

Hospital and Research Center (the chronic care hospital of the University of Chicago, Department of Pediatrics). Currently, home discharge teams (at Children's Memorial, Wylers, and Michael Reese) are preparing protocols to arrange for progressive preparation for discharge of chronic ventilator-dependent children, either to LaRabida or directly to home or other domiciliary setting now available in the Chicago area. LaRabida is planning to serve as an intermediate care setting. The capabilities of LaRabida are rapidly being enlarged to handle ventilator-dependent patients. It is also anticipated that LaRabida Children's Hospital and Research Center will develop significant programs of research and education around the very complex set of problems which these children present.

It is clear that the maintenance of such a network is going to require extensive ability to monitor patient flow and status, to produce and evaluate educational materials, programs, and protocols, and to bring together funding guarantors to establish the most effective and comprehensive payment programs. Thus, the developing consortium, in addition to seeking consultation for preparing each of the member institutions to provide a uniform standard of care and coordination of services, is also seeking assistance from an organization,² external to the institutional members which will coordinate personnel, parent, and patient education; act as an information clearinghouse; maintain a flow of patient records and appropriate statistics; and act as the center for the coordination of payment sources.

²*Care for Life* is a not-for-profit organization providing services of documentation, education, and demonstration designed to meet these objectives and others that follow (documentation center, community-based options for the disabled).

THE CHILD AT HOME

Mrs. Bette Wartenberg

My name is Bette Wartenberg. I am Donnie's mother. I am here to present the parents' view. I will describe the implications of a child's chronic illness on the family, the financial issues, and the complex problems encountered by my family. In addition I will compare experiences reported by other parents in our parents' group.

Donnie, my sixth child, was born with defects that involved the left side of his body including his left lung, which later on had to be removed. At the time of his birth we were told that Donnie had to undergo immediate surgery because of what is called an omphalocele, which means that his navel and stomach had evolved outside of his abdomen. Within 4 hours of birth he was transported from Joliet Hospital to Children's Memorial Hospital in Chicago, where the first stage of surgery was performed immediately.

For us as parents, the first shock in the delivery room was knowing that our child had multiple birth defects. We were overpowered by fear of losing our child. Later, the fear was intensified by observing our child in the ICU, when his heart stopped 18 times and he had to be resuscitated. Only because of the prompt response from health care personnel, Donnie survived all this without brain damage.

During his first 3 years in an acute intensive care unit, Donnie underwent a total of 20 operations. Most of the time he was breathing with the help of a machine—a ventilator—receiving numerous intravenous infusions and treatments while we were watching as helpless by-standers. We often did not understand what was done, the reason why, and we had no knowledge of the alternatives.

Our main social contacts were other parents of critically ill children in the ICU waiting area who, over a period of months, became like close friends to us. Some were the unlucky ones; their children died. We grieved with them, always thinking that we could be next. After years of this, we shut ourselves off and avoided contacts with those parents—even to the point of being abrupt.

We did not receive professional help to deal with the psychological stress we were under. My husband dealt with it by talking constantly about it, while I tried not to think or talk about it, which caused great problems between us. We lost a lot of our friends. They did not know what to say, so it was easier for them not to see us. Besides, we were no fun to be with, because we were constantly talking about our problem.

During his years in the ICU, attempts were made to wean Donnie off the ventilator. A pediatrician forcefully suggested that we take Donnie home, that is, to die. We took Donnie home. He had a tracheostomy; that is, a hole in his trachea. He was breathing poorly by himself; we thought he would not live much longer. We were not prepared to properly take care of him at home. We did not even know how to regulate the oxygen flow. He was home for two months, only to return to the Children's Memorial ICU because of pneumonia and failure to thrive. By then, we had lived through two months of a nightmare with no help, no medical caregivers, no sleep—only worry. We were exhausted and burned out.

We shared this experience years later with other parents who at the time were sent home unprepared, with a child who could not breathe by himself without a mechanical aid. This couple had ventilated their child by hand 24 hours a day, taking turns day and night for months, until the decision was made that the child needed a mechanical ventilator at home.

Our home is in Joliet, Illinois, 60 miles from Children's Memorial Hospital in Chicago. Rather than spending 2 to 4 hours on the road a day, we chose to move into the waiting rooms at Children's Memorial Hospital, where we lived for over a year. We slept on the couch, showered in the basement locker rooms, ate hospital food, and paid parking fees. Our 5 children, ranging in age from 17 to 12 years, were left unattended most of the time. They learned to take care of themselves. After about a year, my husband and I decided that one of us had to stay at home in Joliet because our other children were beginning to feel the effects of our absence. I went to Joliet, returning to the hospital occasionally, and my husband stayed with Donnie. Consequently, he lost his business and to live we had to borrow money from family members. Besides dealing with this stress, there was no money or time to go on vacations with the other children. We haven't had a family vacation for 10 years!

Our insurance covered \$100,000 of Donnie's care. After a few months, we were told to apply for financial assistance to Illinois Public Aid and the Division of Services for Crippled Children. Children's Memorial Hospital was very helpful in helping us apply. We qualified because Donnie was born with multiple deformities.

Why is it much easier to get aid if a child is born with defects than if some illness or accident causes defects at a later date? Others in our parent-group had children who had problems getting financial help. One parent was called into the hospital billing department and was presented with an astronomical hospital bill and was asked "How are you going to pay for this?" Some parents were advised to go on unemployment, go on public aid, and even get a divorce.

After spending the better part of 3½ years in an Acute ICU, Donnie was transferred into an intermediate care unit for his long-term care. Repeated attempts to wean him from his breathing machine caused him to be lethargic, puffy, and turn blue. He ceased to grow. The only time he was well was when he was on his ventilator. Then he became a very active, happy child. His many arrests had apparently not damaged his brain. He had become a very precocious child, even inventing his own sign language!

Even though we were at his bedside as much as possible, many of the functions of a parent were taken over by nurses and other health caretakers. Correcting bad behavior or eating habits is hard to accomplish outside of a family setting.

Since Donnie was confined to this unit by being on the ventilator, he lacked opportunity for an education appropriate for a 4 year old. At this time he got ½ hour of tutoring a day. Children's Memorial Hospital, being an acute care hospital, was unable to provide additional education for a chronically disabled child.

