Pediatric Skilled Nursing Facilities in the United States: Locations, Descriptions, and Networks

By
Sister Katherine Smith, S.P.

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APPROVED:

[redacted]

Cecelia Capuzzi, R.N., Ph.D., Associate Professor, Research Advisor

[redacted]

Caroline M. White, R.N., Dr.PH., Professor, Committee Member

[redacted]

Charles Hawley, M.P.A., Director of Long Term Care and Housing,
Sisters of Providence Corporations, Committee Member

[redacted]

Bar[redacted]D., Associate Professor,
Acting Department Chairperson

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". . . Sometimes joy
is like that, coming quick as dandelions
springing to attention while the sun
shudders still—little—from the melting
winter . . ."

Abstract

Title: Pediatric Skilled Nursing Facilities in the United States: Locations, Descriptions, and Networks

By: [redacted]

Approved: [redacted]
Cecelia Capuzzi, R.N., Ph.D., Associate Professor

The purpose of this study was to identify pediatric skilled nursing facilities within the United States and to describe their characteristics and support networks. The setting was the mainland United States and Alaska. The few known facilities were geographically and organizationally isolated. The study question was, "Will identification and facilitation of communication among the facilities result in networking, and eventually result in coalition-building and political activism?" This exploratory study located 49 facilities in 20 states; the investigator visited a purposive sample of 20 facilities in 18 states, using a focused interview guide to obtain data about the independent variables, the facilities' milieus and support networks, and the dependent variable, facility effectiveness.

Data were examined using summary statistics and content analysis. The facilities had wide ranges of contextual and support network characteristics. The investigator sorted the facilities into effectiveness groups based on their responses to an array of questions related to a definition of organizational effectiveness.

A directory of pediatric skilled nursing facilities was developed as a result of this study; a copy was sent to each facility to assist with networking. The directory and the study results are being disseminated to health care professionals to assist families in accessing this level of care for their children.

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CHAPTER I

Introduction

The survival rate of medically fragile infants and children has dramatically increased in recent years because of significant technological improvements in medical care. Children who otherwise might not have lived following premature birth or traumatic injuries such as car or near-drowning accidents are surviving the acute care phase. Many of these children endure, but with serious health and neurological impairments.

There is a dearth of resources available to assist families with the care of medically fragile children. Unnecessarily extended or repeated stays in acute care hospitals can pauperize families and are an inappropriate use of health care resources. Although it has become common for hospitals to discharge children with long term serious health problems to their parents, not all families have the physical, psychological, emotional, social and financial resources to provide 24-hour nursing care in their homes on a long term basis. Even when care is provided by a home health agency, the cumulative stress of the child's illness, its impact on other family members, and the constant presence of strangers in the home can be destructive to the family.

Some state facilities for the mentally retarded, for example those in Oregon and Washington, which in past years were a resource for individuals with significant cognitive and developmental impairments, traditionally excluded admission to children under a minimum age level, usually six. In addition, they ordinarily

provided a skilled level of nursing care only during the acute illnesses of their residents. State facilities for the mentally retarded are currently functioning under a federal mandate to reduce their numbers of residents, and to place as many residents as possible in community-based settings. In the recent past, these facilities have been reluctant to admit young children, or to admit children with serious health impairments.

Some communities in the United States developed pediatric skilled nursing facilities to address the needs of medically fragile children and their families. Yet, these facilities are few in number and are geographically isolated from one another. Moreover, many are not aware of the others' existence. There is lack of coordination among pediatric skilled nursing facilities. Even among those facilities known to one another, there is no system for intercommunication.

There are common operational concerns, based on the characteristics of their patient populations, yet most facilities address these issues in isolation from each other. Each facility must implement state and federal licensing and certification regulations, which are usually designed for an adult population. Funding for children in nursing homes is often under the Medicaid and Social Security systems, designed for the larger population of adult nursing home patients. These regulations are not always responsive to the needs of children and their families. In addition to regulatory issues, each pediatric facility must address operational issues and funding concerns.

