SPECIAL STUDY FOR THE MINNESOTA LEGISLATURE

Reimbursement by Third Party Payors of Home Health Benefits For "Technology-Dependent Individuals"

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This report was written by Jeanne McGee, Ph.D., of Research Insights, Inc., Excelsior, Minnesota, under contract to the Minnesota Department of Health. In preparing this report, Dr. McGee reviewed position papers submitted to the Department of Health by several organizations, conducted a literature review, attended a series of meetings convened by the Department of Health, and did additional research that included a number of telephone and personal interviews, both local and national.

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The 1987 Minnesota Legislature has directed the Minnesota Department of Health to prepare this report which addresses the issues concerning reimbursement by third-party payors of home health care benefits for technology-dependent individuals.

EXECUTIVE SUMMARY

In recent years, dramatic advances in life-sustaining medical technologies have saved and prolonged many lives, but they have also brought a host of medical, ethical, and financial dilemmas. As our medical technology improves, some of the people whose lives are saved by such supports as mechanical ventilators and intravenous feeding remain dependent on these devices for months, years, or a lifetime.

Financing the care for this special population is a tremendous problem. Though the total number of these "technology dependent individuals" is small (perhaps several hundred in Minnesota, depending on how the group is defined), the costs of their care are extraordinarily high, mainly because they require complex nursing care for a prolonged period of time. It typically costs several hundred thousand dollars or more per case to care for the technology-dependent; these costs are well beyond the reach of nearly all families. Some families are either uninsured or underinsured. In any case, private insurance coverage for these catastrophic cases tends to be inadequate, and public sources such as Medicaid often pay for a substantial portion of the care.

Many technology-dependent individuals can now be cared for safely at home at lower cost. Substituting family caretaking for paid professional nursing care is the major source of savings in home care, though the monetary and non-monetary costs to the family may be very high. Effective home care requires a willing and able family, thorough training of the volunteer caretakers, and a cadre of services and supports to help the family render high quality care. Discharge planners and case managers play a vital role in orchestrating and monitoring the provision of these needed services and supports.

Though home care has been shown to be a viable and less expensive option for many technology-dependent individuals, many third-party payors that cover hospital care will not pay for home care. As a result, many patients are medically able and eager to go home, but cannot afford to do this.

The basic problem is one of unequal and inequitable access to home health care by technology-dependent individuals. There is a related problem of equity which must also be addressed: the need to equitably distribute the extraordinary costs of this care among the various private and public payors.

Concerns related to these two problems are raised in the position papers prepared by Pathfinder/Children's Home Health Care Task Force (CHHCTF), the Minnesota Council of HMOs, and the Insurance Federation of Minnesota.

The paper by the CHHCTF stresses the need to gain broader recognition of the level and range of services that are needed to provide safe care in the home setting, the monetary and non-monetary costs to the family of providing home care, and the vulnerability of child and family when the service level is inadequate. Based on its experiences as an advocacy organization, the CHHCTF is particularly concerned about financing problems and cost shifting issues, bureaucratic obstacles and delays, and the difficulty of finding case managers and HMO contact persons with the requisite knowledge and authority to meet the needs of technology-dependent children. The CHHCTF believes that pressures for cost containment and the prospective payment system create incentives to undertreat, and it urges that actions be taken to ensure "the best care for [technology-dependent] children and their families while still considering the economic realities of reimbursement of home-based services."

The position paper by the Minnesota Council of HMOs focuses on what should be the appropriate role for HMOs in providing home health care for the technology dependent. Emphasizing the fragility of the current health care market in Minnesota, this paper stresses the need for a more equitable distribution of financial responsibility for the high cost care of the technology dependent among all third party payors (public and private, including self-insured employers). HMOs are particularly vulnerable because unlike indemnities, HMOs cannot presently set a lifetime dollar maximum for these catastrophic cases. This position paper stresses that unless HMOs gain the ability to set some appropriate limits on home health care expenses for these exceedingly costly cases, the open-ended liability they face for these cases of unknown duration could threaten the viability of the HMO. Noting that bills have been introduced in the Congress which could provide some federal funding for the technology dependent, and perhaps have other kinds of impact as well, the Council's paper urges close tracking of these legislative proposals.

The paper by the Insurance Federation of Minnesota urges that the Minnesota Legislature be apprised of the findings and recommendations of the report of Federal Task Force on Technology-Dependent Children scheduled for release in April 1988. This report will contain data on costs and an appendix on financing. It recommends case management and case-by-case flexibility as ways of developing minimum standards for home care services, and recommends that costs of care not covered by third party payors be equally shared by the health care user population in some manner.

Representatives from the CHHCTF, the Council of HMOs, and the Insurance Federation have identified three broad areas of common ground on which to build toward better access and more equitable financing of home health care for the technology dependent. These three areas are shown below; they represent a starting point toward an integrated solution to many of the concerns expressed in the position papers.

1. STANDARDIZED DEFINITIONS: The need to develop a set of agreed-upon standardized definitions of the target population ("technology-dependent individuals") and of the key terms used in contracts that define home care benefits for this population.

2. EXPERT REVIEW PANEL: The need to establish a multidisciplinary expert advisory review panel to improve communication and coordination of home care for the technology dependent. This panel is envisioned as a fully representative, medically-oriented, independent source of expert counsel and assistance with dispute resolution.

3. SPECIAL CARE FUND: The need for a special statewide technology care fund to provide a "safety net" for the technology dependent and a form of "stop loss" for individual health plans facing the extraordinarily high costs of caring for this population. Totally separate from the Minnesota Comprehensive Health Association (MCHA), the fund would be jointly public and private (funded by both public and private sources in some manner); it would be established apart from HMOs and commercial insurers and essentially pick up where private coverage leaves off to ensure continuity of care and a more equitable and dependable source of financing.

RECOMMENDATIONS

Recommendation 1:

That no action be taken at this time to mandate comprehensive benefits for home health care for technology-dependent individuals, because necessary data are lacking and because such action would in any case have very undesirable effects on health care premiums and on the fragile health care market.

Mandating of benefits requires good data on incidence and costs of care, both of which are lacking. It is presently impossible to predict with a reasonable degree of accuracy either the current or future size of the population of technology-dependent individuals. It is likewise very difficult to project costs of care for this group because costs are so highly variable and the group as a whole is quite small.

Mandating of comprehensive home health care benefits would likely trigger substantial increases in insurance premiums and could threaten the fragile health care market.

The three remaining recommendations are directly related to the three-point agenda (standardized definitions, "safety net" care fund, and expert review panel) developed jointly by the third party payors, the advocacy organizations, and others who have attended the series of meetings convened by the MDH.

Only recommendation #2 requires action from the Minnesota Legislature; this recommendation would direct a state agency to develop a plan for a Demonstration Project. Recommendation #3 deals with standardized definitions; it requires action from the MDH and the DOC. Recommendation #4 supports the ongoing development of a multidisciplinary expert advisory and review panel by an ad hoc committee of volunteers composed of third party payors, advocacy organizations, providers, and state agencies; it requires continued cooperation from the relevant state agencies but no formal action at this time from any part of state government.

Recommendation 2:

That the Minnesota Legislature designate an appropriate state agency to prepare for the Legislature a proposal for a Demonstration Project to determine the feasibility and costs to fill gaps in coverage for home health care for technology-dependent persons.

The plan for the Demonstration Project shall address at a minimum the following questions:

1) Definition of the eligible population;
2) Estimated number of persons eligible for the demonstration project;
3) Services to be rendered;
4) Costs of care;
5) Case management;
6) Feasibility and cost-effectiveness of transitional care facilities and other alternatives to hospital care such as group homes;
7) Implications for the Demonstration Project of findings in the report to be issued by the Federal Task Force on Technology-Dependent Children in April 1988;
8) Implications for the Demonstration Project of developments in proposed federal legislation that affects health care for chronically ill technology-dependent individuals;
9) Financing mechanisms;
10) Consideration of benefits and costs with respect to private and public payors.

The Commissioner of the designated state agency shall establish a task force to work on plans for the Demonstration Project. This task force shall include representatives of third party payors, employers, providers, consumers, advocacy organizations (for adults, children, and seniors), and the Department of Human Services, Department of Education, Department of Commerce, and Department of Health.

The Demonstration Project proposal shall be submitted to the Minnesota Legislature on or before January 15, 1989.

Recommendation 3:

That the Minnesota Department of Health repeal existing language in rules that allows HMOs to exclude benefits for home health care, and that concurrently, the Department of Health and the Department of Commerce adopt definitions of the key terms used in describing home health care.

The terms to be defined in a standardized way shall include, but not be limited to, "technology-dependent individuals," "skilled nursing care," "transitional care," "subacute care," and "custodial care."

In developing these uniform definitions, the Minnesota Department of Health and the Department of Commerce shall consult with representatives from third party payors, providers, advocacy organizations, and state agencies.

Recommendation 4:

That state agencies (Department of Human Services, Minnesota Department of Health, Department of Commerce, Department of Education) continue to support the efforts of the informal ad hoc committee that is presently working toward the establishment of a multidisciplinary expert advisory and review panel on home health care for technology-dependent individuals.

This committee of volunteers is composed of representatives from third party payors, advocacy organizations, providers, and state agencies; it was formed during the series of Minnesota Department of Health meetings on home health care for technology-dependent individuals.

The advisory and review panel is conceived as supplying both expert consultation and assistance with dispute resolution. Since any recommendations it may make will be non-binding, there is no need for legislative or formal state agency action to establish it.

In order to establish the expert advisory and review panel, the following issues at a minimum must be addressed:

1) What is the mission and what are the priorities of the panel (case-specific advice and assistance with dispute resolution, outreach and education);
2) What is the anticipated workload for the panel and the anticipated meeting schedule (ad hoc or on a regular basis);
3) What are the rules of procedure for receiving cases, deliberating, gathering additional information, conveying advice and recommendations, following up or re-assessing;
4) What groups should be represented, what types of people should serve on the panel, and how should the specific members be selected;
5) How to provide for continuity of membership, yet have the people most familiar with individual cases available (perhaps by having a "core group" of regular members that is supplemented by additional persons with interest or expertise related to a specific case)
6) Who convenes the meetings and handles the administrative responsibilities;
7) How should the services of the advisory and review panel be marketed;
8) Who pays for operating costs (marketing/publicity and production/distribution of brochures and educational materials, administrative, compensation for participants, etc.);
9) For how long should members serve and should they be compensated;
10) How should special outside "experts" be compensated.

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SPECIAL STUDY FOR THE MINNESOTA LEGISLATURE:

Reimbursement by Third Party Payors of Home Health Benefits For "Technology-Dependent Individuals"

Origin and Overview of this Report

In 1987, Pathfinder, an organization devoted to improving systems of care for children with chronic health conditions, requested that the Minnesota Legislature mandate coverage of home health care services for children with long-term dependence on life-sustaining technologies such as mechanical respirators. Responding to this request, the Legislature ordered a special study of the issues concerning reimbursement by third party payors of home health care benefits for "technology-dependent individuals."

Following a brief introduction, this report summarizes the issues raised in position papers prepared by Pathfinder/Children's Home Health Care Task Force, the Council of HMOs and the Insurance Federation of Minnesota, highlighting areas of agreement and disagreement. A three point agenda of broad areas of consensus is identified. The remainder of the report addresses the medical, financial, policy and other issues involved in third party payment of home care for the technology-dependent, and provides recommendations to the Legislature.

Besides the formal position papers, this report draws heavily on the discussion by a broad range of stake holders in recent meetings held by the Department of Health. Participants at these meetings included representatives from advocacy groups, health plans, insurers, home health care providers, physicians, nurses, state departments (health, human services, education, commerce), health policy analysts, lobbyists, and family members of technology-dependent persons. These discussions were supplemented by interviewing a number of other people and reviewing the relevant literature.

I. INTRODUCTION

Background

In recent years, dramatic advances in life-sustaining medical technologies have saved and prolonged many lives, but they have also brought a host of medical, ethical, and financial dilemmas. Technology-dependent individuals are a case in point. As our medical technology improves, some of the people whose lives are saved by such technology remain dependent on it for months, years, or a lifetime.

For example, aggressive treatment of very low birth weight premature infants occasionally results in a long-term and exceedingly costly dependence on medical supports such as respirators and intravenous feeding [17]. These infants and others who have prolonged dependence on life-sustaining technologies are "low incidence, extremely high cost," or "catastrophic" cases. Dealing with the needs of these technology dependent individuals forces us to confront our societal obligation to assure equitable access to health care within a context of scarce medical and financial resources.

At the global level, health care competes for scarce resources with other vital national and local needs including education, social services, transportation, law enforcement, and defense. At the next level, there is competition for finite health care resources among various diseases and treatment programs, including other very expensive applications of high technology such as organ transplants. At the micro-level, scarce resources (medical and financial) must ultimately be allocated among individual patients. Potential willingness aside, our society is simply unable to provide unlimited health care for all persons. Instead, a more pragmatic goal might be to assure equitable access by all citizens to a reasonable level of health care [9].

At present, however, our allocation of health care resources reflects a fragmented political process more than an overall distribution scheme oriented toward equitable access by all. It is in this context that catastrophic cases involving long-term depndence on technology present such a challenge in terms of public policy and financing.

Strongly biased toward providing "cure-oriented" acute care in hospital settings, our health care delivery and financing systems are both ill-prepared to deal with the long-term needs of chronically ill technology-dependent individuals. It typically costs several hundred thousand dollars or more per case to care for the technology-dependent; these costs are well beyond the reach of nearly all families. Some families are either uninsured or underinsured. In any case, private insurance coverage for these catastrophic cases tends to be inadequate, and public sources such as Medicaid typically pay for a substantial portion of the care [10].

Because our public policies and our health delivery and financing systems have not kept pace with the needs of the long-term technology-dependent, it is sometimes hard or impossible to act in the best interest of these patients in a cost-effective manner [19]. Public and private reimbursement policies are a key factor. Because these policies are oriented toward covering acute care episodes in hospital settings, they sometimes preclude the most cost-effective and/or desirable types of care for these long-term catastrophic cases. Many technology-dependent individuals now can be cared for safely at home at lower cost, yet many payors that cover hospital care will not pay for home care. As a result, some patients are medically able and eager to return home, but cannot afford it. In other cases, short-term cost savings to the third-party payor overrides all other considerations.

In one of the meetings held by the Department of Health to discuss these issues, the group as a whole generated the following statement of the basic problem that triggered the request to the Minnesota Legislature for mandated home health care benefits:

"Unequal and inequitable access to home health care by technology-dependent individuals"

There is a related problem of equity that must also be addressed:

"The need to equitably distribute the extraordinary costs of this care among the various private and public payors"

Those who call for better access to home care acknowledge that recent pressures for health care cost-containment have intensified the problem of how to meet the extremely expensive health care needs of technology dependent individuals in an equitable way. In the past, patients, their families, and their physicians tended to be insulated from cost considerations in their decision-making about life-sustaining technologies. For the elderly in particular, the costs have typically been public costs (Medicare, VA, Medicaid, and other public programs). Recent pressures for cost-containment, particularly prospective payment systems, have forced consideration of the public costs of private treatment decisions [1, 2, 9, 23, 27].

Health care providers and insurers are presently under extreme financial pressure; Minnesota hospitals, HMOs, and major insurers are experiencing some serious losses in many parts of their businesses. Though it is important to meet the needs of the technology dependent, it must be done in a way that will not threaten the viability of those who provide and pay for the care. HMOs are particularly vulnerable to financial instability from these catastrophic cases because, unlike the indemnity companies, their liability is in many ways unavoidably open-ended.

There is no simple solution to the related questions of 1) how to assure equitable access to home care for the technology dependent, and 2) how to equitably distribute costs of this care. Generating an appropriate policy response requires thorough consideration of the following questions:

"Who should pay, for whom, under what circumstances, for what level of care, in what setting, as decided by whom, with what kinds of terms and limits?"

The remainder of this report explores these questions and the related issues, then presents recommendations to the Minnesota Legislature.

II. POSITION PAPERS

Prepared by
Children's Home Health Care Task Force (CHHCTF),
the Minnesota Council of HMOs, and the
Insurance Federation of Minnesota

The three organizations listed above have prepared position papers on issues related to home care for the technology-dependent; these papers are included as Appendix A. This section of the report describes each group's perspective and summarizes the major concerns and recommendations expressed in each paper.

Position Papers Address a Subset of the Issues

The two longer position papers prepared by CHHCTF and the HMO Council concentrate on the issues of primary interest to them, which are those related to HMOs' benefits for technology-dependent children. These issues represent a subset of the broader set of issues related to third party payors' benefits for home health care for technology-dependent individuals (adults as well as children) which is addressed in this report.

Children's Home Health Care Task Force's Perspective

The Children's Home Health Care Task Force is a coalition of agencies and individuals interested in home care issues for technology-dependent children. The Task Force began in 1984 and it includes representatives from hospitals, home care agencies, state and county health and human services programs, interested consumers, and advocacy organizations (including Pathfinder, a cooperative effort of the Comprehensive Epilepsy Program of Minnesota, Gillette Children's Hospital, and the International Diabetes Center of the Park Nicollet Medical Foundation).

As an advocacy group devoted to improving health care for children with chronic conditions, the CHHCTF puts the bests interests of the technology-dependent child as paramount, and looks at all issues related to HMOS and home care from this vantage point. Major concerns expressed in the CHHCTF's nine page position paper include the need to gain broader recognition of the level and range of services that are needed to provide safe care in the home setting, the monetary and non-monetary costs to the family of providing home care, and the vulnerability of child and family when the service level is inadequate.

Based on its familiarity with actual cases in Minnesota, the CHHCTF is particularly concerned about financing problems and cost shifting issues, bureaucratic obstacles and delays, and the difficulty of finding case managers and HMO contact persons with the requisite knowledge and authority to meet the needs of technology-dependent children. The Task Force believes that pressures for cost containment and the prospective payment system create incentives for HMOs to undertreat technology-dependent children; it urges that actions be taken to ensure "the best care for [technology-dependent] children and their families while still considering the economic realities of reimbursement of home-based services."

Perspective of the Minnesota Council of HMOs

Representing Minnesota HMOs, the Council's 16 page position paper addresses the issues in terms of what should be the appropriate role for HMOs in providing home health care for the technology dependent. Emphasizing the fragility of the current health care market in Minnesota, this paper stresses the need for a more equitable distribution of financial responsibility for the high cost care of the technology dependent among all third party payors (public and private, including self-insured employers).

HMOs are particularly vulnerable because unlike indemnities, HMOs cannot presently set a lifetime dollar maximum for these catastrophic cases. This position paper stresses that unless HMOs gain the ability to set some appropriate limits on home health care expenses for these exceedingly costly cases, the open-ended liability they face for these cases of unknown duration could threaten the viability of the HMO.

Noting that bills have been introduced in the Congress which could provide some federal funding for the technology dependent, and perhaps have other kinds of impact as well, the Council's paper urges close tracking of these legislative proposals.

Perspective of the Insurance Federation of Minnesota

The Insurance Federation of Minnesota represents 119 insurance companies, service bureaus, and individual members. In its four page position paper, the Federation strongly urges that the Minnesota Legislature be apprised of the findings and recommendations of the report of Federal Task Force on Technology-Dependent Children scheduled for release in April 1988. This report will contain data on costs and an appendix on financing.

In the meantime, the Federation offers several definitions of key terms, recommends case management and case-by-case flexibility as ways of developing minimum standards for home care services, and recommends that costs of care not covered by third party payors be equally shared by the health care user population in some manner.

Areas of Consensus: A Three-Point Agenda

The three position papers described above have been presented and discussed at meetings convened by the Department of Health and attended by several dozen people representing a wide range of organizations and viewpoints.

At the most recent meeting in early February, representatives from the CHHCTF, the Council of HMOs, and the Insurance Federation identified three broad areas of common ground on which to build toward better access and more equitable financing of home health care for the technology dependent.

The areas of basic agreement are as follows:

1. ***STANDARDIZED DEFINITIONS:***

The need to develop a set of agreed-upon standardized definitions of the target population ("technology-dependent individuals") and of the key terms used in contracts that define home care benefits for this population.

- Uniform definitions are needed for more consistent regulation and to keep up with changes in technology and appropriate settings of care. They also appear to be the key to putting appropriate limits on third party payors' obligations to provide care (particularly home care) for the technology dependent.
- To make the definitions mutually acceptable, all stakeholders would need to be actively involved in developing them.

2. ***EXPERT REVIEW PANEL:***

The need to establish a multidisciplinary expert advisory review panel to improve communication and coordination of home care for the technology dependent.

- This panel is envisioned as a fully representative, medically-oriented, independent source of expert counsel that would increase understanding of issues involved in home health care for the technology dependent and assist in the decision making about individual care plans.
- The panel could be called upon for fact finding, counsel, and assistance with dispute resolution by any interested party (third party payors, providers, advocacy groups, patients and their families, state agencies).
- Presumably such a panel could help address concerns raised by the CHHCTF position paper about cost shifting, conflict of interest, and inadequate levels of care.
- The panel would encourage and supplement (not usurp) case management by health providers and payors.

3. ***SPECIAL CARE FUND:***

The need for a special statewide technology care fund to provide a "safety net" for the technology dependent and a form of "stop loss" for individual health plans facing the extraordinarily high costs of caring for this population.

- The fund would be jointly public and private (funded by both public and private sources in some manner); it would be established apart from HMOs and commercial insurers and essentially pick up where private coverage leaves off to ensure continuity of care and a more equitable and dependable source of financing.
- This fund would be totally separate from the Minnesota Comprehensive Health Association (MCHA) since it would be designed to provide particular benefits for narrowly defined population (not a qualified plan for the uninsurable).

- O Participants agree on the basic goal behind this separate care fund, but recognize that many complex issues of definition and implementation would need to be addressed.

These three areas of common ground represent a starting point toward an integrated solution to many of the concerns expressed in the position papers. The agenda items outlined above are a "package" in the sense that they are interdependent; each one provides a necessary element of a total improvement program. For example: it is necessary to put some reasonable limits on benefits for home care for the technology dependent (Point # 1 on definitions addresses this), at the same time ensuring that the decision making related to these definitions is well-informed and fair (Point # 2 on the review panel addresses this), and at the same time ensuring that there is a "safety net" that provides continuity of needed care (Point # 3 on the care fund addresses this).

Timelines differ for the three elements. The expert review panel is conceived as a voluntary/advisory group and thus requires no legislative action. Work on establishing this panel can begin immediately (and is in fact already underway). The development of uniform definitions and the establishment of a care fund are more complex and require the involvement of state regulators (Department of Health for HMOs and Department of Commerce for commercial insurers); these are longer-range objectives.

Though the payors, providers, and advocacy groups have identified this three point agenda, there are many related points and other issues to be examined. This section of the report pulls together information and viewpoints from all sources (the three position papers, discussion at meetings, a literature search, and supplementary interviews) to discuss the full set of key issues involved in third party payment for home care for the technology dependent. Since most of these issues are linked in one way or another to the three point agenda, a closer examination will help clarify some of the challenges posed by the agenda.

For each issue, relevant quotations from the position papers are shown, areas of clear agreement and disagreement are identified, findings from background research is summarized, and recommendations are made.

ISSUE 1

APPROPRIATENESS OF HOME CARE FOR TECHNOLOGY-DEPENDENT INDIVIDUALS

Home Care Can Be A Safe and Cost-Effective Alternative

There is general agreement among payors, providers, and advocacy groups (and in the literature) that home care has been demonstrated to be an appropriate option for many technology-dependent individuals [29, 6].

- Parties agree that effective home care requires careful training of the caregivers, a broad range of supportive services, and careful monitoring of the quality of home health care [31, 30, 26, 7, 13, 6].
- They disagree over the specifics of which services, who should provide them and for how long, what the family's role should be, who should make the decisions, etc. These areas of disagreement are discussed below.
- Parties agree that it is difficult to project costs and make accurate cost comparisons by setting (home v. hospital). Costs of care are seen as extremely high regardless of setting, but parties agree that home care frequently offers a cost-effective alternative.

Home Care: Benefits and Requirements

There is little objective evidence about the relative effectiveness of home care and hospital care, but people tend to assume that home care is preferable, given a choice [18, 2, 1]. Though hospitals and other medical institutions excel at providing complex acute medical care, patients who face a prolonged dependency on medical technology are generally thought to be better off if they can be cared for in their own homes. Assuming that home care is safe and appropriate care (and much evidence suggests that it can be), most people regard it as preferable to institutional care in terms of quality of life.

Home care is seen as particularly beneficial for children's developmental and social growth. Pediatricians, chest specialists, nurses, and other professionals strongly endorse home care as desirable for the majority of children with severe disabilities and chronic illnesses.

Not all technology-dependent individuals are candidates for home care, however. Adequacy of funding for home care is the first requirement, and it can override all other considerations. Most families with insurance have better coverage for inpatient care than for the type of intensive home care needed by the technology-dependent (see section below on financing the care), though insurers occasionally make contractual exceptions when home care appears to be a cost-effective alternative (see Appendix J, "Insurance Coverage," and Appendix B to the Council of HMOs position paper which is contained in Appendix A to this report).

Most financing requires that home care be demonstrably less expensive to the third-party payor than institutional care; some patients are precluded from considering home care due to family or medical characteristics that make home care a more expensive alternative to their insurers [1, 2, 3, 15]. The amount paid for hospital care also affects the cost comparisons of hospital and home care; for example, below-market payments by Medicaid for hospital care can narrow the gap between the costs of hospital and home care to the point that home care cannot be cost-justified as the less expensive option.

Assuming that financing is not an insurmountable obstacle to home care, there are other requirements. Discharge criteria typically require that the patient's condition be "stabilized" [6: p. 12], that capacity for self-care or family care be demonstrated [31], that the home environment be suitable (modified to accomodate equipment as needed), and that the necessary supportive services be readily available (professional nursing care, durable medical equipment maintenance, social services, back-up systems, educational services, etc.). In demonstration projects and other home care programs for the technology-dependent, case managers typically monitor and facilitate completion of all discharge criteria (see Appendix G on programs in Minnesota and Iowa and Appendix F on a Michigan demonstration project).

ISSUE 2

CONTEXT: FINANCIAL VULNERABILITY AND THE NEED TO ESTABLISH LIMITS

Recognize That The Health Care Market In Minnesota Is Quite Fragile; HMOs Are Particularly Vulnerable

There is acknowledgement on all sides that high cost, low incidence cases of prolonged technology dependence could pose a serious threat to the financial stability of Minnesota HMOs. Though these cases are costly for any third-party payor, HMOs are acknowledged to be particularly vulnerable. As the Council of HMOs puts it, "Under Minnesota law, HMOS do not presently have the ability to impose lifetime, contractual financial maximums for certain episodes of care like traditional insurance carriers can. This statutory difference provides traditional indemnity carriers with an unfair advantage in the marketplace and allows those carriers to better predict what their actual experience will be" (page 10).

Other excerpts from position papers:

> Council of HMOs' Key Conclusions # 3: "The economic environment for HMOs in Minnesota is fragile and should be viewed as a sign that the local HMO industry cannot stand to have broad, mandated benefits added to its already long list of comprehensive benefits."
>
> Council of HMOs' Recommendation # 2: " Achieve recognition by state regulators that HMOs must be allowed to determine contract benefit limitations for health services provided to technology-dependent individuals in the home setting, or face the reality that HMOs may be pushed toward financial insolvency."
>
> HHCTF excerpt from page 1: "All third party payors face the large and highly variable costs of serving children who are technology dependent. However, the indemnity plans have pre-determined parameters which limit the extent of coverage, while managed health plans face the unique situation of potentially unlimited liability for a child who is technology-dependent."
>
> HHCTF excerpt from page 7: (Following criticism of HMOs for cost shifting and undertreatment): "We believe that these examples are responses from managed health care plans threatened with unlimited liability. We must work together to find better solutions that can serve the needs of the children of our community and make us proud of ourselves and our respective institutions."

Responsibility of HMOs to Provide Home Health Care

The CHHCTF cites instances in which the CHHCTF believes that health plans have abdicated their responsibility to provide health care for the technology dependent; the task force calls for a basic commitment from third party payors to support home health care for the technology dependent:

Excerpts from position papers:

> CHHCTF Summary of Concerns # 7: "There have been several instances where health plans have abandoned children and their families in the marketplace to avert ongoing home care responsibility. This may take the form of cancelling an employer group to avoid a particular adverse selection. This form of avoiding adverse selection makes the child, his family, and the employer particularly vulnerable."
>
> CHHCTF Recommendation # 6: FINANCIAL: "[There must be a] commitment on the part of managed health care plans to financially support home care for children who are technology dependent."

The Council on HMOs acknowledges that HMOs have a responsibility to provide certain home health services to technology-dependent individuals, but insists on the need to place reasonable limits on these services. Discussion at recent meetings suggests that HMOs regard definitions of key contractual terms as their most viable method of imposing such limits (this issue is discussed at length below). Caps on total expenditures or units of service are not viewed as a viable option because of state regulations (though these could potentially be changed) and because of requirements imposed on Minnesota HMOs that are federally qualified (judged very difficult to change).

Financial Responsibility Should Be More Equitably Distributed Among Payors

Noting their own competitive disadvantage on the "unlevel playing field," the HMOs call for a more equitable distribution of financial responsibility among all parties, including the self-insured employers (who are estimated to account for more than half of the insured persons in Minnesota but who are exempt from a good deal of the regulation that HMOs and commercial insurers face).

Excerpts from position papers:

> Council of HMOs' Recommendation # 1: " Educate policymakers and consumer advocacy groups that in order to provide the broad array of healthcare services needed to keep technology-dependent individuals in a non-acute, home setting, the financial responsibility for providing those services must be spread equitably among private payors (indemnity insurance carriers, HMOs, self-funded health plans, and health service organizations, i.e., Blue Cross/Blue Shield), state and federal government, and the health plan policy holder."
>
> Council of HMOs' Recommendation # 5: "The Minnesota Department of Health should bring together experts and qualified laypeople to consider ways to equitably spread the financial burden of home care needs, for the technology dependent population, among multiple payors."

Conclusion

Parties agree on the fragility of the health care market, the special vulnerability of the HMOs, and the need for a more equitable distribution of the financial responsibility for providing home care for technology-dependent individuals.

ISSUE 3

DEFINING "TECHNOLOGY-DEPENDENT INDIVIDUALS"

What should be the basis for defining the target population of "technology-dependent individuals"? Should it be linked to specific diagnoses? Invoke functional criteria? Make explicit reference to the need for hospital-level services? Specify the nature of the dependence on "technology"?

There is no consensus on answers to these questions. For example, the Minnesota Legislature and the CHHCTF both refer explicitly to the need for hospital-equivalent services:

- O In requesting this special study of reimbursement issues for home care, the Minnesota Legislature referred to technology-dependent individuals as "individuals with a medical condition which would require inpatient hospital services in the absence of home or community-based care, and who are dependent upon medical technology in order to avoid death or serious injury" (emphasis added).

- O Excerpt from position paper:

> CHHCTF Recommendation # 1: "DEFINITIONAL: There needs to be an acceptance by managed care plans as to the definition of in-lieu-of-hospitalization discharge. The in-lieu-of-hospitalization discharge is fundamentally different from other patient discharges; the child is able to be discharged to the home setting by virtue of the high level and quality of services provided which make the home setting safe and effective."

The position paper by the Minnesota Council of HMOs calls for consensus on a more precise diagnosis- or condition-related definition of "technology-dependent individuals, as well as uniform definitions of terms in general:

> Council of HMOs' Key Conclusions # 1: "The focus population needs to be distinctively defined (i.e. by disease states)."

> Council of HMOs' Recommendation # 3: "Reach consensus .... on [a definition of] the term 'technology dependent individual.'"

> Council of HMOs' Key Conclusions # 4: "Uniform definitions of key terms relevant to the technology dependent population should be adopted, by consensus, of third-party payors and state regulatory agencies."

> Council of HMOs' Recommendation # 3: "Reach consensus on pertinent definitions used in member contracts...."

Arriving at a satisfactory definition is not easy. As noted in an Office of Technology Assessment (OTA) report, "Technology-Dependent Children: Hospital v. Home Care, A Technical Memorandum, (hereafter referred to as the OTA report on children), after 5 years of public debate, there is still no consensus:

> From a clinical perspective, the crucial distinguishing characteristic of these children is that they require special equipment and an intense level of medical services that are beyond the normal capabilities of untrained families. From an insurance perspective, the crucial characteristic of these children is that it may be possible to care for them more appropriately and less expensively if the funding and services are made available. Although the two populations described by each of these characteristics overlap considerably,... they are not identical. [1: page 31]

This OTA report on children stresses that the size of the technology-dependent population varies dramatically with the clinical criteria used in the definition.

Since many diagnoses or conditions can give rise to long-term dependence on life-sustaining technologies, but they do not always do so, a satisfactory definition may ultimately require a combination of criteria related to diagnosis, functional limitations, and need for particular services (see Appendix B, "Implications of the Population Definition").

The best sources for such a comprehensive definition are the OTA report on children and another OTA report, Life-Sustaining Technologies and the Elderly (hereafter referred to as the OTA report on the elderly).

[Note that much of the available literature, including these two OTA reports, focuses on either the very young or the very old, because these two groups are disproportionately at risk of becoming technology-dependent. Though we will use the age-specific discussions in the two OTA reports to generate a definition, the ultimate goal is to make the definition applicable to all "technology-dependent individuals," regardless of age.]

Defining "Technology-Dependent Children"

The OTA report on children defines a "technology-dependent child" as one who "needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further injury. This definition is independent of the setting of care or the particular credentials of the caregiver." (Pages 3-4) [The Council on HMOs uses this definition in their position paper].

Noting that technology-dependent children are a diverse group with a great range of medical diagnoses, many of them very rare, the report identifies four separate populations that differ on clinical characteristics.

The first three groups are narrowly defined and limited to children whose technology dependence is both life-threatening and requires frequent and complex nursing tasks:

O GROUP I (Ventilators): Children dependent at least part of each day on mechanical ventilators (includes both positive and negative pressure devices; ventilators is the preferred term for what used to be called respirators).

[Note that individuals in the process of being weaned from a ventilator, or who have just been weaned off the ventilator, often need special attention, special monitoring, and a program that may be more complex than the pre-weaning program, since some ventilator-dependent patients are less stable after weaning [6: p. 11].

O GROUP II (Intravenous Technologies): Children requiring prolonged intravenous administration of nutritional substances or drugs.

O GROUP III (Other Respiratory or Nutritional Devices): Children with daily dependence on other device-based respiratory or nutritional support, including tracheostomy tube care, suctioning, oxygen support, or tube feeding.

The fourth group includes a broad range of children whose technology is less life-threatening and requires less frequent or less complex nursing tasks. Children in this group are less at risk of prolonged institutionalization than those in the first three groups, and they are less universally recognized as "technology-dependent." As we will see in the next section that deals with estimating the size of the target population, including Group IV in the definition greatly increases the number of "technology-dependent" children.

O <u>GROUP IV (Other)</u>: Children with prolonged dependence on other mechanical devices that compensate for vital body functions who require daily or near-daily nursing care. This group includes:

- Infants requiring apnea (cardiorespiratory) monitors
- Children requiring renal dialysis as a consequence of chronic kidney failure
- Children requiring other medical devices such as urinary catheters or colostomy bags as well as substantial nursing care in connection with their disabilities.

These four groups are intended to be mutually exclusive. Children with multiple conditions who could potentially be put in more than one of these groups are classified in the lowest-numbered group that applies to them.

Defining "Technology-Dependent" Elderly

The OTA report on the elderly has chapters that deal with each of the following life-sustaining technologies: resuscitation, mechanical ventilation, dialysis for chronic renal failure, nutritional support and hydration, and life-sustaining antibiotic therapy. Our focus on prolonged dependence means that the chapter on resuscitation is not directly relevant (though it may precede mechanical ventilation or other technology dependence). Renal dialysis is not pertinent either, since we are focusing on reimbursement problems and the costs of renal dialysis are largely covered by a federal program. The remaining technologies, mechanical ventilation, life-sustaining antibiotic therapy, and nutritional support/hydration, correspond to the definitions given above for technology-dependent children (Groups I and II).

Life-sustaining antibiotic therapy is administered at home in some cases, for example, for patients on a mechanical ventilator, dialysis, or nutritional support who wish to avoid admission to a hospital [2: pages 338-339]. Life-sustaining antibiotic therapy differs from mechanical ventilation and nutrition/hydration in that it does not involve a device that compensates for loss of a vital body function such as breathing or digestion.

Definition of Technology-Dependent Individuals

Based on the discussion above, the OTA definition for children is adapted to refer to technology-dependent "individuals" (rather than just children):

> "A technology-dependent individual is one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further injury."

O This definition is independent of the setting of care, though the phrase "substantial and ongoing nursing care" may well imply hospital-equivalent services.

O This definition is also independent of the particular credentials of the caregiver.

O Under this definition, a variety of diagnoses may be associated with technology-dependence (see Appendix C, Background Information on Medical Conditions and Technologies, which describes chronic obstructive pulmonary disease (COPD) and bronchopulmonary dysplasia (BPD), two of the more common diagnoses associated with mechanical ventilation). Some of the more common diagnoses are given below in a table taken from the OTA report on the elderly:

Table 6-1.—Diagnoses Associated With Risk of Respiratory Failure and Subsequent Mechanical Ventilation in Adults[a]

Pulmonary diseases
- Chronic obstructive pulmonary disease (COPD)
  - Asthma
  - Bronchitis
  - Emphysema
- Chronic restrictive lung disease
- Adult respiratory distress syndrome
- Interstitial lung disease
- Acute bronchial asthma
- Pneumonia
- Pulmonary edema
- Pulmonary embolism
- Tuberculosis
- Lung cancer

Neuromuscular disorders
- Amyotrophic lateral sclerosis (ALS)
- Diaphragmatic paralysis
- Guillain-Barre syndrome
- Myasthenia gravis
- Kyphoscoliosis and senile kyphosis
- Multiple sclerosis
- Muscular dystrophy
- Poliomyelitis
- Tetanus

Neurological disorders
- Cerebrovascular accident (stroke)
- Brain trauma
- Status epilepticus
- Drug overdose, poisoning
- Coma resulting from metabolic disorders

Cardiac disorders
- Cardiogenic shock
- Cardiac arrest
- Congestive heart failure
- Severe dysrhythmias

Major surgery (with general anesthesia)

Injury, trauma
- Chest injuries, including trauma during cardiopulmonary resuscitation (CPR)
- Spinal cord injuries
- Hypothermia
- Burns, smoke inhalation

Other
- Metastatic cancer
- Aspiration

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[a] Diseases associated with short- as well as long-term ventilation are included because of the potential for the former to evolve into the latter.

SOURCE: Office of Technology Assessment, 1987.

(p.208)

Some of the life-threatening infections that may require intravenous antibiotic therapy are described in another table from the same report:

Table 9-1.—Life-Threatening Infections That Commonly Affect Elderly People[a]

Pneumonia is the leading cause of death due to infectious diseases and it ranks sixth as a cause of death for people of all ages in the United States (31). Bacterial pneumonia, along with influenza, is the fourth most common cause of death in elderly people, accounting for 185 deaths per 100,000 persons (40). Mortality rates range from 10 to 80 percent, depending on the bacteria involved and the degree of lung destruction (8).

Nosocomial (hospital-acquired) pneumonias are the most deadly and account for approximately 15 percent of hospital-acquired infections (75). Recent studies suggest that the risk is comparable in nursing homes. Several diseases or condition-associated factors that predispose people to pneumonia are more frequent in the elderly population or affect the elderly more severely—e.g., chronic bronchitis, congestive heart failure, stroke, and dementia (8).

Urinary tract infections are common bacterial infections in older persons, especially women (37). They are the most common infections in hospitalized patients, affecting 1 million patients per year (31). The prevalence of urinary tract infections increases with age, level of care, and decreasing functional capacity. The reasons that urinary tract infections are so frequent in older persons are unknown, but may include prostate problems in men; loss of pelvic support, fecal incontinence, and loss of local bladder mucosal defense mechanisms in women; and use of urinary catheters in both sexes (86).

Infected decubitus ulcers (bed or pressure sores) are associated with immobility, malnutrition, and diabetes, all of which result in poor circulation and skin breakdown. One study found decubiti were the leading source of infection among 532 patients in nursing homes, with a prevalence rate of 6 percent (26). Despite appropriate medical and surgical care, elderly patients with pressure sores associated with bacteremia have a very poor prognosis. The overall mortality associated with sepsis (spread of the infection to the bloodstream) due to pressure sores is approximately 40 percent, and the highest rates (78 percent) have been documented in elderly patients (16).

Iatrogenic infections (infections resulting as a complication of medical treatment) are often related to the use of medical devices. In the late 1970s, for example, an estimated 850,000 infections were related to medical devices, accounting for approximately 45 percent of all hospital-acquired infections in the United States. Infections resulting from the use of life-sustaining technologies such as mechanical ventilators, dialysis machines, and nutritional support equipment constitute a substantial portion of the iatrogenic complications due to medical devices (8,64). During infusion therapy for total parenteral nutrition (TPN) (see ch. 8), for example, infection can be caused by contamination. Infectious bacteria gain access most frequently at the site where the device penetrates the skin (32).

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[a] OTA selected these four infections for emphasis in this chapter because of their prevalence and importance for critically, chronically, and terminally ill, and severely debilitated elderly people

SOURCE: Office of Technology Assessment, 1987.

The table below is from the OTA report on children. It categorizes children who tend to be cared for in programs emphasizing alternatives to hospitalization. Note that only a subset of the children described in this table would likely meet the definition given above for "technology-dependent" (mainly those in the last four groups).

Table 2.—The Population of Children Currently Served in Programs Emphasizing Alternatives to Hospital Care

Categories	Description	Services	Sample diagnoses
Children who have *acute medical/surgical problems*	Children with acute medical/ surgical problems who are discharged early from the hospital but who continue to need individualized technical care for limited periods of time	These children may require medications, unusual feedings, monitoring of vital signs, certain forms of technical treatment, etc.	Severe infectious disease Postoperative conditions Low-birthweight infants
Children who have a *terminal illness*	Children requiring technical care for a terminal illness that is expected to result in death within 6 months.	These children may for a period of time require oxygen, assistance in feeding, and/or medication for comfort.	Terminal cancer Renal failure
Children who are *severely intellectually disabled*	Children who as the result of an illness, trauma, congenital anomaly, or hereditary disease are severely intellectually disabled so that they cannot and will not in the future be able to care for themselves.	These children require varying degrees of assistance in feeding, defecation, urination, positioning, and other personal care.	Severe microcephaly Severe post meningitis Severe hydrocephalus
Children who have *chronic medical problems*	Children who will have chronic medical problems for long periods of time and are dependent on technical care.	These children may require complex alimentation, certain medications, suctioning, catheterization, intravenous therapy, tracheostomies, equipment monitoring, prescribed therapy regimens, and/or colostomies/ ileostomies.	Chronic malabsorption syndrome Severe cystic fibrosis Multiple congenital anomalies Severe seizure disorder Dystrophies Atrophies Myasthenia Chronic aspiration syndrome Short gut syndrome
Children who have *chronic respiratory problems*	Children who will be oxygen dependent for relatively long periods of time.	These children will require oxygen and may require suctioning or cardiopulmonary monitoring	Chronic bronchopulmonary dysplasia (BPD)
	Children who need ventilation assistance for periods of time	These children will require ventilator care and bronchial suctioning. They may require cardiopulmonary monitoring and gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease Tracheo-bronchial malacia Ondine's curse
	Children who are completely ventilator dependent	These children require constant ventilator care, bronchial suctioning, and cardiopulmonary monitoring and may require gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease
Children who have *Central Nervous System (CNS) dysfunction*	Children who have CNS problem, either the result of trauma or CNS disease so that they cannot and will not be able to care for themselves.	These children may require assistance in physical positioning, feeding, defecation, and/or urination. (Some may also be ventilator dependent.)	Progressive CNS disease Spinal cord trauma

SOURCE J. MacQueen, "Alternatives to Hospital Care," unpublished, Aug. 5, 1980

0 Regardless of the specific diagnosis, technology-dependent individuals are those whose dependence on a medical device is both life-threatening and requires frequent and complex nursing tasks. The three groups described above as constituting the more restrictive OTA definition would be included (ventilators, intravenous devices, other respiratory and nutritional devices); Group IV (other) would be excluded.

0 For some purposes, it may be appropriate to specify the "frequent and complex nursing tasks" needed by technology dependent individuals. Some type of functional assessment tool would have to be developed for this purpose. Although some studies are underway to fine-tune the specification of nursing care needs of disabled children, these studies have not focused on technology-dependent children [1].

Discussion

The term "in lieu of hospitalization" favored by the CHHCTF captures the key point that a discharge to home care for the long-term technology dependent is no ordinary hospital discharge. Technology dependent individuals who are the focus of this inquiry into reimbursement issues are those who are sent home because "hospital like" services are able to be created in their homes. These individuals require prolonged, complex care of a type that is generally available only in an intensive care unit (ICU) or other specialized medical unit. Home care "works" for the technology dependent because family members and other caretakers can be trained to do the complex nursing and because it has proven possible to install and maintain the necessary equipment in the home.

To third part payors and especially to HMOs, the term "in lieu of hospitalization" is problematic. These groups favor a definition of "technology-dependent individual" that makes no explicit reference to setting or the need for hospital-equivalent services.

In part, this controversy over the term "in lieu of hospitalization" may reflect concerns about the interpretation of reimbursement obligations in this new "gray area" of home care for the technology dependent. If the phrase, "in lieu of hospitalization," is explicitly included as part of the definition of the target population, could it be taken to imply that the home care services should be reimbursed just the same as hospital expenses? Also, what happens to third party payors' obligations when patients' conditions fluctuate or show substantial improvement? As a patient's disability becomes either more or less immediately life-threatening, and the frequency and level of skilled medical intervention either increases or decreases, the essentially arbitrary boundary between the narrowly-defined "technology dependent" and less life-threatening disabilities begins to blur.

Conclusions

0 The OTA definition of technology-dependent individuals, which is independent of setting and independent of caregiver credentials, is a good starting point. It may need to be refined for contractual purposes (see Appendix B).

O On balance, it seems desirable to exclude the term "in lieu of hospitalization" from the formal definition of "technology dependent individuals." However, the unique character of a discharge to home that is premised on availability of high technology medical equipment and the provision of complex nursing care must be recognized. The implications for reimbursement of this unique discharge should be identified and openly debated in order to clarify the responsibilities of third party payors and assure that financing of care for the technology dependent is not compromised by choosing the home setting over the hospital setting.

ISSUE 4

ESTIMATING THE NUMBER OF TECHNOLOGY-DEPENDENT INDIVIDUALS

Fragmented and Non-Comparable Data

The two OTA reports, one on children and the other on the elderly, have made exhaustive attempts to estimate the incidence (number of new cases during a period of time) and prevalence (number of cases at a given point in time or during a particular time interval) of technology-dependent individuals throughout the United States. The OTA concludes that data on current utilization of life-sustaining technologies are highly unreliable.

Differences in data collection methods, definitions, and time periods make available data fragmented and non-comparable. Even when reasonably good estimates are available for extent of home use of one of the technologies (such as mechanical ventilators), it is generally impossible to correct for the use of multiple technologies (for example, one person on a ventilator who has nutritional support could be counted twice).

Though the data are inadequate, and therefore all estimates must be viewed with some skepticism, it is important to examine what we do know in order to determine the best available estimate of the size of the target population of technology-dependent individuals.

The total number of technology-dependent people depends on the rate of occurence of new cases during a period of time ("incidence"), and the duration of technology dependence for existing cases (patients who are dependent may die, they may outgrow or be weaned from dependency on the device, or they may remain technology-dependent for long periods of time or permanently) [35, 12, 6].

When we count the number of technology dependent people at a single point in time, the result is "point prevalence." A more useful count for program planning, reimbursement, and policy-making purposes is "period prevalence," or the number of cases over a given time interval, such as the total number of technology dependent people in one year. Since few data sources report period prevalence, the OTA reports have extrapolated the available data to reflect total numbers in the United States in a one year period.

The quantity and quality of data available for estimating the number of technology-dependent persons varies considerably by age group. We have more information about technology-dependent children than any other age group; we also have quite a bit of information about elderly persons who are technology-dependent. We know the least about the age group from 18-64, and this relative lack of information is a major concern for the project at hand because it includes all age groups.

Available data also vary greatly by the type of technology dependence. We know the most about those in Group I, who are on mechanical ventilators. Some of the data have been obtained from medical equipment suppliers, since people on a ventilator must deal with vendors for maintenance and repair. Respiratory therapists are another source of information for indirectly estimating the size of the ventilator-dependent population, particularly those who are cared for at home. Data on other types of technology-dependence are obtained from various other sources; for example, state-based programs and national home nutrition programs provide information about the number of people receiving nutritional support and hydration in the home.

We know the most about how many cases exist at a single point in time, and much less about the two determining factors of incidence (new cases) and duration. Knowing so little about both incidence and duration makes it extremely hard to estimate the need for services and project costs of care.

Estimates of the Number of Technology-Dependent Individuals

To estimate the size of the target population in Minnesota, we need estimates of the number of persons in Minnesota in each of the three groups (those who are ventilator-dependent, require prolonged intravenous therapies, require other device-based respiratory or nutritional support) that comprise the OTA definition of technology-dependent individual. Ideally, we also need to know what percentage of this target population is either currently receiving care at home, or is medically able to receive care at home.

There is a Minnesota-specific estimate (based on a survey) available for ventilator-dependent persons being cared for in their homes, but no comparable estimate for the other groups.

In Spring 1986, Alex Adams, Clinical Director of Respiratory Therapy at Health East, contacted all vendors who supply home care equipment to ventilator-dependent persons in Minnesota to obtain the following information about their ventilator-dependent home care clients: age, degree of ventilator dependency (parttime or fulltime), type of ventilator, and diagnosis/disease.

This survey showed a total of 86 Minnesotans who were ventilator-dependent and receiving home care in Spring 1986. Twenty-three percent of the 86 were 20 years old or younger, 33% were between 21 and 50, 24% were 51-60, and 20% were 61 or older. Just under half of them were dependent fulltime on the ventilator. (See Appendix B for a more detailed report of the survey findings).

A similar estimate is made by the Minnesota Home Care Advocacy Program which puts the number of ventilator-dependent persons in Minnesota at 100 (basis of this estimate is not reported; estimate presumed to be of ventilator-dependent persons receiving home care; see position paper 4 in Appendix Q).

Since Minnesota-specific estimates are not available for the other two groups of technology-dependent individuals, we must estimate the numbers for Minnesota from OTA estimates. The OTA has adjusted and synthesized the available data from numerous sources to arrive at estimates of the number of technology-dependent individuals in the United States [1, 2]. In some cases, estimates are age-specific (for children, for persons 65 and older) and in others, the estimates are for all ages combined.

These OTA estimates have been used to calculate estimates for Minnesota. A few of the OTA estimates are expressed as rates per 100,000 individuals; these estimates are easily converted by applying them to Minnesota's population figures. Other estimates are given in terms of number of persons; these estimates are converted by multiplying by .018, since Minnesota's population represents .018 or 1.8% of the U.S. population.

Results of these calculations are summarized in the table below (see Appendix B for copies of tables from the OTA reports that form the basis for these Minnesota estimates). Question marks in this table indicate data that are not available.

ESTIMATES OF THE NUMBER OF TECHNOLOGY-DEPENDENT INDIVIDUALS IN MINNESOTA BASED ON NATIONAL ESTIMATES BY THE U.S. OFFICE OF TECHNOLOGY ASSESSMENT

	TOTAL (all ages, (all settings)	BY AGE			BY HOME SETTING	
		< 18	18-64	65 +	Now At Home	Could Be At Home *
<u>GROUP I</u>: Long-Term Ventilator-Dependent						
		by age = at home only:				
Actual MN survey: (see text)	?	20[c,h]	49[c,i]	17[c,j]	86[c]	?
		by age = all settings:				
Based on OTA estimates:	77[a]-118[b]	12-36[d]	42-83[e]	23-40[b] 21-64[g]	27[a]	44[a]
<u>GROUP II</u>: Nutritional Support						
Enteral (tube)	15,266[b]	?	?	8,100[b]	259[f]	?
Parenteral	10,015[b]	6-13[d]	?	4,140[b]	83[f]	?

(table continued on next page)

ESTIMATES OF THE NUMBER OF TECHNOLOGY-DEPENDENT INDIVIDUALS IN MINNESOTA BASED ON NATIONAL ESTIMATES BY THE U.S. OFFICE OF TECHNOLOGY ASSESSMENT

(continued)

	TOTAL (all ages, (all settings)	BY AGE			BY HOME SETTING	
		< 18	18-64	65 +	Now At Home	Could Be At Home *
GROUP II, cont.						
Prolonged IV Drugs	?	5-149[d]	?	?	?	?
GROUP III:						
Other Device-Based Respiratory or Nutritional Support	?	18-108[d]	?	?	?	?

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* "Could be at home" = those who are already at home + those who are hospitalized but are deemed able to be cared for at home; see [11]

[a] Based on converting U.S. estimates in Table 1 [11] to Minnesota estimates by multiplying by .018; see table in Appendix R.

[b] Table 1-1 OTA report on the elderly [2] (MN = 1.8% of U.S. estimate).

[c] Minnesota survey data collected by Alex Adams in Spring 1986; see text.

[d] Table 1 of OTA report on children [1] (MN = 1.8% of U.S. estimate).

[e] Derived from column 1 of this table (minimum and maximum) minus minimums of columns 2 and 4 of this table)

[f] Table 8.3 of OTA report on the elderly [2] (MN = 1.8% of U.S. estimate).

[g] OTA report on the elderly [2]: Based on applying reported rates per 100,000 persons 65+ to Minnesota's population of 548,933 persons 65+; rates used are for North Central region which includes MN (3.8/100,000) and the maximum reported rate (11.6/100,000).

[h] Persons 20 and younger.

[i] Persons aged 21-60.

[j] Persons 61 and older.

Conclusions

There are many problems with the data and process of estimation.

- It is clear from the number of question marks in the table above that many of the estimates we need are simply not available.
- In the one case (for ventilator-dependent individuals) where we are able to compare actual Minnesota data with Minnesota estimates derived from OTA's national estimates, the actual Minnesota numbers are far higher (three times higher) than the OTA-based estimates (86 persons in home care compared to OTA's estimate of 27 persons).

  There are many factors which may contribute to this discrepancy. First, the OTA estimates are minimum numbers because the OTA source is an AART survey which was not exhaustive: the survey was done in 37 states and each state was asked to contact "at least 10 institutions," which means that many ventilator-dependent individuals were likely not included in the survey findings. Although the findings based on the 37 states have been extrapolated to the 50 states (see Appendix R), the numbers are still biased on the low side.
- One of the biggest problems with estimating the total number of technology dependent individuals is that there is no good way to judge what percentage of these individuals are potential candidates for home care. We have some crude estimates for technology-dependent individuals being cared for at home (or potentially- i.e., medically- able to be cared for at home) for Group I and part of Group II, but no estimates at all for prolonged IV drug use (part of Group II) or for Group III.
- Even where estimates are available, double counting of individuals is a potential problem, such as when a ventilator-dependent individual is also on parenteral (IV) nutrition. The OTA has defined the categories as mutually exclusive, but sources used for the estimates typically ask about one technology only and therefore cannot correct for this type of double counting.

With these limitations in mind, the following numbers are the best available partial estimate of the target population of technology-dependent individuals for whom home care might be appropriate:

- About 90 to 100 ventilator-dependent individuals (based on 86 in 1986, rounded up because home care is probably becoming more prevalent);
- About 342 persons on enteral and parenteral nutritional support (derived from OTA estimate; nursing requirements and length of time on nutritional support is unknown).
- An unknown number of persons receiving prolonged IV drug therapy (probably quite small; some ventilator-dependent persons being cared for at home may receive prolonged IV drug therapy).
- An unknown number of persons using other device-based respiratory or nutritional support.

The Future Size of the Target Population

When contemplating new regulations or reimbursement policies, it helps to have a sense of the likely growth rate of the target population. Unfortunately, it is even harder to estimate the future size of the technology-dependent population than it is to estimate the current size.

There are a number of factors which can be expected to affect future utilization of life-sustaining technologies, many of which work in opposite directions, leaving the net change extremely hard to predict. The major ones are grouped below according to their presumed impact.

Factors Likely to DECREASE the Number of Technology-Dependent Individuals

- Cost containment strategies [27, 9];
- Increasing reticence to use high-technology interventions near the time of death;
- Improved prenatal tests to detect severe, chronic disease;
- Improved prevention (including better prenatal care to prevent very low birth weight premature births, accident prevention such as increased use of motorcycle helmets, prevention of smoking and lower rates of smoking) [14];
- Improved ways of treating neonatal disorders that decrease long-term dependency on technology, such as better success in preventing chronic lung disease (see Appendix C, "Changing Technology in the Neonatal Intensive Care Unit").

Factors Likely to INCREASE the Number of Technology-Dependent Individuals

- Aging of the population;
- Increased reimbursement for care (especially long-term home care) of the technology-dependent [24];
- Availability of technology in new settings; improvements in technology that make life-sustaining medical devices less burdensome and invasive (example: portability of ventilators) [7, 25, 30];
- New technological breakthroughs that make it possible to substitute for vital bodily functions. (Example: 25 years ago, the technology for providing prolonged intravenous feeding - TPN, or total parenteral nutrition- was not available. Before TPN, infants born with non-surgically correctable bowel deformities did not survive because there was no way to substitute for a non-functioning digestive system for a prolonged period);

- Emergence of new severe chronic diseases (e.g. AIDS);
- Lessened social acceptance of genetic counseling and abortion;
- Aggressive treatment of low birth weight premature infants and other high risk cases; aggressive treatment of the terminally ill (see Appendix N, "Biomedical Ethical Issues Related to Home Care For the Technology Dependent") [25].

Factors Likely to Have Mixed or Unpredictable Effects on the Number of Technology-Dependent Individuals

- Changes in public attitudes, especially about the quality of life obtainable under prolonged technology-dependence and the biomedical ethical issues of withholding and withdrawing treatment [Appendix N];
- Changes in medical practice patterns and in the procedures and guidelines for making treatment decisions that involve life-sustaining technologies.

The potential impact of improved funding for home care is a serious concern, since many believe it will increase the size of the technology-dependent population. As the OTA report on children suggests,

> It is possible that providing opportunities for children to be in home or home-like settings, combined with enhanced funding for long-term care, eliminates some of the social, financial, and medical disincentives to initiate and maintain long-term technology dependence. The three states with the highest identified prevalence of technology-dependent children all have aggressive home care programs to serve such children; North Carolina, a state with few ventilator dependent children, does not. More families may consider it worthwhile to maintain the life of a terminally ill child as long as possible if they can afford to take the child home, and physicians may consider it appropriate medical care to prescribe long-term ventilation for children (p. 31).

There is no evidence of overall increase in the incidence of most severe chronic disabling conditions, but there is an increase in the survival rates for those with such diseases, which means that the total number of tecnology-dependent people is on the rise. The OTA concludes that during the next decade or so, the size of the technology-dependent population is likely to increase, but in the longer run, technological improvements, especially those related to premature birth and treating its complications, may lead to stabilization or even a decrease in the size of the technology-dependent population [1, 2].

Conclusions

- Because the size of the "technology-dependent" population is so dependent on the way that "technology dependent" is defined, and because the costs of the care are so high, the payors, providers, and advocacy groups agreed at one of the recent meetings that it is wise at the outset to define "technology-dependent individuals" as Groups I, II, and III of the OTA definition, excluding Group IV.

- Even when "technology dependent" is defined relatively narrowly, it is impossible to produce an estimate of the current size of the population that is good enough to serve as the basis for calculating actuarial risk.

- It is harder yet to estimate the likely growth rate of the technology dependent population. Numerous factors will affect the future size of this group, and many of them work in opposite directions.

- In general, high costs and invasiveness of the technology tend to restrict use; low cost (generous reimbursement) and low risk may encourage overuse. There is much concern that improved financing for home care will encourage greater use of home care, driving net total costs for this very expensive care even higher.

Recommendation

- Comprehensive benefits for home care for the technology dependent population should not be mandated because it is impossible to predict with a reasonable degree of accuracy either the current or future size of this population.

ISSUE 5

DEFINING THE LEVEL AND SETTING OF CARE

Definitions Related to Nursing Care Provided in the Home

Regardless of the setting, caring for technology-dependent individuals requires complex nursing skills. Home care has been successful because it is possible to teach family members and other volunteer caretakers the set of skills necessary to provide safe and proper care for a technology-dependent patient at home [26, 3, 4, 5] (see Appendix D for a sample list of nursing tasks and equipment for home care involving ventilators and infusion technologies).

This section discusses some of the terms for defining home care for technology dependent individuals, focusing on ways in which definitions may restrict the liability of third party payors. Issues related to the family members' roles as caregivers and decision makers about home care are covered in a separate section that follows.

Definitions As A Means To Limit Liability

The ability to train family members and other caregivers to provide complex nursing care raises issues of how to define the type of care provided in the home, particularly since the position papers and group discussion to date suggest that definitions may form the cornerstone of reimbursement policies for home care for the technology dependent [developing standardized definitions is point #1 of the three point agenda agreed upon by the CHHCTF, the Council of HMOs and the Insurance Federation].

We have seen that the payors, providers and advocacy groups concur that it is essential to develop standardized definitions of key contract terms related to home care for the technology dependent. Though the groups agree on the need for uniform definitions, they disagree sharply on the specifics of some key definitions, including how to define "skilled nursing" provided in the home.

Much of the disagreement between HMOs and advocacy groups over this and other definitions outlined below can be traced to a fundamental conflict in their underlying objectives. From an advocacy group's perspective, definitions should not function to unduly restrict what they regard as needed and appropriately reimbursable services. From the HMOs' and some other payors' views, definitions are, in fact, the essential vehicle for restricting services.

There is no question but that HMOS must gain more ability to limit their exposure. Long-term home health care can be exceedingly costly; benefits for this care are typically not provided by HMOs or commercial insurers (except under special conditions on a case-by-case basis). Because of the comprehensive nature of their services, HMOs are particularly vulnerable to "liberal" (and potentially very costly) interpretations of such terms as "home health care" and "skilled nursing care." To the extent that HMOs continue to face a potentially unlimited liability for very high cost episodes of care, they face possible insolvency and put the health care needs of their total membership in jeopardy.

Putting a cap on total costs is one way to limit exposure; many self-insured plans and commercial insurers impose maximums of this sort. This option is not presently available to HMOs because it is inconsistent with the requirements for "federal qualification" and several Minnesota HMOs are federally qualified. Since caps are not a viable option, the HMOs see definitions as the primary means to place some clear and reasonable limits on their obligation to supply long-term home care for the chronically ill technology dependent. The question then becomes, how can definitions be used to limit services? Who is to judge when and where to draw the line that determines fair and reasonable limitation of services?

Definitional Disputes

The Council of HMOs' position paper proposes the following definition of "skilled nursing care":

> Council of HMOs definition from page 9: "SKILLED NURSING CARE: Licensed nursing services which are medically necessary and provided as part of a formal home care program ordered by a Plan physician. A service is not regarded as skilled when it is possible to teach a non-medical person the skills required to administer the care safely and effectively." (emphasis added).

This definition links "skilled nursing care" to credentials of the caregiver, arguing that since a parent can be taught to do the complex nursing tasks, these tasks do not truly represent "highly skilled nursing" (and therefore the costs of this care need not be reimbursed).

This insurance-oriented line of reasoning is rejected by the CHHCTF and not supported by the medical literature. From a medical standpoint, the essential caregiver qualification is demonstrated competence, not credentials. (Credentials do play a role in who should supervise the caregiver, however; most examples in the literature suggest that RNs or MDs retain supervision over caregivers.) [3, 4, 5, 7].

Intensive training can be used to bring a non-professional to a "highly skilled" professional level on a limited set of nursing skills needed to care for a particular technology-dependent person. This training has depth but not breadth; it is customized to the unique needs of the patient. The training does not make the parent into a health professional, but it does permit a parent or other non-medical person to function at the level of a health professional in a very narrow set of skills.

The tasks themselves do not become unskilled simply because it is possible to teach them to a non-professional; in the absence of such intensive training, professionals would be needed to provide the highly skilled nursing care. In fact, training is often provided for professionals as well as lay persons; nurses sometimes need special instruction on how to care for the technology-dependent.

In recent years, demonstration projects, hospital programs and professional associations have developed elaborate educational materials for use in training both lay persons and professionals about home care procedures for the technology dependent; there are many accounts of the process and many resources available for use by others. Teachers and bus drivers have been successfully trained, as well as parents, relatives, and neighbors [1, 3, 4, 5, 7].

In the most rigorous programs, training for parents and other volunteer caretakers involves contractual obligations for two or more persons to spend a certain number of hours in training in order to meet discharge criteria. Because the care is highly skilled, and because the safety of the patient depends on competent performance, these training programs typically require a "trial period" at the conclusion of training during which the trainee handles all care independently in the presence of the trainer or other professional. The trainer judges whether the volunteer caretaker is competent to handle the responsibilities (and acts as emergency backup, if needed). Trial periods can last 24 hours or more, and may include simulated emergencies (see reference 31 for a detailed account of training methods and such trials).

This type of documented competence provides both medical and legal assurances that the family is ready to handle the responsibilities of providing skilled nursing care. The literature includes accounts of refusal to discharge a patient to the home due to inadequate skills on the part of the parent or other caretakers.

Assuming that adequate training is available (as needed) to bring volunteer and paid caregivers up to speed on the required nursing skills, the literature suggests that caregiver qualifications should be based on training and demonstrated competence rather than on particular credentials (such as RN). To do otherwise precludes some medically appropriate and cost-effective options. According to participants at the Brook Lodge Invitational Symposium on the Ventilator-Dependent Child [6], requiring RNs to provide home health care inflates the cost unnecessarily:

> "In the home, care by registered nurses is mandated in many states even though licensed nurses or trained aides have proven equally effective, more readily available, and much less expensive. Salary differentials could be used to estimate excess costs attributable to licensure restrictions. " (page 20)

Obviously, the level of needed nursing skill will vary by patient. For example, people on ventilators who require frequent suctioning will need more highly skilled care than those who do not. Guidelines for home health care of ventilator-dependent individuals prepared by the Respiratory Care Section of the American College of Chest Physicians [7] stress that selecting appropriate caregivers for home health care depends in part on the patients' characteristics:

> "Infants and younger children often require professional nursing assistance because of the intrinsic instability of their respiratory system. Many older children can be successfully managed using nonprofessional attendants." (page 23S)
>
> "Years of experience with poliomyelitis and spinal cord injury patients have shown that most ventilator-assisted adult patients can be cared for by a non-credentialed personal care attendant." (page 6S)" (see also Appendix Q for materials on personal care attendants from the Minnesota Home Care Advocacy Program).

The literature stresses the need to be flexible in matching the training and skills of the caregiver to the needs of the patient. Then after a nursing plan has been established, each case needs to be individually assessed and monitored for changes in requirements or family conditions:

> "The decision about how much or what level of in-home nursing assistance is required must be individualized. One must consider not only the medical needs of the ventilator-assisted child, but also the psychosocial and economic realities of family life in order to have the greatest chance of success with home care. Additionally, caregiver needs change and should be frequently reevaluated." (page 23S)

The CHHCTF makes the same point:

> **CHHCTF Recommendation # 4: COMMUNICATIVE AND COORDINATIVE: "We look to managed health care plans to support a process for periodic reevaluation of the child that will determine the need for ongoing services in the home. That process will evaluate the child's physiologic improvement, degree of technology dependence, and the family/psychosocial support structure in the context of a multi-disciplinary health care conference."**

Defining the Level of Care: "Transitional," Subacute," and "Custodial Care"

A basic dilemma in setting limits on benefits for long-term home health care for the technology dependent is that changes in a patient's condition may alter the need for nursing services. There are vital distinctions to be made, from both a medical and an insurance standpoint, between home health care that provides "acute-care-equivalent" services in the home setting, and home health care that provides something less than "acute-care-equivalent" services.

Our health care delivery and financing systems are both biased toward cure-oriented acute care; the long-term home health care needed by chronically-ill technology-dependent persons is an anomaly. Particularly in the absence of a cap on expenditures or services, one way that third-party payors may limit their exposure in such costly cases is to reimburse for the "acute-care-equivalent" services but not for the "something less than acute-care-equivalent" services. Another way to limit exposure is to define care for the chronically ill as non-reimbursable.

For the most part, the definitions proposed in the Council of HMOs' position paper stress prognosis and/or chronicity rather than differences or changes in levels of nursing services required:

> Council of HMOs definition from page 9: "TRANSITIONAL CARE: This is a transition period between acute hospitalization and subacute care during which skilled nursing care is safely and efficaciously provided in the home. There is no longer a need for 24 hour physician availability; the primary physician determines that discharge to the home is safe, and the home care agency accepts the risk of caring for the patient in the home. RNs become the primary caregivers as there is not yet an established care plan that is proven safe for laypersons to administer. During this transition period, member co-payments will be waived and limits to the intermittent care will be exceeded with approvals for extended hours or visits for RN services. The patient's support system is being trained in the knowledge and skills necessary to provide care at home."

> Council of HMOs definition from page 9: "SUBACUTE CARE: Patient's physiological condition has stabilized with no change in condition expected, and support system has been trained in the knowledge and skills necessary to provide care at home and can demonstrate that knowledge and skill. The care plan has been established and shown to be successful over a reasonable period of time. Ongoing services which are directly related to maintaining or gaining weight, maintaining on or weaning from technical support, or to support a level of routine maintenance or supportive care in activities of daily living." (emphasis added)

> Council of HMOs definition from page 8: "CUSTODIAL CARE: Provisions of room and board, nursing (includes skilled nursing), personal care designed to assist an individual in activities of daily living, or such other care which is provided to an individual whose condition, in the opinion of a Plan physician, is not expected to change within one month." (emphasis added)

The Council of HMOs' definition of "transitional care" is consistent with other definitions in the literature that describe what it takes to accomplish the shift in settings from hospital to home care. Sometimes the term is used even more broadly, as in the following definition:

> "...those services that support the move of the child from an institution to home and community. At times, special transitional care units provide such services, although, more typically, transitional care services refer to activities that directly strengthen the capacity of the family and community to care for the child at home. Transition to the community requires 1) careful planning and discharge efforts, 2) determination of special home equipment and service needs, 3) educational activities for family and community providers, and 4) development of an explicit plan to provide nursing care and other support services as needed." [32: p. 531]

Taken together, the three definitions proposed by the Council of HMOs describe a logical progression:

- From hospital discharge to "transitional care" (training of caregivers, adjustment to home care)
- From transitional care to "subacute care" (linked to prognosis: "no change in condition;" caregivers are trained)
- From subacute care to "custodial care" (condition not expected to change within a month; "skilled nursing care" is explicitly redefined as "custodial care" under these circumstances).

These definitions for "acute care" and "custodial care" are based on expectations of change in the patient's condition (prognosis/chronicity), not on changes in the level of nursing skills required. The references to prognosis/chronicity serve to limit the HMO's liability: The HMO position paper maintains that HMOs should provide "acute hospitalization, transitional care, intermittent/part-time skilled home care... [They should not] be compelled to provide coverage for: respite care, custodial care, sub-acute care, long-term care for chronic conditions, and nursing care when non-medical persons can be taught to safely provide the services formerly provided by a nurse" (p.8).