Then in 1978 a new idea was presented to us by a new staff physician. Give Donnie optimal ventilation so he can grow. Prepare him to go home safely with his ventilator. With our memories of the past experience, the

idea horrified us. But after meeting with qualified medical personnel, we were assured that we would be trained and would have medical help to support us. Donnie needed to go home in order not to become socially handicapped. Once while I was talking to him on the phone, I told him I was sitting at the kitchen table. After he hung up, he asked his nurse "What is a kitchen table?" My other children were delighted when we told them that Donnie could come home, and they were anxiously awaiting his arrival.

In 1978 no money was allocated by Federal or State law to care for ventilator-dependent children at home. The State knew how to pay the high costs of intensive care but had no experience in providing funding for less expensive care at home. A long period of negotiation took place. The State officials finally found the solution to pay 100% for 2/3 less expensive medical care at home. We were luckier than others in the parents' group who were faced with the spend-down money (money to be paid according to income by the family to the State).

Some parents in our group had private insurance. The insurance company refused to change their reimbursement policy for home care. The insurance company was willing to pay everything in hospital, but refused payment for home care. As a result, the insurance company rapidly spent the \$500,000 in the hospital. This money could have lasted for years at home. They had no incentive to change. Therefore, public funds were needed sooner, because the private insurance money was gone so quickly while the patient remained in the ICU. So the burden was transferred to the State and ultimately to the taxpayer.

Transition

It took nine months from the time the decision was made to send Donnie home before it really happened. During that time we built a specially adapted addition to our house. Regular meetings with the health care team were held. These meetings clearly defined goals acceptable to all, and provided clear objectives and specific plans for action. Each team member had accountability. The home discharge team included the dedicated clinical staff who had cared for Donnie over the years. The coordinator was his nurse; the educator was his respiratory therapist. Both were caregivers who had received him in the ICU shortly after his birth. The team also involved physical and child-life therapists, special service staff, social workers, etc. Initially, several members had to overcome their own fear and negative thinking, but the more educated they became, the more they were able to overcome this barrier.

My husband and I were trained to handle Donnie's ventilator equipment by both classroom teaching and "hands-on" experience. We passed a test and were certified. Nurses we recruited, selected, and hired to provide 24-hour home care were trained with us at the hospital, in the classroom, and at the bedside. Community support services, including a primary physician and emergency room staff in Joliet, were well-informed about their responsibility prior to their consent. Nursing, physical therapy, and respiratory therapy plans and exact procedures were clearly written, and local suppliers of medical equipment were found, motivated, and well-

prepared. Funding was finally approved because of highly motivated and responsible actions of the leaders and staff of the Division of Services for Crippled Children, the Illinois Department of Public Health and SSI Disabled Children's Program.

The team work of all these individuals made the home program a reality.

Home

On September 10, 1979, our son came home to stay. It has been a difficult task. We are dealing with a lack of privacy, the ventilator breaking down, lack of service for equipment, and difficulties in getting medical supplies.

However, the benefits of having Donnie at home far outweigh the difficulties.

We are now a normal family, maybe different in some ways, but we are all together, sharing all the experiences of life. We no longer divide our time among our children. Donnie's health has improved; he has grown several inches. His oxygen need has decreased. His social life is no longer limited to the ICU where he never knew the difference between day and night. He is now getting an education, doing average-to-above-average work. He no longer has to regard cardiac arrests in the bed next to him as his only occasion for "social-get-together." Instead he goes to weddings; he was a ring bearer at his brother's wedding where he never missed a dance. Donnie is a joy to be with. He loves his religion. He celebrated his Holy Communion last month. He tolerates being off the ventilator with oxygen longer. He races his race car (recently he placed first in competition), climbs trees, and he even fell and broke his arm at a birthday party. Donnie worries right now whether he will get married one day. He is concerned that it is not much fun to go trick or treating, because no matter how he dresses up, everybody recognizes him by his tracheostomy. His nightly prayer includes: "Dear God, if you are listening, please get rid of my trach so I can play football."

We know we can go back to Children's Memorial Hospital any time we have any problems with Donnie. He will be well taken care of by loving people who know him and care for him and us.

We are deeply grateful to the staff of Children's Memorial Hospital. They never gave up hope. And thank God nobody pulled the plug in the ICU. Thank you.

WORK GROUP RECOMMENDATIONS

INTRODUCTION TO WORK GROUPS

*When The Voices of Children Are Heard On The Green
And Laughter Is Heard On The Hill,
My Heart Is At Rest Within My Breast
And Everything Else Is Still.*

William Blake

All of those participating in the Workshop have made a commitment to improving the quality of life for children with handicapping conditions and their families. In sharing this common goal, they shared a common struggle—a struggle that is bounded by our limits in knowledge, technology, and resources. It is a struggle that taps boundless human compassion and tests every bit of creativity. The task of the work groups was to challenge each limit and to invoke all of our talents to solve the urgent problem of extending humanistic and comprehensive care to *all* handicapped children and their families.

They were a diverse group with a diverse perspective: parents, professionals from many disciplines, public and private service providers, financiers, and policymakers. The interaction of their combined perspectives has the potential for generating unique strategies and solutions that can serve to shape a nationwide effort. As a case example, the ventilator-dependent children provide a rich opportunity to go forward with innovative strategies that can affect all handicapped children and their families.

For a day and a half, ten working groups examined two key areas of concern: organizational and financial considerations. In each area a broad range of issues was addressed by the groups. Organizational considerations included the scope of approach to delivery of essential services, institutional roles and limitations, and public and private organizational roles and limitations. The groups examined the means of overcoming deterrents to care in the community, of promoting family autonomy, of setting standards for quality assurance, and of defining educational and research needs.

Financial considerations included approaches to reimbursement for ventilator-dependent children, reimbursement for community-based care and for tertiary and intermediate institutional care, cash-flow dynamics, multiple sources of funding for comprehensive care, and research in financing services.

Each group also examined existing processes and mechanisms—their advantages and limitations, the deterrents to improvement, and strategies for the evolution of family and community management of care for these children.