Each facility is presumed to have developed successful strategies for developing support networks within its own community and state system, allowing it to come into existence and to continue operating. However, when there is isolation from others providing similar services, a facility loses opportunities to collaborate with others who have faced the same kinds of problems. Developing a network among pediatric skilled nursing facilities could promote exchange of information and mutual support, and could effect positive change. Identification of successful strategies for the initial development and continuing operation of pediatric skilled nursing facilities could provide models for states who do not yet have this critical component in the continuum of pediatric health care. Eventually, building a coalition of the networked pediatric skilled nursing facilities would add a dimension of political power; a stronger collective voice for advocating pediatric long term care needs.

The study problem can be stated: "Will identification and facilitation of communication among pediatric skilled nursing facilities result in networking and eventually in coalition-building and political activism?" However, before a networking intervention is undertaken, more information is needed about the identity of the pediatric facilities, their locations, and their current concerns. Thus, the specific purpose of this study was to identify facilities within the United States that provide skilled nursing care to children and to describe the characteristics of their support networks. Ultimately, this information will be helpful for building a network of pediatric skilled nursing facilities.

Review of Literature

The review of literature addresses the research on medically fragile children, social networks including coalitions, and organizational effectiveness. Specifically, the discussion of medically fragile children includes definitions of terms, the incidence in the United States, types of services including pediatric skilled nursing facilities, and needs of families. The discussion of networks includes definitions of terms, a description of social exchange theory, and a discussion of the structural characteristics and processes of networks. The discussion of organizational effectiveness includes definitions of terms and criteria for determining effectiveness.

Medically Fragile Children

Definition. The Washington State Department of Social and Health Services (1990, p. 2) defined the medically fragile as

> Individuals [whose] chronic health-related dependence continually or with unpredictable periodicity necessitates *24-hour a day skilled health care supervision and ready availability of skilled health care providers* for the individual's survival. Further, if the technology, support and services being received are interrupted or denied, he or she may, without immediate health care intervention, experience irreversible damage or death. Or,
>
> Individuals whose chronic health related dependence does not require 24-hour supervision or skilled health care providers, but for whom *life-threatening incidences are unpredictable*. Without regular monitoring

and the availability of licensed providers, deterioration will be such as to cause the individual's medical needs to increase.

This is the definition of medically fragile children needing pediatric skilled nursing care that was used in this study.

Incidence. Although a definition exists for identifying the population, there are no figures estimating the numbers of medically fragile children who have a high acuity level, but who do not necessarily require ventilator or high-technology nutritional support. There are estimates that between 2,300 - 17,000 children nationwide per year require ventilator or nutritional support (Markens, 1990) and a study at Vanderbilt indicated that approximately 10-15% of the childhood population, or an estimated 7.5 million children under 18 years, have a chronic illness (Hobbs et al., 1983). It is further believed that approximately 750,000 (1-2%) of the nation's children have a severe chronic illness which impairs their daily functioning so that they are unable to do all that their peers without chronic conditions are able to do. Probably the numbers of medically fragile children are greater than those requiring ventilator or nutritional support and are included within the estimate of children with severe chronic illness; they constitute a significant group requiring special health care attention.

Types of facilities. There are six types of residential settings providing services to medically fragile children: hospitals; rehabilitation or transition units; home care; medical foster care; state institutions for the mentally retarded; and

nursing homes. This study focused on nursing homes that care for children exclusively or in designated units of adult facilities.

Child and family needs. Children with severe chronic health impairments often experience prolonged and repeated hospitalizations at the initial diagnostic phase and during continued treatment over the years (Gale, 1989). There are numerous studies indicating the negative effects of prolonged hospitalization on the child's psychological development and on the parent-child relationship (Hazlett, 1989). The child's physical well-being also can be compromised during hospitalization, through such factors as sleep deprivation and overstimulation, particularly in an intensive care unit (Hazlett, 1989). While it is clearly in the child's best interest to keep hospitalization episodes to a minimum, determining and accessing the most appropriate alternative type of care can be a significant dilemma.

Recently in the professional literature there are references to pediatric rehabilitation units for ventilator-dependent children (Posch, 1988; Reynolds, 1988) and transition units for ventilator-dependent children (Merkens, 1990), with the goals of providing care in a more normal environment while vacating intensive care and acute care pediatric beds in the hospital. While these units address important needs, they do not take into account the needs of children who require 24-hour nursing care but who are not ventilator-dependent.

