible. It's through their knowledge and care that these children are able to be treated in their homes. And obviously, without the care, love and understanding of the parents, these children would not even have a small hope of successfully recovering, going on to lead fulfilling lives.

It's this unity of purpose that makes this program a success. When all the concerned parents are striving for a common objective, many worthwhile goals can be obtained. I believe the goals contained in Missouri's waiver are very humane and certainly with your continued efforts and help they are attainable and they will be obtained. ●



Polio Survivors Prove The Value Of Home Care Services

by Gini Laurie

It is a privilege to be here with so many persons dedicated to home care services. I hope that we will be able to make history repeat itself. I hope that by directing attention to ventilator-dependent persons, all disabled persons will benefit in the same way that the earlier nationwide systems of home care services benefited all of them.

That system, which existed from 1953 to 1959, freed hundreds and hundreds of ventilator-dependent polio survivors from custodial care in hospitals — freed them to live self-directed and productive lives in their communities for 30 years. That system was the genesis of the independent living movement. Those polio survivors have been the role models of the spinal cord injured and all other severely disabled persons since the early 1950s. The lives of those polio survivors prove the value of home care services.

I was directly involved with the system because my volunteering started in 1949 and coincided with the development of the regional

respiratory polio centers which created that home care system. The centers were developed by the National Foundation for Infantile Paralysis to reduce the costly custodial care of 400 ventilator-dependent polio survivors of former epidemics who were scattered across the country in hundreds of hospitals. Sixteen regional centers were established at medical school/teaching hospitals to accept groups of those chronic ventilatory patients and to develop a positive approach to their care.

They were established just in time for the very severe polio epidemics of the early 1950s which filled all the 16 centers. Since no one had had experience with such numbers of seriously disabled persons on ventilators, the centers were a team learning experience for everyone. The patients and their families were important members of that learning team from the very beginning. The centers had weekly patient-staff conferences, which were the key to the integration of the program. Here,

all of the services working with the patient met to discuss with the patient his or her present status, treatment plan, anticipated goals, and time factors.

The first organized home care system was created by Dr. John E. Affeldt, who was the medical director at Rancho Los Amigos Hospital in Los Angeles County in 1953. At that time, Rancho had the largest number of patients in the country — 158 who were ventilator-dependent.

When Los Angeles County realized that these long-term patients were unnecessarily occupying \$37/day hospital beds when they could be cared for at home for \$10/day with attendants, equipment maintenance, and other supporting services, a home care program was set up and 152 went home.

A semi-trailer, with a complete workshop, made the rounds regularly — maintaining and repairing the ventilators. The hospital functioned as an information service to the polio survivors and to their personal physicians — an al-

most umbilical cord relationship.

The transition from hospital to home was gradual and meticulously planned and scheduled. The staff made home evaluations and the necessary adaptations for ventilators and accessibility. The first visits were for hours, then a day, then overnight, then weekends, with emphasis on training the family and the disabled individuals in the use and maintenance of the ventilators and in assisting each one to resume his/her own place in the family and the community.

At our center, the disabled individuals signed out when they left for a trial visit and signed in when they returned. In the interval, they were on their own.

At first, attendants were trained at the hospital. But it was soon found that attendants changed so often, it was a waste, and families and the disabled individuals were much better at training another person to take care of personal needs.

Each disabled individual and the parents or the spouse had to become experts in medical, personal, and equipment needs and had to be able to delineate those needs to the changing attendants or to whom ever was at hand.

The centers and their home care systems resulted in tremendous savings of money, and a greater degree of self-sufficiency and independence for ventilator-dependent people than had been thought possible.

As of 1959, the National Foundation reported the following savings: The average hospital time was cut from one year to seven months; home care costs were 1/10 to 1/4 of hospital care.

As of January 1959, the National Foundation reported that there were 1,756 ventilator-dependent polio survivors in the United States. Of these, 1,271 were at

home. The Foundation study estimated that 40% of those at home would have remained in custodial care for the rest of their lives if the center's service systems had not been the means of making the transition from hospital to home care. Unfortunately, the centers lasted less than a decade. The programs became too costly for a voluntary organization when the public lost interest in polio after the vaccine. By 1959, the National Foundation had to change its emphasis from polio to birth defects, and to curtail the polio programs.

After the centers and the attendant care programs stopped, the polio survivors scrounged on their own. Some found funds for attendants from welfare or churches or relatives. Others found foreign or other relatively inexpensive live-in attendants or part-time students or retired neighbors. Later, some moved to California, New York or one of the few other states with attendant care.

Fortunately, there were no special segregated residences built for ventilator-users. They solved their problems as individuals, not as a group of ventilator-users. Remarkably few had to go to nursing homes or VA hospitals.

Polio survivors have been among the founders and the leaders of the nationwide independent living centers, which are sources of information on attendants. For attendant care is the linchpin of independent living.

Throughout its 25 years, the *Rehabilitation Gazette* has been a proponent of home care and attendants and a force for independent living. It has documented the lives of severely disabled persons around the world and acted as an international clearinghouse on polio and ventilator dependency.

(For a brochure on its information services and a list of the back

issues, write to Gazette International Networking Institute (GINI), 4502 Maryland Avenue, St. Louis, MO 63108 (314)361-0475.)

Among the ventilator-dependent readers who have recounted their family lives and their careers in the *Gazette* are attorneys, clergy, computer programmers, engineers, physicists, professors, physicians (who changed to such no-hands fields as radiology, dermatology, psychiatry and allergy), rehabilitation counselors, therapists, teachers, and writers. Their casual/careful approach to travel is typical of their adaptation to life with a ventilator. More than 40 ventilator-dependent persons from around the world were among the 439 registrants at the *Gazette's* Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability held here at this Sheraton in May of last year. We expect even more at the third conference which will be here in May 1985.

Many of the polio survivors have been ventilator-dependent since they were children. Some went to grade and high school by tutor or telephone. Others attended with their ventilators and then went on to college and graduate school. Some were disabled while they were students and others after they had married and had children.

One example, is an Indiana physician who contracted polio in 1955, shortly before he graduated from medical school. He received his medical degree while he was still hospitalized. After rehabilitation, he completed his internship and residency. He practices dermatology fulltime. He is married and has two children. He uses oral positive pressure continuously by day and sleeps in an iron lung. He has traveled widely, including a recent trip to a medical meeting in Australia. He rents or borrows an

iron lung when he travels and he is working on a portable lung so that he can travel extensively in Europe.

Another example, a Minnesota adoption specialist, was disabled in 1950 at age 27. She and her husband, a psychologist, have adopted 13 children, most of them disabled. She uses a pneumobelt by day and a trach-connected ventilator at night.

She is one of the few polio survivors in the United States who uses a tracheostomy. Most of the tracheostomies that were performed at onset were later closed and other means of ventilation used. They include many permutations and combinations, such as:

- Cuirass by day and rocking bed at night
- Glossopharyngeal breathing by day and lung or positive pressure by night
- Oral positive pressure by day and lung at night

Our panel will share more personal experiences to *emphasize* the safety, economy, and satisfaction of home care and to *demonstrate* the educational, vocational, and productive potential of severely disabled individuals, including those who have been ventilator-dependent for more than 30 years.

Finally, a few observations based on almost a lifetime of volunteering with persons who are severely disabled . . .

The most important contributions of the service system created by the regional centers were:

- The *team approach* that included the disabled persons and the family in the planning
- The *positive attitude* toward discharge home
- The *training of disabled persons to train attendants* and to be experts in their own care
- The *treating of each disabled person as an individual*. No group solutions. No mini institutions. Each individual was seen as having the right to make decisions as to the way in which to lead one's life.

This is absolutely fundamental to the *dignity and integrity* of each individual human being, and includes the right to place one's self at risk and the right to make mistakes — in other words — the right of persons with disabilities to live as do all people in society. ●

Disabled Take Advantage Of Artificial Breathing Devices

by Jack Genskow, PhD



I'm only a representative of a much larger group, those of us who require artificial breathing aids in order to live. My role here is to share a bit of my personal experience of 28 years using a breathing aid.

We ventilator-dependent people are a group of individuals each with our own unique solutions to our life situations. I contracted polio at age 19 on my summer job, which was running a horseback riding stable. This was following my first year on scholarship at Yale. I spent 24 of the next 32 months in six different hospitals, including the National Foundation's Respiratory Centers in Omaha and Chicago. Initially, I was totally dependent on the iron lung and nearly totally paralyzed. It took me five months to get out of the lung. I still have quadriplegic involvement, and use a motorized wheelchair.

Much of my breathing is still voluntary; that is, if I were to pass

out or become unconscious I would essentially stop breathing. I now use a rocking bed to sleep on at night. On trips such as this, I use a portable chest respirator and a chest shell. For the first six years, I didn't know how to glosso pharyngeal, or "frog" breathe, so I carried a small positive pressure blower with me with a transformer in case I got tired or had to cough. If I needed to, I'd just plug into the nearest outlet to let the blower breathe for me.