The groups presented their recommendations to Drs. MacQueen and Ketrick who synthesized these and identified common themes to present to the Surgeon General at the close of this Workshop.

RECOMMENDATIONS

The participants in the workshops were assigned to ten working groups of approximately fifteen persons each. Each group was assigned specific, related sets of issues to examine in depth. The groups were to define existing processes and mechanisms, their advantages and limitations, and the deterrents to improvement. They were also asked to develop strategies for the evolution of family and community management of the care of ventilator-dependent children.

The work groups looked at what was working in the system, defined numerous needs and problems and deterrents, and suggested strategies for improvement. The diversity of perspectives, the flow of ideas, and various tangents of the interactions present in the work groups cannot be covered adequately in this document, but some of the more pressing programs, needs, and strategies are distilled and categorized here. For the purpose of providing a framework for presentation, ten categories have been defined. The deliberations are reported under these headings:

1. Data
2. Institutional Matters
3. Family Considerations
4. Regionalization
5. Standards for Quality Assurance
6. Abuse and Overutilization
7. Professional Education
8. Family Education and Public Awareness
9. Research
10. Finance and Reimbursement

Most of the topics cut across the lines into more than one of the above categories, so that reference may have to be made to more than one section in order to find all the suggested strategies for any given topic.

CATEGORY 1: DATA

There is a need for accumulation, dissemination, and utilization of data.

DEFINITION OF THE ISSUE AND ITS EFFECTS:

If we had adequate epidemiologic and demographic information we would be better prepared to develop programs for the care of ventilator-dependent children.

On a case-by-case basis we have figures which demonstrate significant dollar savings for home or community care, when contrasted with in-hospital tertiary care, but these numbers need to be refined and monitored. Because such a limited number of programs for home care are now functioning, we have not been able to accumulate data for the "ripple" which the move of large numbers of ventilator-dependent children from tertiary units might have on the financial structure of the medical system as a whole.

SUGGESTED STRATEGIES

1. Convene a working group to define, within a time frame, the needed information. The group should have representation of economists, statisticians, and health care providers.
2. Implement a continuing data collection and information system.
3. Disseminate the collected information to organizations and reimbursing agencies which can apply it to improving care and financing.
4. Conduct epidemiological studies to follow the natural history of diseases which leave children ventilator-dependent.
5. Conduct a survey to determine the current patient care and reimbursement status in each of the States.
6. Conduct cost-effectiveness studies to assess the quality and costs of care in various settings.

CATEGORY 2: INSTITUTIONAL MATTERS

Multi-tiered institutional models should be adopted to provide care for ventilator-dependent children. There are 3 major groups: acute care facilities, transitional units, and non-institutional alternatives.

DEFINITION OF THE ISSUE AND ITS EFFECT

Acute care facilities should be reserved for care from the onset of medical crisis until stabilization. Transfer should then be effected to a transition, intermediate, or rehabilitation unit to prepare for long-term placement. Very few such transitional centers are now available for ventilator-dependent children. As a result, many children remain domiciled on expensive acute care units for far longer than is medically necessary. There have been serious barriers impeding transfer to home. There are almost no facilities for non-institutional living for those ventilator-dependent children for whom the biological home is not a viable alternative. Eventual placement in a home or home-like community-based living arrangement should be the goal for these children.

SUGGESTED STRATEGIES

1. Promote the development of transitional units, such as intermediate care centers or rehabilitation facilities that are pediatrically oriented.
2. Devise non-institutional, home-like living arrangements, such as group-living with shared services, foster homes, or subsidized adoption.
3. Work to remove the social and economic deterrents and barriers which prevent transfer to care at home.
4. Develop precise clinical and social criteria for transfer from one level of care to another.
5. Provide financial aid for tertiary units to allow them a major role in preparing patients and families for transition.

6. Provide for study of European programs of group living arrangements, which have been in successful operation for a number of years.
7. Study the effects on tertiary care financing after the long-term, ventilator-dependent children are moved from the tertiary beds.
8. Develop regional affiliation among institutions at the various levels. Provide financial incentives for those institutions participating in such a consortium.

CATEGORY 3: FAMILY CONSIDERATIONS

Starting at the earliest acute stages, the family must be encouraged to develop a strong involvement in the care of the ventilator-dependent child.

DEFINITION OF THE ISSUE AND ITS EFFECTS

The family of the ventilator-dependent child is often overwhelmed by the process of coping with the acute phase of the child's illness. The family unit is disrupted by the persistent encroachment of a new way of life for which there has been no preparation. Because of this devastating strangeness, the parents can easily come to rely on well-intentioned "professional parentalism" in their early decision making. As the patient stabilizes and becomes ready for an alternative to an acute unit, the family may have become too functionally paralyzed to participate in the process of considering such alternatives. After care at home has been inaugurated, continuing monitoring of family function must ensue.

SUGGESTED STRATEGIES

1. Encourage an early "bonding" process for the family to come into intimate physical contact with their child as soon as it is comfortable for them to do so.
2. Have the family assume as complete a responsibility and authority as possible from the earliest stage in the illness. This should be done in consultation with health and social service professionals.
3. Develop tools to assess the family's readiness for each transitional step.
4. Make parent counseling, mental health assistance, and specific therapy available where indicated.
5. Aid in formation of parent support groups and a parents' network for exchange of information and feelings.
6. Hospital staff education should be directed towards sharing responsibility with the parents in whatever way is compatible with the best medical care for the patient.
7. Provide for respite assistance for the family with a child at home.
8. Assist in structural changes in the home which make it easier for the ventilator-dependent child to lead as normal a life as possible.

9. Enhance payment of outstanding vouchers promptly, so that the family does not have the added burden of unpaid bills. A system should be inaugurated with third-party payers for advance allocation of reimbursement, so that the family can plan a reasonable financial budget with knowledge that monies are available when needed.

CATEGORY 4: REGIONALIZATION

All institutional, social, service, financial, and professional functions on behalf of the ventilator-dependent child should have regional coordination. A regional system can be developed at State level, across State lines, or intrastate, and with tertiary care center participation. The strongest emphasis should be on the community-based component of the regional system.