Care of children in their own homes is a widely-accepted ideal, yet it is increasingly recognized that this alternative is not feasible for all families. The support systems that must be in place for successful home care are extensive and are

not available in all communities. The American Academy of Pediatrics (1984) issued guidelines for home care for children with chronic diseases which included medical stability of the patient; at least two trained caretakers, who are family members if possible; evidence of parental involvement in the child's care; demonstration of safety in performance of medical and nursing procedures; a home situation reasonably assuring medical safety; availability of home health providers in the community; availability of required equipment and supplies such as oxygen, feeding tubes, and ventilator parts in the community; and contingency plans for emergencies, such as transportation and power back-up for those on life support systems. Later, the Academy added appropriate schooling, family counseling, systems for checking both the children and the equipment, and the provision of respite care for families to the list of requirements for home care (American Academy of Pediatrics, 1986).

Even with such extensive systems in place, not all families can cope with the long term care of a chronically ill child. Parents struggle with disrupted sleep patterns; stressful time schedules; restricted activities; inability to meet the needs of other family members; loss of privacy; unreliable nursing care and other limited, inflexible community support services; lack of adequate, skilled, affordable day care for working and sometimes single parents; high indirect costs such as long distance telephone calls, transportation, and home modifications, which are not covered by insurance or Medicaid; increased complexity in the child's medical condition and care requirements; and the family's physical, emotional, and financial exhaustion (Gale, 1989; Hazlett, 1989; Luckenbill, 1988; Scharer & Dixon, 1989).

Medical foster care, placement of the child in a medically trained foster care provider's home, is an alternative that is often explored when home care is not feasible. This alternative relieves the parents of the physical burden of the child's 24-hour care, but also increases parents' psychological burden of worry and guilt for lacking the resources to care for their own child. In any case, the same kinds of community support systems required for home care must be in place for foster care. The same kinds of system deficiencies that become problematic for parents providing home care also impede successful medical foster home care.

Deinstitutionalization and normalization, values embraced in the last few decades as national norms, radically changed the models of custodial care in state institutions for physically and mentally handicapped persons (Glick et al., 1983). State institutions for the mentally retarded are aggressively moving as many residents as possible to community-based settings. They refuse admission to any person who could be maintained in a community setting, particularly infants and young children. These facilities traditionally provide only a basic level of medical care, and, therefore, are not a resource for medically fragile children.

References to long term care facilities, such as pediatric skilled nursing facilities, providing a planned 24-hour nursing care program for medically fragile children who no longer require an acute level of care are generally absent from discussions of care alternatives. Prior to 1983, there were no reports in the literature on pediatric nursing homes, and there are very few articles on this component in the continuum of pediatric health care since that time. Glick et al. (1983) reported on

a Massachusetts initiative establishing such facilities in response to the crisis created by the deinstitutionalization of severely handicapped children for whom community care was unrealistic. Shannon et al. (1987) updated the progress of these Massachusetts facilities. The American Academy of Pediatrics (1984) made a passing reference to the use of intermediate or chronic care facilities rather than acute care medical facilities and Perrin & Ireys (1984) recommended the development of community childhood chronic illness centers. In 1985, Bell described a program in a skilled nursing facility for children in Illinois. In 1988, Reynolds reported a pediatric component of a skilled nursing facility in Columbus, Ohio. A parent wrote a provocative article in a popular magazine which explained why she would not be taking her young son home for the holidays, and described the nursing facility in Iowa where he lived (Kupfer, 1988). The *Parade* section of the Sunday newspaper described a palliative care unit in Bayside, New York (Ubel, 1989). Merkens (1990), reporting on a chronic illness transitional unit in a Chicago hospital, considered that a similar project could be developed by a pediatric rehabilitation or chronic illness institution.

Despite the dearth of articles on pediatric nursing homes, evidence indicates that other unpublished and unreported facilities are providing this type of care, and that the need for the care is increasing with the rise in the survival rate of children who are health impaired. Known facilities have increased their numbers of pediatric patients and have waiting lists. A recent telephone search of all 50 states resulted in a preliminary list of 49 facilities that provide regular, planned programs of

pediatric skilled nursing care to medically fragile children (M. Graham, personal communication, July 1, 1990).