In the literature, some definitions of subacute care and of custodial care emphasize prognosis/chronicity, like the ones proposed by the HMO Council, but others are based on differences in skill level.

EXAMPLES:

- "Custodial care" defined in terms of prognosis/chronicity:

  Custodial care is "care rendered to a patient:
  1. who has a mental or physical disability that is expected to be prolonged;
  2. who requires a protected, monitored, or controlled environment, whether in an institution or in the home;
  3. who requires assistance to support the essentials of daily living; and
  4. who is not under active treatment that will reduce the disability to the extent necessary to enable the patient to function outside the protected environment." (as defined by CHAMPUS and quoted in the OTA report on children, p. 164)

- "Custodial care" defined in terms of skill level required:

  > "Custodial care" means care which is designed chiefly to assist a person to meet her or his activities of daily living. The care is of a nature that does not require the services or supervision of trained medical or paramedical personnel. Examples of custodial care include, but are not limited to, help in walking and getting in and out of bed; assistance in bathing, dressing, feeding, and using the toilet; preparation of special diets; and the administration of medication that can usually be self-administered." (from MCHA)

The position paper by the Insurance Federation describes "custodial care" as "provision of room and board and personal care designed to assist an individual in activities of daily living."

"Subacute care" is typically defined in terms of nursing skill level rather than prognosis/chronicity; it refers to care that is just below "acute care." "Subacute care" is often used to describe one part of a full continuum of care; it may refer to the capabilities of a particular care unit or institution. For example, to deal with the problem of appropriate institutional placement and payment for technology-dependent persons when home care is not feasible, the state of California has defined the needed level of care as follows:

> "Subacute level of care means a level of care needed by a patient who does not require acute care but who requires more intensive licensed skilled nursing care than is provided to the majority of patients in a skilled nursing facility...The state proposes to reimburse subacute units at a higher rate than SNFs." (p. 91 of OTA report on the elderly; see also Appendix K of this report)

Impact of the Proposed Definitions

The CHHCTF is concerned about how definitions such as those proposed by the Council of HMOs affect technology dependent children and their families. Regardless of whether nursing needs change or not, when it is clear that care will be prolonged and the technology-dependent person's condition seems unlikely to change, reimbursement can be terminated by an HMO or other payor, or worse yet, cancelled retroactively.

Excerpts from position paper:

> CHHCTF Summary of Concerns # 1: "The inadequate provision of needed services results in cost shifting to a family that is not capable of providing hospital level services to their child in the home setting."
>
> CHHCTF Summary of Concerns # 2: "The provision of inadequate services is particularly insidious because it gives the appearance of third party payor compliance but may expose the child to life-threatening danger in the home setting or at least the imminent risk of rehospitalization. This is often a result of the lack of nursing (tertiary and public health) or tertiary level medical input to the discharge planning process and to the continued management of the child in the home setting."

The definitions that link benefits to prognosis or chronicity help third party payors limit their exposure, but they cause great stress by leaving the patients and their families uncertain from day to day about their insurance status. Though it is necessary to set limits in some manner, these definitions as proposed have the potential to be imposed in ways that could shift costs unfairly from the insurer to the family, and financially penalize families that have opted for home care (would coverage have been cancelled if there had been no transfer to home?).

Obviously, how the definitions are interpreted and who makes the decisions are crucial factors in using definitions as the major means of imposing limits on home health care benefits (see section below on financing of care).

The third party payors acknowledge this dilemma, and view the three point agenda (standardized definitions, multidisciplinary expert review panel, and separate care fund to provide a "safety net") as an integrated and interdependent approach with the potential to address the dilemma. The multidisciplinary review panel could presumably help ensure fair and equitable interpretations of definitions of "subacute" and "custodial" care, and the care fund could presumably pick up where private coverage leaves off when definitions are invoked to deny benefits. During discussions of this three point agenda, it was suggested that there would need to be a "double standard" of contract definitions; key contractual terms would need to be more liberally defined for the care fund than for private insurance.

Conclusions

- The health insurance system has not kept pace with innovations in treatment setting and caregiving for technology dependent individuals for whom "cure" is not a realistic goal but who require complex and highly skilled nursing care for an extended period of time.
- Home care for such individuals may often cost less than hospital care, but it is still very costly, and HMOs and other third party payors must have reasonable ways to place limits on the extent of their liability for this type of care. Meanwhile, some source of financing must be found to insure continuity of care for individuals in this situation. It seems reasonable to expect that the burden of this care be spread as broadly as possible; the "safety net" care fund has been suggested as one approach to explore.

Recommendation

- Support the collaborative process of definition development and refinement proposed in the three point agenda. It may be helpful to have a 3rd party that is more "neutral" act as convenor and facilitator.

ISSUE 6

RESPONSIBILITIES OF THE FAMILY

Defining The Family's Obligations

As the OTA report on the elderly points out [2: page 25], the physical, psychological, and financial burdens of home care for technology-dependent individuals are very great for both the patients and their families. Specific effects of the technology itself can include inability to speak or eat, discomfort and limited mobility associated with tubes and catheters, physical restraints, loss of independence and control, dietary regimens, restricted activities, and anxiety (see materials from Minnesota Home Care Advocacy Program in Appendix Q for more discussion). Impacts on the family include radical lifestyle changes, loss of privacy, disruption of parental employment and career building, disruption of siblings' lives, and continuing financial worries.

It is hard to imagine the combined impact of these factors, but several evaluation projects have documented the great stresses of caring for a technology-dependent person at home [3, 4, 5]. As a paper on the biomedical ethics of high technology neonatal care puts it, "Home care of children with serious illnesses or disabilities can require parental acts of care bordering on the heroic" [17: p. 27].

The literature shows that substituting family caretaking for paid professional nursing care is the major source of savings in home care, though both the monetary and non-monetary costs for the family may be very high in home care. It also shows that effective home care depends on the quality and quantity of support services that are provided to the family, which in turn depend heavily on reimbursement.

Some observers are concerned about the impact of the cost containment pressures in this situation. Though family caretaking reduces costs to third party payors, not all families are willing and able to provide such caretaking, and not all health plans are willing to spend the money for the services such as paid nursing and respite that may be needed for home care to be safe and work well for the families. There is some concern expressed by the CHHCTF and echoed in the literature that health plans eager to contain costs may exert inappropriate pressure on families or fail to provide an adequate level of services [1, 3, 4, 6, 16]. The same pressures exist in situations where a net savings in home care must be demonstrated and cutting home care services is the only way to achieve the savings. These circumstances may trigger cost shifting that runs counter to the best interests of patients and their families.

As the CHHCTF points out, not every child should go home, because cost savings to the third party payor is not the only factor to be considered:

> CHHCTF excerpt from pages 5-6: "The cost of home care may be greatly affected by the amount of sophisticated home care that can be shifted to the family but it must be kept in mind that families differ greatly in this regard and indeed a family may change over time in its ability to deliver that care....The use of family members to care for these children can involve very high costs to the family in terms of lost income, career opportunities, leisure time, or time for routine household tasks."

The extent of a parent's duty to provide home care is a controversial topic. The position paper by the Council of HMOs stresses the obligations of parents:

> Council of HMOs' Recommendation # 8: "Prior to discharging a technology-dependent individual to the home, an evaluation of the family's willingness and ability to help care for the individual and to accept and support the professional health care personnel that will be in the home should be accomplished. Parents and/or families of technology-dependent individuals must recognize their responsibility to offer caring and parenting to the child in the home setting and should not abdicate their parent role to health care personnel" (emphasis added)
>
> Council of HMOs excerpt from page 7: "It is a further position of the Council that a family's ability and interest in learning 'skilled' nursing services should not be a detriment to the plan's decision to withdraw professional nursing support" (emphasis added)

The CHHCTF stresses the need to put the child's interests first, assessing case-by-case whether home care by parents is desirable. Others argue as well that there are legitimate limits on the obligations of parents; parents should not be required to sacrifice their other children and themselves. Sustaining the family as a cooperative unit is another moral consideration [3, 4, 5, 6; also see Appendix N].

Who Should Make the Decisions

There is strong support in the literature for getting families involved in the decison making related to home care for technology dependent individuals. For example, the Brook Lodge Symposium proceedings make the following recommendations about decision making:

- Involve the family in all aspects of the care and decision-making;
- Recognize the family's needs in home care planning and follow-up;
- The needs and reactions of siblings should be considered in any home care plan;
- Children and adolescents represent two distinct situations for the family (adolescents can be more actively involved in the decisions that affect them, and their needs and concerns are distinctive);
- Options for ventilator-dependent children must recognize special family situations [6].

There is similar support in the literature for technology dependent adults to be actively involved in decision making about their own care, stemming in part from increasing skepticism about the traditional paternalistic role of physicians and reinforced by court rulings that tend to support autonomy in matters of withholding and withdrawing life-sustaining technologies (see Appendix N and the OTA report on the elderly).

Decision making in principle differs from decision making in practice, however. It is clear from program evaluations of technology-dependent demonstration projects and other sources that many families perceive no range of options available to them, nor do they feel as if the ultimate decision is really theirs [3, 5]. They often feel that the only possible choice is between hospital or home care, and that this choice is dictated to them by reimbursement policies and the lack of alternative settings for care (see section below and Appendix O).

ISSUE 7

ESTIMATING THE COSTS OF HOME CARE

Problems in the Definition of Costs

Costs of care for patients with life-sustaining technologies depend on whether one is considering costs to public payors, costs to private insurers, costs to the family, uncompensated costs to hospitals, or total resource costs. There are many components that make up the total resource costs. Costs can be direct (direct medical costs, such as nursing care and direct non-medical costs, such as transportation), indirect (such as lost income by a family caregiver), and intangible (pain, suffering, family tensions and stress).

Generally, when costs of care for the technology dependent are compared by setting, the comparison is limited to just one group of total resource costs-the direct medical costs to third-party payors. Even then, the "costs" are most likely to be either charges (billed amounts) or expenditures, neither of which may accurately reflect true costs. For example, data on Medicare expenditures understate actual costs of care because they do not include the deductible and coinsurance paid by the beneficiary, charges that exceed Medicare's allowances, and the costs of care not covered by Medicare such as outpatient drugs and nursing home care. Payments made on the basis of DRGs and heavily discounted payments are especially problematic as indicators of "costs."

As this discussion suggests, available data on costs are piecemeal, incomplete, and frequently not directly comparable. All cost estimates presented here must be interpreted with caution.

Conceptual and Policy Issues in the Comparison of Home Care and Hospital Costs

As the OTA report on children points out, the costs of caring for the technology dependent are both high and highly variable. In part, the costs depend on the type of technology dependence. For example, it is extremely costly to care for those on ventilators in a hospital setting because these individuals typically require the level of skilled nursing services found only in the ICU.

Less expensive institutional care is generally available only in special respiratory units of rehabilitation or long-term care facilities, and there are very few such units (and many of them do not serve children). Further, there is little incentive presently to maintain or expand such respiratory units because these units are adversely affected by the cost containment strategies of prospective payment. Many individuals with prolonged dependence on mechanical ventilators are "DRG losers;" Medicaid or other payors may pay substantially less than actual cost for these cases.

Since ICUs are so extremely expensive, and alternative institutional settings are not readily available, there is growing interest in home care as a more appealing as well as less expensive option.

Home care is very often, but not invariably, the least expensive alternative for the technology-dependent. Cost-effectiveness depends on individual circumstances but, most of all, on whose costs are at issue. We have noted that costs to private and public insurers tend to be lowest when the technology-dependent are cared for at home because families provide most of the highest cost services- nursing care and housing. At the same time, home care can involve very high direct, indirect, and intangible costs to the family-costs that are seldom considered in the home care v. hospital cost comparisons. For example, direct costs of home care to the family may include higher out-of pocket expenses to the extent that insurance coverage is more comprehensive for inpatient care than for home care (as it generally is). Indirect and intangible costs to the family include lost income, foregone career opportunities, lost leisure time, impact on siblings, stress-induced illnesses of family members, etc.

Hiring more caregivers would reduce these costs to families, but increase the costs to third-party payors. Under some circumstances, substituting more paid nursing care for unpaid family caretakers could ultimately make home care more expensive than hospital care to third-party payors. This tradeoff in total costs to the family v. direct medical costs to the third party payors is a major policy dilemma [19, 15, 1, 3].

Acting in the best interests of the technology-dependent person and at the same time reducing costs can pose a tremendous challenge. For example, Minnesota's Medicaid model waiver program for home care requires that costs to Medicaid be lower for home care than for institutional care. In cases where private insurance will cover some or all of hospitalization, but none of home care, there is obviously no cost savings to Medicaid to pay for home care. In cases where Medicaid is the only payor, but where home care costs are relatively high, it can be difficult to show a cost savings to Medicaid for home care, because in many circumstances Medicaid pays well below cost for hospitalization (it can be as low as 60% of costs for outliers on DRGs associated with life-sustaining technologies).

There are some technology-dependent individuals who are willing and able to be cared for at home, but who cannot afford it (and so are effectively prevented from doing it) because of the provisions of their insurance coverage that either exclude the type or extent of home care that would be needed, or require a net savings for home care that cannot be demonstrated (see Issues # 10, 11, and 12 below for more on insurance and financing of care).

In many cases, however, home care will be less expensive to third-party payors than institutional care. We have seen that successful home care requires a willing and able family, thorough and well-documented training of caretakers, and a cadre of services and supports to help the family render high quality care in the home. As home care becomes a more viable alternative to ICUs, there is some concern that third-party payors will have a financial incentive to hasten the discharge of the technology-dependent even if the family is not adequately prepared to take the person and no other alternatives have been developed.

Besides this concern about inappropriate or premature discharges to home care, the continued expansion of home care benefits and the accompanying increase in the number of technology-dependent children at home will raise other issues and have a number of secondary effects. According to the OTA report on children, these include the following:

- Increased early discharge from neonatal intensive care units;
- Problems in the quality of nursing care and equipment support in the home (see also Appendix Q, position paper on quality of home care by the Home Care Advocacy Program; and references 5, 20, and 23 for concerns about quality related to home care and the elderly);
- Increased charges for home services as demand increases, especially in areas where there is little competition in home health services or there are severe nursing shortages;
- Greater-than-anticipated costs to payors due to the "woodwork" effect of increased demand triggered by increasing availability of financing for home care;
- Increased demand for appropriate foster care or institutional care alternatives such as group homes for technology-dependent adults with no available caretaker, and for technology-dependent children whose parents are either unwilling or incapable of caring for them at home;

- Increasing numbers of technology-dependent children attending public schools, which will force clarification of payment and liability issues with respect to third-party payors and school districts (see Issue # 15 below on education for technology-dependent children and Appendix P on the same topic);

- Need to better define the role of the case manager and to ensure that the case manager is in a position to balance the interests of the family, the third-party payor, and other parties [1:pages 9-10].

Factors that Affect Costs and Cost Trade-offs

Although many factors affect the relative cost-effectiveness of home v. hospital care, there is consensus in the literature that the fundamental savings in home care results from the nursing and housing costs that are borne by the family. Other factors that tend to make home care less expensive are lower laboratory costs due to fewer routine tests [12, 13], the ability to substitute less expensive nursing care (aides or LPNs instead of RNs), and the degree to which the positive psychological effects of home care may speed rehabilitation or recovery (thus lessening total long-run costs of care).

There can be high start-up costs associated with home care, which include household renovations, training, equipment, and extra hours of paid nursing during the transition period until the family caretakers have fully demonstrated their competence and feel confident about their responsibilities. Start-up costs are easier to justify when the person is expected to remain technology-dependent for a prolonged period and if the ongoing costs of care at home are expected to remain relatively low.

The "catch 22" problem in the literature is that only the cases that promise a cost savings tend to be discharged to home, so by definition, the literature shows that home care is less expensive than hospital care. Since having an (unpaid) family caretaker is the key to demonstrating a savings in home care, it is not surprising that most home care programs have been oriented toward children, for whom parents (mainly mothers) tend to be available as caretakers. As Appendix E shows, for example, mothers were the primary caretakers for 95% of the 141 ventilator-dependent children receiving home care through three statewide demonstration projects. Of mothers who had previously been employed, over 80% quit their jobs to care for these children.

Technology-dependent adults are much less likely to have a readily available caretaker, and we know much less about the relative cost-effectiveness of home care for adults. From the literature that is available, it appears that technology-dependent adults may have a harder time than children in meeting the conditions that make home care a viable option (see Appendix Q for information and viewpoints on caretakers for technology-dependent adults by the Minnesota Home Care Advocacy Program).

Unless a spouse or other family caretaker is available, it is unlikely that home care will be cost-effective for technology-dependent adults who require anything that approaches 24 hour nursing care. For those adults with more limited nursing care needs, "self-care" at home may be a cost-effective option; these people may live alone and manage their own care which is provided on a part-time basis by paid attendants or nurses. One individual in this situation is included in the cost comparisons by setting of eight cases in Minnesota provided in Appendix I. There are also examples in the literature of technology-dependent children who make the transition to such self-care when they become adults [2].

Cost Estimates by The OTA

Tables on costs from the OTA reports on children and on the elderly are shown below [1, 2].

Table 1-2.—Charges for Life-Sustaining Technologies

	Hospital inpatient	Community setting
Dialysis		
Per treatment	--	$68-$200
Per year	—	$20,000-$30,000
Nutritional support		
Enteral		
Per day	$4-$132[a, b]	—
Per year	$1,450-$28,200	$3,000-$12,000
Parenteral		
Per day	$25-$500[b]	—
Per year	$9,125-$182,500	$50,000-$100,000
Mechanical ventilation		
Per day	$824[c]	—
Per year	$300,760[c]	$21,235-$216,000

[a] Daily hospital charges for enteral nutrition average $43, for parenteral nutrition the average charge is $196 per day.

[b] Includes formula, equipment and staff time, not hospital stay, 1985 data.

[c] Average charges, including hospital stay, for patients in 37 States, 1985 data.

SOURCE: Office of Technology Assessment, 1987

Table 15.—Comparative Charges for Home v. Hospital Administration of Intravenous Antibiotics as Reported in the Literature

Study	Home charges	Hospital charges	Comments
Antoniskis, et al., 1978	$69 per day	$243 per day	Separate home and hospital groups studied.
Eron, 1984	$10 per day in charges incurred only by home patients (training clinic visits)	$170 per day in charges incurred only by hospital patients (room charge in community hospital)	Other charges (for services provided to both home and hospital patients) are assumed equal.
Harris, et al., 1986	$207 per day	$428 per day	Charges are for patients treated initially in the hospital, then at home. Hospital charges may include surgery.
Rehm and Weinstein, 1983	$1,652 per illness	$7,380 per illness	Hospital charges are estimates (patients all got home care). Charges are averages over 4 years of the program.
Stiver, et al., 1978	$40 per day	$137 per day	Hospital charges are estimates (patients all got home care)

NOTE: All home infusions in these studies were administered by patients or their families.

SOURCES: See references 6, 50, 78, 132, and 151.

Both of the tables above compare costs by setting. The numbers in these tables reflect many of the problems associated with cost estimation and appropriate comparisons by setting that were discussed above. For example, some of the costs reported for hospitalization include room charges and others do not. On the table that summarizes charges for all the main technologies, there are enormous ranges which probably reflect differences in definitions as well as differences in the circumstances surrounding particular cases. Since the costs vary so much, and the incidence of cases is very low, such broad estimates do not provide a good basis for third party payors to predict their exposure.

Cost Estimates From the National Evaluation of Home Care Programs for Ventilator-Dependent Children

To accurately document costs, and to make defensible cost comparisons between home care and hospital care, requires a detailed data base and some complex adjustments to render costs by setting more directly comparable. Careful work of this sort has been done in an evaluation of three statewide programs that served 141 children [3]. This evaluation is limited for our purposes because it focuses on a subset of the population of technology-dependent individuals (ventilator-dependent children), but it contains the most useful and comprehensive data on costs that is presently available. These data are particularly valuable because information on the patients is also provided (see Appendix E).

In this study, home care costs include nursing and therapy services and physician fees, equipment rentals, disposable materials and prescription drugs, costs of administering the home care program, indirect costs to the family including lost time from work, and all hospital readmissions after initial discharge. The average home care costs for the 36 ventilator-dependent children were $490 per day ($14,700/month), of which $315 per day went for nursing and MD fees (see Table 4 in Appendix E).

The table below (taken from Table 5 in Appendix E) summarizes per diem cost differences in home and hospital care, showing home care to be substantially lower in cost (even after adjustment - see below). Home care costs were lower for 30 of the 36 children. As the table below shows, home care was on average $294 less per day, which represents an average savings per child of nearly $9,000 per month over hospital care.

Summary of Hospital-Home Care Per Diem Cost Differences For 36 Children In Three Demonstration Projects

	Hospital CHARGES Less Home Care	Unadjusted Hospital COSTS Less Home Care	Adjusted Hospital COSTS Less Home Care
BY PROJECT:			
State A (n=14)	$ 923 *	$ 548 *	$ 378 *
State B (n=12)	951 *	488 *	450 *
State C (n=10)	438 *	150	-12
TOTAL (n=36)	$ 795 *	418 *	294 *

* Significantly different than zero at $p < .01$.

Appendix E provides detailed excerpts on the methods for calculating costs, including the components of hospital and home care costs, and on adjustments used to correct for the typical biases found in data of this sort.

[The "adjusted hospital costs" used to calculate the differences shown in the table above have been corrected for "averaging bias" and "maturation bias." Averaging bias: ventilator-dependent children consume lower-than-average resources in ICUs, which means that an "average" (unadjusted) ICU charge overstates their resource use. Maturation bias: changes in the child's condition affect resources needed, so if the child's condition differs by setting, the comparisons of resources needed by setting will be biased. For example, if a child's condition improves at home, then home care resource needs will be relatively lower than (and therefore not directly comparable to) the previous hospital resource needs. See Appendix E.]

Minnesota Cost Data

Documentation of costs from several Minnesota sources is available. The table on the next page is based on the report of Minnesota HMO cases that is included in the position paper by the Council of HMOs (Appendix A).

As noted previously and shown in the table below, costs of care for technology-dependent individuals are high, and highly variable. The HMO cases (some of which are ongoing) have a range of total costs (to date) from $59,135 to nearly one million dollars; the average total cost is several hundred thousand dollars. Monthly home care costs for these HMO cases range from $300 to $20,000, with about $8,000 as the average monthly cost. This average monthly home care cost of $8,000 represents only costs to the HMO; it does not include the indirect costs and costs to the family that were included in the national evaluation study (preceding table) which reported average monthly costs of $14,700.

Summary Of Costs of Care for 12 Technology-Dependent Patients Reported By Minnesota HMOs

	Hospital	Home Health Care Per Month	Home Health Care Total	TOTAL COST: Hospital + Home Care
Patient:				
A	$ 57,935	$ 600	$ 1,200	$ 59,135
B	87,172	300	2,400	89,572
C	44,684	10,104	80,833	125,517
D	-	20,000	160,000	160,000
E	170,000	7,500	30,000	200,000
F	-	-	-	200,000/yr
G	232,790	4,282	7,565	240,355
H	313,000		47,000	360,000
I				400,000
J.	192,003	8,579	214,467	406,470
K	243,600	13,884	187,430	431,030
L	891,627		49,945	941,572
Range:				
lowest	44,684	300	1,200	59,135
highest	891,627	20,000	214,467	941,572
Average:				
mean	248,090	8,156	78,084	301,138
median	192,003	8,040	48,472	220,178

Source: Appendix A to position paper prepared by the Minnesota Council of HMOs, December 1987 contained in Appendix A to this report.

Hospital costs represent totals for acute care and should not be interpreted as "hospital equivalents" of the home care costs reported. In some cases, "total cost" represents the total cost during a given time period and in others it represents the total cost of the episode of care; status of some cases (closed or ongoing) is unclear in source document.

Another source of Minnesota data is the Medicaid Model Waiver (CAC) Program (see Issue 11 below). Estimated monthly costs for those served on this program are summarized below in a table taken from Appendix L (see Appendix L for additional cost data).

This table shows that the 29 clients currently being served on the CAC program have an average of about 15 hours per day of paid nursing services. The estimated monthly cost of home care for these current CAC clients ranges from $494 to $20,824, with an average of $11,254. The seven former clients remained on the program for an average of just under 1 year (range = 3 to 21 months).

Summary of Nursing Services, Length of Program Service and Estimated Monthly Costs For Former and Current Clients Served on CAC (6/85 - 1/88)

		ALL Clients (n=40)	Former Clients Only (n=7)	Current Clients Only (n=29)
PAID NURSING SERVICES:				
Range:	lowest	1 hr/day	5 hrs/day	1 hr/day
	highest	24 hrs/day	24 hrs/day	24 hrs/day
Mean Daily Nursing		14 hrs/day	15 hrs/day	15 hrs/day
Median Daily Nursing		16 hrs/day	16 hrs/day	16 hrs/day
LENGTH OF TIME ON CAC				
Range:	lowest		3 months	
	highest		21 months	
Mean Number of Months			11.5 months	
Median Number of Months			10 months	
ESTIMATED MONTHLY COST				
Range:	lowest	494	2,760	494
	highest	20,824	18,997	20,824
Mean cost		11,120	11,585	10,254
Median cost		11,940	11,619	12,543

NOTE: "All clients" includes four persons who were approved but never served on the program.

A third source of data on costs for Minnesota cases is from a survey of ventilator dependent adults described in Appendix I. These data are very useful because they are based on actual recent cases in Minnesota of adults who have been treated in three different settings: ICU/acute care; PRCU or "Prolonged Respiratory Care Unit," a transitional care facility for adults; and home. Hospital data are billed charges. The data on home costs are also more comprehensive than usual, including transportation and housing costs; these costs are shown in the table below.

Average cost of home health care for this group of ventilator-dependent adults in Minnesota is $6,544 (range = $2,046 - $19,172). As the table shows, caregivers account for about 2/3 of these home care costs. Note that three of the patients have no caregiver costs; if these three are excluded, caregiver costs for the remaining five persons average about $7,000 per month and the total average home health care cost for these five is $9,129 (which is much closer to the other Minnesota estimates reported above).

Monthly Home Care Expenses Reported by Eight Ventilator-Dependent Adults in Minnesota in 1985

	TOTAL MONTHLY HOME CARE EXPENSES	BY TYPE OF EXPENSE							
		Caregivers		Equipment		Supplies		Other	
		$	% of total	$	% of total	$	% of total	$	% of total
Patient:									
A	$ 2,323	0	-	1,450	62%	343	15%	530	23%
B	5,382	4,151	77%	866	16%	105	2%	260	5%
C	6,260	4,234	68%	1,369	22%	361	6%	296	5%
D	2,343	0	-	1,290	55%	206	9%	847	36%
E	9,448	6,912	73%	1,090	12%	411	4%	1,035	11%
F	2,046	0	-	1,365	67%	262	13%	419	20%
G	5,381	4,226	79%	302	6%	228	4%	625	12%
H	19,172	15,480	81%	1,170	6%	450	2%	2,072	11%
AVERAGE (mean)	$ 6,544	4,375	67%	1,113	17%	296	5%	760	12%

SOURCE: Alex Adams of Health East; see Appendix I.

[The three patients with no caregiver expenses are in the following situations: two have spouses who provide full-time care and the other (who is on a ventilator at night) provides self-care].

Cost comparisons by setting for this same group of eight ventilator-dependent Minnesotans are shown below in another table taken from Appendix I. This table shows that the average monthly cost of home care for these eight individuals represents about 1/3 of the average costs that these same people incurred while in a transitional facility, and just 1/10 of the costs of their care in an ICU.

Summary of Comparisons Across Settings of Monthly Expenses For Eight Ventilator-Dependent Adults in Minnesota

Average Monthly Expenses By Setting			HOME CARE AS A PERCENT OF	
Home	PRCU (transitional)	ICU (acute)	PRCU (transitional)	ICU (acute)
$ 6,544	$ 19,351	$ 64,513	35%	10%

(SOURCE: Alex Adams of Health East; see Appendix I)

Summary of Cost Data

The table on the next page summarizes data on costs from the sources already discussed (National Home Care Evaluation, Minnesota HMOs, Medicaid Model Waiver Program, survey of ventilator-dependent persons) and from several additional sources, including the Michigan program for "responauts" (ventilator-dependent persons). As noted in the table, more detailed information from all these sources is contained in various sections of the Appendix to this report.

Summary of Cost Estimates for Home Care

Data Source/ Program	Number Of Patients	Percent Who Use Ventilator	Average Per Diem Costs	Average Monthly Costs
MINNESOTA				
Minnesota CAC (Medicaid Model Waiver Program; Appendix L) (6/85-1/88)	40 (mostly children)	22 %	$ 371	$ 11,120
Minnesota ventilator-dependent adults; Appendix I) (1985)	8 (adults)	100 %	218	6,544
Minnesota HMO members (Appendix A to Council of HMOs position paper and table in this report)	12	not known	272	8,156
ELSEWHERE				
Pediatric Home Care: Evaluation of Three Demonstration Projects; Appendix E (1986)	36 (children)	100 %	490	14,700
Michigan Responaut Demonstration Project; Appendix F (1987)	7 (children)	100 %	275	8,250
Study cited in OTA Report on Children (Kahn 1984); Appendix I	26 (children)	100 %	267	8,000

Each of the sources shown above defines "home care costs" in a unique way, so the dollar amounts are not directly comparable. The most comprehensive accounting of costs is done by the Pediatric Home Care evaluation; costs for this program are the highest of those listed above. Additional information on each of the sources/programs shown in this table is provided in an Appendix.

Conclusions About Estimating Costs of Home Care for Technology-Dependent Individuals

- Based on the cost data described above, it is clear that good cost estimates and good comparisons by setting require explicit and comprehensive definitions of medical and non-medical components of costs. Most of the data shown above fall short in several ways, generally by excluding some of the components of costs (non-reimbursed costs, indirect costs, costs to individuals/families), and by reporting the most conveniently gathered data, such as hospital charges (rather than adjusted hospital costs). Consequently, all cost estimates must be regarded with some skepticism.

- Home care is quite consistently shown to be less costly than institutional care for those patients receiving home care (many of whom are receiving home care precisely because it is cheaper for them). In some cases, the net savings in home care is very dramatic.

- Costs of both hospital and home care for technology-dependent individuals are high and highly variable because so many different factors affect costs. The best available cost estimates for home care are based on ventilator-dependent individuals: Monthly home care for these cases averages from about $8,000 to about $14,000. Paid nursing services account for the bulk of the costs; equipment costs average about $1,000 per month and supplies average several hundred dollars per month. Unfortunately, we have almost no information on the average duration of cases, so it is impossible to estimate average total home care costs.

- Costs of case management have been reported at about $4,000 per case per year by several demonstration projects [4].

- According to the evaluation of the Michigan program for ventilator dependent children [5], home care costs are predictably higher in the first few months at home, then taper off as nursing needs gradually decline. Home care plans that do not initially demonstrate a net savings for home care over hospital care may do so after several months.

Recommendation

- Comprehensive benefits for home care for technology-dependent individuals should not be mandated because it is impossible to predict the costs of this care with a reasonable degree of accuracy.

ISSUE 8

DISCHARGE PLANNING AND CASE MANAGEMENT

It is discharge planners and case managers who orchestrate the complex arrangements that make it possible for a technology-dependent persons to be cared for at home. Not all home care is arranged by discharge planners/case managers, but the process tends to be more comprehensive and more efficient when it is [5, 3, 4, 26, 31].

Materials are included in the appendix to give a sense of what is required to arrange home care for ventilator dependent children. Details on case management in the Minnesota Medicaid Model Waiver program and in an Iowa home care monitoring program are in Appendix G; the discharge process and case management for 141 ventilator-dependent children in three home care demonstration projects are provided in Appendix E, and annotated checklists of case management procedures for the Michigan responaut home care program are in Appendix F.

Many of the concerns expressed in the position paper by the CHHCTF are linked to their perceptions of shortcomings in communication and coordination of care. The problems the task force has identified are described below; as the task force points out, many could be greatly reduced or eliminated by more knowledgeable, systematic, and timely discharge planning and case management.

Potential Problems Caused By Lack Of Knowledgeable And Authorized Decision Makers

Excerpts from position paper:

> <u>CHHCTF Summary of Concerns # 3</u>: "In most successful attempts to discharge children who are technology-dependent, in lieu of hospitalization, there has been an inordinate delay caused by lack of access to persons within the third party payor organization who understand the principles involved and have the authority to make decisions. The sophisticated discharge planning required to place a child who is ventilator-dependent in the home may be foreign to the generic third party payor case manager/payments coordinator."

> <u>CHHCTF Summary of Concerns # 4</u>: "Decisions regarding the provision of medically needed services in the home setting have, on occasion, been made by the medical director of the plan who may not have expertise with that technology, who may not be a pediatrician....."

In the concerns quoted above, the CHHCTF traces part of the problem to lack of specialized knowledge about technology-dependent individuals and their needs. Home care for these cases is a relatively new phenomenon, and the cases themselves are rare, so many discharge planners and case managers lack experience as well as knowledge. Bureaucratic delays compound the problems that stem from lack of knowledge and experience; the CHHCTF calls for health plans to designate a representative who has the authority to expedite arrangements:

> <u>CHHCTF Recommendation # 2</u>: "COMMUNICATIVE AND COORDINATIVE: ...HMOs must designate a specific individual within their organization who will be available to discuss medical and nursing decisions with the discharge planning team and the families."

The Need For Case Management And A Well-Coordinated, Multidisciplinary Discharge Planning Process

As the following excerpts from position papers show, there is consensus on the merits of strengthening internal case management (third party payor case management).

Insurance Federation of Minnesota Recommendation # 2: "We recommend that third party payor case management be recognized as an integral part of the home care and that steps be taken to foster cooperation and communication between third-party payor case management teams, providers, and consumers."

CHHCTF Recommendation # 3: COMMUNICATIVE AND COORDINATIVE: "Managed health care systems need to support a discharge planning process similar to that required by the Federal Medicaid Community Based Model Waiver. This multidisciplinary discharge planning process is the national and community standard for determining the amount and quality of services needed to effect safe and effective home care for a child who is technology dependent. An HMO staff person with decision making authority should be a member of the discharge team."

CHHCTF Recommendation # 4: COMMUNICATIVE AND COORDINATIVE: "We look to managed health care plans to support a process for periodic reevaluation of the child that will determine the need for ongoing services in the home. That process will evaluate the child's physiologic improvement, degree of technology dependence, and the family/psychosocial support structure in the context of a multi-disciplinary health care conference."

Case Management Should Be Required In Conjunction With Special Funding Pool

Case management is viewed as an integral part of the special care fund (point 3 of the three-part agenda agreed upon by the Council of HMOs, the CHHCTF, and the Insurance Federation).

Excerpt from position paper:

Council of HMOs' Recommendation # 4-D: "Require that within the funding pool, a case management system be maintained. For individuals previously covered in a case-managed plan, the plan would retain responsibility for the case management function; for those plans without a case management system, the plan would be required to purchase those services from another entity. The interdisciplinary panel would monitor this function."

Medically Necessary Care And Cost Containment

Though there is consensus on the merits and virtual necessity of sound case management, the CHHCTF is concerned that many case management decisions are made within a managed care system where CHHCTF believes that financial or business considerations may drive the decision making to the point of overriding the medical opinions of experts and jeopardizing the care of the patient:

CHHCTF Summary of Concerns # 4: "Decisions regarding the provision of medically needed services in the home setting have, on occasion, been made by the medical director of the plan who may not have expertise with that technology, who may not be a pediatrician, and who has a vested self-interest in preserving the assets of the plan. This can become a serious conflict of interest situation particularly when the plan's own physician decides in favor of the plan and is in disagreement with expert nursing or tertiary medical consultation."

In the quotation shown below, the CHHCTF would seem to view any case management that is done by third party payors as an inherent conflict of interest situation that is best avoided:

> CHHCTF Summary of Concerns # 5: "Once the technology-dependent child is in the home setting, in lieu of hospitalization, the reassessment of needed services may be in the hands of a case manager employee of the third party payor, whose decisions represent a conflict of interest. The reevaluation of medically needed services is a decision of the family and health care team that can only be based on the assessment of the child's physiologic progress and the integrity of his family/psychosocial support system."

As the excerpt from the HMOs' paper shown below points out, conflict of interest situations are not confined to HMOs:

> Council of HMOs excerpt from page 13: "... it must be recognized that the potential for conflicts of interest is not limited to health plans. Treating physicians, home health care agencies, and hospitals along with other health care organizations, may have relationships that form financial interdependencies...."

In any case, in an era of scarce resources and escalating costs, the position taken by the CHHCTF on case management and conflict of interest seems unrealistic and unwarranted. Case management by managed health plans and other third-party payors plays a vital role in coordinating services and reducing the costs associated with over-service and unnecessarily expensive services which occurs in the fee-for-service system. It is in everyone's interest to closely monitor the costs of health care. Financial considerations should not be the sole basis for decisions, but they certainly must be included as an important aspect of the decision-making process.

At the same time, miscommunications of various sorts do occur, conflicting pressures sometimes exist, and unwise decisions are occasionally made. By suggesting that outside review mechanisms be developed, the Council of HMOs reinforces the proposal for a multidisciplinary expert review panel (point two of the three point agenda) that would help all parties (patients, providers, payors) achieve the goal of high quality care that is provided in a cost-effective manner.

> Council of HMOs excerpt from page 13: "As the community moves forward in the discussion, it may be appropriate to develop mechanisms for making and reviewing treatment decisions for this population in a setting which is further removed from all conflicting financial interests."

ISSUE 9

MULTIDISCIPLINARY EXPERT ADVISORY REVIEW PANEL

The Need To Encourage Cooperation and Discourage Media Exploitation

Payors and advocacy groups are united in their support of an expert review panel. They agree on the need for multi-disciplinary teamwork and cooperation among payors, providers, patients and their families to meet the needs of technology-dependent persons, and see an important role for an outside advisory body in this process. Besides providing some balance in conflict of interest situations that may pit cost containment pressures against medical judgments, an independent expert review panel could provide a useful and constructive forum for dispute resolution.

Since there is no such panel presently available, consumers with a complaint against their health plan have on occasion used the media as their forum instead. Both HMOs and the CHHCTF agree that having a review panel could help prevent misuses of the media by providing the knowledge and objective perspective of expert "outsiders" to assist in resolving disputes.

Excerpts from position papers:

> <u>Council of HMOs' Recommendation # 11</u>: "The provider/payor community must recognize their responsibility to deal with these cases efficiently and effectively, especially regarding prompt coordination with multiple health care professionals in the discharge planning process and advocacy groups should cease using the media to exploit the transition of technology dependent individuals from hospital to home."

> <u>CHHCTF Recommendation # 5</u>: COMMUNICATIVE AND COORDINATIVE: "We look to managed health care plans to support a centralized arbitration process by a multidisciplinary team operating with the input of physicians and nurses expert in the care of children who are technology dependent. There must be an effective method of resolving impasses between the child/family and his health plan so as to avoid the public polarization that we have seen in the past."

Proposed Review Panel Could Provide Quality Assurance for Care Fund Cases

In addition to serving an advisory and arbitration role, it has been suggested that the expert review panel might be involved in oversight for the cases that are funded from the special care fund:

> <u>Council of HMOs' Recommendation # 4-C</u>: "Establish an interdisciplinary panel including HMO medical directors, representatives from Children's Home Health Care Task Force, home health agencies, and other interested parties that would review the home care treatment plan established for the patients and monitor the care being supplied through the funding pool's contracted providers to assure quality care."

ISSUE 10

INADEQUATE INSURANCE COVERAGE

Insurance Coverage Is Usually Inadequate For Prolonged Home Care

Access to financing for home health care for technology-dependent individuals depends on the extent of private and public insurance coverage, particularly on whether long-term care in the home is covered. Some people have no health insurance at all (see Appendix J; low income families are less likely to have insurance) and many more people are "underinsured." The literature suggests that only a small percentage of American families have insurance that provides truly adequate coverage for home health care of a prolonged nature. Most insurance coverage falls short because of overall maximums, absence of catastrophic stop-loss, or exclusion of the benefits that are needed.

- Many policies specify maximum amounts (annual, per episode, lifetime) to be paid. The prolonged and exceedingly expensive care required by many technology dependent individuals can rapidly exceed such maximums. Though there is a trend in the health insurance industry toward higher lifetime maximums (up to $1 million from $250,000), many families are faced with lower limits, and even a million dollars may not be enough in some cases.

  The national evaluation of 141 technology-dependent children served on three programs shows that 58% had a cap on total expenses, and 35% had a limit of less than one million dollars [3]. More information on their insurance coverage, including sources of payment for home care and hospitalizations, is available in Appendix E.

- Another major problem in health coverage for the technology dependent is that the expenses are so high that coinsurance/out-of pocket amounts can be out of reach. For example, few families can afford to pay 20% of costs for a long period if costs are several hundred dollars per day. Fortunately, many health insurance policies have catastrophic "stop-loss," which puts a cap on the family's out of pocket expenses. One source says that 3/4 of employees have this type of protection [1].

- Limits on covered services are a major problem for families with insurance who wish to care for a technology dependent person at home. If home health care is covered (and it often is not), the coverage is typically oriented toward a recovery period from an acute care episode: it provides coverage for "intermittent/part-time" skilled nursing care, which often translates into a limited number of visits by an RN or LPN. Technology dependent individuals who are being cared for at home are far more likely to require "shift nursing," or "private duty" nursing, which is very seldom covered.

- We have seen in a previous section that definitions oriented toward chronicity or prognosis can limit the financing of prolonged home health care for the technology dependent; such definitions are quite common.

We have noted that some HMOs and commercial insurers make exceptions on a case-by-case basis when home care appears to be a cost-effective alternative to hospital care [Appendix J and Appendix B to the Council of HMOs position paper contained in Appendix A]. One problem, particularly hard on single parents, is that home care tends to be lower only when parents take on a share of the nursing care, yet parents need to stay employed to maintain their health insurance coverage. This is an important consideration, since technology dependent persons find it virtually impossible to get health insurance.

Public Funding and Charitable Sources

Public programs are the other major payor for health care for the technology dependent. In addition to the regular Medicaid program, Minnesota has a Medicaid model waiver program (more on this below) and there are some other federally funded or subsidized programs that provide assistance under certain conditions; these include SSI maintenance payments to disabled people and social services block grant funds that can sometimes help with transportation, housekeeping and similar expenses.

Along with Medicaid, charities are often seen as the funder of last resort. In fact, most charitable foundations are oriented toward research, public education, and advocacy. Very few provide support for nursing services or other medical care. There are great variations in the resources available by disability, but most foundations that provide financial assistance to individual patients cover items that are typically non-reimburseable [Appendix K).

ISSUE 11

INEQUITABLE DISTRIBUTION OF FINANCIAL RESPONSIBILITY FOR HOME CARE FOR THE TECHNOLOGY DEPENDENT

Mandating Home Care Benefits

Financing of home care is clearly an enormous problem. Mandating of home care benefits has been proposed to the Minnesota Legislature as a way to deal with this problem. As already noted, the lack of good estimates of the size of the population and of the costs of care would pose a major problem if benefits were to be mandated. It is likely that HMO and commercial insurance premiums would rise dramatically if benefits adequate to cover prolonged home care were mandated. There is another very serious shortcoming to mandated benefits as a "solution" to the financing problem, which is the lack of equity among payors because self-insured employers would be exempt from such a mandate. The OTA report on children notes that 13 states have laws that require home health care services, but it dismisses mandated benefits as a viable solution because of this exemption of self-insureds. In Minnesota, it is estimated that about half or more of insured persons are covered by self-insured employers who would be exempt from a mandate.

The Need for More Equitable and Better-Coordinated Financing of Care

The problems of inequitable financing of home care are stressed in the position papers:

> <u>Council of HMOs' Key Conclusions # 2</u>: "All third-part payors (self-insured plans as well as traditional insurance companies) must be included in the consideration of who shall pay for the home health care services of technology-dependent individuals."
>
> <u>Insurance Federation of Minnesota Recommendation # 3</u>: "We recommend that the cost of care for technology dependent individuals which are not covered by third-party payors be equally shared by the health care user population. A method currently being reviewed at the federal level is an inpatient hospital tax which would be utilized to create a risk pool."
>
> <u>Council of HMOs' Recommendation # 1</u>: Educate policymakers and consumer advocacy groups that in order to provide the broad array of healthcare services needed to keep technology-dependent individuals in a non-acte, home setting, the financial responsibility for providing those services must be spread equitably among private payors (indemnity insurance carriers, HMOs, self-funded health plans, and health service organizations, i.e., Blue Cross/Blue Shield), state and federal government, and the health plan policy holder."

In order to provide continuity of high-quality care, all possible resources (private payor, state and federal, family caregivers, charitable and voluntary community efforts) must be coordinated. The need for better coordination of financing is clear; how to accomplish it is not.

Medicaid Model Waiver Program: Controversy Over Cost Shifting And Access To This Program By HMO Members

In 1985, Minnesota received approval to establish a Medicaid Model Home And Community Based Waiver program (CAC) that was authorized to serve up to 50 chronically ill children (see Appendix L for more on CAC). Besides the regular Medicaid services, this model waiver program offers case management, environmental modifications to the home, respite care, homemaking services, family counseling and training, and foster care.

To be eligible for this program requires that:

- 0 The person be under 65 (until October 1987, the CAC program served only children);
- 0 The person be hospitalized or at risk of hospitalization;
- 0 The person be eligible for Medicaid (deeming waiver);
- 0 The person (or parent, in the case of children) chooses community care;
- 0 The costs to Medicaid of community care must be less than the costs to Medicaid of institutional care (cost savings are figured on a case-by-case basis rather than on average for all served on the program).

The federal government offered this model waiver program to give states the option of eliminating situations where individuals must remain institutionalized in order to retain Medicaid eligibility even though they could receive the needed services at home and at less cost to Medicaid. The deeming rules that make a child eligible for Medicaid after one month of hospitalization regardless of parents' income are extended to community based care.

This program has served approximately two dozen persons to date (exact figure to be supplied). A key provision of this program which has generated controversy is the requirement that the costs to Medicaid of community care must be less than the costs to Medicaid of institutional care. This is a federal requirement, since the waiver is granted on the condition that costs not exceed what they would be without the waiver. There are differences of opinion on how the requirement should be interpreted. The Council of HMOs believes that technology-dependent persons with some insurance coverage should not be categorically excluded from eligibility, and the CHHCTF maintains that the HMOs are attempting to cost-shift:

> CHHCTF Summary of Concerns # 6: "We have witnessed attempts to cost shift onto the Federal Medicaid Community Based Model Waiver (CAC Program). The Medicaid waiver was created to serve children eligible for Medicaid and to save money through the timely, effective, and safe hospital discharge of technology-dependent children. Continued attempts to cost shift to this beneficial program result in delays in patient discharge and increased total costs to the health plan. Indeed the appeals process at the Department of Human Services is upholding the interpretation of the purpose of the Medicaid waiver by denying its services to children who have an existing form of health insurance."

Council of HMOs excerpt from page 12: "The fact that 31 slots have been funded and approved and may go unused is ironic and sad for HMOs have been accused of attempting to cost shift onto...CAC. .....It is the contention of the Minnesota Council of HMOs that the CAC Medicaid waiver program should be utilized whwnever possible and certainly when an applicant's health insurance or HMO home health care benefits run out. Currently, it is not clear to the Minnesota Council of HMOs whether or not federal regulations exist that totally preclude an applicant who has insurance or HMO coverage from eligibility for the waiver program after a certain level of contract benefits have been utilized."

Council of HMOS recommendation # 6: "Encourage the MDH to review the Minnesota Department of Human Services opinion on insurance being a barrier to eligibility for the Medicaid waiver program Community Alternative Care Program (CACP). Consider seeking changes to Minnesota's current CACP program to broaden classification of who is eligible."

A paper based on an evaluation of the CAC program describes the problem in the following way:

> Eligibility for waiver changed over the course of the program's existence, with acceptance and then denial of waiver to insured children. Insurance is tied to the demonstration of Medicaid savings which bars children who have:
>
> 1) inadequate insurance (unless so grossly inadequate that Medicaid would pay part of the hospital care and home care would cost less);
> 2) Medicaid and insurance;
> 3) medical needs in excess of homecare costs (unless care plans can be revised to show a savings to Medicaid);
> 4) insurance that will not cover home care costs;
> 5) insurance that carries high co-payments;
> 6) care levels that are lower than "at risk for hospitalization" and not mentally retarded....
>
> While waiver has demonstrated Medicaid savings for uninsured eligible children, it has served a small population of medically fragile children. This is true because eligibility policies have served as stringent gatekeepers to the program.... The two criteria which restrict eligibility -- level of care and savings to Medicaid-- present problems to the health care system at large when looking at the bigger picture of placement and reimbursement for medically fragile children... demonstrating savings to Medicaid, although more easily defined and consistently applied after the new policy interpretations were enacted, carries many ethical issues. When cost assumes primary importance in a program's direction, humanitarian concerns may take a back seat. If a family has to accept service reductions in order to demonstrate Medicaid savings, their child's safety and their health may be at stake. Financial concerns have caused some children to be detained in the hospital while kinks in reimbursement were worked out. For nonwaiver children, a safe and adequate careplan becomes an even more serious issue because allowed services vary according to individual insurance coverage, not need, and for some families coverage is inadequate.

> The need for third party payors to assume responsibility for adequately providing care for children on home care programs is crucial for the child's and family's survival. In addition, more effort should be expended toward identifying those children who have exhausted private payor sources, and fall through public programs' eligibility cracks.... The waiver, while a help to some, did not solve the problem of how this society plans to care and pay for medically fragile children. [15: pages 14-15].

ISSUE 12

CARE FUND FOR THE TECHNOLOGY DEPENDENT

Establish A Funding Pool To Pay Costs Of Care For The Technology Dependent When Third Party Coverage Is Exhausted

The HMOs, the Insurance Federation, and the CHHCTF all support the proposal to develop a care fund for the technology dependent which would provide a "safety net" to help pay for the costs of care when third party coverage is exhausted.

Excerpts from position papers:

> CHHCTF Recommendation # 8: FINANCIAL: "The idea of financial risk pooling with other payors, including the government, could provide a base over which to spread these tremendous costs and, at the same time, protect an individual health plan from the vicissitudes of random selection."
>
> Council of HMOs' Key Conclusions # 6: "Should federal initiatives fail or be delayed, Minnesota should consider establishing a risk-pool vehicle (similar to the Minnesota Comprehensive Health Association) whereby all third-party payors would contribute funds to eliminate the present situation of potentially unlimited expenditures for home care services for the technology dependent."
>
> Council of HMOs' Recommendation # 4: "Establish a funding pool mechanism similar to the Minnesota Comprehensive Health Association (MCHA), but with self-insured entities included, that would assume responsibility for funding on-going home health care of technology-dependent individuals once the third-party payor entity has reached a "to-be-determined" case expenditure maximum. Consensus would have to be reached regarding the diagnoses/conditions deemed to categorize an individual "technology-dependent." Once the case is in the funding pool, the administrators may enter into favorable, discount charge arrangements with care providers and case management experts."
>
> Council of HMOs' Recommendation # 4-A: "Reach consensus as to the benefits to be available to qualified individuals through the funding pool."
>
> Council of HMOs' Recommendation # 4-B: "Coordinate efforts and coverage between the private funding pool and public payor programs such as the Medicaid waiver program to provide a broad array of benefits --custodial and other appropriate servcies necessary to support the technology-dependent individual and his/her family."

Council of HMOs' Recommendation # 4-C: "Establish an interdisciplinary panel including HMO medical directors, representatives from Children's Home Health Care Task Force, home health agencies, and other interested parties that would review the home care treatment plan established for the patients and monitor the care being supplied through the funding pool's contracted providers to assure quality care."

During recent group meetings, it was emphasized that the fund would not be a part of MCHA, nor would it be modeled directly on MCHA, since the intent is clearly quite different. The care fund is conceived as something that would be funded by some yet-to-be-determined combination of public and private funding. In discussing how the private side might be funded, the Insurance Federation suggested the basic principle of a "user tax," perhaps analogous to the new federal excise tax on immunizations designed to create a care fund for children who get adverse reactions to the immunizations. An inpatient hospital excise tax, for example, would ensure a broader and more equitable base of funding than other means such as contributions from insurers (from which self-insured employers would likely be exempt).

There is consensus that such a care fund could go far toward addressing some of the equity and access problems documented throughout this report. There is also consensus that there are many obstacles to implementing the fund, including restrictions on mingling public and private funds. Many difficult questions would have to be addressed. What services would be covered? What would be the relationship between the fund and ongoing insurance (e.g., coverage of acute care)? Between Medicaid and the fund? Could cost savings to public sources be demonstrated?

Conclusions

Private insurance as presently structured does not meet the needs of most technology-dependent children and their families. Public funding and programs pick up some of the slack, but there are problems of restricted eligibility, necessity to "spend down," and burdens of uncompensated care borne by hospitals for those who "fall through the cracks."

Because the costs of care are so extraordinarily high, it is likely that some form of public funds will be used at some stage for most chronically ill technology-dependent persons. Because the incidence is low, it is most equitable to spread the burden of the care as broadly as possible.

Third party payors should assume their fair share of responsibility, but their financial viability should not be threatened in the process.

Deliberations about financing solutions should weigh the non-monetary costs to families and the best interests of the technology-dependent person.

Recommendation

Support the ongoing collaboration among the CHHCTF, the Council of HMOs, and the Insurance Federation in seeking to devise a care fund for the technology dependent.

ISSUE 13

MONITOR INVESTIGATIVE AND LEGISLATIVE EFFORTS AT THE FEDERAL LEVEL

Minnesota Should Use The April 1988 Report Of The Federal Task Force On Technology-Dependent Children As A Resource

As the position papers point out, it is important to monitor developments at the federal level and to take advantage of the federal investigation, findings, and recommendations on how to deliver health care to technology-dependent children.

Excerpts from position papers:

> Insurance Federation of Minnesota Recommendation # 1: "The Minnesota Department of Health should track the work of the Federal Task Force on Technology Dependent Children and provide the Minnesota Legislature with a summary of the report [to be issued in April 1988] to be used as a resource for the Legislature."
>
> Insurance Federation of Minnesota Recommendation # 3: "...In view of the comprehensive study being done by the Federal Task Force on Technology Dependent Children, we recommend that the report to the Minnesota Legislature be postponed until the report of the Federal Task Force is delivered to the United States Congress."
>
> Council of HMOs' Recommendation # 9: "The Minnesota Department of Health should be directed to track the work of the federal task force on technology-dependent children and of related bills introduced into Congress in 1988 and should provide the Minnesota Legislature with a summary of these initiatives to be used as background for the State legislators' deliberations."

Congressional Bills That Address Catastrophic Cases/Technology-Dependent Children

Several bills that could have far-reaching impact on health care funding for technology-dependent individuals are presently being considered in the Congress. It is important to monitor these legislative initiatives, particularly to anticipate potential changes in federal funding, such as provisions for catastrophic cases, that could make it easier to finance care for this population.

A description of the relevant bills is included in Appendix M.

Excerpts from position papers:

> Council of HMOs' Key Conclusions # 5: "There are four bills in Congress which address financing for technology dependent children. (One of the bills, H.R. 2762, offered by Representative Pepper seeks to address catastrophic Medicare claims and would include technology dependent children."
>
> Council of HMOs' Recommendation # 9: "The Minnesota Department of Health should be directed to track the work of the federal task force on technology-dependent children and of related bills introduced into Congress in 1988 and should provide the Minnesota Legislature with a summary of these initiatives to be used as background for the State legislators' deliberations."

ISSUE 14

LACK OF ALTERNATIVE PROGRAMS AND FACILITIES

The lack of alternative placements in Minnesota narrows the choice for most technology dependent persons to home v. hospital, and reimbursement is often the decisive factor. This lack of a full continuum of care is one of the biggest frustrations faced by technology dependent persons, their families, their physicians, their discharge planners/case managers, and their third party payors [see Appendix O for descriptions of the key alternatives that are needed].

Excerpts from position papers:

> Council of HMOs' Recommendation # 7: "Commence a study to determine whether or not a skilled nursing facility or transitional care center for the technology-dependent population can be established in the Twin Cities. (Due consideration should be given to modeling such a special skilled nursing or transitional facility to that of Care Centers of Michigan. Care Centers is a nursing home that has accepted ventilator-dependent patients since 1983. Their program provides long-term placement, and transitional placement to permit training and preparation of patients who will eventually return home, and/or short-term respite for family caregivers."
>
> CHHCTF Recommendation # 7: FINANCIAL: "We look to managed health care plans to work cooperatively with providers to develop creative alternatives for effectively addressing the complex needs of these children and their families. These needs can be addressed and financial risk to the managed health care plans reduced through creative endeavors such as economy of scale activities and risk pooling. The managed health care plans are urged to join providers to form a task force to explore and implement service alternatives. [Economy of scale programs include transitional care units, medicalized day care centers and group foster homes.]"

Alternative placements such as foster homes, group homes, or transitional care facilities can offer economies over home care by allowing one full-time caretaker to provide nursing services for several technology dependent individuals. At the same time, they offer a more "home-like" setting than hospitals. These facilities would probably be conducive to the spontaneous development of informal support systems among the families of the technology dependent persons as well as among the patients themselves. This would help reduce the stress and social isolation experienced by all those involved.

Having alternatives to the home v. hospital choice is especially important to technology-dependent adults who have no voluntary caretaker, and to families who are not well-suited, for whatever reason, to care for their child at home. As the evaluators of the three SPRANS home care projects stress, families should not be 'forced' to take their child home or made to feel that they are 'bad parents' if they are not able to do so [3].

Foster homes are one alternative for technology-dependent children under such circumstances. Developing foster home options presents some special challenges. It is very hard to find people willing to take on the responsibilities and intensive time commitments required of foster care for technology-dependent individuals. Often, the arrangements needed to make foster care an acceptable alternative may make it more costly (but not necessarily less desirable) than hospitalization.

Foster care also presents some ethical dilemmas. Under certain conditions, releasing a child to be cared for in a foster home instead of in his or her own home is necessary to secure financing-- federal funding can be more generous toward foster caretakers than toward the actual parents [1, 3, 5, 6].

Transitional care facilities designed to meet the special nursing needs of technology-dependent individuals represent another point on the full continuum of care that is not available in Minnesota. At present, there is no pediatric alternative care facility in Minnesota, and there are very limited specialized nursing-home-type alternatives for adults. Several individuals and groups have had great interest in developing such facilities but have run into major barriers in the form of reimbursement difficulties and licensing hurdles. Apparently the CHHCTF is currently working on creating more alternative care options.

Recommendation

Support the efforts of the CHHCTF and others to encourage the development of foster and group home options; conduct a feasibility study on alternatives such as transitional care units and group homes.

ISSUE 15

EDUCATION FOR TECHNOLOGY-DEPENDENT CHILDREN

The public costs of caring for technology-dependent children include the costs of their education, which has special requirements that can be quite expensive. The literature on education for the technology-dependent being cared for at home is extremely limited; much of what is known is summarized in the Appendix to the OTA report on children which is included as Appendix P to this report.

Public schools are mandated by Public Law 94-142 to provide educational and necessary related supportive services to handicapped children. These services presently provided by the schools can include physical and speech therapy, adminstration of medications, and even urinary catheterization [1:92].

> Since school attendance may account for more than one-fourth of a child's time and care needs, one consequence of this federal mandate is to shift substantial portions of the cost of a child's medical care services from Federal to State and local governments (i.e., from Medicaid to the public schools) and from private health insurers to the public. The issue of who will pay for the medical care of these children is a growing one. Public schools, pressed for funds, may often be reluctant to pay for additional full-time nurses and special transportation vehicles and to assume legal liability for medical care during school hours. At the same time, private insurers - and Medicaid- will seek to minimize their costs of serving technology-dependent children at home by shifting financial reponsibility to the schools [1:92].

There are several options in terms of who provides the care during school time and who pays for it (see Appendix P). The law that "mainstreams" children with special needs into the regular school system will soon be expanded to include ages 0-3. There is much speculation about the implications of this expansion for the cost-shifting issues related to technology-dependent children that are outlined above, particularly since premature infants will be included in the mandate for educational services.

Data are not readily available on how educational services for technology-dependent children cared for at home are presently being handled in Minnesota, and how the costs are paid. The Minnesota Department of Public Health Nursing has expressed interest in compiling this information and also in studying how to effectively coordinate nursing services and educational services for this special group of students.

ISSUE 16

VOLUNTEER EFFORTS

Encourage Volunteer Efforts That Support Home Health Care For The Technology Dependent

The Council of HMOs recommends that volunteer assistance for the technology dependent be encouraged:

> Council of HMOs' Recommendation # 10: "Volunteer organizations of health professionals and other community volunteers should be encouraged to offer home health support services to families with technology-dependent individuals."

It may be more practical and helpful for families in high stress home care situations if volunteer efforts were oriented more toward services such as babysitting, errand running, and housekeeping than toward actual home health care services. Providing the nursing care requires intensive training and it is unlikely that volunteers would commit the effort, or that the family would reach a high comfort level with occasional volunteer caretakers. Regardless of the services offered, volunteer efforts would need to be organized in a way that did not require a lot of family time and effort to coordinate.

ISSUE 17

EDUCATION FOR HEALTH PROFESSIONALS AND OTHERS

Home care represents innovative care for chronically ill technology dependent individuals, so there is much need to educate health professionals (including discharge planners and case managers) and the public about the unique nature of these cases. There is a need for better understanding of the day-to-day costs and benefits of prolonged technology dependence. Health professionals and the public also need to understand that decision making in these cases is not just one decision with a predictable outcome, but a whole series of decisions with biomedical-ethical overtones that are typically made in a context of great clinical uncertainty [6, 3, 17].

The national evaluation of three programs concludes that new home care programs for technology-dependent individuals should expect lack of understanding and should not be surprised to face some outright opposition. It proved difficult in several programs to find physicians who were supportive and willing to handle cases [3, 5].

It is not surprising that many health professionals are poorly informed about home care options and its special case management requirements, since most of the practical information about home care for technology-dependent individuals has appeared in journals, books, and unpublished documents within the past two years. The Brook Lodge Symposium held in 1984 is one of the milestones in changing opinion about the desirability and viability of home care for ventilator-dependent persons. The two book length OTA reports appeared in mid-1987; these two publications are the most comprehensive resources to date and they have become more visible due to publicity on the Federal Task Force on Technology-Dependent Children. During the past few years, several professional associations have published detailed guidelines on managing home care for the technology dependent [32, 7]. Detailed evaluations and educational materials based on a number of demonstration projects are probably the most useful materials for discharge planners and case managers, and these are just beginning to emerge ([reference # 6 and Appendix E].

IV. SUMMARY OF RECOMMENDATIONS

Recommendation 1:

That no action be taken at this time to mandate comprehensive benefits for home health care for technology-dependent individuals, because necessary data are lacking and because such action would in any case have very undesirable effects on health care premiums and on the fragile health care market.

Mandating of benefits requires good data on incidence and costs of care, both of which are lacking. It is presently impossible to predict with a reasonable degree of accuracy either the current or future size of the population of technology-dependent individuals. It is likewise very difficult to project costs of care for this group because costs are so highly variable and the group as a whole is quite small.

Mandating of comprehensive home health care benefits would likely trigger substantial increases in insurance premiums and could threaten the fragile health care market.

The three remaining recommendations are directly related to the three-point agenda (standardized definitions, "safety net" care fund, and expert review panel) developed jointly by the third party payors, the advocacy organizations, and others who have attended the series of meetings convened by the MDH.

Only recommendation #2 requires action from the Minnesota Legislature; this recommendation would direct a state agency to develop a plan for a Demonstration Project. Recommendation #3 deals with standardized definitions; it requires action from the MDH and the DOC. Recommendation #4 supports the *ongoing development of a multidisciplinary expert advisory and review panel by an ad hoc committee of volunteers composed of third party payors, advocacy organizations, providers, and state agencies; it requires continued cooperation from the relevant state agencies but no formal action at this time from any part of state government.*

Recommendation 2:

That the Minnesota Legislature designate an appropriate state agency to prepare for the Legislature a proposal for a Demonstration Project to determine the feasibility and costs to fill gaps in coverage for home health care for technology-dependent persons.

The plan for the Demonstration Project shall address at a minimum the following questions:

1) Definition of the eligible population;
2) Estimated number of persons eligible for the demonstration project;
3) Services to be rendered;
4) Costs of care;
5) Case management;
6) Feasibility and cost-effectiveness of transitional care facilities and other alternatives to hospital care such as group homes;
7) Implications for the Demonstration Project of findings in the report to be issued by the Federal Task Force on Technology-Dependent Children in April 1988;
8) Implications for the Demonstration Project of developments in proposed federal legislation that affects health care for chronically ill technology-dependent individuals;
9) Financing mechanisms;
10) Consideration of benefits and costs with respect to private and public payors.

The Commissioner of the designated state agency shall establish a task force to work on plans for the Demonstration Project. This task force shall include representatives of third party payors, employers, providers, consumers, advocacy organizations (for adults, children, and seniors), and the Department of Human Services, Department of Education, Department of Commerce, and Department of Health.

The Demonstration Project proposal shall be submitted to the Minnesota Legislature on or before January 15, 1989.

Recommendation 3:

That the Minnesota Department of Health repeal existing language in rules that allows HMOs to exclude benefits for home health care, and that concurrently, the Department of Health and the Department of Commerce adopt definitions of the key terms used in describing home health care.

The terms to be defined in a standardized way shall include, but not be limited to, "technology-dependent individuals," "skilled nursing care," "transitional care," "subacute care," and "custodial care."

In developing these uniform definitions, the Minnesota Department of Health and the Department of Commerce shall consult with representatives from third party payors, providers, advocacy organizations, and state agencies.

Recommendation 4:

That state agencies (Department of Human Services, Minnesota Department of Health, Department of Commerce, Department of Education) continue to support the efforts of the informal ad hoc committee that is presently working toward the establishment of a multidisciplinary expert advisory and review panel on home health care for technology-dependent individuals.

This committee of volunteers is composed of representatives from third party payors, advocacy organizations, providers, and state agencies; it was formed during the series of Minnesota Department of Health meetings on home health care for technology-dependent individuals.

The advisory and review panel is conceived as supplying both expert consultation and assistance with dispute resolution. Since any recommendations it may make will be non-binding, there is no need for legislative or formal state agency action to establish it.

In order to establish the expert advisory and review panel, the following issues at a minimum must be addressed:

1) What is the mission and what are the priorities of the panel (case-specific advice and assistance with dispute resolution, outreach and education);
2) What is the anticipated workload for the panel and the anticipated meeting schedule (ad hoc or on a regular basis);
3) What are the rules of procedure for receiving cases, deliberating, gathering additional information, conveying advice and recommendations, following up or re-assessing;
4) What groups should be represented, what types of people should serve on the panel, and how should the specific members be selected;
5) How to provide for continuity of membership, yet have the people most familiar with individual cases available (perhaps by having a "core group" of regular members that is supplemented by additional persons with interest or expertise related to a specific case)
6) Who convenes the meetings and handles the administrative responsibilities;
7) How should the services of the advisory and review panel be marketed;
8) Who pays for operating costs (marketing/publicity and production/distribution of brochures and educational materials, administrative, compensation for participants, etc.);
9) For how long should members serve and should they be compensated;
10) How should special outside "experts" be compensated.