DEFINITION OF THE ISSUE AND ITS EFFECTS

The ventilator-dependent child at home needs essential services. At present, there is no coordination of delivery of these services, nor are there uniform methods of payment. There is, as one group put it, "no one in charge." A regional system for coordination of efforts can be developed within and among organizations which already exist, with each regional system responsible for defining and arranging each of its levels of service.

SUGGESTED STRATEGIES

1. Grants from the Federal level should be provided for pilot projects to delineate implementation issues in developing the structure of a new regional system for delivery of care.
2. Encourage communication among all providers of medical and nursing care, education, social services, recreation, transportation, psychosocial support, emergency services, equipment vendors, and respite assistance at the community level. This will enhance the coordination of community assets into the regional system and allow for easy entry of the patient into these facilities when transferred from hospital-based care.
3. Funding must be found to develop regional systems beyond the initial pilot projects. In time, the regional systems should become self-sustaining.
4. Public and private reimbursing agencies should participate in the development of the regional system. Such participation will allow for a more rapid solution of problems, with resultant savings. Those agencies which already exist for the family should be incorporated into the financial plan, whether Medicaid, Crippled Children's Services, Blue Cross/Blue Shield, or private insurers.
5. The coordinating center should accept responsibility for the patient's transition from one level of care to another.

6. The regional system should be developed with the objective of providing coordination of all community resources for the humane care of the child in the least restrictive environment compatible with medical status.

CATEGORY 5: STANDARDS FOR QUALITY ASSURANCE

Standards should be developed and quality assurance controls should be built into both institutional and community-based programs.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Standards should be written for the various levels of institutions and non-institution living arrangements, as they are being developed. Most importantly, standards should be set for the essential services and personnel which are necessary to support the ventilator-dependent child in the home. Quality controls cannot be instituted until minimal standards for services are established. The family of the patient will be able to make better decisions on contracting for services when they have standards to guide them.

SUGGESTED STRATEGIES

1. Professional organizations should be encouraged to work together to establish and promulgate needed standards of care.
2. Each system should provide a qualified home discharge team and should implement a post-discharge monitoring mechanism.
3. Standards should be established for medical criteria.

CATEGORY 6: ABUSE AND OVERUTILIZATION

There is a concern that abuse and inappropriate utilization will occur once systems are established for providing improved services for the ventilator-dependent child.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Technology may be used inappropriately, and there may be inappropriate use of personnel and equipment. Patient populations may enter into the system by way of unwarranted discharges to home care or because patients now on mostly self-sustained home care may apply for entry into the system.

SUGGESTED STRATEGIES

1. Establish safeguards against abuse and inappropriate utilization and provide for monitoring in the regional systems.
2. Establish standards and/or regulations to insure against cost inefficiency for all services provided.

3. Insure charges for community based services (i.e., group homes) are realistic and monitored to prevent abuse.
4. Set up central purchasing of equipment with loan or rental to the appropriate patient population.
5. Inaugurate monitored competitive bidding for equipment and provision of services.
6. Review past experiences of national programs requiring complex medical technology to identify problem areas and identify ways to avoid similar problems.

CATEGORY 7: PROFESSIONAL EDUCATION

Personnel delivering care at all levels must be adequately educated.

DEFINITION OF THE ISSUE AND ITS EFFECTS

Professionals often find it difficult to work with the disabled because of attitudinal problems. They must develop sufficient background associated with the problems of disability and the needs of the extended families very early in the course of their training. Training of professional personnel must take place at all professional levels of pre-service and in-service education to allow updating and familiarity with new techniques at all levels. Medical, nursing, and allied health schools, schools of health administration and economics, business schools, and biomedical engineering centers should be involved.

Paraprofessional workers are an important part in the service delivery system and must similarly receive basic and appropriate continuing education.

SUGGESTED STRATEGIES

1. Incorporate education for care of the disabled into the curricula of higher learning.
2. Inaugurate and supervise an education program for health workers as a major function of the tertiary centers in the regional system.
3. Develop a national clearinghouse to allow for access to resource material.
4. Sponsor continuing education courses aimed at professional and paraprofessional personnel.

CATEGORY 8: FAMILY EDUCATION AND PUBLIC AWARENESS

The public remains unaware of many of the problems of the disabled. Families of ventilator-dependent children need ongoing educational support. Ventilator-dependent patients must be included in the educational mainstream when possible.

DEFINITION OF THE ISSUE AND ITS EFFECT

The public, and particularly the legislators, is unfamiliar with the needs of ventilator-dependent children. They are not aware of the beneficial effects on our social structure when the disabled are transferred to a more normal, productive life in our communities. Parents need continuing education from the earliest stage of the child's disability through the transition which results in the ventilator-dependent child being cared for at home. The child's education becomes one of the most essential services in planning for care at home.

SUGGESTED STRATEGIES

1. Groups should be formed to increase public awareness.
2. Government officials and third party payer executives at all levels should be made aware of the cost and humane benefits which result from a system of community care for the ventilator-dependent child.
3. Parents' groups should be formed to keep parents informed of their rights.
4. A national clearinghouse should be devised to provide parents with information about care and specific services for their children. There should be local community outlets for such a center.
5. Liaison should be developed with the community school system to allow for tutoring and entry, and, if possible, mainstreaming the child into the system.
6. Ongoing education experiences for the child and family must be provided by or arranged by the health providers.
7. Education of the child should be a part of the case management plan.

CATEGORY 9: RESEARCH

Basic research aimed at prevention of disability is of major importance. Research is needed also to define the problem more thoroughly and to investigate and evaluate possible solutions.

DEFINITION OF THE ISSUE AND ITS EFFECTS

We have very few programs for the delivery of care to the ventilator-dependent child that extend beyond the acute care unit of the tertiary center. We have presented the case for the benefits of care at home. As programs for these children evolve, careful research and evaluative studies must be conducted.