In summary, the literature review indicated that approximately 750,000 of the nation's children were estimated to have a severe chronic illness which impaired their daily functioning, and that approximately 2300 - 17,000 of those children required ventilator or high-technology nutritional support. The numbers of medically fragile children who had a high acuity level but who did not necessarily require ventilator or high-technology nutritional support were probably greater than the number of children who do require such support and were contained within the higher estimate. They constitute a significant group requiring special health care attention.

The literature also chronicled the struggles of parents attempting to care for their medically fragile child at home and the burdens on families which makes care at home unfeasible. There was a dearth of references in the literature to long-term, out-of-home nursing care as an option for children and families.

Networks

Definitions. Select authors' discussions of networks build upon each other to form a comprehensive definition. Fisher (cited in Froland, 1978, p. 16) defined networks as "a specified set of links among social actors." Mitchell (cited in Laumann, 1973, p. 7) expanded this and defined a social network as "a specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behavior of the persons involved." Other authors cite groups or aggregates as the

unit of analysis and the linkages between these groups are considered a network (Gottlieb, 1981). Mulford (1984, p. 136) was interested in the linkages between individuals and organizations and defined social networks as a "set of nodes (e.g., persons, organizations) linked by a set of social relationships (e.g., friendship, transfer of funds, overlapping membership) of a specific type."

Coalitions. Coalitions are a type of network. A coalition is defined as a "temporary alliance among distinct parties, persons, or states for joint action to achieve a common goal or purpose in government or politics" (Chavigny, 1988, p. 179). Coalitions function as alliances of individuals or groups temporarily setting aside their individual and perhaps incompatible interests, and working together for common goals in government or politics (Chavigny, 1988; Mulford, 1984; Rothenberg, 1985). Coalitions have power for political change (Kelly, 1985) because the combined voice becomes more effective (McCray, 1986), and through them small groups can effect major change (Trani-Shirley, 1988). Successful coalition actions can enhance the reputations of those individuals and organizations who participate (Poteet & Monk, 1988). According to Marwell et al., (1988) the overall density of social ties within a coalition, that is, the extent to which the people known by one person tend to know each other, increases the coalition's prospects for common goals and common action. In another view, however, Granovetter (1982), argues for the "strength of weak ties" (p. 105), postulating that weak ties bridge cliques of high-density strong ties, and provide access for the members of the cliques that they otherwise would not have.

Network characteristics. Networks are studied by describing their structural characteristics and by describing the processes or exchanges which occur. Size, composition of networks (i.e., the numbers and categories of members), homogeneity of network members, and linkages are the most common structural network characteristics researchers measure. The types of relationships that define a particular network determine the composition of its members (Froland et al., 1981). According to Hirsch (1981), the greater the size and heterogeneity within a network, the more reliable and effective the members' mutual support is likely to be. Linkages can be horizontal, that is, ties between people with similar interests; they can be vertical, for example, connections between facilities and governmental agencies. Linkages can be based on interactions that are coordinative, collegial, or directive regarding authority and responsibility for carrying out tasks of the network (Froland et al., 1981).

Common process characteristics of networks are reciprocity, frequency and duration of contact, and communication. Members of networks may originate, provide, or receive information or support; if there is reciprocity, they initiate interactions with others while being the recipient of others' exchanges (Pilisuk, 1986). Reciprocity (i.e., mutual exchange) and frequency of contact (i.e., the number of times contact is made) between members of a network are more likely to result in resource exchanges (Mulford, 1984). Frequency and duration of contact between members of a network can have a positive impact on intimacy (i.e., the degree of closeness of contact) (Froland, 1978).

Communication is a key concept to network and coalition theory. Members enter the organization to give and to receive information and support, a process dependent on relationships, which in turn are dependent on communication. Members of a network are potentially both "nodes" to give or receive information, and "links" to initiate the flow of information (Lipnack & Stamps, 1982). Networks are decentralized, with communication flow managed by the nature of the relationships among the participants. Coalitions, due to the nature of their political and economic activities, tend to be more centralized, with communication managed by the nature of the issues at hand. Clear, concise, and accurate communication of issues promotes credibility, an essential component for working within coalitions (Chavigny, 1988).