* * * * * * * * * * * * * * * *

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APPENDIX

A. POSITION PAPERS

- 0 Children's Home Health Care Task Force
- 0 Minnesota Council of HMOs
- 0 Insurance Federation of Minnesota
- 0 (see also Appendix Q on the Minnesota Home Care Advocacy Program)

B. DEFINING THE TARGET POPULATION AND ESTIMATING ITS SIZE

- 0 "Implications Of The Population Definition" (Appendix C Of The OTA Report On Children)
- 0 Miscellaneous Tables That Show The Basis For OTA Estimates Of The Size Of The Technology-Dependent Population (From OTA Report On Children and OTA Report On The Elderly)
- 0 Findings From A 1985 Survey Of Equipment Vendors To Determine The Number Of Ventilator-Dependent Persons Being Cared For In Their Homes In Minnesota
- 0 Incidence Data From the National Head Injury Foundation

C. BACKGROUND INFORMATION ON MEDICAL CONDITIONS AND TECHNOLOGIES

- 0 BPD: Bronchopulmonary Dysplasia (a description of the condition and estimates of its incidence)
- 0 COPD: Chronic Obstructive Pulmonary Disease (brief description)
- 0 "Changing Technology In The Neonatal Intensive Care Unit" (From The OTA Report On Children)
- 0 "Description of Nutritional Support And Hydration" (From The OTA Report On The Elderly)
- 0 "Tube Feeding Techniques: Placement, Indications For Use, And Associated Risks, " Plus Illustration Of Feeding Tube Routes (From OTA Report On The Elderly

D. HOME CARE FOR THE TECHNOLOGY DEPENDENT: NURSING SKILLS, EQUIPMENT, AND SUPPLIES

- 0 "Checklist Of Respiratory And Infusion Skills For Home Care Patients And Families" and "List Of Supplies For Home Infusion Therapies"

E. PEDIATRIC HOME CARE: RESULTS OF A NATIONAL EVALUATION OF PROGRAMS FOR VENTILATOR-ASSISTED CHILDREN

- O Background On Program Goals, Target Population, And Program Organization
- O Measurement of Hospital And Home Care Charges And Costs
- O Tables Showing Hospital And Home Care Costs
- O Profile Of 141 Ventilator-Assisted Children In Three Demonstration Projects
- O Tables That Describe Hospitalizations, The Discharge Process, and Home Care

F. EVALUATION OF MICHIGAN'S RESPONAUT HOME CARE DEMONSTRATION PROJECT

- O Executive Summary of Findings and Recommendations
- O Specialized Home Care Continuum: Phases and Outcome Objectives (Describes Stages in The Transfer Of Home Care Responsibility to Families)
- O Summary of Guidelines For Various Aspects of Case Management/Home Care, With Assessment of Extent To Which The Guidelines Have Been Met and Comments On Issues and Problems Encountered

G. CASE MANAGEMENT AND THE COORDINATION OF SERVICES FOR HOME CARE FOR THE TECHNOLOGY DEPENDENT

- O Description of Case Management from Minnesota's Medicaid Model Waiver Program
- O Description Of The Iowa Home Care Monitoring Program That Illustrates How A Broad Range Of Community Resources Are Mobilized To Provide Home Care For Technology-Dependent Children

H. PROFILE OF SELECTED PROGRAMS INVOLVED IN HOME CARE FOR THE TECHNOLOGY DEPENDENT

- O Excerpts From "Alternatives To Hospitalization For Technology Dependent Children: Program Models": Tables That Provide Information On Programs in Illinois, Iowa, Louisiana, Maryland, and Pennsylvania (Number and Ages Of Children Served, Diagnoses, Degree Of Ventilator Dependency, Physical Care Needs, Daily Nursing Support, And Costs Of Case Management)
- O "Selected Institutional Programs Involved In Care And Discharge To Home Of Ventilator-Dependent Children" (Appendix From Brooklodge Symposium For The Ventilator-Dependent Child; brief descriptions of mainly hospital programs)

I. COSTS OF HOSPITAL AND HOME CARE FOR THE TECHNOLOGY DEPENDENT

0 Summary Of Cost Estimates For Home Care In Minnesota And Elsewhere

0 Cost Comparisons Of Hospital And Home Care For Eight Technology-Dependent Persons In Minnesota

0 Costs Of Hospital v. Home Care For Four Ventilator-Dependent Children In The Michigan Responaut Demonstration Project

0 Table From OTA Report On Children That Summarizes The Literature On Hospital v. Home Care Costs

0 Miscellaneous Tables from OTA reports

0 Fact Sheet and Lifetime Cost Data by Setting for Persons With Severe Head Injuries from The National Head Injury Foundation

J. INSURANCE COVERAGE

0 Tables On Extent Of Private Health Insurance Coverage From OTA Report On Children

0 Descriptions Of How Several Private Insurance Companies Have Provided Augmented Home Care Benefits To Technology Dependent Children (also see Appendix B to the Council of HMOs position paper included in Appendix A of this report)

K. FINANCING OF CARE

0 "Medicaid Coverage Of Subacute Care In California" (From OTA Report On The Elderly)

0 "Charitable Organizations" (From OTA Report On Children)

L. MEDICAID AND THE MINNESOTA MEDICAID MODEL WAIVER PROGRAM (CAC)

0 CAC: Summary of Nursing Services, Length of Program Service, and Estimated Monthly Costs For Persons Served By CAC

0 CAC: Listing Of CAC Client Characteristics And Costs

0 CAC: Tables from Waiver Program Evaluation Showing Characteristics of the Children Served, Estimated Costs, and Breakdowns of Start-Up And Miscellaneous Costs

0 Description Of Minnesota's Home And Community Care Waivers (Including CAC)

0 Comparison Of State Medicaid Options For Extended Home And Community-Based Care (From OTA Report On Children)

M. DESCRIPTIONS AND STATUS OF PERTINENT FEDERAL LEGISLATION UNDER CONSIDERATION

- O Senate 1740: Medicaid Chronically Ill and Disabled Children Amendments of 1987 (sponsored by Durenberger)
- O Senate 1537: Care Management and Catastrophic Health Care for Children Act of 1987 (sponsored by Chafee)
- O Senate 1711: A Bill To Amend The Social Security Act To Establish A National Commission On Children (sponsored by Bentsen)
- O House 2762: Medicare Long-Term Home Care Catastrophic Protection Act of 1987 (sponsored by Pepper)

N. BIOMEDICAL ETHICAL ISSUES RELATED TO HEALTH CARE FOR THE TECHNOLOGY DEPENDENT

- O "Principles for Decisionmaking Regarding the Use of Life-Sustaining Technologies for Elderly Persons, as Developed by Project Advisory Panel" (from the OTA Report on the Elderly)
- O "NIH Workshop Summary: Withholding and Withdrawing Mechanical Ventilation" (Appendix E from OTA Report on the Elderly)
- O Excerpt from "Imperiled Newborns," a Hastings Center Report edited by Arthur Caplan and Cynthia Cohen (December 1987)

O. DESCRIPTIONS AND ILLUSTRATIONS OF ALTERNATIVE CARE PROGRAMS AND FACILITIES

- O Descriptions of Two Facilities That Provide Day Health Care for Technology Dependent Children (Prescribed Pediatric Extended Care Center and Children's Respite Care, Inc.)
- O "Alternative Settings Of Care" (Foster and Adoptive Care, Community Group Homes, Institutional Settings) (Appendix D from the OTA Report on Children)
- O (see also Appendix Q on the Minnesota Home Health Advocacy Program)

P. EDUCATIONAL SERVICES FOR TECHNOLOGY DEPENDENT CHILDREN

- O "The Educational System As A Source of Health Care Services And Funding" (Appendix E of the OTA Report on Children)
- O Excerpt from "'Medically Fragile' Handicapped Children: A Policy Research Paper"

Q. **MINNESOTA HOME CARE ADVOCACY PROGRAM: For the Disabled by the Disabled**

O Program Description

O Position Papers:

1. "Shortage of Home Care Nurses"
2. "Need to Increase Attendant Hours and Allow the Disabled To Make the Final Choice of Care Giver"
3. "The Need to Make Home Care a Nursing Specialty"
4. "Need to Allow Ventilator Patients to Have Their Own Caregivers Present When Hospitalized"
5. "The Need to Define Home Care Case Management: Agency Responsibilities and Client Rights"
6. "The Right of the Disabled to Work"
7. "Client Rights and Agency Responsibilities"
8. "Medical Assistance and Private Insurance: Re-evaluating Criteria, Re-considering Priorities"
9. "The Failure of Home Care Agencies to Regulate Client Care and Client Safety: The Myth of Agency Protection"
10. "A New Model for A New Age of Home Care"

O Copies of Media Coverage

R. **ESTIMATED NUMBER OF VENTILATOR-DEPENDENT PERSONS IN MINNESOTA DERIVED FROM NATIONAL ESTIMATES BY THE OTA**

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A. POSITION PAPERS

- 0 Children's Home Health Care Task Force
- 0 Minnesota Council of HMOs
- 0 Insurance Federation of Minnesota

Insurance Federation of Minnesota
1310 Pioneer Building
336 N. Robert Street
St. Paul, MN 55101
(612) 292-1099

February 8, 1988

The Insurance Federation of Minnesota represents 119 insurance companies, service bureaus and individual members. One objective of the Insurance Federation of Minnesota is to work with government in the development of public policy and through cooperation, compromise and collective initiative, solve problems together. The members of the Federation which write health coverage in Minnesota recognize their responsibility to participate in the public policy discussion concerning the technology dependent individual issue and assist in the special study mandated by the 1987 Legislature. In an attempt to respond to this law, the Insurance Federation has contacted its members, the Health Insurance Association of America, and staff persons of the Federal Task Force on Technology Dependent Children. In view of the short time allowed, this paper does not propose to set forth the collective views of any or all of these parties but merely attempts to offer additional perspectives on this complex, emotional issue.

In 1987, the legislature mandated that a report addressing the technology dependent individual be prepared by the Commissioner of Health. This report must include recommendations for the adoption of (1) home care definitions, (2) minimum standards for home care services, (3) the costs of providing home care, and (4) resolution of the issue of cost shifting of home care. The industry recognizes the need for consensus on these issues and recommends the following:

RECOMMENDATION

A comprehensive study on technology dependent children is being done by a Federal Task Force. The Federal Task Force report will discuss recommended alternative mechanisms for long term care for technology dependent children and will contain an appendix on sources of financing. This report will prove to be an invaluable source of information for the Minnesota Legislature. This report is due in April of 1988.

The Minnesota Department of Health should track the work of the Federal Task Force and provide the Minnesota Legislature with a summary of the report to be used as a resource for the Legislature. In the interim, we are providing the following response to the legislature's requests:

(1) DEFINITIONS

Home Care - A home health care program, prescribed in writing by a person's doctor for the non-custodial and institutional care and treatment of a person's sickness or injury in the persons home, in lieu of hospitalization.

Custodial Care - Provision of room and board and personal care designed to assist an individual in activities of daily living.

(2) MINIMUM STANDARDS FOR HOME CARE SERVICES

Case management by third party payors in cooperation with providers is an effective method of establishing and developing medical standards for home care in a changing environment. We recommend that third party payor case management be recognized as an integral part of home care and that steps be taken to foster cooperation and communication between third party payor case management teams, providers and consumers.

Through case management, insurers are actively participating in discussions about the feasibility of providing care in a non-acute home setting. In appropriate cases, home care, as an alternative to hospitalization, is being covered by insurers. The review is done on a case-by-case basis so that the unique circumstances of each situation can be considered.

(3) COSTS OF PROVIDING HOME CARE

In an attempt to provide meaningful information on the costs of providing home care, the Federation contacted the Federal Task Force on Technology Dependent Children. The Task Force is unable to release any verbal information on its report until mid-February. As stated previously, the Federal Task Force report will discuss recommended alternative mechanisms for long term care for technology dependent children and contain an appendix on sources of financing.

(4) COST SHIFTING

We recommend that the cost of care for technology dependent individuals which are not covered by third party payors be equally shared by the health care user population. A method currently being reviewed at the federal level is an inpatient hospital tax which would be utilized to create a risk pool. This should be addressed in the Federal Task Force report.

Again, in view of the comprehensive study being done by the Federal Task Force, we recommend that the report to the Minnesota Legislature be postponed until the report of the Federal Task Force is delivered to the United States Congress.

B. DEFINING THE TARGET POPULATION AND ESTIMATING ITS SIZE

- "Implications Of The Population Definition" (Appendix C Of The OTA Report On Children)
- Miscellaneous Tables That Show The Basis For OTA Estimates Of The Size Of The Technology-Dependent Population (From OTA Report On Children and OTA Report On The Elderly)
- Findings From A 1985 Survey Of Equipment Vendors To Determine The Number Of Ventilator-Dependent Persons Being Cared For In Their Homes In Minnesota
- Incidence Data From the National Head Injury Foundation

Appendix C

Implications of the Population Definition

Introduction

The way the population of technology-dependent children is defined and enumerated has clear implications for the costs to third-party payers of paying for care, and the access of these children to different care alternatives. The broader the definition, the larger the number of children who may become eligible for special benefits. Providing enhanced insurance coverage for technology-dependent children may itself lead to an increase in the size of the population, through encouragement of more aggressive medical practices.

The definition of technology dependence presented in Chapter 2 was developed for the purpose of enumerating the population, not for describing it for insurance or program eligibility purposes. These two definitional purposes overlap to some extent, but they can also conflict. The pragmatic, data-based definition applied in this technical memorandum would be inappropriate if applied in a program context without other considerations. To be applied appropriately to eligibility, a definition of technology dependence must take into consideration the following questions:

- Does the definition include all children who would reasonably be considered to be technology dependent?
- Is the definition flexible, or would it need to be revised frequently to accommodate new groups of deserving children?
- Can the definition identify children with similar needs for health care, so that they can receive the same level of benefits (horizontal equity); and can it distinguish those with greater need from those with lesser need (vertical equity)?
- Can the definition distinguish between children for whom home care is less expensive than institutional care from those for whom it is more expensive (possibly because the child would not be institutionalized even in the absence of home care benefits)?
- Is the definition compatible with distinguishing children for whom home or community-based care is feasible and desirable, and can it provide a basis for estimating the cost of services provided in these environments?

Three potential specific approaches to identifying the population are to use: 1) diagnosis, 2) functional limitation, or 3) medical services needed. These approaches are not necessarily mutually exclusive, but their benefits and drawbacks can be discussed separately from one another.

Three Alternative Approaches

Definition Based on Diagnoses

Diagnoses could be used as a basis for identifying children as technology dependent, an approach that has two attractions. First, in most cases diagnoses provide distinct and verifiable information. Second, diagnostic data on hospitalized patients are regularly collected and analyzed on a national basis.[1] A definition of technology dependence based on diagnosis could be specific (e.g., bronchopulmonary dysplasia) or broad (e.g., any chronic lung disease).

There are a number of serious problems with using this approach. First, there is not a one-to-one correspondence between diagnoses and the need for long-term intensive nursing care. Table 26 lists a few of the many diseases (some of them very rare) that can lead to life-sustaining dependence on respiratory or nutritional support. Maintaining a comprehensive list might be very difficult, preventing some technology-dependent children from being included. Also, only a small proportion of the children with these diseases require prolonged technology supports. For example, of children with muscular dystrophy or cystic fibrosis, only those in the later stages require ventilators or even less intensive respiratory support such as frequent suctioning and oxygen (4,79). Thus, any definition that includes diagnostic criteria must rely heavily on other criteria as well.

Defining the population based on broader categories of diagnoses or disorders would be considerably less cumbersome but correspondingly less specific. It, too, would produce categories that are larger, probably many times larger, than the population of children that is usually institutionalized and is dependent on life-sustaining medical devices.

Definition Based on Functional Limitation

Identifying disabled people, particularly the elderly, according to their functional limitations and their ability to carry out certain activities of daily living has been common for some time. Activity limitation questionnaires have been used in surveys to provide na-

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[1] Diagnoses are coded onto hospital discharge abstracts, according to the conventions of the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) coding system. These codes and other information from discharge abstracts are then maintained, summarized, and analyzed by a number of different government and private organizations.

Table 26.—Some Conditions That Can Lead to Dependence on Respiratory or Nutritional Support

Conditions that can lead to dependence on respiratory support:
brainstem aneurysm
bronchopulmonary dysplasia
central hypoventilation syndrome (Ondine's curse)
congenital heart disease
cystic fibrosis
Ellis-van Creveld syndrome
encephalitis
interrupted phrenic nerves
multiple sclerosis
muscular dystrophy
myelodysplasia
near-drowning
nemaline rod myopathy
neonatal asphyxia
Pierre-Robin syndrome
Pompe's disease
radiation lung damage
severe head injury
spinal muscular atrophy
subglottic stenosis
upper spinal cord injury
Werdnig-Hoffman disease

Conditions that can lead to dependence on nutritional support:
Alagielle's syndrome
chronic diarrhea
congenital bowel defect
cystic fibrosis
failure to thrive
inflammatory bowel disease
ischemic bowel disease
liver disease
milk/soy protein intolerance
motility disorder
necrotizing enterocolitis
neoplasms
neurological disorders of swallowing
radiation enteritis

NOTE: These diagnoses constitute only a partial list of conditions that can lead to dependence on respiratory or nutritional support. Conditions listed here are actual diagnoses of children using these technologies, as recorded in a national nutritional support database and a summary of children served by special Title V programs in three States in 1985.

SOURCES: L. Heaphey, The Oley Foundation, Albany, NY, personal communication, Aug. 21, 1986; M.J. Aitken and L.A. Aday, "Home Care for the Chronically Ill and/or Technology Assisted Child: An Evaluation Model," unpublished, November 1985.

tional estimates of disability prevalence and severity in the population (63) and in studies of resource utilization among nursing home residents (133,140,182). Scales to measure activity limitation are relatively well developed and seem to be good predictors of the intensity of required nursing and personal care services for many elderly and disabled people.

The main limitations of these scales are that each person must be assessed individually and frequently, which is time-consuming and leaves considerable discretion to the assessor; and the scales are not well suited to identifying the specific skilled nursing services an individual may need.[2]

Another approach could be to identify children by the limitations of their normal body functions, such as eating or breathing. This approach (the one used in this technical memorandum) has intuitive appeal because it would identify those children who use specific technologies that replace or compensate for normal body functions. The limitation of this approach is the difficulty in distinguishing levels of care needed in conjunction with the various technologies.

Definition Based on Type or Amount of Services Needed

A third approach might be to identify technology dependent children by the type or amount of medical services they require. This might take the form of defining the population according to the need for certain nursing services, such as catheterization. Or, it might take the form of an indirect but explicit indication of level of services needed, such as prior institutionalization or time in a neonatal intensive care unit. Finally, the population might be identified by the type of long-term care plan required by its members. For example, the defined population might include children whose documented care plans specify hospice care and long-term chronic, continuous care, but not children requiring intermittent monitoring, occasional crisis care, or post-acute, recuperative care.

Considerations in Applying the Definition

Within the group of children identified as technology dependent, there will exist considerable variation in health and social needs. Ideally, an appropriate definition should be able to be applied in such a way that differences in need among children can be discerned with appropriate differences in benefits provided to them. For example, two children might be equally ventilator dependent, but one might be able to dress and feed himself while the other cannot. This example emphasizes the value of functional assessment in applying a definition equitably.

Home care may be feasible and desirable, but not cheaper than institutional care, for some children. It

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[2] Although there is considerable experience in applying specific assessments of a person's ability to function, few of these applications have assessed any limitations in basic body functions that require nursing skills (e.g., the need for colostomy care). One survey that includes these categories is currently being conducted on children with six types of disability and chronic illness (73).

these children are to be included, the definition should have a mechanism for detecting those children for whom the medical, psychological, and developmental benefits of home care are high in relation to the additional costs of home care. This criterion again implies that the definition should include some indication of relative need and prognosis over time. A child with a long-term or terminal illness, for example, might benefit more from the psychological and social aspects of home care than a child recovering rapidly from an acute condition, and consequently it might be desirable to be able to distinguish the former child from the latter for the purposes of providing benefits.

Meeting a particular definition need not necessarily imply absolute access to a special program or set of benefits. A definition can also be thought of as a screening mechanism to most easily identify the bulk of children who would benefit from extensive individual assessment and a particular set of services. One possibility is that some fairly rigid, easily identified characteristics be used for rapid screening purposes, but that actual eligibility for benefits be dependent on the child's functional or nursing assessment score, where activity limitations, degree of independence capability, and limitations of body functions are all evaluated.

Table 9.—Estimated Prevalence of Selected Chronic Conditions in Children, Age 0 to 20, 1983

Condition	Prevalence per 100,000 children, 1980	Approximate number of children in the United States, 1983
Mental retardation	2,500	1,781,300
Asthma (moderate and severe)	1,000	712,500
Diabetes mellitus	180	128,300
Congenital heart disease (severe)	50	35,600
Spina bifida	40	28,500
Sickle cell anemia	28	20,000
Cystic fibrosis	20	14,300
Hemophilia	15	10,700
Leukemia (acute lymphocytic leukemia)	11	7,800
Chronic renal failure	8	5,700
Muscular dystrophy	6	4,300
Traumatic brain injury	5	3,600

SOURCE: Prevalence rates from G.L. Gortmaker and W. Sappenfield, "Chronic Childhood Disorders: Prevalence and Impact," *Pediatric Clinics of North America* 31(1):3-18, February 1984. Population size estimates calculated by OTA based on prevalence rates and U.S. Census population data

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Table 4.—Data Sources Used as Bases for OTA Estimates

Source	Population included	Original purpose of information collection
State data:		
Illinois	All ventilator-dependent children in State; all other children served in State program for handicapped children	State information; evaluation program for similar State programs
Louisiana	Ventilator-dependent children served in special State home care program	State information; evaluation program for similar State programs
Maryland	Children dependent on respiratory support devices who are served in special State home care program	State information; evaluation program for similar State programs
Massachusetts	People dependent on ventilators for longer than 3 weeks	Survey to determine the numer of ventilator-dependent individuals
New Mexico	All children served by State Medicaid waiver for technology-dependent children; other similar children identified in State but not eligible for the program	State information, Medicaid requirements
North Carolina	All children in State who are ventilator dependent and have been medically stable for at least 2 months	Demonstrate potential need for pediatric respiratory unit
Wisconsin	Children eligible for Medicaid home services on the basis of being disabled and at a level that would otherwise require institutionalization	State information, Medicaid requirements
American Association for Respiratory Care	Respiratory therapists nationwide via their State representatives (37 States responded); asked to provide information on all ventilator-dependent patients they were serving	Document the number of ventilator-dependent persons and the degree of institutionalization
Commercial nutrition registries	Individuals served by companies or organizations maintaining the registries between October 1984 and April 1985	Develop a database of persons on home nutritional support technologies
OAISIS registry, Oley Foundation	Patients served by hospital and community-based programs responding to a 1985 survey of such programs	Develop ongoing database of characteristics of persons using home nutritional support
Hambrecht & Quist home infusion market analysis	National hospital discharge data and detailed information from a nonrandom sample of hospitals	Provide estimates of the current and future market for home infusion technologies
Abbott Laboratories home infusion market analysis	Not specified	Provide estimates of the current and future market for home infusion technologies

SOURCES: M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985, E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; K. Valdez, Human Services Department, Santa Fe, NM, personal communication, July 22, 1986, P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, July 22, 1986; G. Worley, Duke University Medical Center, Durham, NC, personal communication, July 1986, Care for Life, paper prepared for U.S. Congress, Office of Technology Assessment, 1985; Oley Foundation, paper prepared for U.S. Congress, Office of Technology Assessment, 1985; B.B. Rucker and K.A. Holmstedt, *Home Industry Therapy Industry* (San Francisco, CA: Hambrecht & Quist, April 1984); Blue Cross and Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicaco, IL: BC/BSA, January 1986)

Table 3.—Major National Health Surveys and Data Systems

Survey or data system	Population surveyed	Periodicity	Relevant data elements	Selected limitations
National Health Interview Survey (NHIS)	Approximately 40,000 households (about 30,000 children).	Annually	Activity limitations, certain chronic conditions, hospital and physician use	Institutional population excluded, sample too small to detect very rare conditions, functional limitation measures very general
NHIS Child Health Supplement	1 child per above household (about 15,000 children)	1981; may be done in future again	Detailed perinatal and child care, child development, child health problems	Same as NHIS
National Medical Care Utilization and Expenditures Survey	Approximately 6,600 households (about 4,500 children)	1977, 1980, planned 1987	Same as NHIS plus additional data on income, insurance, medical expenditures	Same as NHIS
National Hospital Discharge Survey	Discharges from approximately 420 short-stay hospitals	Annually	Age, race, sex, medical diagnoses, procedures done in the hospital	Sample too small to detect very rare conditions, not an unduplicated count of persons, no data on outpatients, nonhospitalized children
National Ambulatory Medical Care Survey	Office visits to approximately 3,000 physicians	Annually from 1963-1981; 1985	Age, race, sex, reason for visit, diagnoses, procedures performed	Sample too small to detect very rare conditions, excludes clinic and institutional visits, not an unduplicated count of persons
National Health and Nutrition Examination Survey	Households, including about 6,000 to 7,000 children	1971-1975; 1976-1980; planned 1988	Data from physical exam and laboratory tests	Small sample, institutionalized population excluded
Birth Defects Monitoring Program	Discharges from 928 hospitals, about 22% of U.S. births	Annually	Discharge abstract data for 161 birth defect categories	May not be representative sample of births, newborn data only, cannot directly detect technology dependence
Office of Special Education	State-reported data on children served in special education programs	Annually	Number of children served by handicapping condition category	Handicapped categories very broad, categories not consistently defined among States, do not include children not served by programs
Survey of Institutionalized Persons	Persons living in facilities with average stays over 10 days	1976 only	Age, race, sex, cost of care, condition treated, physical limitations	Limitation categories very broad, noninstitutionalized population excluded, data old, analysis excluded some institutions
Census of the Population	All households, sample of institutionalized persons	Every 10 years	Age, race, sex, education, region, type of institution	No health-related functional data included, institutional categories very broad

SOURCES: E.M. Ellman, National Association of State Directors of Special Education, Inc., Washington, DC, personal communication, January 1976; M.A. McManus, S.E. Malus, C.H. Norton, et al., *Guide to National Data on Maternal and Child Health* (Washington, DC: McManus Health Policy Inc., 1986); U.S. Department of Commerce, Bureau of the Census, *1976 Survey of Institutionalized Persons: A Study of Persons Receiving Long-Term Care*, Current Population Reports Special Studies, series P-23, no. 69, June 1978; U.S. Department of Education, Office of Special Education, 9th Annual Report to Congress on the Implementation of the Education of the Handicapped Act, 1987.

Table 5.—Estimates of the Number of Ventilator-Dependent Children

State	Survey year	Survey period	Age group	Number ventilator dependent	Rate per million children	Extrapolation to U.S. per survey period: Under 18	Extrapolation to U.S. per survey period: Under 22	Extrapolation to U.S. per year[a]: Under 18	Extrapolation to U.S. per year[a]: Under 22	Percent in institutions
Illinois	1985	1 year	0-21	74	19.0	1,191	1,500	1,191	1,500	36%[b]
Louisiana	1986	1 year	0-21	35	23.8	1,305	1,643	1,305	1,643	13%[b]
Maryland	1985	1 year[c]	0-17	26	23.9	1,498	1,886	1,498	1,886	23%[b]
Massachusetts . .	1983	1 month	0-15	14	13.5[d]	843	1,062	1,096	1,381	86%[e]
New Mexico . . .	1986	< 1 month	0-21	4	7.4	577	726	753	948	75%
North Carolina . .	1986	1 month	0-17	7[f]	4.3	268	337	421	530	43%
AARC survey (37 States)	1985	1 month	0-17	445	8.3	520	655	679	845	55%[d]

[a] See footnote 7 in text for explanation of conversion from monthly to annual prevalence

[b] Illinois, Louisiana, and Maryland have active programs to place ventilator-dependent children at home

[c] Not reported, apparently at least a year

[d] Adjusted for 82 percent response rate. Remaining institutions were assumed similar to responding ones

[e] Figure applies to all patients in the survey, including adults

[f] Four of the seven children had been discharged home on ventilators during the past 3 years. It is unknown whether all four children cared for at home are still alive and ventilator-dependent, but they were assumed to be so for the purposes of this table. Thus, in converting from monthly to annual prevalence, 4/7 of the U.S. extrapolation was not converted up, since this part of the number represents a 3-year prevalence rather than a 1-month one

SOURCES: Office of Technology Assessment, 1987. Data from K. Kirkhart, Children's Hospital, New Orleans, LA, personal communication, January 1987; M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985; K. Valdez, Human Services Department, Santa Fe, NM, personal communication, July 1986; G. Worley, Duke University Medical Center, Durham, NC, personal communication, July 1986; Care for Life, "Life Sustaining Technologies and the Elderly: Prolonged Mechanical Ventilation," paper prepared for U.S. Congress, Office of Technology Assessment, 1985.

Table 6.—Estimates of the Number of Children Requiring Parenteral Nutrition

Source	Basis for estimate	Comments on manipulation	Extrapolated U.S. estimate
Commercial registries, 1984-85	373 children under age 18 on home parenteral nutrition documented on one of two registries supported by home nutrition companies.	Assumed to be a national minimum estimate.	373 children on parenteral nutrition under age 18 (per 7-month period).
Illinois, 1985	5 children requiring parenteral nutrition served by State program (compared to 22 children in program on ventilators).	Total of 74 ventilator-dependent children known in entire State. Assumed children on parenteral nutrition are represented in proportion.	341 children on parenteral nutrition under age 22 (at time of program documentation).
New Mexico, 1986	2 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition. Used simple extrapolation.	232 children on parenteral nutrition under age 18; 292 under age 22 (at time of survey).
Wisconsin, 1986	4 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition. Used simple extrapolation.	At least 192 children on parenteral nutrition under age 18 (at time of documentation). Fewer children on parenteral nutrition than on ventilators.
Hambrecht & Quist market estimate, 1983	Estimated U.S. home care market of 2,700 patients per year requiring parenteral nutrition.	About 13% of patients in commercial registries under age 18; apply to this figure.	351 children on parenteral nutrition under age 18 in 1983 (for 12-month period); market assumed growing.

SOURCES: Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," paper prepared for Office of Technology Assessment, September 1985; E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; G. Cleverly, Human Services Department, Santa Fe, NM, personal communication, 1986; P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986; B.B. Rucker and K.A. Holmstedt, *Home Infusion Therapy Industry* (San Francisco, CA: Hambrecht & Quist, Inc., April 1984)

Table 7.—Basis for Estimate of the Population of Children Requiring Extended Intravenous Drug Therapy

Intravenous antibiotic therapy:	
Total home intravenous antibiotic therapy market, 1984 (patients/year)[a]	2,000 to 5,000
Proportion children (range given in literature reports of individual programs)[b]	4.3% to 46.6%
Implied total number of children per year on home therapy	86 to 2,330
Inflation for past exclusion of patients for home care due to financial, medical, or psychosocial reasons[c]	166%
Total number of children per year receiving prolonged antibiotic therapy	143 to 3,868
Intravenous chemotherapy:	
Total home intravenous chemotherapy market, 1984 (patients/year)[a]	2,500
Approximate proportion children[d]	5%
Total number of children per year, minimum estimate	125
California hospital discharges of children with leukemia undergoing venous catheterization (discharges/year)[e]	160
Extrapolation to U.S. (discharges/year)	1,469
Leukemia as proportion of all childhood cancers[f]	33%
Extrapolated U.S. number, all childhood cancers	4,407
Total number of children per year undergoing chemotherapy	125 to 4,407
Total intravenous drug therapy population, children per year	**268 to 8,275**

[a] See reference 137.

[b] See references 50,78,96,130,151.

[c] Up to 40 percent of all patients in the studies cited here were rejected for home therapy for these reasons. Since 4 of every 10 original patients were excluded and 6 of every 10 were included, the figure for potential home antibiotic therapy must be re-inflated by 166% to estimate the total maximum number of children that would be eligible if these barriers did not exist.

[d] A Pennsylvania report on 139 patients receiving outpatient (not home) chemotherapy gives the range of ages of these patients as 16 to 86, with a mean age of 57 (86). It is unlikely that more than 5 percent of these patients were under age 21.

[e] See reference 15.

[f] See reference 98.

SOURCE: Office of Technology Assessment, 1987.

Table 8.—Basis for Estimate of the Number of Children Requiring Other Nutritional and Respiratory Support

Information source	Data	Implications	Comments
OASIS registry, Oley Foundation	147 children ages 0-10 in registry; 92 require parenteral nutrition	Ratio of enteral to parenteral nutrition is 1:1.67	Proportion of children also using respiratory support unknown; proportion of tube-fed population covered by registry unknown
Commercial registries	368 children in registry requiring enteral nutrition (i.e., tube feeding)	Ratio of enteral to parenteral nutrition is 1:1.01	Same as Oley Foundation registry
Hambrecht & Quist market analysis	7,500 persons in U.S. received home tube feeding in 1983	990 tube-fed children per year in the U.S. at home	Based on discharge data and sample of hospitals. Extrapolation assumes that 13.2% of tube-fed populaton are children (from commercial registry proportion)
Abbott Laboratories market analysis	5,500 persons in U.S. received home tube feeding in 1983	726 tube-fed children per year in the U.S. at home	Unknown basis for estimate. Same assumption of 13.2% children as above
California hospital discharge data for children	97 gastrostomy procedures, 15 closures in 1983	777 children tube-fed through gastrostomies each year	Of net addition to population of 82 gastrostomies, assumes each child received only one gastrostomy and required it for one year
State data:			
Illinois	36 children on Group III technologies served by home care program	2,445 Group III children per year in the U.S.	Ratio of ventilator: Group III children in program 22:36; apply this to extrapolation of 1,500 ventilator-dependent children in U.S. to yield total Group III estimate
Maryland	87 children in State requiring respiratory support; 61 require other than ventilators	3,513 children in the U.S. per year requiring respiratory support other than ventilators	Assumes Maryland identified the universe of such children in the State
Wisconsin	49 children served in State program require tube feeding; 49 require respiratory assist devices (other than ventilators)	2,401 U.S. children requiring tube feeding at any one point in time; up to 4,800 requiring respiratory support. Ratio of ventilator: Group III supports about 1:10	Presumably is an underestimate if not all similar children are served by State program. Probably considerable overlap between tube feeding and respiratory support groups. Prevalence of Group II probably overstated
North Carolina	8 hospitalized children in State with prolonged oxygen dependence (compared to 3 on ventilators)	Ratio of ventilator: oxygen support about 3:8	One-month survey, hospitalized children only
New Mexico	1 ventilator-dependent child; 18 other children requiring respiratory and nutritional support	Ratio of ventilator: Group III supports about 1:18	Prevalence of Group III probably overstated due to small number of ventilator-dependent children served

SOURCES: M.J. Aitken and L.A. Aday, *Home Care for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*, unpublished, November 1985; J. Bates, San Diego Children's Hospital, San Diego, CA, personal communication, July 1986; Blue Cross/Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: Blue Cross/Blue Shield Association, January 1986); G. Cleverly, Human Services Department, Santa Fe, NM, personal communication, August 1986, L.L. Heaphey, The Oley Foundation, Albany, NY, personal communication, August 1986; E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; Oley Foundation, Inc., "Nutritional Support and Hydration for Critically and Terminally Ill Elderly: Utilization in the Home," contract paper prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, September 1985; B.B. Rucker and K.A. Holmstedt, *Home Infusion Therapy Industry* (San Francisco, CA: Hambrecht & Quist, April 1984); and P. Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986

A Survey to Determine the Number of Ventilator-Dependent Persons Being Cared For in Their Homes in Minnesota

Date of Survey: Spring 1986

Conducted by: Alex Adams, Clinical Director of Respiratory Therapy at Health East

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Methods

Mr. Adams contacted all vendors who supply home care equipment to ventilator-dependent persons in the state of Minnesota and asked for information about the people the vendors were supplying with mechanical venilator equipment and services in Spring of 1986. Patients' names and addresses were not requested; the survey asked only for the following information:

- Age
- Degree of ventilator dependence (Full-time/part-time)
- Type of ventilator
- Diagnosis/disease

This survey provides the best available estimate we have of "point prevalence" -- the number of people at a given point in time-- of home-based ventilator dependent individuals in Minnesota. Short of having a state registry, getting data from vendors is viewed as the easiest and best available way to get such an estimate, since all patients at home need a vendor for maintenance and repairs even if they own their ventilator.

SURVEY FINDINGS

According to this survey, 86 ventilator-dependent people were receiving home health care in Minnesota in Spring 1986.

By Age

Less than 10	16
10 - 20	4
21 - 30	7
31 - 40	9
41 - 50	12
51 - 60	21
61 - 70	14
Over 70	3

Total patients = 86

By Degree of Dependence on the Ventilator

Full-time	39	
Part-time	47	(e.g., off during the day and on at night)

By Ventilator Type

Positive pressure	63
Other	23

"Other" includes mostly polio patients from the 1950s who are still using devices from that era such as rocking beds and negative pressure devices such as "turtle shells," and "body wraps."

By Disease Conditions

29	Polio
8	ALS (Lou Gehrig's disease)
8	COPD (chronic emphysema)
8	Unknown
7	Muscular dystrophy
6	Quadraplegia
6	Sleep apnea
2	Brain stem infarct
1	Guillaume Barre
1	Multiple sclerosis
1	Multiple trauma
1	Ondine's curse
1	Spinal cord lesion
1	Warner Kauffman syndrome
1	Central hypoventilation
1	Spina bifida
1	Respiratory insufficiency
1	Multiple diagnoses
1	Rheumatoid disease
1	Ehler-Dandles syndrome

National Head Injury Foundation Inc.

333 Turnpike Road, Southborough, MA 01772 (617) 485-9950

COMPARATIVE INCIDENCE AND PREVALENCE OF BRAIN DAMAGE FROM TRAUMA AND OTHER NEUROLOGIC DISABILITIES*

DISORDER	INCIDENCE 100,000/YEAR	PREVALENCE PER 100,000
TRAUMATIC BRAIN DAMAGE, MODERATE TO SEVERE	20+	800
SPINAL CORD INJURY	3	50
MULTIPLE SCLEROSIS	3	60
CEREBRAL PALSY	9	250
MUSCULAR DYSTROPHIES (HEREDITARY)	1.2	20

*DATA FROM KURTZKE, J.F. NEUROLOGY 32:1207, 1982

+DATA FROM KRAUS ET AL, AMER J EPIDEMIOL, 1984

over

SEVERITY OF BRAIN INJURY IN PERSONS SURVIVING TRAUMATIC HEAD INJURY IN THE UNITED STATES*

SEVERITY OF BRAIN DAMAGE	INCIDENCE 100,000/YEAR	NO. OF SURVIVORS PER YEAR
SEVERE	6	13,500
MODERATE	14	30,500
MILD	131	294,750

*Based on San Diego Study by Kraus Et Al, Amer J Epidemiol, 1984

COMPARATIVE INCIDENCE AND PREVALENCE OF BRAIN DAMAGE FROM TRAUMA AND OTHER NEUROLOGIC DISABILITIES*

DISORDER	INCIDENCE Per Year	PREVALENCE
TRAUMATIC BRAIN DAMAGE, MODERATE TO SEVERE	44,000+	1,000,000 TO 1,800,000
SPINAL CORD INJURY	6,750	112,500
MULTIPLE SCLEROSIS	6,750	135.000
CEREBRAL PALSY	20,000	560,000
MUSCULAR DYSTROPHIES (HEREDITARY)	2,700	45,000

*DATA FROM KURTZKE, J.F. NEUROLOGY 32:1207, 1982
+DATA FROM KRAUS ET AL, AMER J EPIDEMIOL. 1984

5/84

C. BACKGROUND INFORMATION ON MEDICAL CONDITIONS AND TECHNOLOGIES

- BPD: Bronchopulmonary Dysplasia (a description of the condition and estimates of its incidence)

- COPD: Chronic Obstructive Pulmonary Disease (brief description)

- "Changing Technology In The Neonatal Intensive Care Unit" (From The OTA Report On Children)

- "Description of Nutritional Support And Hydration" (From The OTA Report On The Elderly)

- "Tube Feeding Techniques: Placement, Indications For Use, And Associated Risks, " Plus Illustration Of Feeding Tube Routes (From OTA Report On The Elderly"

DESCRIPTION OF NUTRITIONAL SUPPORT AND HYDRATION

The Need for Nutritional Support and Hydration

People who do not take in adequate amounts of food and fluids will eventually die of malnutrition and dehydration or complications of these conditions. Malnutrition is a disorder caused by inadequate intake of calories, protein, carbohydrates, fats, vitamins, minerals, trace elements, or any combination thereof. The effects of malnutrition depend on its severity and duration and which specific nutrients are lacking. In general, however, the effects include weight loss, listlessness, and depression; decreased ability to resist infection, to recover from illness, and to withstand surgery or other treatments; impaired wound healing; decreased cardiac and respiratory muscle strength, confusion, coma, and eventual death (115,139,143,203).

Dehydration, the loss of body water in excess of intake, is caused by decreased fluid intake or inability to conserve fluids as a result, for example, of renal disease or severe diarrhea. Dehydration results in dry mucous membranes; decreased sweat, saliva, and tears; muscle weakness, rigidity, or tremors; confusion, hallucinations, and delerium; abnormal respiration; coma; and eventual death. Reduced body water also alters the concentration of electrolytes such as sodium and potassium, with severe and sometimes life-threatening consequences (210).

People with a variety of conditions are at risk of malnutrition and dehydration. Although some conditions that cause malnutrition or dehydration occur more often in elderly people than younger people, none is unique to elderly people.

People who are physically unable to swallow, digest, or absorb food and fluids taken by mouth are at obvious risk of malnutrition and dehydration. This group includes:

- people who are comatose;
- people who are physically unable to swallow;
- people who have an obstruction of the gastrointestinal tract;
- people who are unable to eat following gastrointestinal surgery; and
- people with acute or chronic diseases that cause inability to digest or absorb nutrients.

Without tube or intravenous feeding and hydration, such people will become increasingly malnourished and dehydrated. As their immune function is reduced, they may die from infections before death can occur from malnutrition or dehydration.

Critically ill patients who are physically able to swallow, digest, and absorb at least some food and fluids taken by mouth may also be at risk of malnutrition and dehydration. Malnutrition in some critically ill patients is caused by anorexia (decreased appetite) associated with certain diseases, such as cancer. In addition, many acute and chronic diseases and treatments such as surgery increase the body's requirements for nutrients; if intake is not increased correspondingly, malnutrition can develop rapidly (115). (p. 278)

Table 8-1.—Tube Feeding Techniques: Placement, Indications for Use, and Associated Risks

Nasogastric tubes may be placed by a physician, another health care professional, the patient, or a trained family member. The position of the tube must be tested before each feeding, because the tube can be mistakenly placed in the patient's lungs; if food or fluids are put in the tube while it is in the patient's lungs, severe respiratory distress will occur, potentially causing death. Other risks of nasogastric tube feeding include irritation of the nose, throat, and esophagus, and aspiration, a condition caused by regurgitation of the stomach contents into the lungs.

Nasoenteral tubes are usually placed by a physician or a specially trained nurse and must be tested every few days by a trained health care professional or by X-ray. These tubes are recommended for short-term use in patients for whom regurgitation and aspiration are likely or whose stomach or upper intestinal functions are impaired.

Potential problems include the difficulty of passing the tube through the pylorus (the small opening at the lower end of the stomach) and laceration of the pylorus or other parts of the gastrointestinal tract if the tube is removed too rapidly. In addition, feeding into the duodenum and jejunum tends to cause diarrhea.

Pharyngostomy and esophagostomy tubes must be surgically placed by a physician. Esophagostomy tubes are seldom used now. Pharyngostomy tubes are recommended for long-term use because they do not irritate the nose and throat like nasogastric and nasoenteral tubes. Potential problems include aspiration, scarring of the insertion site, and swallowing difficulty.

Gastrostomy tubes are placed by one of two methods. Surgical placement, that is always by a physician, is done with a local, spinal, or general anesthetic. A newer method, percutaneous endoscopic placement, does not require surgery or general anesthetic. Gastrostomy tubes are recommended for long-term use and when swallowing is impaired as a result of obstruction or neurological disease.

Potential problems include aspiration, skin irritation around the tube site, and displacement of the tube into the abdominal cavity. In addition, the small balloon that is sometimes used to hold the gastrostomy tube in place can obstruct the pylorus and interfere with gastric emptying.

Jejunostomy tubes are surgically placed. These tubes are recommended for long-term use or when there is a problem with gastric emptying or regurgitation. Potential risks include skin irritation around the tube site, clogging, displacement of the tube, and diarrhea.

SOURCE: Adapted from Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, November 1985.

(p. 282)

Box 6-A.—Chronic Obstructive Pulmonary Disease

COPD, also known as chronic obstructive lung disease, designates a group of diseases characterized by chronic airflow limitation, especially during expiration. Asthma, chronic bronchitis, and emphysema, as well as much less common diseases, such as bronchiectasis and cystic fibrosis, are examples. Diseases of the airway are characterized by excessive mucus secretion of the bronchorespiratory tree and chronic inflammatory changes in the small airways (in chronic bronchitis) or by abnormal enlargement of the alveoli and destructive changes in the alveolar walls, resulting in abnormal gas exchange (in emphysema). Chronic productive cough and difficulty breathing are the main manifestations. COPD is progressive and thought to be irreversible (35). If severe, hypoxemia, cor pulmonale, congestive heart failure, and eventual respiratory arrest can result.

COPD is seldom symptomatic before the age of 55 or 60 (111). An estimated 4 million Americans suffer from some form of the disease (114). In 1984, COPD, bronchitis and asthma, and pneumonia with pleurisy (diagnosis-related group (DRG) 86, 96, and 89, respectively) were among the 10 most frequent DRGs for hospital discharges (14). Closely associated with cigarette smoking and workplace chemicals (especially coal mining, asbestos, steel, and flax), emphysema is more common among men than women (35), and it is the fastest growing cause of death in the United States (30).

Treatment of COPD is directed toward reversing the abnormalities of the airway and their effects. Most patients are treated effectively with oxygen, bronchodilators, and other drugs, without resort to mechanical ventilation. As the disease progresses, however, severe ventilatory failure becomes chronic and mechanical ventilation may be the only treatment option.

(p. 208)

Box B.—Bronchopulmonary Dysplasia

One of the most common sequelae of neonatal intensive care, and one with particular implications for technology dependence, is bronchopulmonary dysplasia (BPD). First recognized in the early 1960s (154), this condition sometimes occurs in infants requiring mechanical ventilation soon after birth. An infant with BPD is unable to be weaned from ventilation during the first month after birth due to certain changes in the lung that can often be detected by X-ray (71).

Pneumonia, meconium aspiration, patent ductus arteriosus, and apnea of prematurity are among the many conditions that can lead to the initial need for assisted ventilation (and, thus, sometimes BPD) in newborns (71). The most common reason for initial ventilation, however, is respiratory distress syndrome. This syndrome, characterized in its initial stages by an increasing need for oxygen, is often experienced by very premature infants because an essential lining layer in the lung (pulmonary surfactant) has not yet developed (99).

Table 10 presents estimates of the annual incidence of BPD by birthweight category. There are no nationally representative data on the incidence of BPD. A multi-center study of 700 to 1,500 g babies in 1983 and 1984 found that one-third of the survivors had chronic lung disease (11). OTA used this 33 percent estimate for very-low-birthweight infants, although other researchers reported rates of BPD incidence among their institutional populations varying from 25 to 75 percent of respiratory distress syndrome survivors under 800 g at birth, and from 13 to 62 percent of survivors weighing less than 1,000 g at birth (17,25,45,74,85,138).

Researchers have not reported in the literature on BPD incidence among the larger low-birthweight infants, but the authors of a recent review article about BPD estimated its incidence at 10 to 20 percent among infants with RDS who receive mechanical ventilation and survive (71). OTA adopted the low end of this estimate, 10 percent, in calculating the BPD incidence among babies weighing 1,501 to 2,500 g.

Only a relatively small proportion of the babies developing BPD are obvious candidates for technology-dependent home care. In their eight-center study, Avery and colleagues found that about 4 percent of infants weighing less than 1,500 g at birth still needed supplemental oxygen at 3 months of age (although the range among institutions was considerable) (11). BPD can take mild, moderate, or severe forms, and infants are weaned from the ventilators and/or oxygen support after variable periods of time.

In the future, the incidence of BPD will likely decline, although extremely low-birthweight babies susceptible to BPD—including babies weighing less than 500 g at birth—are increasingly surviving (162). Refinements of existing techniques and newly introduced neonatal technologies might substantially reduce BPD in premature infants within a few years.

Table 10.—Estimated Incidence of Bronchopulmonary Dysplasia, 1984

Birthweight (grams)	U.S. births (1984)	U.S. neonatal mortality (1980)	Neonatal survivors	Percent survivors with BPD	Total infants with BPD per year
500-1,500g	39,045	43.1%	22,217	33%	7,332
1,501-2,500g	202,606	2.4%	197,743	1%[a]	1,977
				Total	9,309

[a] Goldberg and Bancalari (71) estimate that approximately 10 percent of infants with respiratory distress syndrome (RDS) get BPD. If approximately 10 percent of all surviving infants get RDS (174), then approximately 1 percent of all survivors get BPD.

SOURCE: Office of Technology Assessment, 1987. Numbers of U.S. births from U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Advance Report of Final Natality Statistics, 1984, Table 24," *Vital Statistics Report* 35 (4, supp.):July 18, 1986. Neonatal mortality rates from U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, "National Infant Mortality Surveillance (NIMS)," unpublished tables, May 1986. BPD incidence rates approximated from M.E. Avery, Boston Children's Hospital, Boston, MA, personal communication, July 23, 1986, and ranges presented in J.D. Horbar, "A Multicenter Survey of 28 Day Survival and Supplemental Oxygen Administration in Infants 701-1500 Grams," paper presented at the Ross Laboratories Special Conference on Topics on Neonatality, Washington, DC, Dec. 7-9, 1986.

Box C.—Changing Technology in the Neonatal Intensive Care Unit

Preventing the complications of mechanical ventilation in newborns has been a focus of research for some time. Changes in the way artificial ventilation is administered to newborns have been an important part of that research (71,153). However, medical practices and the use of technology still vary widely among perinatal centers. Avery and her colleagues surveyed eight centers in 1983 and 1984 for their experience with chronic lung disease in infants weighing 700 to 1,500 g. The researchers found that some institutions did significantly better than others, and that routine management techniques used for the very small infants might explain the differences (11). Refinements in existing techniques may thus hold promise for reducing the development of bronchopulmonary dysplasia (BPD) in ventilated infants in the future. Some new technologies, such as the high frequency ventilator (which delivers multiple small breaths instead of slower, larger ones) and extracorporeal membrane oxygenation (essentially a heart-lung machine for newborns with severe asphyxia), may also have some effect.

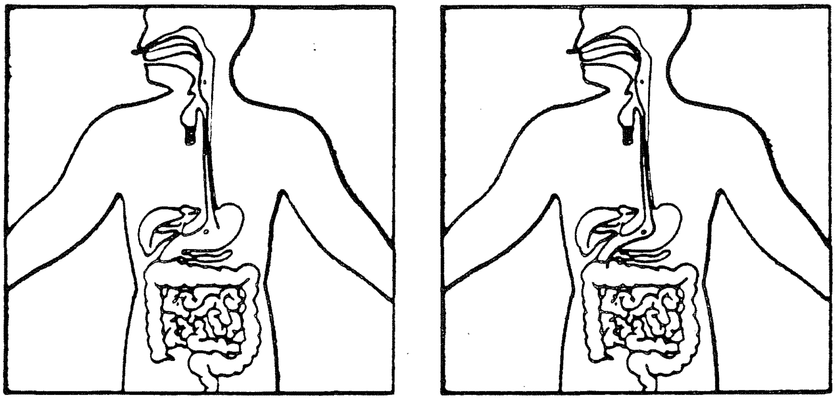
Other technologies under investigation focus on preventing respiratory distress syndrome (RDS), the precurser of BPD in most infants. The administration of steroids to mothers in preterm labor in order to accelerate infant lung maturation has been used and studied for 16 years (9), but concerns about the long-term effects of the therapy have prevented its routine use (43). Recent large-scale studies are somewhat contradictory but suggest that the technology can reduce the incidence and severity of RDS, and may improve survival in some very premature infants, with no evidence of negative long-term effects (43,174). Even if antenatal steroid therapy does become generally accepted as useful, however, it will have several limitations. It clearly does not work for all babies. And in addition, because the therapy must be initiated at least 24 hours before delivery in order to be effective, many women in preterm labor cannot be candidates for its use.

Treating surfactant deficiency by administering artificial or natural (animal lung) surfactant to the lungs of very premature babies at or soon after birth has the potential to greatly reduce the incidence of severe RDS. The basic chemistry of lung surfactant has been known for a long time, but research is ongoing regarding the best mixture, the optimum dose, and the timing and frequency of administration. At least five recent clinical trials testing natural surfactants document that surfactant-treated infants have less severe RDS (and, presumably, less likelihood of developing BPD) than control infants (66,89,100). Studies with artificially produced surfactant, on the other hand, have shown essentially no benefit to respiratory function (76,183).

Large-scale, multi-center trials are being undertaken in Europe, Japan, and the United States to continue to test surfactant experimentally. It is possible that surfactant therapy could become generally available for preterm babies within 2 to 5 years (10,143).

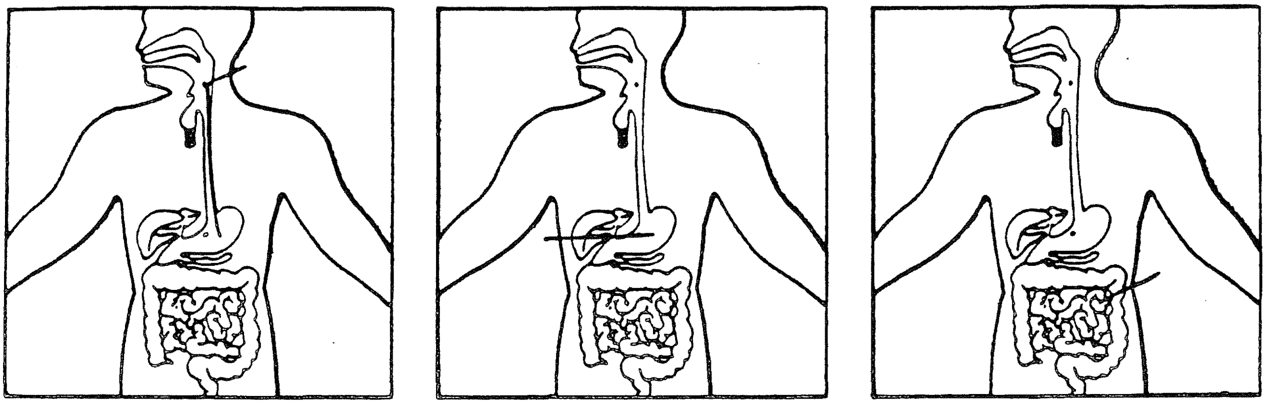
from Life-Sustaining Technologies and the Elderly, Office of Technology Assessment, July 1987

Figure 8-1.—Tube Feeding Routes



Nasogastric tubes are placed through the nose, down the esophagus, and into the stomach.

Nasoenteral tubes are placed through the nose, down the esophagus, through the stomach, and into the duodenum (first loop of the small intestine) or jejunum (second loop of the small intestine).



Pharyngostomy and esophagostomy tubes are placed through the neck, into the throat or upper esophagus, and into the stomach.

Gastrostomy tubes are placed through the abdomen into the stomach.

Jejunostomy tubes are placed through the abdomen into the small intestine.

SOURCE: Adapted from Ross Laboratories, *Tube Feeding Clinical Application* (Columbus, Ohio, 1980) reprinted with permission

D. HOME CARE FOR THE TECHNOLOGY DEPENDENT: NURSING SKILLS, EQUIPMENT, AND SUPPLIES

- "Checklist Of Respiratory And Infusion Skills For Home Care Patients And Families" and "List Of Supplies For Home Infusion Therapies"

Table 11.—Checklist of Respiratory and Infusion Skills for Home Care Patients and Families

Respiratory skills:

1. The disease process:
   - lung disease and its treatment
   - short- and long-term prognosis and goals
2. Pulmonary hygiene measures:
   - avoidance of infection (hand-washing and sterile technique)
   - adequate systemic hydration
   - chest physiotherapy procedure
   - sterile suctioning procedures
   - tracheostomy care procedure
   - tracheostomy tube cuff care procedure
   - signs of airway infection and cor pulmonae that should be reported to the doctor
3. Use and maintenance of the equipment:
   - daily maintenance of the ventilator
   - oxygen use, abuse, and hazards
   - cleaning and changing of ventilator circuits
   - resuscitation bag use and cleaning
   - suction machine use and cleaning
4. Nutrition counseling:[a]
   - maintenance of ideal body weight
   - special dietary restrictions as needed
5. Physical therapy:
   - ambulation, where possible
   - general strengthening exercises
   - relaxation exercises
6. Educational and diversional activities:
   - encouraging child self-care
   - sedentary activities
7. Access to services:
   - nurses
   - physicians
   - respiratory equipment suppliers
   - therapists
   - emergency power
   - other services

Infusion skills:[b]

1. Understanding of components of home infusion therapy:
2. Sterile procedures:
   - caring for medications and solutions
   - preparing medications and solutions for infusion
3. Infusion techniques:
   - measuring components, using syringes, bottles, and bags
   - setting up the infusion
   - starting the infusion
   - discontinuing the infusion
   - operating the infusion pump
4. Recognizing complications:
   - of the catheter
   - of the infusion
   - of the medications

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[a] This table is based on one for adults Most infants on ventilators require enteral tube feeding for at least the beginning weeks or months Thus, the families of these children must also be trained in infusion skills relating to tube feeding and care

[b] Not all skills are applicable to all kinds of infusion therapy

SOURCES: List of respiratory skills adapted from J Feldman and P.G Tuteur, "Mechanical Ventilation: From Hospital Intensive Care to Home," *Heart & Lung* 11(2)162-165, March-April 1982 Infusion skills adapted from Blue Cross and Blue Shield Association, *Infusion Therapics in Home Health Care* (Chicago, IL: BC/BSA, January 1986)

Table 12.—Supplies Needed for Four Home Infusion Therapies

	Therapies for which supplies are needed			
Supplies	Parenteral nutrition	Enteral nutrition	Intravenous antibiotics	Chemotherapy
Intravenous catheter	X		X	X
Intravenous tubing	X		X	X
Medications	X		X	X
Nutrient solutions (e.g., lipids)	X			
Intravenous solutions (dextrose or saline)	X		X	X
Infusion pumps	X	X	X	X
Heparin lock and dilute solution	X		X	X
Needles and syringes	X		X	X
Dressings (gauze and tape or transparent	X	X	X	X
Nasogastric, gastrostomy, jejunostomy tubes		X		
Enteral bag and tubing		X		
Enteral feeding preparations		X		

SOURCE: Blue Cross and Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: BC/BSA, January 1986).

E. PEDIATRIC HOME CARE: RESULTS OF A NATIONAL EVALUATION OF PROGRAMS FOR VENTILATOR-ASSISTED CHILDREN

O Background On Program Goals, Target Population, And Program Organization

O Measurement of Hospital And Home Care Charges And Costs

O Tables Showing Hospital And Home Care Costs

O Profile Of 141 Ventilator-Assisted Children In Three Demonstration Projects

O Tables That Describe Hospitalizations, The Discharge Process, and Home Care

Program Overview and Selected Data on Utilization and Costs

PEDIATRIC HOME CARE:
Results of a National Evaluation of Programs For Ventilator-Assisted Children

This evaluation of 3 demonstration programs was conducted by the Center for Health Administration Studies of the University of Chicago. Findings shown here are <u>excerpts from a pre-publication book-length draft</u> prepared in July 1987 by Lu Ann Aday, Ph.D., Marlene J. Aitken and Donna Hope Wegener (used with authors' permission). The manuscript will be published as a book by Pluribus Press in 1988.

Contents Of This Appendix

Background and Program Goals

Following the 1982 Surgeon General's Workshop on Children With Handicaps and Their Families, the Division of Maternal and Child Health issued a request for proposals for demonstration projects to develop regionalized, comprehensive, coordinated systems of care for ventilator-dependent children and their families. Three SPRANS (Special Projects of Regional and National Significance) programs in three different states were funded; Pediatric Home Care provides a formal assessment of the success of these programs in meeting their three basic goals:

0 To develop and implement a regionalized system of care for ventilator-assisted children;

0 To develop and implement a comprehensive, coordinated model of home care for ventilator-assisted children;

0 To improve the well-being of patients and caregivers and reduce costs.

Notes On Data Included In This Appendix

The three demonstration programs differ in many ways, and collectively, they represent a valuable resource for program planning and development. This Appendix presents discussion and summary tables on patient characteristics, hospitalizations and rehospitalizations, the discharge process, and home care.

Except for cost data, all information is based on the total combined sample of about 141 children and their families served by all three programs. Cost data are based on a subset of 36 children and their families for whom complete data were available. Data are broken out by program (= by state, since the three programs are in different states) in addition to combined totals.

Target Population

The three state programs differ in their eligibility criteria, which results in differing case-mix of the target population. In Sites A and B, children must require mechanical ventilation for a set number of hours each day over a prolonged period of time; in Site C, services are available to all children in the state with respiratory disabilities (see below for more on target population).

Program Descriptions

Since the number of technology-dependent is small, and the services they need are beyond the scope of any single organization, the demonstration projects are designed as regional approaches which aim to develop and coordinate the resources of a large network of organizations and agencies. Given the complexities of financing the very high cost care for this population, the projects encourage participation of both private and public funding sources and the development of resources to meet the special needs of this group of children. Education and training of service providers and families is another major function; this includes developing educational placement options.

All three programs stress the importance of a comprehensive, coordinated model of home care, but they differ in design and focus.

- Site A (Midwestern state) began by developing a Pediatric Discharge Model for use in consulting with and training discharging institutions and providers. Next, it worked on assessing the status of children and their families in the home environment and the development and validation of home health care models. Key participants: a major tertiary care hospital, a small hospital for chronically ill children, and the state's Title V Crippled Children's Services organization.

    - Originally designed to serve persons between 6 months and 21 years who were on prolonged ventilation, the program expanded its eligibility criteria to include: those children requiring medical technology to support life or serious injury; those who required two or more highly specialized multiple care services, those who required services to prevent imminent rehospitalization, and those who had chronic health problems who did not meet the criteria of the other categories but needed assistance for social and environmental reasons.

- Site B (Southern state) used a core interdisciplinary team from the main sponsoring hospital to provide consultative and technical assistance to VAC families and health professionals. It used an external advisory council for the development and networking of community and statewide resources for VACs. Key participants: state's crippled children's services agency, children's hospital that served as the base of the program, university's pulmonary center and intensive care unit, and (to a lesser degree) the public hospital's intensive care unit.

    - Target population defined as any ventilator-dependent children and their families in the state.

- Site C (Eastern state) was a community-based consortium which provided consulting, coordination, and patient advocacy with the consortium hospitals and other agencies on VAC post-discharge services. Organizations represented in the consortium: state Crippled Childrens Services agency, county health department, county board of education, two parents' support organizations, a hearing and speech agency, five area hospitals.

    -Target population defined as state residents under the age of 18 who were ventilator-dependent of respiratory-impaired. Other requirements: must meet SSI criteria for chronic disability; must have been hospitalized for thirty or more days or meet the level of care for acute, chronic, or specialty care, and have the potential for long-term hospitalization; must require specialized support to prevent prolonged hospitalization for respiratory ailments; must be medically stable and able to be maintained at home.

(See draft for an assessment of the effectiveness of each site in meeting its goals, including detailed accounts of structure, evolution of the programs, and organizational dynamics.)

Excerpts from Chapter 9, "What Impact Did The Programs Have On The Costs Of Care For Ventilator-Assisted Children?"

BACKGROUND ON HOSPITAL v. HOME CARE COSTS

- The data that follow are based on 36 children for whom adequate hospital billing information were available.

- Data include both direct and indirect costs of illness, institutional and non-institutional costs, the distribution of costs by type of service, relative costs in the three different states, and amounts charged by providers of services.

- Comparisons are made for estimates of costs and estimates of charges; ideally, policy decisions should be based on costs, which more accurately reflect the societal resources necessary to provide care.

  - Cost estimates are based on hospital reports of cost-to-charge ratios.

- The major comparison is between the average daily charges/costs during the period prior to discharge and the average daily charges/costs of all care (<u>including rehospitalizations</u>) provided post-discharge.

  - The day of interest for the cost comparison is a carefully defined "standardized day."

    - A "standardized day" in the hospital represents a day in which the child is stable enough to go home; this is operationalized as an average day during the two months prior to discharge.

    - The "standardized day" for home care encompasses all days subsequent to the first time the child was discharged from the hosptial requiring the assistance of a ventilator. This includes all rehospitalizations.

- Data from medical experts are used to adjust for "maturation bias" (the possibility that the health status and resources necessary to care for the child changed after discharge due to the natural course of the child's illness- which makes the hospital and home care charges not comparable because the child's condition differs in the two settings).

SUMMARY OF FINDINGS ON HOSPITAL v. HOME CARE COSTS

Conclusion:

Home care programs reduced the charges and costs of care for ventilator-dependent children. The bulk of this savings can be attributed to the substitution of parental for professional nursing services in the home. Additional savings are apparently realized through the elimination of laboratory tests and procedures.

O <u>Costs of Home Care</u>:

- Per diem home care costs average $490 across all 36 cases, and range from $121 to $923.

- Nursing and therapy costs are by far the largest component; together they account for about 2/3 of all costs. Equipment rentals, and materials and drugs, account equally for most of the rest of the costs.

- State B has the lowest average daily cost ($329); more than $200 lower than the averages in States A ($591) and C ($611). This can be attributed to the substitution of parental for professional nursing services for most of the children receiving home care in State B.

O <u>Home v. Hospital Costs</u>:

- Home care is less expensive than hospital care.

  o Hospital <u>charges</u> exceed home care costs by $795 per day on average.

  o Hospital <u>costs</u>, which more accuratelt reflect resource use than do charges, exceed home care costs by $418 per day on average.

  o Home care costs were lower for 30 of the 36 children.

  o Even when hospital costs are adjusted to control for averaging bias and maturation (that is, for the lower-than-average resource utilization in ICUs by ventilator-dependent children, and for changes in the child's condition that affect resources needed), home costs are lower by $294 on average.

- Cost savings vary by state and by the particular comparisons being made.

  o For example, savings using unadjusted hospital costs are highest in State A; savings using adjusted hospital costs are highest in State B. In State C, adjusted hospital costs are actually less than home costs (by a statistically negligble amount). The reasons for apparent lack of savings in State C, relative to States A and B, are that a) hospitals in State C are much less costly than in State A, and b) children in State C receive much more professional nursing at home than children in State B. However, there is no evidence that home care is less efficiently provided in State C.

- Based on multivariate analysis of the home care and hospital costs, the evaluation researchers draw the following conclusions:
  - o Cost savings vary by diagnosis. The most substantial cost savings appear to come from children with BPD. Home care for children with CA or DNS appears to be less cost effective than home care for children with "other" diagnoses.
  - o As families gain experience with caring for their children at home, home care costs fall (by approximately $20 to $25 per day for each year the child is home).
  - o The demand for home nursing care is sensitive to out-of-pocket expenses; the cost-effectiveness of home care is affected in particular by the nature of insurance (limits on coverage, caps on expenditures, etc.).

O <u>Sources of Cost Savings in Home Care</u>

- The substitution of parental nursing for professional nursing is the key source of savings.
  - o For non-BPD cases, this substitution appears to be the only source of savings.
  - o When 24 hour nursing services are provided, home care costs are roughly equivalent to hospital costs. The average cost of 24 hour home nursing for a child in the sample was $490.
- There may be additional savings in home care from the less intensive ordering of tests, procedures, and supplies.
  - o This type of savings is particularly likely in cases where hospital services are very intensive (which makes the contrast greater between hospital costs and home care costs).

O <u>Impact Of Home Care On The Families</u>

- When families are able to obtain 24 hour home nursing services, home and hospital charges will be roughly equivalent. This raises an important issue: what are the non-pecuniary costs of substituting parental for professional nursing care, and do they justify the cost savings?
  - o Evidence from this evaluation suggests that the substitution of parental for professional nursing in the home leads to greater stress in the home. On the other hand, families that have full to nearly full-time professional nursing have stress that stems from lack of privacy.
  - o Many other non-pecuniary costs to the family are not systematically measured in this evaluation study, but the researchers urge that they be carefully considered. These include the impact on careers of the parents and academic performance of siblings, reductions in the number and length of vacations, limits on family mobility, and limits on the desirability of having additional children.

MEASUREMENT OF HOSPITAL AND HOME CARE CHARGES AND COSTS

Calculation of Hospital Costs

Total costs of care in the hospital include:

- Costs incurred by the hospital;
  - To convert charges to costs by using cost-to-charge ratios, charges from patient bills were first aggregated into four cost centers (room charge, such as intensive care; respiratory therapy; supplies; other), then a cost-to-charge ratio was applied for each cost center.
  - To minimize the effects of fluctuations of charges and costs, the highest and lowest weeks of the eight week period were eliminated, and the average of the remaining six weeks was calculated.
  - According to physicians who treat ventilator-assisted children, these children consume fewer resources than the average intensive care patient. Therefore, using average ICU costs inflates the actual costs of care for these children. The data given below include an adjustment for this which is based on the fact that step-down units that house predominantly ventilator-assisted children cost approximately 75% of ICU care.
  - Adjustment for any changes in the child's condition which alter the need for resources and thereby bias the comparison of costs in the two settings (see "maturation bias" above) was made by using judgments from physicians. Based on clinical information, a panel of physicians was asked whether the child's resource needs at the time of the family interview would best be approximated by the resources in an ICU, a step-down unit, or a regular care ward.
    - Table 3 gives room costs before and after adjustment. If a child had been in an ICU but the experts felt that his/her resource needs could be met in a step-down unit, then 75% of the ICU cost is reported as the "adjusted room cost." If the experts felt that the child's condition would improve so that he/she could be placed in a regular care ward, then the hospital's regular care ward per diem cost is given as the "adjusted room cost."
- Costs of physician services;
  - Since reliable information on actual physician payments could not be obtained, physician payments were estimated by assuming that each child was visited by a pediatrician five times a week for an average of 30 minutes each visit. Average fees by region (American Medical Association data) were used in the estimate.
- Indirect costs borne by the family.
  - Families' reports of such expenses as transportation, lodging, telephone, lost time from work.

Calculation of Home Care Costs

Home care costs include:

- O <u>Nursing and therapy services and physician fees</u>;

  - Wherever possible, vendors were identified and contacted to obtain information on their charges. When vendors could not be contacted, the average charge for all vendors in that state who provided services to children in the sample was used as an estimate. Families were asked about the frequency of visits to physicians' offices; physicians' fees were estimated in the same way as for hospital costs, using AMA data on average fees.

- O <u>Equipment rentals</u>;

  - Rental fees are used to calculate equipment costs. Actual rental fees are used whenever possible; average rental fees are used for the estimate when actual fees are not available. Rental fees are used even in the several cases where families purchased the equipment because rental fees include depreciation, cleaning, and maintenance, and thus more fully represent the actual cost.

- O <u>Disposable materials and prescription drugs</u>;

  - Basic costs of materials costs are estimated by using Program C estimates of the costs of materials commonly used by <u>all</u> children. Extra costs are added for those children who used oxygen and/or feeding tubes, since these are the two biggest predictors of materials costs.

  - Drug use at home is assumed to be comparable to drug use in the hospital during the last two months of hospitalization; per diem pharmacy costs for the last two months of hospitalization are used as the estimate of home prescription drug costs.

- O <u>The costs of administering the Ventilator-Assisted Children (VAC) Program</u>;

  - VAC Program activities that include coordination and consultation on the delivery of home services are assumed to be approximately equal to non-administrative costs of the programs. These non-administrative costs are allocated equally to each child for whom program involvement was active. Children for whom program activity was minimal received half allocations. [This method excludes administrative costs of research, fund raising and long-range planning done by the VAC programs].

- O <u>Indirect costs to the family (including lost time from work)</u>;

  - Parents were specifically questioned about such costs as home remodeling, increased utility charges, lost income from work, babysitting, and transportation. Unless indirect costs included home remodeling or lost income, these costs were minor (relatively speaking). One time costs such as remodeling and car purchase are amortized using straight line depreciation over a five year period. Lost leisure time is not included here; it proved impossible to get reliable estimates (many parents say they spend all of their waking hours caring for their child in "some" way).

O <u>Hospital readmissions</u>.

- Readmissions were typically for tune-ups or fare-ups; data on readmissions were obtained from the families and the hospitals. Costs for readmissions are calculated in the same way as hospital costs (described above).
  - o In most cases, the per diem cost of a readmission was within 10% of the per diem cost of the initial hospital stay.

O <u>Calculation Of Average Per Diem Cost Of Home Care</u>

- There are two components: per diem variable costs of care and per diem fixed costs of care.
  - o Per diem fixed costs of care are the home care costs that must be borne whether the child is at home or not (that is, these costs continue during any rehospitalizations). These include rental cost of equipment, administrative costs, amortized fixed home costs.
  - o Since costs of rehospitalization are treated as part of the costs of home care, adjustments must be made for the period of time a child spends in each setting. Variable home care costs are calculated by using a weighted average that adjusts for periods of rehospitalization; these costs include nursing, therapy, disposable materials, prescription drugs, and variable indirect home costs. To these are added the costs of rehospitalization which are similarly adjusted by using a weighted average.

TABLE 1

Summary Of Per Diem Hospital <u>CHARGES</u> For 36 Children In Three Demonstration Projects

	Room CHARGE	Physician CHARGE	Ancillary CHARGE	Indirect Expenses	Total CHARGES
BY PROJECT:					
State A (n=14)	$ 778	$ 21	$ 623	$ 37	$ 1,461
State B (n=12)	360	21	858	40	1,280
State C (n=10)	615	25	384	23	1,048
TOTAL (n=36)	$ 593	$ 22	$ 635	$ 34	$ 1,285

TABLE 2

Summary Of Per Diem Hospital <u>COSTS</u> For 36 Children In Three Demonstration Projects

	Room COST	Physician COST	Ancillary COST	Indirect Expenses	Total COSTS
BY PROJECT:					
State A (n=14)	$ 667	$ 21	$ 366	$ 37	$ 1,089
State B (n=12)	370	21	387	40	817
State C (n=10)	469	25	243	23	761
TOTAL (n=36)	$ 513	$ 22	$ 339	$ 34	$ 907

TABLE 3

Summary of <u>Adjusted</u> Per Diem <u>COSTS</u> Of Hospital Care For 36 Children In Three Demonstration Projects

	Room COST	ADJUSTED Room Cost	Total COST	ADJUSTED Total Cost
BY PROJECT:				
State A (n=14)	$ 667	$ 461	$ 1,089	$ 919
State B (n=12)	370	334	817	781
State C (n=10)	469	307	761	599
TOTAL (n=36)	$ 513	$ 376	$ 907	$ 784

TABLE 4

Summary of Per Diem Home Care Costs For 36 Children In Three Demonstration Projects

	Nursing & MD fees	Equip-ment	Materials & Drugs	VAC Program	Indirect Costs	r*	Total
BY PROJECT:							
State A (n=14)	$ 355	$ 81	$ 70	$ 0	$ 25	.98	$ 541
State B (n=12)	141	61	68	8	18	.96	329
State C (n=10)	469	32	108	6	11	.94	611
TOTAL (n=36)	$ 315	$ 62	$ 78	$ 5	$ 19	.96	$ 490

* "r" = the proportion of post-initial-discharge days spent in the home (as opposed to in the hospital due to rehospitalization)

TABLE 5

Summary of Hospital-Home Care Per Diem Cost Differences For 36 Children In Three Demonstration Projects

	Hospital CHARGES Less Home Care	Unadjusted Hospital COSTS Less Home Care	Adjusted Hospital COSTS Less Home Care
BY PROJECT:			
State A (n=14)	$ 923 *	$ 548 *	$ 378 *
State B (n=12)	951 *	488 *	450 *
State C (n=10)	438 *	150	-12
TOTAL (n=36)	$ 795 *	418 *	294 *

* Significantly different than zero at $p < .01$.