SUGGESTED STRATEGIES

1. Research should be undertaken in those factors which could improve the outcome of pregnancies.
2. Regional systems as they are developed should contain a research component.
3. Research on treatment interventions to measure outcomes should be undertaken.
4. Research is critical to measure cost effectiveness. There should be an immediate cost effectiveness study of the functioning programs in Pennsylvania, Illinois, and New York, with particular attention to the true dollar and social benefits of the various alternatives.
5. Research of other financial and reimbursement issues (e.g., prepayment plans) should be pursued.
6. Research should be undertaken to determine effective methods for education of professionals and for patient education.
7. Research is needed to establish qualifications necessary for personnel to participate in the management of ventilator-dependent children in various settings in a regional system.
8. Research should be an integral part of any of the strategies implemented as a result of this Workshop.

CATEGORY 10: FINANCING AND REIMBURSEMENT

Financial and reimbursement considerations are the overriding deterrents to the care of ventilator-dependent children in the least restrictive, most humane environments compatible with their medical needs.

DEFINITION OF THE ISSUE AND ITS EFFECTS

On a case-by-case basis, it has been demonstrated that considerable savings can be achieved by providing for the more satisfactory and humane care of ventilator-dependent children at home or in homelike alternatives in their communities. Unfortunately, our current private financial, insuring, and reimbursing systems did not evolve from a base designed for funding of care for children with chronic or long-term health problems. As the number of ventilator-dependent children increases, financing has to be restructured to deal with the new problems. The processes for paying expensive in-hospital acute care bills function fairly smoothly to certain limitations. On the other hand, the processes of funding community based care of ventilator-dependent children is uncoordinated, and in many situations, non-existent.

When a child is successfully transferred home, reimbursement becomes very complicated. A multitude of essential services is provided by a great variety of agencies, individuals, and vendors. The bills from all these sources are accumulated by the reimbursing party and must, in most cases, be analyzed and paid individually. Time is lost; statements are paid late; billing errors are common; both creditors and reimbursers become frustrated; and, as a result, the already difficult process of care at home becomes more cumbersome.

The reimbursement and financial systems for long-term community care of ventilator-dependent children need restructuring for flexibility and modernization.

SUGGESTED STRATEGIES

1. Work with major providers of third-party payment to improve reimbursement schedules.
2. Encourage maximum coordinated participation by government and private reimbursement agencies and in regional systems.
3. Develop methodology for advance reimbursement to families of children on care at home. Allocations of a specified amount of money should be made prospectively to be used over a finite period of time. Incentives should be built into this system to control costs.
4. As a corollary of the above, a new method of managing vouchers from individual service suppliers should be developed. Up-front money or bank accounts should be provided to allow for prompt payment of bills. Retrospective reimbursement should be eliminated or, at least, minimized.
5. Methods should be developed for "pool" purchase of equipment where that is found to be medically appropriate and more cost-effective.
6. Title V should play a major role in planning, promoting, and developing regionalized systems of care utilizing all available resources, rather than serving only as a third-party payer for small number of "eligible" children.
7. Financial counseling should be made available to the family.
8. Tax credits should be allowed for changes in the structure of the home which are necessitated by the child's disability.
9. The tax deductibility of medical expenses should be liberalized for families of patients on care at home.
10. Government requirements for "spend-down" should be minimized or eliminated.
11. Current policies and procedures for waiving Medicaid eligibility requirements should be kept in place.
12. Hospital cost containment processes should be encouraged and monitored to minimize the escalating cost to the system as a whole.
13. Coordination and management of services to children within a regional system of care should be recognized as essential; financing mechanisms should be developed.
14. Possibilities for arrangement of catastrophic illness funding, disaster pools, or revolving accounts should be investigated.
15. The financial support system for ventilator-dependent children should be closely monitored and modified as necessary to prevent abuse.
16. All changes made in the financial support system for ventilator-dependent children should have as their underlying objective the attainment of the most humane care in the least restrictive environment and at the lowest cost.

CHILDREN WITH OTHER HANDICAPS

CHILDREN WITH DISABILITIES: IMPLICATIONS FOR CARE

Alfred Healy, M.D.

In November 1981, President Reagan cited the case of Katie Beckett, a 3 year old child, as an example of government regulations gone awry. Medicaid rules permitted payment for Katie's care in a highly intensive tertiary hospital but could not pay for care if Katie was taken home. President Reagan granted a waiver to permit payment for Katie's care at home.

The highly visible case of Katie Beckett publicized a health care delivery system that was not geared toward providing the best of life-sustaining technology in what we, in the area of services to the handicapped, would call "the least restrictive environment." The goal of providing services in the least restrictive environment is basically a humanitarian one. However, what has been most publicized about the case of Katie Beckett and similar ones is that this least restrictive environment is also often, dramatically, the least expensive one in which to provide services. What can we learn about health care delivery for this population of ventilator-dependent children, and how do the issues relate to our provision of services for handicapped children as a whole? Are there common elements to assist us in understanding the needs of children with disabilities?

First, we need to review both the children's health care system in general, and services to children with handicaps, as they exist in this country today, and then examine some of the factors that have influenced their development. Second, I would like to discuss a community-based evaluation and planning system for those children who have a high likelihood of living with restrictions on their functional lives—and to suggest methods we might use to reduce that likelihood.

Children's health care in this country is changing. Every person, whether provider or consumer, who has the opportunity to observe the process of health care delivery, or to measure its outcomes, must be impressed with the way the system has changed and continues to change in a very positive manner. Signs of positive change can be seen in increases in life expectancy and tremendous reductions in morbidity. Mention only needs to be made of poliomyelitis, erythroblastosis, and modern therapeutic approaches to childhood malignancy to confirm the occurrence of these changes.

Similarly, the status of children with disabilities in this country is changing. Those working with the education, therapy, counseling, housing, employment, or social needs of the handicapped—and with parents, neighbors, and friends of the disabled—are aware of the tremendous changes that have occurred in this field in the past two decades. Indicators of these changes include the early identification of those with disabilities and the removal of numerous barriers that interfere with opportunities for children with disabilities to become productive citizens.