But "frog breathing" has really been a life saver for me and has made my life much simpler. Without frog breathing I have a maximum vital capacity of 350cc's, but with frog breathing I have a maximum vital capacity of 2800cc's. As you may know, frog breathing is a method of pushing, or "swallowing," mouthfuls of air with the tongue into the lungs, which then inflate a mouthful at a time. My wife brought a book home from

work that showed me how to do it, and the first time I yelled at her she was delighted.

My wife and I met when she was a student nurse at my third hospital, and we started dating later when I was in the Chicago Respiratory Center. We have two children — Karen, 19, and Ken, 17. We've traveled as a family unit all over the country — from Florida and Maine to Texas and Colorado, usually driving, but sometimes flying. Lil and I spent our 1961 honeymoon in the Bahamas where her dad lived. When airlines wouldn't let me fly without a doctor's permission, we found a small island hopping boat that took us across the Gulf.

Respiratory disabilities haven't prevented opportunities from presenting themselves in my life either. I attended college with the support of what was then the Division of Vocational Rehabilitation Services, and the March of

Dimes National Foundation. Then I received fellowship support which led to a PhD in counseling and rehabilitation psychology. Illinois DVR hired me to develop and direct their Residential Evaluation Center and Service. Currently, I'm associate professor in human development counseling at Sangamon State University. (The vice president's comment on my employment interview was, "I guess it's what you have to say, not how loud you say it, that's important.")

Although we haven't gotten rich, I have paid more than \$70,000 in personal income taxes back into the economy since 1965.

One of the ironies of my life, which I think has implications for this conference, stems from my being turned down for rehabilitation services by an Illinois DVR counselor in 1957 because I was too severely disabled to benefit. The irony in that is that currently I'm appointed by Illinois Governor Thompson, as chairman of that state agency's Advisor's Council. Illinois and rehabilitation have come a long way.

Important factors in living my life with a disability included: 1) good medical care and planning in the early stages of recovery, especially by the National Foundation of Respiratory Centers; 2) ongoing support and respiratory equipment, provided, again, by the National Foundation and Life Care Systems; 3) an effective social support system, including first, my wife and family, and then of course, friends; and 4) an opportunity to live in the community as anybody else where I can have control of my own life.

The essential lesson to learn from that counselor 25 years ago is: Don't let your perception of the severity of a young person's disability today limit his or her potential for tomorrow.

Parent Of Ventilator-Dependent Child Welcomes Waiver

by Chuck Frame



Since we are talking about waivers, I think it might be helpful to explain what a waiver means to those of us who have been living under spend-downs for so long. It means that the additional burden of financial disaster isn't added to the already heavy load of dealing with a disabling condition. It means that the family who spends nearly all its time caring for a child at home for free doesn't have to pay additional penalties for the privilege of doing so. It means that a family of five can keep more than \$436 per month for their own expenses. It means siblings in the family can continue developing their own talents like piano lessons and college educations with less resentment toward the disabled brother or sister.

Waivers also make the statement that finally the family is recognized as part of the home care process. It doesn't change attitudes in one fell swoop, but it is one step in getting rid of the concept that when the child is in the hospital, the responsibility is all on the hospital. And if the child is ta-

ken home, the hospital relinquishes all care and the responsibility is all on the parents — an either, "We do it," or "You do it," attitude. Home care needs to be a team effort.

We have been caring for our child, Melissa, at home for three years without any help — 24 hours a day, seven days a week. The minute she entered a local hospital, we were hardly allowed to touch her, much less convince them that turning her head from one side to the other during suctioning would help the catheter go to each lung more easily. A half hour earlier we had revived her from respiratory arrest using oxygen and a rouché bag, and suddenly we were excluded from her care. No team work.

Insurance companies foster the separation by paying for hospital care, but by being reluctant to pay for home care, no matter how healthy the patients become at home. Is this true with everyone involved? Of course not. The fact that there are families here with children at home proves that there are people from all areas involved

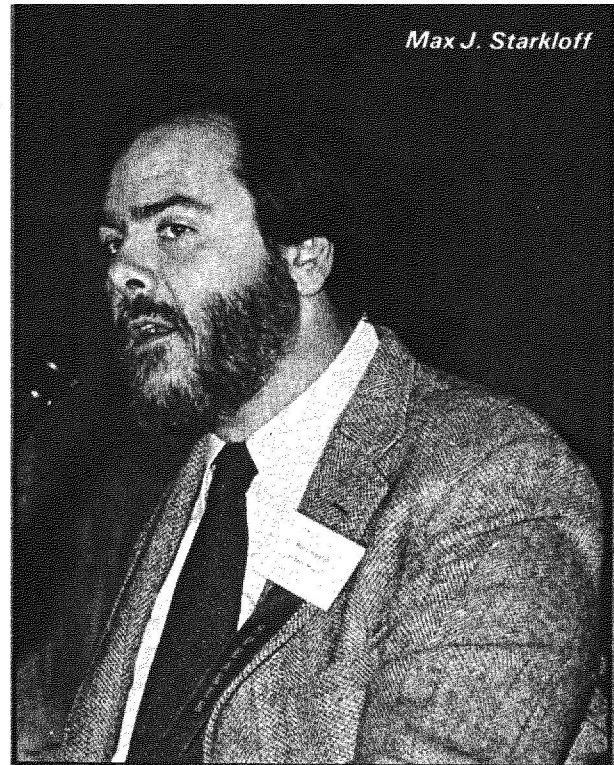
who've worked cooperatively to resolve these problems. Nevertheless, to have something like the waiver finally say, "We recognize your contribution and are willing to do something about it," is very significant to us.

But there is still work to be done. At present only 10 states have made applications for the model waiver available to them. That leaves a lot of families in the other states without relief. Why is there such lack of cooperation? The inconsistency from state to state is very frustrating for families who are trying to get help.

Hospitals need to develop more follow-up programs once the patient is home. Yes, there is still work to be done. But the benefits of alternative care are worth the efforts we put into overcoming these problems. The patients are healthier, costs are reduced, families have a better chance at being families and life becomes more than just existence. Melissa has been in the hospital, and Melissa has been home. And, for Melissa and her family, home is better. ●

Disabled Use “Independent Living” Concept In Rehabilitation

by Max Starkloff



Max J. Starkloff

After I became disabled in 1959, I moved from my house into a nursing home because I didn't realize I could live independently. I knew I didn't want to spend the rest of my life in a nursing home — I wanted to contribute to the community. Then I began to watch other disabled people going through some of the same problems I was going through, and I wanted to resolve the situation.

Some disabled individuals in Berkeley, CA, and in Massachusetts formed organizations which dealt with the “independent living” concept. I visited the group in California to see what they were doing and came back to St. Louis to look into the possibility of forming a group of our own. Although things move a little slower in Missouri than in California, I began to see disabled persons dealing with their own problems. I thought if the concept worked in Missouri, it could work anywhere in this country.

Independent living evolves

when disabled persons realize they need physical or personal assistance, and they pool their professional backgrounds and personal experiences to form a base for action. I lived in a nursing home only because I needed physical and financial support. I figured the financial support was there if I could only find the physical assistance. I knew my own needs and physical limitations. One of the main focuses of independent living is to develop a good attendant program. It seems to be one of our biggest problems. When a disabled individual needs attendant services and comes into an independent living center for that support, he or she can learn from other people's experiences. They share problems with others and get peer support.

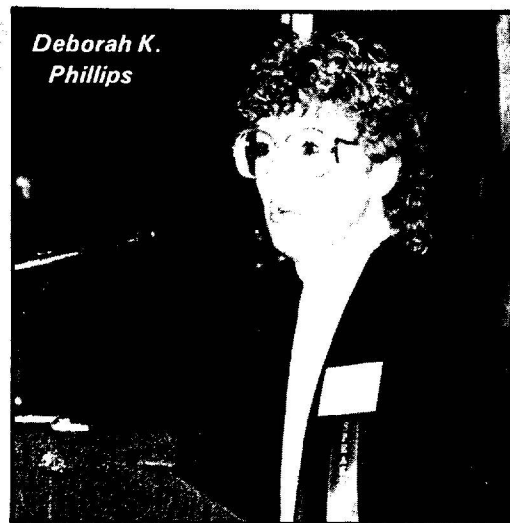
Role modeling also plays an important part of the independent living program. That is when an individual can come to the center and observe other disabled per-

sons going on with their lives in a natural and normal way. They talk about how they're going to mow their lawns, their families, and who will do the shopping. The visitors develop confidence because they figure if others can live independently, they can, too.