TABLE 6

Profile of 141 Ventilator-Dependent Children in Three Demonstration Projects

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
AGE	6%	< 1 year	2	4	8
	35	1-2	18	17	48
	28	3-5	32	25	26
	11	6-10	16	17	7
	11	11-20	23	21	2
	1	21+	2	-	-
	9	Deceased	7	17	9
	4.5	Mean age in years	7.1	6.8	2.7
SEX	64%	Male	66	50	67
	36	Female	34	50	33
RACE	70%	White	89	71	60
	24	Black	7	25	32
	7	Other	4	-	5
AGE AT PRIMARY DIAGNOSIS	51%	At birth	42	33	60
	28	Less than 1 year	28	38	26
	20	1-20 years			
	1.5	Mean age at primary diagnosis	2.4	3.0	1.7
PREMATURE BIRTH	58%	(% yes)	30	38	77
	30	mean gestational age in weeks	33	33	29
	55	mean birthweight in ounces	80	72	48
VENTILATOR STATUS	95%	% ever on a ventilator	100	100	91

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
HOURS PER DAY CURRENTLY ON A VENTILATOR	5%	Never vented	-	-	9
	45	Technology discontinued	9	25	67
	1	Less than 8 hrs/day	2	-	1
	14	8-12	21	21	9
	12	13-23	23	17	5
	23	24 full-time	44	38	9
PROGNOSIS	7%	Get worse	10	11	5
	16	Stay about the same	127	21	10
	44	Get better	27	16	59
	33	Not sure	37	53	27
PUBLIC-PRIVATE FINANCING	40%	Public only	48	38	37
	41	Private only	33	25	49
	19	Public and private	19	38	13
TYPE OF INSURANCE (% yes)	52	Medicaid	64	58	44
	54	Private- through work	49	58	55
	2	Private- through other group	2	-	2
	7	Private- individual purchase	5	-	10
	29	Title V	54	46	13
	5	Prepaid group or HMO	-	4	8
	3	CHAMPUS	-	4	5
	3	Reduced price clinic	-	4	3
	3	Other	2	8	2
TYPE OF COVERAGE	Hospital:				
	74%	all	79	74	72
	26	part	21	26	28
	Doctors' expenses in hospital:				
	74%	all	74	77	73
	26	part	26	23	27
	Doctors' expenses outside hospital:				
	59%	all	58	74	56
	34	part	33	22	38
	Nurses' services at home:				
	69%	all	79	52	69
	23	part	16	29	25
	Other ancillary services at home:				
	64%	all	67	56	64
	27	part	27	17	30

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
TYPE OF COVERAGE, cont.					
	Supplies at home:				
	50%	all	59	41	48
	46	part	38	55	48
	Equipment at home:				
	73%	all	58	74	56
	26	part	33	22	38
	Prescriptions at home:				
	54%	all	54	43	56
	35	part	41	52	29
MAXIMUM DOLLAR LIMIT ON INSURANCE	58%	(% yes)	54	68	58
	35%	Limit less than $1,000,000	31	25	41
	65	Limit from 1-2,000,000	69	75	59
	38%	Certain services are limited (% yes of those with total dollar cap)	53	36	33
FAMILY TYPE	12%	Single parent	14	-	14
	67	Two parent	75	71	63
	21	Extended family	11	29	23
FAMILY INCOME	15%	Less than $11,000	12	12	16
	20	11,000-19,999	23	29	16
	27	20,000-29,999	28	21	28
	18	30,000-40,000	26	21	13
	20	More than 40,000	12	17	25
EDUCATIONAL STATUS OF FAMILY	20%	Less than high school graduate	18	24	20
	30	High school graduate	36	24	30
	41	Some college	41	43	41
	9	College graduate	5	10	10
EMPLOYMENT STATUS OF FAMILY	84%	One or more family members works full-time	80	86	86
	5	One or more family members works part-time	12	-	2
	11	No family members working	7	14	12

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
PRINCIPAL CAREGIVER IS MOTHER	95%	% yes	95	96	95
EMPLOYMENT STATUS OF PRINCIPAL CAREGIVER	23%	Works full-time	15	30	26
	15	Works part-time	28	-	14
	61	Not currently working	57	69	60
PRINCIPAL CAREGIVER QUIT WORKING DUE TO CHILD'S ILLNESS	86%	% yes (of principal caregivers who previously worked outside the home)	87	94	83
MORE THAN ONE CAREGIVER IN HOUSEHOLD	73%	(% yes)	70	83	71
FATHER IS THE OTHER CAREGIVER	69%	(% yes)	83	67	64
THERE ARE OTHER CARE-GIVERS OUTSIDE THE HOUSEHOLD	31%	(% yes)	24	46	30
RELATIONSHIP OF OUTSIDE CARETAKER TO CHILD	84%	A relative	88	53	92
	15	Neighbor or unrelated person	12	47	8
PLACEMENT	80%	Home	75	79	82
	3	Hospital; previously discharged	5	-	3
	1	Nursing home	-	4	-
	-	Group home	-	-	-
	2	Foster home	2	-	2
	1	Other place	-	-	1
	4	Hospital; never discharged	11	-	2
	9	Deceased	7	17	9

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
SERVICES PROVIDED BY SPRANS PROGRAM	6	Patient advocacy	-	9	6
	23	Financial assistance	13	14	28
	39	Discharge planning/training of caregivers	67	36	35
	16	Emotional/general support	13	23	14
	36	Case management	-	23	47
FAMILY'S SATISFACTION WITH SPRANS INVOLVEMENT	48	Positive or very positive	33	45	53
	40	Neutral or mixed	67	41	33
	12	Negative or very negative	-	14	15

TABLE 7

Characteristics Of Hospitalizations

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
PRE-DISCHARGE HOSPITALIZATION LENGTH OF STAY	6%	Up to 30 days	3	15	6
	11	31-60 days	-	5	17
	14	61-90 days	6	30	12
	5	91-120 days	3	-	7
	15	121-180 days	6	15	19
	27	More than 6 months but less than 1 year	42	20	22
	12	1-2 years	23	5	10
	298	Mean length of stay in days	459	243	244
NUMBER OF RE-HOSPITALIZATIONS	27%	None	27	10	32
	26	1-2	21	10	32
	27	3-5	15	60	23
	16	6-10	30	15	9
	5	11-20	6	5	4
	4.4	Mean number of rehospitalizations for those who have had any re-hospitalizations	5.3	4.5	3.8
REHOSPITALIZATION LENGTH OF STAY	58%	Up to 7 days	62	62	53
	32	8-30 days	30	29	35
	6	31-60 days	5	2	8
	2	61-90 days	1	2	2
	1	91-120 days	1	-	1
	-	121-180 days	1	-	-
	2	More than 6 months but less than 1 year	-	4	2
	-	More than 1 year	1	-	-
	18	Mean length of stay in days	20	20	16
LENGTH OF TIME SINCE DISCHARGE	13%	Less than 6 months	6	10	18
	21	6-11 months	19	5	27
	33	12-24 months	22	50	32
	28	25-60 months	44	25	22
	5	61 or more months	9	10	1

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
TYPE OF UNIT PRE-DISCHARGE HOSPITALIZATION	78%	Intensive Care Unit	78	74	80
	11	Stepdown/Transitional	-	-	19
	15	Regular ward	22	26	9
	2	Other	-	5	1
TYPE OF UNIT RE-HOSPITALIZATION	55%	Intensive Care Unit	75	63	38
	12	Stepdown/Transitional	6	3	19
	35	Regular ward	19	38	45
REASONS FOR RE-HOSPITAL-	20%	Surgery	12	4	29
	12	Tuneup/evaluation/testing	21	8	9
	18	Pneumonia/respiratory distress	26	20	15
	69	No weight gain/infections/ dehydration/trach removal	8	15	21
	53	Other	47	70	50
TYPES OF PAYORS FOR PRE-DISCHARGE HOSPITALIZATION	43	Medicaid	45	39	43
	64	Private Insurance	81	78	53
	3	State Title V Agency	10	6	-
	7	Other	-	17	7
	39	Family	42	28	40
TYPES OF PAYORS FOR RE-HOSPITALIZATION	47	Medicaid	69	55	32
	57	Private Insurance	44	55	66
	7	State Title V Agency	7	26	-
	6	Other	2	15	4
	15	Family	15	10	16

TABLE 8

Characteristics Of The Discharge Process

	TOTAL (3 sites combined) n=141		BY PROGRAM SITE A n=44	B n=24	C n=73
ELEMENTS OF DISCHARGE PLAN (% yes)	91%	Doctor had certain conditions	88	95	92
	92%	Plans were developed for emergencies	97	90	91
	97%	Trained while child still in hospital	97	90	99
	84%	At least 2 family members trained	94	89	79
	60%	Family home was checked for safety	70	63	55
	66%	Local physician was contacted for care	73	68	63
	47%	Plan was developed for educational services for child	45	37	50
	66%	Contract with vendors for maintenance, service	82	63	61
	19%	Arrangements for family social-psychological support	27	5	19
CASE MANAGEMENT	37%	Family case manager	38	32	38
	52	Health professional case mgr.	62	21	56
FINANCING PLAN	42%	Private funding	52	47	36
	54%	Public funding	68	53	48
	12%	Other sources	13	26	8

TABLE 9

Characteristics of Home Care

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
CASE MANAGER	19%	Physicians	17	7	23
	33	Nurse	41	13	33
	4	Other	10	7	1
	44	None	31	73	43
SPECIALTY OF PRINCIPAL PHYSICIAN FOR CHILD	18%	Neonatologist	26	6	18
	56	Pediatrician	48	22	66
	18	Pulmonologist	10	50	14
	8	Other	16	22	1
NURSES PROVIDE HOME CARE	86%	% yes	94	67	87
	39%	1-8 hours/day	14	91	41
	29	9-16 hours/day	28	9	33
	5	17-21 hours/day	10	-	3
	28	22-24 hours/day	48	-	23
	13	Mean number of hours/day	18	3	12
OTHER PROFESSIONALS PROVIDING SERVICES IN THE HOME	34%	Respiratory therapists	68	17	24
	37%	Occupational therapists	29	11	46
	41%	Physical therapists	23	39	49
	4%	Recreational therapists	3	6	4
	16%	Speech therapists	10	11	20
	2%	Child counselors	3	6	-
	14%	Social workers	19	11	12
	38%	Teachers	35	39	39
	3%	Dieticians	6	11	-
	20%	Other professionals	13	17	23
	3.1	Mean number of professionals seen for those with 1+	3.2	2.8	3.2

	TOTAL		BY PROGRAM SITE		
	(3 sites combined)		A	B	C
	n=141		n=44	n=24	n=73
EDUCATIONAL PLACEMENT	68%	(% yes)	78	60	65
	5%	Regular preschool	7	-	6
	9	Special education preschool	4	17	9
	18	Regular classroom	26	42	9
	8	Special education classroom	15	-	6
	37	Infant stimulation program at home	15	25	51
	12	Tutor at home	19	17	8
	11	Other	15	-	11
PAY OR NOT	10%	Yes (had to pay)	11	8	9
(If no program) REASONS FOR HAVING NO EDUCATIONAL PROGRAM	58%	Too young or state had no 0-3 mandate	63	29	64
	2	MD advice	-	-	4
	10	Parental preference	-	14	12
	30	Other	38	57	20

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F. EVALUATION OF MICHIGAN'S RESPONAUT HOME CARE DEMONSTRATION PROJECT

- Executive Summary of Findings and Recommendations
- Specialized Home Care Continuum: Phases and Outcome Objectives (Describes Stages in The Transfer Of Home Care Responsibility to Families)
- Summary of Guidelines For Various Aspects of Case Management/Home Care, With Assessment of Extent To Which The Guidelines Have Been Met and Comments On Issues and Problems Encountered

Michigan Department of Public Health
Bureau of Community Services
Division of Services to Crippled Children

RESPONAUT HOME CARE GUIDELINES

2-YEAR DEMONSTRATION PROJECT

PROJECT FINDINGS AND RECOMMENDATIONS

Developed through Contract with:

Health Care Management Consultants
Detroit, Michigan 48207

OCTOBER 1987

SPECIALIZED HOME CARE DEMONSTRATION PROJECT
Michigan Department of Public Health
Division of Services to Crippled Children

RESPONAUT HOME TRANSFERS: FINDINGS AND RECOMMENDATIONS

EXECUTIVE SUMMARY

October
1987

The Division of Services to Crippled Children (DSCC), within the Michigan Department of Public Health, operates under a legislative mandate to locate and serve Michigan residents from birth to 21 years of age who have, or are suspected of having, a crippling condition. The Division of Services to Crippled Children has the responsibiity to review the care provided these patients and to evaluate whether care is safe and appropriate. In addition, DSCC must assure reasonable cost and cost effectiveness in the utilization of public funds. One strategy for meeting these responsibilities is to establish and consistently apply standards of practice and care. It is the purpose of this report to present findings on the application of guidelines developed by a State of Michigan Task Force for transfer of DSCC-eligible ventilator dependent clients to home or a home-like setting.

Since 1981, the State of Michigan DSCC has received increasing numbers of requests to fund home care systems of children with chronic respiratory insufficiency requiring mechanical ventilatory assistance.

> All of these children have the potential to return to home or a home-like atmosphere and society has long been aware of the deleterious effect of institutionalization on their growth and development.
>
> (Ribble, 1943)

> The responauts in this study support previous documentation that home care enhances growth and development, does not increase the number or intensity of recurrent infections, and in many cases ventilatory support can be decreased sooner than expected
>
> (Laurie, 1984)

def

*Mechanical support for ventilation needed for more than one month for more than four hours per day despite application of traditional weaning methods.

Despite the fact that families can cope with complicated home care systems and despite the major advantages to responauts, home care of responauts is not possible without some risk, stress, and expense to families and state funding agency. The constant demand on families inherent in the home care of child responauts makes it difficult for family members to manage their own lives and also, effectively care for and manage their growing child's evolving life plan. The uncertainties surrounding most responaut outcomes and the financial and social support of families -- from extra- and intra- familial sources -- compound the issue.

Very little data is available on the home transfer of responauts and the progress of their case. Due to this limitation, a project was designed to identify, monitor, and assess certain pertinent features.

The project was operated on the principle that Case equals Family.

The findings and recommendations from eighteen responaut candidates for home care, and eleven who entered home care, are presented in this report of the twenty month demonstration project. They are quite positive considering the severity of the children's functional handicaps.

Home care is definitely an alternative that is cost-effective and can be satisfactory to families and state funding agencies.

The responaut population studied in this demonstration project form a small sample of children under 21 years of age requiring ventilatory assistance. The results are preliminary and must be interpreted as such.

The sample is purposive, heterogeneous, and too small for application of findings to a broader population. The data will add to the composite data picture to concretize standards of care and practice.

SUMMARY OF PROJECT FINDINGS

Demographics of Responauts

Upon entrance to their home care program, all eleven responauts were under three years of age or over fifteen.

Using five underlying disease groups to categorize the responauts:

Group I......Ventilatory Muscle Dysfunction,
Group II.....Central Hypoventilation Syndrome,
Group III....Restrictive Lung Disease,
Group IV.....Obstructive Lung Disease, and
Group V......Mixed,

we found:

All five teenagers in Group I,
One infant in Group II,
No one in Group III,
Two infant/toddlers in Group IV, and
Three infant/toddlers in Group V.

Guidelines for Planned Home Entry and Long Term Home Care

For the most part, the Guidelines proved effective for planned home transfers of children with chronic respiratory insufficiency.

Because of the wide variation in responaut underlying disease states, we became increasingly confident that guidelines for home care of a responaut are applicable to other children with chronic functional disabilities requiring long term, high technology support and complex care.

Extra-familial Case Management

There is no way to quantify the benefits of a case manager. However, it is hard to imagine the complex process being streamlined without the case manager role. The case manager was heralded by caregivers and family.

Over time, the role became a definitive, successful, middle management role of "making sure the systems were in place so the care plan could be executed." In addition, the case manager was a systems "trouble shooter" advocate, buffer in agency conflicts, and supporter of the family. The first line managers -- nursing supervisor and durable medical equipment (DME) company supervisor -- were accountable to the case manager.

Extra familial case management intensity varied by the Triad of Variables and time.

The average case manager hours and visits were:

Home Care Timeline	Case Manager Hours
One to three months pre-home entry	12 - 14 hours (2-8 hospital visits)
From discharge to three months post-home entry	20 hours (4 home visits)
Three to six months post-home entry	10 hours (1-2 home visits)
By nine months after home care entry	3 hours (1 home visit)

Intra-Family Home Care and Management Continuum

Findings support the intial assumption that family function is correlated with case timeline. Families advanced along this continuum much more rapidly than anticipated.

Families were usually able to case-manage with intra-familial resources by six to nine months after home care entry.

Financial Considerations

- Home Care Costs
  - First quarter costs are higher than costs in other quarters in all instances, but one. This is true even when rehospitalization costs are included in home care dollar totals.
  - The major home care costs for responauts are DME company and nursing costs. When these costs are combined, there is a range from 39 to 70 percent in individual responaut cost reductions from the first quarter to the fourth quarter.
- Home Versus Hospital Care Costs

  In all instances, home care costs are less than hospital care costs. This is true even when all pre-discharge related costs and rehospitalization costs are included as part of home care costs.

- Home Care Versus Alternative Institutional Placement Costs of Teenagers

  Home care costs for three teenagers for the first quarter were higher in two out of three cases than institutional placement. Over a year's time, home care costs for the three teenage responauts was less than the statewide institutional DRG per diem for teenage responauts. The savings for one year of home care over comparable institutional reimbursements for the three responauts is estimated to be $42,891, or seventeen percent.

- Cost by Underlying Disease State

  The three responauts with mixed underlying disease states (Group V) were all under three years of age. They had repeated, costly rehospitalizations and prolonged high home care costs. Responauts in Group V were the most medically fragile and the most difficult to care for, demanding the most nursing support for the longest time. Cost data is preliminary and incomplete, but trends indicate much higher home care costs for infant/toddlers in the mixed underlying disease state, Group V. It appears at least two infant/toddler cost package models are warranted; one for those with mixed underlying disease states and one for those with singular disease states.

- Cost of Intermittent Skilled Nurse Visit

  If all 184 approved Intermittent Skilled Nurse visits had been utilized during the first home care quarter by the eight responauts for whom cost data is available, intermittent skilled nursing would have equalled about three percent (or $10,672) of the total first quarter home care and rehospitalization costs of $292,426.

Nursing Caregiver Support

- Intermittent Skilled Nurse (ISN) Visits

  > The greatest number of approved (based on projected need) ISN visits for all eleven responauts at home were during the first quarter totaling 230 visits. A downward trend is apparent until a minimum number of visits is reached. It appears that a minimum is reached by six to nine months, the same time the extra-family case manager transfers the case for intra-family management.

  > During the first quarter, the number of approved ISN visits for infant/toddlers was more than double that approved for

teenagers. This reflects the major long term demands of infant/toddler responauts and the wide flucuation in their Triad of Variables demonstrated during the project.

- > Families found ISN visits helpful. The case manager found them critical to program success.

- > If all 184 visits were utilized for eight responauts for whom first quarter costs are available and the reimbursed rate was $58 per visit, the total cost for their first quarter ISN visits would be $10,672, or three percent of their total home care costs of $292,426 for the quarter.

o Continuous Nursing Support RN/LPN

- > A core, continuous, daily nursing support package, found satisfactory to most families, caregivers, and funding agencies, started with sixteen hours per day and tapered to a minimum support level of eight to ten hours (to allow for sleep) per day by three to five weeks. Individual programs varied from this core based on their Triad of Variables.

- > Due to several factors, we were unable to secure specific levels of RN/LPN nursing caregivers or the total number of approved hours of support.

- > The key variables for family satisfaction with caregiver packages were that: there was enough time coverage for respite, caregivers showed up, caregivers were knowledgeable about pediatric care and the community and were willing to learn their child's care.

- > Agency nursing caregiver show rates declined dramatically around some holidays. Show rates on the holidays themselves were not cited by families as a problem.

o Continuous Nursing Support Aides/Attendants

- > Aides were trained to provide care, observe for specific signs and symptoms of distress, intervene with appropriate procedures, and if all else failed, institute an emergency plan.

- > Aides were successfully used to provide school coverage for two project responauts.

- > Aide care was a viable part of the home care package, increasing support time while reducing costs. Family members were involved in the selecting, training, approving, and/or monitoring of the aides.

  - When aides were hired by a home health agency, the intermittent skilled nurse supervised the aide. If the aides were hired by the family, the family was responsible for supervision. In both cases, the intermittent skilled nurse monitored and updated the care plan for care and recertification purposes.

  - Some agencies refused to provide aide care for responauts because they perceived the sitaution as libelous.

Pediatric Community Support

Finding pediatricians to care for responauts was a time intensive role of team members. The issue of utilization of pediatricians versus specialty care physicians is not clear.

Durable Medical Equipment, Supplies, and Respiratory Therapist Support

- Types of Ventilators Utilized

  - Volume ventilators were used on all children without lung disease. Some problems are reported.

  - Time-cycled, pressure-limited ventilators were used on all infant/toddlers with lung disease. These ventilators were expensive to maintain, but had a mechanism to avoid condensation in the tubing and possible fluid in the lungs.

- Back-up Ventilators for Safety and/or Mobility

  - Volume ventilators provided safety and mobility.

  - A second ventilator for back-up safety and mobility for children on pressure-limited ventilators was not economically feasible, nor technologically practical.

  - Current pressure-limited ventilator equipment for infants/-toddlers with lung disease prohibits practical mobility.

- Comparison of Rental Versus Purchase

  - All ventilators funded by the State of Michigan were rented.

  - A purchased LP6 volume ventilator and accessories cost (agency charge) about $21,282 per year, including respiratory therapist time for maintenance and monitoring.

A rented LP6 volume ventilator costs (agency charge) about $28,850 per year. Purchasing a volume ventilator for long term use accrues savings of about $7,568 during the first twelve months of home care. Savings would multiply as initial purchase was spread over a greater time period.

- Supplies
  - "Clean" tracheal suctioning technique was instituted without any reported increase in respiratory infections. Estimates of the accrued savings by the use of "clean" technique rather than "sterile" technique range from $8,910 to $60,247 for one year of home care for eleven responauts depending on the type of catheter used for suctioning.
  - In all instances, equipment fit into a bedroom. Two grounded outlets were a minimum requirement for the ventilator and one for the suction machine.
  - No reports of power overload occured in twenty months of responaut home care monitoring.

Discharge Centers

Experienced teams with a rehabilitation or transitional care focus, rather than intensive care mission, provided an easier transition to home care. The intensity of caregiver time on an intensive care unit is in direct oppostion to one of the project goals -- to turn the majority of responsibility for their child back to the parents. It is difficult to separate families from the intense protection of an intensive care unit.

Foster Care Placement

Two infant/toddler responauts of the eleven in home care were in foster care placement. To make the foster care system satisfactory to most families, resources will probably consume costs over the DRG per diem.

School

- Individualized Educational Planning Committee Meetings were more appropriately done after home entry.
- Two responauts attend school part time with aides; one responaut attends school with an LPN, another an RN.

- Homebound education is not a reality during summer months.
- There is great disparity between what various school districts offered responauts in terms of support <u>and</u> education. One family moved from one county to another, where the school system would better accomodate the responaut to facilitate the educational program.

Nutritional Support

Nutrition was a major concern for most project responauts.

Speech Therapy

- Speech problems are characteristic of persons needing ventilatory support and they are exaggerated in the young infants and toddlers whose speech is yet to be developed.
- Speech augmentation technology is less than adequate.

SUMMARY OF RECOMMENDATIONS

Implement for testing the intra-family managed teenage case model suggested in the report.

When cases <u>stabilize</u> -- nursing hours and skill level of caregiver has tapered to a case specific minimum, and <u>families are case managing</u>, it would be best to return cases to the proven competent system of Regional Nurse Consultant. They would be responsible for cost audit and system monitoring. The Intermittent Skilled Nurse then becomes a family community resource consultant, advocate, and supporter, empowering families to succeed in their case management. Inherent to the ISN's success is trust by the family. The ISN will need to visit on a regular schedule. Documentation for recertification can be completed on these visits. Cases with overriding social problems should be referred to Department of Social Services case workers for specific problem resolution. Mutually exclusive roles will then be possible.

Guidelines

Distribute a revised set of guidelines that reflect project findings and future plans of the state health department.

Case Manager

Use a case manager system to streamline and expedite the period between planned home entry and long term case stabilization.

Intermittent Skilled Nurse Visits

Maintain a minimum level of approved intermittent skilled nursing visits after cases have stabilized. Use project averages to guide the approval process. Monitor ISN visits approved and utilized, adjusting minimal numbers accordingly until a valid standard is reached.

Continuous Nursing Support

Authorize and pay for specific caregiver level to achieve care plan driven expenditures.

An allotment of two extra nursing care hours per day once the case stabilizes would provide families accessible time, over the core minimal needed, to use as they need for the achievement of a successful home care package.

Pediatric Home Care

- Community pediatricians for the traditional care of responauts were extremely difficult to locate, consuming intensive team time. How much the pediatrician versus the tertiary care center specialists are utilized for traditional pediatric care and how the roles of the local health department and the ISN overlap and support the traditional pediatric care role needs to be explored.
- Develop a training module.

Durable Medical Equipment, Supplies, and Respiratory Therapist Suport

- Purchase volume ventilators rather than rental when long term use is anticipated.
- Rental of the time-cycled, pressure-limited ventilator is recommended due to the cost and complexity of equipment and relatively short usage time before conversion to a different ventilator or weaning.

- Neither rental or purchase of a portable infant time-cycled, pressure-limited ventilator is recommended until technological change makes it more practical to be mobile.
- Explore systems to reward the self-monitoring of supply usage and ordering by families. The following features would be included:
  - Public knowledge of financial parameters
  - Accrual of funds for application in other care plan areas
- Add a guideline supporting "clean" tracheal suction technique. No reports of increased infection occured with "clean" rather than "sterile" technique and projected savings range from $810 to $5,477 per responaut per year, or $8,910 to $60,247 for the eleven responauts in home care, depending on type of suction catheter utilized.
- Explore ways to reduce continuous nursing care costs and the equipment and supply costs to accrue major savings.
- The determination of electrical system adequacy must rest with the durable medical equipment company.

Foster Care

The eligibility for foster placement of a child who requires continuous care as stated in the Michigan Tripartite Agreement in Foster Care needs to be reviewed and related to the findings of this project and the realities of available, accessible resources.

Nutrition

Nutrition was a major concern for most project responauts and appropriate, tailored nutritional counseling must be explored.

Miscellaneous

- Consider children with chronic functional disabilities requiring high technology, intensive, long term care a category for the purpose of intensive, costly, resource allocation.
- After the initial crisis of home entry is over (about six weeks to three months), we agree with Perrin (1987) that about fifteen percent of family needs reflect disease-specific issues, while 85 percent of needs are common to all families with chronically ill children.
- Continue intense long term monitoring and audit of home care systems -- program and cost components and individual patient factors -- to develop statistically significant composite models for various age groups of children in this small group of children consuming a larger share of available resources.
- Collect cost data on infant and toddler responauts that will screen the best home ventilator assistance candidates.

Responaut Home Care Guidelines: 2 Year Demonstratio
Project: Project Findings & Recommendations
Michigan Dept. of Health / Services to Crippled Children, Oct. 198

SPECIALIZED HOME CARE DEMONSTRATION PROJECT
Division of Services to Crippled Children
Michigan Department of Public Health

SPECIALIZED HOME CARE CONTINUUM
Phases and Outcome Objectives

Home care of responauts is a dynamic process with fluctuating degrees of intra-family case management and home system stability from pre-discharge to long term stabilization. When objectives of one continuum phase are met, the program progresses to the next phase. Conversely, rehospitalization of the responaut or a family crisis may precipitate a return to an earlier phase.

The position of the family on the continuum helps predict the personnel needed to assist in home care. Caregiving and managerial support is essential as the family integrates the responaut into daily family life patterns. As family caregivers gain skill, knowledge, and confidence, the amount of extra-familial professional support decreases until a satisfactory minimum is determined.

1. PRE-DISCHARGE/DISCHARGE PHASE (one to three months)

At the end of this phase:

- The responaut has been clinically stabilized.
- A funding plan for 100% coverage is approved.
- Home equipment has been used for testing and training purposes in the hospital.
- The family and other home team members understand and have demonstrated all facets of the child's program.
- A 24 hour home care situation or simulation of home care is completed successfully.
- Home modificiations have been made.
- All equipment, emergency, and care plans are approved.
- The supplies, equipment, and medicines for one month of care are in the home or with the client.
- A non-emergency transport system with a restraint system is available.
- The responaut is moved from the discharge facility to home, maintaining stability.

2. EARLY TRANSITIONAL PHASE (from home care entry to six weeks post-home care entry)

At the end of this phase:

- The case management role has been transferred from the discharge facility manager to the community manager.

SPECIALIZED HOME CARE DEMONSTRATION PROJECT
SPECIALIZED HOME CARE CONTINUUM
Phases and Outcome Objectives

- The responaut has been integrated into daily family routines including appropriate rest and activity cycles.
- Families are successful caregivers and trainers of caregivers.
- Most caregivers are consistent (core home staff obtained).
- The roles of the home health team members are understood by and satisfactory to family.
- All discharge plans, protocols, and communication mechanisms as they are implemented in the home, school, or work setting have been tested and revised.

3. **LATE TRANSITIONAL PHASE** (six weeks to four months post-home entry)

At the end of this phase:

- Families are monitoring supply, use, and ordering.
- Needs, plans, and costds for care have been evaluated and modified.
- The responaut has been integrated into the community with a specific work, play, and/or learning schedule.
- Familiesd are coordinating the hiring, training, and evaluation of staff.
- Families are coordinating educational, vocational, and recreational activities of the family and responaut.
- A schedule for case review and support by a designee of DSCC has been developed.

4. **LONG TERM STABILITY PHASE** (by six to nine months after home entry)

At the end of this phase:

- Case management is intra-familial, with monitoring, audit, and recertification done by designee of DSCC.
- A comprehensive assessment schedule is implemented.

Responaut Home Care Guidelines: 2 Year Demonstrati
Project: Project Findings + Recommendations

Michigan Dept. of Public Health/
Services to Crippled Children
October 1987

SPECIALIZED HOME CARE DEMONSTRATION PROJECT

HOSPITAL GUIDELINES*

Guidelines	Achievement in Practice Yes	No	Comments
RESPONAUT			
1. General			
a. No major therapeutic interventions needed for one month prior to discharge from hospital.	Y		Guidelines should include: No ventilator volume changes or weaning from oxygen during month prior to discharge.
b. The discharge goals set for each responaut by each discipline in the discharge facility and the community are achieved.	Y	N	Hospital teams set and achieve goals pre-discharge. Less uniformity meeting community caregiver goals. When community caregivers aware of time frame, three weeks use of home ventilator equipment for testing and teaching adequate. DME company reimbursement being explored. Weaning plans inadequate. The DME company respiratory therapist coordinated the home pulmonary program in most instances, communicating with the tertiary care medical supervisor. There is no guideline for weaning. In practice, the tertiary physician doesn't designate a community person to coordinate the respiratory program.
c. A means to assess clinical stability in the home is developed prior to discharge from the hospital.	Y		Intermittent Skilled Nursing Visits, the Guidelines, and the care plan.
2. Specific			
a. Optimal ventilation is attained.....based on an assessment of blood gases.	Y	N	Blood gases are a component of hospital assessment. In the home, Respiratory Status is determined by child's clinical picture. Capillary blood gases were done occasionally.
b. Nutritional Status..... Nutritional intake is adequate for age, size, and disease.	Y		Hemoglobin/Hct done at discharge and as needed. Grids used to follow growth pattern. Five of our responauts had major nutritional problems. Reimbursement for nutritional counseling and care plan revision complicate if at all possible.

*These guidelines refer to pages 9 to 22 of the "Guidelines For Home Care Of Children With Chronic Respiratory Insufficiency."

Guidelines	Achievement in Practice		Comments
	Yes	No	
c. Stamina.....Tolerance to the clinical care plan is stable or increasing.	Y		Sleep/wake cycle, Respiratory Capacity, and energy reserves are used to develop and evaluate project goals.
d. Infection.....			
1) Chronic infectious or inflammatory processes are controlled with treatment that can be continued in the home setting.	Y		Infections only evident in respiratory diseased children (BPD) and one child with bellows dysfunction. All 4 cases of pneumonia treated at home successfully. Clean suctioning technique used on all children with one new catheter per shift.
2) Routine health supervision for age is maintained to the extent possible. This should include pneumoccoccal vaccine at 24 months or after; Influenzae vaccine at 3 years of age or after, when indicated.		N	In practice, wellness is separated from illness or problematic care. In one case, 20 pediatricians were called before one agreed to take on the case. Responauts are not on an immunization schedule. ISN's provided guidance and surveillance for health problems.
e. Data base for home care (see Guidelines for categories of data).	Y		The data base suggested in the Guidelines is obtained on a patient profile prior to discharge. A general developmental assessment is requested as there is no developmental tool appropriate for most responauts. The Bailey tool and the DDST were used frequently. The intermediate school district assessed children after discharge. The Respiratory Deficit Scale was not sensitive enough. The Respiratory Capacity Scale was developed. See Appendix B. The Self-Care Capacity Scale is not sensitive enough to provide meaningful classification. The Self-Care Deficit Scale found in Guidelines, based on function, needs refinement.
FAMILY READINESS			
1. Assessment of Readiness--Pre-Discharge Phase (see Guidelines for behaviors).	Y		All the conditions of readiness were observed for prior to discharge. When parents say they are ready, they overcome insurmountable odds.

Guidelines	Achievement in Practice Yes	No	Comments
2. Preparedness--Pre-Discharge			
a. The discharge facility will provide a pre-discharge orientation program for all potential caregivers.	Y		The DME company respiratory therapy supervisor and hospital personnel train family. In all cases, two family members were trained. Again, when parents state they are ready, they usually are.
b. Family and responaut are aware of the risks in home care.	Y		Not always aware of the amount of responsibility, time, and energy. Case manager has become increasingly emphatic.....informing family that they are bottom line, "agencies fall through, nurses call in sick, etc."
c. Family demonstrates readiness.	Y		A 24 hour home simulation is required in lieu of actual home practice to limit cost and complexity. If family does all care, home practice is realistic.
3. Demonstration of Readiness--All Phases			
a. Family caregivers maintain expertise in care components.	Y		Competent Intermittent Skilled Nurses reinforce, re-educate, and help families with what they do and don't know. Too often, however, visits are used to orient private duty nurses. HHA caregivers frequently did not show up and agencies had no replacement causing families anger and frustration. Every family asked for the opportunity to have a fund of money to use for hiring and training their own personnel. All families, but one, were ready to manage home care by six months post-discharge.
b. Family caregivers grow in their ability to manage all aspects of the case.	Y		
c. Achieve mobility for the responaut and family members.	Y	N	Mobility of infants and responauts with lung disease on 24 hour ventilatory assistance is restricted. Responauts with lung disease or high respiratory rates require pressure vents. The Healthdyne pressure vents used are expensive, leaving limited funds for transport vent. Healthdyne portable or transport vents need compressed air. Compressed air tank lasts about 20 minutes-not practical. Families must travel with several

Guidelines	Achievement in Practice Yes	No	Comments
			tanks. If child on oxygen, other tanks necessary, again, lasting abou 20 minutes. None of the families using a pressure vent were mobile. Volume vents are small, fit on chai or stroller, and don't require compressed air to drive them, a marine battery will power the vent for 12 hours. A back-up portable ventilator for responauts on volume vents is practical and essential for mobility.
TRAINING*			
1. Pre-Discharge Phase			
a. Discharge facility professionals provide education to responauts, family members, and community service personnel.	Y		Hospital staff teach child care. DM company teaches equipment in hospita and home with prior arrangement. HHA's don't want to fund training th cadre of nurses needed. Training takes about 4-8 hours per nurse; reimbursement covers 8 hours. Usuall HHA supervisor trains. DME company R offers an inservice in home. Not wel utilized. Most new caregivers need help. Advance 2 week schedule of nurse caregivers pre-discharge helps assure coverage. This lets family know who is new to the case, therefore, when they need to be home to train. In one case, there were 7 different nurses first week; 9 differen nurses first month.
b. The discharge facility team, community personnel, and family will complete a home care plan and emergency guide.	Y		The hospital plan needs tailoring t home. Ex: Most hospitals use sterile technique for suctioning and tracheostomy care. Clean technique used o all responauts at home. CM followed up details of emergency plan. For instance, ambulances required by law t go to nearest hospital; responaut must go to pre-selected hospital.

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* Refers to community and hospital guidelines.

	Achievement in Practice		
Guidelines	Yes	No	Comments
c. The caregivers and community service personnel demonstrate documented competency in the care and management of the responaut and his life support equipment.	Y	N	Family caregivers demonstrate competency. About half the hired community caregivers demonstrate competency initially. See Page 57, 93, 1b, and Page 93, 2a.
2. Transitional and Long Term Stability Phase.....There is a plan for training caregivers and documenting the process.	Y	N	See Page 61 and Page 94, 1a. In practice, families train most caregivers even in the first quarter of home care. Accountability for HHA nurses showing at scheduled times is appalling. This keeps the home care system in flux.
FINANCIAL READINESS			
An appropriate long range funding plan is arranged prior to discharge.	Y	N	An appropriate short range funding plan was arranged. This is a time intensive major part of the case manager role. Home care financing based primarily on patient DRG per diem. The lack of a mechanism for families to self-manipulate expenditure of funds in response to realities of day-to-day Triad performance is in conflict with the goal of family self-management. A case manager or bureaucrat is always necessary to access funds. No mechanism to bank saved funds for future use. Long term funding system inflexible for a care system in dire need of flexibility. DSCC, foster care, and chore service funds provide short term flexibility. See Pages 50, 51. The ability to fund aide care vis-a-vis nursing care hampered by bureaucratic funding mechanisms and fear of liability. Determining actual costs of specific items is sometimes clouded by cost shifting.

Guidelines	Achievement in Practice		Comments
	Yes	No	
HOME READINESS--PRE-DISCHARGE			
The physical environment of the home, indoors and out, is evaluated in terms of responaut safety, independence and mobility.	Y		Hospital OT's and DME company RT's do this assessment. Quality varies. Wiring modifications and a ramp if child is mobile and in a wheel chair are essential. Anything else is nice, but not critical.
TRANSPORTATION--ALL PHASES*			
A reliable, appropriate transport system is available and accessible. A mechanism for restraint of the responaut and his equipment is part of the transport system in compliance with restraint laws pertaining to people, equipment, and high pressure gases.	Y		Regular restraint systems are used. Mobility of infants restricted by need for pressure-limited vents. See Page 64. No agency purchases vans. Some children restricted to school and home travel because families can't afford van.

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* Refers to community and hospital guidelines.

COMMUNITY GUIDELINES*

Guidelines	Achievement in Practice		Comments
	Yes	No	
CASE MANAGEMENT			
1. Case management is provided by a qualified person/agency not providing direct reimbursable services to the responaut.	Y		Highly successful.
2. The Case Manager (CM) is involved one month prior to discharge.	Y		DSCC CM notified 2-3 months prior to discharge. Hospitals discharging large numbers of technology dependent children require least amount of CM time. CM must educate families and staff on funding sources and procedures, responaut care guidelines, home care as an option -- it's risks and benefits, etc.
3. The Local Health Department or community agency that will do the case management review in the Long Term Stability Phase is identified by DSCC during the Late Transitional Phase	Y		Although local health departments were targeted for long term case review, ability and willingness of agencies highly variable. One community case manager was in charge from day one of home care. Agencies for long term follow-up ideally identified before home care program.
COMMUNITY SERVICE READINESS			
1. Community health care providers are available 24 hours/day, 7 days/week, until otherwise.	Y	N	DME company response time good. Nursing agency show rates undependable. Physicians, variable.
2. Medical supervision and community hospital service, consultation, supervision, and follow-up are identified prior to discharge.	Y	N	Willing, qualified pediatricians/physicians hard to locate. Community physicians did not attend pre-discharge conference or training. Families used R.T. and tertiary agency plysicians for pulmonary and specialty care. Anticipatory guidance through ISN visits. Immunizations of infants not current.

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*These guidelines refer to pages 9 to 22 of the "Guidelines for Home Care of Children With Chronic Respiratory Insufficiency."

Guidelines	Achievement in Practice Yes	No	Comments
3. Nursing Supervision and Community Nursing Agency Service			
a. A Medicaid/DSCC approved home health agency and primary care nurse supervisor are identified and notified pre-discharge.	Y		
b. The nursing care ISN is knowledgeable in the care of children and community health systems.	Y	N	The supervisor, in practice, is the ISN. Master's Prepared Clinical Nurse Specialists (CNS) were knowledgeable. Preparation and knowledge of other ISN's was highly variable.
c. A plan for intermittent and continuous care and provision of professional pediatric nursing assessment, respite, and attendant care developed.	Y		Plan set, but plan not always followed because HHA's can't consistently provide: - specific level of care provider requested - number of hours of service requested - trained and/or knowledgeable providers (in pediatric chronic illness care and case specifics) - caregivers who show when scheduled A two week pre-approved schedule with names of caregivers and shifts promotes compliance with attendance. A pre-arranged schedule showing HHA's and families the projected plan for tapering of services, if all goes as planned, has also promoted compliance of attendance. When available, Master's Prepared CNS' are excellent on site to make sure plan is carried out and altered. The CM puts the pieces in place so the care plan can be carried out, straightens out systems problems, and consults as needed.
4. Respite Care....An extended time period away from the care of the child. One week per year should be considered the minimum for parents of responauts at 3 and 4 on the RC scale and 3 or 4 on the SCD scale.	Y	N	Respite needs varied by external support, age and functional status of the child, and family status more than by respiratory capacity of the child. All responauts required intermittent care and/or supervision. If responaut requires 24 hour care and/or supervision, 8 hours of community caregiver time per day allows family

Guidelines	Achievement in Practice Yes	 No	Comments
			sleep, but no daytime respite. One family used no extra-family support. A foster family of an infant needed 3 respites in the first six months of home care, in addition to extra-family support at home.
5. Respiratory Care Service			
a. Medicaid/DSCC approved durable medical equipment provider and credentialed respiratory therapist or nurse supervisor are identified.	Y		Two Durable Medical Equipment (DME) companies used. One company carried over 90% of the project population.
b. The respiratory care supervisor is knowledgeable in the care of children and expert in the use of ventilators and related equipment.	Y		Limited cases prohibit all state DME companies acquiring expertise in pediatric vent care. Families need to know of services and experience and choose their DME company. A responsive, knowledgeable DME is critical during the initial stabilization period and during weaning.
c. Accountability is simplified when all durable medical respiratory equipment needed in the home is provided by the same provider.	Y		DME gives family cost and what's approved with check list. Families order supplies needed each month by check list. One family put supply list on home computer. Families state ability to purchase supplies from alternate sources could save money.
d. Home equipment is available for responaut use in the hospital 3-4 weeks prior to discharge.	Y		Usually 2-3 weeks pre-discharge. System to reimburse the DME company being explored. Some hospitals charge ventilator fee during this time.
e. Appropriate training of care givers prior to discharge.	Y		Yes-family and nursing supervisor; No-continuous caregivers and medical.
f. A trial period of family care is provided lasting at least 24 hours.	Y		Complicated and costly to send children home for a weekend. Trial in hospital. Mock equipment failures simulated by staff, solved by parents.
g. Equipment is selected with goals of optimal ventilation, growth, development, independence, and mobility when growth and development is possible.	Y	N	Vent needs of responauts with diseased lungs limits mobility because of limits of technology. See Pages 63 and 64.

Guidelines	Achievement in Practice Yes	No	Comments
h. Alternative inexpensive vehicles for mobility may be obtained from commercial equipment suppliers.			Not tested
i. When rental of ventilator and accessories exceed purchase price and cost of service contract (6-9 months), the ventilator is purchased.		N	All ventilators were rented. See Pages 64-69 for rental versus purchase prices. Purchase of volume ventilators for long term use cost effective.
j. A service contract for preventive and emergency maintenance is obtained for ventilators and accessories (rented or purchased) prior to discharge and reviewed with each re-certification.		N	There were no service contracts. DME companies follow manufacturer's recommendations for maintenance. They also add items based on experience. Equipment is prior approved. Visit home on regular schedule. See Table 21 for visit schedule.
k. Prompt emergency services are available. Time frames are delineated in care plan and service contract.	Y		No service contracts.
l. There is a plan to meet the needs of the responaut in case of mechanical failure.	Y		All caregivers learn manual resuscitation. Caregivers taught respond to child first, equipment second.
m. The decision to place back-up ventilator in the home is made based upon specific criteria.	Y		Family desires, mobility, and cost are variables. DME company vendor becomes "back-up" when no back-up vent available. DME company response time and trained caregivers critical.
n. The safest, most cost effective system of delivering oxygen to a responaut in the home is utilized, with special attention paid to need for mobility.	Y	N	The DME company assesses safety and mobility factors. Need system to monitor type, amount, and cost of oxygen delivery over time with re-certification. Mobility of infants with diseased lungs is a problem. See Page 64.
o. Provider Responsibilities for equipment.	Y	N	There are no medical provider Guidelines for equipment use. DME company supervisor responsibility for home assessment of modifications for safety of electrical circuitry must be assured. Nursing supervisors not always knowledgeable and skilled with home equipment prior to discharge, and cannot or do not prepare for others to be trained.

Guidelines	Achievement in Practice Yes	No	Comments
6. Non-Durable Supplies.....A local pharmacy and non-durable supply company** is identified.	Y		Families feel savings could be accrued if had funds to purchase supplies at various sources.
7. Laboratory/X-Ray**..... Facilities for laboratory and x-ray are identified.	Y		
8. Local Health Department (LHD)			
a. The LHD is informed of the discharge.	Y		
b. Involvement in the community health plan will be what the locally based services involvement is with all DSCC client families.	Y	N	LHD-Local Based Services (LBS) performance varies. One child went directly to home care with LBS case management. In some areas, LBS is not in operation. DSCC Regional Nurse Consultants, and/or local social service case worker back-up some cases.
9. Mental Health....A psychosocial assessment of the responaut is done at least once a year, or more often if necessary.		N	Families routinely refuse mental health counseling. Want respite, community support, and contact with other responaut families. Families want help to make project a success and as streamlined as possible.
10. Emergency Service			
a. A comprehensive emergency plan is written, available, accessible, and acceptable to all involved agencies.	Y		Basic emergency plan done by DME company and hospital personnel. Letters from tertiary care institution MD critical to ensure transport to appropriate hospital. CM helps here.
b. The plan is confirmed in writing before discharge.	Y		
c. The plan is tested in the Early Transitional Phase and every six months thereafter.		N	Families are responsible. The plan is tested when an emergency occurs; too complicated to do otherwise.
d. A communication device is part of the plan.	Y		System, not device, important. An inexpensive monitoring device has been used in two care plans. One child bangs feet on floor.

**If DSCC or Medicaid is to reimburse for service or supplies, these must be certified Medicaid providers.

Guidelines	Achievement in Practice		Comments
	Yes	No	
EDUCATION/VOCATION			
1. A request for an Individual Educational Plan is made by family or discharge facility personnel at least 30 days before discharge. In interim, school personnel who will be working with responaut are trained in care and management of the responaut.		N	Most school districts want to evaluate the child after they are home. No evaluations done during summer. Delays children's fall start-up. School attendants are trained at home.
2. When a responaut cannot attend a traditional school, alternate arrangements are made.	Y		Homebound education varies with the district and time of year. Schools need not provide homebound GED training as GED considered adult education. Vocational Rehabilitation and DSS sources for GED training.
3. At the Individual Educational Plan Conference eligibility and an appropriate program are determined. The case manager and representative from discharge facility and community attend.	Y		Case Manager must attend to ensure school placement when appropriate.
4. Adaptive aids, and in some cases teacher aides, may be needed to insure the least restrictive environmental placement of the student.	Y		Four teen responauts attend school. Aides used by two, RN or LPN by others. Infants and toddlers have homebound educational services during the school year. A half hour visit one time each month during the summer is the best summer service, the worst is none. One teenage responaut is pursuing a GED through DSS. School system reluctant in one case. Insisting on RN level coverage. The level of provider in all instances could be aide.
SOCIAL SERVICES AND SUPPORT			
1. All options for service are explored by the case manager and family.	Y		Plymouth Elks purchased a communication device. Very time consuming, with little reward.

	Achievement in Practice		
Guidelines	Yes	No	Comments
2. Parent support groups are used when available.	Y		Respite hours could be used to attend.
RECREATION--SOCIALIZATION			
To the degree possible, recreation includes both outdoor and indoor activities, excursions in the community and beyond, with emphasis on independent mobility and peer interaction.	Y		Except for infant responauts on 24 hour pressure-limited ventilation. See Page 64.
CERTIFICATION--RE-CERTIFICATION PROCESS			
The certification process for Medicaid clients is a paper trail of stampers and approvers. One person does not have mutually exclusive role of approval with input from others. See Recommendations.			
1. DSCC certifies a responaut's home care program through a prior approval system.	Y		
2. Case conferences held at three months and regularly as needed thereafter to determine care plan, bring up problems for resolution.		N	A three month conference is too late and too complex to arrange. Learned patterns, good or bad, are established, parents are angry and frustrated by seemingly unwieldly systems. A one month conference prescheduled at final discharge meeting works best. Family chooses site. Case manager chairs this conference. Thereafter, conferences as needed with whomever is pertinent. Family can schedule.

MINNESOTA MEDICAID MODEL WAIVER PROGRAM (CAC)

ATTACHMENT V

MINNESOTA'S PLAN FOR EVALUATION AND EVALUATION INSTRUMENT

Referrals to the Waiver Program normally will arise from the individual's tertiary care facility clinical staff, although community members and/or parents, spouses or legal guardians can initiate the intake process. When home and community placement becomes a realistic option for the individual and his/her family, a referral will be made to the Waiver Unit of the Health Programs Section, State Department of Human Services, who will verify Medical Assistance eligibility and begin to arrange the required evaluation for eligibility into the waiver program.

The tertiary care facility discharge planning team will identify both current services received and future services needed through the individual's discharge plan. This discharge plan will provide background for the development of an individual plan of care developed by members of the hospital discharge team and key community providers.

HOSPITAL DISCHARGE PLANNING TEAM

Each individual's health service needs and functional abilities will be comprehensively assessed by the hospital discharge planning team. The individual's case manager will be the primary nurse, the medical social worker, the county social worker or county public health nurse.

The hospital discharge planning team membership will depend on the individual's specific service needs but should include the following disciplines:

- Case Manager;
- Parent/guardian or spouse of the individual;
- Attending medical specialist/responsible physician;
- Primary nurse;
- Medical social worker;
- County social worker;
- Occupational therapist;
- Speech therapist;
- Respiratory therapist;
- Physical therapist;
- Nutritionist;
- County public health nurse; and
- Services for Children with Handicaps representative. (for individuals under 21 years of age)

Obligatory hospital discharge planning team members include the following:

- Case Manager;
- Parent/guardian or spouse of the individual;
- Attending medical specialist/responsible physician;
- Primary nurse (RN);

- Medical social worker:
- County social worker:
- County public health nurse: and
- Services for Children with Handicaps representative.
  (for individuals under 21 years of age)

The assessment process will consider such factors as: the continued level of institutional care that the individual would require: family capacity for managing the individual's activities of daily living; household: formal and informal support systems available in the home: family environment and individual's mental functioning; financial resources available: and physical environment in addition to the individual's health care requirements. If a client is not found eligible for services, FFP will not be claimed for the cost of screening/assessment.

This representative will be a public health nurse or a medical social worker. (See Qualifications.)

The hospital discharge planning team will develop an individual patient plan of care for those services which would be essential to provide smooth entry for the individual and his/her family into the home and community-based setting. This treatment plan will include the medical and all other services to be provided, their frequency and duration, and the type of certified providers who may furnish those services. The patient care plan must be approved in writing by the case manager, individual's parent/spouse or legal guardian and attending physician. This plan of care and associated costs will be sent to the Department of Human Services so overall cost projections can be monitored. (See Appendix A for Plan of Care format.)

The discharge planning team would continue to be a resource to the community-based physician, the case manager and members of the community interdisciplinary team; a specific individual designated for ongoing contact with the case manager would be identified before discharge.

CASE MANAGER

The hospital discharge planning team, based on the patient's individual needs and resource availability, will identify the appropriate professional discipline of the case manager. The discharge planning team, in consultation with service providers from the individual's county of residence will identify the specific individual who would agree to assume the role of case manager. The State Department of Human Services Waiver Program will monitor vendor payment accountability with the assistance of the assigned case manager. The State Department of Human Services has the overall responsibility for maintaining costs under the waiver. Case manager responsibilities shall include the following:

- Provide the individual and/or family with information about care choices, available services, recipient rights;
- Coordinate services to avoid duplication and fragmentation;
- Initiate referrals as appropriate to the client plan of care and current family needs;

- Assume responsibility for regular evaluation of client condition and family functioning as specified in the plan of care;
- Assure the coordination of billing for waivered services through the Waiver Unit of the Department of Human Services; and
- Coordinate communication and information flow between community interdisciplinary team delivering services to individual, tertiary care facility responsible for individual and Department of Human Services Waiver Unit caseworker.

COMMUNITY INTERDISCIPLINARY TEAM

To facilitate the transition from the tertiary care setting to the individual's home and community environment, an interdisciplinary team will be identified within the community to develop and implement a community service program based on the individual plan of care developed by the center discharge planning team. Liaison should be established between the center-based responsible physician and the community-based physician who will be responsible for the individual's ongoing medical care needs. Liaison should also be established and maintained between the tertiary care facility primary nurse who is a member of the hospital discharge planning team and the county public health nurse to facilitate smooth entry into the local community service network.

This community interdisciplinary team may include, but is not limited to, the following members:

- Case manager;
- Parent/guardian or spouse of the individual;
- Primary caretaker (if different from above);
- Community-based responsible physician;
- County social worker;
- County public health nurse;
- Services for Children with Handicaps regional representative (for individuals under 21 years of age); and
- Liaison from the discharge planning team.

Please see Appendix B for a copy of the Evaluation Instrument to be used by Discharge Planning team when evaluating individuals for waiver program eligibility. Also included is a Physical Facility Checklist for the Home (Appendix C) to be completed by the assigned case manager.

A formal assessment of each individual will be completed by the case manager in conjunction with the community interdisciplinary team every six months.

G. CASE MANAGEMENT AND THE COORDINATION OF SERVICES FOR HOME CARE FOR THE TECHNOLOGY DEPENDENT

- Description Of The Iowa Home Care Monitoring Program That Illustrates How A Broad Range Of Community Resources Are Mobilized To Provide Home Care For Technology-Dependent Children

Iowa Home Care Monitoring Program

Excerpt from "Alternatives to Hospitalization for echnology Dependent Children," National Maternal & Child Health Resource Center, 1987, included as an illustration of how a broad range of community resources are mobilized to provide home care for technology-dependent children

The regional center CHSC nurse and the Central Office CHSC nurse consultant are responsible for convening a community based care conference of members of the community services network team for the purpose of developing the Community Services Network Plan of Services for the child and the child's family. This team is made up of the individuals who may become or are involved with the child's care in the home setting. The team may include all or some of the following individuals: the child's family, the child's local physician, a community hospital representative, home health agency representative, emergency support personnel, equipment vendor representatives, area education agency representative, family support group members, community service program representatives and representatives of programs funding home care.

The Community Services Network Plan typically contains the following elements:

1. Family. The child's family is the child's primary care provider and generally receives instruction in the provision of certain of the child's medical care needs while the child is in the hospital The Community Services Network Plan identifies the services, both medical and nonmedical, that the family will provide and the services that the family wishes others to provide.

2. Medical. The Community Services Network Plan identifies a local physician who is responsible for providing the child's primary care and who carries out the recommendations regarding medical care by the Hospital Plan of Services. As a member of the community service team, the local physician must be involved in developing the Community Services Network Plan and the physician must know who is responsible for various types of needed services.

3. Hospital. After the child returns home from the hospital, medical problems frequently recur requiring temporary rehospitalization of the child. The Hospital Plan of Home Services identifies community, regional or medical center tertiary care hospitals to provide the follow-up services the child may need and includes plans for rehospitalization of the child should that need arise. The Community-Based Care Plan incorporates those elements of the Hospital Plan.

4. Home Care Programs. The Community Services Network Plan identifies the nurses or health aides, either public or private, who are responsible for providing support to the family in their home care duties. Nurses or health aides provide the elements of home health care not requiring direct physician involvement that are too complex or frequent for the family to provide. Other health services are provided as needed by professionals such as respiratory therapists, physical therapists, occupational therapists, nutritionists, and psychologists. These services vary and are determined by the needs of the individual child and family. Formal written contracts are negotiated directly between the child's family and home care agency. Monitoring of home care services is provided by the regional center CHSC nurse to assure quality care.

5. Funding Agency. While home care costs are generally less expensive than hospital care costs, the costs of home care are nonetheless often considerable. Sources of financing the home care of the child are reviewed and identified in the Community Services Network Plan. Families of children requiring long-term specialized medical care in the home may be eligible for the Model Waiver Program under which the Title XIX Medicaid Program covers the cost of many home care services. The Community Services Network Plan includes the arrangements that have been made in this regard by the family, DHS and CHSC.

6. Emergency Support. Many of the children requiring specialized medical home care need support services such as alternative electrical systems, transportation and medical care in the event an emergency arises. The Community Services Network Plan lists those who are responsible for providing emergency services, and advanced planning for possible emergencies is done with those providers.

7. Education. The children who need long-term specialized medical home care vary in their need for educational services. Infants and small children may need home-based early intervention programs or pre-school programs and school-age children may need special education services. Since Iowa has a regionalized public special education program with a mandate to provide services for all children from 0-21 years of age,

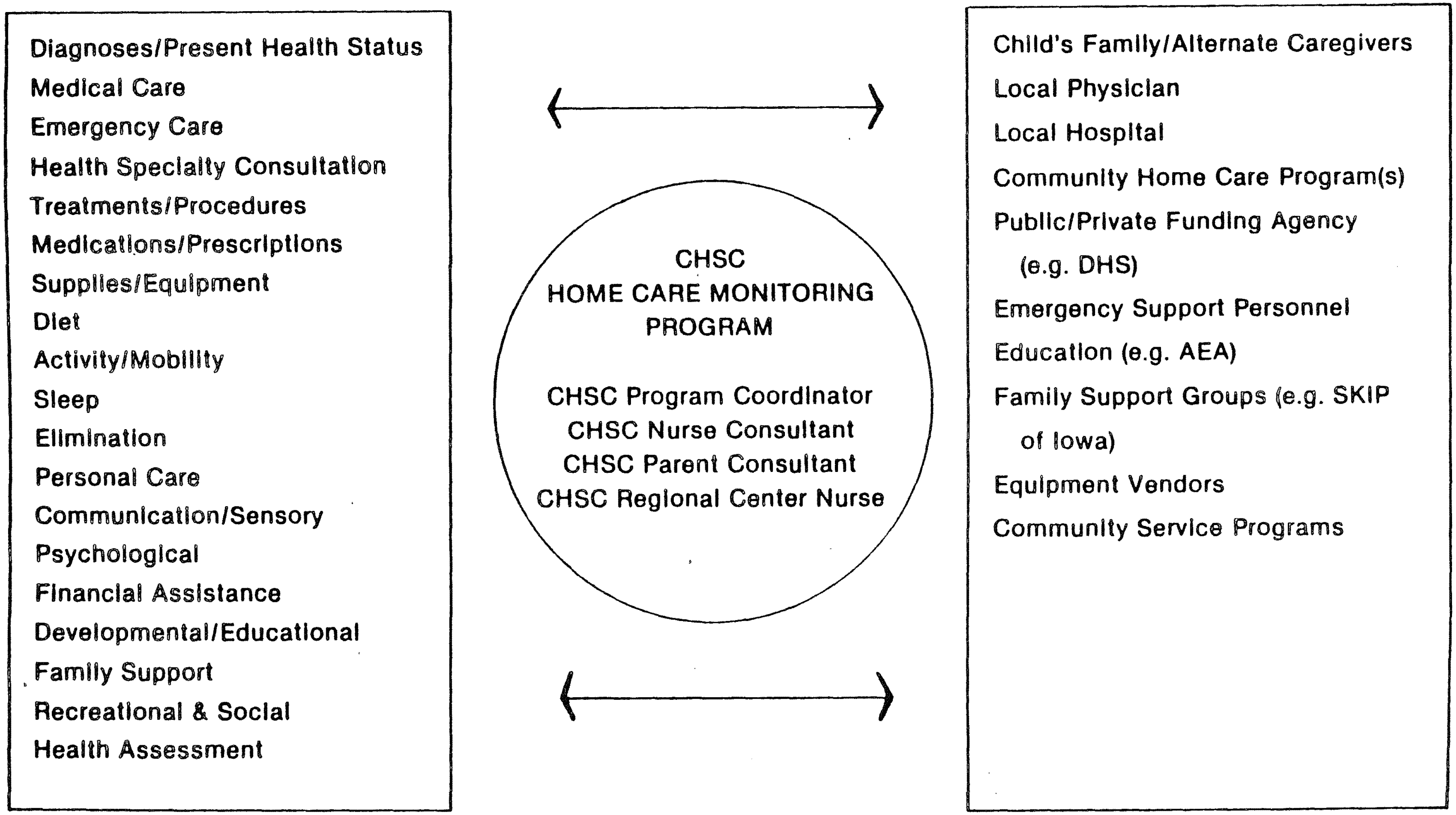
children receiving long-term specialized medical home care have access to appropriate educational services and to "related services." The Community-Services Network Plan identifies the service to be provided and indicates how these services are to be provided.

8. Family Support Group. Parents who provide long-term specialized medical care in their home often have a need for the support and counsel of other families who have comparable problems. SKIP of Iowa (Sick Kids Need Involved People), a nonprofit organization of parents with personal experience in caring for children with specialized medical care needs is a major family support group with which the Home Health Care Monitoring Program has developed a close relationship. Family support groups such as SKIP assist in the Community Services Network Plan development by providing a parent representative to meet with the family during the development of the plan to work with the CHSC Home Care Monitoring Program coordinator in formulating the plan, to help the family gain access to state and federal resources, to help educate various community resource personnel as needed for each child, to link the family with other families for ongoing support, and to maintain a network with various support groups that can provide further consultation with parents.

9. Equipment Vendors. Many children who receive long-term specialized medical care in the home require special equipment with 24-hour availability of services, maintenance, and supplies. These special needs make it necessary for the regional center CHSC nurse to work with the family to identify vendors who agree to provide on-call services with formal written contracts being negotiated directly with the child's family. The Community-Based Care Plan identifies agreements with equipment vendors, and the regional center CHSC nurse who serves as case manager monitors the vendor's reliability.

10. Community Service Programs. The ability of families to cope with the physical and emotional demands of providing long-term specialized medical care for a child in the home is, to a large degree, determined by the support the family receives from other family members, friends, and the community. Needed support services may include respite care, home health aides, and special transportation arrangements. The Community Services Network Plan includes the arrangements made for such services and indicates how they are interrelated. The regional center CHSC nurse who serves as the case manager monitors the services to assure quality of services.

CHSC HOME CARE MONITORING PROGRAM: COORDINATION OF HOSPITAL PLAN OF SERVICES AND COMMUNITY SERVICE NETWORK PLAN



- Diagnoses/Present Health Status
- Medical Care
- Emergency Care
- Health Specialty Consultation
- Treatments/Procedures
- Medications/Prescriptions
- Supplies/Equipment
- Diet
- Activity/Mobility
- Sleep
- Elimination
- Personal Care
- Communication/Sensory
- Psychological
- Financial Assistance
- Developmental/Educational
- Family Support
- Recreational & Social
- Health Assessment

CHSC
HOME CARE MONITORING
PROGRAM

CHSC Program Coordinator
CHSC Nurse Consultant
CHSC Parent Consultant
CHSC Regional Center Nurse

- Child's Family/Alternate Caregivers
- Local Physician
- Local Hospital
- Community Home Care Program(s)
- Public/Private Funding Agency (e.g. DHS)
- Emergency Support Personnel
- Education (e.g. AEA)
- Family Support Groups (e.g. SKIP of Iowa)
- Equipment Vendors
- Community Service Programs

CHSC HOME CARE MONITORING PROGRAM

HOSPITAL

UNIVERSITY OF IOWA HOSPITALS & CLINICS NICU/PICU

Responsibilities

1. Assist in conducting continuing education program(s) for regional nurse.
2. Assist in education of regional nurse for specific patients/clients.

Hospital Care Team

Physician(s)	Nurse(s)	Support Services	Child's Family
(a)	(b)	(c)	(d)

Responsibilities

(a) 1. Identify children who are candidates for home care.
(a) (b) (c) 2. Identify and prepare family/alternate caregivers to provide home care.
(a) (b) (c) 3. Refer to CHSC home care monitoring program.
(a) (b) (c) (d) 4. Develop hospital plan of home services in cooperation with program coordinator, parent consultant and regional nurse.

IOWA REGIONAL HOSPITALS NICU/PICU

Responsibilities

1. Assist in education of regional nurse for specific patients/clients.

CHSC

Program Coordinator & Nurse Consultant

Patient Care Responsibilities

1. Cooperate with staff of referring NICU/PICU in creation of hospital plan of home services.
2. Serve as liaison between referral hospital care team and community services network team.

Administrative Responsibilities

1. Monitor the reporting & evaluation system to maintain quality assurance.
2. Conduct continuing education program(s) for regional nurses to assure they will have the skills needed to assure quality care.
3. Supervise regional nurses activities in developing and implementing the hospital plan of home services and the community services network plan.
4. Develop standards for home care.

Regional Center Nurse & Nurse Consultant

Patient Care Responsibilities

1. Assist in development and implementation of hospital plan of home services.
2. Organize the community services network plan.
3. Serve as liaison between members of the community services network team.
4. Serve as case manager to coordinate and monitor hospital plan of home services and community services network plan.

Administrative Responsibilities

1. Identify local personnel and resources needed to provide home care as recommended in the hospital plan of home services.
2. Convene case planning conferences of local providers to create community services network plan.
3. Designate who will be responsible for providing "hands on" care to maintain quality assurance.
4. Monitor records that are kept for reporting and evaluation system.

Program Parent Consultant

Patient Care Responsibilities

1. Assist families to examine home care options.
2. Provide direct family support.
3. Assist families with financial plans.

Administrative Responsibilities

1. Parent advocacy.
2. Review and monitor financial status of referred families.
3. Assist in development of hospital plan of home services and community services network plan.
4. Identify and network with various family support groups.

COMMUNITY

Community Services Network Team*

Child's Family	Child's Local Physician	Community Hospital	Home Care Programs	Funding Agency	Emergency Support Personnel	Education	Family Support Groups	Equipment Vendors	Service Programs
(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(i)	(j)

Responsibilities

(a) Provide for child's daily physical, emotional and social needs.
(b) Provide primary medical services for acute care, crisis intervention and health maintenance.
(c) Make acute hospital care available and be lifeline for patients from home to appropriate hospital.
(d) Supervise or provide "hands on" patient care in the home.
(e) Pay for services provided child elegible for public/private financial assistance.
(f) Assure that transportation and required services such as electricity, etc., will be available on a 24-hour basis.
(g) Provide a variety of intervention, educational, and related service programs in the home.
(h) Provide support to family with advice and counsel.
(i) Be available on 24-hour call to provide or service equipment used in home care.
(j) Provide services such as respite care and special transportation.

*Not all of these individuals/agencies will be necessary for each child.

H. PROFILE OF SELECTED PROGRAMS INVOLVED IN HOME CARE FOR THE TECHNOLOGY DEPENDENT

- Excerpts From "Alternatives To Hospitalization For Technology Dependent Children: Program Models": Tables That Provide Information On Programs in Illinois, Iowa, Louisiana, Maryland, and Pennsylvania (Number and Ages Of Children Served, Diagnoses, Degree Of Ventilator Dependency, Physical Care Needs, Daily Nursing Support, And Costs Of Case Management)

- "Selected Institutional Programs Involved In Care And Discharge To Home Of Ventilator-Dependent Children" (Appendix From Brooklodge Symposium For The Ventilator-Dependent Child; brief descriptions of mainly hospital programs)

ALTERNATIVES TO HOSPITALIZATION FOR TECHNOLOGY DEPENDENT CHILDREN: PROGRAM MODELS

Josephine Gittler, J.D., and Milo Colton, Ph.D.

Future Directions of Services for Children
with Special Health Care Needs

M&CH
NATIONAL MATERNAL & CHILD HEALTH
RESOURCE CENTER

ILLINOIS DIVISION OF SERVICES FOR CRIPPLED CHILDREN: HOME HEALTH CARE PROGRAM

TABLE ONE
PROGRAM ENROLLMENT: 1979-1986

CATEGORY	NUMBER	PERCENT
Year:		
1979-1980	2	2
1981	2	2
1982	2	2
1983	9	8
1984	15	13
1985	31	27
1986*	53	46
TOTAL	114**	100

*Enrollment during first eleven months of 1986.

**Information as to the precise date of enrollment was unavailable for thirteen cases.

TABLE THREE
AGE OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
Age:		
3-11 Months	5	4
12-23 Months	30	24
24-35 Months	20	16
36-47 Months	13	10
48-59 Months	13	10
5-7 Years	16	13
8-10 Years	9	7
11-13 Years	4	3
14-17 Years	8	6
18-21 Years	9	7
TOTAL	127	100

TABLE FIVE
MEDICAL DIAGNOSIS OF ENROLLEES

CATEGORY	NUMBER*	PERCENT
Medical Diagnosis or Condition:		
Seizures	38	30
Structural Airway Abnormalities	28	22
Bronchiopulmonary Dysplasia	27	21
Sensory Deficit(s)	27	21
Nutritional Disorder(s)	23	18
Severe Central Nervous System Defect(s)	20	16
Orthopedic Anomaly (Congenital and Acquired)	18	14
Quadriplegia	17	13
Hydrocephaly/Microcephaly	17	13
Gastrointestinal Reflux	15	12
Hypotonia	14	11
Degenerative Neuromuscular	14	11
Craniofacial Anomalies	13	10
Other Respiratory Deficits	12	9
Congenital Heart Disease	12	9
Chronic Heart Failure/ Cor pulmonale	10	8
Gastrointestinal Defect - Acquired	8	6
Gastrointestinal Defect - Congenital	8	6
Cerebral Palsy	8	6
Phrenic Nerve Paralysis	6	5
Genitourinary Disorder	6	5
Apnea	6	5
Thoracic Lesion or Syndrome	4	3
Cystic Fibrosis	3	2
Metabolic Disorder	3	2
Miscellaneous Integumentary Problems	3	2
Other	12	9

(N=127)

*Many of the 127 individuals enrolled had more than one diagnostic condition.