Let's now review a few of the reasons why the health care system in general is evolving in this way. A number of trends have contributed to positive changes, including:

1. A significant increase in the availability of individual and personalized health care. The number of health care personnel has expanded and the fiscal and physical accessibility of health facilities has improved.
2. An increased personal involvement of patients and parents in assuming responsibility for their own health care. This involvement resulted from improved patient education and involvement in the decision-making process regarding the type and location of the required health service.
3. A recognition that services must be delivered or made available as close to the patient's home community as possible.
4. A realization that technical and human resources need to be targeted at patients with specific problems and that it is possible to measure accurately more subtle outcomes than mortality or gross morbidity.
5. An increased ability to move quickly from the research laboratory to clinical investigation followed by clinical application.

What then are the specific factors that assisted the growth and improvement of programs for some of the disabled, and how did those forces evolve?

1. Care became individualized. There was a shift in thinking from "All Down Syndrome children are alike," to "All Down Syndrome children require a continuum of evaluation services to document their individual strengths and deficits."
2. The settings for providing required services were critically examined and, in many instances, found to restrict the development of social, intellectual, and functional life skills. As a consequence, considerable numbers of children and adults moved from institutional settings and were placed in community-based residential homes and care facilities.
3. Parents and guardians became involved in decisions regarding their children's participation in educational programs and the provision of related services.
4. Patients and their parents or guardians were provided specific legal safeguards to ensure their participation in or knowledge of programs through such legislation as *PL 94-142, The Education for All Handicapped Children Act*, and Section 504 of the *Rehabilitation Act of 1973*.
5. Statewide planning for coordination of services was mandated, and specific accountability was required of states to ensure the delivery of services. These changes were seen in *PL 94-142* and in *PL 95-602, The Developmental Disabilities Act*, and in some aspects of the Health Block Grants.

6. Many programs were devised that implemented the interdisciplinary process, one that recognizes the need for a variety of professional expertise in the evaluation and care of disabled persons and that no one discipline has exclusive "rights" to a patient, irrespective of the problem or the "importance" of the discipline.

How do these trends in the health care system and the service system for the disabled relate to the problem facing this conference? What can we learn that will assist all handicapped children—and conversely, what elements of the care system for the disabled child can be applied to the problem of the ventilator-dependent child?

A cohort of children with respiratory conditions was identified that required a specific technological advance—the creation of appropriate respiratory life support systems so these children could lead independent lives. But the creation of the technological hardware did not resolve the clinical problem. The remaining problem is to identify successfully the social, political, educational, attitudinal and financial steps which will allow the available hardware to be placed in the hands of those children who desperately require it, and do so in a coordinated manner that does not burden the patient or the parent with overwhelming financial responsibilities. We also must provide this ventilatory assistance in a way that will least interfere with the child's developmental process. When we have minimized financial burdens and developmental interference, our system can be said to be operational. Our service delivery goals for the approximately seven to eight million other children who are labeled as handicapped in this country are very similar.

An important step in the achievement of these goals is the differentiation between a person who is disabled—one who has a condition or infirmity that interferes with life function—as opposed to a person with handicaps because either society or the person himself places barriers in the path of a functional life, barriers to living in "a least restrictive environment." Such barriers may be physical (the inability to enter a building in a wheel-chair because of a flight of stairs), discriminatory (the exclusion from qualified employment), or attitudinal (the lack of understanding of some health care financial underwriters that out-patient care may be less expensive and more useful in maintaining academic and social interests than in-hospital care).

Katie Beckett requires a ventilator for a health impairment, but she also desperately requires an environment in which to learn how to play and to delight in gaining developmental skills along with her peers. She requires an environment that will provide exciting sensory stimuli so she has facts and data to develop concepts and ideas, and she needs the opportunity to practice muscular skills so she may communicate with her world through the motor system. She also requires a nurturing and supportive social system—read "family" if at all possible—to surround her and react to her behavior so she may learn from her actions and those of her playmates.

We must not interpret "least restrictive environment" to mean "normal." Universal mainstreaming is as inappropriate as blanket institutionalization for disabled children. A home can be as restrictive as an institution if the child is not given every opportunity to develop. The bottom line

questions should be, is the child being given every opportunity to learn or develop inherent abilities and have we, as a responsible society, removed all barriers and placed the child in the most opportune setting for developmental interactions to occur?

In this country there are hundreds of ventilator-dependent children in tertiary care centers. Many of these children no longer need to be there. There are also hundreds of thousands of children in this country with health impairments or other disabling conditions who are alive today because of advances in scientific knowledge and its clinical application. Children with cystic fibrosis, hemophilia, arthritis, malignancies, muscular dystrophy, and other conditions now survive longer and demand full active participation in life. We have obligations to remove the barriers to active functional lives for all of these children.

These children and young adults with health impairments face similar problems in receiving known methods of optimal care, in the least restrictive environment. One barrier facing them is the inability of many health care personnel to recognize the need for a system to plan individualized non-hospital care for each patient in a manner that permits all social, health, education, and family resources to be parlayed into a continuum of care. This barrier is a common thread running through all care systems, including in-hospital care, but I wish to emphasize today the out-of-hospital need. This community need has been recognized for decades, but the solutions for implementation continue to escape those charged with ensuring access for all children to optimal community services. This need to use available community resources through effective communication and planning is especially important today when such a large percentage of in-hospital costs are due to utilization by a rather concentrated segment of all children, namely children with chronic disabilities restricting their functional life.

To function properly as part of the comprehensive services for handicapped children, a health care plan must consider the handicapped child not as a sick child but as a well child with a disability. There is still a tendency, even among some health professionals, to view the handicapped child as unwell and to see health care being performed in a segregated environment. A mentally retarded child, or a blind child, for example, may not have any unusual health-related problems. In other cases, the handicap itself may be health related, or may have chronic health-related aspects to it—such as in the case of the child with asthma or the child with spina bifida. In any case, the children are best and most economically cared for in the mainstream of the health care system, where they have access to the full range of primary, secondary, and tertiary services, not in a system set aside for the exclusive use of the handicapped.

It is especially important to understand that the comprehensive services required by children with handicaps will vary with the functional system or systems affected and the severity of the impairment. At birth, two percent of all liveborn infants have discernible handicapping conditions. By age five, approximately ten percent are considered handicapped. There must be a recognition that we require differing screening and identification systems with differing capabilities during that five-year period. We need to structure

a system that flows from a medical/nursing orientation for infants and toddlers under 30 months when almost all discernable or evolving handicaps are health-related, to a cognitive orientation with an educational perspective for the older child. This is a time when almost all new disabilities are related to the central processing system. Development-appropriate screening activities can then be provided that are cost effective and reduce duplication of effort. However, to be efficient, a process of communication must be established between the child's physician and the school during all such identification projects.