The independent living concept is very important to the entire rehabilitation process because disabled individuals are becoming a part of that rehabilitation process at a professional level. We need to realize that disabled individuals play a large advocacy role in making sure that favorable legislation is passed concerning their needs. We've seen a lot of progress in the area of the Rehabilitation Act and rehabilitation programs, but the only way we can continue to grow is to expand the involvement of disabled persons in the movement. Health care professionals and the handicapped need to work hand-in-hand to accomplish some of our goals. ●

Persistence And Good Education Pays Off For Disabled

by Deborah Phillips



I come from a long line of non-conformists — my mother's heart is on the wrong side, and I have an undiagnosed disability. When my parents discovered that my disability was developing (I lost the use of my arms when I was 7 years old), they, as non-conformists do, disregarded the advice of the experts and kept me in the parochial school where I was enrolled and never treated me differently from anyone else.

The important thing to remember about dealing with people who have disabilities is that there are many resources in the community from which to get help. My office happens to be one, and there are similar commissioners' offices in most of the major metropolitan areas. I admit there are only a few female commissioners and directors of these offices, but as women with disabilities, that just means we have a double problem to overcome.

Our office is part of the metropolitan city government, and we've been in existence for five years — not as part of the mayor's office, but as part of the Department of Human Services and the Department of Welfare. Our job is two-fold: One is to serve disabled people and the other is to serve the

city of St. Louis. We have the interesting position of being a non-political body whose primary function for city government is to advise and confer.

Anyone who works with architects or engineers knows that there is absolutely nothing you can tell them about accessibility. We came into some money two years ago, and the chief architect for the city decided to make City Hall accessible. He contacted me for my input, and I suggested he make one set of the public bathrooms accessible and that he lower the telephones — things like that. There are also about one thousand steps just to get to the front door of the building. We've convinced our board of public service to give us the money, so hopefully the Civil Courts building will be accessible for mobility impaired people.

This is the kind of work we do, and this is the kind of resource we try to be for organizations like Paraquad.

We don't take the approach that everyone is alike. Our approach is to match the individual person to the resources that meet the needs of that person. You have to articulate your needs. It's very important, especially in Missouri, to be persistent. It is very low in

legislation for the disabled, and because of that, some of the metropolitan areas like St. Louis and Kansas City have been more progressive. When dealing with a metropolitan municipal part of government, you need to present your information in a concise way. It's persistence and perseverance that's kept us in business, and we're fortunate that the city considers us one of its priorities.

I never went to a special school, and I don't feel cheated or warped from the experience. I've always had the fortunate luck to have gotten a good education. Parents of disabled children need to realize that education is one way we can overcome and become part of the mainstream of society. Another way is to develop an excellent sense of humor.

It's important to remember that even though a person has a disability, it's exactly that, and that having a disability does not make us a homogenous group. Within our population is as much diversity as in any other population. And that's a good reason to have an office like mine and an organization like Paraquad to work together to help meet some of the needs of disabled persons. ●

England And France Set Examples Of Home Care Programs

by Allen Goldberg, MD

The issues we will discuss today are based on recent history — the world-wide polio epidemic of the 1950s which led to the development of new approaches to medical technology and health care organization. The epidemic featured a severe form of polio that took the lives of countless children and adults, often in their most productive years. People died because of paralysis of their respiratory muscles. The realization of the need for artificial ventilation led to the development of the modern techniques of upper airway management and mechanical ventilation such as tracheostomy and positive pressure ventilation. This new technology resulted in a reduction of mortality from respiratory failure from 90% to 20%; however, many of the survivors remained dependent on ventilatory assistance — some for a lifetime.

The comprehensive medical needs of the polio survivors required an interdisciplinary health care team of physicians and allied health personnel. A new approach to the medical treatment of chronic illness and long-term disability was developed. This medical challenge created the basis for the concepts of health care including administration, clinical methodology

and research as featured in the system of specialized respiratory (polio) care centers.

One success of these specialized centers resulted from research: The discovery of the polio vaccine. This discovery in 1956 of an effective preventative measure against polio all but eliminated one of the medical scourges of all time. But the "polio story" did not end there for the survivors. Some had to remain in institutions for undetermined periods of time because they depended on breathing machines and had nowhere else to go. These were the first ventilator-dependent children and adults.

They discovered new approaches to their care and answers to their needs which were major dimensions of "self-help." Working with professionals, families, volunteer organizations and friends, they created outreaches from the regional polio centers such as home care and other community-based living alternatives and support services. The centers and home care resulted in a tremendous financial savings and a greater degree of independence and self-sufficiency than was ever dreamed possible for people so severely disabled.

Since the creation of modern

critical care and rehabilitation medicine from the polio experience, countless people with serious illnesses have survived who would have died years ago. Some of these survivors now constitute a new population of people dependent upon life-supportive technology. Examples include high spinal cord injury, severe muscular dystrophy, and a variety of other neurologic, muscular and pulmonary diseases that previously resulted in early death. These survivors must needlessly and inappropriately remain in institutions at enormous cost in economic and human terms because they have no alternatives.

This is only part of the current crisis in health care delivery. Excessive health care costs have mostly exceeded our ability to pay. In 1980, the health sector claimed 13¢ of every non-defense federal budget dollar. The national health expenditures approximated \$70 billion in 1970 and \$247 billion in 1980. Projected costs for 1990 are over \$1 trillion! In 1970, national expenditures accounted for 7.2% of expanding gross national product and, in 1990, it is projected to account for 15%.

Our medical reimbursement system is set up to pay for all acute

care costs, but it is not designed for financing home care or other suitable alternatives. Unless we design better operational systems and more adaptable reimbursement mechanisms, we face the danger of curtailment of services and a resultant decline in the quality of life (or even survival) of many disabled people.

In the United States, the possibility for home care or alternatives for chronic respiratory disabled children and adults are limited to a few demonstrations. For adults, existing facilities include respiratory rehabilitation centers (Goldwater Memorial Hospital Howard A. Rush Respiratory Rehabilitation Center in New York, The Institute of Research and Rehabilitation in Houston, TX, and Rancho Los Amigos in Downey, CA) which evolved from their polio experience, some skilled nursing facilities without rehabilitation services, and scattered home care experiences. Concerning children, home care demonstration projects have been implemented in Massachusetts, Texas, Pennsylvania, Illinois, and other states. A major problem exists, however, because we don't know where all of these children are or who is dealing with them. A need exists to document and register this information.

I have been aware of the regional approach to ventilator-dependent persons in England and France. This year, I was given the opportunity by the World Rehabilitation Fund to do a comprehensive study on these programs. The International Exchange of Experts and Information Program has been funded by the National Institute of Handicapped Research to acquire knowledge of exceptional programs, practices, and policies in other industrialized nations to enhance the knowledge base of rehabilitation in the United States. I will now

present a synopsis of my study, describing the programs and giving their histories, analyzing operational systems, and suggesting their benefits.

The English solution — the "responaut program"

The first program concerns "responauts" who are ventilator-de-



Allen I. Goldberg

pendent persons who are severely physically disabled and live independently in England. They coined the term "responauts" themselves because, like the astronauts, they ventured into the unknown. The original responauts were polio survivors. In 1965, some of these people stayed at home without any established system of services and some remained in polio centers which were closing.

At the same time, the acute intensive care unit just developed by Geoffrey Spencer at St. Thomas' Hospital, had long-term ventilator-dependent survivors. To serve

both populations, the Phipps Respiratory Unit (PRU) at the South Western Hospital was created. From this location the responaut program evolved as an organized series of services available to anyone in England who depends upon prolonged mechanical ventilation or who has a respiratory disability that requires referral to Dr. Spencer. The establishment was a collaborative effort among the health care professionals, patients and families, hospital administrators, and government authorities. The responauts initiated public, private and government involvement which resulted in "Responaut Study," a major success of self-help.

The "Responaut Program" consists of the following services:

- Comprehensive medical/rehabilitation care in the PRU
- Planning for a safe discharge to home or a variety of community alternatives
- Home care, either provided by one of 17 PRU attendant staff, who live in the home of responauts, or community-based caregivers, provided by a government agency or government fund
- Home maintenance service of all respiratory, technical and personal needs on a regular and emergency basis

The PRU remains the base unit because this arrangement provides security for the patients, professionals, and administrators, and guarantees standards of care and quality-assurance. It also provides the most coordinated operational basis as well as a medico-legal basis for the protection of all involved parties. The PRU is where patients are first admitted for evaluation, stabilization, and eventual discharge. After the 1973 Responaut Research Project, all participants could go home. This allowed the PRU to function as a

short term unit for more acute illnesses, minor adjustments in prescriptions and outpatient assessments. The hospital patient length of stay was 568 days in 1968; 18 days in 1975; and 11.9 days in 1983. Today, even though the responauts are home, they are still the charge of St. Thomas' Hospital. The PRU team leaders which serve the patients include a physician, nurse, physical (respiratory) therapist, and social worker. The current health care/social legislation in England provides a complex reimbursement policy, partly statutory — partly discretionary. The social worker coordinates a financial program for each responaut among a variety of options from local and health authorities.

To complement home care, the PRU home maintenance service (which includes three medical technicians, three service vehicles, a hospital-based workshop and inventory of major equipment and supplies) coordinates a very personal service from the PRU. The service does routine maintenance of the equipment and minor/major emergency replacement. Since its onset, 411 patients have been served by the "Responaut Program;" as of June 1983, 223 persons were benefitting from it.