Exchange theory. There are several theories regarding networks, including exchange theory which hypothesizes that participants' recognition that another has something they need and that they have something of value to exchange stimulates a reciprocal relationship (Levine & White, 1961). People are willing to pay a cost in order to get a valued reward so long as the cost and the reward continue to be in an acceptable ratio as perceived by the one seeking the reward (Simpson, 1976). Individuals and groups consider the benefits and burdens of exchanging a resource they control for another they need or want. Support network exchanges include aid, affirmation of ideas or actions, and affect, the expression of positive feelings (Norbeck et al., 1981). Within political activities, scarce resources are allocated to various interest groups by continuous exchanges of controlled resources for desired

resources (Kalisch & Kalisch, 1982). The resources can be human, such as a labor force; material; or psychological, such as power and advocacy. A valued resource in a network exchange may well be access to the power to influence political or economic policies (Kalisch & Kalisch, 1982). Contrarily, Pilisuk (1986) discarded economic and reinforcement concepts as exclusive motivation factors, and argued that supportive transactions within the broad view of human interdependence go beyond equal cost and gain of a short-term duration; true caring will eventually balance out over many years.

Network development. Different types of relationships provide different types of support, such as friends assisting one another through stressful transitions, social service agencies providing material assistance during a family crisis, or mental health workers guiding patients' adjustments to community living (Gottlieb, 1981). Networks can be latent among interconnected individuals and can be intentionally activated from those specific types of linkages for a specific purpose, such as the mobilization of powerful business leaders to deal with a community problem (Pilisuk, 1986).

The structure and the process of networking provide opportunities for people to come together voluntarily as interdependent parts of the whole for the purpose of sharing information, ideas, resources, advice and moral support (Baker, 1985; Beal, 1988; Christy, 1987; Dossey, 1987; Lipnack & Stamps, 1982; O'Connor, 1982; Murphy, 1988). The individuals' goals may be to enhance professional collegiality, or individual or professional growth (Beal, 1988; Christy, 1987; Puetz, 1983).

Individuals may seek a sense of belonging, freedom from isolation, or the formation of a social community, interacting with others with common interests (Christy, 1987; O'Connor, 1982). A sense of belonging and the experience of others' support can promote well-being, security, creativity, better performance of one's responsibilities, the ability to cope more effectively, and risk-taking (Norbeck, 1981).

Cooperative networks can be formed as a way of establishing relationships between organizations to access needed resources (Mulford, 1984). According to Aldrich (cited in Mulford, 1984), organizations in networks who have unequal access to resources develop dependencies on each other. The goals of the interrelationship in a cooperative network are the exchange of information and ideas, mutual support, and change effected in areas of concern (Lipnack & Stamps, 1982). The necessary initial step in the networking process is awareness of and acquaintance with other persons or groups who have values and concerns in common (Mulford, 1984).

In order to build a coalition, it is necessary to link the members and to understand the participants. If the participants in the coalition are organizations, it is important to know the history and traditions of each organization, in order to identify common issues for political action (Chavigny, 1988). Identification of a common goal for collective action may take several efforts of formulation and reformulation. Building trust among the participants is accomplished through communication and through the shifting of power to those who have information and share it (Trani-Shirley, 1988). Existing coalitions can be enhanced by working through the network of participants to draw in additional members who share similar

concerns and are willing to engage in political activity to accomplish the coalition's objectives (Arkin, 1986; Puetz, 1983).

Advocacy networks. In writing about developing networks among parents, two authors described the opportunity for sharing, listening, problem-solving and learning the role of advocate (Winch & Christoph, 1988). In the business world, diverse and perhaps normally adversarial groups such as forest product industries and environmentalists have formed ad hoc coalitions to achieve a single, mutually desired government affairs goal (Rubinstein, 1987). One businessman commented, "A sure way to communicate a political message is to have people arguing on your behalf from unexpected places" (Kay, cited in Rubinstein, 1987, p. 35). Separately, the organizations within a coalition can be small and have little power; as a group the aggregate can be perceived as a strong force (Craig, 1987). Proactive, information-based political strategies were found to be effective in influencing legislators and policymakers in creating a more favorable environment for organizations (Mulford, 1984).