TABLE SIX
ENROLLED POPULATION: ETIOLOGY OF MEDICAL CONDITIONS

CATEGORY	NUMBER*	PERCENT
Etiology of the Problem:		
Prematurity	43	34
Multiple Congenital Anomalies	28	22
Genetic	21	17
Trauma	16	13
Perinatal Asphyxia	9	7
Central Hypoventilation Syndrome	5	4
Gastrointestinal Malformation	5	4
Central Nervous System Lesion	5	4
Myelomeningocele	3	2
Postmaturity	2	2
Hydrocephalus	2	2
Thoracic Lesion or Syndrome	2	2
Other/Unknown	6	4
TOTAL	127	117*

*Total exceeds 100 percent due to rounding.

TABLE SEVEN
PHYSICAL CARE NEEDS OF ENROLLED POPULATION

CATEGORY	NUMBER*	PERCENT
Physical care needs:		
Feeding Tubes	53	42
Tracheostomy	40	32
Ventilator Dependent	45	35
For 24 hours	32	25
For less than 24 hours	13	10
Respiratory Treatments	19	15
Phrenic Nerve Pacers	7	6
Hyperalimentation	5	4
Temperature Regulation	5	4
Other	6	5
None	6	5

(N=127)

*Some of the 127 individuals enrolled in the program have more than one type of physical care need.

TABLE EIGHT
DAILY NURSING SUPPORT RECEIVED BY ENROLLEES

CATEGORY	NUMBER	PERCENT
17-24 hours per day	24	35
9-16 hours per day	18	26
1-8 hours per day	15	22
None	12	17
TOTAL	69*	100

*Data were not available for all cases.

ILLINOIS HOME CARE PROGRAM
PERSONNEL RESOURCES AND COSTS[1]

1 Position Title	2 (FTE) Number of Positions	3 Total Annual Salaries[2]	4 Percent of Time:[3]	5 Total Salaries Required	6 Medicaid Waiver Caseload	7 Cost per Medicaid Waiver Case
Professional Staff						
Program Service Managers	10	$ 300,527	16	$ 47,762	36	$1,326.72
Medical Social Consultants	14	342,294	19	65,955	36	1,832.08
Nursing Consultants	31	773,181	15	118,339	36	3,287.20
Hearing and Speech Consultants	6	137,824	3	4,142	36	115.05
Division Consultants	6	154,944	11	16,810	36	466.95
SUBTOTAL	67	$1,708,770		$253,008	36	$7,028.00
Support Staff						
Program Consultant Aides	11	189,670	8	15,034	36	417.61
SUBTOTAL	11	189,670		15,034	36	417.61
TOTAL	78	$1,898,440		$268,042	36	$7,445.61

1. Personnel resources and costs reflect only the personnel resources and costs associated with provision of case management services to Medicaid model waiver children.

2. Salary figures do not include fringe benefits.

3. Percent of time figures are based on a 1986 time-motion study conducted for DSCC.

TABLE NINE

IOWA MOBILE AND REGIONAL CHILD HEALTH SPECIALTY CLINICS PROGRAM:
HOME CARE MONITORING PROGRAM

TABLE ONE
CURRENT PROGRAM ENROLLMENT: 1984 TO PRESENT

CATEGORY	NUMBER	PERCENT
Year:		
1984	1	3
1985	0	0
1986	27	93
1987 (As of 3/1/87)	1	3
TOTAL	29*	99**

*Figure does not include six inactive cases.

**Total is less than 100 percent due to rounding.

TABLE THREE
AGE OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
Age:		
3-11 months	4	14
12-23 months	2	7
24-35 months	7	24
36-47 months	1	3
48-59 months	2	7
5-7 years	5	17
8-10 years	3	10
11-13 years	1	3
14-17 years	4	14
18-21 years	0	0
TOTAL	29	99*

*Total is less than 100 percent due to rounding.

TABLE SIX
DAILY NURSING SUPPORT OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
17-24 hours per day	0	0
9-16 hours per day	2	7
1-8 hours per day	15	52
None	12	41
TOTAL	29	100

TABLE FIVE
MEDICAL DIAGNOSIS OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
Medical Diagnosis or Problem:*		
Congenital Heart	5	17
Other Congenital Anomalies of Nervous System (Encephalocele, Lissencephaly, Meningomyelocele)	5	17
Cerebral Palsy	4	14
Quadriplegia	3	10
Other and Unspecified Congenital Anomalies (Prader Willi Syndrome, Arteriovenous Malformation)	2	7
Other Conditions of Brain (Post Viral Encephalopathy)	2	7
Multiple Congenital Anomalies (Lowe's Syndrome, Goldenhar's Syndrome)	2	7
Astrocytoma	1	3
Chromosomal Anomalies (Trisomy 13)	1	3
Disorders of Carbohydrate Transport and Metabolism (Nonketonic Hyperglycemia)	1	3
Other Congenital Anomalies of Metabolism (Cystic Fibrosis)	1	3
Other Congenital Anomalies of Digestive Tract (Short Gut Syndrome)	1	3
Seizure Disorder	1	3
TOTAL	29	97**

*The International Classification of Diseases, Ninth Revision, Clinical Modification, Commission on Professional Hospital Activities, Ann Arbor, Michigan, was used in compiling the data on medical diagnosis or problem.

**Total is less than 100 percent due to rounding.

TABLE SEVEN
SOURCE OF FINANCING FOR SERVICES*

CATEGORY	NUMBER	PERCENT
Medicaid Model Waiver Program	26	90
Private Insurance**	19	66
Other	4	14

*Many of the children served were covered by both the Medicaid Program and private insurance.

**Private insurance figures include coverage by Blue Cross/Blue Shield or a commercial insurance company.

IOWA CHSC HOME CARE MONITORING PROGRAM:
PERSONNEL RESOURCES AND COSTS[1]

1 Position Title	2 (FTE) Number of Positions	3 Total Annual Salaries[2]	4 Percent of Time	5 Total Salaries Required	6 Total Active Caseload	7 Average Cost Per Case
Central Office Professional Staff						
Pediatric Nurse Practitioner	1.0	$29,300	100	$29,300	29	$1,010
Registered Nurse	1.5	36,630	100	36,630	29	1,263
Social Worker	.6	12,000	100	12,000	29	414
Subtotal	3.1	$77,930	100	$77,930	29	$2,687
Central Office Support Staff						
Secretary	.75	$10,428	100	$10,428	29	$ 360
Subtotal	.75	$10,428	100	$10,428	29	$ 360
TOTAL	3.85	$88,358	100	$88,358	29	$3,047

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1. Personnel resources and costs figures include central office resources and costs, but they do not include regional office resources and costs.

2. Salary figures do not include fringe benefits.

TABLE EIGHT

LOUISIANA
VENTILATOR ASSISTED CARE PROGRAM

TABLE ONE
PROGRAM ENROLLMENT 1983 TO PRESENT

CATEGORY	NUMBER	PERCENT
Year:		
1983	11	26
1984	4	9
1985	17	40
1986	11	26
1987 (As of 03/01/87)	—	—
Total	43	101*

*Total exceeds 100 percent due to rounding.

TABLE TWO
STATUS OF POPULATION SERVED

CATEGORY	NUMBER	PERCENT
Number Currently Enrolled (March 1, 1987)	29	67
Number Deceased	7	16
Number Weaned	7	16
Total	43	99*

*Total is less than 100 percent due to rounding.

TABLE THREE
AGE OF THE POPULATION SERVED

CATEGORY	NUMBER	PERCENT
Age:		
3-11 month	4	9
12-23 months	4	9
24-35 months	3	7
36-47 months	5	12
48-59 months	3	7
5-7 years	10	23
8-10 years	3	7
11-13 years	1	2
14-17 years	5	12
18-21 years	3	7
over 21 years	2	5
Total	43	100

TABLE EIGHT
POPULATION SERVED BY PROGRAM: MEDICAL DIAGNOSIS

CATEGORY	NUMBER	PERCENT
Specific Medical Diagnosis or problem:*		
Anterior Horn Cell Disease (Werdnig-Hoffman Disease)	10	23
Other Paralytic Syndromes (Quadriplegia)	7	16
Other Respiratory Conditions of Fetus and Newborn (Bronchopulmonary Dysplasia	4	9
Other and Unspecified Congenital Anomalies (Multiple Congenital Anomalies)	4	9
Symptoms Involving Respiratory System and Other Chest Symptoms (Hypoventilation)	3	7
Muscular Dystrophies and Other Myopathies	3	7
Spina Bifida	3	7
Other Congenital Anomalies of Nervous System (Myelodysplasia)	2	5
Intercranial Injury of Other and Unspecified Nature	2	5
Other Congenital Anomalies of Heart	1	2
Congenital Anomalies of Respiratory System	1	2
Disorders of Carbohydrate Transport and Metabolism (Pompe's Disease)	1	2
Other Malignant Neoplasms of Lymphoid and Histiocytic Tissue (Non-Hodgkins Lymphoma)	1	2
Encephalitis, Myelitis, and Encephalomyelitis	1	2
Total	43	98**

*The International Classification of Diseases, Ninth Revision, Clinical Modification, Commission on Professional Hospital Activities, Ann Arbor, MI, was used to compile data relative to the section on medical diagnosis and problem.

**Total is less than 100 percent due to rounding.

TABLE SIX
CURRENT ENROLLEES:* VENTILATOR DEPENDENCY

CATEGORY	NUMBER	PERCENT
Ventilator Dependent for 24 hours	14	48
Ventilator Dependent for less than 24 hours	15	52
Total	29	100

*In addition to the twenty-nine ventilator assisted individuals enrolled in the program, there are seven individuals who have been weaned from the ventilator and receive only minimal program services.

TABLE SEVEN
CURRENT ENROLLEES: DAILY NURSING SUPPORT

CATEGORY	NUMBER	PERCENT
None*	18	62
1-8 hours per day	4	14
9-16 hours per day	2	7
16-21 hours per day	5	17
Total	29	100

*Fifty-two percent of the children currently enrolled in the program receive 4-168 hours of nursing/attendant care per week.

TABLE NINE
SOURCE OF FINANCING FOR SERVICES*

CATEGORY	NUMBER	PERCENT
Medicaid Program	26	60
Handicapped Children's Services Program	24	56
Private Insurance	16	37
Muscular Dystrophy Association	10	23
Office of Mental Retardation and Developmental Disabilities	3	7
Office of Human Development	4	9
Medical Program	1	2
Unknown	2	5

N=43

*Note: Many of the individuals served by VACP had more than one source of financing.

VACP OF LOUISIANA
PERSONNEL RESOURCES AND COSTS

Position Title	(FTE) Number of Positions	Total Annual Salaries[1/]	Percent of Time	Total Salaries Required	Current Active Caseload[2/]	Cost Per Case
Home Care Professional Staff						
Project Director	0.05	$ 3,814	100	$ 3,814	29	$ 131.52
Project Co-Director	0.10	6,500	100	6,500	29	224.14
Project Co-Director	0.10	6,000	100	6,000	29	206.90
Project Coordinator	1.00	35,458	100	35,458	29	1,222.69
Project Nurse Consultant	1.00	30,832	100	30,832	29	1,063.17
Case Manager Nurse[3/]	0.50	12,480	100	12,480	29	430.34
Respiratory Therapist	0.15	5,038	100	5,038	29	173.72
Physical Therapist	0.05	1,544	100	1,544	29	53.24
Occupational Therapist	0.05	1,176	100	1,176	29	40.55
Speech Pathologist	0.05	1,925	100	1,925	29	66.38
Social Worker	0.25	6,032	100	6,032	29	208.00
Recreation Therapist	0.05	980	100	980	29	33.79
Education Consultant[4/]	0.10	3,120	100	3,120	29	107.59
SUBTOTAL	3.45	$114,899	100	$114,899	29	$3,962.04

1. Salary figures do not include fringe benefits.

2. Figure does not include seven individuals who have been weaned from ventilation and who receive minimal program services.

3. This position is not funded by the VACP Federal Grant; it is funded by Children's Hospital.

4. This position is not funded by the VACP Federal Grant; it is funded by the State Department of Public Education and another Federal Grant from the Federal Division of Maternal and Child Health.

VACP OF LOUISIANA
PERSONNEL RESOURCES AND COSTS

Position Title	(FTE) Number of Positions	Total Annual Salaries	Percent of Time	Total Salaries Required	Current Active Caseload	Cost Per Case
Home Care Support Staff						
Administrative Assistant	0.50	$ 7,395	100	$ 7,395	29	$ 255.00
Data Assistant	0.50	8,392	100	8,392	29	289.38
SUBTOTAL	1.00	$ 15,787	100	$ 15,787	29	$ 544.38
TOTAL	4.45	$ 130,686	100	$ 130,686	29	$4,506.42

MARYLAND COORDINATING CENTER
FOR HOME AND COMMUNITY CARE

TABLE ONE
STATUS OF CHILDREN REFERRED

CATEGORY	NUMBER	PERCENT
Status:		
Currently enrolled	58	24
Deceased	28	12
Graduated from program*	20	8
Services not desired**	57	24
Ineligible for program	17	7
Moved	5	2
Other (Remained hospitalized or rehospitalized)***	57	24
Total	242	101****

*Children were weaned from ventilator.

**Children were referred to program, but services were refused. In the majority of these cases, the insurers responsible for funding the child's home care costs refused to pay for CCHCC case management services.

***The referred children remained hospitalized or were rehospitalized shortly after being discharged.

****Total is more than 100 percent due to rounding.

TABLE TWO
PROGRAM ENROLLMENT: 1984 TO PRESENT

CATEGORY	NUMBER	PERCENT
Year:		
1984	8	14
1985	12	21
1986	34	59
1987 (As of 3/1/87)	4	7
Total	58	101*

*Total is more than 100 percent due to rounding.

TABLE SIX
DIAGNOSTIC CONDITION OF ENROLLED CHILDREN

CATEGORY	NUMBER	PERCENT
Medical Diagnosis or Problem:*		
Other Respiratory Conditions of Fetus and Newborn (Bronchopulmonary Dysplasia)	21	36
Symptoms Involving Respiratory System and Other Chest Symptoms (Hypoventilation, Apnea, Ondine's Curse, Gunshot Wound, Reactive Airway, Minimum Aspiration, Airway Obstruction)	8	14
Other Congenital Anomalies of Heart	5	9
Other Congenital Musculoskeletal Anomalies (Pierre Robin Syndrome, Achondroplasia, Prune Belly, Brittle Bone)	4	7
Other Paralytic Syndromes (Quadriplegia)	2	3
Intercranial Injury of Other and Unspecific Nature (Head Trauma, Motor Accident)	2	3
Other Cerebral Degenerations (Encephalomalacia)	2	3
Effects of Other External Sources (Near Drown, Post Drown)	2	3
Other Congenital Anomalies of Nervous System	2	3
Anterior Horn Cell Disease	1	2
Cerebral Degenerations Usually Manifested in Childhood (Butten-Mayou Disease)	1	2
Congenital Anomalies of Respiratory System (Laryngeal Tracheomalaera)	1	2
Disorders of Muscle, Ligament, and Fascia (Arthrogryposis)	1	2
Chromosomal Anomalies (Down's Syndrome)	1	2
Epilepsy (Seizures)	1	2
Other and Unspecified Disorders of Nervous System	1	2
Encephalitis, Myelitis, and Encephalomyelitis (Cerebellitis)	1	2
Infantile Cerebral Palsy (Cerebral Palsy)	1	2
Chronic Renal Failure (End Stage Renal)	1	2
Total	58	101**

*The International Classification of Diseases, Ninth Revision, Clinical Modification, Commission on Professional Hospital Activities, Ann Arbor, MI, was used to compile data relative to the section on medical diagnosis and problem.

**Total is more than 100 percent due to rounding.

TABLE THREE
AGE OF ENROLLED CHILDREN

CATEGORY	NUMBER	PERCENT
Age:		
3-11 months	10	17
12-23 months	8	14
24-35 months	11	19
36-47 months	10	17
48-59 months	2	3
5-7 years	8	14
8-10 years	2	3
11-13 years	1	2
14-17 years	5	7
18-21 years	1	2
over 21 years	-	-
Total	58	98*

*Total is less than 100 percent due to rounding.

TABLE TEN
SOURCE OF FINANCING FOR SERVICES*

CATEGORY	NUMBER (N=58)	PERCENT
Medicaid Program		
Waiver	37	64
Non-waiver	9	16
Private Insurance	8	14
Children's Medical Services Program	2	3
Other	4	7

*Note: This table indicates the source of financing for services, equipment or supplies for the fifty-eight children currently enrolled in the CCHCC program. Many of these children have more than one source of funding.

TABLE EIGHT
DAILY NURSING SUPPORT OF ENROLLED CHILDREN

CATEGORY	NUMBER	PERCENT
No Daily Nurse Support	4	7
1-8 Hours Per Day Nurse Support	10	17
9-16 Hours Per Day Nurse Support	32	55
17-24 Hours Per Day Nurse Support	12	21
Total	58	100

TABLE SEVEN
VENTILATOR DEPENDENCY OF ENROLLED CHILDREN

CATEGORY	NUMBER	PERCENT
Ventilator Dependent for 24 Hours	6	55
Ventilator Dependent for less than 24 Hours	5	45
Total	11	100

TABLE NINE
DAILY NURSING SUPPORT OF CHILDREN USING VENTILATORS

CATEGORY	NUMBER	PERCENT
No Daily Nurse Support	0	0
1-8 Hours Per Day Nurse Support	1	9
9-16 Hours Per Day Nurse Support	6	55
17-24 Hours Per Day Nurse Support	4	36
Total	11	100

MARYLAND CCHCC PERSONNEL RESOURCES AND COSTS

Position Title	(FTE) Number of Positions	Total Annual Salaries[1]	Percent of Time	Total Salaries Required	Total Cases Managed Annually	Unit Cost
Home Care Professional Staff						
Executive Director	1.0	$ 37,000	100	$ 37,000	58	$ 637.93
Clinical Care Coordinators	3.0	81,720	100	81,720	58	1,408.97
Clinical Director	0.8	23,800	100	23,800	58	410.34
Policy Analyst	1.0	32,000	100	32,800	58	551.72
Family Services Coordinator	0.8	21,120	100	21,120	58	364.14
Financial Coordinator	1.0	28,750	100	28,750	58	495.69
Educational Coordinator	0.8	21,120	100	21,120	58	364.14
Medical Director	0.1	7,500	100	7,500	58	129.31
SUBTOTAL	8.5	253,010	100	253,010	58	4,362.24
Home Care Support Staff						
Resource Specialist	1.0	$ 18,832	100	$ 18,832	58	$ 324.69
Executive Assistant	1.0	16,750	100	16,750	58	288.79
SUBTOTAL	2.0	35,582	100	35,582	58	613.48
TOTAL	10.5	$ 288,592	100	$ 288,592	58	$4,975.72

1. Salary figures do not include fringe benefits.

TABLE ELEVEN

PENNSYLVANIA

VENTILATOR ASSISTED CHILDREN/HOME PROGRAM

TABLE ONE
STATUS OF ENROLLED POPULATION 1979 TO PRESENT

CATEGORY	NUMBER	PERCENT
Status:		
Currently enrolled (As of 3/1/87)	40	59
No longer enrolled		
Deceased	12	18
Graduated from program*	10	15
Became ineligible for program**	4	6
Other	2	3
TOTAL	68	101***

*Individuals were weaned from ventilator.

**Individuals reached twenty-one years of age.

***Total is more than 100 percent due to rounding.

TABLE TWO
CURRENT ENROLLED POPULATION: YEAR OF ENROLLMENT

CATEGORY	NUMBER	PERCENT
Year of Enrollment:		
1979-80	1	3
1981	3	8
1982	3	8
1983	-	-
1984	2	5
1985	16	40
1986	12	30
1987 (As of 3/1/87)	3	8
TOTAL	40	102*

*Total is more than 100 percent due to rounding.

TABLE THREE
AGE OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
Age:		
3-11 Months	1	3
12-23 Months	9	23
24-35 Months	4	10
36-47 Months	8	20
48-59 Months	2	5
5-7 Years	6	15
8-10 Years	-	-
11-13 Years	3	8
14-17 Years	3	8
18-21 Years	4	10
TOTAL	40	102*

*Total is more than 100 percent due to rounding.

TABLE SIX
DIAGNOSTIC CONDITION OF ENROLLED POPULATION

CATEGORY	NUMBER	PERCENT
Medical Diagnosis or Problem*		
Other Respiratory Conditions of Fetus and Newborn (Bronchiopulmonary Dysplasia)	9	23
Symptoms Involving Respiratory System and Other Chest Symptoms (Hypoventilation)	9	23
Muscular Dystrophies and Other Myopathies	8	20
Other Paralytic Syndromes (Quadriplegia)	3	8
Other and Unspecified Congenital Anomalies (Vater's Syndrome)	3	8
Spina Bifida (Arnold-Chiari Syndrome)	2	5
Anterior Horn Cell Disease (Werdnig-Hoffman Disease)	1	3
Myoneural Disorders (Myasthenia-like Syndrome)	1	3
Other Ill-Defined and Unknown Causes of Morbidity and Mortality (Respiratory Failure)	1	3
Information Unavailable	3	8
TOTAL	40	104**

*The <u>International Classification of Diseases, Ninth Revision, Clinical Modification</u>, Commission on Professional Hospital Activities, Ann Arbor, Michigan, was used in compiling the data on medical diagnosis and problem.

**Total is more than 100 percent due to rounding.

TABLE SEVEN
ENROLLED POPULATION: DAILY VENTILATOR USE

CATEGORY	NUMBER	PERCENT
Ventilator use for 24 hours	12	30
Ventilator use for less than 24 hours	28	70
TOTAL	40	100

TABLE EIGHT
ENROLLED POPULATION: DAILY NURSING SUPPORT

CATEGORY	NUMBER	PERCENT
Ventilator assisted 24 hours		
17-24 hours per day	3	8
9-16 hours per day	8	20
1-8 hours per day	1	3
None	-	-
SUBTOTAL	12	31
Ventilator assisted less than 24 hours		
17-24 hours per day	4	10
9-16 hours per day	8	20
1-8 hours per day	7	18
None	9	23
SUBTOTAL	28	71
TOTAL	40	102*

*Total is more than 100 percent due to rounding.

PENNSYLVANIA VENTILATOR ASSISTED CHILDREN/HOME PROGRAM
PERSONNEL RESOURCES AND COSTS

1 Position Title	2 (FTE) Number of Positions	3 Total Annual Salaries[1]	4 Percent of Time	5 Total Salaries Required	6 Current Active Caseload	7 Average Cost Per Case
Professional Staff						
Program Director	0.5	$ 52,500	100	$ 52,500	40	$1,313
Program Administrator	1.0	35,048	100	35,048	40	876
Registered Nurse	1.4	39,645	100	39,645	40	991
Social Worker	0.6	17,807	100	17,807	40	445
SUBTOTAL	3.5	$145,000		$145,000	40	$3,625
Support Staff						
Secretary	1.0	15,000	100	15,000	40	375
SUBTOTAL	1.0	15,000		15,000	40	375
TOTAL	4.5	$160,000		$160,000	40	$4,000

[1] Salary figures do not include fringe benefits.

TABLE NINE

Appendix C

Selected Institutional Programs Involved in Care and Discharge to Home of Ventilator-Dependent Children

Bronson Methodist Hospital
252 E. Lovell
Kalamazoo MI 49007

John Hartline, M.D., Director,
Neonatology Services
616/383-6469

Institutional Description
Bronson is a 478-bed short-term general acute care hospital.

Program Description
The focus of Bronson's program is on infants with bronchopulmonary dysplasia (BPD) who will continue to require oxygen and ventilatory assistance for months or years. The goal of the program is to provide comprehensive services for stabilized BPD patients who can safely be managed at home.

Hospital Discharges
Initially four Bronson patients were identified as candidates for this program. One of these patients subsequently became independent of ventilatory support and was discharged. A second child has been discharged and is at home requiring continuous positive airway pressure. Planning for the discharge of the remaining two candidates is underway at this time.

Children's Home Health Network of Illinois
East 65th Street at Lake Michigan
Chicago IL 60649

George Kouba, Executive Director
312/363-6807

Institutional Description
The Network is a non-profit corporation established in November, 1982, by the Illinois Division of Services for Crippled Children, Children's Memorial Hospital (Chicago), and La Rabida Children's Hospital and Research Center (Chicago). Its primary objective is to support the transfer of children with prolonged ventilator dependency to their homes or alternative home-like settings. The corporation has its own board and is not a subsidiary of any of the three founding organizations.

Program Description
In July, 1983 the Illinois Division of Services for Crippled Children received a federal Maternal and Child Health SPRANS grant to develop a comprehensive progam that will support the transfer of Illinois children with prolonged ventilator dependency to their homes or to the least-restrictive environment possible and will monitor the care they receive.

Hospital Discharges
The Network entities have discharged 23 children out of seven hospitals in the state of Illinois. Planning for seven more discharges from six additional hospitals is underway.

Children's Hospital
200 Henry Clay Avenue
New Orleans LA 70118

Joanne Gates, M.D., Associate Medical Director
504/899-9511

Institutional Description
Children's Hospital is a 105-bed, short-term pediatric hospital with a major commitment to rehabilitation.

Program Description
The Louisiana Interagency Home Care Program for Ventilator Dependent Individuals is a collaborative effort funded by a federal Maternal and Child Health SPRANS grant. It involves an interagency group including Children's Hospital, the Tulane Pediatric Pulmonary Center, and Louisiana Handicapped Children's Services. The project will plan an organized, coordinated regional approach to services provided to ventilator-dependent children and their families. The project is functioning within the administrative and organizational structure of Children's Hospital.

Hospital Discharges
Since 1980, 11 ventilator-dependent children have been discharged to their homes or to alternative settings. The ages of these children have ranged from 10 months to 20 years.

Children's Hospital of Philadelphia
34th and Civic Center Blvd.
Philadelphia PA 19104

Robert Kettrick, M.D., Director,
Ventilator-Dependent Children Home Program
215/596-9386

Institutional Description
CHOP is a 238-bed, short-term acute care institution affiliated with the School of Medicine of the University of Pennsylvania.

Program Description
State legislation providing state funding for the discharge planning and home care management of ventilator-dependent children living in Pennsylvania has been an important factor in the development of a program at Children's Hospital. The program currently provides:
1. Consultation by a multi-disciplinary team with families and/or institutions who may be considering home care.
2. Supportive services to families and/or institutions.
3. Reimbursement for services, disposable goods and nursing.
4. Coordination of the development of Individual Service Plans.

Hospital Discharges
Since 1977, 23 children have been discharged to their homes. Their ages have ranged from 6 months to 14 years.

Children's Memorial Hospital
2300 Children's Plaza
Chicago IL 60614

Allen I. Goldberg, M.D., Medical Director,
Division of Respiratory Care
312/880-4630, or Laura Frost, Coordinator,
Ventilator-Dependent Discharge Program
312/880-4106

Institutional Description
The Children's Memorial Hospital is a 265-bed, private, not-for-profit pediatric regional medical center providing medical, surgical, neonatal, dental and psychiatric services for children from birth to age 16 (or older when continuing services are needed). It has been a member of the McGaw Medical Center of Northwestern University since 1946.

Program Description
The Ventilator-Dependent Discharge Program (VDDP) is a hospital-based, interdisciplinary program which provides a mechanism to facilitate the safe discharge of the ventilator-dependent patient. The program is implemented by a core team consisting of a medical director; program coordinator; nursing, respiratory care, and social work coordinators; and representatives from administration and finance. The core team has pre-set criteria for admission to the program and for discharge. It has also developed educational modules for teaching parents and caregivers in the home. After a patient has been identified as a discharge candidate, the core team expands to an extended discharge team which includes all the primary care givers, in-house support systems, and outside resources. The composition of the extended discharge team changes with each patient.

Hospital Discharges
To date, 14 children on ventilators have been discharged. The VDDP has also served as a resource for coordinating the discharge of other respiratory-dependent patients, and has worked in close cooperation with the Illinois Division of Services for Crippled Children/SSI Program in each discharge.

Children's Orthopedic Hospital
4800 Sand Point Way, N.E.
Seattle WA 98105

Lilla O'Grady, M.D., Clinical Assistant Professor, University of Washington
206/523-8848

Institutional Description
Children's Orthopedic Hospital is a 188-bed, short-term acute care institution that is affiliated with the School of Medicine of the University of Washington.

Program Description
In 1979, an intermediate care unit was developed to support the growing number of ventilator-dependent children within the hospital. The staff of this unit provides the home care training and planning for patient discharge.

Hospital Discharges
Since 1976, seven children under 11 years old have been discharged to their homes.

Coordinating Center for Home and Community Care
c/o Sick Kids (need) Involved People (SKIP)
216 Newport Drive
Severna Park MD 21146

Karen Shannon, Executive Director, SKIP
301/647-0164

Program Description
A consortium of local, state and regionally-based organizations is developing a non-profit Coordinating Center for Home and Community Care (CCHCC) to meet the needs of respiratory disabled children. The consortium includes the Maryland Crippled Children Service, the Anne Arundel County Health Department, the Anne Arundel County Board of Education, Sick Kids (need) Involved People, the Hearing and Speech Agency of Metropolitan Baltimore, Parents and Children Together, The Children's Hospital National Medical Center, the University of Maryland Hospital, Johns Hopkins Hospital and Mount Washington Pediatric Hospital. The CCHCC will serve as the structure to support

the discharge of respiratory disabled children to the most-natural homelike setting commensurate with their medical and habilitative needs.

Hospital Discharges
Six children have been sent to their homes during the last three years. They have ranged in age from 5 months to 6 years.

Craig Hospital
3425 S. Clarkson
Englewood CO 80110

Robert Menter, M.D., President, Medical Staff
303/789-8202

Institutional Description
Craig is an 80-bed rehabilitation hospital that serves adults and children.

Program Description
Craig provides comprehensive rehabilitation services for patients with spinal cord injuries or head trauma, some of whom are ventilator-dependent. Patient referrals come from throughout the United States.

Hospital Discharges
Since 1976, 16 ventilator-dependent patients ranging in age from 4-18 years have been discharged to their homes. Most of these patients were survivors of auto accidents who had become high quadriplegics.

La Rabida Children's Hospital and Research Center
East 65th Street at Lake Michigan
Chicago, IL 60649

Mark J. Merkens, M.D.
Director, Chronic Illness Transitional Unit
312/363-6700

Institutional Description
La Rabida Children's Hospital and Research Center, the chronic care hospital of the Department of Pediatrics, University of Chicago Pritzker School of Medicine, is a 77-bed hospital with active out-patient and community outreach programs. In the last 20 years, La Rabida has progressively refocused its mission to conform with the changing patterns of chronic illness in childhood.

Program Description
The Transitional Care Program at La Rabida offers an alternative environment which prepares chronically ill children for home and community life. The Chronic Illness Transitional Care unit is a homelike environment that responds to the multiple needs presented by ventilator-supported children. This program, which provides a full range of medical and non-medical services, emphasizes patient education, family care, normal growth and development, and discharge planning.

Hospital Discharges
The Chronic Illness Transitional Unit opened in early 1984. It will build on the experience of the hospital's Transitional Care Program in discharging to home children with ventilator dependency and other chronic conditions such as bronchopulmonary dysplasia and chronic tracheospomy.

Rancho Los Amigos Hospital
7601 E. Imperial Hwy.
Downey CA 90242

Donna Barras, M.D., Director,
Pediatric Spinal Cord Injury Program
213/922-7022

Institutional Description
Rancho Los Amigos is a 637-bed, short-term general medical and surgical hospital with a major commitment to rehabilitation services.

Program Description
The Pediatric Spinal Cord Injury Team includes a pediatrician, nurse, physical therapist, occupational therapist, respiratory therapist, psychologist, social worker, recreation therapist, orthotist, dietitian, liaison nurse, and others as needed. Team and record management involve a problem-oriented approach. Comprehensive medical care and rehabilitation services are provided to all patients. The former is ongoing and the latter is divided into the following four phases: 1) admission, 2) treatment, 3) discharge preparation, 4) transition into the community. Follow-up care is provided through the outpatient clinic.

Hospital Discharges
During the past 15 years, 150 spinal cord injury patients have been admitted. Of these, 20 have been high quads who have required respiratory assistance.

Howard A. Rusk Respiratory Rehabilitation Center
Department of Rehabilitation Medicine
New York University at Goldwater
Memorial Hospital
Franklin D. Roosevelt Island
New York NY 10044

Augusta Alba, M.D., Associate Director,
Department of Rehabilitation Medicine
212/750-6777

Institutional Description
Goldwater Memorial Hospital is a 912-bed facility which has specialized in long-term rehabilitation and treatment of chronic illness since 1939. As part of the Health and Hospital Corporation of the City of New York, the hospital maintains a long-standing affiliation with New York University Medical Center. The Howard A. Rusk Respiratory Rehabilitation Center first opened in 1955 as a regional center of the National Foundation of Infantile Paralysis. A 25-bed unit which cares for neuroparalytic patients with ventilator-dependency, it is integrated into the Department of Rehabilitation

Medicine with a full complement of general rehabilitation services.

Program Description
The rehabilitation program uses the team approach to patient care and focuses on the individual's discharge potential; the goal is discharge of each patient as a viable, productive and self-supporting member of society, living outside the institution in the general community whenever possible. The program benefits from the services of a rehabilitation laboratory, with pulmonary technicians who evaluate and train patients on portable respiratory equipment; a round-the-clock respiratory therapy service; medical service, including a modern intensive care unit; a nursing staff trained to care for this type of patient; and a nurse practitioner program.

Discharge planning coordination is carried out by the Public Health Nursing Service which is also integrated into the Department of Rehabilitation Medicine. This staff acts as a liaison between the hospital and community. The Center continues to follow the patients in the community with periodic one-day evaluations.

Hospital Discharges
The Center has averaged one discharge per year to the community of a ventilator-dependent child, out of approximately 15 discharges per year to the community and to other hospitals.

Santa Clara Valley Medical Center
751 S. Bascom
San Jose CA 95128

Dea Halverson, M.D.,
Chief of Pediatric Rehabilitation
408/279-5249

Institutional Description
Santa Clara Valley Medical Center is a 427-bed, short-term acute care hospital.

Program Description
The Pediatric Rehabilitation Program provides inpatient rehabilitation services for children with spinal cord injuries, head injuries and neuromuscular disorders; some of these children are ventilator-dependent.

Hospital Discharges
Between 1978 and 1983, four ventilator-dependent children aged 4 to 13 were discharged to their homes.

Texas Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston TX 77030

Gunyon Harrison, M.D.
Professor of Pediatrics and Rehabilitation
Baylor College of Medicine
Director of Cystic Fibrosis and Related
Respiratory Disease Center
Baylor College of Medicine
713/797-5249

Institutional Description
The Institute is a 91-bed physical medicine and rehabilitation hospital affiliated with the Baylor College of Medicine.

Program Description
Most ventilator-dependent patients (adults as well as children) are those with spinal cord injuries. High quadriplegics might typically be hospitalized for nine months for rehabilitation. A comprehensive clinical team is responsible for the care of each patient. Patient referrals are received from throughout the nation.

Hospital Discharges
Between 1962 and 1982, 21 children have been discharged to their homes. The most common condition represented among these discharges is spinal cord injury.

The University of Michigan Hospital
Ann at Observatory
Ann Arbor MI 48109

Virginia Nelson, M.D., Chief of Pediatric
Medicine and Rehabilitation Services
313/764-7165

Institutional Description
The University of Michigan Hospital is a 900-bed, short-term acute care institution that serves as the clinical facility for the University of Michigan's School of Medicine.

Program Description
Spinal cord injured children with resultant ventilator dependence are the only types of patients that have been discharged to their homes. These children have been inpatients on the Pediatric Physical Medicine and Rehabilitation Service and a comprehensive rehabilitation team has been responsible for their care. The social worker and primary nurse of the team coordinate home care planning.

Hospital Discharges
Six ventilator-dependent children have been discharged to their homes.

University of Wisconsin Hospitals
Room ES/369
600 Highland Avenue
Madison WI 53792

Rita Giovannoni, Program Coordinator,
Pulmonary Rehabilitation
608/263-9051

Institutional Description
The University of Wisconsin Hospitals is a 540-bed, short-term acute care facility.

Program Description
The Pulmonary Rehabilitation Center of the University of Wisconsin Hospitals and Clinics provides acute and chronic care management for ventilator-dependent children. The team responsible for such services includes pediatric pulmonology, nursing, respiratory therapy and social work. Referrals come from Wisconsin, northern Illinois, northeast Iowa and the Upper Peninsula of Michigan.

Hospital Discharges
The Center has discharged four ventilator-dependent children since 1979.

I. COSTS OF HOSPITAL AND HOME CARE FOR THE TECHNOLOGY DEPENDENT

O Summary Of Cost Estimates For Home Care In Minnesota And Elsewhere

O Cost Comparisons Of Hospital And Home Care For Eight Technology-Dependent Persons In Minnesota

O Costs Of Hospital v. Home Care For Four Ventilator-Dependent Children In The Michigan Responaut Demonstration Project

O Table From OTA Report On Children That Summarizes The Literature On Hospital v. Home Care Costs

O Fact Sheet and Lifetime Cost Data by Setting for Persons With Severe Head Injuries from The National Head Injury Foundation

Cost Comparisons of Home and Hospital Care
For 8 Ventilator-Dependent Persons in Minnesota

Date of Survey: 1985

Conducted by: Alex Adams, Clinical Director of Respiratory Therapy at Health East/Bethesda Lutheran Hospital

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Methods

The data summarized below are from interviews conducted by Alex Adams with eight ventilator-dependent patients in Minnesota in 1985. These eight persons are those who had been treated in all three settings- intensive care unit (ICU), Prolonged Respiratory Care Unit (PRCU), and home- and for whom comparative data were thus available. Patients were questioned about their actual expenses for home health care. Hospital charges (billed amounts) they incurred while being treated in an acute care setting (intensive care unit) and in the Prolonged Respiratory Care Unit at Bethesda Lutheran Hospital in St. Paul were also obtained.

Patient Characteristics and Living Arrangements

All eight patients are adults. Two are in their late 20's; both are ventilator dependent due to cervical fractures (trauma). One is mid-40's and has muscular disease. Two in their fifties have polio, and the remaining three persons are in their 60's (their disease conditions are polio, COPD, and ALS).

Of these eight cases, one uses mechanical ventilation only at night, and two others go off of the ventilator occasionally for brief periods. The remaining five persons are dependent full time on a ventilator.

Five of these eight people live alone; one lives in a family situation and each of the remaining two lives with a spouse who provides full-time care.

Definition of Costs

During the interviews, Mr. Adams obtained <u>actual expenses</u> for the home care from the patients. These expenses are itemized in Table 1 on the next page. Costs for the other two settings, the ICU and the PRCU, are <u>billed amounts</u>. (Billed amounts are higher than actual hospital "costs," but by an unknown amount).

Comments and Cautions About the Data Shown Below

These data are very useful for several reasons:

- They are based on actual recent cases in Minnesota who have been treated in three different settings (acute care, transitional, home);
- They include people in the 18-64 year old group about whom we have so little information;
- The patients collectively represent a range of ages, diagnoses, degree of ventilator-dependency (though most are full-time dependent), and household composition (informal caregiver availability);
- They include more comprehensive data on home care costs than are generally available; most home care cost comparisons understate the actual costs of home care by focusing only on the costs that are typically reimbursed/reimbursable, such as equipment, supplies, and nursing care. The actual expenses for home care reported here represent a more adequate estimate of actual home costs because they include many items that are often not included, such as transportation and housing costs.

Drawbacks include the following:

- Lack of comparability between actual expenses (home care) and billed charges (hospital care). Hospital charges overstate actual hospital costs by an unknown amount.
- Patients' condition is, of course, not a constant. It is likely that the patients in this cost comparison study needed more intensive care while in the ICU than at home; some of the cost differential reflects a difference in intensity of care rather than a difference in the costs of providing essentially comparable care in different settings.

SURVEY FINDINGS

Findings are summarized in the four tables that follow. The first shows the itemization of expenses/billed amounts that are compared. Table 2 gives detail on home care expenses, Table 3 compares home care expenses and hospital charges, and the last table highlights home care expenses as a percentage of hospital charges.

Table 1

Itemization of Expenses Shown in Tables 2-4

HOME	PROLONGED RESPIRATORY CARE UNIT (in Hospital)	ACUTE CARE (Intensive Care Unit)
Residence - including taxes and insurance	Room charge	Room charge
Caregivers: Attendants &/or nursing personnel	Ancillary charges: a. Medications b. Respiratory care c. Supplies d. Clinical laboratory e. Physical therapy/ occupational therapy	Ancillary charges: a. Medications b. Respiratory care c. Supplies d. Clinical laboratory
Equipment: Ventilator, suction, bed, oxygen, etc.		
Supplies: Suction, catheters, trach tubes, gauze pads, etc.		
Other: a. Residence (rental or mortgage payment, if any, plus taxes and insurance)* b. Nutrition (food or enterals**) c. Medications d. Utilities (gas, oil, electricity, water) e. Transportation f. Insurance		

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* Residence expenses are total (not prorated); the majority of patients live alone

** For most of these patients, "nutrition" is primarily the cost of food. For patient H, about $1,500 is spent each month for tube feeding formula.

Table 2

Monthly Home Care Expenses Reported by Eight Ventilator-Dependent Adults in Minnesota

	TOTAL MONTHLY HOME CARE EXPENSES	BY TYPE OF EXPENSE							
		Caregivers		Equipment		Supplies		Other	
		$	% of total	$	% of total	$	% of total	$	% of total
Patient:									
A	$ 2,323	0	-	1,450	62%	343	15%	530	23%
B	5,382	4,151	77%	866	16%	105	2%	260	5%
C	6,260	4,234	68%	1,369	22%	361	6%	296	5%
D	2,343	0	-	1,290	55%	206	9%	847	36%
E	9,448	6,912	73%	1,090	12%	411	4%	1,035	11%
F	2,046	0	-	1,365	67%	262	13%	419	20%
G	5,381	4,226	79%	302	6%	228	4%	625	12%
H	19,172	15,480	81%	1,170	6%	450	2%	2,072	11%
AVERAGE (mean)	$ 6,544	4,375	67%	1,113	17%	296	5%	760	12%

The three patients with no caregiver expenses are in the following situations: two have spouses who provide full-time care and the other (who is on a ventilator at night) provides self-care.

Table 3

Monthly Expenses For Eight Ventilator-Dependent Adults in Minnesota: Comparison of Expenses in Three Settings (Home, Prolonged Respiratory Care Unit, Acute Care)

	Home	PRCU	ICU
Patient:			
A	$ 2,323	$ 25,691	$ 70,242
B	5,382	17,300	56,577
C	6,260	18,723	58,194
D	2,343	17,452	61,500
E	9,448	18,387	71,156
F	2,046	17,517	64,428
G	5,381	19,609	60,756
H	19,172	20,129	73,250
AVERAGE (mean)	$ 6,544	$ 19,351	$ 64,513
(median)	5,382	18,555	62,964

Table 4

Summary of Comparisons Across Settings of Monthly Expenses For Eight Ventilator-Dependent Adults in Minnesota

Average Monthly Expenses By Setting			HOME CARE AS A PERCENT OF	
Home	PRCU	ICU	PRCU	ICU
$ 6,544	$ 19,351	$ 64,513	35%	10%

National
Head
Injury
Foundation Inc.
333 Turnpike Road, Southborough, MA 01772 (617) 485-9950

HEAD INJURY IN THE UNITED STATES

- There are approximately 700,000 head injuries in the United States every year
- Half of these (350,000) head injuries stem from automobile crashes
- One out of 80 children born this year will die of a vehicular-induced head injury, probably before reaching 25 years of age
- Head injuries are responsible for up to 60 percent of auto trauma deaths
- The most frequent reason for visits to physicians for emergency care is head injury
- Each year, more than 140,000 Americans die as a result of head injuries
- There are between 70,000 and 90,000 head injuries in the United States each year that result in coma or extremely debilitation loss of body function
- Head injury accounts for 500,000 hospital visits every year
- There are 2,000 cases of persistent vegetative state in the United States every year caused by head injury
- Head injuries require 3.5 million days of hospitalization and cost more than 35,000 man years of working ability each year
- Each severe head injury survivor requires between $4.1 million and $9 in care over a lifetime
- Those survivors who have sustained severe head injuries in any one year alone will require a total of up to $630 billion in lifetime care
- The typical survivor of serious head injury requires between five and 10 years of intensive rehabilitation
- Head injury kills more Americans under the age of 34 than all other causes combined

Compliments of
National Head Injury Foundation, Inc.
333 Turnpike Road
Southborough, MA 01772
(617) 485-9950

*Addendum to: "The Need for Coverage for Persons with Traumatic Brain Injuries by Catastrophic Insurance Legislation"

Average of Total Lifetime Costs for an Individual With SEVERE Head Injury in Appropriate Settings

I.	Acute Medical Care		
	A. Average length of stay - 60-90 days		
	B. Average cost per diem	$ 2,000	
	C. TOTAL (mean of 75 X $2,000)		$ 150,000
II.	Acute Rehabilitation Costs		
	A. Average length of stay - 90-120 days		
	B. Average cost per diem	$ 550 to 600	
	C. TOTAL (mean of 105 X $575)		$ 60,375
III.	Extended Rehabilitation		
	A. Average length - 15 months		
	B. Average cost per month	$13,000	
	C. TOTAL		$ 195,000
IV.	Residential Programs for Life Remainder (average age of head injured, 15-25 years)		
	A. Average length - 30-60 years		
	B. Average cost per annum	$60,000 to 125,000	
	C. TOTAL (mean of 45 X $92,500)		$4,162,500
	TOTAL LIFETIME AVERAGE		$4,567,875

References: Paul M. Deutsch, Ph.D. and Associates
Center for Rehabilitation Studies
College of Health Related Professions
University of Florida
Gainesville, Florida

The Greenery Group

(s16)

Selected Tables Related to Costs of Care for Technology-Dependent Individu Taken from OTA Reports on Children and the Elderly

Table 13.—Sample Home Respiratory Care Costs That Were Reimbursed by a Third-Party Payer, 1985

One-time purchase of equipment	Unit cost
Suction equipment	$ 714.29
Manual resuscitator	157.31
Emergency 12V battery	70.00
Heating nebulizer	324.00
Total one-time cost	$ 1,265.60

Monthly services and supplies	Monthly cost
Home assistance:	
Nursing	$ 7,320.00
Rentals:	
Backup ventilator	200.00
Ventilator	450.00
Suction device	50.00
Apnea monitor	200.00
Oxygen system	130.00
Supplies:	
Ventilator tubing	100.00
Oxygen masks	55.20
Liquid oxygen	816.00
Nebulizer	123.60
Sterile water	79.50
Tracheostomy tubes	143.70
Suction catheter w/ gloves	315.00
Cardiac leads	10.00
Total monthly cost	$9,993.00

SOURCE: M. Mikol, SKIP of New York, Inc., New York, NY, personal communication, June 1986.

Table 6-5.—Reported Monthly Charges for Hospitalized Ventilator Patients

	Date	Location	No. of patients	Patient's ages	Charges[a]
Davis, et al.	1975-76	St. Louis, MO	100	Avg. 67	$12,300
Sivak, et al.	1978	Cleveland, OH	N.A.[b]	N.A.	$15,600
Feldman & Tuteur	1981	St. Louis, MO	2	Avg. 57	$17,500
Splaingard, et al.	1982	Houston, TX	N.A.	N.A.	$15,000
Banaszak, et al.	N.A.	Milwaukee, WI	2	Avg. 61	$15,469
Giovannoni	1982	Madison, WI	5	N.A.	$32,800
AARC	1985	37 States	3,771	All	$25,063

[a] Reported charges are not adjusted for inflation.

[b] N.A = Not available.

SOURCES: 1. H.D Davis, III, S.S. Lefrak, D. Miller, et al., "Prolonged Mechanically Assisted Ventilation: An Analysis of Outcome and Charges," *Journal of the American Medical Association* 243(1):43-45, 1980.

2. E.D. Sivak, E.M. Cordasco, W.T. Gipson, et al, "Clinical Considerations in the Implementation of Home Care Ventilation: Observations in 24 Patients," *Cleveland Clinic Quarterly* 50:219-225, summer 1983.

3. J. Feldman, and P.G. Tuteur, "Mechanical Ventilation: From Hospital Intensive Care to Home," *Heart and Lung* 11(2):162-165, 1982.

4. M.L. Splaingard, R.C. Frates, Jr., G.M. Harrison, et al., "Home Positive Pressure Ventilation: Twenty Years Experience," *Chest* 84:376-382, 1983.

5. E.F. Banaszak, H. Travers, M. Frazier, et al., "Home Ventilator Care," *Respiratory Care* 26(12):1262-1268, 1981.

6 R. Giovannoni, "Chronic Ventilator Care: From Hospital to Home," *Respiratory Therapy* 14:29-33, 1984.

7. AARC survey in 37 States, reported in Care for Life, "Prolonged Mechanical Ventilation," prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1985.

Table 14.—Summary of Comparative Average Monthly Charges Presented in the Literature of Ventilator-Dependent Individuals in Hospital and Home Settings

Source	Average hospital charge	Average home charge	Number of patients	Adults (A)/ children (C)	Home costs include some professional shift nursing	Comments
Banaszak, et al., 1981	$15,469	$3,535	2	A	No	—
Burr, et al., 1983	19,613	2,388	6	C	Not given	All hospital charges (not just maintenance charges) are included in hospital figure.
Cabin, 1985	29,113	5,201	1	C	Not given	Hospital charges include charges before patient was medically stable. Home charges include first month home.
Care for Life, 1985	25,063	1,853	—	A,C	Not given	Based on survey of State respiratory therapist representatives' estimation of average charges.
Donn, 1982	19,071	389	12	C	No	Received nasal oxygen only (not ventilation).
Feldman, et al., 1982	17,500	5,704	2	A	Yes (1 patient)	—
Goldberg, 1983	27,435	7,310	2	C	Yes	—
Goldberg, et al., 1984	24,590	7,425	2	C	Yes	—
Kahn, 1984	22,000	5,400	26	C	No (If included, home charges are $8,000)	Hospital charges from intermediate care unit.
Lee, 1983	40,590	5,490	8	C	Not given	Charges are averages during one year, not necessarily before initial discharge home. Two patients were not hospitalized that year.
Perry and Lierman, 1985	51,517	7,361	2	C	Yes (1 patient)	Hospital charges include surgery, acute care. Home "charges" include estimated cost of some services provided at no charge.
Sherman, et al., 1982	40,332	1,943	9	C	Not given	Charges presented here are averages of ranges given in literature report.
Sivak, et al., 1983	15,600	1,760	10	A	Yes (4 patients)	Hospital charges are estimated and include physician charges. Home charges do not include physician charges or initial costs. If startup charges are included, home charges rise to $1,894.
Splaingard, et al., 1983	15,000	775-16,900	47	C	Yes (patient represented by high home charge figure)	Hospital is a rehabilitation hospital. Home care cost does not include drugs.

SOURCES: See references 13, 26, 28, 32, 42, 55, 68, 69, 92, 103, 128, 146, 147, and 149.

Costs of Hospital v. Home Care For Four Ventilator-Dependent Children in The Michigan Responaut Demonstration Project

	HOSPITAL COSTS		HOME CARE COSTS	
	Per Diem	Monthly	Per Diem	Monthly
Patient:				
A	$ 1,595	$ 47,846	$ 433	$ 12,981
B	1,082	32,449	202	6,071
C	1,754	52,608	371	11,135
D	996	29,890	162	4,850
AVERAGE	$ 1,357	$ 40,698	$ 292	$ 8,759

Home care costs include rehospitalizations.

The Michigan Responaut Program has served 11 ventilator-dependent children. This table (based on Table 13, page 45 of the evaluation report) shows the four children for whom complete data on hospital and home care costs are provided in the report. See Appendix F of this report for more information.

J. INSURANCE COVERAGE

- O Tables On Extent Of Private Health Insurance Coverage From OTA Report On Children
- O Descriptions Of How Several Private Insurance Companies Have Provided Augmented Home Care Benefits To Technology Dependent Children

Table 16.—Number and Percent of Children Aged 0 to 12 Years Covered Only by Private Health Insurance, by Income Status, United States, 1986

	Income status			
	Less than 100% of poverty	100% to 199% of poverty	More than 200% of poverty	Total
Total number of children (in thousands)	10,861.6	9,997.7	23,658.9	44,518.2
Number with private health insurance (in thousands)	1,520.6	6,198.6	20,346.6	28,065.8
Percent with private health insurance	14%	62%	86%	63%

SOURCE: U.S. Department of Commerce, Bureau of the Census, Current Population Survey, unpublished data, March 1986.

Table 17.—Surveys of Employer-Sponsored Group Health Insurance Plans

Study	Survey year(s)	Sample	Employee groups covered by survey	Percent of plans (p) or employees (e) with maximums	Percent of plans (p) or employees (e) with lifetime maximums of $500,000 or less	Percent of plans (p) or employees (e) with lifetime maximums of less than $1 million	Percent of plans (p) or employees (e) with stop-loss catastrophic coverage
U.S. DOL-BLS	1984	Probability sample of 1,326 business establishments meeting industry-specific minimum size requirements (ranging from 100 to 240 employees)	Full-time employees	1984: 82% (e)[a]	1984: 52-57% (e)	1984: 53-58% (e)	1984: 76% (e)
Wyatt Co.	1978-84	In 1984, 1,115 firms of all sizes (but mostly large) participating in the study	Salaried employees	1984: 87% (p) 1980: 88% (p)	1984: 52% (p) 1980: 60% (p)		1984: 88% (p)
Hewitt Associates	1979-84	250 major employers; 68% in Fortune 100, 32% in Fortune 500	Salaried employees	1984: 82-87% (p) 1979: 89-90% (p)	1984: 56% (p)[b] 1979: 75% (p)		1984: 87% (p) 1979: 59% (p)
Fox & Yosphe	1986	Random sample of 60 firms of all sizes selected from Dunn & Bradstreet's U.S. Business Directory (small firms) and Business Insurance Directory (medicine and large firms)	All employees	1986: 67% (p)	1986: 16.3% (p)	1986: 25.5% (p)	1986: 80% (p)
Battelle/EBRI	1977-78	Probability sample of small nonagricultural business establishments (less than 250 employers)	All employees	1978: 75-83% (e)[c]			

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[a] Calculated as percent of employees with major medical coverage who are subject to overall plan maximum. About 90 percent of plan participants in this sample had major medical coverage. The remainder had basic benefits only, which may not be subject to lifetime limits but which are often subject to specific maximum limits on services.

[b] Calculated as the percent of all employees with lifetime maximums less than this amount. An additional 4 percent of employees who were not subject to lifetime maximums in 1984 were subject to annual or "per cause" maximum.

[c] This is an overstatement, because employees subject to more than one maximum are double-counted.

SOURCES: See references 33, 58, 83, 175, 186.

Box D.—Individual Benefits Management Among Private Insurers

A few private insurance companies have chosen to provide augmented home care benefits to technology-dependent children when it can be shown that by doing so the insurer is likely to save money, or at least to extend the length of time the child will be covered before reaching a lifetime maximum. Following are brief descriptions of four examples.

Blue Cross/Blue Shield Federal Employees Benefits Program

The Blue Cross/Blue Shield Association negotiates, on behalf of the 90 independent plans, a benefits package contract with the U.S. Office of Personnel Management. This contract is one of many health insurance options that a Federal employee may choose. All Blue Cross and Blue Shield plans agree to provide this benefit package to enrolled Federal employees in their local jurisdictions. The present contract provides employees with the option of enrolling in a "high" plan, with benefits including 90 home health days of medically necessary service and no hospital benefit limit; or a "low" plan, with a lower premium, higher deductibles and coinsurance, a $2 million limit on covered benefits, and no home health benefits.

Under a pilot project, begun when the first case was brought to the attention of the program in 1983, the Blue Cross/Blue Shield Federal Employee Program can provide home benefits in excess of the contracted benefits to technology-dependent individuals, including children, who: 1) would be eligible for coverage if in the hospital, and 2) will be less expensive to care for at home (155). A number of individuals who have been extended special benefits under this pilot project have been children, primarily infants with respiratory disorders, heart disease, tube feeding or parenteral nutrition requirements, and multiple handicaps.

Aetna

Aetna Life & Casualty is a national for-profit insurance company with regional offices that administer its plans. The company offers augmented home benefits to any policyholder who would be eligible for coverage if in the hospital and will be less expensive to care for at home. Aetna has provided this service since 1983 to all age groups. The company estimates that the program saved $3.5 million in the first year of implementation, $12 million in the second year, and $26 million in the third (38).

Aetna had served 26 children under age 16 in the program as of March 1986. Savings for each case under the program are calculated at least every 6 months, and all cases over $6,000 in cost or with care lasting longer than 6 months are monitored and reviewed by the company's medical director. Benefits can range from an apnea monitor to extensive equipment purchase, home modifications, nursing, and therapy. Benefits cease when the patient is completely rehabilitated or the lifetime benefit level is reached. In the latter case, the patient may keep purchased equipment (38).

The Equitable

The Equitable Life Assurance Society of the United States, a for-profit insurance company, offers a Medical Case Management program as an optional amendment to group health insurance policies. The policy amendment itself carries no extra charge, but in agreeing to the amendment the group policyholder (the employer) agrees to pay the costs of a case coordinator for any relevant cases that arise. As of January 1, 1986, 255 group policyholders had a medical case management agreement with The Equitable, covering approximately 910,000 employees about 2,500,000 total persons (employees plus eligible dependents) (136).

Patients may be referred to the case management program by the company's pre-admission review service, the source of eligibility verification, the employer, the employee or dependent, claims personnel, or providers. The company uses a diagnosis-based trigger for identification of appropriate cases to ensure early referral and the opportunity to establish a rapport with the patient, family, and provider. Included in the diagnostic profile are a number of diagnoses associated with neonatal problems (e.g., congenital heart anomalies or respiratory distress syndrome) and trauma. More diagnostic categories can be added to accommodate the client's need (136).

Under the case management program, case coordinators at The Equitable screen potential cases, assess the medical and other needs of accepted patients, prepare care plans, coordinate the necessary care, and monitor progress. Patients in the program can receive services that would not be reimbursed under the usual insurance contract, such as home modification, family counseling, and transfer to a special rehabilitation hospital (136).

John Hancock

John Hancock Mutual Life Insurance Co., which has a health insurance component, operates a medical case management program that is very similar to The Equitable's. It concentrates on serving trauma patients, high risk infants, and (in the case of older patients) stroke. The program brings a case consultant to certain of these cases to coordinate care and provide benefits not normally available to beneficiaries, such as specialized rehabilitation services and home services, in order to reduce costs while providing appropriate care (56).

K. FINANCING OF CARE

- "Medicaid Coverage Of Subacute Care In California" (From OTA Report On The Elderly)
- "Charitable Organizations" (From OTA Report On Children)

Box E.—Medicaid Coverage of Subacute Care in California

California has recently confronted the problem of appropriate institutional placement (and payment) for technology-dependent persons when home care is not feasible. On August 19, 1986, the State held public hearings on proposed Medicaid regulations establishing a category of subacute care in skilled nursing facilities (SNFs). (As of March 1987, it appeared that the Health Care Financing Administration will allow California to implement these regulations, but Federal approval was not yet final.) The revised text of the proposed regulations adopts additions to State Medicaid regulations, as follows.

Definition.—"Subacute level of care means a level of care needed by a patient who does not require acute care but who requires more intensive licensed skilled nursing care than is provided to the majority of patients in a skilled nursing facility." A subacute care unit is "an identifiable unit of a skilled nursing facility accommodating beds including contiguous rooms, a wing, a floor, or a building that is approved by the Department for such purpose" (30). Subacute care units are subject to all of the State certification and licensing requirements applicable to skilled nursing facilities. They may be in hospital-based or freestanding SNFs.

Staffing.—"Subacute care units shall employ sufficient licensed staff to provide a minimum daily average of 4.8 actual licensed nursing hours per patient day for non ventilator dependent patients, and a minimum daily average of 6.2 actual licensed nursing hours per patient day for ventilator dependent patients" (30). At least one registered nurse (RN) and one licensed vocational nurse (LVN) must be on each shift, and the ratio of LVNs to RNs cannot exceed 4 to 1. Both RNs and LVNs must have prior acute care experience. The unit must be able to provide, within the institution or through contract, laboratory, X-ray, respiratory therapy, and pharmacy services.

Services.—The proposed regulations define subacute care services as "a type of skilled nursing facility service which is provided by a subacute care unit" (30). Patients must be under the care of a physician who makes frequent visits and must have 24-hour access to services in an acute-care hospital. They must require special supplies or equipment, 24-hour nursing, and administration of three or more of the following treatment procedures:

1. traction and pin care for fractures;
2. total parenteral nutrition;
3. inpatient physical, occupational, and/or speech therapy, at least 2 hours per day, 5 days per week;
4. tube feeding;
5. tracheostomy care with suctioning;
6. oxygen therapy and/or inhalation therapy treatments at least four times per day;
7. continuous or frequent intravenous therapy via a peripheral and/or central line;
8. medically necessary isolation;
9. debridement, packing, and medicated irrigation with or without whirlpool treatment; and
10. continuous mechanical ventilation for at least 50 percent of each day (30).

Medicaid Payment.—The State calculated payment amounts for these new subacute facilities based on hourly costs of nursing care and facility costs reported by SNFs, adjusted by the more intense nursing requirements of the subacute care units and predicted higher use of supplies and electricity (29). The resultant recommended maximum daily rates for SNF subacute level of care were:

- $221.93 for ventilator-dependent patients in hospital-based units, $6,658 /mo
- $187.71 for other eligible patients in hospital-based units,
- $140.62 for ventilator-dependent patients in freestanding units, and $4,219/mo
- $109.62 for other eligible patients in freestanding units. $3,289 /mo

CHARITABLE ORGANIZATIONS

Charitable organizations have long been visible sources of research and services to aid the disabled. About 20 national children's health charities operate in this field, ranging in size from very large organizations such as the National Easter Seal Society to small organizations such as the Retinitis Pigmentosa Foundation (117). The missions, disease orientations, and structures of the various charities are similarly diverse. The majority of national charitable organizations focus their efforts on one disease or closely associated set of diseases. However, an organization may concentrate on research, public education and political lobbying, direct provision of services, family education and support, or any of a number of other activities.

Charitable organizations have functioned as last-resort providers for many families with technology-dependent children. One of their most important functions in this regard is as a provider of family support and education. Table 25 lists the expenses of selected foundations for various services, including medical services and patient education. Spending for these services range from 15 percent of expenditures (March of Dimes) to 92 percent of expenditures (Easter Seal Society) (27). "There is no strong relationship between prevalence of a chronic condition and relative magnitude of foundation support. . . . Consequently, children with certain disabilities have more resource available to them than others" (27). Researchers who interviewed a number of national charitable organizations concluded:

> Although foundations expend a significant amount on direct services, they tend to provide assistance to cover only those services that are not otherwise reimbursable and that place an unreasonable financial strain on families with disabled children. These services included transportation, educational and recreational activities, physicial and occupational therapy, special medical equipment, and to a lesser extent, medical care (27).

Table 25.—Total Amount of Expenses Allocated for Programs of Selected Foundations, 1979 and 1980 (millions of dollars)

Private foundation	Total program services	Research	Medical services and patient education	Public and professional education	Community services/advocacy
Muscular Dystrophy Association, 1979	$56.6	$18.0	$33.3 59%	$5.3	—
March of Dimes, 1980	49.9	10.2	7.6 15%	18.4	$13.6
Cystic Fibrosis Foundation, 1980	11.1	1.7	4.2 38%	3.6	1.5
American Diabetes Association, 1980	9.7	1.7	2.7	3.6	1.7
Arthritis Foundation, 1980	6.0	2.9	[a]	2.3	0.8[a]
Leukemia Society of America, 1980	3.9	2.2	1.0	0.5	0.2
American Kidney Fund, 1979	1.5	0.04	0.9	0.2	0.4
Easter Seal Society, 1979[b]	85.7	0.5	79.1 92%	6.1	—

[a] The Arthritis Foundation combines patient and community services into one category.

[b] The Easter Seal Society includes the combined expenditures for the national and all State and territorial Easter Seal Societies.

SOURCE: J.A. Butler, P. Budetti, M.A. McManus, et al., "Health Care Expenditures for Children With Chronic Illnesses." *In:* N. Hobbs and J.M. Perrin (eds.), *Issues in the Care of Children With Chronic Illness* (San Francisco, CA: Jossey-Bass, 1985).

L. MEDICAID AND THE MINNESOTA MEDICAID MODEL WAIVER PROGRAM (CAC)

- O CAC: Summary of Nursing Services, Length of Program Service, and Estimated Monthly Costs For Persons Served By CAC
- O CAC: Listing Of CAC Client Characteristics And Costs
- O CAC: Tables from Waiver Program Evaluation Showing Characteristics of the Children Served, Estimated Costs, and Breakdowns of Start-Up And Miscellaneous Costs
- O Description Of Minnesota's Home And Community Care Waivers (Including CAC)
- O Comparison Of State Medicaid Options For Extended Home And Community-Based Care (From OTA Report On Children)

APPENDIX L

MINNESOTA MEDICAID MODEL WAIVER PROGRAM
COMMUNITY ALTERNATIVE CARE (CAC) FOR THE CHRONICALLY ILL UNDER 65

TABLE 1

Summary of Nursing Services, Length of Program Service, and Estimated Monthly Costs For Former and Current Clients Served on CAC (6/85-1/88)

	ALL Clients (n=40)	Former Clients Only (n=7)	Current Clients Only (n=29)
PAID NURSING SERVICES:			
Range:			
lowest	1 hr/day	5 hrs/day	1 hr/day
highest	24 hrs/day	24 hrs/day	24 hrs/day
Mean Daily Nursing	14 hrs/day	15 hrs/day	15 hrs/day
Median Daily Nursing	16 hrs/day	16 hrs/day	16 hrs/day
LENGTH OF TIME ON CAC			
Range:			
lowest		3 months	
highest		21 months	
Mean Number of Months		11.5 months	
Median Number of Months		10 months	
ESTIMATED MONTHLY COST			
Range:			
lowest	494	2,760	494
highest	20,824	18,997	20,824
Mean cost	11,120	11,585	11,254
Median cost	11,940	11,619	12,543

NOTE: "All clients" includes four persons who were approved but never served on the program.

MINNESOTA MEDICAID MODEL WAIVER PROGRAM
COMMUNITY ALTERNATIVE CARE (CAC) FOR THE CHRONICALLY ILL UNDER 65

TABLE 2

Summary of CAC Client Characteristics (Age and Care Requirements) at Time of Approval for Program and Estimated Monthly Costs of Care at Most Current Assessment

(As of 9/01/87)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
Approved but never served: (n=4)						
	3	tracheostomy, bronchomalacia pacemaker, OT,PT	7 hrs/day	$ 6,924	none (insurance settlement)	none
	13	illiostomy, gastrostomy, nutritional therapy	13 hrs/day	9,311	none (death of child)	none
	<1	continuous O2, OT, gastrostomy, apnea monitor	16 hrs/day	13,214	none (death of child)	none
	<1	continuous O2, gastrostomy, nebulization treatments	8 hrs/day	7,897	none (Medical Assistance Program meets needs)	none
Former clients: (n=7)						
	3	tracheostomy, gastrostomy, O2, vesicostomy	9 hrs/day	$ 10,564	3 mo.	

(cont. next page)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
<u>Former Clients cont.</u>:						
	18	tracheostomy, gastrostomy, O2	16 hrs/day	11,619	16 mo.	
	4	CPAP at night, tracheostomy, gastrostomy	24 hrs/day	14,093	17 mo.	
	1	tracheostomy, O2	5 hrs/day	2,760	21 mo.	
	1	ventilator, tracheostomy	16 hrs/day	13,409	10 mo.	
	11	ventilator, tracheostomy, RT, Clinitron	16 hrs/day	18,997	10 mo.	
	<1	gastrostomy, tracheostomy, apnea-heart monitor continuously	16 hrs/day	9,652	3.5 mo.	
<u>Current clients</u>: (n=29)						
	14	tracheostomy, gastrostomy, CPAP	12 hrs/day	1,030		
	3	ventilator, tracheostomy, gastrostomy	20.5 hrs/day	19,397		
	5	gastrostomy, tracheostomy	24 hrs/day	15,243		

(continued next page)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
Current clients, cont.						
	4	trachesotomy, gastrostomy	24 hrs/day	9,023		
	15	TPN at night via portacath RN XI WK (blood drawing)	RT 2x/day	1,818		
	1	tracheostomy, gastrostomy, O2 vesicostomy	16 hrs/day	14,982		
	1	tracheostomy, gastrostomy	8 hrs/day	1,400		
	<1	gastrostomy, apnea monitor	4 hrs/day	4,162		
	14	totally dependent, chokes easily	10 hrs/day (home health aide)	494		
	14	syringe feeding	10 hrs/day (home health aide)	10,923		
	4	ventilator, tracheostomy	24 hrs/day	20,372		
	1	nutritional therapy, hyperalimentation, ostomy	6.3 hrs/day	14,570		

(cont. next page)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
Current clients, cont.:						
	<1	O2, apnea monitoring, low birth weight formula, PT, OT	1 hr/day	5,384		
	20	totally dependent, ventilator, gastrostomy, tracheostomy	24 hrs/day	20,824		
	1	tracheostomy, gastrostomy, CPAP, OT, ST	16 hrs/day	17,265		
	<1	O2, apnea monitor, gastrostomy	8 hrs/day	7,452		
	3	tracheostomy, gastrostomy, ventilator	16 hrs/day	14,966		
	1	tracheostomy, gastrostomy, O2, PT, OT	16 hrs/day	14,824		
	<1	gavage feedings, suctioning, OT, PT	6 hrs/day	4,852		
	1	tracheostomy, gastrostomy, PT	12-18 hrs/day	13,794		

(continued next page)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
Current clients, cont.:						
	2	gastrostomy, respiratory treatments-nebulizer, suctioning, PT, OT, ST	15 hrs/day	14,940		
	32	ventilator, tracheostomy	24 hrs/day	18,494		
	2	ventilator, tracheostomy, gastrostomy, PT, OT	16 hrs/day	12,262		
	4	gastrostomy, OT	12 hrs/day	8,833		
	4	tracheostomy, frequent suctioning, gastrostomy, PT, OT, ST	5.5 hrs/day	5,413		
	15	tracheostomy, gastrostomy, frequent suctioning, OT, PT	16 hrs/day	12,543		
	41	ventilator, tracheostomy, gastrostomy	24 hrs/day	19,700		

(continued next page)

	Age	Care Requirements	Average Daily Nursing	Estimated Monthly Cost	Total Time On CAC	Total Cost to CAC
Current clients, cont.:						
	2	tracheostomy, gastrostomy	16 hrs/day	3,783		
	24	ventilator, tracheostomy	24 hrs/day	17,618		

Note that age and care requirements reflect client characteristics at time of approval for program; they are not updated on this list. Estimated monthly costs are updated periodically, and the most recent estimates are shown here.