Because not all responauts have families to go home to, they require other options and services in order to live somewhat independently in the community. These services were not created specifically to meet the needs of the responauts; however, they take advantage of the existing resources designed for other purposes. Examples include the Netley Holiday Home (Respite Care) and the Chailey Heritage Hospital and School (education and rehabilitation engineering).

The financial basis of the responaut program is the original arrangement between St. Thomas'

Hospital and the Department of Health and Social Security; legislation, which provides both statutory and discretionary funding; and supplemental funds from a variety of charities.

The French approach — the regional association

As in England, the solution for the ventilator-dependent person in France evolved from the efforts of multiple concerned parties. These people looked for community options for groups of polio survivors who faced no other choice but prolonged institutionalization. The former polio centers in which they lived, evolved into intensive care and rehabilitation centers. The concept created was "ventilator assistance at home."

Two not-for-profit organizations helped to implement the concept for the polio survivors. The Association of Mutual Help for Polio and Handicapped People (ADEP) and the Association of the Lyon Region for the Fight Against Polio (ALLP) evolved into the "core" of the cost effective regional solutions for ventilator and oxygen dependent persons in the greater Paris and Lyon regions. They also formed the base for a new national organization, the National Association for Home Care of Respiratory Insufficiency (ANTADIR). This national organization deals with issues such as mass purchasing, national statistics and surveys, collaborative research, and information exchange.

ADEP was initially created to improve hospital life and later developed as a means to send patients home or on to independent living alternatives. It was created by and for the polio survivors who had to remain forever in the Raymond-Poincare Hospital, Gareches, France. It is now a multipurpose

not-for-profit organization contracted to provide home ventilator services, community-based living alternatives for ventilator-dependent adults, and documentation of information for the demonstration of an effective self-help group which has expanded to help others. As ADEP grew to meet existing demands, it received requests from the government to serve as the model for development of other regional associations and to develop a national organization to deal with issues appropriately. Currently, ADEP serves over 650 persons.

The services of ADEP are described in a contract between three major reimbursement agencies and ADEP. This arrangement is the basis of all negotiations with any other reimbursement resources. The prospective reimbursement package permits ADEP to provide the following services:

- Acquisition, delivery, installation of a large variety of durable medical equipment
- Oxygen (tank/extractor)
- Provision of all required accessories
- Routine/emergency home maintenance service
- Required electrical modifications for equipment/home
- Required installation of telephone
- Communication with medical resources (community, institutional); regional coordination of services/care
- Administration of the program (quality assurance)
- Evaluation of the programs (accountability)

ADEP Home Care Program is divided into four services: admissions, maintenance (technical service), medical social service, and administration. The admissions process creates all necessary documentation required for

The current health care/social legislation in England provides a complex reimbursement policy, partly statutory – partly discretionary.

each new prescription of service such as medical and administrative records, requests for equipment loan or purchase, reimbursement, communication with third party sources, etc. They also contact an ADEP nurse who is initially involved with patient education and preparation for home.

The home maintenance service consists of 10 persons including secretaries, staff, technician, inventory persons, and a driver. Eleven vehicles stand by, fully stocked and prepared to make major repairs. Six of the vehicles are radio-dispatched, making an emergency service possible by an on-call technician. All the technicians are qualified in mechanics and/or electronics and have had on-the-job training. Preventive maintenance is provided on a bi-monthly basis. The service guarantees a greater quality assurance, decreased risk, increased security and it reduces costs.

The medical social service provides medical evaluation and follow-up, supervised by two physician specialists. These physicians also make home visits when requested by ADEP nurses or technicians. The ADEP nurses visit the patient in the hospital to determine what equipment is needed and to plan required inventory.

The accounting and administration of ADEP Assistance is centralized with several designated administrative assistants and accountants who report to a director. The center keeps all records, statistics and creates monthly accounts of all activities, equipment and patient status. This organized documentation of services facili-

tates communication with the sources of third party payment.

The founder and president of ADEP, Andre Dessertine, created the organization as a means to help others help themselves and instituted the philosophy which implements:

- Greatest possible degree of independence compatible with physical status
- Reinsertion into urban setting for a full opportunity for a social life
- Medical security to degree required by the medical condition

ADEP emphasizes medical security to reassure medical personnel, public authorities and the disabled person that alternatives to institutionalization were appropriate. In special housing set up for the disabled (Foyer d'ADEP), each ventilator-dependent person has several methods to reach personal care attendants or medical staff who are on call. The medical care is given by a combination of health care professionals and well trained, highly motivated personal caregivers.

In 1964, the ADEP Documentation Center was established which stored information concerning the studies and experiments which aided the disabled. The center was officially established as an Information and Documentation Service in 1974, and currently available to anyone concerned with issues related to disability. Today the service receives over 100 French and other language periodicals from multiple sources. The information is systematically classified according to defined themes. The center has

also proven to be helpful in research.

The other organization which exists in France, the ALLP (Lyonnaise Regional Association for the Fight Against Polio) is also a not-for-profit organization which coordinates the total program and services required by the ventilator-dependent persons in Lyon and the surrounding areas. It, too, as the services in London and Paris, originally served the polio survivors.

During the polio epidemics of the 1950s, the Croix-Rousse Hospital in Lyon was designated as the center of expertise for the management of acute respiratory failure. Care was provided in a polio unit: The Service of Professor Sedallian. When the hospital reached capacity in the mid 1950s, it was thought the ventilator-dependent patients might do better at home. A mechanical device was developed (Vincent-Gandot) and the first patient went home in September 1960. That person is still at home and is living a full life with his wife and family.

In the first years of the program, the hospital staff volunteered their services. In 1961, the ALLP began to send home non-polio ventilator-dependent patients. Later in 1967, the leaders of ALLP negotiated a contract with regional reimbursement authorities who provided a prospective payment of \$5 per patient. Most recently, the ALLP has begun to serve oxygen-dependent persons at the request of the Regional Social Security.

The original polio center is now a multidisciplinary adult ICU with an acute care and chronic respira-

“In England, charities play a strong advocacy and political role, and have a great impact on government policies for the disabled.”

tory rehabilitation section, both under the direction of Professor Dominique Robert. It plays a major role in the preparation of patients, families and caregivers for the transition to home.

The ALLP is located on the hospital grounds of the Croix-Rousse, adjacent to the Pavillion Paul Sedallion. The physicians determine the standards of respiratory care and lend quality assurance to the program. Primary medical care is given by a local physician. The RN role is determined by the needs of the patient at home. The nurse understands the patient's status in each situation. The visiting nurse makes home visits where her role is to implement quality assurance, continuity of care and to evaluate all problems.

The medical technician has responsibility for both the equipment and the medical and psychological needs of the client. In addition to pre-scheduled routine maintenance visits, the technician is available at all times for emergency needs. These people are factory-trained and are responsible for the repair of all equipment.

The services of the ALLP are spelled out in a contract which features categories for prospective reimbursement. The rate depends upon the need for ventilation, tracheostomy care, and oxygen, including the method of oxygen administration as well as the source. The prospective charges range from \$4/day to \$22/day with a mean rate of \$9/day. The contract spells out the specific objectives of the program, the criteria for the program, the daily prospective

rate, the description of covered services and personnel, and the interrelationship of involved parties. It also specifies required documentation and explains the role of an advisory committee. Attached to the contract is a complete home ventilator care protocol. Currently, ALLP serves over 450 persons.

Another essential component of the successful transition from institution to home in the Lyon regional program is the intermediary (secondary) center. It permits the fullest preparation and education of each ventilator-dependent person at a location with significant cost reduction. Of the three centers in the Lyon region, Bellecombe is the largest with a capacity of 130. The average length of stay at this transitional care center is 55 days, during which time the patient is well-educated in his/her equipment and self-care.

Despite the fact that the ALLP existed, a few ventilator-dependent polio survivors remained for years at the Croix-Rousse Hospital. As an alternative to prolonged institutionalization, the ALLP followed the model of ADEP and created the Foyer d'ALLP. All of the survivors obtained education but they could not earn an income or they lost their government benefits. However, they used their education in managing their lives and their homes.

The ADEP and ALLP do not provide primary caregivers. In France, it is impossible to have 24-hour nursing surveillance; therefore, ventilator-dependent persons at home require a highly committed family to participate in care. The

reasons for unavailability are that there is simply an inadequate number of available health care professionals, and those who are available, prefer to work independently at a higher rate. There are times, however, in the home when situations arise and the family must call in help. At these times, it is possible to have a new type of personal caregiver. These people may have two roles: 1) Domestic (housekeeping, feeding, and cooking); and 2) Health (physical care, personal hygiene). For chronic respiratory patients, often the duties require medical expertise. The Association provides these caregivers with 8-15 days training for this purpose.

The "auxiliaire de vie" as the caregivers are known, is a recent development in France. The position has just risen to a professional status by federal regulation.