In summary, concepts from the business world and from social systems related to networking and coalition-building can suggests strategies for developing and maintaining networks and can be translated to political strategies for pediatric nursing facilities. Intelligent, unified advocacy by a pediatric long term care coalition can educate legislators to the growing numbers of these "children of technology" and to their particular needs within the overall nursing home environment, resulting in

appropriate regulations directed at improving the quality of pediatric long term nursing care.

Pediatric skilled nursing facilities respond to a growing social need by providing out-of-home long term nursing care to medically fragile infants and children. These facilities currently function in several states but in isolation from each other; each operates within its own regional support network. Given the opportunity for national networking, each organization would have to weigh the benefits and burdens of exchanges of information, ideas, resources, advice, and moral support. If the network became more cohesive and began to function as a coalition, the pediatric skilled nursing facilities would have to weigh the costs and rewards of a collective identity.

Organizational Effectiveness

Definition. Organizations are social systems which establish purposive goals and structure members' activities toward achieving them. Organizations have identifiable boundaries determining which elements are inside or outside the entity. They are open systems, interacting with and adapting to the environment in order to survive. As systems, they acquire input elements from the environment, transform them through specific processes, and return outputs to the environment (Daft, 1989).

Organizations are complex systems, incorporating many individuals and groups within the whole and fulfilling multiple functions. An organization is itself a total system and can be analyzed either from an individual-oriented or a system-oriented

perspective. This study was interested in the function of the organization, the Pediatric Skilled Nursing Facility, as a whole.

Effectiveness criteria. Schein (1970) defined systems-level criteria for evaluating an organization's effectiveness. His criteria recognized that organizations' environments provide unpredictable inputs to their systems. With that acknowledgement, he suggested that an organization's effectiveness could be defined as "its capacity to survive, adapt, maintain itself, and grow" (Schein, 1970, p. 118).

Bennis (1966) viewed organizations as functioning in a dynamic, changing society. Because the environment was dynamic, organizations must be creative, flexible, problem-solving entities in order to respond to new demands. Bennis proposed criteria for a healthy and effective organization that were based on a definition for a healthy personality by Marie Jahoda (Bennis, 1966, p. 52) and included these elements: adaptability, (i.e., the organization's ability to problem-solve and to change flexibly in response to internal and external stresses); a sense of identity, (i.e., the organization's knowledge, insight, and harmony about itself and its mission); and the capacity to test reality, (i.e., the organization's ability to identify and accurately analyze internal and external environmental factors that impact it). Bennis further suggested that the processes of adaptability, which he equated with problem-solving, was the most important determinant of organizational health, and that adaptability was dependent on the sense of identity and the capacity to test reality.

In order to describe organizational dynamics, Kotter (1978) developed a model of structural elements and organizational processes. Structural elements included external environment, technology, social system, dominant coalition, employees and other tangible assets, and formal organizational arrangements. Key organizational processes included converting matter or energy, transporting matter or energy, gathering information, communicating, and decision-making (Kotter, 1978, p. 24.) Kotter submitted that an organization's effectiveness was its ability to adapt quickly in an environment of change; when a change caused the organization's structural elements or processes to be in a state of nonalignment, an effective organization was able to move quickly into a new state of alignment.

In summary, organizations are interdependent on their environments in the fulfillment of their purposes and the achievement of their goals. In dynamic, rapidly-changing environments, organizations must adapt quickly and creatively to challenges and threats in order to survive and thrive.

Conceptual Framework

The conceptual framework for this study was based on network theory from an exchange perspective whereby networks are viewed as a social structure composed of individuals and/or groups who exchange rewards or bear the burden of costs. Norbeck (1981) suggested that aid, affect, and affirmation are exchanged in supportive relationships. Individuals or groups who engage in networks may acquire rewards in the form of information, ideas, prestige, friendship, affiliation, human or material resources, advice or moral support. Costs to participants in networks may

be in the form of energy output, financial commitment, negative group identity, loss of previous supporters' esteem, or loss of financial support.