Table 2

Waiver Children Demographics: Diagnosis, Severity, Prognosis

Age (yrs/mos)	Sex	Diagnosis	Severity*	Prognosis**
1.1	M	brochopulmonary disease	3.9	2
1.8	F	syndrome	2.6	2
2.1	F	central nervous disorder	4.4	2
2.3	F	syndrome	4.0	1
2.6	M	syndrome	3.6	1
2.10	M	bronchopulmonary disease	3.6	1
2.10	M	bronchopulmonary disease	2.9	1
3.0	F	syndrome	2.9	2
4.0	M	central nervous disorder	4.2	5
4.8	M	degenerative hereditary disease	3.6	2
5.2	M	spinal cord injury	3.7	1
6.0	F	coma	4.7	4
6.7	M	coma	4.6	4
12.1	M	degenerative hereditary disease	4.5	5
16.5	F	degenerative hereditary disease	1.6	3
20.5	M	spinal cord injury	4.1	1

* <u>Severity</u>
1=normal
5=severest

** <u>Prognosis</u>
1=improving or stable with expected improvement
2=stable with hope
3=stable, long-term deterioration
4=stable with no hope
5=n/a, deceased

Table 6

Estimated Costs for Waiver Children

Case Number	Number of Assessments[1]	Total months	Start-up Costs[2]	Nursing Care[3]	Home Health Aide & Homemaker	Therapy[4]	Case Management	Presciptions & Nutrition	Non-durable Supplies	Durable Equipment	Family Counseling/ Training	Respite/ Foster Care	Miscellaneous[5]	Subtotal Home Care Costs	Depreciation of start-up costs	Total Homecare costs	Average cost per month	Severity
1	3	12	---	73,439	---	11,680	---	450	13,742	7,894	800	---	---	108,006	---	108,006	9,000	4.0
2	4	23	2,943	228,851	3,411	13,631	3,141	8,239	42,797	19,526	2,880	6,504	6,876	335,856	1,127	336,983	14,651	3.6
3	1	4	11,647	109,500	---	2,352	1,648	6,500	7,231	4,850	---	---	2,500	134,581	776	135,357	33,839	4.1
4	4	18	126	59,761	---	5,830	2,600	216	12,839	14,474	---	---	5,760	101,480	126	101,606	5,644	2.9
5	1	2	5,802	11,088	---	2,736	384	620	1,675	1,034	4,224	---	46	21,807	192	21,999	10,999	4.2
6	2	12	3,273	141,060	---	2,750	3,128	23,760	23,899	42,405	1,020	---	---	238,022	648	238,670	19,889	4.5
7	2	18	896	244,416	---	10,114	3,377	1,742	39,201	16,527	9,230	---	8,368	332,975	896	333,871	18,548	3.6
8	1	19	2,908	126,148	---	46,841	4,560	---	432	895	---	---	1,235	180,111	912	181,023	9,527	4.7
9	2	24	164	243,833	---	---	200	4,381	10,822	14,305	---	---	224	273,765	164	273,929	11,413	4.6
10	2	18	2,510	48,900	2,090	3,502	5,760	1,187	265	2,940	---	2,042	---	66,686	738	67,424	3,745	4.4
11	3	23	4,374	292,920	---	58,656	15,732	2,173	22,246	18,850	2,800	---	17,247	430,625	1,656	432,281	18,794	3.6
12	2	18	---	560	---	35,312	3,700	22,656	700	76	---	---	1,164	64,168	---	64,168	3,564	1.6
13	1	8	16,618	183,960	---	1,500	2,400	720	15,288	16,440	---	---	3,000	223,308	2,208	225,516	28,189	3.7
14	3	18	500	25,818	---	7,200	1,440	870	1,914	3,240	---	---	---	40,482	500	40,982	2,276	2.9
15	1	6	3,497	7,152	1,344	8,640	3,600	1,800	1,038	4,022	600	1,512	3,473	33,180	348	33,528	5,588	3.9
16	1	6	---	25,704	---	35,952	1,008	1,884	7,025	2,400	---	---	1,398	75,371	---	75,371	12,562	2.6
TOTAL		229	55,258	1,823,110	6,845	246,696	52,578	77,198	201,114	169,878	21,554	10,058	51,291	2,660,523	10,291	2,670,714	11,662	---
Percent of subtotal costs		---	---	68.4%	.3%	9.3%	2.0%	2.9%	7.6%	6.4%	.8%	.4%	1.9%	100%	---	---	---	---

1) Only complete acceptable assessments
2) See Table 7 for a breakdown of total start-up costs
3) Includes nursing supervision
4) Physical, speech, nutritional, occupational, respiratory therapy
5) See Table 8 for a breakdown of total miscellaneous costs
6) Depreciated over 5 years if over $1,000 and expensed immediately if under $1,000

Table 7

Breakdown of Total Start-up Costs

Category	Amount	% of Total
Modifications to home	9,409	17%
Initial education	5,808	11%
Durable medical equipment	34,236	62%
Case management opening visit	1,124	2%
Nursing care	2,510	5%
Prescriptions	107	0%
Non-durable supplies	1,370	2%
Transportation	448	1%
Physicians	246	0%
TOTAL	55,258	100%

Table 8

Breakdown of Total Miscellaneous Costs

Category	Amount	% of Total
Physician fees	17,628	34%
Special education	6,764	13%
Lab fees	14,056	28%
Transportation	11,760	23%
X-Rays	1,037	2%
Social worker	46	0%
TOTAL	51,291	100%

Minnesota's Home and Community Care Waivers

Authority: Omnibus Budget Reconciliation Act (OBRA) of 1981 (P.L. 97-35); Section 2176. Section 2176 added 1915 (c) to the Social Security Act

Currently Approved 2176 Waivers:

Elderly - Preadmission Screening/Alternative Care Grants (PAS/ACG)
MR/RC - Home and Community Based Waiver for Persons with Mental Retardation or Related Conditions
Chronically Ill Under 65 - Community Alternative Care (CAC)
Disabled Under 65 - Community Alternatives for Disabled Individuals (CADI)

	PAS/ACG	MR/RC	CAC	CADI
Previous Dates	7/23/82- 6/30/85	7/1/84- 6/30/92		
Currently Approved Dates	7/1/85- 6/30/88	7/1/87- 6/30/92	4/1/85- 3/31/88	10/1/87- 9/30/90
Number of Possible Recipients	FY 86 - 1,947 FY 87 - 2,271 FY 88 - 2,649	FY 88 - 1,665 FY 89 - 2,287 FY 90 - 2,748 FY 91 - 3,000 FY 92 - 3,000	4/85 - 16 4/86 - 32 4/87 - 50	87 - 200 88 - 450 89 - 650
Number of individuals currently receiving waivered services	1321	1118	19	0

10/31/87

	PAS/ACG	MR/RC	CAC	CADI
Eligible Persons	A. Age 65 or over. B. Applicant to a nursing home who is at risk of SNF or ICF placement. C. Eligible for MA. D. Has been screened by PAS. E. Individual chooses community care. F. MA community costs < MA institution. (individual)	A. Any age. B. Individual diagnosed with MR or RC and at risk of ICF/MR placement. C. Eligible for MA (deeming waiver). D. Has been screened by MR/RC screening team. E. Client/guardian chooses community care. F. MA community costs < MA institution. (state average)	A. Under age 65. B. Resident of a hospital or at risk of in-patient hospital care. C. Eligible for MA (deeming waiver). D. Parent/Guardian/Individual chooses community care. E. MA community costs < MA institution. (individual)	A. Under age 65 B. Applicant to a nursing home who is at risk of SNF or ICF placement C. Eligible for MA (deeming waiver D. Certified as disabled. E. Has been screened by PAS. F. Individual parents, spouse or guardian chooses community care. G. MA community costs < MA institution. (individual)
Average Cost for Community Based Services	FY 86 $2,572 FY 87 $2,726 FY 88 $2,890 rounded to the nearest dollar	FY 88 $18,054 FY 89 $19,733 FY 90 $21,542 FY 91 $22,682 FY 92 $23,874	4/85-3/86 $128,296 4/86-3/87 $136,909 4/87-3/88 $147,323	10/87-9/88 $14,119 10/88-9/89 $14,825 10/89-9/90 $15,566

	PAS/ACG	MR/RC	CAC	CADI
Covered Services	A. Regular MA services. B. Case Mgmt. C. Adult Day Care. D. Respite. E. Homemaker F. Home Health Aide. G. Foster Care. H. Personal Care Attendant.	A. Regular MA services. B. Case Mgmt. C. Day Habilitation. D. In home family support E. Respite. F. Homemaker. G. Adaptive Aids. H. Supported Living Services.	A. Regular MA services. B. Case Mgmt. C. Respite. D. Minor adaptations to the home. E. Family counseling and Training. F. Foster Care. G. Homemaker. H. Extended MA.	A. Regular MA services. B. Case Mgmt. C. Adaptations. D. Homemaker. E. Respite. F. Adult Day Care. G. Family Counseling & Training H. Independent Living Skills I. Extended Home Health Services. J. Extended Personal Care Attendant.
Related Programs	ACG under 180-day eligibility Community Health Services Title XX/CSSA Title III	Family Subsidy SILS (Semi Independent Living Services) Title XX/CSSA	Title XX/CSSA Services for Children With Handicaps Community Health Services	Title XX/CSSA Community Health Services Disease related organizations
State Administrative Contact	Mary Bruns 612/297-2243 Wally Goettl 612/296-2213	Bob Prouty 612/296-2136	Phyllis Zwieg 612/296-2916 Cathy Griffin 612/296-2917	Lynda Adams 612/296-1551 Cathy Griffin 612/296-2917

Table 20.—Comparison of State Medicaid Options for Extended Home- and Community-Based Care

Option	Categorical eligibility	Income eligibility	Number of individuals able to participate	Geographic areas	Allowable services	Time period
Individual waivers (no longer newly awarded)	Disabled individuals who, because of relatives income, would otherwise be eligible for Medicaid only if institutionalized	Deeming rules are waived	One person per waiver	Not applicable	Regular State Medicaid services only	Individuals eligible until waiver no longer needed
Regular 2176 waiver	State may target to aged or disabled, mentally retarded or developmentally disabled, or mentally ill. Individuals must require level of care provided in ICF, ICF/MR, SNF, or hospital	States may waive deeming rules; may increase income eligibility to 300% of SSI standard	All persons meeting eligibility criteria	May be less than statewide	Can offer certain services otherwise not authorized under Medicaid law; can provide more extensive coverage of regular services	3-year waiver; 5-year renewal
Model 2176 waivers	States can define specific categories of disabled individuals. Individuals must require level of care provided in ICF, ICF/MR, SNF, or hospital	States must waive deeming rules	50 or fewer slots per waiver program	May be less than statewide	Similar to regular 2176 waivers; must offer at least one service in addition to those provided by regular Medicaid	3-year waiver; 5-year renewal
State plan amendment	Disabled individuals under age 19 who, because of relatives' income, would otherwise be eligible for Medicaid only if institutionalized; individual must require level of care provided in a hospital, ICF, ICF/MR, or SNF	Deeming rules are waived	All persons meeting eligibility criteria	statewide	Regular State Medicaid services only	State option

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

M. DESCRIPTIONS AND STATUS OF PERTINENT FEDERAL LEGISLATION UNDER CONSIDERATION

O Senate 1740: Medicaid Chronically Ill and Disabled Children Amendments of 1987 (sponsored by Durenberger)

O Senate 1537: Care Management and Catastrophic Health Care for Children Act of 1987 (sponsored by Chafee)

O Senate 1711: A Bill To Amend The Social Security Act To Establish A National Commission On Children (sponsored by Bentsen)

O House 2762: Medicare Long-Term Home Care Catastrophic Protection Act of 1987 (sponsored by Pepper)

Description + Current Status of Congressional Bills Under Consideration Which Have Implicatio For Federal Financing of (and other impact on) Health Care for the Technology Dependent

S.1740 DATE INTRODUCED: 10/01/87

SPONSOR: Durenberger

REFERRED TO: Senate Committee on Finance
COSPONSOR(S): CURRENT (1)
Stafford:

SHORT TITLE AS INTRODUCED:
Medicaid Chronically Ill and Disabled Children Amendments of 1987

LATEST OFFICIAL TITLE:
OFFICIAL TITLE AS INTRODUCED AS OF 10/01/87:
A bill to amend title XIX of the Social Security Act to permit States the option of providing comprehensive medical assistance to chronically ill and disabled children with a family income meeting a particular income standard, and for other purposes.
LEGISLATIVE ACTIONS:

Oct 1, 87 Read twice and referred to the Committee on Finance.

S.1537 DATE INTRODUCED: 07/23/87

SPONSOR: Chafee

REFERRED TO: Senate Committee on Finance
COSPONSOR(S): CURRENT (4)
Moynihan; Daschle; Matsunaga; Stafford (A-10/01/87):

SHORT TITLE AS INTRODUCED:
Care Management and Catastrophic Health Care for Children Act of 1987

LATEST OFFICIAL TITLE:
OFFICIAL TITLE AS INTRODUCED AS OF 07/23/87:
A bill to amend title V of the Social Security Act to provide care management to certain children and to provide care management and health care to children with high cost catastrophic health care needs.
LEGISLATIVE ACTIONS:
Jul 23, 87 Read twice and referred to the Committee on Finance.

ABSTRACT:
Amends title V (Maternal and Child Health Services) of the Social Security Act to establish programs providing payments and health care management services on behalf of children with high cost health care needs.

DIGEST:
Care Management and Catastrophic Health Care for Children Act of 1987 - Ame
title V (Maternal and Child Health Services) of the Social Security Act to
authorize appropriations for new programs under which: (1) the Secretary o
Health and Human Services makes payments on behalf of children with high co
catastrophic health care needs and establishes special projects designed to
enhance the delivery of health care and health care management services to
such children; and (2) each State provides health care management services
children with anticipated annual medical expenditures in excess of $5,000.

Defines "care mangement" as advocacy on the child's and family's behalf to
secure needed services and entitlements in accordance with a written
management plan which is: (1) developed in collaboration with the child's
parents or legal guardians and at least one attending physician; (2) subjec
to the approval of such parent or legal guardian; and (3) updated annually
whenever there is a significant change in the child's condition. Sets the
Federal share of care management costs at 80 percent of the total amount
expended by States in providing health care management.

Defines "children with high cost catastrophic health care needs" as childre
under age one suffering from a condition, illness, or disability which resu
in medical charges of $50,000 or more in the first year of the child's life
Makes such children eligible for payments under this Act if their family
income is below the Federal poverty level and the medical charges paid by t
family exceed ten percent of the family's gross income. Continues such
payments after the child's first year for so long as the family satisfies s
eligibility requirements.

Provides payment for the items and services which are considered "medical
assistance" under title XIX (Medicaid) of the Act, but prohibits payments
items and services covered under a third-party plan for which payment has
made in full. Bases payments for inpatient hospital services on hospital
specific departmental ratios of costs to charges for services provided and
payments for other items and services on Medicare (title XVIII of the Act)
payment levels. Directs the Secretary to develop, and report to the Congr
by December 31, 1988, regarding, a prospective payment system for inpatien
hospital services provided to children.

S.1711 DATE INTRODUCED: 09/22/87

SPONSOR: Bentsen

REFERRED TO: Senate Committee on Labor and Human Resources
COSPONSOR(S): CURRENT (17)
Moynihan; Chafee; Bradley; Cranston; DeConcini; Durenberger;
Graham; Inouye; Matsunaga; Mitchell; Reid; Riegle; Stennis;
Bingaman (A-11/10/87); Bond (A-11/10/87); Leahy (A-11/10/87);
Weicker (A-11/10/87):
LATEST OFFICIAL TITLE:
OFFICIAL TITLE AS INTRODUCED AS OF 09/22/87:
A bill to amend the Social Security Act to establish a National Commission on Children.
LEGISLATIVE ACTIONS:
Sep 22, 87 Read twice and referred to the Committee on Labor and Human Resources.
Sep 30, 87 Committee on Labor and Human Resources requested executive comment from Health and Human Services Department, Education Department, GAO, OMB.

H.R.2762 DATE INTRODUCED: 06/24/87

SPONSOR: Pepper

REFERRED TO: House Ways and Means
House Energy and Commerce
COSPONSOR(S): CURRENT (102)
Roybal; Borski (A-08/04/87); Biaggi (A-08/04/87);
Florio (A-08/04/87); Frank (A-08/04/87); Kildee (A-08/04/87);
Savage (A-08/04/87); Vento (A-08/04/87); Solarz (A-08/04/87);
Traficant (A-08/04/87); Wise (A-08/04/87);
Gray, of IL (A-08/04/87); Rodino (A-08/04/87);
Traxler (A-08/04/87); Owens, of NY (A-08/04/87);
Hayes, of IL (A-08/04/87); Jones, of NC (A-08/04/87);
Harris (A-08/04/87); Dymally (A-08/04/87); Oakar (A-08/04/87);
St Germain (A-08/04/87); Weiss (A-08/04/87);
Hertel (A-08/04/87); Brown, of CA (A-08/04/87);
Yates (A-08/04/87); Pelosi (A-08/04/87); Dellums (A-08/04/87);
Lewis, of GA (A-08/04/87); Kastenmeier (A-08/04/87);
Howard (A-08/04/87); Kaptur (A-08/04/87);
Lehman, of FL (A-08/04/87); Price, of IL (A-08/04/87);
Sabo (A-08/04/87); Clay (A-08/04/87); Defazio (A-08/04/87);
Ackerman (A-08/04/87); Gephardt (A-08/04/87);
Gilman (A-08/04/87); Bonior (A-08/04/87);
Foglietta (A-08/04/87); Yatron (A-08/04/87);
Collins (A-08/04/87); Eckart (A-08/04/87);

Annunzio (A-08/04/87); Wilson (A-08/04/87);
Rahall (A-08/04/87); Towns (A-08/04/87); Bilbray (A-08/04/87)
Ford, of MI (A-08/04/87); Mavroules (A-08/04/87);
Kennedy (A-08/04/87); Crockett (A-08/04/87);
De Lugo (A-08/04/87); Staggers (A-08/04/87);
Mfume (A-08/04/87); Ford, of TN (A-08/04/87);
Edwards, of CA (A-08/04/87); Johnson, of CT (A-08/04/87);
Garcia (A-08/04/87); Coyne (A-08/04/87); Cardin (A-08/04/87);
Boxer (A-10/06/87); Mica (A-10/06/87);
Johnson, of SD (A-10/06/87); Lantos (A-10/06/87);
Markey (A-10/06/87); Wolpe (A-10/06/87): Matsui (A-10/06/87):
Lowry (A-10/06/87); Torricelli (A-10/06/87); Roe (A-11/19/87)
Scheuer (A-11/19/87); Smith, of FL (A-11/19/87);
Gordon (A-11/19/87); Perkins (A-11/19/87);
Moakley (A-11/19/87); Jontz (A-11/19/87); Hutto (A-11/19/87);
Stokes (A-11/19/87); Kostmayer (A-11/19/87); Fish (A-11/19/87
Bennett (A-11/19/87); Rangel (A-11/19/87); Bryant (A-11/19/87
Dwyer (A-11/19/87); Mollohan (A-11/19/87); Tallon (A-11/19/87
Gejdenson (A-11/19/87); Fauntroy (A-11/19/87);
Mrazek (A-11/19/87); Miller, of CA (A-11/19/87);
Kolter (A-11/19/87); Oberstar (A-11/19/87);
Schumer (A-11/19/87); Hawkins (A-11/19/87);
Coleman, of TX (A-12/11/87); Hochbrueckner (A-12/11/87);
Espy (A-12/11/87); Waxman (A-12/11/87); Martinez (A-12/11/87)
Wheat (A-12/11/87):

SHORT TITLE AS INTRODUCED:
Medicare Long-Term Home Care Catastrophic Protection Act of 1987

LATEST OFFICIAL TITLE:

OFFICIAL TITLE AS INTRODUCED AS OF 06/27/87:
A bill to amend title XVIII of the Social Security Act and the Internal Revenue Code of 1986 to provide long-term home care benefits under the medicare program for chronically ill individuals and children, to provide quality assurance for home care services, and for other purposes.

LEGISLATIVE ACTIONS:
Jun 24, 87 Referred to House Committee on Energy and Commerce.
    Jul 13, 87 Referred to Subcommittee on Health and the Environment.
Jun 24, 87 Referred to House Committee on Ways and Means.
    Jul 2, 87 Referred to Subcommittee on Health.

ABSTRACT:
Amends part A (Hospital Insurance) of title XVIII (Medicare) of the Social Security Act to provide part A coverage for long-term home care furnished t chronically ill individuals. Establishes a quality assurance system for ho care services under a new title XXI of the Social Security Act entitled "Ho Care Quality Assurance."

DIGEST:

Medicare Long-Term Home Care Catastrophic Protection Act of 1987 - Amends p A (Hospital Insurance) of title XVIII (Medicare) of the Social Security Act provide part A coverage of long-term home care furnished through home healt agencies to chronically ill individuals who are under a physician's care. Requires physicians to establish and periodically review a written plan of long-term home care for each of their patients who receive such coverage. Lists the services which comprise long-term home care. Defines a "chronica ill individual" as an individual who requires assistance with at least two daily living activities or has a similar level of dependency due to cognitive impairment. Holds monthly payments for long-term home care to 75 percent of the average monthly payment under the Medicaid program (title XIX of the Act) for skilled nursing facility services.

Amends title II (Old Age, Survivors and Disability Insurance) of the Act to cover, under part A of the Medicare program, long-term home care provided to children who: (1) are chronically ill and require assistance with at least two daily living activities; or (2) require a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability. Holds monthly payments for the latter category of children to the amount which would be payable under the Medicaid program if such children were institutionalized.

Adds a new title XXI to the Social Security Act entitled "Home Care Quality Assurance." Requires the Secretary of Health and Human Services to promulgate a home care consumer's bill of rights which includes rights: (1) facilitating consumer participation in the planning and delivery of services; (2) requiring consumer notification regarding services, charges for services, and the termination or reduction of services; (3) protecting consumer dignity, privacy, and property; and (4) ensuring service from properly trained and competent individuals.

Requires home health agencies to: (1) satisfy Medicare home care agency requirements; (2) provide consumers with copies of the home care bill of rights; (3) implement grievance review procedures and provide copies of such procedures to consumers; (4) provide consumers with schedules of the services to be provided; (5) have methods for identifying and reviewing a home care consumer's needs and coordinating the provision of services with other home health agencies; (6) ensure that each home care provider whom they employ or have under contract receives training; and (7) evaluate annually and supervise each home care provider whom they employ or have under contract. Conditions coverage of durable medical equipment services on providers: (1) issuing written instructions to and training the home care consumer and staff in the operation of such equipment; and (2) formulating an emergency plan for providing services to the consumer.

Directs the Secretary to establish procedures for conducting an equal number of announced and unannounced surveys of a home health agency's compliance with title XXI participation conditions, with more frequent surveys required for agencies with poor compliance records. Authorizes the Secretary to contract with States having survey procedures equivalent to those the Secretary would otherwise apply to conduct such compliance surveys and transmit their results to the Secretary annually. Directs the Secretary to develop procedures for reviewing State surveys, with more frequent review required if peer review organizations (PROs) find at least ten percent of State-surveyed agencies to have serious or chronic quality of care problems.

Directs the Secretary to promulgate regulations, within one year of this Act's enactment, pursuant to which PROs shall monitor the provision of home health services, devoting at least 75 percent of their efforts to quality assurance. Requires the inclusion of: (1) both documentary review and personal interviews of home care consumers and providers in the PRO review process; and (2) representatives of home care providers and consumers in PRO membership.

Requires the Secretary to establish a Consumer Board to oversee the review activities of PROs. Directs the Board to report to the Secretary and the State's chief executive on October 1 of each year regarding such review activities.

Requires the Secretary to develop methods for monitoring continuity in the provision of health care and outcome-orientated criteria for monitoring the quality of home care. Requires that PROs: (1) establish and operate statewide toll-free hotlines for receiving home care questions and complaint and (2) assist consumers in resolving home care quality problems. Directs Consumer Boards and PROs to cooperate with State and local officials in educating consumers regarding quality assurance programs and the assistance available for consumers with quality assurance problems.

Requires the Secretary to issue regulations which impose sanctions against agencies and providers failing to comply with this Act. Requires the Secretary to report to the Congress on January 1 of each year regarding the availability, adequacy, and use of sanctions. Requires the Secretary to develop incentives to contractor compliance with title XXI participation conditions, including an annual directory of home care agencies having a consistent record of compliance with such conditions. Directs the Secretary to: (1) encourage States to develop home care provider licensing and certification policies; and (2) issue a biennial report on State implementation of such policies.

Establishes a Home Care Quality Assurance Council with which the Secretary must consult in implementing and administering title XXI of the Social Security Act.

Directs the Secretary to award grants for home care agency and provider training programs and furnish States, and home health agencies and providers with training materials.

Directs the Secretary to: (1) conduct, and issue a report regarding, studie on home care quality assurance measures; and (2) report to the Congress on January 1 of each year regarding the nature and performance during the preceding fiscal year of the home care quality assurance system.

Authorizes appropriations from the Federal Hospital Insurance Trust Fund to carry out title XXI. Directs the Secretary to issue regulations by 1988 fo implementing title XXI.

Permits disabled individuals to purchase part A (Hospital Insurance) Medica coverage during the 24-month waiting period preceding their entitlement to such coverage.

Amends the Internal Revenue Code to subject all of an individual's wages an self-employment income to the Hospital Insurance tax.

N. BIOMEDICAL ETHICAL ISSUES RELATED TO HEALTH CARE FOR THE TECHNOLOGY DEPENDENT

O "Principles for Decisionmaking Regarding the Use of Life-Sustaining Technologies for Elderly Persons, as Developed by Project Advisory Panel" (from the OTA Report on the Elderly)

O "NIH Workshop Summary: Withholding and Withdrawing Mechanical Ventilation" (Appendix E from OTA Report on the Elderly)

O Excerpt from "Imperiled Newborns," a Hastings Center Report edited by Arthur Caplan and Cynthia Cohen (December 1987)

from Life-Sustaining Technologies + the Elderly
Office of Technology Assessment Report, July 1987

Appendix E

NIH Workshop Summary: Withholding and Withdrawing Mechanical Ventilation

In October 1985, a workshop entitled "Withholding and Withdrawing Mechanical Ventilation" was sponsored by the National Heart, Lung, and Blood Institute, American Association of Critical-Care Nurses, American Association for Respiratory Care, American College of Chest Physicians, American Thoracic Society, and the Puritan Bennett Foundation. The 3-day meeting brought together clinicians, researchers, lawyers, ethicists, and others.[1]

Proceedings of the workshop, as summarized in an article in *American Review of Respiratory Diseases*, are reproduced here.[2] They focus on the difficulty of arriving at optimal treatment decisions and the use of institutional policies and other means to help patients and caregivers make better-informed decisions regarding the use of mechanical ventilation.

Introduction

The second half of the 20th century has seen a movement toward shared decisionmaking between physician and patient in medical care. This welcome trend has causes that include rapid technological advances, a more health-conscious public, better understanding of the limitations of health care, and the emergence of less autocratic health-care providers. However, these developments have been accompanied by a new way of dying in that the last days of life are often spent in an expensive hospital environment in which the patient, through mental incompetence or physical incapacity, is unable to make decisions about personal medical care.

The widespread use of mechanical ventilation has occurred in the last two decades. Mechanical ventilation first became available outside the operating room and recovery room in the mid-1960s. At that time each major hospital usually had one intensive care unit, and patients were admitted based on the judgment of the director and the family physician. This resource was applied only to patients who seemed likely to recover. Today the situation has changed, although mechanical ventilation remains only supportive, until the patient's underlying disorder of the central nervous system, neuromusculature, or lung improves spontaneously or responds to specific therapy. Every hospital now has the capacity to institute mechanical ventilation, and paramedical personnel often initiate the process by manual ventilation in the home as part of cardiopulmonary resuscitation. Endotracheal intubation and mechanical ventilation are frequently instituted by medical personnel who have little previous knowledge of the patient, and since this therapy is immediately life sustaining, it is often impossible to contact the family, surrogate, or personal physician prior to its initiation. As a result, the ability to prolong life or the dying process is no longer in the hands of a few, select medical personnel but is available in every medical facility where emergency medicine is practiced and in most mobile life support units. This capability, although beneficial in many cases, carries with it the potential for overwhelming emotional hardship, agonizing pain, and devastating financial cost for the patient and the patient's family.

Prognosticating Outcome in the Severely Ill

Decisionmaking about life-sustaining therapy is complicated by our inability to prognosticate outcome in the severely ill or injured person. Subgroups of patients with particularly poor prognoses who undergo mechanical ventilation have been difficult to identify. For instance, it is common knowledge that severely immunosuppressed individuals and those with liver failure who develop acute respiratory failure have a

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[1] **Steering Committee**: Thomas M. Hyers, M.D., *Chairman*; Dick D. Briggs, Jr., M.D.; Leonard D. Hudson, M.D.; Suzanne S. Hurd, Ph.D.; Albert R. Jonsen, Ph.D.; John J. Lombard, Jr., J.D.; Louise M. Nett, R.N., RRT; Thomas A. Raffin, M.D., Robert M. Rogers, M.D.; and Gordon L. Snider, M.D.

[2] Reproduced from "NIH Workshop Summary: Withholding and Withdrawing Mechanical Ventilation," *American Review of Respiratory Diseases* 134: 1327-1330, 1986, used with permission

from Life-Sustaining Technologies + the Elderly, Office of Technology Assessment, July 1987

Box 1-A.—Principles for Decisionmaking Regarding the Use of Life-Sustaining Technologies for Elderly Persons, as Developed by Project Advisory Panel

NOTE: *Members of the Advisory Panel to this OTA assessment (see title page) sought to express their strong convergence of opinion regarding many of the fundamental questions regarding the use of life-sustaining technologies for elderly persons. The following list of principles for decisionmaking was developed at the final meeting of the Panel, in February 1986. These are the personal views of the majority of Panel members, all of whom were present at the meeting or subsequently polled. It should be noted that dissent, while rare, was in some cases strong. These principles do not necessarily reflect the opinion of OTA, staff for this assessment, members of the Technology Assessment Board or members of the assessment's requesting committees. With these caveats, the following principles are offered to Congress and the public for consideration.*

- An adult patient who is capable of making decisions has the right to decline any form of medical treatment or intervention. However, an individual does not necessarily have a right to unlimited medical treatment or intervention.
- Decisions regarding the use of life-sustaining treatments must be made on an individual basis and should never be based on chronological age alone. Chronological age per se is a poor criterion on which to base individual medical decisions; however, age may be a legitimate modifier regarding appropriate utilization of life-sustaining medical technologies.
- Diagnosis alone is a poor criterion for decisions about the use of life-sustaining technologies. Because of the great variability among patients with the same diagnosis, patient assessment must also include measures of functional impairment and severity of illness.
- Cognitive function is an important marker of the quality of life.
- The courts are not and should not be the usual route or determinant for making decisions about the use of life-sustaining technologies or for resolving the dilemmas these technologies may create.
- There is little need or room for Federal legislation concerning the initiation, withholding, or withdrawal of specific life-sustaining technologies.
- There is a major need for a clear, workable definition of the appropriate role of surrogates in health care decisionmaking, including the nature of their responsibilities and their suitability to make decisions.
- There is a need to recognize that a process exists, or should exist, for making decisions about the use of life-sustaining technologies. The process described by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research could serve as a model.
- A physician or other health professional who does not want to follow the wishes of a patient who is capable of making decisions regarding his or her treatment should withdraw from that case.
- Socioeconomic status should not be a barrier to access to health care, including life-sustaining interventions.
- There is an important need for education of the public and health care providers regarding the nature and appropriate use of life-sustaining technologies.
- There is a specific need for improved clinical information that would predict the probability of a critically or seriously ill patient's survival, functional status, and subsequent quality of life.
- There is a wide range of medical and legal disagreement and varying levels of emotional strain and moral conflict about the appropriate use of life-sustaining technologies. The great heterogeneity of the American population makes consensus difficult and increases the likelihood of formal institutional decisionmaking procedures.

poor prognosis, but these perceptions are based on limited anecdotal evidence from a few medical centers. In this regard, physiologic scoring systems such as the APACHE II scheme may prove useful to categorize severity of illness and help predict outcome (1). The most useful prognostic data have been obtained on patients with coma (2). In this large series, less than 2 percent of patients with nontraumatic, nondrug-induced coma, who lacked at least two of corneal, pupillary, and oculovestibular responses within hours of the onset of coma, ever regained independent function. However, most patients who receive mechanical ventilation have less predictable outcomes.

The Persistent Vegetative State

Decisionmaking about mechanical ventilation often concerns patients in a persistent vegetative state, since many patients in this state are maintained on ventilators. These individuals are not brain dead, but rather appear to be awake with open eyes and sleep-wake cycles. They can be seen to follow movement with their eyes and sometimes will swallow food placed in their mouths. However, they neither speak, follow commands, nor show cognitive awareness of themselves or their surroundings. This state may rapidly follow coma, and if it persists for more than a few weeks, usually indicates an extremely poor chance for recovery of independent function (3). Unfortunately, the onset of this state is difficult to predict and its outcome only becomes apparent after weeks of therapy.

For most patients who are supported by mechanical ventilation, the prognosis is less clear. Furthermore, for some individuals with more favorable prognoses, mechanical ventilation and other intensive medical treatment may be perceived as so burdensome that it is declined by the patient or the surrogate. In each of these circumstances, health care professionals are increasingly called on to provide counsel and advice about withholding or withdrawing mechanical ventilation and other life-sustaining therapy. What are the elements involved in making and implementing these decisions? Can high-quality patient care be maintained? Detailed answers to these questions were orginally given in a publication of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research entitled "Deciding To Forego Life-Sustaining Treatment" (4). In the following sections we describe some procedures for making and implementing these decisions, and we outline topics that require further study and development.

Withholding and Withdrawing Therapy

Mechanical ventilation is an example of life-sustaining therapy because it substitutes for an essential physiologic process that is not functioning properly. However, the simplest supportive measures can place undesirable and intolerable burdens on the dying or irreversibly incapacitated patient by unnecessarily prolonging suffering. In such a patient, intravenous feeding, antibiotic therapy, and even enteral feeding are now regarded by many as appropriate for withdrawal when the burden of the treatment outweighs any benefit the patient can derive. It has become increasingly acceptable to contrast the benefit and the burden of specific treatment rather than regard it as ordinary or extraordinary (5). In this way an extremely painful or invasive treatment might be advocated if it were likely to result in significant improvement, but even a minimally supportive treatment might not be condoned if the prognosis were dismal (6,7).

With mechanical ventilation, however, we deal with immediacy, literally with the breath of life. Because of this immediacy we are often reluctant to withhold this treatment, and we are even more ambiguous about withdrawing mechanical ventilation. Our reluctance and ambiguity have practical reasons. First, the decision to withdraw is more often made by a surrogate, whereas the decision to withhold is more likely to be made by the patient. Surrogate decisionmaking is less precise. It is more likely to be tediously scrutinized by the press, the courts, and other parties. Decisions to withdraw take longer to implement; the family and usually the entire intensive care unit team must be prepared more carefully. Finally, withdrawing therapy is humiliating to many physicians. Withholding therapy always leaves a doubt about whether the therapy might have worked, but withdrawing is the public admission that therapy has failed, which may be difficult for the treating physician to accept. Withdrawal of mechanical ventilation is particularly poignant since it often leads quickly to death. However, these differences are practical and emotional. There are no ethical or legal differences between withdrawing and withholding mechanical ventilation.

Decisions to withhold or withdraw mechanical ventilation must be based on an essentially similar decisionmaking process. The decision to withhold generally deserves more scrutiny than the decision to withdraw, but rarely gets it. A rationale for withholding therapy is also adequate for withdrawing it. Furthermore, the act of withdrawal is generally a more informed act because the therapy has been initiated and shown not to work. It is clear in medicine that a therapy should be discontinued when it is not working or is so burdensome to the patient that it cannot be tolerated. Finally, the decision to withdraw mechanical ventilation from a dying or irreversibly incapacitated patient cannot be said to cause death. It merely allows death to occur from whatever necessitated mechanical ventilation in the first place (4).

That the patient can refuse treatment of any kind is regarded as a fundamental legal right in our society. It is relatively easy to respect the decision of the competent patient who can understand the prognosis, is informed of the therapeutic alternatives, and voluntarily makes a decision regarding medical care. In cases where a physician cannot in conscience comply with the decision, the patient's care should be transferred to another physician. However, decisionmaking for the person who is not legally dead but is incompetent or incapacitated becomes more difficult.

In recent years two powerful instruments have emerged that allow the individual more control in circumstances when competence or physical capacity may be compromised. These instruments are the living will (8) and the durable power of attorney (9,10). The living will is a written and witnessed document that expresses the patient's desires about medical care in the event of incompetence or incapacity. The living will generally cannot specify the exact circumstances under which an individual would want therapy withheld, although health care professionals have in some instances prepared very detailed living wills for themselves. Being an advance directive it lacks the moral force of contemporaneous decisionmaking by the patient. A physician might consider it inappropriate for fulfill the directive of a living will because its general language does not reflect a full understanding of the specific treatment decision to be made and the benefit that might be obtained. It should be noted, however, that no civil or criminal action has been successfully brought against a practitioner for following the instructions of a living will.

In an effort to codify the concepts of the living will, currently 35 States and the District of Columbia have enacted laws related to a patient's legal right to refuse medical treatment. Even in States which have no legislation, living wills are being recognized as an indication of the patient's intentions, including the right to refuse treatment. These laws are widely known as natural death acts, and although they give some legal foundation to the concept of the living will, they also raise as many questions as they answer (11,12). Perhaps most importantly, few of these laws provide for appointment of a proxy decisionmaker in the event of a patient's incompetence or incapacity. In response to this need, the concept of durable power of attorney is being increasingly used to provide for a surrogate decisionmaker. The word "durable" means that the authority of the surrogate continues to be effective when the patient becomes incompetent or incapacitated. Unlike the common law nondurable power of attorney, the surrogate has authority when it is most needed. This concept is legally accepted in all States with the exception of the District of Columbia, which has no enabling legislation. It is a somewhat stronger idea than the living will because it allows for more flexibility in the decisionmaking process in response to the circumstances that affect the patient. Previously, durable power of attorney was used more often to protect an individual's business and financial interests, and consequently the application of this instrument to decisionmaking on health care matters is relatively new. Living wills and durable power of attorney generally apply only in the event of the patient's incompetence and each is easily revokable. It must be recognized that in each State there will be differences in the applicability of laws relating to durable power of attorney and living wills. More uniformity across the States in regard to these acts is needed (see proposed "Uniform Rights of the Terminally Ill Act" by the National Conference of Commissioners on Uniform State Laws, 645 N. Michigan Avenue, Suite 510, Chicago, IL 60611, (312) 321-9710).

Making and Implementing the Decision To Withhold Cardiopulmonary Resuscitation and Mechanical Ventilation

The decision to withhold cardiopulmonary resuscitation and mechanical ventilation is not a trivial one and should not be rushed by the caregiver. In many instances a minimum of several discussions with the patient, family, and other interested parties over a few days is necessary. For the competent patient or the incompetent patient's legally recognized surrogate, the decision must be *voluntary* after full *disclosure* about *prognosis* and *therapeutic alternatives*. The caregiver may make medical recommendations but must not impose personal opinions about quality of life on the decisionmaker. In all instances it is desirable that there be unanimity about the decision among family and other interested parties. The need for unanimity becomes crucial when the patient is incompetent and there is no legally authorized surrogate, since unhappy family members or caregivers who were not included in the decisionmaking process can unnecessarily complicate it. When irreconcilable differences exist between parties interested in this decisionmaking process, introduction of a *facilitator* in the form of a clergy member or ethicist can be extremely useful.

While competent patients are legally entitled to refuse any treatment, including those that sustain life (such as mechanical ventilation), physicians serve patients best by maintaining a presumption in favor of sustaining life and rendering optimal treatment. In other words, when in doubt, the physician should err in favor of sustaining the life of a patient for whom there may be a question of competency or other problems that cannot be easily resolved. In the case of an incompetent patient, treatment could be revoked later by a recognized surrogate. This revocation could be based on specific instructions from the patient or on the patient's best interests if no clear prior directive had been given to the surrogate.

Given the desire of many patients to take an active role in the decisionmaking processes related to their health care, physicians and nurses should take the necessary time to discuss life-sustaining treatment with patients so that well-informed decisions about treatment can be made in advance. The attending physician, who presumably has established a prior relationship with the patient, should initiate these discussions, possibly in the presence of close family members, and most importantly before any emergent, life-sustaining intervention becomes necessary. The patient can best communicate this decision by making an explicit statement to the physician and at the same time executing a prior directive, such as durable power of attorney or a living will. Resolving the logistics of carrying out the directive falls on the patient, physician, hospital, and particularly, emergency room personnel. If possible, copies of prior directives should be made part of the patient's medical record. More readily available means to communicate a prior directive such as a necklace or bracelet, a microfilm chip attached to the driver's license, or similar identification should be widely available. Health care institutions have an obligation to establish clear procedures for communicating the existence of such a directive as well as providing for its implementation.

Patients, family members, and health care professionals are often uncomfortable discussing life-sustaining treatments such as cardiopulmonary resuscitation and mechanical ventilation when the patient is feeling well. Historically, medical and nursing education has provided little training in this area. The uncertainty of medical prognostication, as well as the reluctance of physicians and family members to accept responsibility for value judgments of this type also contribute to the uneasiness. Many patients, however, have definite opinions regarding cardiopulmonary resuscitation and mechanical ventilation and are willing to discuss these when asked. For example, in patients with a chronic illness such as advanced chronic obstructive pulmonary disease, which is likely to progress to the point where mechanical ventilation will be necessary to sustain life, open discussion among physician, patient, and family is essential. A second example is that of the healthy elderly. Discussions about a future catastrophic event, while often uncomfortable, can potentially prevent much pain and suffering. The use of prior directives regarding cardiopulmonary resuscitation and mechanical ventilation is appropriate in both instances.

Although economic considerations pervade many aspects of health care, caregivers should not allow the cost of treatment to dominate decisionmaking about withholding mechanical ventilation. On the other hand, the patient may factor into a prior directive the dire financial consequences that prolonged hospitalization might have on loved ones and refuse treatment on that basis.

There are many areas of potential conflict in decisions to withhold mechanical ventilation that require further clarification. Decisions about allocation of life-sustaining resources are implicitly made daily in medical practice. However, institutional policies that take into account both ethical and legal aspects of withholding therapy should be clarified and declared. Mechanisms for communication of advance directives among institutions, physicians, patients, and their families need to be developed.

Implementing the Decision To Withdraw Mechanical Ventilation

The decision to withdraw mechanical ventilation is usually made after a patient has received this and other treatment in an intensive care unit. Many individuals can be involved in the process, but a surrogate frequently makes the decision because the patient is incompetent or incapacitated. When it becomes clear to the health care team and family that mechanical ventilation is no longer benefiting or is excessively burdensome to the patient, a representative of the provider team, usually the attending physician or the responsible critical care unit physician, should meet with the patient and the family. The representative describes the options and the medical implications of continuing or withdrawing mechanical ventilation. The representative may give a medical recommendation, but the decision to withdraw or to continue resides with the patient if competent, or with a surrogate if the patient is incompetent or incapacitated. Living wills and durable power of attorney can greatly facilitate this decisionmaking process, but the steps are generally the same whether or not a prior directive exists. The following recommendations outline the decisionmaking process and its implementation.

It is the responsibility of the individual institution to assure the existence of written policies about withdrawing mechanical ventilation. These procedures must be consonant with appropriate ethical principles and with legal precedents that pertain to that locale. Important elements include:

1. Provision for continuing communication and consultation among all parties of interest. These include the patient, the family, physicians, nurses, respiratory therapists, social workers, and others.
2. These deliberations should result in a general agreement about withdrawing or continuing therapy. When they do not, some mechanism of resolution of conflict should exist. In some hospitals this may be a standing ethics committee. In other hospitals it could be an *ad hoc* committee. In many instances it is clergy known to the family. In a few instances, the courts have been involved in this decisionmaking process, although it is generally agreed that the courts are not well equipped to deal with this problem and their intervention should only be sought when an irreconcilable conflict arises.
3. When and if a consensus is reached that further ventilatory support is neither benefiting nor is desirable for the patient, the following events should occur.
4. A signed and witnessed note should be placed in the medical progress notes by the responsible physician that it is the patient's or the surrogate's decision that mechanical ventilation will be withdrawn. This documentation can briefly outline the events that led up to the decision, the patient's likely prognosis, and the parties to the decisionmaking process.
5. Once the documentation has occurred in the medical progress notes, an order can then be written to withdraw mechanical ventilation. This withdrawal procedure should provide for the patient's comfort and dignity. Although no details of a recommended withdrawal procedure are given here, in most cases the responsible physician should direct the procedure personally. Withdrawal procedures that result in great dyspnea or discomfort to the patient should be avoided, and the use of narcotics to blunt dyspnea and discomfort may be desirable.

Further Studies and New Directions

A diversity of further studies is needed. The medical literature is still imprecise about prognosis in many severe illnesses. More precise prediction of outcome is needed in both adult and pediatric illnesses that necessitate mechanical ventilation. Early predictors of the emergence of a persistent vegetative state would be useful. Subgroups of patients requiring mechanical ventilation who have a particularly high mortality rate or permanent loss of cognitive function (nearly 100 percent) need early identification.

There is a lack of study of the psychosocial implications of withholding and withdrawing mechanical ventilation. Very little is know about the perceptions of the healthy elderly and their desires regarding critical care and withdrawing and withholding mechanical ventilation. Most medical orders that withhold resuscitation or mechanical ventilation are ambiguous, and it is not clear to many physicians how to write a "do not resuscitate" order (13,14). Physicians perceive many problems when they withhold and withdraw mechanical ventilation. Their perceptions and fears are not well understood and only recently have studies begun to explore this area (15,16). While there are no ethical or legal differences between withholding or withdrawing mechanical ventilation, caregivers continue to be confused about the legal significance of withdrawal of therapy, and efforts should be undertaken to correct this misunderstanding (17).

In a practical manner it is difficult to communicate advance directives to emergency medical and intensive care unit personnel. Innovative devices and procedures are needed in this area. Few people know about living wills and durable power of attorney and how to implement them. Health care professionals should be encouraged to include information about prior directives with maintenance medical programs for chronically ill patients.

Careful collection of information about functional status and quality of life following weaning from mechanical ventilation would be useful since there is widespread fear that data about quality of life is currently being misinterpreted and inappropriately applied. With the extensive use of home ventilator therapy in this country, studies are needed of the psychosocial implications of long-term ventilation. There is little published information on the social adjustment of premature infants or adults who receive long-term mechanical ventilation. Reimbursement schemes for patients receiving mechanical ventilation at home are poorly developed. Some of this information will be difficult to obtain and much of it is subject to change as new technology and treatments are applied. However, taken as a whole, this body of information will help patients and caregivers make more informed decisions about life-sustaining treatments.

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(excerpt)

Imperiled Newborns

Despite attempts to achieve compromise and consensus, discussion of the ethics of neonatal care has been stridently polarized. "Treat all infants, without consideration of quality of life, with every possible intervention" stands against proposals for infanticide based on this very quality of life consideration. National legislation designed to resolve tensions instead contributes a definition of child abuse that could include as abusers clinicians struggling to provide sensitive and humane care for infants. A curious sense of unreality clings to arguments in this area: it is almost as if no one is listening to anyone else.

One explanation offered by many dedicated biomedical and ethical "listeners" was that much of the published debate not only represented extreme or marginal perspectives but also ignored important realities of neonatal care. If this were true, it seemed desirable to create a forum for exploration of what might prove to be a more fertile middle ground. If a broader consensus existed than had previously been apparent, it deserved a convincing and highly visible articulation. With this guiding conception, a Hastings Center project was begun in 1984. The aim of the project was to assemble a group of knowledgeable participants who could grapple with the controversies not only as previously defined, but also within paradigms that the group itself might create or discover.

Struggle they did. Shifting from a focus on treatment decisions for handicapped newborns to one on the management of ill premature and other infants, the group perceived children as subject to many perils beyond physical impairment. Congenital illnesses, trauma from birth, prematurity, and even inadequate insurance coverage and the medical interventions of beneficent families and professionals came under scrutiny as potential sources of distress and injury. The group considered interventions designed to advance life at any cost as "aggressive," and sought to defend a child-centered best interest standard as particularly well suited to reflect the values implicit in providing medical care and in parenting.

The report of the project, as expressed in this issue of the Hastings Center Report, *addresses issues of substance, procedure, and vision. While not a strict consensus document, the report represents the group's central views and considerations. As such, it consolidates previous approaches to neonatal ethics with its broader aims, thereby providing a coherent base for future analysis.*

No doubt the group could have gone further. Yet we hear in this distillation of its dialogue an emerging rather than stagnating discourse, and disagreement without acrimony.

Both the March of Dimes Foundation and the J.M. Foundation provided funding that enabled The Hastings Center Research Project on the Care of Imperiled Newborns to hold more than fifteen meetings during the period from 1984 to 1987. Many experts from disability groups, family self-help associations, right-to-life associations, medical societies, state and federal agencies, and academia were generous in sharing their expertise and experiences, and project participants gave unstintingly of their time and energy in the work that led to the writing of this report.

Kathleen Nolan

Introduction

The moral dilemmas of neonatal intensive care have been the subject of heated discussion and debate during the past two decades. Parents, physicians, nurses, lawyers, administrators, theologians, bioethicists, and even judges have all had a voice in the cacophony of controversy regarding the provision of care for imperiled newborns. As the technology of neonatology has continued to advance, the ethical issues have likewise multiplied and arguments have proliferated.

All of this activity has produced a spate of books and articles as well as numerous legal and regulatory battles. Yet, we believe, in all of this there are many ethical issues still to be addressed, looked at in new ways, and brought together more comprehensively. We have chosen several that we consider the most significant to highlight and examine more fully.

First, in recent years there has been a growing acceptance in some American hospitals of a "treat, wait, and see" approach to the dilemma of whether and when to initiate care. That is, rather than tradition of caring, receptiveness and the refusal to abandon persons in need reflected in the common roots of the words "hospital" and "hospitality." Active killing, at one level, may be an effort to sweep away the failures of technological medicine. In fact, families and professional caregivers have much to offer dying and suffering persons.

What Care Should Be Given When Aggressive Measures Are Forgone?

As we have seen, while we reject any policy permitting active killing, there are instances when aggressive treatment should not be continued. However, the duty to care for patients does not end once aggressive measures are abandoned. Parents, nurses and physicians can still play a major role in caring for the infant. They can offer comfort with whatever measures are available, including warmth, food and touch.

For those infants capable of feeling pain, relieving that pain is a matter of the highest priority. Suffering, other than that chosen by the person in the service of some greater good, is an evil. Modern medicine has the ability to diminish greatly the pain or suffering of seriously ill newborns. Although there may be some dispute about whether the most premature infants possess the neurological capacities to experience pain, in the absence of clear and convincing evidence to the contrary, we should assume they can and act accordingly.

Rather than diminishing, the moral duties of medical caregivers take a different form once we accept that a patient is dying, and lies beyond the reach of our curative powers. Sophisticated treatments intended to provide comfort have an important role. But, as Paul Ramsey reminds us, care and companionship may be at least as important. He says we should care, but only care for the dying. Before aggressive therapies were available, nurses and physicians were more accustomed to caring for dying patients. That art needs to be renewed.

The interests of the dying infant's family also ought to be considered. Those interests need not conflict with doing what is best for the infant. Some hospitals have made provisions for parents to hold their infants once invasive therapies have ceased. This could benefit infants and their parents. Another measure has been to allow the families to see and hold their infants once they have died. Some hospitals have tried to adapt concepts of hospice care in their practices with dying infants and their families. These worthy efforts to accept the realities of death, and to provide institutional support for families, deserve to be implemented and developed further.

Section 6: Familial and Social Obligations to Seriously Ill and Disabled Children

While our society acknowledges a duty to save infants who are seriously ill or impaired at birth, it tends to overlook their needs once the critical period for them is over. Families are left with the responsibility of attempting to provide for the special needs of their children with insufficient support from the community. The family resource, which is precious to our society, is at risk of being overwhelmed by the complex problems that families face when they attempt to get decent care for these special children. Once the family resource is depleted, it is rarely revived. An important goal for the coming years is to assist these infants and their families to build on their many strengths by developing improved medical, financial, and social support for them after neonatal intensive care ends.

Financial Costs of the Care of Infants Born at Risk

Even with monumental efforts to coordinate multiple sources of reimbursement, families of children who are seriously ill or disabled have costs far in excess of what they can afford. At present, cross-subsidization of those who cannot pay by those who can ensures that neonatal intensive care is available to infants regardless of their parents' financial means. Such care as of 1986 totalled approximately 3 billion dollars a year throughout the country. The treatment of a single infant may cost as much as $250,000, not counting special services, institutional care, or the expenses covered by parents.

If proposed federal and state reductions in Medicaid funds are put into effect, neonatal intensive care units would face serious financial losses. Cost containment efforts by private insurers, such as the adoption of DRGs for neonatal intensive care, also threaten to reduce financial support available for the treatment of future newborns. Critically ill children of poor families will be hardest hit by these measures.

In fact, these heavy costs raise questions about whether neonatal intensive care will continue to be available for all infants in the future as new methods of reimbursement cut into the funding available for it.

Once the neonatal period is past, families may face additional financial expenses for subsequent medical and surgical treatment, which is often inadequately covered by health care insurance. Infants born at risk are more prone to permanent and serious disabilities, and their treatment is correspondingly more expensive.

There is wide variation in third party coverage depending upon income, geographic location, severity of condition, and type of services. Reimbursement is primarily geared toward acute care, involving medical and surgical services. The additional out-of-pocket costs of hospitalization for children of young families are 30 percent greater than for adults due to restrictions set by third party payers. Third party coverage is insufficient to fund entirely the costs of hospitalization, physician visits, special medical procedures, nursing care, and drugs to families of these infants. Other essential costs, such as those for therapy, special foods, transportation, child care, modifications in the physical setting at home, special equipment and cosmetic devices, and respite care are not usually covered by third party carriers at all. In the current payment setting, extended visits to doctors are discouraged, as is attention to family, developmental, or social problems. A family's financial future can be ruined by the expenses the family incurs for the treatment of an infant who is born at risk.

Services Available to Infants and Families

In recent years, the services available to families with children who have special needs have decreased, rather than increased, as reductions in programs have been necessitated by funding cuts. The service system that is currently available to infants born at risk and their families tends to be fragmented and rigid. Parents find that they need help in negotiating the byzantine bureaucracy of health care and social services in large hospitals. Specialists who work with these children for only brief periods of time and at a distance from their homes may not become familiar with their distinctive needs and those of their families. The long-range plans developed by local practitioners for the treatment of these infants do not necessarily mesh with those of specialists because of their distance from one another and consequent lack of communication.

Access of these infants and their families to nonmedical services varies tremendously. Infants with a specific health problem may be fortunate enough to live in a community in which there is a comprehensive program especially directed toward children with that problem. Or local practitioners may offer coordination of their medical treatment with nonmedical services.

A few medical institutions are experimenting with new modes of integrating medical and nonmedical services; they are developing comprehensive care clinics that go beyond the provision of strictly medical care to assist families in caring for their children at home. Some private support groups have arisen to help parents close the service gaps in the medical care system. These are not the norm, though. There is a pressing need for a coordinated, comprehensive program for the care of seriously ill or disabled infants and their families if their children are to realize their potential and if the integrity of their families is to be preserved.

Family Responses

Since there is great variation among family structures, values, resources, and stages of growth it is difficult to generalize about how families react to the birth of a newborn with special needs. Disabilities and major medical problems also vary tremendously; their impact on families is too global for detailed analysis. As Ann Turnbull suggests, we must first ask "What kinds of families with what kinds of characteristics have what kinds of impact from their children with what kinds of disabilities?" Reports from families who have had a member who was born seriously ill or disabled, however, provide some basis for ascertaining how they respond to their role as caregivers for these infants.

Families with children who are seriously ill or disabled often can find meaning and satisfaction in their lives, despite many obstacles. They are able to derive genuine joy from their children, as do other parents. They discover that their mutual commitment to the child has created an increased closeness among their members, "involvement," and personal growth. Siblings, by their own accounts, have become more sensitive and caring adults due to their experiences in helping to care for a seriously ill or disabled family member.

Families in a supportive environment surrounded by friends, relatives, and physicians, and who have access to services to ameliorate the negative effects of illness or disability, can respond well to the responsibilities of care of an infant with illness or disabilities. Some parents even point out that families in which children do not require such significant degrees of care encounter problems of different sorts with their children, and maintain that theirs is not a special burden.

Even so, families may experience stress of different kinds when responsible for the care of a child with serious illness or disabilities. The degree of stress experienced apparently has little relationship to the severity of illness or disability of their child. Apart from concerns about finances, the greatest single source of stress that they describe is the responsibility for home health care. When some parents have attempted to provide intensive care at home for their infants in need of dialysis or ventilator support, they have found this too stressful to continue. Parents who have not had the responsibility of providing such intensive care also report that the demands on their energy and inner resources are high, and that some of them experience "burn-out" over an extended period of time. Fatigue is a major problem for families whose children require constant care.

Families also describe stress created by their fears about an uncertain future. Their anxiety is generated not only by the ambiguity that surrounds their child's future development and needs, but also by their concern about whether adequate services will be available for them at later points in time. They face the possibility that they will have a lifetime of extensive and unassisted responsibility for their child that will not taper off as the child grows older. A related source of stress for families is their feeling of social isolation and stigma. Researchers have found, for instance, that 74 percent of parents of children who are severely developmentally disabled have neighbors who object to having their child associate with the disabled child. In 40 percent of these families, parents are never able to go out together; one always has to be home to care for the child. Social isolation becomes a way of life that is, in essence, forced on these families.

Relations with professionals, such as physicians, nurses, social workers, or other clinicians, can assist families in overcoming these problems. Some professionals have identified the need to allow parents to control immediate and long-range planning for these children. However, in some instances, families report that rather than alleviate stress, some professionals create additional pressures due to unresponsiveness, repetitive questions, numerous referrals, and lack of support and information.

Some families find the problems overwhelming. They report that their experiences of fatigue, loss of free time, marital tension, anger, depression, guilt, and a sense of helplessness and isolation tend to wear them down. Some experience a "chronic sorrow" that they cannot overcome. There are some reports of a higher rate of child abuse and marital breakup in families with children who are seriously ill or disabled. The contemporary realities of shifting employment currents, new roles for men and women, and rapid mobility can make a positive parental response to children who need extensive care difficult to sustain, for careers are attenuated and movement to suit employment limited. The reverse is also true in that parents who have wished to remain at home to care for their children have been forced into the workplace in order to meet the expenses of their child's treatments. Some families are unduly stressed by the complex problems of caring for a child with special needs without community assistance. They need more than the traditional biomedical services if healthier, more functional families and children who are contributing, vital members of the community are to emerge from the experience of serious illness or disability.

Family Duties and Their Limits

Parents have a moral duty to care for their children and to attempt to promote their wellbeing. This generally means that parents feel an obligation to provide their children not only with the necessities of life, such as adequate food, clothing, shelter, and health care, but with such additional goods as education, and the basic material and moral support necessary to grow into adults who can think and act independently. However, parents do not have a duty to provide every good possible for their chldren. This is a finite world in which parents have limited resources and other obligations to fulfill; they cannot direct their attention exclusively to the provision of a full panoply of goods to one child.

Home care of children with serious illnesses or disabilities can require parental acts of care bordering on the heroic. Some participants in the discussion of parental duties assume that parents are morally required to provide such extraordinary care unconditionally and sacrificially for their seriously ill or disabled infants, even though in the wider society to do so would be supererogatory, or beyond what is required as a matter of duty. They maintain that the distinction between morally required acts and acts of supererogation does not hold within the family. In family life, it is contended, even radical forms of self-denial are moral necessities.

One justification for this position is that parents incur a duty to perform heroic acts on behalf of their children when they knowingly and voluntarily conceive and give birth to them. They give these children existence, and consequently owe them a duty of extraordinary care, no matter how burdensome. They tacitly undertake to provide that degree of care for their child that they can without radical sacrifice of their own basic, legitimate interests and without derogation from intrafamilial and other duties.

Others maintain that although parents have duties of care toward their children, there are limits to what should be required of them for their children's sake. Unlimited benevolence or efforts on behalf of one's children cannot be morally obligatory. There is a distinction between obligatory and supererogatory acts within the family, although the line between them is drawn on a higher moral plane than it is outside the family. Some "golden mean" must be developed within the moral requirements of parenthood so that parents are not required to sacrifice the rest of the family or themselves in caring for their child.

There is a proper form of individual self-love or self-respect, they suggest, that requires affirmation of one's basic life plans and goals, rather than self-abnegation. When caring for a child with severe health problems would require parents to sacrifice the basic goals that define who they are as persons, such care can become supererogatory.

Sustaining the family as a cooperative unit is also an important moral consideration in this view. Siblings within the family, as well as the child who is ill or disabled, are owed care so that they, too, can reach their full potential. When caring for one child would require parents to deny the interests and needs of other children, a stark dilemma of justice within the family is raised. Parents cannot be held to a self-contradictory moral requirement of benevolence toward one child at the expense of the basic wellbeing of other children. The high requirements of mutual obligation within the family have moral limits.

The duties of care of parents thus do have their moral limits. However, this does not entail that infants who require special care at a supererogatory level should be denied it so that they will die and relieve their families and society of the burden of caring for them. Parents who judge it beyond their capabilities to provide extensive care for their children are not justified in abandoning these children to death. As a moral ideal, when parents cannot care for the child who is seriously ill or disabled, they have a responsibility to find others who will do so. When parents do not attempt to find assistance, or there is none, the state has an obligation to step in to assure that the child receives available appropriate care from some source other than the parents.

Alternative Provisions for Care

The alternatives currently available to parents who cannot provide needed care to their infants are limited and often unacceptable. Although adoption is possible, and some of the "Baby Doe" situations indicate that there are couples in our society who are willing to accept infants whose care will be extensive, it is generally very difficult to find homes for seriously ill or impaired children.

Foster homes provide another recourse to parents who do not wish to relinquish custody of their child altogether. Some specialized pediatric treatment centers in hospitals are developing a cadre of foster parents who are trained to care for children with medical problems for a period of time when parents can no longer cope, and who return these children to their parents when they are able to care for them again. Such programs are only at their beginning stages and do not cover the care of children once the period of critical illness has passed.

The arrangements that have been available for infants with serious illnesses or disabilities whose parents wish to retain custody, but who cannot provide the special care that they need at home have been woefully inadequate. If anything, they have *decreased* in recent years. A substantial number of children remain in acute care hospitals for want of suitable alternatives. In some states, children with severe disabilities have been placed in large residential centers when space has been available. This has not usually been a satisfactory arrangement. There are serious questions about the harm of institutionalization and whether the need of these developing children for individual attention can be met within large-scale facilities. Some state institutions are viewed by knowledgeable experts as warehouses for human beings who are allowed to remain alive in ostracization. Robert Burt describes a remote rural institution in one state "housing some five thousand retarded children in conditions of unrelieved horror."

In some states, pediatric nursing homes have been developed as an alternative. However, a recent study of these homes for children with multiple severe disabilities in one state revealed that low standards of care and financial disincentives had resulted in less than optimal educational and rehabilitative services. Even though there was doubt that the level of care provided in these nursing homes was satisfactory, sufficient numbers of parents were interested in placement of their child within them that applications outran bed availability. In other states, multiply disabled children have been placed in geriatric facilities inappropriate to their special needs when no other placement could be found for them.

The current situation is most discouraging to parents. They do not see any remotely acceptable alternatives for their children on the horizon. If there are limits to the obligations of parents, these are tempered by the parental realization that no other satisfactory care may be available for their infants. Parents who face major disruptions of family life in caring for their children at home say that they have no other choice but to do so. They are reluctant to expose their child to the serious problems that they believe would result if the child were placed in an institution or with another family. They may have a choice in principle, but find that choice meaningless in fact.

Some states have enacted programs that discourage the family from serving as the primary caregiver to the child who is seriously ill or disabled. Currently, when family members provide care to their children with special health care needs at home, they are placed at risk financially, physically, socially, and emotionally. Yet ours is a society that places great value on the role of the family in the care and upbringing of children. We must value, support, and energize the family resource as we develop future programs for children with special needs.

How Much Care is Society Obligated to Provide?

It is a well established legal principle within American society that the state has a legitimate interest in protecting and preserving the wellbeing of children. From an ethical point of view, society has a powerful duty to ensure the welfare of children. The fact that children are both needy and vulnerable creates a duty to provide for them on the part of the rest of society. **While society normally expects parents to bear the responsibility of caring for and meeting the needs of their children, should they fail to do so, both the law and a broad spectrum of moral theories recognize the legitimacy of interventions by other parties and, indeed, an obligation to do so.**

The legal and ethical expectations of society for the welfare of children brook no exceptions where children with disabilities or chronic diseases are concerned. There is no valid moral reason for excluding any subgroup of children from the ordinary welfare society has provided children in particular and vulnerable persons more generally.

For example, Americans are agreed that every child merits an education at public expense if need be. That being the case, it makes no sense to offer education to children without fitting it to individual needs. The commitment to making education available for all children entails responsibilities on the part of the community to assist children with disabilities or serious illnesses in fully realizing their potential. A similar argument pertains to other social services that all children are thought to require.

In considering the obligations that society has to children in need as a consequence of disability or chronic illness, the question of the limits of beneficence must be raised. In a utopian world all the assistance that might possibly be required by disabled or chronically ill children and their families would be rendered by the community when necessary. However, in the real world of limited resources and competing claims for communal benevolence, the costs, in terms of overall financial obligations to society and in terms of resources that might be denied to other equally deserving and needy groups within society, force an examination of the ethics of allocation with respect to public policy in this area.

Some have argued that since the government has articulated an explicit public policy mandating aggressive care for all infants who are not born dying or in a permanent vegetative state, regardless of their degree of disability or the quality of life such children will lead should they survive, the government has thereby incurred a special duty to provide for the needs of such children. It is hypocritical in the extreme, advocates of this interpretation of moral responsibility argue, to create a set of survivors of neonatal care through legislative and regulatory policies and then simply to drop them from the purview of societal concern upon discharge from a neonatal intensive care unit.

There is some plausibility to the view that government involvement in medical decisionmaking creates a reciprocal obligation of government to provide care for those who survive. Such a view, however, does not present a sound basis for grounding the obligations of either government or the community as a whole to provide for the welfare of children—for those with disabilities or those who have other needs.

"Baby Doe" survivors are not the only children whose lives are extended as a result of a societal commitment to attempt to rescue those who might benefit from aggressive medical care. Many children who are not born with disabilities or diseases, but who suffer injuries or acquire diseases later on in life, are also the beneficiaries of a community ethos and medical ethic that favors actions that are intended to preserve life despite the possibility of failure or untoward outcomes.

Policies favoring treatment are not all that different from those that have been applied to other infants and young children who are not capable of giving informed consent for interventions that health care professionals believe to be in their best interest. We see no reason for drawing a morally relevant distinction between one set of children whose medical needs arise as a result of decisions to intervene at birth, even if motivated by law or regulation, and other children whose needs arise as a consequence of a different set of etiological and historical circumstances.

This position is both politically and morally sound. To accord special treatment to one group of children with disabilities as against others with equal needs solely on the grounds of etiology would violate a basic moral maxim that persons with equal needs ought to be treated equally.

What binds these children together as a moral category is the commonality of their vulnerability and the obviousness of their need for assistance. While their histories may and do differ, we believe that children with disabilities or chronic illnesses have far more in common from the moral point of view in terms of rights and claims for a just share of community resources than they have morally significant differences. The real questions are how to determine what interventions, medical or social, are actually in the best interests of children with disabilities or chronic illnesses and what obligations does the community have to assure that those interventions are provided?

A central moral question at the national level is whether we have created a social policy that is adequate for meeting the medical, economic, and social needs of children with disabilities or chronic illnesses whatever the reason for their survival. It is the consensus of our research group that our country must do more to meet its obligations to these children.

American social policy is simply not meeting the needs of its most vulnerable citizens—children with disabilities and chronic illnesses and their families. As acute care medical technology and expertise grows, the number of children with disabilities and chronic illnesses and the number of families who will care for them will continue to grow. We believe that the ethical case for according a far greater priority to meeting the basic medical, economic, and social needs of these children and their families is self-evident. Society has a specific moral duty to address the needs of children who cannot realize their full potential in society without the assistance of others.

Section 7: Conclusion

The work of The Hastings Center Newborns Project has been to open a new conversation rather than to close off prior discussion. Our exchange of ideas and opinions led not to uniformity or unanimity but to judgments based on certain features of an at least partially shared moral framework. We have endeavored to articulate the grounds of our conclusions and to suggest directions for future investigations. We present the following summary as a product of this distillation:

- It is clear that parents, health care providers, courts, and governmental officials have legal and ethical responsibilities toward children with disabilities. Congenital anomalies such as Down syndrome, uncomplicated instances of spina bifida, blindness, or other mildly to moderately disabling conditions provide no moral basis for either withdrawing or withholding treatments. Disabilities, in and of themselves, do not provide a basis for failing to accord children born with them the same access to medical and social services that would be given to any other child afflicted with a problem requiring medical intervention.
- Recent debates about the morality of the treatment of imperiled newborns have narrowly focussed on dilemmas raised by children born with significant congenital anomalies. The questions surrounding premature newborns or those born with injuries as a result of the birth process need much greater attention: How should physicians and nurses cope with uncertain prognoses for extremely premature infants in the neonatal intensive care unit? How ought research and innovative interventions to be distinguished from efficacious therapies in dealing with a child who has suffered asphyxia or a traumatic injury? What ethical norms ought to guide the continuation of treatment efforts once they have been initiated in an intensive care unit?
- There has been a great deal of discussion and debate about the need to assure that no infant is the victim of discrimination, abuse, or neglect at birth. There has not been a corresponding discussion of the moral responsibility that families and the community have to assure that infants with

special needs, whether present at birth or not, do not become the victims of discrimination, abuse, or neglect by the community. The focus of moral discussion must reflect issues of treatment and care that extend beyond the boundaries of the neonatal intensive care unit.

- Discussion must begin to focus on the treatment decisions that confront professionals and parents after the newborn period. Decisions may be more painful after there has been time to form powerful emotional bonds with a child, either in the hospital or in the home, but if it becomes clear that further treatments may prove futile or terribly burdensome, then painful decisions must be confronted. To make decisions earlier in life in order to decrease the emotional burden is to sacrifice the interests of the infant to the emotional needs of others.
- A moral framework acknowledging the centrality of quality of life considerations as reflected in a concern for protecting the best interests of children is appropriate for guiding decisionmaking for children with severe disorders and diseases that prove unresponsive to medical interventions. The President's Commission for the Study of Ethical Problems in Medicine advocated a "best interest" standard that focuses exclusively on the interests of imperiled children, not the interests of their families or of the community as a whole. This is the most appropriate moral norm to utilize when attempting to decide whether treatment ought to be withdrawn or withheld. In special circumstances, the "best interest" standard is inapplicable and a "relational potential" standard may be substituted.