Developing an American approach

To help apply these programs from England and France to the national-regional-local realities in the United States, it is necessary to look at the reasons why these programs were successful.

In England, charities play a strong advocacy and political role, and have a great impact on government policies for the disabled. Charities develop new services and programs based upon demonstrated needs. Government and charities work together in the process of mutual cooperation.

In France, all programs are coordinated by not-for-profit voluntary organizations (associations) which provide quality assurance, case-

"In France, all programs are coordinated by not-for-profit voluntary organizations (associations) which provide quality assurance, case-monitoring, and accountability."

monitoring, and accountability, resulting in cost containment. They are small, flexible, permitting multiple interdependent roles for members.

It is also helpful to look at the evolution of these services and their reimbursement. In England, all programs began with a leader, a small group of concerned people, and private money. Each had an initial success which captured the government leaders' attention and later led to government support, commitment, and appropriations for the program. In France, the programs evolved from successful initial demonstrations followed by negotiation with multiple reimbursement resources. Once a prospective rate for defined services was established, the operation grew to meet expanding needs.

The funding of England's home care services is supported with public funds based upon legislation. Ventilators at home are prescribed by a physician and must be provided by law. Charities supplement costs not covered by public programs. All health care and personal service expenditures are part of a finite allotment which must be divided among multiple competitive and worthwhile organizations.

France's funding is based mainly upon public monies. Reimbursement is distributed by agencies which represent a region and/or vocation. Multiple interest groups compete for a finite sum of health care funds, somewhat like the public/private health care financing in the United States. The reimbursement agencies have cho-

sen to utilize the regional association as responsible case-managers.

The attitude toward disability in England seems to be one of concern, due to adequate media coverage, parliamentary discussion and effective advocacy by charities. This favorable awareness also exists in France due to similar reasons. In addition, France established an organization to deal with important public policy issues concerning disability.

What began as the "Responaut Program" in a local area in England grew to national scope due to the expertise developed and the number of persons who required special services. Programs in France were designed to meet geographic, political and economic realities. As the demands for the service grew, a study was done which led to the creation of a national organization. There now exists some concern about regional/national role definitions.

In both England and France, a base unit of excellence (health care institution) guarantees a high standard of care. The base unit also serves as a facility for the stabilization of the patient, initial family education, training and preparation for home, and for meeting subsequent health care needs. Both English and French programs highlight personal, high quality home care surveillance which guarantees competent and reliable preventive maintenance, emergency repair service, and communication to all involved persons.

The equipment in both countries

is simple and reliable. Home ventilators/respirators do not have to meet dictated standards and regulations. The quality is assured by the home-unit. Also, in both countries, malpractice suits are less likely because legal contingency fees are not incentives, and the services provided are quite personal.

The United States reality

The United States is larger geographically and more complex socially than England and France. Uniform health care and personal service delivery is far more of a challenge. Services for the disabled are currently determined politically more by state and local policy than by regional or federal regulations or legislation. Quality of care often is more a result of social or economic class — or even chance!

The economics of health care delivery are vastly different than during the past three decades. During that period of post-war economic boom, there was an enormous growth of the health care system. There were vast qualitative and quantitative improvements in the provision of health care. This was only possible due to the nation's overall economic well-being in the '60s and '70s. Much of this was spurred by the comprehensive entitlement programs which permitted health care by a cost-reimbursement policy with no limit in sight. All national opinion polls showed strong public support for improving and expanding health care during this period — at any cost.

“Unless we design better operational systems and reimbursement mechanisms, we face the danger of curtailment of services, denied health care, and decline in the quality of life.”

However, since the mid '70s, we have had a vastly different situation. The nation itself experienced a deterioration of economic performance by indications such as slowed economic growth, continued inflation, and reduced purchasing power of the consumer. This was accompanied by a change in public mood. Many people found it difficult to handle expenses of routine health care. People became concerned about economic issues and were opposed to a limitless increased spending on health care. At the same time, the public demanded the right of access to appropriate services.

There has been a real decline in public spending for health care and in methods of reimbursement. (Change from "Cost-reimbursement" to fixed, pre-set payment determined by "diagnostic related groups," to "prospective payment," to "preferred provider organizations" who respond to "requests for proposals.") Often these systems do not have built-in flexibility required to adapt to unique solutions and rapidly changing conditions.

Also philanthropic spending for health care has been reduced. The private sector has responded to a "hidden tax shift" (moving the burden of reimbursement from public to private sources) with a retrenchment, and a re-thinking of who, what and how they will reimburse present health care delivery and new proposed models.

Hospitals, our major provider of care since the 1960s, now face an economic austerity which will limit new program development

and expansion of services. At the same time, a huge private sector home care industry is preparing to serve the disabled. It is estimated in Naisbitt's book, *Megatrends*, that the growth of the home health care industry will be 20-fold over the period from 1970-1990.

Major public policy decisions are about to be made concerning home health care. Up to now, private and public reimbursement authorities have not yet developed or adapted mechanisms to meet the home care equipment and service funding requirements. There are gross inequalities based upon the financial resources of various social classes. All involved are concerned about issues such as quality-assurance and malpractice-liability, a major hidden cost of health care in America. Policy experts appropriately wonder if the trend to deinstitutionalize will lead to better health care at less cost.

Throughout my study, I attempted to ascertain if there was applicability of the English and French models in the United States. I believe that reimbursement and liability are the major barriers to developing appropriate, cost-effective, personal services for severely-disabled persons.

Although the major reimbursement systems for European operating programs I observed are public, there are certain elements that make my observation abroad applicable to the United States:

- All good programs start privately through charitable or voluntary organizations
- All evolve with the patience and

cooperation of multiple involved interests working together in partnership (government, consumer, organizational, professional)

- All reimbursement issues have similar conflicts. The same issues are within "government systems" (finite allotments) as are in a private/public system

- All good programs must be initiated in small scope with a defined focus. They must demonstrate their worth before growth and government support.

- Most programs can adapt to meet multiple needs and hence optimize available resources.

The current reality in the United States is that excessive health care costs have nearly exceeded our ability to pay. Furthermore, they are no longer acceptable to third party payment sources, public policy experts, and the general public. New concepts and options are being considered including home health care, increased consumer involvement, prospective reimbursement, and a wholistic approach to wellness. All this demands a reassessment of how we as health care professionals play our role to the ultimate benefit of those we care about: Our patients.

The English and French programs have independently shown that the complex challenges of the ventilator-dependent person can be creatively faced and met. When caring people join and find common concerns for mutual benefits, conflicting problems become opportunities for positive interaction. By the right process, solutions can meet all needs. Health care institu-

tions can be better utilized for their appropriate mission, and the health care professional's time can be better directed. Money can be saved by utilizing motivated, less expensive personnel who can work with qualified allied health personnel, and consumers can have a high quality, personal service which meets their needs because they have had input into the design. Third party payors can have quality assurance and competent case management resulting in cost containment while government officials can meet their political agendas. Voluntary (not-for-profit) organizations can play an important and worthwhile role of social responsibility.

Currently in the United States,

there are many organizations that care about people (religious service organizations, and community based voluntary groups such as Rotary, Lions, Kiwanis, Veterans' groups, etc.) and have "grass roots" resources. Many such organizations search for new directions and challenges. They can provide personal, local support. However, the funding required is beyond the capability of any voluntary organizations. The cost of home care services is still high. Funding must be found from multiple sources, including public and private sector monies which can be channeled responsibly by a well-defined, well-coordinated reimbursement process.

Unless we design better opera-

tional systems and reimbursement mechanisms, we face the danger of curtailment of services, denied health care, and the resultant decline in the quality of life, or even survival, of some disabled persons. Past demonstrations in America, and those described in this report from abroad, have proven that a higher quality of care can be more appropriately provided in the family or another community option at a cost savings. We can provide better services for less money. The solutions of the problem of the ventilator-dependent person will have far-reaching and universal benefits. The solutions can have appropriate application to many other complex health care and societal problems we face today. ●

Home Care Standards Present Unique Medical And Legal Challenge

by Larry Shinnick

It was nearly 25 years ago that the American Medical Association (AMA) finally decided that jet travel was medically safe. I mention this curious fact only to underscore the amazing pace at which the process of technological innovation challenges the advancement of human health care. Nearly 15 years ago, severe birth defects such as when the baby's stomach organs are outside the body, had a 85% mortality rate. Today that rate is down to 5%. Ten years ago, spina bifida had a mortality rate of 90% — today the survival rate is 90%.

People with complex and multiple handicaps have the right to the best quality of life possible. This can be achieved only by providing them with medical, physical, social and psychological care sufficient to help them realize their maximum potential for health, education and self-fulfillment. To realize these goals, economic barriers to health care are being removed by the federal government. As an example, the 1976 Social Security Amendment provides social security insurance for disabled children. Many of these programs identify and provide services to crippled children because their health care costs are truly catastrophic.