Networks provide the opportunity for members to increase their degree of connectedness with others and to move from positions of isolation to positions of solidarity. The sense of belonging and security that stem from social support promote well-being, increased ability to cope, creativity, and risk-taking in individuals; organizations, which are goal-oriented aggregates of individuals, enjoy similar experiences of competency from supportive relationships in networks. Creativity and risk-taking promote problem-solving and adaptation, thus increasing organizations' effectiveness.

Some rewards and costs are related to politics, the "authoritative allocation of scarce resources," and may be sources of power (Kalisch & Kalisch, 1982, p. 31). In a satisfactory political exchange, members increase their collective power. But, in order to enter into relationships with others, it is necessary to know their identities and characteristics.

The context or milieu in which an individual facility operates can influence its ability to operate effectively. This context can be the environment within the facility, or outside the facility in the community, at either the local, state, or national level.

The environment can have a direct impact on the facility's effectiveness. For example, some states developed licensing regulations specific for pediatric facilities that recognize characteristics particular to children and eliminate problematic requirements of adult facilities which led to survey deficiencies. The environment

also can impact a facility's effectiveness indirectly. For example, a facility in a rural location can experience the area's nursing shortage, which in turn creates staffing deficiencies for the facility.

Knowledge of other pediatric skilled nursing facilities' existence and ways of functioning is anticipated to be of significant interest to other similar facilities and is expected to stimulate contact among the facilities. It is surmised that facilities are more likely to exchange information when each recognizes that it can benefit from the other and is willing to pay the necessary cost with a resource it controls. It is further reasoned that if, in the past, certain contextual variables have been barriers to the facilities' effectiveness, the power gained from forming a coalition will overcome these barriers.

The hypothesis for this study was that information about and communication among pediatric skilled nursing facilities will lead to the development of a network among the facilities, with exchanges of resources related to ongoing operational issues as well as resources related to implementation of state and federal licensing, certification, and reimbursement regulations. A further hypothesis was that the network will mature and eventually engage in the political activities of a coalition, taking proactive roles in shaping governmental policies and regulations related to pediatric skilled nursing home care, both at the federal level and at state levels.

Figure 1 represents the conceptualization of the entire process from identification and description of the facilities to political activism as a coalition. The entire process takes place within the context, or milieu, of the facilities individually

and as an aggregate. The diagonal line represents the scope of this study, which was limited to the identification of pediatric skilled nursing facilities within the United States and a description of the network characteristics.

Research Questions

The specific research questions were:

1. What are the structural characteristics of the support networks of the pediatric skilled nursing facilities?
2. Do the facilities participate in exchanges within their networks, and if so, what are the types of exchanges?
3. What are the network structural characteristics, i.e., size, linkages, and composition, that correspond with the nursing facilities' effectiveness?
4. Under what contextual circumstances does a facility seem to be effective?