It must be remembered that during the elementary-school years, the majority of disabilities are related to the central processing system. Of the eight million handicapped individuals aged between birth and 21 years, only 20 percent have handicaps related to sensory deficits, motor disabilities, health impairments, or emotional disorders. The remaining 80 percent of all school-aged children with handicaps have mental retardation, learning disabilities, or language dysfunctions. Of this 80 percent, the majority have single system disabilities, those without complicating secondary disabilities that require a major coordination of services.

There are few, if any, studies to assist in understanding the percentage of children with disabilities who require primary, secondary, or tertiary level care of their health or medical needs. Discussions with experienced clinicians suggest that approximately 85 percent of all children with disabilities can be adequately cared for by primary care physicians communicating with the one "system" used by all children, the school. An additional 15 percent require referral to secondary physicians. Many have secondary complicating conditions that require coordinating functions between the primary referring physician and other community-based services or assistance agencies. Of the 15 percent requiring secondary level services, about one-third will also require, either occasionally or continuously, the medical or health care services of a tertiary center.

Approximately 85 percent of the health and medical needs for children with handicaps can be provided through the primary care system, aided by a modest level of communication between the physician and the school, as the physician provides ongoing health care supervision. Examples would include children with non-organic mental retardation, uncomplicated seizure disorders, or language dysfunctions. The primary care physician has a responsibility to ensure that all medically remediable aspects of the handicapping condition have been evaluated and treatment initiated if possible.

Secondary level health care and coordination of many health and non-health-oriented services is required by three groups:

1. Those children referred from primary care physicians for diagnostic services, or evaluation of complications from their original disability.
2. Those labeled health impaired—such as children with cystic fibrosis, hemophilia, juvenile rheumatoid arthritis, asthma, diabetes, cerebral palsy, or muscular dystrophy, of such a degree of severity they require a level of care greater than that available in the primary care system.

3. That group of children with complicated and interconnected health, social, and educational needs labeled as having "chronic conditions requiring long term care; of psychosocial and learning problems; behavioral and environmental effects; and problems related to family stress and parental actions and inactions. These problems require a multidisciplinary approach above and beyond traditional nursing and physician care." The basic need for this group is coordinated care as opposed to the direct provision of medical care.

Tertiary level care is required for that five percent with disabilities such as severe asthma, cystic fibrosis, cerebral palsy, muscular dystrophy, spina bifida, or similar conditions that require the expertise of those usually found in a medical center or university program. Irrespective that such care requires highly specialized personnel and sophisticated surgical and rehabilitative technology and treatment methods, the majority of the follow-up care to such tertiary care procedures is accomplished back in the local community using community resources. Studies have been accomplished that demonstrate cost efficiency when such community care is coordinated with that done in the tertiary center.

From these discussions, we can draw three important conclusions relating directly to the original question, "Will the disabled children of this country also continue to be handicapped?"

First, there is a constant need to recognize the concept of individual differences in all children—especially those with disabilities—so that they may receive appropriate services. Not all children with cerebral palsy should be programmed with the mentally retarded; not all ventilator-dependent children require the same system as Katie Beckett—if our system is to minimize financial burdens and minimally interfere with a disabled child's development.

Second, there is a need to structure a community-based system to coordinate the evaluation and planning of services for the fifteen percent of disabled children who have complicated or multifaceted disorders and to recognize that this entails more than medical or nursing care. There must be a smooth flow of information between all social, medical, educational, and family concerns; responsibility and accountability for providing and following up on services must be assigned and accepted.

Third, there must be a realization by all the remaining service providers, health planners, legislators, and health financiers, that such community-based evaluation and planning is necessary if barriers to maximum achievement for all disabled persons are to be removed.

There is no one uniform formula to guide individual communities toward such a system. Each state must review its individual health, education, and social service state plans that meet the state's individual geographic, political, and demographic needs; each state must work cooperatively to create a community-based system for those disabled children who require a coordinated evaluation and planning function.

This workshop is an important step toward developing such a system. Using the ventilator-dependent child as a focus for concentrated discussion

and planning will undoubtedly alert many persons to the need for the system. However, the larger effort must be in furthering communication between state Maternal and Child Health programs (including Crippled Children's Services), with state education agencies, local education agencies, and those professional organizations whose members have critical roles to play in formulating new methods of sharing evaluation and planning functions. This effort is currently underway in twelve states due to very innovative collaborative efforts funded by the Office of Maternal and Child Health and the Office of Special Education, and involving the American Academy of Pediatrics and the national network of University Affiliated Programs.

Other states have combined planning functions between State M and CH and State CC programs as they move to plan cooperatively and implement the provisions of block grants. Not surprisingly, state educational agencies are finding these extremely useful forums in which to participate and further mutual goals.

A last but extremely critical need is for each person attending this Workshop to realize the tremendous task remaining before us. Our task is to educate our fellow workers and to influence schools preparing psychologists, insurance executives, physicians, nurses, dentists, therapists, teachers, social workers, lawyers, business executives, and administrators about the needs discussed in this Workshop. Our personal actions can be multiplied a thousandfold if we accept the challenge of working with our University and Community College peers to include these concepts in their students' professional preparation and in the in-service education programs available to practicing professionals. In addition, we must share a similar education program with parents of disabled children and with the general public.

The best of available science was not able to prevent Katie from becoming disabled—even in the sophisticated, caring system currently in place. Conferences like this one should go a very long way to remove barriers that could bar her from enjoying a full productive life, barriers that could also make her become handicapped. Thank you for allowing me to share these thoughts with you today.

IMPLICATIONS FOR CARE: THE TITLE V PERSPECTIVE

John C. MacQueen, M.D.