Since modern medical technology has increased the survival rate of individuals with multiple and complex health care needs, the 1980s bring a real need to develop alternate methods of providing this health care. Institutional intensive care units, where the bulk of

these patients now receive their care, have provided an extremely high level of care, but have also been found to have two major drawbacks.

First, for optimum growth and development, the individual needs to be in the loving environment of his home as a member of the family. Secondly, institutional care is an expensive method of health care. It has been shown recently that the same services can be provided in the home with approximately a 60% reduction in costs.

As we all know, federal DRG (Diagnosis Related Group) regulations recently became effective Oct. 1, 1983. DRGs restrict the limits of reimbursement a hospital is entitled to receive for the care and services rendered to Medicare eligible patients. It has been predicted strongly and repeatedly that the number of and sophistication of services rendered in the home environment will be dramatically increased as a direct result of DRGs and by the passage of Medicaid waivers for certain services.

It seems clear that these two items are indicative of an increased awareness that high-tech services can be efficiently and safely rendered in the home environment. It is reasonable to predict that there will ultimately be a greater emphasis by both state and federal governments as well as other reimbursement mechanisms to encourage such services in the home. Thus, home care professionals will have to become cognizant of and willing to assume any and all increased and transferred liability

risk associated with the rendition of services in the home.

Until recently, ventilator-dependent children and adults have been cared for on an in-patient, in-hospital basis. Now sufficient technology exists to permit a significant number of ventilator patients to be cared for in their own home. By analogy then, it's possible to examine the various types of risks which health care personnel face in a hospital setting, and forecast the types of risks the home health care personnel should be willing and able to accept in the home care setting. It's long been established that physicians, nurses and other allied health care personnel must adhere to certain standards of care or be held accountable if the patient suffers injury or harm as a direct result of the providers falling below that standard of care. Generally speaking, that standard is known as that of a reasonable man — a standard by which a person is judged in accordance with what a reasonable person with similar training would have done under the same circumstances. By such a standard, the nurse, medical technician, or physician can be evaluated in his or her community by the standards that exist in that community. But this standard falls short of providing specific answers because it must, by its nature, be applied on a case-by-case basis.

Establishing standards for the home care of ventilator-dependent patients presents a unique medical and legal challenge. Consequently, home health care professionals should possess the requisite train-

ing and education enabling them to properly deal specifically in the home environment. Monitoring, supervision, provision of medication, observation and notation of important warning signs, patient charting, patient assistance, and timely summoning of physician assistance are all responsibilities that are present in the home setting. In theory, the duties and responsibilities of treating ventilator-dependent patients in the home would be extremely similar to treating ventilator-dependent patients in a hospital setting. The legal liabilities associated therewith would also be quite similar.

There are legal precedents that would adequately demonstrate that physicians and nurses and technicians have been successfully sued for violating applicable standards of care. By way of illustration only, health care professionals have been found liable recently in the following situations:

1. Failure of physical therapist to follow and adhere to the physician's order.
2. Negligent administration of an enema and of failure to report timely to the attending physician.
3. Mislabeling, mishandling of a blood sample by a nurse.
4. Improper injection of medication by a nurse.
5. Insufficient number of nurses assisting a patient in walking to a restroom.

These examples are drawn from the hospital environment but can be reasonably expected to occur in the patient's home. A more recent case occurred in Hawaii where a hospital was found to be negligent in failing to properly monitor a child's post-operative tonsillectomy. Specifically, it was found that the delay in discovering the child's respiratory and cardiac arrest was the result of failure to

monitor on a "minute-by-minute basis." One can readily see from this example the clear analogy to the degree of care observation in monitoring that would likely accompany ventilator-dependent cases in the home care setting.

I do not believe that home care is unnecessarily risky or dangerous. Home health care providers are well-advised, not only to consider, but also to evaluate and prepare for the potential liabilities that precedent has shown to exist.

While providing a safer and more comfortable environment for the patient, there are many things that home health care providers may do to substantially minimize malpractice risks discussed earlier. Among these are the following:

- Careful screening of potential employee credentials.
- Increased emphasis on continuing education.
- Keeping abreast of state-of-the-art technology.

Malpractice cases are definitely moving in the direction of requiring physicians and nurses and other health care personnel to remain current with the latest developments in medical technology. A central focus of such cases is prompt, complete and accurate patient charting, and adequate nurse supervision.

An important factor which will undoubtedly have legal ramifications, although the cases are not yet present in the books, is an acknowledgment by home care professionals that the atmosphere of caring for ventilator-dependent persons in their own home may vary substantially from the traditional in-hospital setting. Patients, their families, and their relatives may be more lenient about adhering to physician and nurse orders in the home. Once a health protocol has been established, it will be absolutely critical for home care

providers to assure strict compliance in spite of the attitude of the parents and families.

Another important factor in providing care for the ventilator-dependent persons in the home is the social and psychological advantages. As a parent myself, I can readily envision that a child receiving health care in the home would enjoy a better outlook on life. This certainly tends to offset the incremental increased risk of health care delivery outside the institutional setting.

It's my belief that recent developments in medical technology permit health care personnel to take advantage of the psycho-social value associated with caring for a patient in the home setting. Economic incentives intended to foster home care are now in place with the advent of Medicaid waivers and prospective reimbursement plans. Legal liabilities and malpractice concerns are ever present, and present reasonable questions which must be addressed openly. The study and analysis of liabilities that have arisen in the hospital setting, can be used to forecast home care legal risks. Such analysis permits the conclusion that recent advancements in medical and communication technology, taken together with continuing education, substantially reduce the legal risks associated with home care. Physicians and nurses and other health care professionals are quite correct that the benefits of the home care setting far outweigh the incremental risk of legal liability. The conscientious home care provider will be setting new standards for reasonable care in the community. These standards do not exist at the present time, but there is no reason to fear their development. There is no substitute for adequate training and for ongoing education. ●

St. Louis Meets Needs Of Children With Chronic Treatable Disease

by Dr. Thomas Aceto

For the past quarter of a century, I have had the opportunity to care for children and adolescents who have serious, chronic, treatable disease, both as a pediatric endocrinologist and as a medical administrator. My definition of "serious, chronic, treatable disease" is this: *Serious* — Requiring a team of health care professionals
Chronic — Of many years duration; eg., three to a lifetime.
Treatable — Including drugs, surgery and counseling

Prognosis — Often not cured, but with therapy, patients look, feel, act better and become functional adults. Without therapy, many will not function, nor will they survive.

There are children in St. Louis with serious, chronic treatable diseases where I think the health care system is doing a reasonable job of meeting their needs. One example concerns a hemophiliac who is subject to recurrent episodes of serious bleeding requiring frequent transfusions and help from a health team of professionals. Now the patient's care, including intravenous therapy, is given at home by parents, patients and visiting nurses. The fiscal support includes the following: Department of Health, Education and Welfare — Great Plains Regional

Comprehensive Diagnostic and Treatment Center; Missouri Crippled Children's Services; Bi-State Hemophilia Society; Missouri Hemophilia Program; and the Illinois State Hemophilia Program. However, the three organizations which absorb the cost are St. Louis University Hospital, Cardinal Glennon Memorial Hospital for Children/Sisters of St. Mary, and the St. Louis University School of Medicine.

The second group of children I think are making progress are those with learning disabilities. These children are problematic in identification, classification and management. Their testing is very time consuming, requiring approximately 20 hours of professional time per patient. Subsequent education and management plus re-evaluation are time consuming also.

In this state, as part of the tertiary care system, these children whose families have limited incomes can be evaluated and helped via the local school system. Fiscal aid is provided through the State of Missouri Regional Center, Missouri Crippled Children's Services, Missouri Medicaid, and Knights of Columbus. Again, absorbing the costs are Cardinal Glennon Memorial and the St. Louis University

School of Medicine.

Forming another group are those children with cancer. They need many medications, much laboratory re-evaluation, a full team of health care professionals and in some cases, major surgery and subsequent radiation. Generally these children are offered treatments on an ambulatory basis; however, there need to be periods of hospitalization occasionally. In these cases, the fiscal support comes from the Candlelighters, Leukemia Society, American Cancer Society, Tricia Phillips Children's Cancer Fund, Cardinal Glennon Memorial/Sisters of St. Mary and St. Louis University School of Medicine.

Another bright spot concerns the program for the mentally retarded adults. In the city of Cape Girardeau there is a remarkable program for mentally retarded adults who are capable of working. In that program are sheltered workshops, supervised recreation, supervised independent living, and transportation. The financial support for the program comes from the Social Security income of the individual client, contributions from the Knights of Columbus, Missouri Department of Mental Health, and United Way.

These are all examples of programs which offer some financial support for families who are medically indigent. Children with other serious, chronic, treatable diseases are not so fortunate. There is no fiscal support for the medically indigent except for the generosity of individual physicians and individual religious orders for the following:

1. Children with hypothalamic pituitary tumors
2. Babies and children who have been battered
3. Teenagers and young adults with complications of diabetes mellitus
4. Children with chronic inflammatory disease of the bowel
5. The multiply handicapped
6. Children with asthma

For some, virtually no fiscal assistance is available. This group encompasses teenagers with serious, chronic, emotional problems.