Federal and state laws and regulations incorporate a sanctity of life or "vitalistic" standard for guiding decisions where newborns are concerned. However, recent court decisions in many states acknowledge the appropriateness of a "best interest" standard for the same set of treatment decisions for adults. We can find no legitimate reason for supporting such an asymmetry and believe that the interests of children with chronic diseases and disabilities would best be served by reconciling any such differences in existing laws and regulations.

- Despite the claims of some commentators to the contrary, active killing conflicts with standards protecting the best interests of children. In addition, arguments for active euthanasia frequently turn upon considerations of the interests and welfare of society, factors that are simply not appropriate as variables to guide the decisions of medical professionals or family members. Moreover, the possibilities for error and abuse inherent in the legalization of active euthanasia, when combined with the onus placed upon health professionals to violate their existing professional moral strictures against any involvement with procedures that actively hasten death, make the enactment of any public policy that would countenance the active killing of either children or adults morally repugnant.
- Most decisions concerning treatment for children are best handled by informed, open, and frank discussions among health care professionals and the families of children with medical needs. A newly evolving procedural mechanism, infant ethics committees, has been created in many institutions to help enhance the possibilities for communication at times of great emotional crisis. These committees ought to be available to and utilized by both health care professionals and families.

Mandatory prospective review by ethics committees should not generally be necessary in making decisions about the course of treatment that any patient, child or adult, might receive. However, routine retrospective review of decisions to withhold or withdraw care is highly desirable for both the education of health care providers regarding their responsibilities and options and in order to maintain public confidence that close scrutiny is given to each and every decision to withdraw or forgo care.

- Much greater attention needs to be given to educating the health professions and the public about the kinds of medical problems and disorders that can occur at birth or during infancy. Government agencies, schools, professional societies in health care, and religious organizations must endeavor to do a better job than is presently being done to communicate clearly with the general public about the possibilities and problems that are associated with disability and disease in infancy. Greater efforts must be mounted to educate those of childbearing age about the risks imposed by unhealthy behaviors upon the developing fetus. Open and frank discussion should be encouraged among pregnant women and their physicians concerning the possibility of congenital disorders or chronic diseases and the options available for detecting them *in utero* and for coping with them should they be present in a newborn.

Finally, we believe that society is not presently fulfilling its clear obligation to assist infants and children with disabilities. The moral duty to provide such assistance rests upon the twin foundations of the presence of clear and self-evident need on the part of many children and their families and the obligation society has to insure that all citizens have an equal opportunity to fulfill their abilities and potentials. The moral claims of children with medical needs, of whatever etiology, should receive the highest priority among competing claims for social resources.

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O. DESCRIPTIONS AND ILLUSTRATIONS OF ALTERNATIVE CARE PROGRAMS AND FACILITIES

- O Descriptions of Two Facilities That Provide Day Health Care for Technology Dependent Children (Prescribed Pediatric Extended Care Center and Children's Respite Care, Inc.)
- O "Alternative Settings Of Care" (Foster and Adoptive Care, Community Group Homes, Institutional Settings) (Appendix D from the OTA Report on Children)

ABSTRACT Date 3/12/87

Project Title: Prescribed Pediatric Extended Care (PPEC) Center
Organization Name: Family Health and Habilitative Services, Inc.
Address: 5700 SW 34th Street, Suite 323
Gainesville, Florida 32608

Project Director: Patricia M. Pierce, Ph.D. Phone (904) 377-3447

Project Period 11 / 01 / 84 To 09/ 30 / 88
Mo. Day Yr. Mo. Day Yr.

PROJECT GOALS AND OBJECTIVES:

The primary goals of the project were to: 1) design and implement a model community-based, cost-effective, day health care facility for medically and technologically dependent children; and 2) to develop model standards for community-based day health care services serving medically and technologically dependent children.

MAJOR ACCOMPLISHMENTS TO DATE:

In collaboration with the Department of Pediatrics, University of South Florida, Family Health and Habilitative Services has opened the model PPEC Center in Tampa, Florida. Beginning full operations in June, 1986, the PPEC has served 12 medically dependent children, and has an average census of 7. Services provided include medical day care, parent training and developmental programming. Model standards for community-based day health care services have also been developed; these standards have also been incorporated into proposed legislation to establish a licensure category for community-based day health care facilities for medically dependent chidlren in Florida.

RELEVANCE TO WORKSHOP PRIORITY AREA(S):

PPEC is an innovative service delivery model, which incorporated a family-centered, community-based approach, and provides a cost effective alternative to hospital-based care or home-based private duty nursing services. Case management, the coordination and integration of services, is a major component of the program. Another emphasis of the program is training parents to play an active role in the care and of their child, and in the development and implementation of the comprehensive plan of care.

PRODUCTS (MANUALS/STANDARDS/SIGNIFICANT REPORTS):

Model standards for community-based health care of medically and techology dependent children.

Model legislation for the licensure of community-based, day health care facilities serving medically and technologically dependent children.

ABSTRACT

Date 4/9/87

Organization Name: Children's Respite Care, Inc.
Address: P.O. Box 421120
Sacramento, Calif. 95842-1120
Ann Silvernail Community Liaison
Contact Person: Caroly Altrock Project Dir Phone (916) 344-6735
(916) 771-0730

PROGRAM GOALS AND OBJECTIVES:

SEE ATTACHMENT A

MAJOR ACCOMPLISHMENTS TO DATE: Children's Respite Care, Inc. provides
daycare on a regular or a respite basis and 24-hour care on an intermittent bas
to meet the needs of children with chronic or terminal illness. Until the oper
of this project in December, 1985, there were no formal childcare services avai
t these families. A full range of services are offered including quality chil
r sing and social work support. An on-going parent group has been establishec
inservice material has been developed. A community educational service has bee
provided. Liaison with hospitals, physicians, agencys and schools has been mac
A pre-school program for the younger children has been developed. Individualiz
multidisciplinary plans have been developed. Integration of the educational sc
and medical needs of these children has been accomplished.

RELEVANCE TO CONFERENCE PRIORITY AREA: C.R.C.Inc. was authorizes to
a demonstration project for chronically and terminally ill children pursuant tc
Assembly Bill 3005 (Tucker), Chapter 1473, Statutes 1984. This legislation was
direct result of a grassroots community effort, which involved concerned parent
and professionals. Upon receiving an inquire for child care, the parent is inv
to visit the center with or without the child. They are given a full tour of
center, if after viewing the center the family remains interested, the parent
given a packet of forms to take to their physician. When these forms are comp
an appointment is made with the parent(s) and the Nursing Supervisior. A Nurs
Assessment is made and if the child falls within the scope of our program, a Chi
Care Assessment is also completed. Slots available for care are reviewed alon

(Continued on back)

PRODUCTS (MANUALS/STANDARDS/SIGNIFICANT REPORTS):

Policies and Procedures

Parent Handbook

Phone (916) 344-6735 Attachment [illegible]

PURPOSE

- To provide day care and relief for families responsible for the daily care of children with chronic and terminal illnesses.
- To provide these children with opportunities for growth and development similar to their healthy counterparts.

OVERALL OBJECTIVES

To promote, develop and operate a continuum of child care and respite services for children with chronic or terminal illnesses.

BACKGROUND

The long-term care of chronically ill children is a major health problem. The numbers of these children is increasing as medical and technological advances enable physicians to save more critically ill infants, control the progression of life-threatening illnesses, and treat defects. Chronic illness drains the child and every family member for an indefinite period of time. Without day care and respite care, parents of these children become over stressed, while the children have no opportunity for socialization or educational development.

SERVICES PROVIDED

- Full or part-time child care: day, evening (Friday and Saturday) and weekend care. Pre-school program, meals and snacks.
- Pre-enrollment screening to determine special care needs for each child, including diet, rest, medication, medical interventions and activity level.
- Individualized care plans to fit abilities and interests of the child.
- Coordination of care with the child's primary physician/providers.

EXPECTED OUTCOMES

- Relief from stress for individuals primarily responsible for the care of chronically ill children.
- Increased opportunities for parents to work or return to school.
- Reduction of the number of families dependent on welfare funds.
- Reduction in hospital admissions and lengths of stay.
- Reduced costs for long-term hospital care.
- Establishment of an ongoing, permanent support system for families with chronically ill children.
- Increased opportunity for optimum physical, mental and social development of the chronically ill child.

FOR FURTHER INFORMATION

Contact Carolyn Altrock, M.S.W., Project Director
P.O. Box 421120, Sacramento, California 95842-1120
Phone (916) 344-6735

from OTA Report: "Technology-Dependent Children: Hos
v. Home Care: A Technical Memorandum"

Appendix D

Alternative Settings of Care

Introduction

Most of the public discussion surrounding technology-dependent children, and most of the evidence discussed in this technical memorandum contrasts two settings of care for these children: hospital care, usually in an acute-care[1] hospital; and home care with the children's natural families. Within acute-care hospitals, technology-dependent children have access to the full spectrum of medical services and equipment, monitoring, intensive nursing, professional backup, and emergency services that can be mobilized immediately. The children typically reside in intensive care units or specialty wards (e.g., burn units), but they may reside in general nursing wards (for children not requiring mechanical ventilation) or, sometimes, "step-down" transitional care wards.

In contrast to acute-level hospital care, home care offers an environment most nearly like those in which non-technology-dependent children grow up. From the perspective of third-party payers of health care, traditional home care offers the financial advantage of basic living expenses that are borne by families. Many technology-dependent children currently living at home have highly trained and motivated parents and other caregivers, whose time attending the child is also free to the payer. At home, unlike in an institution, the needed quantity of some services—e.g., the number of paid nursing hours or the amount of respite care—depend as much on the social, psychological, and financial characteristics of the family as on the physical condition of the child.

As more payers finance and perhaps even emphasize nonhospital care, other settings of care may also become important for technology-dependent children. These alternative settings of care may serve three possible purposes:

1. *Transitional care* for children who are moving from hospital to home or other long-term care. Transitional care is appropriate after the child has become medically stable, while the home (or other setting) is being prepared for the child and the myriad of financial and administrative details are being completed. It usually includes an emphasis on training the family and gradually increasing the care the family provides. Transitional care can be provided in a special hospital unit or in a separate rehabilitative or subacute care facility.
2. *Respite care* for technology-dependent children who are living at home. Institutional or foster home respite care may be an important option in situations where qualified professional nurses are not available for home respite care, or where a family vacation or emergency might make the home an inappropriate setting of care for a short period of time.
3. *Long-term care* for children whose parents are unwilling to have them home, negligent, abusive, or simply unable to cope with them. Extensive supportive home services and counseling may help parents cope with having a technology-dependent child at home. Even so, there will be a small group of children for whom care settings other than a natural home must be explored as a long-term option.

A Michigan task force on home care guidelines for ventilator-dependent children summarized the need for these three types of options as follows:

> As the child's condition stabilizes, there should be progression from the intensive care setting to one of habilitation/rehabilitation and eventually to a home-like environment. If the home is not a short or long term option for care, alternative, home-like situations such as foster homes and small group homes must be explored. Such institutional alternatives must always remain an option to avoid crisis when home care ceases to be feasible or is not longer the best option for the responaut [ventilator-dependent child], family, community and fiscal agencies (114)

Foster and Adoptive Care

For technology-dependent children who cannot return to their natural family home (temporarily or long-term), a foster or adoptive home may become the setting of choice. If home care services and financing become more accessible to children whose families are able and willing to accept them and help care for them, children needing foster or adoptive homes are likely to become a growing proportion of the residual institutionalized population.

Foster home need is likely to be greater among this population than the child population in general, because in addition to the need to find homes for children with incompetent or abusive parents, there is a need to find homes for technology-dependent children whose parents simply cannot accept their extensive disabilities. Furthermore, technology-dependent children are considered to be harder to place in foster homes than other children. A concerted drive to serve all

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[1] "Acute-care hospital" as used here means a hospital that provides complex medical care to patients and has an average length of patient stay of less than 30 days.

technology-dependent children at home would soon run up against a shortage of available foster homes.

A lack of foster and adoptive homes may become an equal or greater barrier to home care than a lack of sufficient home medical care benefits. The total number of foster care homes in the United States dropped from 594,000 in 1977 to 187,680 in 1984, attributed in part to greater efforts to keep children with their natural parents (the number of foster children has dropped from roughly 500,000 in the late 1970s to roughly 250,000 in 1984) but also to a greater drop in families willing to take in foster children (77,90).

The Federal Government provides matching subsidies with the States to families who adopt children with special needs, as well as to those families who provide them with foster homes (Public Law 96-272). Children in both categories for whom Federal subsidies are provided are automatically eligible for Medicaid. Ironically, those same children may *not* be eligible for Medicaid if they remain with their natural families.

Community Group Homes[2]

The group home provides a community-based option, midway between institutionalization and a family home, that could be attractive for some technology-dependent children if it were available. Group homes for adults who are ventilator-dependent due to polio have existed in England and France for a number of years (67), and a few similar group homes have recently opened in California (115), though apparently none are accepting young children at present. Louisiana is considering the establishment of a group home that could accommodate ventilator-dependent children as well as other developmentally disabled children (97).

For some children, the costs of group home care might actually be lower than either hospital or family home care because a single trained nurse might be able to care for more than one technology-dependent child. However, OTA knows of no present examples of group homes that accept, or were designed for, technology-dependent children. The relative rarity of such children in the population suggests that group homes organized for this purpose would probably be practical solutions only in densely populated areas.

Institutional Settings of Care

With appropriate enhancement of facilities and staff, a multitude of subacute institutional settings could be appropriate for many technology-dependent children who cannot, for whatever reason, be placed in home care. None of these are likely to be appropriate for all such children, nor are they likely to be preferred over hospital care (e.g., in a special long-term care unit) in all cases. But they may well be appropriate options for a proportion of the population. Unfortunately, even when they might be appropriate, they are likely to be unavailable.

Hospital Settings

Some acute-care hospitals have "step-down" units with the capacity for intensive care but an emphasis on transition to a less intensive setting. A few hospitals have experimented with special wards in which the parent cares for the child during part or all of the day (51,119).

A fairly recent phenomenon is the development of special pediatric respiratory centers, focused specifically on the long-term care needs of medically stable, ventilator-dependent children. Such centers may be in acute-care tertiary hospitals, or in chronic care and rehabilitation hospitals. In both cases, the centers have generally been developed as "step-down" units that serve the needs of ventilator-dependent children (and their families) in the transition to long-term community-based care. However, in practice many children live on such wards indefinitely.

Children's Hospital of Philadelphia has one of the best-known pediatric respiratory units in an acute-care hospital. Similar units exist at a few other acute and long-term care hospitals, though not all are exclusively pediatric.[3] Ranchos Los Amigos Hospital, for example, a rehabilitation hospital that serves some children as well as adults, first established a special respiratory unit in 1952 to better serve its long-term polio patients on respirators (2). Other pediatric respiratory units and intensive care units in extended-care hospitals exist (e.g., in Chicago, IL; Pittsburgh, PA; Washington, DC; and Baltimore, MD) or are being contemplated, but they are still rare.

Skilled Nursing and Intermediate Care Facilities

Skilled nursing facilities (SNFs) are an important source of care for many elderly, chronically ill people, but they do not generally have sufficient staff to provide intensive nursing services and usually do not

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[2] Many group homes are apparently regulated as foster homes.

[3] The distinction between rehabilitation, chronic care, and other types of long-term care hospitals is largely one of self-definition, associated with how a hospital sees its mission. It is not clear that rehabilitation hospitals are more likely than chronic care hospitals (or vice versa) to establish respiratory units.

provide an environment conducive to pediatric care and child development. The children most likely to be found in SNFs, where they are accepted at all, are those who are comatose or have low mobility but few constant skilled medical needs—perhaps daily medications or, at most, the need for multiple daily tube feedings (97). Intermediate care facilities (ICFs) are more likely to care for children, but they are even less likely to be able to provide intensive medical care than SNFs.

SNFs do sometimes accept technology-dependent adults. For instance, a 1985 survey of ventilator-dependent patients in long-term care facilities in Pennsylvania documented 55 such patients in 4 nursing homes and 1 skilled/intermediate care facility, all of whom were adults (94). Likewise, a few SNFs in California accept ventilator-dependent patients, but none are known to accept such patients under age 16 (115).

At least two SNFs in the United States (one in New Jersey and one in Ohio) are equipped to serve children exclusively and can provide the complex care needed by technology-dependent children (139). In many ways, these SNFs are more similar to pediatric long-term care hospitals than they are to geriatric SNFs. For example, the pediatric SNF in New Jersey is staffed to provide 6.5 nursing hours per patient per day, almost three times the nursing intensity provided in geriatric SNFs in that State (139).

A trend towards making SNFs a more common site of care for ventilator-dependent individuals and other individuals (not necessarily children) needing post-acute complex care seems to be taking place. Three States have recently proposed or established regulations for "super-SNF" subacute care, and at least 13 others have instituted some reforms that can allow for extra payments to nursing homes for complex care patients (88). California, for example, has proposed regulations that will enable its Medicaid program to pay for care in specially certified SNF units that have a higher level of nursing intensity and skill than normal SNF care (30). These subacute units will receive a higher per diem rate than the usual SNF rate. A description of California's subacute care regulations is presented in box E.

ICFs are less oriented toward complex medical care than SNFs, and they are thus even less likely to accept technology-dependent patients or to be able to provide them with comprehensive care. ICFs are typically institutions in which most residents require relatively little skilled nursing but considerable custodial care (e.g., dressing, feeding, bathing, or just frequent attention). Homes for the mentally retarded are probably the most familiar form of ICFs. There may be a few technology-dependent children who are alert but need a highly protected environment and for whom an ICF with enhanced services and staff might be an appropriate setting.

P. EDUCATIONAL SERVICES FOR TECHNOLOGY DEPENDENT CHILDREN

O "The Educational System As A Source of Health Care Services And Funding" (Appendix E of the OTA Report on Children)

O Excerpt from "'Medically Fragile' Handicapped Children: A Policy Research Paper"

Appendix E

The Educational System as a Source of Health Care Services and Funding

Introduction

An important aspect of the cost of care for technology-dependent children in the home setting is that substantial portions of this cost may be borne by public schools. Public schools are mandated by Federal law to provide educational and necessary related supportive services to handicapped children (Public Law 94-142). Schools, through special education programs, regularly provide medical services such as physical and speech therapy, medication administration, and even urinary catheterization to children (179). Since school attendance may account for more than one-fourth of a child's time and care needs, one consequence for technology-dependent children of this Federal mandate is to shift substantial portions of the cost of a child's medical care services from Federal to State and local governments (i.e., from Medicaid to public schools), and from private health insurers to the public.

The issue of who will pay for the medical care of these children in the schools is a growing one. Public schools, pressed for funds, may often be reluctant to pay for additional full-time nurses and special transportation vehicles and to assume legal liability for medical care during school hours. At the same time, private insurers—and Medicaid—will seek to minimize their costs of serving technology-dependent children at home by shifting financial responsibility to the schools. School districts may respond by serving most of these children with occasional home visits in order to avoid the extraordinary nursing costs and potential lawsuits. Clear Federal and State policies on this issue could greatly aid in minimizing total costs, encouraging education in the environment most appropriate to the individual child, allocating public dollars appropriately (e.g., to Medicaid or to public school assistance), and preventing the emotional and financial stress of legal battles.

Local Options for Complex Medical Care in Schools

The issue of complex medical care for children attending public schools can be summarized in three questions:

1. Where is this care provided?
2. If it is provided in the school, who provides it?
3. If it is provided in the school, who pays for it?

For some children, such as those with frequent and uncontrollable seizures, home education may be the only feasible choice. In these cases, school districts may provide an individual teacher for a few hours a week in the child's own home. In such cases, the child's nursing needs are usually met by the normal home caregiver (a parent or home nurse), and reimbursement for that care is indistinguishable from reimbursement for the child's usual home care. The school system pays for the teacher's time and transportation.

Many technology-dependent children receive their education in special classes or schools. In some of these schools, nursing care is provided by full-time professional nurses. In others, the teachers themselves, or a classroom aide, may be trained to provide these services. In either case, the school system generally pays for the medical care, since the nurses or teachers are providing care to a number of children.

The third setting of care and education for a technology-dependent child is in a normal classroom. This setting is particularly appropriate for a child who is intellectually normal and has no mental or emotional constraints to maintaining a normal class schedule. However, the dilemmas regarding who shall provide, and pay for, the nursing care needed by a technology-dependent child are particularly acute in this setting.

Three options exist for providing nursing care in a normal school classroom. First, care may be provided by a school nurse. In most schools, a nurse provides services to all children, and the nurse may even serve more than one school. The school district is responsible for the salary of the nurse and any other costs associated with nursing services. Technology-dependent children, however, are characterized by their need for the uninterrupted availability of nursing services. For a school to provide such services, the school district must hire an additional full-time nurse or aide for each technology-dependent child in the district, as well as the regular nurse. Under this option, the insurer avoids all nursing costs during school hours.

A second option for providing care in a normal classroom is through a home nurse, whose salary and expenses are covered through Medicaid or another third-party payer, who accompanies the child while at school. Although the effect of this option is the same as the first—a full-time nurse for every technology-dependent child—it is clearly less desirable to the third-party payer, which must now pay the costs, and more desirable to the school district, which need not. If Medicaid is paying for home care, the nurse would be paid for through public funds in any case, but the source of the funds is administratively distinct.

A third option is to train teachers and other regular school personnel to provide the necessary nursing care. Louisiana, for example, has chosen to train bus drivers, teachers, school nurses, and principals to perform both routine and emergency procedures that might be needed by ventilator-dependent children (97). In this case the costs incurred are training costs, which may be paid by the district, the health insurer, or some other source, and possibly the costs of a smaller student-to-teacher ratio in the classes that include these children so that the teachers are not overburdened.

There are few Federal or State legal or administrative guidelines regarding who should pay for these nursing services in the schools, or how they should be provided. A survey of education and public health departments in all 50 States (but not the District of Columbia) regarding the provision of a specified list of nursing practices[1] found that 13 States (26 percent) had no written State guidelines regarding the provision of any of these services in the schools (184). An additional 13 States had guidelines only for medication administration. Only six States (12 percent) had guidelines covering all listed procedures. The remaining 18 States (36 percent) had written guidelines covering some, but not all, of the specified procedures. The lack of comprehensive guidelines in most States may reflect the fact that serving medically complex students is an issue that is usually addressed on the local rather than the State level (184).

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[1] The nursing practices included in the survey were catheterization, seizure management, medication administration, respiratory care, tube feeding, positioning, colostomy/ileostomy care, and other (including allergy shots).

"MEDICALLY FRAGILE" HANDICAPPED CHILDREN
A POLICY RESEARCH PAPER

Great Lakes Area
Regional Resource Center

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EXECUTIVE SUMMARY

The Great Lakes Regional Resource Center, upon request from the State Educational Agencies that it serves, researched and studied the major policy issues regarding special education for "medically fragile" handicapped children. The result is the identification of criteria for educational decision making related to the following policy and procedural issues: (1) determining eligibility for special education, (2) determining eligibility for related services, (3) determining the extent of responsibility for providing a free appropriate public education, (4) determining the extent of responsibility for providing related services, and (5) determining the extent of responsibility for providing placement in the least restrictive environment.

The following criteria has been identified through issues presented by SEA work group members and decisions reported in the Education for the Handicapped Law Report.

Determining eligibility for special education

Criteria No.1: Child must be evaluated and must meet the criteria for one or more handicapping category, most likely, "other health impaired".

Criteria No.2: Child's handicap must "adversely affect educational performance" so as to necessitate special education. Handicap must interfere with the child's ability to function and learn in the regular education setting and classes. "Adversely affects educational performance" must be interpreted as including the child's everyday functioning in school, even though the child has no intellectual impairments.

Criteria No.3: Eligibility for special education must be based upon special education need and not upon whether benefit is derived from special education.

Criteria No.4: Child must be capable of sufficient independent life support and cognitive ability in order to need or benefit from special education.

Determining eligibility for related services

Criteria No.1: To be eligible for related services, the handicapped child must be eligible for special education.

Criteria No.2: To be eligible for related services, the services must be "necessary to assist the handicapped child to benefit from special education" as determined by the child's current evaluation and IEP.

Criteria No.3: "Necessary to benefit from special education" must be interpreted as including the child's everyday functioning in school, even though the child has no intellectual impairments.

Determining the extent of responsibility for providing a free appropriate public education

Criteria No.1: Schools are only required to provide handicapped children with a reasonable opportunity to learn, not the best education or maximum benefit possible.

Criteria No.2: To the maximum extent appropriate, handicapped children should be educated with nonhandicapped children. However, the requirement to educate handicapped children in the least restrictive environment is not more important than providing an appropriate education. Placement in the least restrictive environment must be balanced with providing an appropriate education.

Criteria No.3: Handicapped children must be provided the same basic opportunities for a meaningful education as nonhandicapped children.

Criteria No.4: Handicapped children are entitled to an individualized education program with sufficient support services developed around their specific educational needs. The individual education program must be developed by a team of educators, parents and other professionals who are knowledgeable about the child, the meaning of the evaluation data, and the placement options.

Criteria No.5: An appropriate education should include an extended school day or school year if a handicapped child is to benefit from special education and related services.

Determining the extent of responsibility for providing related services

Criteria No.1: Medical services when provided by a licensed physician need only be provided for diagnostic and evaluative purposes within the meaning of PL94-142.

Criteria No.2: A medical service can be a related service, not subject to the medical exclusion of PL94-142, when such services can lawfully be provided by someone other than a physician.

Criteria No.3: The medical service must be of a kind in which the required service personnel, as defined in PL94-142, can reasonably be expected to provide the service. Highly specialized training or knowledge must not be needed to provide the service.

Criteria No.4: The service enables the child to remain at school during the day without jeopardizing the health and safety of the child, and allows access to an appropriate education.

Criteria No.5: Occupational and physical therapy are related services, not subject to the medical service exclusion of PL94-142, and must be provided when they are necessary to assist a handicapped child to benefit from special education.

Criteria No.6: Transportation must include additional assistance, if necessary, besides travel to and from school, i.e., bus aide to provide assistance, assistance with wheel chair or walker to gain access to school building, and specialized equipment if required to provide special transportation.

Determining the extent of responsibility for providing placement in the least restrictive environment

Criteria No.1: The requirement to educate handicapped children in the least restrictive environment does not supercede the need for providing an appropriate education.

Criteria No.2: To the maximum extent appropriate, handicapped children must be educated with children who are not handicapped.

Criteria No.3: Special classes, separate schooling or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with use of supplementary aids and services cannot be achieved satisfactorily.

Criteria No.4: The placement of handicapped children is based upon a completed IEP. Handicapped children should be educated in regular classes until lack of progress under the IEP proves such placement to be inappropriate.

Criteria No.5: IEP development, review and revision, annual review of placement, and reevaluations are conducted or supervised by personnel responsible for the provision of FAPE to each child served by the public agency.

Criteria No.6: Placement is determined at least annually.

Criteria No.7: The placement decision is made by a group of persons knowledgeable about the child, the meaning of the evaluation data, and the placement options.

Criteria No.8: A continuum of alternative placements is available to each public agency to implement the IEP of each handicapped child.

Criteria No.9: Children must be placed on the basis of individual needs and not as a result of the category of handicapping condition or configuration of the service delivery system.

Criteria No.10: Placement is not made on the basis of availability of related services.

Criteria No.11: Each handicapped child attends the school which would be attended if the child were not handicapped unless attendance at another school is specifically required to implement the IEP.

"Medically Fragile" Handicapped Children
A Policy Research Paper

Introduction

This research paper was initiated as a result of a needs assessment conducted by the Great Lakes Area Regional Resource Center on behalf of the State Educational Agencies that it serves. Educators have recognized that there is a need for the development of policies and procedures for educational decision making regarding the delivery of special education and related services in the least restrictive environment for medically fragile handicapped children. Medically fragile, most likely, meets the criteria of the handicapping category "other health impaired" and is subject to the policies and procedures that apply to this category.

The Education of the Handicapped Act (PL94-142) and Section 504 of the Rehabilitation Act provide the basic legislation for the education of handicapped children. By law, handicapped children have access to a free appropriate public education consisting of special education and related services delivered in the least restrictive environment. However, much controversy exists regarding the implementation of these laws with regard to medically fragile handicapped children. A complex set of policy issues relate to the delivery of special education and related services in the least restrictive environment. Educators, parents, health-care providers, and other professionals are concerned about the identification and evaluation of these children, their safety, liability of service providers, funding of programs and services, and other controversial issues.

The content of this paper examines the major policy issues that affect educational decision making for medically fragile handicapped children. The paper is comprised of two major sections. The first section defines the term medically fragile and examines the major policy issues and criteria for educational decision making relevant to those issues. The second section is an appendix compiled from the Education for the Handicapped Law Report listing Court decisions, SEA decisions, OCR rulings, and EHA opinions that are related to the policy issues and criteria for decision making.

Medically Fragile Defined

The term medically fragile has a meaning similar to a chronic or acute illness, physical disability or other health impairment that can be extremely disabling or life-threatening. It is distinguished from other health impairments because of the acuteness and severity of the problems that usually require prolonged or intermittent hospitalization, institutionalization, or homebound placement. Medically fragile children are medical-technology assisted children who are dependent on life-support equipment. The uniqueness and severity of each child's handicap requires that they be educated on a case-by-case basis. Frequent absences from school for medical treatment and therapy necessitates individualized educational instruction with related services either in the classroom, hospital, institution, or at home.

Some types of complex medical problems which this definition would include are: ventilator dependent, tracheostomy dependent, oxygen dependent, B.P.D., bronchial or tracheal malacia, nutritional problems requiring hyperalimentation or gasterostomy tube dependency, congestive heart problems, post-trauma children requiring long-term, high-tech care, apnea monitored children, and kidney dialysis.

The term is not specifically described as a handicapping condition, as defined in PL94-142 or Section 504, but in most cases it is included under the handicapping category of "other health impaired". Other handicapping categories might include "multihandicapped" or "orthopedically impaired". As defined in PL94-142, "other health impaired" means (a) having an autistic condition which is manifested by severe communication and other developmental and educational problems: or (b) having limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes, which adversely affects a child's educational performance.

Determining Criteria for Educational Decision Making

Both PL94-142 and Section 504 are compliance and regulatory laws. OCR and the Courts have consistently applied a broader focus regarding the interpretation of the definitions and regulations of PL94-142 and Section 504 than has SEP and SEAs. The interpretations of the Courts are based upon the determination that "the unseverability of medical and educational needs for certain services is the very basis for holding that the services are an essential prerequisite for learning. Schools are required to provide a comprehensive range of services to accomodate a handicapped child's educational needs" (U.S. App. Ct., DE, Kruelle, 1981 p.552:350). The interpretations of OCR are based upon the determination that "there is a legal duty to provide medical, emotional or psychiatric services where appropriate" (OCR 1980 p.257:82). By definition, a medically fragile child may be considered handicapped and require special education and related services under Section 504, yet may not be considered handicapped under PL94-142.

The controversy behind the law and its regulations centers upon how far schools are required to go in meeting the educational and daily life needs of handicapped children. In general, where the life need of a handicapped child has a direct bearing on the ability of the child to receive an appropriate education, it is likely that special education and related services will be required to meet those needs.

SEP and SEAs oppose a broad interpretation of the law and its regulations based upon the following arguements:

1. SEAs and LEAs would assume additional fiscal responsibilities, and the benefit of some services is questioned in relation to their cost.

2. Other state agencies may use the regulations to indicate that they no longer have financial responsibility for various services.

3. Private insurance companies may refuse benefits to parents for their child's service costs on the premise that the SEA/LEA must provide those services at no cost to the parents.

4. SEAs and LEAs would assume increased responsibilities for coordinating and

providing not only educational services, but social, psychological and health services as well.

OCR and the Courts support a broader interpretation of the law and its regulations based upon the following arguements:

1. It is impossible to separate the medical, social and emotional needs from the educational needs of children. Schools are required to provide a comprehensive range of services to accomodate a handicapped child's educational needs.

2. Cost cannot be allowed to enter into a discussion of regulatory interpretations. If a service fulfills the definition of related services and is required to assist a handicapped child to benefit from special education, then it must be provided at no cost to the parents.

Major Policy Issues and Criteria for Educational Decision Making

Determining eligibility for special education: Under PL94-142, special education means specifically designed instruction, at no cost to parents or guardians, to meet the unique needs of a handicapped child, including classroom instruction, instruction in vocational and physical education, home instruction, and instruction in hospitals and institutions.

In order to be considered handicapped under PL94-142, medically fragile children must meet the criteria for one of the eleven handicapping categories and must also need special education. If it is determined the handicapping condition "adversely affects the child's educational performance", the child is considered to be handicapped, and as such, is eligible for special education. The child whose handicap does not "adversely affect educational performance" does not meet eligibility criteria for special education.

The primary issue regarding eligibility for special education is determining how broadly one can interpret the requirement that the handicapping condition must "adversely affect educational performance". The question that is raised is whether the interpretation of the requirement should be limited to the child's intellectual ability, or should it be extended to include the child's ability to function and participate in school, even though the child has no intellectual impairment. There is not a clear uniform definition to determine the "adversely affects educational performance" criteria which would make a medically fragile child eligible for special education.

The main factor for determining whether a medically fragile child would benefit from special education is the extent to which the illness or disability interferes with daily functioning and learning. Children with severe physical and health impairments most likely need to be placed in special education. However, children with moderate physical and health impairments, who perform well academically, could be placed successfully in regular education settings and classes if the necessary related services were provided. Thus, for many medically fragile children the real issue about eligibility for special education centers on the provision of related services, which is discussed in the next section.

The following criteria provides some guidelines for determining eligibility for special education.

Criteria No.1: Child must be evaluated and must meet the criteria for one or more handicapping category, which in the case of a medically fragile child, would most likely be "other health impaired". (EHA 1984 p.211:343)

Criteria No.2: Child's handicap must adversely affect educational performance so as to necessitate special education. Handicap must interfere with the child's ability to function and learn in regular education settings and classes. (SEA PA 1979 p.501:227)

Criteria No.3: "Adversely affects educational performance" must be interpreted as including the child's everyday functioning in school, even if the child has no intellectual impairments, e.g., ability to safely attend, ability to function and learn in both academic and nonacademic school activities, and to prevent regression of academic performance even though the child performs well academically. (SEA CA 1984 p.506:274)

Criteria No.4: Eligibility for special education must be based upon special education need and not upon whether benefit is derived from special education. (SEA WI 1983 p.505:220)

Criteria No.5: Child must be capable of sufficient independent life support and cognitive ability in order to need or benefit from special education. (SEA IL 1984 p.506:239)

The following decisions broadly interpret "adversely affects educational performance", confirming eligibility, even though the child has no intellectual impairments.

(SEA TX 1983 p.505:126) Child is eligible for special education, even though she has no significant intellectual impairment, related services are necessary in order for her to safely attend and participate in school.

(SEA MA 1984 p.505:335) Child is eligible for special education even though he functions at grade level, since he functions with enormous effort and at significant cost mentally, emotionally and physically.

(SEA MA 1984 p.506:353) Child with superior cognitive potential is eligible for special education because without early intervention and related services, physical impairment would interfere with educational progress.

(SEA AK 1984 p.506:101) Child whose intellectual abilities are unimpaired is eligible for special education because without related services child's impairment would restrict her ability to participate in regular school.

Determining eligibility for related services: Under PL94-142, related services means transportation, and such developmental, corrective, and other supportive services as may be required to assist a handicapped child to benefit from special education.

In order for medically fragile handicapped children to be eligible for related services, they must be eligible for special education and the related services must be "necessary to assist the child to benefit from special education". Under PL94-142 there can be no related services without special education. If eligible, the related services must be for educational reasons and not for reasons that are separate from the educational process.

The primary issue regarding eligibility for related services is determining how broadly one can interpret the requirement that related services must be "necessary to assist the child to benefit from special education". There is not a clear uniform definition to determine the "necessary to benefit from special education" criteria which would make a medically fragile handicapped child eligible for related services.

Again, the main factor for determining whether a medically fragile child would benefit from special education is the extent to which the illness or disability interferes with daily functioning and learning. The real problem occurs when a medically fragile child, who has no intellectual impairments, needs only related services to participate in regular classes and not a special education placement.

The following criteria provides some guidelines for determining eligibilty for related services

Criteria No.1: To be eligible for related services, the handicapped child must be eligible for special education. (EHA 1978 p.211:57)

Criteria No.2: To be eligible for related services, the services must be "necessary to assist the handicapped child to benefit from special education" as determined by the child's current evaluation and IEP. In determining what services are necessary for a handicapped child, the individual needs must be determined on a case-by-case basis. (SEA CA 1985 p.507:121)

Criteria No.3: "Necessary to benefit from special education" must be interpreted as including the child's everyday functioning in school, even though the child has no intellectual impairments, e.g., ability to safely attend, ability to function and learn in both academic and nonacademic school activities, and to prevent regression of academic performance even though the child performs well academically. (SEA AK 1984 p.506:101)

The following decisions broadly interpret "necessary to benefit from special education", confirming eligibility, even though child has no intellectual impairments.

(SEA MA 1985 p. 507:101) Student with hemiparesis is special needs student who continues to require monitoring and occupational therapy; despite his success in regular second grade class, evidence suggests he would regress if occupational therapy were terminated.

(SEA MA 1984 p.506:353) Three-year old child with mild cerebral palsy and superior cognitive potential is eligible for special education, because without early intervention and related services, physical impairment would interfere with educational progress.

Determining the extent of responsibility for providing a free appropriate public education: Under PL94-142, a free appropriate public education means special education and related services which (a) have been provided at public expense, under public supervision and direction, and without charge, (b) meet the standards of the state educational agency, (c) include an appropriate preschool, elementary, or secondary school education, and (d) are provided in comformity with the individualized educational program.

Issues regarding an "appropriate education" center around what and how handicapped children should be taught, and to what extent the instruction and services must be provided. Medically fragile handicapped children are entitled to an individualized education program developed around their specific educational needs. Specifically designed instruction, in addition to instruction in traditional academic areas, may include specialized vocational and career preparation, development of adaptive behaviors, adaptive physical education, health management, basic living self-help skills, and other related instruction.

The specialized instructional and service needs of medically fragile handicapped children are often times seen by educators as being outside the responsibilty of schools. It can be difficult separating educational needs from health, emotional, and social needs and which agencies or professionals should provide appropriate instruction, training and services.

To insure access to a free appropriate public education, critical areas of decision making for medically fragile handicapped children center on (a) an individual education program with sufficient support services developed around the child's specific educational needs, (b) hospital, institutional and homebound placement policies, (c) school absence and attendance policies, (d) school health service policies, and (e) extended school day and school year policies.

Because of the varied and complex needs of these children, effective service delivery and continuity of programming requires policy and procedures which address coordination between special education and regular education and coordination between schools, health care providers, and other community agencies and professionals.

The primary issue regarding the extent of responsibility for providing a free appropriate public education is how broadly one can interpret the extent of "appropriate education". The following criteria provides some guidelines for determining the extent of this responsibility.

Criteria No.1: Schools are only required to provide handicapped children with a reasonable opportunity to learn, not the best education or maximum benefit possible. (U.S. Sup. Ct., Rowley, 1982 p.553:656)

Criteria No.2: To the maximum extent appropriate, handicapped children should be educated with nonhandicapped children. However, the requirement to educate handicapped children in the least restrictive environment is not more important than providing an appropriate education. Placement in the least restrictive environment must be balanced with providing an appropriate education. (U.S. App. Ct., Marana, 1984 p.556:101)

Criteria No.3: Handicapped children must be provided the same basic opportunities for a meaningful education as nonhandicapped children. (U.S. Sup. Ct. NE 1983 p.555:124)

Criteria No.4: Handicapped children are entitled to an individualized education program with sufficient support services developed around their specific educational needs. The individual education program must be developed by a team of educators, parents and other professionals who are knowledgeable about the child, the meaning of the evaluation data and the placement options.

Criteria No.5: An appropriate education must include an extended school day or school year if a handicapped child is to benefit from special education and related services, i.e., to prevent regression of academic performance or restriction of educational progress. (SEA IL 1985 p.507:171)

Determining the extent of responsibility for providing related services: Under PL94-142, related services include audiology, counseling services, early identification, medical services (for diagnostic and evaluative purposes only), occupational therapy, parent counseling and training, physical therapy, psychological services, recreation, school health services, social work services, speech pathology and transportation. This list is not exhaustive and may include other supportive services as may be required to assist a handicapped child to benefit from special education.

Medically fragile handicapped children, because of the acuteness and severity of their handicaps, often times require specialized and extensive services to benefit from special education. These special needs create problems for educators because it becomes difficult determining what are educational services vs. noneducational services. Educators have difficulty in determining the extent of their responsibility for providing many of these services, which traditionally, have been considered noneducational in nature.

Questions often asked by educators in determining the extent of their responsibility for providing related services are: (a) What are the types and nature of services to be provided? (b) What is the extent and frequency of services to be provided? (c) What agency is responsible for providing services? (d) Where and under what conditions are the services to be provided? (e) What professionals will provide the services? (f) Do state laws or regulations place any limitations or restrictions on the services? (g) What are the liability issues regarding the delivery of services?

The primary issue regarding the extent of responsibility for providing related services is how broadly one can interpret the extent of "related services". The following criteria provides some guidelines for determining the extent of this responsibility. As a note, these criteria must be viewed in context of the standard established in (U.S. Sup. Ct., Rowley, 1982 p.553:656) that a State is required to provide an "appropriate" education and not necessarily to maximize a handicapped child's potential. They must also be viewed in context with existing State laws in which it would be impermissible for school personnel to administer certain services.

General Criteria:

Criteria No.1: To be entitled to related services, the handicapped child must be eligible for special education.

Criteria No.2: To be entitled to related services, the services must be necessary to assist the handicapped child to benefit from special education as determined by the child's current evaluation and IEP. In determining what services are necessary for a handicapped child, the individual needs must be determined on a case-by-case basis.

Medical and School Health Services:

Criteria No.3: Medical services when provided by a licensed physician need only be provided for diagnostic and evaluative purposes within the meaning of PL94-142. (See EHA 1978).

Criteria No.4: A medical service can be a related service, not subject to the medical exclusion of PL94-142, when such services can lawfully be provided by someone other than a physician. (U.S. Sup. Ct., Tatro, 1984 p.555:511)

Criteria No.5: The medical service must be of a kind in which the required service personnel, as defined in PL94-142, can reasonably be expected to provide the service. Highly specialized training or knowledge must not be needed to provide the service. (SEA IL 1984 p.506:103)

Criteria No.6: The service enables the handicapped child to remain at school during the day without jeopardizing the health and safety of the child, and allows access to an appropriate education. (Tatro 1984)

In (U.S. Sup. Ct., Tatro, 1984 p.555:511) the Court held that since catheterization could be administered by someone other than a physician, the medical service exclusion was inappropriate and that catheterization was a school health service.

In (U.S. DCt. HI 1982 p.553:529) the same was held for reinsertion of a tracheotomy tube.

In (SEA IL 1984 p.506:103) these standards were further extended, citing ventilator monitoring, mucas suctioning, and a temperature controlled environment as school health services. The services were essential to insure tne child's health and safety during the educational process and could be reasonably provided by school health personnel.

In (U.S. App. Ct. DE, Kruelle, 1981 p.552:350) the District Court gave even a broader interpretation of these standards, when ordering a residential placement for a child, held that it was impossible to separate the medical, emotional and social needs from the educational needs of a child.

In (SEA MA 1982 p.503:207) the physician's testimony was the controlling factor in limiting the scope of related services. The student's educational needs had to be met in a home program because of her susceptibility to life-threatening upper respiratory infections, and that a home health aide and nutritional therapy were medical services that were not the responsibility of the school.

In (SEA NY 1985 p.506:378) again the physician's testimony was the controlling factor in limiting the scope of related services. Testimony suggested that the level, skill and frequency of the therapeutic services needed by the child were well in excess of services typically associated with school health services. Suctioning lung and throat, feeding and medication through a jejunal tube, and providing cardio-pulmonary resuscitation required more skill and time than school health personnel could provide. Training as a licensed practical nurse would not be sufficient and that special training in respiratory care and life-saving would be required.

Occupational and Physical Therapy:

Criteria No.7: Occupational and physical therapy are related services, not subject to the medical service exclusion of PL94-142, and must be provided when they are necessary to assist a handicapped child to benefit from special education. "Necessary to benefit from special education" must be interpreted as including a child's everyday functioning in school, even though the child may have no intellectual impairments.

In (SEA AK 1984 p.506:101, SEA MA 1984 p.506:353) it was held that physical and occupational therapy were needed to prevent regression of academic performance or restriction of ability to participate in school activities. These cases support the interpretation of this standard to include a child's everyday functioning in school; although a handicapped child has no intellectual impairment and performs well academically in regular classes, the child may need occupational or physical therapy to prevent regression of academic performance or restriction of ability to participate in school activities.

In (SEA PA 1980 p.502:176) it was held that where physically impaired child had been successfully mainstreamed, physical therapy was not needed and school was not required to maximize the physical potential of the child. Where regression of performance or inability to participate is not evident, occupational or physical therapy are not required.

In (EHA 1979 211:167) it was held that if a State defines physical therapy as special education, such therapy may be provided to a child who receives no special education; however, if State defines physical therapy as a related service, then it may not be provided to a child who receives no special education. Applicable State law is the determining factor.

In (EHA 1980 211:219) it was held that a school district cannot limit its responsibility for the provision of physical therapy to consultation and evaluation; direct or actual treatment must be provided.

Transportation:

Criteria No.8: Transportation must include additional assistance, if necessary, besides travel to and from school, i.e., bus aide to provide assistance on and off the bus, assistance with wheel chair or walker to gain access to school building, and specialized equipment if required to provide special transportation.

Determining and providing placement in the least restrictive environment: Under PL94-142, the term least restrictive environment means (a) that to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, and (b) that special classes, separate schooling or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes, with the use of supplementary aids and services, cannot be achieved satisfactorily.

Because of the acuteness and severity of the handicaps of medically fragile handicapped children, determining and providing placement in the least restrictive environment, in conjunction with the delivery of special education and related services, is a difficult problem for educators. This is especially true in rural areas where there are limited resources, programs and services.

Questions often asked by educators in determining and providing placement in the least restrictive environment are: (a) Does the risk to the child's health justify placement in the least restrictive environment? (b) Does the benefit that the child receives justify the cost of service delivery and placement in the least restrictive environment? (c) Do the rights of other individuals whose health might be adversely affected prevail over the rights of the child to be placed in the least restrictive environment? (d) Is the child necessarily better served and educated in the least restrictive environment ("appropriate" vs. LRE)

Although segregated arrangements are in conflict with PL94-142 and the goal of educating children in the least restrictive environment, the provision of special education and related services for children with complex medical needs frequently occurs in segregated settings rather than in regular schools. The primary issue is the extent that schools are responsible for providing placement in the "least restrictive environment".

The following criteria provides some guidelines for determining the extent of this responsibility. As a note, in developing policies and procedures for determining and providing placement in the least restrictive environment for medically fragile handicapped children, it is recommended that SEAs follow the standards contained in the SEP Compliance Monitoring Manual 10 - Least Restrictive Environment.

Criteria No.1: The requirement to educate handicapped children in the least restrictive environment must be balanced with the requirement to provide an appropriate education. Least restrictive environment does not supercede the need for providing an appropriate education.
(U.S. App. Ct., Marana, 1984 p.556:101)

Criteria No.2: To the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped. If services which make a segregated facility superior can be feasibly provided in a nonsegregated setting, placement in the segregated school would be inappropriate.
(U.S. DCt., Roncker, 1981 p.553:121)

Criteria No.3: Special classes, separate schooling or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular class with use of supplementary aids and services cannot be achieved satisfactorily. It is recognized that some handicapped children must be educated in segregated facilities because either (a) the handicapped child would not benefit from mainstreaming (b) the marginal benefits from mainstreaming are far outweighed by the benefits gained from services which could not feasibly be provided in the nonsegregated setting (c) because the handicapped child is a disruptive force in the nonsegregated setting. (U.S. DCt., Roncker, 1981 p.553:121)

Criteria No.4: The placement of handicapped children is based upon a completed IEP. Handicapped children should be educated in regular classes until lack of progress under the IEP proves such placement to be inappropriate.

Criteria No.5: IEP development, review and revision, annual review of placement, and reevaluations are conducted or supervised by personnel responsible for the provision of FAPE to each child served by the public agency.

Criteria No.6: Placement is determined at least annually.

Criteria No.7: The placement decision is made by a group of persons knowledgeable about the child, the meaning of the evaluation data, and the placement options.

Criteria No.8: A continuum of alternative placements is available to each public agency to implement the IEP of each handicapped child.

Criteria No.9: Children must be placed on the basis of individual needs and not as a result of the category of handicapping condition or configuration of the service delivery system.

Criteria No.10: Placement is not made on the basis of availability of related services.

Criteria No.11: Each handicapped child attends the school which would be attended if the child were not handicapped unless attendance at another school is specifically required to implement the IEP.

Q. **MINNESOTA HOME CARE ADVOCACY PROGRAM: For the Disabled by the Disabled**

O Program Description

O Position Papers:

1. "Shortage of Home Care Nurses"
2. "Need to Increase Attendant Hours and Allow the Disabled To Make the Final Choice of Care Giver"
3. "The Need to Make Home Care a Nursing Specialty"
4. "Need to Allow Ventilator Patients to Have Their Own Caregivers Present When Hospitalized"
5. "The Need to Define Home Care Case Management: Agency Responsibilities and Client Rights"
6. "The Right of the Disabled to Work"
7. "Client Rights and Agency Responsibilities"
8. "Medical Assistance and Private Insurance: Re-evaluating Criteria, Re-considering Priorities"
9. "The Failure of Home Care Agencies to Regulate Client Care and Client Safety: The Myth of Agency Protection"
10. "A New Model for A New Age of Home Care"

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Position Paper Five

The Need to Define Home Care Case Management: Agency Responsibilities and Client Rights.*

Minnesota has taken an extremely progressive stand on home care. Severely ill and disabled people -- who in past years would most certainly have been institutionalized -- are now receiving state sponsored twenty-four hour home care. But as humane and intelligent as this move may be, it is doomed to fail if the client is not provided with adequate numbers of quality care givers, and responsible and efficient case management.

It must be recognized that there is, at present, a severe shortage of nurses across the country -- especially critical care nurses. If home care is to succeed, it must be as attractive, in terms of financial compensation, benefits, prestige, and emotional rewards, as institutional care.

MHCAP believes that Medical Assistance must have a well defined case management policy, to which home care agencies serving M.A. clients must adhere. Agencies must take into account the environmental, physical, and philosophical differences between home and institutional care, when providing case management.

The following is a case management guideline MHCAP has developed. MHCAP believes the case manager must:

- advertise for r.n.'s, l.p.n.'s, and home health aides.

- prescreen applicants. The prescreening should include an interview, a reference and credential check, and an interview with the client. In the prescreening interview, the applicant should be given a thorough description of the client's disease process or condition, the client's cares and equipment, the living situation, the client's involvement with his/her care, and any stipulations the client has made.

- provide adequate orientation. MHCAP believes a minimum of one and a half shifts of orientation are necessary when a care giver is assigned to the case of a severely ill or disabled person. Depending upon the experience of the care giver, and the complexity of the case -- including equipment and critical care requirements -- more orientation may be necessary. On site orientations mean a good deal of extra work for the nurse on duty, who has to both care for the client and orient the new nurse. MHCAP feels it is only fair that the on-duty nurse receive an orientation fee.

- provide or set up in-service orientation on the client's life-support equipment and procedures, such as vents and home i.v. therapy. This can be done in conjunction with the home care suppliers providing the vent and other equipment, and with the hospital from which the client is being discharged.

- thirty day probationary period. The case manager should establish a thirty day probationary period for new care givers. During this period the care giver could request more orientation in specific areas. If a personality conflict developed, or if the care giver was simply not suited to a specific case, he/she could be transfered to another case -- unless of course, the problem was abuse, incompetence, or dereliction of duty. By offering to orient an individual to more than one case, the case manager could avoid causing that care giver financial hardship if he/she had to withdraw from one case..

- make regular on-site visits to ensure that the client's needs are being met, and that no abuse is taking place.

- responsible for scheduling the care givers. This must be done in a way that shows consideration for both the client and the caregiver: The schedule should be put out with a minimum of one week's -- preferably two to three weeks' -- notice.

Nursing is a stressful occupation -- both physically and mentally. It is an occupation that is subject to a high rate of burnout. Hospital nursing and home care nursing each have their own kinds of stress. A responsible case manager would be aware of these problems and provide its' nurses with adequate support and consideration so that burnout can be avoided. There are several issues that engender burnout and need to be addressed, including:

- financial compensations. As a whole, nurses are shamefully underpaid. Neither government or the private sector can realistically hope to attract first rate professionals unless they are willing to make the nurse's rate of pay equal to his/her education and experience. In order to maintain an adequate number of nurses on long term home care cases, nurses should receive benefits, over-time pay, shift

differential, and holiday pay. A nurse's long term loyalty to a client must also be rewarded, in terms of incentive pay. It is unfair for a nurse who is brand new to a case to receive the same rate of pay as a nurse who has faithfully remained with the client for years.
- Insufficient on-call coverage. One of the fastest ways to ensure burnout is to over schedule a nurse with one client. or to have a nurse work too much over-time because of under staffing or insufficient on-call back up. No matter how good a relationship two people have, they can only be in each other's company for so long without needing a break from each other. A serious illness creates additional physical and emotional stress for both the client and the care giver, necessitating adequate periods of separation.

The case manager should make a variety of cases available to each nurse, to provide variety on the job, and allow the nurse opportunities to use all his/her professional skills.

An adequate number of on-call people must be assigned to each shift of every twenty-four hour case so, if the nurse for the following shift calls in sick there is someone who can fill in. A nurse can't be expected to continue on a case for long if she becomes trapped in a client's home because there is no back up person. An over worked nurse is forced into a dangerous position. He/she is more likely to make mistakes -- jeopardizing the client and increasing his/her own liability.

- lack of peer support. One of the difficulties of home care is the lack of communication between nurses, and between nurses and agency administration. In most cases, home care nurses work in a virtual vacuum, only meeting for a few minutes between shifts, rarely developing supportive working relationships, rarely finding a necessary release for case related frustrations.

The case manager should open channels of communication and actively encourage nurses to share their concerns and frustrations. This could be done in several ways. The agency could put out an in-house newsletter so informational channels would remain open. Support groups could be established, so case problems could be dealt with in a supportive, nonadministrative environment. Other problems could be brought to a staff mediator.

lient Rights. In addition to requiring the case manager to perate in accordance with high state standards, MHCAP is concerned that the home care client's rights are maintained. MHCAP believes the following are basic rights of home care clients, and case managers should be required to maintain these rights.

- the client must have the right to interview applicants. It is the client who will be alone with the care giver. That person will be in the client's home, will be doing the client's cares, and will be performing procedures -- often critical care procedures -- involving the client's body. It is a fundamental right of the client to say who should be involved in such an intimate and critical job.

Each eight hours is not just a nursing shift -- it's also eight hours of the client's life. Severely ill and disabled people have little enough privacy as it is. To be forced to deal day after day with an individual whom one finds personally insufferable, is as serious a problem as incompetence, causing depression and hopelessness. This can be avoided if the client is involved in the selection process.

By this same reasoning, the client must have the right to dismiss care givers.

- the client must be consulted about orientation times, and if agency staff want to visit the client, they must first make an appointment. Nursing care is only one aspect of a disabled person's life. The disabled have as many concerns and personal activities consuming their time as do the able-bodied. There is common misconception that because a person is home bound his/her time is up for grabs. Dropping in without an appointment is the height of insensitivity and inconsideration. The privacy and time of the disabled client must be respected and protected.

- the client must have the right to attend all care conferences. Decisions about the person's life are made at those conferences, and the individual therefore has a fundamental right to be present.The right to read one's chart must also be maintained.

- one of the most important rights is the right to say no -- the right to refuse. This is especially important in the case of people who can't move. The client must be able to refuse medication, food, therapy, and procecures.* To do them in spite of a client's wish to refuse, and to take advantage of the client's physical inability to resist, is a violation of his/her will and body.

The majority of people receiving twenty-four hour care are going to desire and need case management. If that home care is going to work, Human Services must have a well conceived case management plan. MHCAP believes the suggestions in this paper serve as a start toward that plan.

* Refusing life-support, and the right to discontinue life-support are complex issues and will be dealt with in another position paper.

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POSITION PAPER SIX: THE RIGHT OF THE DISABLED TO WORK

It is MHCAP's belief that the U.S. is wasting a great national resource -- the talents and efforts of thousands of severely disabled citizens who desire to be a part of the American work force. Many severely disabled are able to make significant contributions, and want to work. But they are prohibited from doing so because they would lose their Medicaid benefits.

This prohibition not only robs disabled citizens of one of their most basic rights -- it makes no sense economically. Even the most basic medical care becomes impossibly expensive for all but the extremely wealthy. The vast majority of Americans who are now receiving Medicaid are incapable of making anything near the cost of twenty-four hour care. But they are capable of incomes that would make them taxpayers. And they are capable of making social, aesthetic, scientific, and economic contributions, that are often equal to those of ablebodied workers.

It is MHCAP's belief that America must re-evaluate its attitudes toward Medicaid recipients. We stubbornly cling to the Puritanical belief -- although unspoken -- that the unfortunate (in this case, the disabled) are inherently less virtuous, and must therefore, deserve their predicament. Law makers, public officials, and laypersons, must be reminded that disability is not the result of criminal activity. Nor does it stem from a weakness of character. These statements would seem to be unnecessary. And yet Medicaid recipients are denied payment for honest work, as though that payment were profit gained from illicit activity.

Society is not to be congratulated for fulfilling basic responsibilities to its less fortunate members. Nor should it be allowed to use the fulfillment of a moral imperative -- such as the provision of basic necessities of survival -- as a tool to deny another basic human right. The right to work.

The tactic of making essential assistance to the needy a punitive affair, seems on all levels to defy empirical reasoning. It is difficult to understand how preventing any group of people from working, saves the government money. But that Puritan sophistry is, historically, so deeply ingrained in this society's approach to social programing, that humiliation becomes an inevitable part of any assistance. Was it the intention of those who created the

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present policies, to discourage malingering among the severely disabled by forbidding them to work?

The reality is that severely disabled workers are still going to require the same amount of personal care. Unfortunately, a job won't cure quadriplegia. Nor will it take an ALS patient off a vent. And virtually no job is going to make a totally disabled individual solvent enough to pay for catastrophic medical bills.

What the right to work will do is turn a significant number of recipients into tax payers. It will create a new group of useful productive workers. And it will give depressed and hopeless individuals a sense of self-worth and a reason for living.

It must be understood that many people receiving Medicaid benefits are simply too ill to be able to work. After all, the primary purpose of the Medicaid program is to alleviate the ill and disabled of the need to support themselves. It is certainly not our intention to force these people back to work.

We are essentially addressing the issue of self-determination. There are some people who appear to be totally disabled, and yet have the stability, the energy, and the overwhelming desire to work and to assume -- to the greatest degree possible -- responsibility for their lives. With the advancement of technology, that desire is now a reality. MHCAP believes every person -- ablebodied or disabled -- is entitled to that right to work.

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POSITION PAPER SEVEN

PROTECTING THE RIGHTS OF THE HOME CARE CLIENT

CLIENT RIGHTS AND AGENCY RESPONSIBILITIES

The Minnesota Home Care Advocacy Program encourages and participates in the development and delivery of the highest quality of medical, social and supportive services to the ill and the physically challenged.

Position Paper VII touches upon the reasons home care clients need a document to protect their rights, and lists what MHCAP believes are the home care client's basic human and civil rights.

It is clear from past and present human rights violations, that professional home care agencies are not voluntarily going to make client rights a priority issue. Clients and advocacy groups must maintain a constant vigil to ensure that agencies are providing high quality service and are respecting client rights.

Although its day has come, the home care movement is still in its early stages. Agency administrators and their employees must be sensitized to the issue of client rights. Many are not even aware that a disabled individual has the same rights as an able-bodied person. Basic human and civil rights are frequently dismissed by agency administrators and employees as unnecessary inconveniences.

It is with much justification then, that many disabled people requiring twenty-four hour care adamantly refuse to use agencies. They have seen how agencies blantantly disregard their right to privacy. They have seen agencies attempt to abbrogate control. They have been victimized by agencies who promise much and deliver little. Agencies that send poorly interviewed, inexperienced, inadequately oriented -- sometimes abusive -- individuals into their homes. They have heard agencies promise uninterrupted service, and have then been sent scrambling for care givers, because of huge gaps in their coverage. With rare exception, agencies tend to discourage self-determination and self-empowerment, often intimidating and punishing clients -- especially Medical Assistance (Medicaid) clients -- into silent passivity.

In an effort to remedy this situation, and because it believes that for some people a responsible agency can provide a valuable service, MHCAP has developed a Home Care Bill of Rights. It is essential that clients realize that they have rights, and that they know what those rights are. It is also essential that a Code of Ethics be created -- a standardized code of ethical conduct -- against which agencies and their employees can be judged. The National Association for Home Care has drafted an excellent and comprehensive Code of Ethics that could serve as a guideline for care providers. MHCAP, certainly, could never recommend any agency to its clients that refused to formally comply with a well-written Code of Ethics and with MHCAP's Bill of Rights.

Clients will best be served if a Code of Ethics and Bill of Rights is translated into both state and federal legislation. This is the surest way to make sure that agencies are held accountable. There must be serious consequences when a care provider violates a client's rights.

HOME CARE CLIENT'S BILL OF RIGHTS

1. The client has a right to be fully informed of his/her rights and responsibilities.
2. The client has a right to be in charge of his/her care, and to make all final decisions regarding that care. The agency has a responsibility to deal directly with the client regarding those decisions..
3. The client has a right to appropriate and professional care relating to physician orders.
4. The client has the right of choice of care providers.
5. The client has the right to personally and privately interview all potential care givers. The client has the right to make the final decision about all care givers.
6. The client has the right to receive information necessary to give informed consent prior to the start of any procedure or treatment.
7. The client has the right to refuse food, medication, and treatment and to be informed of the consequences of his/her action.

8. The client has the right to privacy.

   Every individual has the right to regard his/her body and home as sovereign entities. This right is not nullified because one is disabled or because one is a Medicaid recipient.

   The agency has a responsibility to make an appointment in advance of all home visits, orientations, interviews, supervisory visits, etc. The client has a right to deny entrance to any individual who hasn't made an appointment.

9. The client has the right to attend all care conferences. The client shall be given reasonable notice in advance of all conferences, and conferences will be held in a location that is most convenient and accessible for the client.

10. The client has a right to read his/her chart and other material pertaining to his/her case.

11. The client has a right to take non-prescription medications without a doctors order.

12. The client has the right to receive a timely response from the agency to his/her request for service.

13. The client has the right to refuse service.

14. A client will be admitted for service only if the agency has the ability to provide safe professional care at the level of intensity needed. The client has the right to reasonable continuity of care.

15. The client has a right to be informed within reasonable time of anticipated termination of service.

16. The client has the right to voice grievances and request changes in service or staff without fear of reprisal or discrimination.

    A fair hearing shall be available to any individual to whom service has been denied or reduced or terminated or who is otherwise aggrieved by agency action. The fair hearing procedure shall be set forth by each agency as appropriate to the unique client situation (e.g. funding source, level of care, diagnosis).

17. The client has the right to know his/her schedule of coverage reasonably in advance of the first of each month.

18. The client has the right to be fully informed of agency policies and charges for services, including eligibility for third party reimbursements.

19. A client denied service solely on his inability to pay shall have the right of referral.

20. The client and the public have the right to honest accurate forthright information regarding the home care industry in general, and the chosen agency in particular, e.g. cost/visit, employee qualifications, etc.

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POSITION PAPER EIGHT

MEDICAL ASSISTANCE AND PRIVATE INSURANCE: RE-EVALUATING CRITERIA, RE-CONSIDERING PRIORITIES

Both Medicaid and most private insurance companies base their decisions to deny or approve a claim, on need and cost-effectiveness. According to those criteria, need, one would assume, would cover care, equipment, supplies, and specific treatments and therapies that are essential to the survival of client, or essential to the clients well-being or rehabilitation. But judging from our own extensive experience with Medical Assistance and private insurance, and from the experiences of MHCAP's clients, the terms survival and well-being are, in reality, very narrowly defined. So narrowly defined, in fact, that they effectively eliminate care, equipment, or treatment, that -- although not necessary for actual physical survival -- greatly enhances one's quality of life.

It is MHCAP's position that care, equipment, and supplies that promote emotional and intellectual survival and well-being and significantly encrease quality of life, must be given priority status. This description would include technological equipment, without which, a paralyzed individual is unable to effectively communicate with others -- either verbally or through writing -- and is therefore emotionally, socially, and intellectually, isolated and alienated from normal human contact.

Private insurance companies often refuse to pay for what they term "custodial home care", care that helps maintain ill and disabled people in their own homes, but doesn't contribute to curing a condition. And Medical Assistance refuses to pay for so-called non-essential items. Denials are often so arbirary and inconsistent -- especially with Medical Assistance -- that one is hard-pressed to find any common denominator underlying the decisions.

Private insurance still has a long way to go in terms of paying for home care and home care related items, although in many cases, private insurance has more liberal benefits than Medical Assistance. The insensitivity that M.A. frequently displays when considering requests from home care recipients is shocking. M.A. officials often adopt an attitude toward recipients that is nothing short of punitive -- shaming them into passivity and silence.

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Many M.A. officials need to be reminded that the funds to pay for a recipient's requests are not coming out of their own pockets, and that a recipient has not committed a crime by becoming disabled. If an individual cannot come to terms with these facts, and cannot deal considerately and compassionately with the disabled -- a group of people who are already over-stressed -- he/she should not be working in the human services field. M.A. officials wield considerable control over the lives of the vulnerable and the disadvantaged. Discretion and understanding are, therefore, essential. M.A. regulations are designed to make the recipient accountable, but policy must also be established that will make the Medical Assistance bureaucracy more accountable to the recipient.

Unfortunately the bureaucracy feeds into the problem by demanding massive amounts of ridiculous and gratuitous documentation. M.A. recipients are overwhelmed with paperwork and red tape when making perfectly reasonable requests. This practice engenders burn-out and fatigue in M.A. workers, which in turn engenders insensitivity to the needs of the very people they were hired to serve -- the ill and disabled.

The people responsible for approval and denial of requests know nothing of the person making the request and often know nothing about the dynamics of the affliction with which the M.A. recipient is dealing. MHCAP has documented cases, for example, of ALS patients -- a condition generally considered terminal -- being denied compressors for "talking trachs" because they weren't enrolled in an occupational rehabilitation program. The apparent rationale behind this decision can only be interpreted to be, "If you are not using this item in a work-related capacity, you don't deserve to talk."

Such absurd reasoning is not limited to isolated incidents. It is all too often the rule, rather than the exception. For example, instead of allowing a client to use a gel or air cushion prophylactically, to prevent decubiti (bedsores), M.A. often makes the person wait until a serious decubitus ulcer exists. M.A. actually asks the doctor to give the dimensions of the ulcer to make sure it's large enough to warrant a cushion. Not only is the disabled person being subjected to inhumane treatment, this policy makes no sense economically. Once the skin breaks down, it is almost certain to become infected. Decubiti are extremely difficult to deal with, often requiring costly hospitalizations and surgical procedures. Surely prevention is the most sensible approach to any problem. The term preventative medicine was not invented by the Minnesota Home Care Advocacy Program.

It is a practice that has been commonly accepted by most medical professionals -- with the possible exception of some who work for Medicaid and Medicare.

One area of major concern to MHCAP is communications for the severely disabled. MHCAP believes the ability to communicate is a basic right. It is only through communication that one's civil and human rights can be defended. And only one's ability to communicate can overcome the terrible depersonalization brought about by a severe disability.

At one time, people with ALS and those with high spinal cord injuries were doomed to lead lives of silent frustration. Silent terror. Silent rage. Their intellects, their emotions, their humor, their wit, and their talents were trapped inside a body that wouldn't work. It is impossible to adequately describe the enormity of that situation; it is impossible to describe the alienation. In many cases, rage was often the only thing that holds them together.

Today, state of the art computer technology makes it possible for these people to once again re-enter the world. This technology transforms persons who appear to be silent, motionless invalids into productive communicating human beings. Fully capable of making enormous contributions to society. To deny this group of people this technology on economic grounds is to deny their very humanity.

It is MHCAP's position that Medicaid must consider this technology a priority, and must make it available to all people in these situations.

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MINNESOTA HOME CARE ADVOCACY PROGRAM

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Position Paper Nine

THE FAILURE OF HOME CARE AGENCIES TO REGULATE CLIENT CARE AND CLIENT SAFETY

The Myth of Agency Protection

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Preface

While debate continues about home care management and regulation practices, the quality of care provided by private and public home care agencies continues to deteriorate. Home care agencies have been touted by many as the "safe" method of recruiting care givers. It is MHCAP's view, on the contrary, that the efficiency, the safety, and the service provided by most home care agencies -- especially by those agencies providing twenty-four hour care -- is in serious question.

Deluged with new cases, agencies are plagued by a nation-wide shortage of critical care nurses. Although agencies are not responsible for the nursing shortage, they must assume responsibility for a number of other problems. These problems include: a weak or non-existent understanding of the philosophy of home care, a sketchy administrative policy based on an institutional model, and, as a rule, inexperienced and underqualified individuals in charge of staffing. As a result, most home care agencies are operating way over their heads. Safety and convenience -- touted to be the advantages of agencies -- are at this point, mainly illusions.

The truth is, inefficiency within home care agencies is rampant, and an inability to provide high-quality, continuous care is the rule. Agencies that provide extended hour care are scrambling for care givers, and as a result, hiring practices are less than stringent. The quality of care has sadly diminished as agencies continue to send underscreened, inexperienced, often unoriented care-givers into the homes of the most physically vulnerable individuals -- seemingly satisfied, in many cases, just to have a "warm body" covering a shift.

Clients go day to day, sometimes hour to hour, with no set schedule. Almost all clients requiring twenty-four hour care suffer from constant gaps in their schedule. Inept staffers are unable to cover shifts, or sometimes just overlook the fact that they haven't covered a shift, and leave paralyzed and voiceless people without care. Foundering, some desperate staffers resort to foisting their own responsibilities for coverage onto clients and caregivers,

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blaming them for problems that are clearly due to their own inability to handle the position.

Most agencies can't control the bedlam of their own internal affairs. It is therefore unlikely that they can responsibly staff a twenty-four hour case -- or several twenty-four hour cases. And it is difficult to understand how, in the face of such blatant incompetence, some legislators and bureaucrats can continue to support the idea of agencies acting as vendors for Personal Care Attendants.

In spite of this criticism, MHCAP is not generically opposed to home care agencies, but is, to the contrary, very much in favor of well-run home care agencies. Unfortunately, MHCAP cannot presently classify any of the agencies providing twenty-four hour care as either well-run or well-structured, which is unfortunate, because they could be an excellent care alternative for many people.

It is not the intention of this position paper to disparage the concept of the home care agency, but to examine the problems that currently exist within that industry. Special emphasis will be placed on the management, structure, professional ethics and conduct, of home care agencies. An attempt will be made to dispel the myths that surround home care, and alternative resolutions will be discussed.

It is MHCAP's desire to see that all home care clients are provided with an adequate and appropriate array of care options. And one has only to scratch the surface, before it becomes apparent that more diverse and higher quality home care alternatives are badly needed.