Title V programs have the legislative responsibility for providing health services to mothers and children. The Title V programs include the State Maternal and Child Health and the State Crippled Children's programs as well as the SPRANS (Special Projects of Regional and National Significance) programs. These programs include the pulmonary center, the genetic, the hemophilia, and other programs of regional and national significance. State programs have been designed to meet the particular needs of each individual State, and thus differ from each other. In addition, each of the SPRANS programs has its own agenda.

Those of us from State programs are not surprised that a new type of medical problem—that of the ventilator-dependent child—has been identified and that a proposal is made to provide services for the children so involved. The Federal-State public health programs for mothers and children have been developed over the years to provide new services for what were then new problems. The early regional programs to provide care for congenital heart disease, rheumatic fever prevention, cleft-palate, PKU identification, development of pediatric intensive care, hemophilia, and genetics programs were created when new problems were identified for which a form of treatment was available. Each of these programs was originally introduced at some type of meeting or conference similar to the one that we attend today.

Those of us from agencies involved with providing services for handicapped children also recognize that the services needed by the ventilator-dependent child are in many ways similar to those needed by hundreds of thousands of other disabled children in the nation. Thus, carefully developed programs meeting the needs of the ventilator-dependent child have been designed: so that the services are family oriented, multi-disciplinary, and coordinated. Each child has an individual plan of care, and some person is responsible to work with the family to assist in carrying out that plan of care so that the costs of the services do not destroy the family's finances. The goal of treatment is one of establishing as much personal independence as possible. These, of course, are the accepted principles of long-term care that have been tested and established during recent decades by those involved with providing services for children with continuing health problems.

Thus, the proposed programs providing services for the ventilator-dependent child differ from the current ones only in the technical nature and complexity of the services needed to address problems unique to these children. This should not surprise us. We are all aware of advances made in the last decades in the diagnosis of acute medical problems and in the difficult and technical forms of treatment. Many of these services may be so technical, however, that the current State Crippled Children's programs, designed to provide traditional services, may have difficulty in providing for these new technologies. This represents a major challenge to those of us

responsible for the design and administration of State programs. Title V programs must respond as they have responded to the development of new programs in the past, even though this may require major changes in the design of some State programs.

Many of us who are responsible for State Crippled Children's Programs have been concerned for some time that services for handicapped children have not evolved into a three-tiered system comparable to the three-tiered American medical care system. The exact role of the Title V programs and, more exactly, the Crippled Children's programs in such a three-tiered system is not clear.

It is apparent that State Crippled Children's Programs must work jointly with those who function in the tertiary care centers, since these centers provide much of the complex technical modern care and conduct research. Similarly, crippled children's programs must work closely with practicing physicians who provide secondary care. Historically, these programs have worked closely with the medical community and have made it possible for the State Crippled Children's programs to be the major subsystem for providing services for the disabled child. Crippled Children's programs must work even more closely with organizations and professionals who provide primary support services in the community.

Reference has been made to special demonstration projects jointly conducted by the Division of Maternal and Child Health and the Department of Education. These projects are exploring how children's services can best be coordinated in the community. The Crippled Children's programs can and should serve as the lead agency in the community to coordinate the network of services required by many children who have chronic health problems and can be involved with payment for those services for which they are responsible.

It would be very unfortunate if free-standing State categorical programs were created to provide services for the ventilator-dependent child. The creation of single disease programs has not proved to be a satisfactory long-term solution. State Title V programs, therefore, should have a significant part in the coordination of services required by ventilator-dependent children.

There is no doubt that our national goal should be access to needed services for all ventilator-dependent children, but the problem of implementing that goal will be very difficult. We must be realistic about the times in which we live. In current national policy, the States determine what public health programs should be provided based on the individual State's assessment of need and available resources. However, the great majority of States do not have in place a process or system to review the needs for health services. Most States are in great financial difficulties and are going to be very reluctant to assume the responsibility for new health programs.

Thus, implementation of the recommendations of this conference will require imagination in program organization and may require more political activity than those of us who are health providers wish to conduct. The Pennsylvania experience proves the possibility of obtaining state funds.

From the perspective of the Title V program, the basic question is how, at this time of public austerity, can we modify and coordinate health programs so we can provide contemporary medical care to the most children? Those of us responsible for Title V programs accept the challenge and will keep high on our agenda the special problems of the ventilator-dependent child.

IMPLICATIONS OF WORKSHOP RECOMMENDATIONS

This Workshop focusing on the ventilator-dependent child has given us a concrete and meaningful way to look at the needs of all children with disabilities and at the needs of their families. The ultimate value of the conference will be determined by its effect on those involved in the care of children with handicaps. The recommendations presented to the Surgeon General have implications for the care of all children with disabilities.

1. *Define the Scope of the Problem*

There remains a need to define better the numbers and types of disabilities experienced by infants, children, and young adults in this country and to better assess the impact on social, health, education, and family related needs. Considerable progress has been made in some areas but a system integrating functional, social, health, and family concerns remains to be defined, accepted, and consistently used by all service personnel and agencies. Needs are magnified when they occur during rapidly changing developmental periods in a child's life or when the child is desperately attempting to minimize the effects of the disability.

2. *Develop Model Standards*

Significant advances in health care for all children have been accomplished through the use of model guidelines and standards for health care. Examples include regionalized perinatal care and improved access to immunizations. These models and standards developed by a consensus of professional associations, were widely distributed and are now generally accepted. Similar models and standards must be developed to identify, evaluate, and provide coordinated care at all levels for persons with disabilities. Care standards for cohorts of disabled children with special needs must be superimposed on generic care standards for all children with disabilities. All standards must focus on family needs, with an eye for innovation and with compassion and concern for the quality of life for each disabled child. Careful consideration must be given to identifying methods of care that conserve and effectively use scarce fiscal and human resources.

3. *Develop Systems of Regionalized Care*

Matching the needs of disabled children with available resources will demand a system of care that reflects concern for generic social, educational, health, and family issues and that can focus on times of transition in disabled children's lives. Targets for concentration of resources will be determined by such factors as incidence, prevalence, and severity of the disability; location of the needed service, and other geographic and demographic characteristics of the population. Traditional methods may suffice for providing community based health care for infants, children, and young adults with relatively uncomplicated disabling conditions. However, regionalized