As we think about the home care of ventilator-dependent children and adults, let us remember that they exemplify the problems of a large group of children, adolescents and adults who have serious, chronic, treatable diseases, but nevertheless, are individuals who can contribute to society and can enjoy their lives. Currently, many of these people receive less than optimal care because of inadequacies in the funding of the health care system and in the health care providers. The problem requires additional changes such as redirection of crippled children's funds from the categorical. Third-party payment for ambulatory care, home care, and psychological support must be instituted. We need to make optimal health care a national priority and to view the needs of the medically indigent as a priority as well as the needs of children. ●

Nebraska Strives To Care For Ventilator-Dependent Children At Home

by Dale Ebers, MD

As a medical director of Services for Crippled Children in Nebraska, I would like to educate you as to what services are available. Maybe this will give us a springboard as to what other things can be accomplished nationwide.

Crippled Children's programs in Nebraska were expanded a great deal under the governorship of J.J. Exon, who is now a senator. He and his wife were very, very interested in chronically disabled children, and through his efforts, our budget was increased considerably and a lot of categories were included in our program which were not in the program before.

We have a unique position in Nebraska where all children who are provided any care under 94142 are coordinated through Services for Crippled Children. So, every child who is disabled in the state of Nebraska has a record in my office, whether they are eligible financially for aid from Crippled Children's or not. We are basically

constituted to provide help for the medically indigent family—not the indigent family. The medical costs of some of these diseases and conditions can be horrendous—you can run through thousands of dollars so fast you can't believe it. If the family or patient is Medicaid eligible, we ask Medicaid people to do the financing, and we do the case management. In that way, we have more uniform control over the quality of care that is delivered, regardless of where that delivery is made in the state.

We hold the basic premise that all children should be cared for at home, or as close to home as possible. That is probably a personal bias that I hope is reinforced in the state.

We have enlarged the area of hyperalimentation. Hyperalimentation means there is a permanent central line into the cardiovascular system, which creates a great possibility of infection. Eighty percent of the kids who are on a program for hyperalimentation have a short

bowel syndrome or intractable diarrhea and are usually between 6 and 18 months of age. Dr. Vanderhoff, who trained at UCLA and came back to Nebraska and wanted to get into this, came to me and asked if Crippled Children's could support this program in the hospital. We discussed the problem and decided we would have to find a way to do treatment at home. Vanderhoff has accomplished this. He developed protocol and he has a nurse who spends about a week teaching parents how to prepare the solutions for treatment. She then supports them at home by visiting or calling once a day for the first few weeks, and then visits once a week. Vanderhoff usually sees them once a month. The program's been going on for about three years now, and this past year it cost \$100,000. If you would have had those kids in the hospital, we would have been spending in the range of half a million dollars. Obviously, that is a very cost effective procedure. ●

Critically Ill Newborns Require Special Treatment

by Herman A. Hein, MD

I would like to share some thoughts with you about a group of youngsters who are ventilator dependent. These are infants with chronic lung disease. By and large when you hear neonatologists talking about chronic lung disease, we are talking about bronchopulmonary dysplasia (BPD). We believe this is a laterogenic disease that results from the use of high concentrations of oxygen and from trauma to the lungs caused by ventilation. Regardless of the causes, these babies are our version of ventilator-dependent patients.

I'd like to share with you the problems these babies create for us in neonatal intensive care, some of the problems I think we create for them. Then I would like to share a possible solution to some of these problems.

In November, there were eight infants less than 12 months old receiving care in Iowa hospitals because they were ventilator dependent. Seven were housed at University Hospitals in Iowa City, and three others had just died within the past several weeks. Presently there are no Iowa infants receiving home ventilator care. There are some older children on ventilators, but not a large number, probably somewhere in the range of four to 10 in the entire state. There are six infants with chronic lung disease that are home and require supplemental oxygen and

another two that are housed at University Hospitals. To the best of my knowledge there are no Iowa infants receiving care in chronic care facilities because they are ventilator or oxygen dependent.

The number of beds available to provide care for critically ill newborns is a chronic problem in most neonatal intensive care units. I am not prepared to discuss why neonatal intensive care units have not expanded their capabilities to meet this need, but I must note that financial matters, including the availability of nursing personnel, are important issues. Contrary to popular opinion, which is consistent with the hue and cry over rising costs of medical care, many hospitals are not financially solvent. A large number of hospitals that provide tertiary neonatal intensive care are teaching institutions, and these institutions are experiencing severe financial constraints. Accordingly, the hope for expanding facilities by these institutions is not a reality in the near future.

In the meantime, babies with chronic lung disease are occupying beds two, four or six months in the neonatal intensive care units. Eventually the chronically ill ventilator-dependent infant is moved to another area of the hospital, usually to a pediatric intensive care unit or to an intermediate type of unit on a pediatric ward. The

move is not based on the baby's or the infant's needs, but rather on the availability of a bed. The net effect of this type of uncontrolled transfer is fragmentation of care.

Related to this matter is the general issue of primary care givers for these infants. Most people would agree that as things evolve, the neonatologists are the ones who are and should be responsible for these babies. But once the baby leaves the NICU, this really isn't true in many instances. Because of the heavy workload of most neonatologists, the logistical type of problem is a major one in trying to give care when the babies are scattered throughout the hospital. For example, in our hospital, once a baby leaves the NICU and goes to the pediatric ICU, it's a three-block walk. If the baby goes over to the intermediate level on one of our pediatric wards, it adds another two blocks. Logistically it gets to be a major problem, resulting in fragmentary care. In my experience there really hasn't been another group of physicians that has leaped forward and said, "I'm sure willing and eager to take care of these kiddies with chronic lung disease." I guess I thought that pediatric pulmonologists would be first in line, but again, in our institution that simply has not been the case. They are willing to consult if requested, but they are not available to take over the primary care.

The problems that infants with chronic lung disease present are complex and varied — respiratory, cardiovascular, nutritional, growth and development, surgical and many, many more. If we are going to be able to provide home care for ventilator-dependent infants, it is important that coordination of hospital and community resources begin some considerable time before this move is anticipated. Given the current state of affairs, I am not very optimistic that this is going to occur with any regularity. To help solve the problems, I believe there are several things we can do.

Facilities should be developed within acute care institutions that provide neonatal intensive care to

house all ventilator-dependent infants who are six weeks of age or older and are making no progress in being weaned from the ventilator. Medical supervision should be provided by a neonatologist or a pediatric pulmonologist, and appropriate consultation can be requested as needed. I would also suggest that a cadre of nurses provide care to the children in this special unit. Using this approach, the following advantages emerge: 1) location of care giving ceases to be a problem; 2) there is continuity of care; 3) coordination with community resources can be anticipated and begun with sufficient lead time; 4) knowledge will accumulate because of the consistency of care given by nurses as

well as physicians and other providers; and 5) practical, problem-oriented clinical research can be fostered.

I believe it's important for us to begin to accumulate a solid basis of knowledge about this vexing problem, including not only aspects of prevention but also those measures that are related to chronic care giving. This information should be refined and disseminated nationwide as soon as possible. Perhaps if major teaching institutions can combine this group of infants in one clinical area and carefully document the results of care giving, we can begin to make progress in what currently is a frustrating experience for parents and caregivers alike. ●

Cooperation And Teamwork – Keys To Future Health Services

by Robert L. Hotchkiss, MD

The environment in Missouri is one of fiscal restraint and that makes discussions about least costly care very appropriate. When I took this position a little over a year ago, I was advised by many of my colleagues against it. They said Missouri was not in the best fiscal shape and that the Division of Health in the state had a major liability in the fact that it was responsible for environmental health, but was located in the Department of Social Sciences. The fact that the Division of Health is linked to the Division of Family Services through the Department of the Social Services, is the bright spot. The biggest challenge was how to get the best possible health care system established in the state within resources available.

Although the resources are on the verge of shrinking again, many new opportunities have come to us

in state government through federal action in 1981, including the possibility for application for state waivers. We view the current application for home health care for the chronically ill child as a major breakthrough. It allows us to get past many of the bureaucratic stumbling blocks that have been built at the state, local and federal levels, to get to the heart of the problem.

The possibility of delivering excellent care in a humane setting at less cost is an immensely desirable goal for all of us. We look forward to the challenge of implementing this program as soon as we get approval from our friends at the federal level. I think the environment in this century will be one of very tight fiscal resources and one in which only through innovation, cooperation and teamwork will we continue to deliver much needed services. ●

Robert L. Hotchkiss, MD, is director of the Division of Health, State of Missouri, in Jefferson City, MO.

Kansas Uses Innovative Programs To Prevent Hospitalization

by Patricia T. Schloesser, MD

At the turn of the century, a Kansas journalist, William Allen White, became nationally known for his editorial "What's the Matter with Kansas?" His theme was that "when anything is going to happen in this country, it happens first in Kansas."

