

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 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 sub-acute care facility.

"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.

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 no longer the best option for the respondent [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

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 (77,9 o).

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 Homes²

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. ³Ranchos 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

²Many group homes are apparently regulated as foster homes

³The 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.

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. tracheotomy 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,
- \$187.71 for other eligible patients in hospital-based units,
- \$140.62 for ventilator-dependent patients in freestanding units, and
- \$109.62 for other eligible patients in freestanding units.