THE MYTH OF AGENCY PROTECTION

There is no one typical home care client. Each client lives in a unique environment, with unique interests and beliefs. Home care clients range in age from infants to those in their eighties and nineties. Some clients are completely capable of managing their own care, and desire -- and certainly have the right -- to do so. Others are less able to make their own care decisions, or haven't the time to do their own scheduling, and therefore desire the more structured set-up an agency can provide -- if that agency is run in an efficient and ethical manner.

When individuals with chronic or catastrophic illness, or their families, reach the point where he/she need home care, how do they find responsible caregivers? Apart from buying major medical health insurance policies, few people are prepared for medical catastrophy -- and there is no reason they should be. It is unrealistic to think that people are going to build "medical bomb shelters", just in case they get ALS, or sever their spinal cord. Most people are medically naive, unknowledgeable about the complexities of the health care system, and totally unfamiliar with home care. They usually have no one with whom they can talk, and no way of knowing which, of the dozens of home care agencies listed in the yellow pages, are reliable.

Most people have no choice but to assume that agency administrators with professional nursing degrees have the necessary experience, education, and ethical standards, to run a professional home care agency. And if they've had bad experiences with personal care attendants, they are even more susceptible to an agency's claim of professional, trouble-free care. Unfortunately, few of these claims are grounded in reality.

It is time that the myths surrounding home care and home care agencies be examined, and it is time that straightforward questions be asked about the quality of care provided by home care agencies. Agencies are not simply running a business; they are assuming responsibility for the lives of the most physically vulnerable members of society. These people are putting their trust -- indeed, their very lives -- in the hands of these agencies. Surely, as consumers, these clients deserve more than agency rhetoric. And surely, home care agencies have an ethical responsibility to deliver the service they initially promise a client. There are many kinds of misrepresentation, and it is MHCAP's opinion that the recruiting of vulnerable -- sometimes desperate -- clients, via empty promises of security, convenience, and professionalism, is one of the more reprehensible.

MHCAP polled a random group of twenty (20) home care nurses. Each nurse had worked for two to five agencies. They were questioned on a variety of subjects, including interview and hiring procedures, reference checks, background information about the client, orientation, home care experience, vent and trach experience, in-services, salary and benefits, working conditions and job stress. Their answers are reflected in the examination of the following issues.

Hiring Procedures

The first myth is that professional home care agencies conduct professional employment interviews, attempting to match nurses to clients according to a knowledge of the client's diagnosis and needs, and a knowledge of the nurse's experience and ability to meet those needs. It is taken for granted by most clients and their families that applicants are given thorough background and reference checks.

The majority of the nurses polled said their interviews lasted an average of fifteen minutes. Five had actually been hired on the basis of a phone call, and had been assigned, sight unseen, to vent dependent clients. One nurse who was hired on the basis of a ten minute phone call, told MHCAP that she informed the agency caller that she had no home care experience. And although she had worked with hospital ventilator patients, there were twenty-four hour a day respiratory therapists to oversee the vents. Only after she began working on the case did she meet the person who hired her. Since she began working immediately, it was clear that no background check was done before she entered the client's home.

Half the nurses were never asked if they had critical care experience. Of the ten who were asked, five had no prior home ventilator experience, and all five were placed with high tech clients.

Most were given extremely sketchy information about their prospective client. Some were even given an incorrect diagnosis. One, recently graduated, nurse said her entire interview lasted fifteen minutes and she was never told the age of her prospective client, and she was given an incorrect diagnosis for the client. The interviewer said the client suffered from quadriplegia. It was not until the nurse met the client that she found out the client had ALS -- a very different diagnosis.

Agency Self-Monitoring

The second myth is that an agency has a system of internal self-monitoring, that covers its employees, and ensures safe, appropriate, and considerate care. It is assumed that agency administrators weed out negligent, abusive, and drug dependent nurses, and that they also take professional action to make certain these individuals can't simply move from agency to agency with impugnity.

An occasional visit by an agency case manager or supervisor provides very little information about what occurs on a daily basis, because caregivers are obviously going to be on their best behavior when being observed. Nurses on a case only see each other at change of shift, so they have little opportunity to witness inappropriate behavior first hand. And an abused client is often too frightened of retaliation to complain. Since the client, and in some cases the client's family, are the only people who are in a real position to observe the caregiver, how does the agency develop a method of self-monitoring? It's extremely difficult to obtain an objective evaluation of a home care nurse.

MHCAP has documented examples of abuse, neglect, drug-dependency, theft and other problems, on cases where the nurses were sent, and supposedly screened and monitored by an agency. Abuse and neglect have little to do with professional degrees. They have much more to do with emotional stability and personal integrity.

Most home care nurses are dedicated and competent professionals who are genuinely concerned about their clients. It is an unfortunate fact, however, that because of the lack of on the job supervision, home care nursing has, in a minority of cases, become a refuge for bad nurses. In many cases, there is no one to oversee a nurse's work except the client. When clients do complain, their concerns are often discounted or totally ignored, or sometimes discussed with the abusive caregiver and dropped -- leaving the client even more vulnerable to retaliation. Because a certain percentage of bad nurses do exist within the home care area, and because it is more difficult to monitor these nurses, the interview and the background checks are even more vital than with hospital nurses.

The Importance of Active Directorial Involvement

It is MHCAP's position that an agency can only have effective self-monitoring if the agency's director is in touch with all aspects of the program. It is this program's experience that most agency directors know virtually nothing about what is happening at the client level. Directors are rarely aware of gross negligence, incompetence, and flagrant violations of client rights, committed by those in charge of staffing and scheduling. In most cases, the cient has no idea who the head administrator even is.

It is understandable that a director gets caught up -- even overwhelmed -- by administrative matters. They rightly delegate client matters to others, and by necessity, trust their judgement. But it is still a serious error for a director to become totally isolated from the client area, for clients are the heart of an agency. Agency directors must always remain aware of how, and if, the agency's publicly declared policies are being implemented. And it has been MHCAP's consistent observation that, at the point a director is no longer in touch with the daily scheduling and happenings of the agency, that that agency is headed for managerial disaster.

This is not to imply that the director need be familiar with the minute details of every case. But it is essential that the director have a general overview of the needs of each client, and keep a close watch to ensure that those individuals whose job it is to meet those needs are indeed meeting those needs. If that is not the case, service begins to disintegrate into chaos.

The director must have enough education and managerial experience to be able to view situations and conflicts objectively, maintaining perspective, so relatively minor conflicts between clients and caregivers or between caregivers on a specific case, don't get blown out of proportion. The agency director must be available to the clients if conflicts can't be resolved through normal channels.

The director of nursing, working under the agency director, must be tactful, extremely organized, and well-educated.. He/she must possess excellent interviewing skills, must be aware of the differences between home and institutional care, and must be attuned and sensitive to the needs of the home care client. This person must make thorough background and refererence checks. Home care is a specialized area of nursing, and the director of nursing requires a broad array of professional and personal skills. He/she should have an understanding of the philosophy of home care, and should have at least a general knowledge of the physical ailments

The above description is of course idealized. But sadly, the average director of nursing has few of these qualifications, and those working under him/her are very often totally unqualified for their positions.

It is MHCAP's position that a director of nursing should require applicants for home care nursing jobs to have a prerequisite of at least eighteen months hospital experience -- preferably including critical care or rehab experience -- before being hired for home care. In addition, nurses new to home care should first aquire experience on cases where the clients are stable, and do not require critical care or high tech equipment. However, because of the nursing shortage, agencies are hiring virtually anyone who comes through their door. Nurses who are hardly out of school are being assigned to critical care clients -- often with a minimum of orientation.

Staffers are the most visible members of a home care agency, and staffing is quite simply an extremely stressful and thankless job. It is also an essential component of every home care agency. A poor staffer sets up an adversarial relationship between nurse and agency, and between client and agency. Agencies must recognize how crucial staffing is, and what a difficult -- sometimes impossible -- job it is. They must hire people who have the organizational skills, the tact, and the sensitivity, that the job demands. The must be willing to pay for the skill and the frustration associated with the job. For a poor staffer not only makes life miserable for the client, but also plays havoc with the agency's credibility.

Under the best of circumstances, staffing is an agonizing process for the clients with severe disabilities. It is frightening and frustrating for the client to be left alone with a new person, no matter how well that care giver may have been oriented. The less turnover and orientation a client has to endure, the better off his/her psyche is going to be. Agencies must remember that they are providing a service. And whether they are being paid directly by the client, by a private insurance company, or by Medicare or Medicaid, is irrelevant. The fact remains that they are in the employ of the client. A truly professional agency understands this, and makes an attempt, not only to respect the client's rights, but to spare the client the ravaging incompetence of administrative personnel. Clients requiring twenty-four hour care have stresses that are unimaginable to the average able-bodied person. Although most persons with severe disabilities hold themselves accountable for their behavior, and make an effort to be reasonable, it must be understood that they are dealing with unreasonable circumstances -- dependence, pain, paralysis, voicelessness, vent-dependence, condescension, and a total lack of privacy. These are conditions that cause anger, resentment, depression, and irritability. It is the responsibility of the agency to hire people who have some sensitivity to these factors. Not in a paternalistic sense, but from the vantage point of compassionate professionalism.

Staffing and Coverage

The third myth is that an agency will provide safe and uninterrupted coverage -- so a client scheduled for coverage will never be left alone -- and will always have an appropriate backup nurse. In their competetive bid for clients, agencies promise uninterrupted coverage, back-up coverage, and the safety this provides the clients. When polling agency clients however, the most frequently heard complaint concerns the unreliability of agencies, and their inability to provide appropriate and consistent coverage. MHCAP receives unabating complaints regarding the following problems:

- endless last minute agency calls to say they can't cover a case, and then throwing responsibility for coverage into the lap of the client. Clients have reported anywhere from five to twenty-five calls per day from the agency staff -- many on the verge of hysteria. This constant harrassment does nothing to reduce the level of stress for either nurse or client.

- consistent gaps in the monthly schedule, so neither the client or the nurses know for sure what's happening.

- incessant and annoying calls to nurses from staffers, who use manipulative techniques, ranging from guilt to veiled threats regarding job security, to coerce nurses into working uncovered shifts.

- relatives having to cover shifts because the agency can't. A major complaint concerns agencies exploiting relatives and abandoning their responsibility for coverage.

- people with severe disabilities left alone and helpless, because agency schedulers fail to cover a shift, or because nurses simply fail to show.

- agencies sending unoriented strangers into the homes of severely disabled clients, despite promises to thoroughly orient every care giver.

Medical and Agency Paternalism

The fourth, and perhaps the most infuriating myth, perpetuated by agencies and Medicaid administrators, is that medical professionals are better at determining the client's needs, and are better at choosing the client's care givers, than is the client.

MHCAP agrees that some clients are vulnerable, and need help in choosing appropriate care givers, and also need the safety and security that agencies could provide if properly run. Realistically, however, it must be recognized that agencies are overwhelmed by administrative, professional, and staffing problems, and therefore, agency users are by no means immune from the problems that plague those clients who do their own hiring of nurses, or have PCA's.

It would be foolish and irresponsible to deny that there are significant problems within the P.C.A. program as it now exists, or with private duty nurses. These problems must be addressed and remedied. But it would be equally naive to think that the majority of home care agencies have a handle on these problems, have remedied them, or are even aware of all the problems.

It is the position of this program that the maintenance of client autonomy and self-determination is a moral imperative in home care. Even while taking measures to ensure client safety, Medicaid must actively support self-empowerment and encourage clients who can to at least take a hand in managing their own care. In many cases, the undermining of a client's autonomy, and the denial of the client's right to control his/her own care, is the same as handing down a death sentence.

Government and home care agencies must realize that it's not an accident that many persons with the most severe disabilities continue to live way beyond their prognosis. They learn to understand the signals their body gives them. They often spot signs of illness far in advance of their nurse or doctor. They know what makes them sick, and when a case manager is a rather blatant conflict of interest. A provider cannot also monitor a case.

A case "co-ordinator" should be in charge of updating paperwork. Although the co-ordinator must work with the client, he/she can't truly be the client's advocate, because the co-ordinator is paid by the agency. If the client is mentally stable, he/she is the only legitimate case manager. The home care agency has no business making independent decisions about the client's care.

As home care becomes a more accepted and more frequently used alternative, the demand for high quality home care nurses already out-weighs the supply. The lure of increased profits, and the fierce competition that exists between home care agencies, is motivating them to pursue and accept new cases -- despite the fact that they are often unable to adequately staff those cases.

It is MHCAP's position that an agency has no business accepting more cases than it can adequately staff, and to do so is functionally and ethically irresponsible. It overstresses both clients and nurses. Clients go through the arduous task of orienting a new nurse and becoming comfortable with him/her, only to have that nurse's hours drastically cut, or lose that nurse altogether to another client.

Nurses can only be spread so thin, and can only work so many hours, without having the quality of their work -- not to mention the quality of their life -- suffer. As home care agencies take on more and more extended hour cases, nurses are pestered to work encreasing hours, and often end up doing double shifts. The extended hour client, who has often had to orient dozens of nurses due to the high rate of turnover, is now asked to orient again -- primarily because he/she is losing nurses to new clients.

MHCAP recognizes the validity of a nurse's need for variety. It also recognizes the client's need for security and consistency. A suggested remedy is to have nurses work a two week block with one client, and then switch for two weeks to another client. This would provide consistency for the client, and relief for the nurse. There are some nurses who prefer to work with only one client, and it's MHCAP's position that agencies have no business using coersive measures to get nurses to accept other cases.

Although the client's physical limitations may necessitate extended hours of care, he/she pays a high price for this coverage. Because by opening the door to nursing care, the client suffers an endless procession of strangers in his/her home, and can bid farewell to privacy. In addition, the client is forced by circumstance to leave the door open to a variety of problems from nurses, including: abuse, neglect, drug addiction, theft, property destruction, racism, and personal conflicts.

What kind of agency assistance can the client expect when seeking resolution to these problems? From MHCAP's experience, and from the experience of MHCAP's clients, not much. Most agencies have poorly developed policies regarding abuse, chemically dependent home care nurses, and theft. If an agency does take action, the client is rarely informed. Moreover, by complaining, the client aquires a reputation for being "difficult", and for being a "trouble-maker" -- making it almost impossible for the client to receive objective treatment from the agency.

Law-makers and Medicaid planners and policy-makers must be clear-sighted in their appraisals of what home care agencies can and should do. Realistically, the vast majority of agencies are profit-making businesses. Even those that are non-profit -- county public health nursing agencies, for example -- make budgetary concerns a first priority. This doesn't mean that there are no responsible agencies. Nor does it mean there are no compassionate agency administrators. It does mean that a profit-making agency has as its first priority profit. MHCAP believes the first priority in government subsidized home care should always be the client. And if a small group model can provide safer, more efficient care, and can provide a client with a higher quality of life, it certainly deserves to be given a chance to prove itself.

October, 1987

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MINNESOTA HOME CARE ADVOCACY PROGRAM
For the DISABLED by the DISABLED

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POSITION PAPER TEN

A NEW MODEL FOR A NEW AGE OF HOME CARE

As greater numbers of people require home care, and as more young people survive spinal cord injuries and disabling illnesses, new alternative models are essential. More people are insisting on care that allows for self-determination, and as has been pointed out in Position Paper Nine, the present home care agency set-up neither encourages -- or in some cases even allows for -- such concepts as self-empowerment or client autonomy.

With the present deluge of new clients comes an almost equal deluge of new home care agencies. The increased numbers of both clients and agencies mean that efficient monitoring is going to be even more difficult than before. It also means that, in an attempt to compensate for this difficulty, client autonomy is likely to be jeopardized.

Several alternatives will eventually be necessary to meet the diverse needs of home care clients. In this paper, MHCAP presents one alternative model. It is not for everyone. It is geared toward those people who are able, and have the desire to manage their own care. It is an alternative for people who need twenty-four hour care, and need at least some skilled nursing care -- possibly all nursing care. It is an alternative for people who require care through Medicaid, but still desire as much privacy and personal autonomy as possible, and don't want the regimentation and intrusiveness that go along with the standard private or public agency.

In an earlier paper the dearth of viable alternatives to the present home care system were discussed. To review: there are many people who could use twenty-four PCA care, but Medicaid still has a two hundred hour per month limit. Although it looks as though that limit may be waived in the near future, there are other problems with the PCA program. The low pay contributes to an extremely high rate of turnover. And there are not enough training and education programs available.

Clients who qualify for skilled nursing care can hire private duty nurses. But this is a day and age when home care agencies are engaged in pay rate wars due to the nursing shortage. Critical care nurses can virtually name their own price -- which in some cases is as much as thirty dollars an hour. So it is highly doubtful -- since Medicaid pays under twelve dollars an hour, and has no overtime, benefits, holiday pay, or shift differential -- that a client is going to be able to hire first rate nurses on anything but the most temporary basis.

At present, private duty is the only way a Medicaid recipient can get skilled nursing care without using an agency. A new model is desperately needed. A model that will face the changing realities of home care. One that will remedy some of the administrative and staffing problems that plague profit-making agencies.

The Small Non-Profit Group Approach to Home Care

MHCAP proposes a program that would provide care givers for groups of from two to three people. Medicaid would pay these groups the same amount it pays professional home care agencies. Since these groups would not be concerned about profit, they could pay their caregivers competitive wages, and put the money that would normally become profit back into the group. That money would be used for overtime, holiday pay, and benefits.

This is not an attempt to compete with, or to do away with, home care agencies. Well-run agencies are badly needed to help care for the hundreds of individuals who will choose to stay at home or return home.

Group members would have the option of sharing some caregivers, but would retain the right to have others that would work exclusively for them. One or two nurses would be administrative assisistants, and would be responsible for staffing and paper work for the group. These nurses would receive a higher rate of pay for these additional duties. They would be chosen by the clients. Although each group would essentially be organized the way the clients and the clients' administrative assistants decide, for the purposes of clarity and illustration, this paper will use the terms staffer and case co-ordinator. These people would work directly with the clients, and would make no independent care decisions.

The staffer would be responsible for scheduling caregivers. He/she could also place ads for new nurses, and could prescreen applicants. The client would, of course, still retain the right to interview all applicants. Enough caregivers would be hired so, if a client and a nurse had a personality clash, the nurse would not be assigned to that client.

Although group members are, of course, individuals, MHCAP believes the clients are best served if their conditions, needs, procedures, and equipment, are similar. Orientations are less stressful if caregivers have some experience and familiarity with the situation.

The group would decide how many weekend shifts and holiday shifts each nurse would be expected to work. Holidays would be scheduled weeks in advance, in an attempt to avoid last minute gaps in coverage.

The case co-ordinator would transcribe doctors' orders, and would be responsible for all paperwork.

Both the staffer and the case co-ordinator would be nurses working shifts on the case. In an emergency, if no one could provide coverage, either the staffer or the case co-ordinator would be responsible to cover the shift.

The clients would choose the staffer and the case co-ordinator, and would work directly with them. Because they would be hired and paid -- via Medicaid -- by the client, and because they wouldn't be employed by an outside agency, they could truly advocate for the client.

A procedure would be established to deal with the problem of "burnout", to ensure that neither the staffer or the case co-ordinator would suffer the long-term effects of stress.

The Importance of Emotional Release and Loyalty

A word about the client's need for catharsis, and the client's need for loyal caregivers. MHCAP suggests that, beside the staffer and case co-ordinator, clients -- especially voiceless clients -- choose an individual from among their caregivers to represent them. This person would communicate the client's needs to the staffer and the case co-ordinator. This person would never act without the client's permission, but it is essential that the client have at least one caregiver who can be a true confidante, and can be trusted implicitly. Paralyzed and non-verbal people sit silent and motionless, with thoughts and emotions trapped inside their heads. Without an ally on the professional staff -- a knowledgeable and understanding friend and caregiver -- it is almost inevitable that they will be overcome by hopelessness.

It takes time for persons with severe disabilities to trust a caregiver -- or for that matter, anyone. Their view of the world has been forever altered. Even the person who has dealt with caregivers for years, has experienced the devastation of being betrayed by someone they thought they could trust. It is MHCAP's view that a caregiver's first loyalty is to his/her client -- regardless of agency affiliation.

Any able-bodied person working with the severely disabled must realize that no matter how well they think they may know a person with disabilities, there is a line of understanding that they can never cross. There is simply no way that they can understand the unabating humiliation, invasiveness, frustration, fear, and alienation associated with physical dependency. And there is no way they can know how they would react under similar circumstances. If they think they can understand, it's time they got out of the business.

Effective Monitoring

When a group has a maximum of three people, and when the staffer and the case co-ordinator are answerable to the client, monitoring automatically becomes more efficient. Abusive and neglectful nurses would be immediately removed, and the client would not have to fear retaliation. They would also be free to take further action.

When only two or three client's are sharing caregivers, it becomes easier to single out addicts and thieves. It is unlikely that people with these pathologies are going to confine their activities to one client. Large agencies rarely take meaningful action, and there is nothing that will provoke a client's feelings of helplessness more than being alone and vulnerable to the mood swings of a drug-dependent nurse, or knowing that someone you thought you could trust is taking advantage of your paralysis, going through your personal things, and stealing them.

Staffing Policy

Staffing is never easy, and the nursing shortage is making the present situations all but impossible. However, small groups should be far easier to staff because a large number of nurses could be oriented for a smaller number of clients.

One of the reasons nurses leave home care agencies -- or sometimes leave home care altogether -- is because they simply can't take the pressure of the agency hounding them to work, and they can't take the stress of constant agency in-fighting. A small independent group would help to create a more co-operative working environment. And because the client would be in charge, in-fighting would be controlled because malcontents and agitators would be removed from the case. The intention of the co-operative group is to provide the most efficient uninterrupted stressfree care possible. Controlling, emotionally needy individuals have no place in this setup.

This program would be based on a new and sound home care model, not an out-dated institutional model. Within the limits of state and federal regulations, each individual or group of individuals could make their own rules. There is no reason that this model could not be equally as cost-effective as agency run home care for which Medicaid is willing to pay. And it's MHCAP's position that the system of monitoring would be far more effective. In terms of self-determination and self-empowerment, there is, in this program's opinion, no comparison between the small group model and the traditional home care agency. In the interest of human rights and in the interest of efficient home care, MHCAP hopes this model will be given serious consideration.

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St. Paul woman silently carries her crusade for disabled to Capitol Hill

By Randy Furst
Staff Writer

hington, D.C.
The subcommittee room suddenly turned quiet, except for the sound of a battery-operated ventilator that keeps a St. Paul woman alive.

Sitting in a wheelchair, Susan Margoles took her crusade to the halls of Congress Thursday, an appeal for disabled people to live in their own homes in dignity.

The 40-year-old-woman, who is paralyzed and unable to speak, communicated to the congressional panel via a letter board, blinking her eyes to spell out words.

"Government-sponsored home care must be made available to severely disabled people," she said. "It must be an alternative to the institution." The House subcommittee chairman, Rep. Claude Pepper, D-Fla., strained forward to listen.

Pepper, who has gained a national reputation for his work on behalf of the elderly and infirm, said that in 50 years on Capitol Hill he had never seen someone so disabled testify before Congress or accomplish what she has done.

"It is the most striking example of courage I've ever seen," Pepper said after the hearing, placing his hand on hers, as she looked at him silently, a slight smile crossing her face.

Margoles has ALS, also known as Lou Gehrig's disease, and has become Minnesota's leading advocate for home care patients. She is executive director of the Minnesota Home Care Advocacy Program, a new state

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Disabled

Continued from page 1A

organization that in a few months has acquired 42 disabled clients, many of whom she visits herself.

Val Halamandaris, president of the National Association for Home Care, who also testified yesterday, said there is no other organization like Margoles' in the United States, and called her remarks "stirring."

Margoles told the Subcommittee on Health and Long-Term Care, "We have a right, just as much as able-bodied people, to take risks.

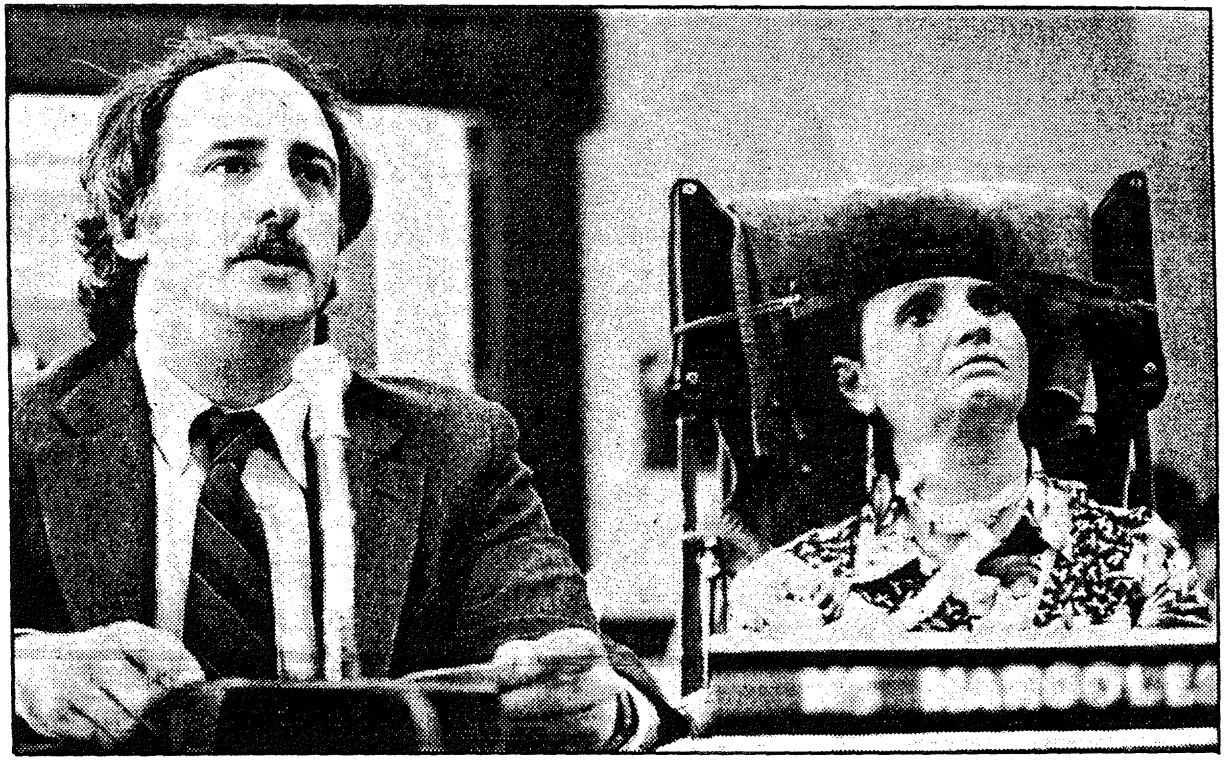
"We must have guidelines to protect us from violations by health care agencies. We have not committed a crime by becoming disabled."

As many as 20 million Americans are getting or are eligible for home care in the United States, according to rough estimates by Pepper. The Congressional Budget Office has estimated that 2 million to 4 million need long-term care, but are unable to receive it, Halamandaris said.

According to a 1985 state study, 32,000 Minnesotans receive government-funded home care, but an estimated 56,000 to 80,000 need it.

Pepper has introduced a home care proposal that would provide nursing care and home services for the chronically ill. He calls it the most cost-effective solution and says many families are driven into financial ruin when they must take care of loved ones at home. Several such families testified at yesterday's hearing.

Some of the problems the disabled face were illustrated yesterday by the extraordinary difficulties Margoles had in giving her testimony.



Associated Press

Susan Margolis testified before Congress Thursday, accompanied by Dick Mersky of Minnesota Home Care.

She normally speaks and writes with a computer, using a device that rests on her eyebrow to activate it, but the device was apparently damaged in transit, so she had to use the letter board to speak.

Part of her testimony was given yesterday by Dick Mersky, associate director of her St. Paul-based organization.

Margoles has become an ever-increasing force in the state politics of home care. Gov. Rudy Perpich visited her at her St. Paul apartment in early June, and promised to back legislation for home care reform that she is supporting, according to state Rep. Howard Orenstein, DFL-St.Paul.

"I think she's a miracle worker," said Orenstein. "Without a voice or without use of her arms or legs, she gives voice to people in a desperate condition."

U.S. Rep. Bruce Vento met her recently and recommended to Pepper that she testify.

"Susan Margoles is the best example of the possibilities of home care," Vento said yesterday. "It is hard to imagine someone with more disabilities."

Nonetheless, the position papers that stream from her computer include pleas for increased training and wages and improved conditions for nurses who take of home care patients.

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Home-care advocates give disabled an option

By Randy Furst
Staff Writer

The van pulled up at the south Minneapolis house of a man with Lou Gehrig's disease.

Out of the van came two people in wheelchairs.

One of them, Susan Margoles, 40, also has amyotrophic lateral sclerosis (ALS), the neurological disease that killed baseball player Gehrig. She is totally paralyzed, unable to speak and unable to breathe without a ventilator. The other, Larry Kegan, 44, is a quadriplegic.

The two were making a house call on a man with a debilitating disease, an effort that is being called one of the most remarkable social service projects in the United States.

"I am in awe of it," said Arthur T. Himmelman, a senior fellow at the University of Minnesota's Hum-

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Minneapolis Star and Tribune
Friday/January 30/1987/ • 5A

Handicapped

Continued from page 1A

Care Advocacy Program.

The program springs from Margoles' campaign more than two years ago to keep herself out of an institution. The St. Paul woman won the support of Leonard Levine, who was then the state human services commissioner, and other officials who pledged to keep her in her home.

She decided to carry on the effort on behalf of others. She now heads the Home Care Advocacy Program, which began in June. It serves 18 people, and Margoles is assisted by Kegan and Dick Mersky as unpaid staff members.

"Many disabled patients are trapped in institutions, not because of an inability to live at home, but because they are unaware that home care is an option," said Margoles.

Using a device that rests on her eyebrow, Margoles is able to type on a computerized video display terminal. That's how she communicates and talks to patients she visits.

"She inspired me so much," said Kristin Westby, 22, who has multiple sclerosis. Margoles visited her at Abbott Northwestern Hospital, and wrote her letters. Now Westby is living in an apartment with an aide.

"Susan told me to just keep believing and keeping faith in myself," Westby said. "What she did is gave me my respect back. She is really a neat lady. And so is Larry. They were just both very uplifting." Said Cath Westby, Kristin's mother, "Susan gave us hope. She's incredible."

The advocacy program has two goals: to make home care a viable alternative for patients requiring 24-hour care, and to empower patients to be their own advocates within medical and social service systems.

H. Eames Bishop, who founded the ALS Society of America and was president for 10 years, said from Los Angeles that the program is a model for the United States. "I'm satisfied Susan is going to leave a big mark on society," he said. "She is an inspiration to all people who have a health disadvantage. She is a fantastic woman."

Kegan, of St. Paul, got involved in the program after seeking Margoles' aid in getting home care for himself. He became paralyzed at age 16 after a diving accident. He is a college graduate who has led an active life, but he had been sinking into a depression because of problems limiting his independence. He was in the hospital when he heard of Margoles' ability to cut through bureaucracy in setting up home care. "Don't give in!" Margoles wrote him. "You can go home. I did, and I will tell you how I petitioned the state for my rights, and how you, too, can get the care you need at home. . . ."

Kegan's physician, Dr. Scott Davies, said that in the past it's been the "squeaky wheels" who got home care. Now, he said, Kegan and Margoles are showing others how to get it. He said it makes a big difference for patients to be at home with an aide rather than in a nursing home.

Margoles and Kegan recently met with south Minneapolis resident David Sheets, 37, who has ALS. "My single greatest fear is I won't be able to remain at home," Sleets told them. He talked of the stress he was under.

"One thing we people should realize about neurological disease is that we people are under stress," Margoles answered. "We don't know what the future will be like, so you don't need the additional stress of not knowing if you'll be able to be at home."

Handicapped

Continued from page 5A

the additional stress of not knowing if you'll be able to be at home."

Later Sheets got word from state officials that he would be able to stay in his home with 24-hour home care. Mersky, associate director of the program, who is able-bodied, called the Sheets decision a victory. The advocacy program, he said, is soliciting public, corporate and foundation money.

Ann Grossman, policy consultant at the state Human Services Department, said the group "goes right along with our efforts to keep people in their homes and in the community as long as possible .... We're real excited about their efforts to improve the quality of life of people with disabilities."

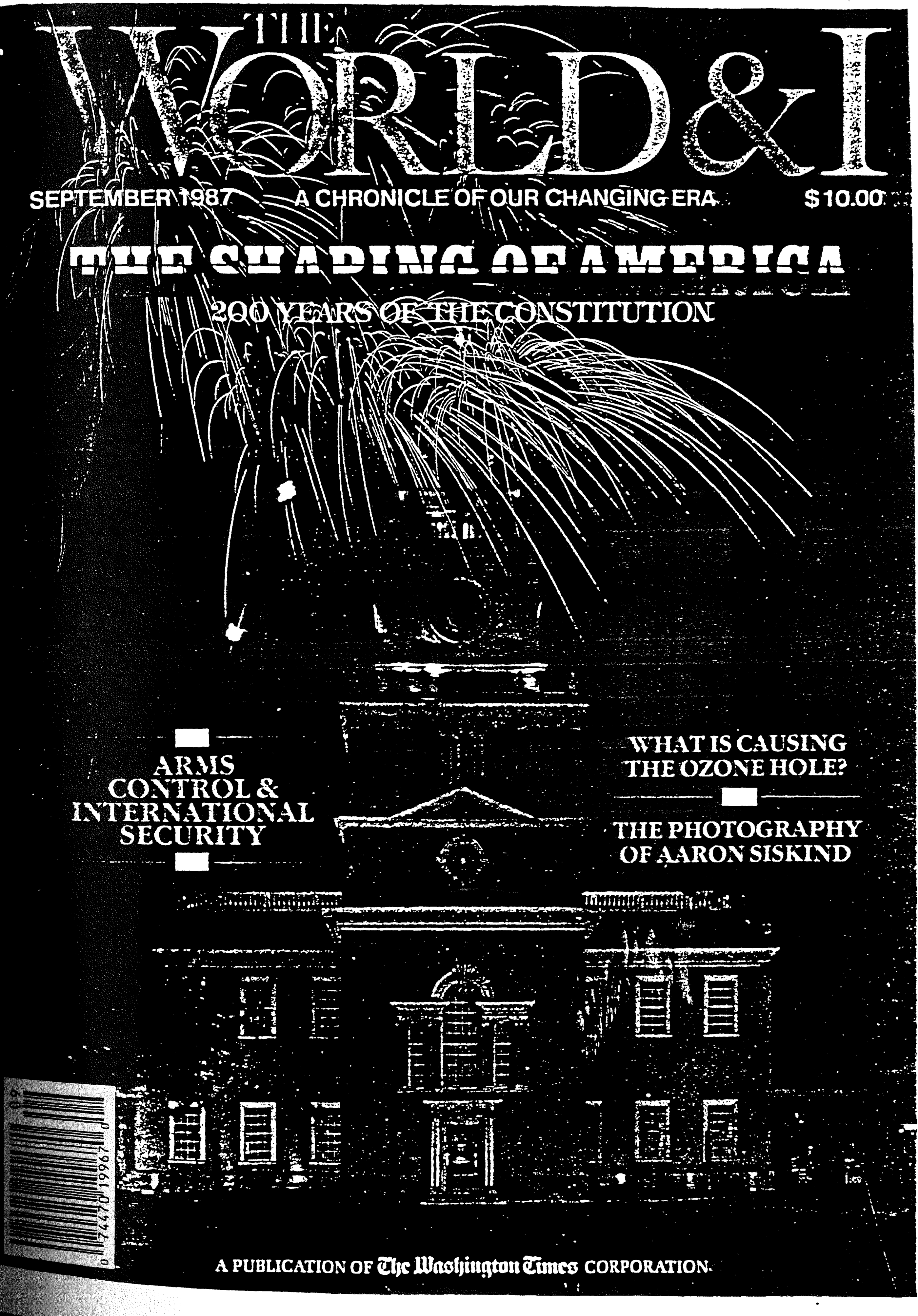
The Humphrey Institute's Himmelman said Kegan and Margoles "are working on some of the toughest problems in human services — the deinstitionalization of extremely disabled people. ... The quality of the work they are doing is as good as anything I have seen by community-based advocates."

Staff Photo by Charles Bjorgen

Susan Margoles, left, David Sheets and Larry Kegan met in Sheets' home recently to talk about what steps they could take to enable him to live at home with 24-hour care. The state agreed to the arrangement.

Levine calls the program "an outstanding, unique effort to expand the horizon for disabled persons in Minnesota. It promotes the independence of these people and affirms their talents, intelligence and dignity."

Margoles said, "Given the chance, the disabled want and can make valuable contributions to their communities. Not only is home care a more humane and sensible alternative, it is far more cost effective," she said. The group can be reached at 627-0101.



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WHAT IS CAUSING THE OZONE HOLE?

THE PHOTOGRAPHY OF AARON SISKIND

A PUBLICATION OF The Washington Times CORPORATION

POETRY IN MOTIONLESS

Susan Margoles is totally paralyzed. She is also an independent, high energy achiever who enjoys life.

BY STEVE KAPLAN

PHOTOGRAPHS BY LARRY MARCUS

Susan Margoles cannot utter a word, yet she has become a spokesperson for the severely handicapped. She cannot move a muscle in her body, yet she has moved a state bureaucracy. She does not have the strength to depress a typewriter key, yet she has written an award-winning children's story.

All of her writing and communicating is achieved by a laborious method of her operating a computer with eyebrow movement.

Margoles is a victim of amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease, a progressive illness that eventually steals all muscle control from its victims, as it has from Margoles. But total paralysis has not immobilized her. She is a powerful presence, a high-energy achiever. And her ideas just might revolutionize the treatment of the severely disabled across the United States.

From her bed she has created the Minnesota Home Care Advocacy Program, an organization that lobbies for more and better home-care programs for the severely disabled. To spread the home-care gospel, Margoles visits the disabled in hospitals. To see her aides carry her from her St. Paul apartment to the van that takes her to various hospitals around the Twin Cities, it looks more like she's off to get help than to give it.

Ten years ago she was an actress, nightclub singer, and social activist. During the height of the Wounded Knee trials, she taught creative writing at alternative schools established by the American Indian Movement (AIM). One day, she tried to start her car after leaving work, but her thumb was too weak to turn the ignition ke

She visited several doctors, w put her through a series of neu logical tests to determine the cau of her loss of thumb control. Aft months of such testing, none of t doctors was willing to give her diagnosis.

"When I asked my doctors wh I had," she explains, "they beca extremely evasive. Finally, I we to the Mayo Clinic. They told the truth—I had ALS—and as d ficult as that was to hear, I w glad that someone was final being honest with me."

ALS is almost always a fat neuromuscular disease. Typicall victims become weaker until th are unable to walk, move, swallo speak, or even breathe. It is t disease that afflicted Senator J cob Javits and actor David Nive among others. It is four times mo

Susan Margoles at home in her apartment—where she has fought so hard to be. Most severely disabled people spend their lives in hospitals.

To see her aides carry her from her St. Paul apartment to the van which takes her to various hospitals around the Twin Cities, it looks more like she's off to get help than to give it.

common than muscular dystrophy and at least as common as multiple sclerosis.

Susan suffered from the anger and denial that inevitably accompany the revelation of the life-threatening nature of a disease. After the initial diagnosis, she went home and, in a blind and burning anger, burned all the tape recordings of her singing.

"I was angry," she explains, "and when the implication is that you only have two or three years to live, it doesn't seem as though there is much reason to keep a demo tape. Singing was very important to me, and destroying those tapes was like ending a part of my life. Later, as the disease progressed, I lost my voice—it was as devastating as losing the use of my body."

She became progressively weaker and less able to participate in normal life until she was finally forced to stop working and became bedridden.

"It was then that I began to descend into a nightmarish existence," she says. "I lost virtually all my strength. I lost my appetite, and I got down to seventy-six pounds. I began having excruciating headaches, and was nauseated most of the day. My breathing was becoming increasingly difficult, and I had choking spells on a regular basis. It was painful just lying in bed, and I was so afraid of choking to death in my sleep that I was getting about an hour of sleep each night."

Even during this most difficult of times, she refused to give up. Every morning she would have her aide wheel her and a huge canister of oxygen to the bathroom, so she could take a shower. "I refused to just stay in bed," she says, "because

When traveling and visiting, Susan communicates with a word board, assisted by a nurse.

if I did I'd have to admit that I was as sick as I felt. If I could get up and do something, I wasn't completely licked."

"When I look back on those days," she continues, "I honestly don't know how or why I survived. The only thing I can think of is that I was more afraid of death than I was afraid of living with my disease. It's impossible to describe the terror associated with being that close to death. Or the feeling of helplessness that comes from being almost totally paralyzed, knowing that if you began to choke you would have no way of letting anyone know. Knowing also, that if it came right down to it, there would be no quick form of suicide."

Taking charge of her life

After years of living like this, she had a tracheostomy (a breathing hole cut in her throat) which miraculously relieved her headaches and nausea. Difficult and slow communication had been achieved by using a word board, held by a nurse. Susan would indicate the group of letters she wanted to choose from, and then individual letters, by looking at them directly. Then she got a computer, which allowed her to form words without the nurse's help: A switch was attached from the computer to her eyebrow. Her word-processing program divides the letters of the alphabet into five different groups. She chooses one of the groups, and then a letter inside the group, by eyebrow movements. By this laborious method she builds words, sentences, paragraphs, and, eventually, position papers, novels, and short stories.

When the state of Minnesota was deciding that Susan should spend the rest of her life in a ho pital, Susan was deciding that tha was something she would never a cept. She was forced to spend he life immobile, but at least she coul spend it at home, among her po sessions and directing her own a fairs. She decided to fight.

Using the telephone and th computer, she researched the cos of home care compared to hospit care. She discovered that not on was home care preferred by most severely disabled people, b it was significantly cheaper well. Her own case tells the st ry. A day's hospital cost—arou $2,500—contrasted greatly $300, the daily cost for living in h own apartment. Armed with th information of almost thre quarters-of-a-million dollars a ye savings to the state she was ab to convince the Minnesota Depa ment of Human Services to set h

Minnesota Home Care Advocacy Program

"We believe that many, if not most, disabled people living in hospitals are unnecessarily institutionalized," says Susan Margoles, summing up the philosophy of the program she helped found, the Minnesota Home Care Advocacy Program (MHCAP). Margoles is totally paralyzed and communicates only with a computer that she operates with her eyebrow movements.

"Many disabled patients are trapped in institutions," she says, "not because of an inability to live at home, but because they are unaware that home care is an option. MHCAP aims to provide a way out of the institution and to help patients control and increase the quality of their lives." The hospital cost of maintaining a severely disabled patient usually runs ten times what it costs to provide home care for that same patient.

Margoles and two other handicapped advocates visit and advise severely handicapped patients across the Twin Cities, and, occasionally, the country. Beyond informing patients of their home care options, MHCAP is intensely in-

An MCHAP board meeting with Susan presiding.

"To the greatest degree possible, I allow no one else to make decisions for me. I remain in charge of my care, and, essentially, in charge of my life."

up in her own apartment.

Once she was comfortably set up at home, she began to encounter the problems of a system that was geared to treating the severely disabled in hospitals, not homes. As those problems arose, she began thinking about solutions, and devising ways to help others in her situation. The severely disabled, she understood, tend to relinquish control of their lives to others. She decided to inspire other severely disabled people by her own story.

Her first client was Larry Kegan—a quadripeligic who has been confined to a wheelchair for almost thirty years. Kegan heard of Margoles' success in obtaining home care for herself and wanted to know if it was possible for him, too.

"When I finally started recovering, I got to thinking about getting out of the hospital. I had to arrange more, and better, home care for myself, and I didn't know quite how to go about doing that," Kegan says. Someone suggested that he call Susan Margoles for help. But when he called her house, he discovered that he couldn't talk to her directly, but had to talk to her nurse. He heard a computer clicking in the background—it was operated by Susan, instructing the nurse what to say.

"I wondered how this lady who can't even talk could help me," he says. "Then these letters started coming to me, perfectly written printouts, that just blew me away. They not only gave me the information I needed, they were witty and well written as well." Margoles instructed him through the letters how to seek help. Doors started opening for him. He received state funding for additional home care, which made his life considerably easier. "I've got the care to do what

volved in political and educational efforts. Its primary goals include:

1. Alleviating the shortage of home-care nurses. There are too few home-care nurses because of low pay and lack of available training. By bringing salaries and benefits into line with those of hospital nurses, more people would be attracted to the profession. Margoles also advocates that home-care nursing become an option in nursing schools. MHCAP is working with the University of Minnesota School of Nursing to develop a home-care specialty field of studies. "The major problem in translating the home-care option into a reality," Margoles says, "is finding qualified home-care nurses who can meet the emotional and physical needs of their clients."

2. Permitting the patient to hire a personal care attendant (PCA), a paramedical, rather than a nurse. PCAs cost less than nurses and often serve the patient just as well. Still, medical assistance limits and may even prohibit their hiring.

3. Allowing patients who require a breathing ventilator to have their own attendant or nurse accompany them when hospitalized, because the ventilator prevents the patient from speaking. Margoles, who uses a ventilator, was hospitalized and unable to communicate to the nurse that she couldn't breathe; she then suffered a respiratory arrest. " The only reason I am still alive is because my attendant walked in and found me," Margoles says. "It is difficult for able-bodied people to understand the sheer terror experienced when one is totally paralyzed, unable to speak, and left alone in a hospital room or the feeling of violation when people are doing things to your body that you don't want done."

4. Defining the social agency's responsibility and the client's rights in home-care management. Severely disabled patients are often treated like sacks of potatoes. Nurses should take pains to respect the client's right and need for privacy as well as his basic right to remain in charge of his own life.

5. Seeking the right of the disabled to work. In an ironic reversal of the American ethos, most Medicaid recipients would lose their medical aid benefits if they earned salaries. Margoles works one hun-

I want," he says. "I don't have to be afraid of being alone anymore."

Kegan decided that he wanted to know more about his mentor, so he made an appointment to meet her. "So I came over and I found out that, besides everything else, she was also a writer, which I had guessed anyway from reading her letters. I told her about the stories I write, which are really only my life adventures in rough draft, and she was excited by them. She offered to help me write my biography. So I began seeing her three days a week to tell her my life's story and adventures. I'd come back a couple of days later, and everything I told her would be completely transcribed, with a cover sheet asking me questions on the story, and requesting certain elaborations so she could give it better color and effect."

Margoles told Kegan about her idea of helping other severely disabled people find home-care help. He became the first volunteer in what was to become the Minnesota Home Care Advocacy Program. Together they visited hospitals, cheering other severely handicapped people with the news that they did not have to spend their lives in the hospital if they didn't want to. They made quite a sight when they went to work: Kegan, in his wheelchair, and Margoles, in her lounge chair, rolling through hospital corridors, breaking stereotypes as blithely as Zsa Zsa broke wedding vows.

The home-care program remained in a formative stage, however, until Kegan introduced Dick Mersky to Margoles. Mersky, a television advertising producer, had heard about Margoles and decided to make a movie of her work.

"I was blown away by what she was accomplishing," Mersky say "and I figured this would make wonderful documentary. You ha to be a very strong person have gone through what she we through and then turn everythi around and come back full force.

As Mersky discussed Margol ideas with her, he got himse involved. He started formulatin programs and planning strategi with her, phasing out his adve tising career. A few months a ter meeting her, he was spendin twelve to fifteen hours a day, seve days a week, without pay, workin on the program. "I got so involve in what they were doing and so i spired by Susan, and the progra required such immediate help th the documentary, and eventual my whole life, got put on the bac burner," Mersky says. "The mo people we were talking to, t more we realized how many de

dred hours a week on the home care advocacy program, yet she cannot receive a penny for her efforts. "Many severely disabled are able to make significant contributions and want to work, but they are prohibited from doing so," she says. "What the right to work will do is to turn a significant number of recipients into taxpayers. It will create a new group of useful, productive workers. And it will give depressed and hopeless individuals a sense of self-worth and a reason for living."■

MCHAP members Larry Kegan (left) and Doug Franzen (middle) visit Mike Broitzman in the hospital.

perate people there were out there who needed our help.

"In my advertising job, I began to lose perspective about what's real and what's not, and what's worthwhile and what isn't. But to me this job has been real inspiring. To create a program and to help all those people every day makes all the work worth it. What I'm doing now, very unlike producing television commercials, has some ultimate value to it." He is now a salaried organizer of the Home Care Advocacy program and Susan's public voice, presenting the programs to the media, to foundations, and to the legislature.

"I do most of what I do for the exact same reason anyone does anything: to maintain the best quality of life."

Prodigious writings

Susan Margoles' paralyzed hands might seem to be full—being a patient advocate, writing a biography with Larry Kegan, and directing a program to change the delivery of medical care to the severely disabled, but that's only part of her activities. She recently wrote a children's story which was given the 1986 Northwind Storyhour Children's Literature Award by the Loft Writers Circle. She is also writing grant proposals, home-care idea sheets, and is working on a novel, about half done—a fictionalized account of her fight with ALS. Her prodigious writings are all the more astounding in view of the method she must use to write.

Though most of Margoles' time is spent working with MHCAP, she has many friends and a social life. It was not always so. As her disease lessened her ability to move and communicate, her friends began to fall away.

"I used to be able to pick up the phone and call her," says her longtime friend, Penny Galinson "But

Susan and Dick Mersky testifying before Rep. Claude Pepper's committee during a recent visit to Washington, D.C.

as the disease progressed we had to go see her in person. Even in person it became increasingly difficult to understand what she was saying, until she just didn't have the ability to speak at all. And every time you visited her you knew it was never going to get better or easier, but only progressively worse. However hard it was to talk with her this time, next time it would be harder. It was just devastating to watch, and emotionally difficult to handle. Though I'm ashamed to say it, it just became easier to stop seeing her at all."

"I went through a time when I was hurt and very angry and felt abandoned," Susan says. "A lot of my friends had dropped out because they couldn't deal with my illness. As I became physically stronger, I also became emotionally stronger, and I decided to face that problem. I decided to have a party and invited all the friends I hadn't seen for a long time. They were both nervous and relieved; it was like I was telling them they could stop feeling guilty and just be my friends."

Susan planned all details of the party, and she directed her home-care workers in making the twenty-item buffet she served —she is an experienced gourmet cook. "The day before the party," she recalls, "I got so sick from anxiety that I thought I was going to have to call it off." The party was a resounding success, and she has had many others since.

"I am often asked how I manage to avoid depression and maintain the will to live," she says. "I'm not always successful. I occasionally have very grave depression and almost incapacitating anger. But most of the time I look forward to life, I enjoy life.

"I find that I am most successful at warding off depression by continuing to make plans for the future. I never stop involving myself in the process of living. A lot of people think that the reason disabled people do anything besides sitting on their butts is because they are making a conscious challenge to their disability. Speaking for myself, I do most of what I do for the exact same reason anyone does anything: to maintain the best quality of life.

"I will not allow my disease to alienate me from the world around me. To the greatest degree possible, I allow no one else to make decisions for me. I remain in charge of my care, and, essentially, in charge of my life."■

Steve Kaplan is a widely published freelance writer living in St. Paul, Minnesota, who is also a contributing editor of St. Paul *magazine.*

Simon and June Margoles with their daughter.

MINNESOTA HOME CARE ADVOCACY PROGRAM

For the DISABLED by the DISABLED

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Dear Client:

The MINNESOTA HOME CARE ADVOCACY PROGRAM is a patient advocacy program of direct service and referral for the severely disabled. It is dedicated to protecting the self-determination of the ill and disabled by: (1) defending the right of the chronically ill and disabled to remain in, and return to, their homes, (2) promoting government-sponsored, twenty-four hour home care, (3) providing support services to disabled people living at home, to help them maintain their independence, and (4) establishing a computer-linked network of information, advocacy, and referral for home care patients.

We believe that many, if not most, disabled people living in hospitals and nursing homes are unnecessarily institutionalized. Even those patients with the most severely debilitating illnesses and physical disabilities can, if provided with twenty-four hour care, live at home.

Many disabled patients are trapped in institutions, not because of an inability to live at home, but because they are unaware that home care is an option. It is the desire of this program to provide a way out of the institution and help patients take control and increase the quality of their lives.

It's often as difficult to de-institutionalize a patient's mind as their body. In spite of the frustration, the boredom, and the oppressively controlling atmosphere of the institution, the very sameness of the routine can create a measure of security they are unwilling to give up. They lose all confidence in their ability to live on their own. They've had other people making their decisions for them for so long that they have to be weaned away from their institutional mind set. It is the desire of the MINNESOTA HOME CARE ADVOCACY PROGRAM to give institutionalized patients the kind of support that will build their confidence to the point where they are able to take control of their own lives.

The director and outreach advocate of this program are themselves disabled and make personal visits to institutionalized patients. We hope that, by example, they will inspire people to look beyond their present situations and see the possibilities of independent living.

Through personal visits and a computer-linked network of information and services, we also provide services to the severely disabled now living at home. Our follow-up program includes continuing support services, advocacy, and encouragement that help people maintain their independence.

As disabled people, our staff know first hand the terrible alienation and feelings of helplessness long-term patients experience in hospitals and nursing homes. No matter how strong we may be, there are circumstances that can make all of us vulnerable and in need of advocacy.

2235 Pinehurst Avenue•St. Paul, Minnesota 55116•(612) 698-HOME

If you answer yes to any of the following questions, you may be in need of patient advocacy. If so, please fill out the attached application. If you wish, a patient advocate will call on you.

Are you now in a hospital or nursing home, wishing to return home with twenty-four hour care, but don't know where to start?

Are you living at home and having trouble dealing with the medical bureaucracy?

Do you believe your civil or human rights are being violated?

Do you believe you are the victim of neglect or abuse?

Are you without medical insurance or under-insured and in need of Medical Assistance or Medicare?

Are you unemployed due to the severity of your disability and believe you may be eligible for Social Security Disability or Supplemental Security Income?

Do you want to leave the hospital or nursing home but need accessible housing?

Are you unable to speak or unable to write and in need of a computer that will help you communicate?

Please give us a call. (612) 698-HOME

MINNESOTA HOME CARE ADVOCACY PROGRAM IS A NONPROFIT ORGANIZATION.

THERE IS NO CHARGE FOR OUR SERVICES.

MINNESOTA HOME CARE ADVOCACY PROGRAM
For the DISABLED by the DISABLED

POSITION PAPER ONE

SHORTAGE OF HOME CARE NURSES

It is the position of the Minnesota Home Care Advocacy Program that the state take the following measures to make private duty nursing more equitable with other forms of nursing:

- increase the rate of pay to make private duty pay equal to the rate of pay suggested by the Minnesota Nursing Association.

- grant time and a half pay for over-time.

- grant double-time pay for holidays.

The fact that private duty nurses do not presently receive any of the above exacerbates an already serious shortage of qualified home care nurses -- one of the most pressing problems in home care today, for patients receiving twenty-four hour care through Medical Assistance. The turnover is extremely high, and the stress on patients from continuous orientations and the lack of coverage takes a high toll.

There are several causes for this problems:

- Rule 47 of Medical Assistance prohibits patients from using agencies to manage their case. They are only allowed to use private duty nurses. Private duty nursing pays less than the county nursing agencies, and therefore fewer nurses are available to patients needing twenty-four hour care. If the pay were more equitable, home care would still be the least expensive care. (see chart A)

- Private duty nursing offers no over-time or holiday pay. Why should nurses interrupt their holidays or work extra shifts when those gestures are not recompensed. M.A. home care clients cannot require care givers contractually to work holidays. They are dependent on the good will of their care givers. One way to increase good will is to offer incentives such as double time pay on national holidays.

- Private duty nursing offers no upgrading of wages according to experience or length of service. Nurses who remain with a client for years receive no more pay than nurses who are new to a case.

Staff turnover is a source of enormous stress for patients. Highly stressed patients develop more health problems because stress affects the immune system. A disabled patient who becomes ill enough to require special medical treatment in the home is going to cost M.A. a significant bill. A disabled home care patient who has to be hospitalized for a temporary illness, such as pneumonia, is going to cost M.A. an enormous bill. So making efforts to reduce stress in a patient's life is cost-effective.

Home care is a humane and sensible alternative to institutional care. Home care is on the increase; it's the least depersonalizing form of care, and in most cases is significantly less expensive. MHCAP believes Medical Assistance must take into account the fact that home care is a reality in Minnesota, and as such must be supported with realistic pay, time and a half for over-time pay, and double time for holiday pay.

Susan R. Margoles
Executive Director
MHCAP

Richard M. Mersky
Associate Director
MHCAP

MINNESOTA HOME CARE ADVOCACY PROGRAM

For the DISABLED by the DISABLED

Position Paper II

NEED TO INCREASE ATTENDANT HOURS AND ALLOW THE DISABLED TO MAKE THE FINAL CHOICE OF CARE GIVER

Not every person in need of twenty-four hour home care requires a nurse. Many individuals -- even some ventilator patients -- can get along very well with well-trained attendants. However, under the Personal Care Attendant (PCA) Program, Medical Assistance limits PCA care to a maximum of two hundred hours per month. M.A. also prohibits ventilator patients from using PCA's.

The Minnesota Home Care Advocacy Program believes this rule is both unrealistic and cost-ineffective. As more and more people become candidates for home care, increasing numbers of care givers will be needed. At present, there is a serious shortage of nurses, and there is no reason to believe the situation will improve in the near future. The two hundred hour limit on PCA's allows a maximum of six and a half attendant hours per day. This means that people on M.A. who require twenty-four hour care are either allowed to use nurses the other seventeen and a half hours, or receive no other care at all -- forcing many people into nursing homes. Why assign nurses to cases where they are neither needed or wanted when there are clients who do require and need nursing care and are desperately understaffed?

This rule also means Medical Assistance is going to pay thousands of unnecessary dollars on cases where the client requires twenty-four hour care, but doesn't require nursing care. This is a foolish expenditure, when the problem could be resolved simply by increasing the PCA hours.

This has been a special problem for vent patients, who have been excluded altogether from using PCA's. There are certainly some clients whose conditions necessitate skilled nursing care. But making a blanket rule that prohibits all vent patients from using PCA's is extremely unwise. Most vent patients are still alive because they have learned how to protect themselves, how to manage their care, and how to survive. They may indeed have many needs -- but they are not in need of the paternalistic protection of bureaucratic officials who know nothing of them, nothing of their abilities, and nothing of their care.

Some clients do need help in making decisions about the type of care giver they need. A visiting nurse or doctor, conversant with all aspects of the client's care, or an advocacy agency run by and for the disabled -- working on a one to one basis with the client -- are in better positions to give a realistic appraisal of need. They are most certainly in a more realistic position than a Medical Assistance official who has never even met or conversed with the client. The best plan is always to thoroughly discuss every care alternative with the client, so that he/she can make the ultimate and informed choice.

Liability is always a concern for government, and is of course a legitimate concern. Unfortunately, the issue often becomes distorted and occasionally over-rides other, equally valid concerns, such as concern for the client's autonomy, and concern for the client's quality of life. All too often, agencies and Medical Assistance officials tend to view a client's life only as a succession of nursing and attendant shifts. It is vitally important to realize that clients are individuals, and that the majority of their lives are completely separate from their care. Their care is a functional necessity; it is not the be all and end all of their existence. If the client's humanity is not taken into account, a devastating form of depersonalization occurs. This leads to severe depression and, occasionally, even suicide.

If government truly wants to make a realistic appraisal of need, then it must be willing to take the long and comprehensive view. It is important to realize that home care is a specialized area of nursing, and is far different from hospital and nursing home care. It must not automatically be assumed that because someone is a nurse, that that person has enough critical care experience to care for a home ventilator patient. Whether the client uses nurses or PCA's, MHCAP believes that home care education and orientation -- not abridging the client's personal freedom -- is essential to ensure the client's safety, and is the key to reducing liability (see Position Paper III.)

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POSITION PAPER THREE

THE NEED TO MAKE HOME CARE NURSING A SPECIALTY

Home care is rapidly gaining favor as an alternative to the institution, both as a humane measure and as a cost-effective measure. There are however several problems that must be addressed if the theoretical virtues of home care are to be translated into reality. The major problem is, and will continue to be, finding qualified home care nurses who can meet the emotional and physical needs of their clients.

Home care is very different from hospital care -- both in philosophy and in routine. When a nurse works in someone's home, the person is no longer a patient -- he/she is a client. No matter how a nurse is hired -- privately, private duty through Medical Assistance, or through a nursing agency, the nurse ultimately works for the client. They are on the client's turf; they are in some respects, unavoidably privy to intimate details of the client's life. They must therefore take pains to respect the client's right and need of privacy, and the client's very healthy desire and very basic right to remain in charge of their care -- in essence, to remain in charge of their life. If a nurse is not sensitive to these needs, and cannot forego the need to assume control of the client's environment, then that individual has no business in home care.

The other major difference between institutional and home care is self-evident. If an emergency occurs in the home, there are no other professionals immediately available to assist. Home care necessitates an individual who can respond in a calm and professional manner to any situation. The client's life is in the hands of the nurse. He/she cannot afford a care-giver who panics under stress. No home care client should have to suffer the anxiety of not knowing if their nurse is going to be able to rise to the occasion. The everyday stresses of a major disability are quite enough to handle.

If Medical Assistance is truly interested in reducing the risk of liability, then they can't automatically assume that by assigning a nurse to a home care case it means that person is in safe hands. Many have had no vent experience, still others have had no hospital experience.

MHCAP believes the way to provide high quality home care nurses is to treat home care nursing care as a specialty. This could be done in two ways: by providing special home care courses in nursing schools, and by providing home care

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workshops. We would like to see an academic institution such as the University of Minnesota School of Nursing take the lead in this area, by offering courses with specific relevance to home care.

The workshop courses would cover such areas as, home ventilation, trach care, and c.p.r., as well as the philosophy of home care, and the dynamics of life-threatening diseases.

The workshops would be presented by MHCAP in conjunction with various hospitals throughout the metro area. The lectures and hands on demonstrations would be given by doctors, nurses, and other medical professionals who actually work in home care. MHCAP would like to see certification for home care nursing.

In addition to education and training as a prerequisite to home care, MHCAP believes nurses should have a minimum amount of hospital experience before they work in a home.

The lack of competent home care nurses is one of the most pressing problems plaguing home care. For too long, home care nurses have been treated as second rate -- as little more than glorified baby sitters. The home care nurse who has the trust and confidence of the client is a very special person, possessng a combination of skills, education, experience, and sensitivity that are rare. A top rate home care nurse is a highly competent professional, and should be treated as such. The lack of home care nurses of this caliber is not going to improve unless home care nursing is given the respect it deserves, and is backed up with realistic incentives such as competetive wages, benefits, and holiday pay. Unless these concerns are dealt with, there is no reason to believe that home care will attract first rate individuals.

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Position Paper IV

NEED TO ALLOW VENTILATOR PATIENTS TO HAVE THEIR OWN CARE GIVERS PRESENT WHEN HOSPITALIZED

It is the position of the Minnesota Home Care Advocacy Program that ventilator patients should have the option of having their own attendants or nurses with them when hospitalized. At present, the system does not allow for this -- it is considered a duplication of services -- and vent patients are consequently left in dangerous and frightening situations. MHCAP believes that the presence of attendants or home care nurse serves a separate and essential function, and is in no way a duplication of services.

Being a quadriplegic is never easy. But being a quadriplegic who's also on a vent -- and as a result has difficulty communicating -- carries with it a whole new set of ramifications. To be a quad on a vent, with a hushed or silenced voice, is to be virtually bound and gagged. Unable to speak. Unable to call for help. Often unable to communicate in any way with strangers.

Without people who understand and can interpret, most vent patients can't tell anyone if they're in pain, if they need suctioning, or if their vent isn't working properly. If their vent tube were to come off, there is no guarantee that the alarm would be heard in the busy hallway. There are also circumstances under which the alarm doesn't go off. It only takes four minutes to die of suffocation.

In cases where the vent patient verbalizes with difficulty, or not at all, the patient's own personal care attendant or nurse may be the only person with whom communication is possible. They are also often the only people who know how to lift, move, and transfer the patient in a way that doesn't cause severe pain. They are, essentially, the patient's only link with the hospital staff.

When a person has surgery for a tracheostomy and is put on a vent, it means a lot of sudden and traumatic changes and additions in the patient's life. In many cases -- depending on the type of trach the patient requires -- it means the patient can no longer speak. This sudden loss of voice causes emotional devastation, enormous frustration, and stark terror. The patient feels even more helpless than before. The last thing an individual in this situation needs is to be left alone in a hospital room, totally vulnerable, and at the mercy of strangers. And any patient who can't communicate is alone -- even in an intensive care unit.

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A trach and vent also mean profound changes in the patient's care plan. Since the personal care attendant is responsible for doing these cares, it is essential that he/she be on hand to learn from the hospital staff. Many doctors request that the personal care attendant be present to get hands-on experience in such procedures as sterile suctioning, trach care. and trach changing.

It is difficult for able-bodied people to understand the terror experienced when one is paralyzed, unable to speak. and left alone. Or the feeling of violation when someone is. without permission. doing things to one's body.

The following quote from the director of MHCAP -- herself a vent patient -- illustrates what can happen to hospitalized vent patients when their own care givers are not present.

> On one occasion, when I was admitted on an emergency basis, for respiratory failure, I was left for over two hours without anyone checking on me. In addition. I was left lying on a dislocated shoulder, and was in excruciating pain the entire two hours.
>
> On another occasion, I couldn't make a nurse understand that I couldn't breathe. She walked out and left me alone. I went into respiratory arrest. The only reason I am still alive is because my attendant walked in and found me unconcious. These are only two of a long list of horror stories.

Being in the hospital is difficult for anyone. For people who can't move or speak, it's a nightmare. They are not only concerned about discomfort -- they quite literally fear for their survival.

MHCAP strongly supports legislation that would give paralyzed vent patients the option of having their own care givers present when hospitalized. This should not be considered a luxury, but simply humane concern and common sense. If the regulations do not presently allow for this. then the regulations must be changed. No individual should fear for his/her life because of the inflexibility of a Medical Assistance regulation.

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Minnesota Home Care Advocacy Program

Richard M.Mersky
Associate Director
Minnesota Home Care Advocacy Program

Introduced by Orenstein

Read FIRST TIME MARCH 19, 1987, and Referred to the Committee on HEALTH & HUMAN SERVICES

Committee Recommendation and Adoption of Report: TO PASS AS AMENDED and Re-referred to the Committee on APPROPRIATIONS, APRIL 6, 1987

FIRST ENGROSSMENT
H.F. No. 1044

A bill for an act

relating to human services; providing for continued attendant services for ventilator-dependent recipients in hospitals; appropriating money; proposing coding for new law in Minnesota Statutes, chapter 256B.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

Section 1. [256B.64] [ATTENDANTS TO VENTILATOR-DEPENDENT RECIPIENTS.]

A ventilator-dependent recipient of medical assistance who has been receiving the services of a private duty nurse or personal care assistant in the recipient's home may continue to have a private duty nurse or personal care assistant present upon admission to a hospital licensed under chapter 144. The hospital, physicians and hospital staff, consistent with the standards of care in the medical community, shall at all times retain final decision-making authority and otherwise retain responsibility for the care and treatment of the ventilator-dependent patient. The personal care assistant or private duty nurse shall perform the services of communicator or interpreter for the ventilator-dependent patient during a transition period of up to 120 hours to assure adequate training of the hospital staff to communicate with the patient and to understand the unique comfort, safety and personal care needs of the patient. The personal care assistant or private duty nurse may offer nonbinding advice to the health care professionals in charge of the ventilator-dependent patient's care and treatment on matters pertaining to the comfort and safety of the patient. After the 120 hour transition period, an assessment may be made by the ventilator-dependent patient, the attending physician and the patient's primary care nurse to determine whether continued services of communicator or interpreter for the patient by the private duty nurse or personal care assistant is necessary and appropriate for the patient's needs. If continued service is necessary and appropriate, the physician must certify this need to the commissioner of human services in order to continue payments. The commissioner may adopt rules necessary to implement this section.

Sec. 2. [APPROPRIATION.]

$....... is appropriated from the general fund to the commissioner of human services for the biennium ending June 30, 1989, to provide reimbursement to the personal care assistants or private duty nurses for their services provided in a hospital under section 1 at the payment rate and in a manner consistent with the payment rate and manner used in reimbursing these providers for home care services for the ventilator-dependent recipient.

1988 LEGISLATIVE SESSION - SUPPLEMENTAL BUDGET

AGENCY : Human Services, Department of
PROGRAM : Health Care & Residential Programs
ACTIVITY : Medical Assistance

Statutory change required: Yes X No ___

ITEM TITLE: Personal Care Assistants to Ventilator-Dependent Recipients

	Governor's Recommendation	
	F.Y. 1988	F.Y. 1989
Expenditures:		
General Fund	$ -0-	$ 49,200
Positions:		
General Fund	-0-	-0-

ITEM SUMMARY:

The Governor recommends $49,200 for F.Y. 1989, to fund proposed amendments to the state Medical Assistance (MA) statute to provide MA payment for private duty nursing or personal care assistant service to hospitalized ventilator-dependent recipients.

BACKGROUND:

There are estimated to be 100 ventilator-dependent patients in Minnesota, most of them eligible for medical Assistance. It is assumed that this number will increase by approximately 20% annually due to neurologic diseases and trauma and 50% of this group is estimated to have an in-patient hospital episode during each year, with MA eligibility covering 80% of such stays. Payment is limited to a maximum of 120 hours per hospital stay at an estimated cost per hour of $9.50, which is an average of the personal care assistant rate and the private duty nursing rate. Federal participation is not available for this service. The payment will be shared 90% state and 10% county.

RATIONALE:

The legislation will permit payment for personal care assistants or private duty nurses to accompany ventilator-dependent clients to the hospital and to provide communication support services to the client for up to 120 hours per hospitalized stay.

R. ESTIMATED NUMBER OF VENTILATOR-DEPENDENT PERSONS IN MINNESOTA DERIVED FROM NATIONAL ESTIMATES BY THE OTA

Estimated Number of Long-Term Ventilator-Dependent Individuals in Minnesota by Setting (Home v. Hospital) Derived from National Estimates by the United States Office of Technology Assessment

	TOTAL	BY SETTING			ESTIMATED POTENTIAL NUMBER FOR WHOM HOME CARE COULD BE APPROPRIATE *
		Hospital		Home	
		Deemed Not Able To Be Cared For At Home	Deemed Able To Be Cared For At Home		
TOTAL	77	33	17	27	44
BY AGE:					
< 17	14	6	3	5	8
18-64	36	13	7	16	23
65 +	26	14	7	5	12
(not reported)	1	-	-	1	1

SOURCE: Data from a 1985 survey by the American Association of Respiratory Therapists as reported by the Office of Technology Assessment [1, 2, 11]. The survey is based on responses from 37 states which account for 85.85% of the total U.S. population. Data reported by the AART/OTA have been extrapolated to the total population of the U.S. and an estimate for Minnesota has been calculated by taking 1.8% of the estimate for the U.S. as a whole, since Minnesota's population is approximately 1.8% of the total U.S. population.

* This estimate = number being cared for at home + number of hospitalized patients deemed able to be cared for at home (columns 3 and 4 of this table). Unfortunately, the basis for determining ability to be cared for at home is not provided in the source documents.