Although Kansas has had many "firsts" this century in public health and mental health programming, home care ventilator dependent persons have not yet become reality. Kansas does have, however, a number of innovative out-of-hospital programs designed to prevent hospitalization in the first place or when necessary, to decrease the length of stay. This preventive approach offers a more normal life experience for the handicapped and their families and is cost effective as well. Some profiles of programs follow.

Cystic fibrosis program

In 1966 the Kansas legislature appropriated funds to the Department of Health and Environment to develop services for all cystic fibrosis children in the state. Since the appropriation was small, the department designed an out-patient program which lessened the need for hospitalization. Funds were earmarked for the provision of

home inhalation equipment and medications at no cost to the families. Centralized purchasing resulted in considerable savings. Diagnostic and case management clinics were established in Wichita and Kansas City. A survey of parents three years after this program was begun, indicated that fewer hospitalizations were necessary and the family morale had been greatly improved. Currently, there are 239 active patients on the registry with 30 over 21 years of age. Most CF children are progressing in school with their peer group and are becoming self-sufficient in early adulthood. In recent years, the Crippled and Chronically Ill Children's Program has paid for hospitalization for cystic fibrosis patients whose families are financially eligible. Third-party reimbursement has also strengthened the financial base of the program in recent years. In one urban area, cystic fibrosis patients are being discharged from the hospital on intravenous therapy at home. This has decreased the average hospital stay from four weeks to one.

Chronic obstructive pulmonary disease (COPD)

The Kansas Lung Association

in cooperation with physicians in urban and rural areas is encouraging home based programs in which patients are taught 13 respiratory skills through individual or group instruction using a self-study manual. A decreased need for hospitalization is anticipated.

Diabetes-outpatient management of the young diabetic patient

The Kansas Medicaid program has had some positive experiences with the outpatient management of severe diabetic children. One of their patients is a 14-year old girl who had been in a Wichita hospital for a total of eight months in a 12-month period including 32 days in intensive care, at a total cost to the agency of \$59,000. Medicaid authorized the purchase of an expensive piece of equipment, an insulin pump, along with a glucometer for monitoring her blood sugar, so that she could be discharged home. The child has remained home for 18 months with no hospitalizations. The Medicaid agency has now authorized the purchase of additional insulin pumps for two other teenagers with equally good results. Dr.

Richard Guthrie, Director of the Kansas Regional Diabetic Center in Wichita, reports that there are 64 persons currently on the insulin pump at home managed by this center. He projects that the total cost of the patient workup and equipment and supplies for the first year would be about \$8,000 compared to an average of \$30,000 per year for repeated hospitalizations. With 64 patients a year, the difference between home cost and hospital cost is \$1,300,000. If we project this figure nationally, such a program could save \$50 million per year.

Prevention of prematurity programs

The cost of premature care can best be illustrated by a case

history as follows. M.H. was born prematurely and weighed slightly over two pounds. His mother was 17 years old and had dropped out of the 10th grade with the pregnancy. She had received late and inadequate prenatal care. The infant was transferred to the intensive care unit at a Level 3 hospital in Kansas City by ambulance for management of the prematurity and associated respiratory problems. He remained in care for 24 days and was returned to a Level 2 hospital in his home community for 14 days of convalescent care. The cost of this hospital care was \$50,000. This infant is developing normally and special education costs have been avoided by the excellent perinatal network program established by the Maternal

and Child Health Block Program. If the family had resided in a community with the special Maternity and Infant Care Program for teenagers (there are 10 such programs across the state), this mother would have received improved prenatal care and the WIC supplemental food program with the likelihood of preventing the birth of a premature infant. Since the cost of this preventive health service for mother and infants averages \$2,000, a cost savings for this patient would be \$48,000.

In summary, I would echo William Allen White and say, "There's nothing the matter with Kansas" as Kansas responds with practical approaches for home based programs to meet the needs of families. ●

Brook Lodge Conference Focuses On Future Of High-Tech Ventilator-Dependent Children

by Eugene E. Bilotti, MSW

In October, 35 people who work daily, hourly and weekly with ventilator-dependent patients came together for a conference in Augusta, MI. Some of the people there had committed major portions of their lives to this population. We didn't have rigid agenda or time frames — we had groups in which we talked about ventilator-dependent children — how to get them home, their problems, what our experiences have been, what we should look forward to in the future. Consequently, we wanted to bring these people together and share experiences for three main reasons.

One is best summarized by the last few words that Betty Wartenberg spoke at the Surgeon General's Workshop in Washington. It made the hair on my neck stand up in the back, and I shivered. Betty, when she finished her speech, said, "I thank you for not pulling the plug on Donnie."

The second experience occurred at the end of the seminar when the very imposing figure of the Surgeon General of the United States stood before us and took the gavel and hit it hard and said, "I'm supposed to make decisions. I declare that this conference is a success, and we're adjourned." And we left.

Those two moments come together to make our first point: We cannot give up on these children, and we shall not give up on these

children. We shall do what we can to maximize their potential, and to make them all what they are capable of being — socially, educationally, and physically.

Our second point is this: These children were not intended to live in an intensive care unit or a high-risk nursery. High-risk nurseries have other reasons for being. These children need a better home. They need better alternative living solutions — if not their own home, then a home-like setting or something else.

Third, one of the major issues we face after medical stability is, "How are we going to pay for these children to go home?" We've heard the figures, and they are hard to believe. Do you really believe that we saved the state of Illinois \$5 million in the last four years on these children? These figures are overwhelming.

The first time I was interviewed for a local paper, they asked how much the children's care cost. I said some of these children's care costs \$45,000 a month. They put down \$45,000 a year. I went back to them and said, it's \$45,000 a month, not a year — a month. They said that's not possible.

It's not only possible, it's happening.

Therefore, we addressed funding issues at Brook Lodge. You would be interested to know that we have no iron-clad solutions.

However, one may be through Title XIX of the Medicaid waiver which is not targeted to ventilator-dependent children alone, but for all severely disabled children who can best be served in their own home.

When we approach an insurance company and show them cost savings and approach them as colleagues, they are willing to listen and will sometimes revise their policies in order to cover these children.

Third, other than the Crippled Children's programs, Title XIX, and the Maternal Child Health Block Grant, there are really no other sources of funding, with the exception of grants and gifts. In Illinois and other states, we can save approximately \$22,000 a month by creating a little ambulatory intensive care unit in the home. It looks like a home, but yet it has equipment — a ventilator, a suction machine, and sometimes a backup generator or ventilator.

We did not spend all of our time on funding at that conference. We also discussed the role of parents. The parents are critical — they are really the case managers — they run the show and make the operation occur. We also talked about involving the parents in training.

Another item we emphasized was the differences that occur from family to family, child to child, situation to situation. They're all different. We had to go to our tenth

child before we had a duplicate diagnosis. Consequently, we have no prototype and no average child. We can't really describe a ventilator-dependent child; therefore, we have to have exhaustive detailed care plans for these kids in the home. How detailed? I recently saw one that ran almost 400 pages. Children's Home Health Network is committed to considering every contingency when the child goes home. You have to keep the roads open, make sure the lights are on and then, while saying that, we have to keep saying to ourselves that every child is a home discharge candidate. Sometimes we have to come to the bitter grips of saying, "This child is not a candidate for home discharge," and that hurts us very much.

We are a government that is ruled by regulations, therefore we are developing standards, guidelines, and regulations for getting these children home.

Home care is not always enough — we need other alternative kinds of places for these children to live such as medical foster homes. Although it may sound impossible,

the Department of Children and Family Services put an ad in the paper concerning a disabled child, and they had 24 people respond. Half of the respondents were nurses, and two or three of them were respiratory therapists. Out of that group we turned out a very, very fine candidate for a medical foster home. We are in the process now of drawing up some guidelines and directions for medical foster homes. There are people who would like to take these children into their homes. Sometimes it's not appropriate and sometimes they cannot leave. Therefore, we have to think about other forms — like hospital schools, upgrading of nursing facilities, other pediatric facilities that will gear their way toward this population.

In order to serve this population, you must have very controlled standards and planned guidelines. The whole system that we are talking about is running against the streams of medicine. For years we've said, "Very ill children belong in hospitals." Now we're saying, "Maybe not." Maybe they need to be in the home, and they are going home in large num-

bers. The Brook Lodge Conference devoted part of its time to the language of the future. We looked at what is going to happen to these high-tech ventilator-dependent children in the future. We must not just think of the child alone, but of the family, the community and of all the institutions that are involved. One of the speakers, Dr. Kohrman, said that we must bring together people who are working with this kind of population to determine their educational needs. What kind of planning do they have for the future? What kind of regionalization do we need in order to put these children in the least restrictive environment? Can we not say that the goal for this population is to bring them to the place that is best for them to grow and develop?

Many of these things we have done before, so we need to collaborate and find out from one another what is being done. The hours are long, the demands great, and the payoffs sometimes very hard to see and very hard to measure; but pediatric practice is exciting as we think about home care in the future. ●