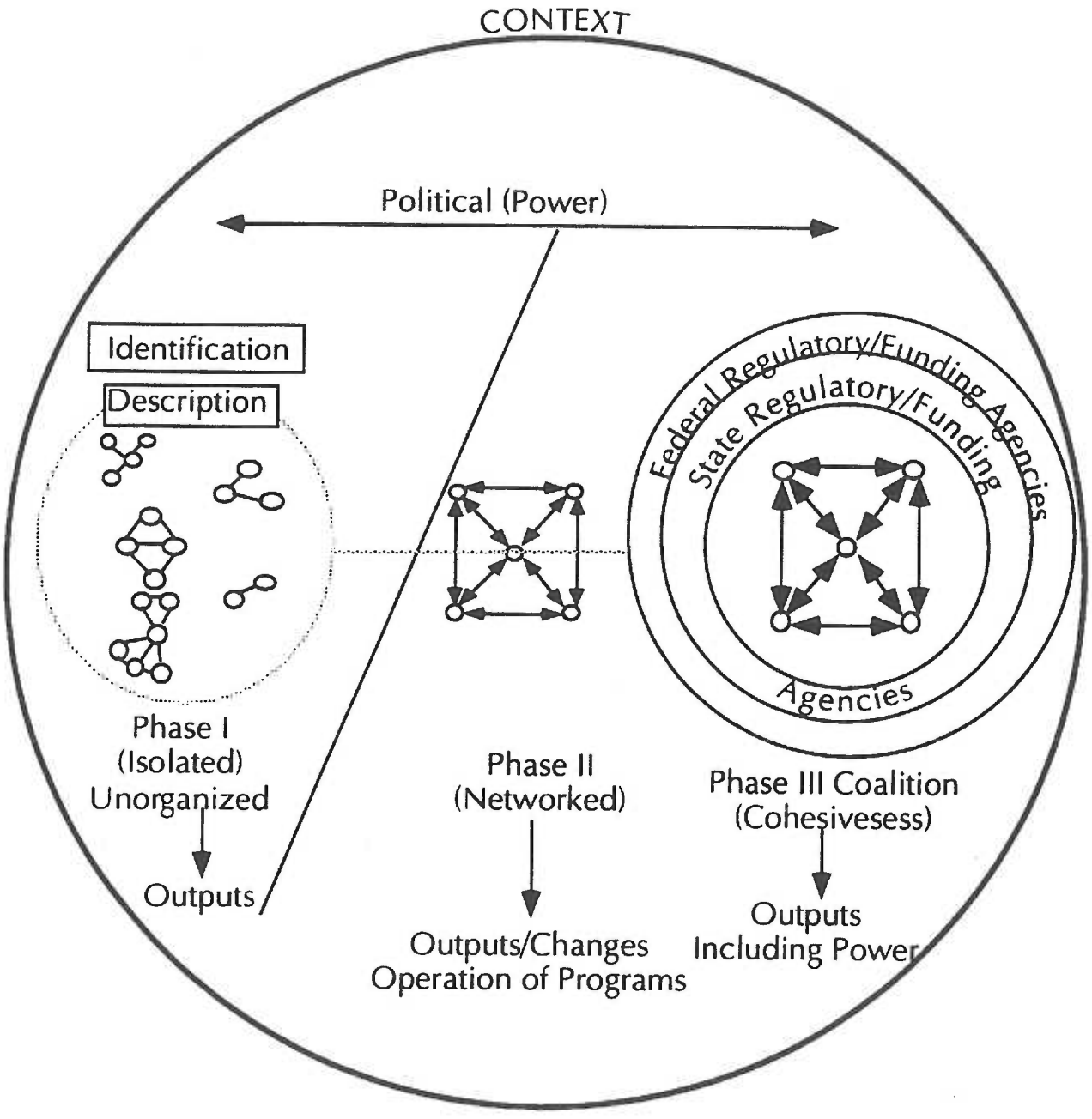

Figure 1. Developmental process of facilities.

CHAPTER II

Methods

Design

The design for this study was exploratory, descriptive, and non-experimental. In order to understand what was occurring and to answer the research questions, in-depth qualitative data regarding the context and the networks of select pediatric skilled nursing facilities in the United States were collected through personal interviews with administrators or key pediatric program staff at their facilities.

Variables

Support Networks

The independent variable for this study was the support networks of pediatric skilled nursing facilities. This variable included characteristics of the networks such as size, linkages, composition, and the exchanges that occurred within the networks.

For this study, the following definitions were used:

Support systems. Support systems are sets of regularly interacting individuals or groups, described by both structural and functional components, which provide resources for successfully achieving and maintaining equilibrium.

Network. Network is an interrelated web of individuals or groups voluntarily linked by a set of common interests and interdependent on one another for the exchange of information, ideas, advice, resources and moral support, and to effect change.

Network characteristics. Network characteristics are descriptions of the properties of the network which include:

STRUCTURAL CHARACTERISTICS

Size: the number of individuals or groups within the network.

Composition: categories of the network members, e.g., pediatric skilled nursing facilities; advocacy groups.

Linkages: the degree to which members in the pediatric skilled nursing facility network are linked to others in that network.

FUNCTIONAL COMPONENTS:

EXCHANGES: voluntary activities between two actors which involve:

Rewards: resources one actor desires which the other actor controls.

Costs: resources given up in order to get the desired rewards.

Context

The context was both an independent and an intervening variable. The context was an independent variable when it had a direct impact on the facility's effectiveness; it was an intervening variable when its impact on the facility's effectiveness was indirect or mediated through some other process. The context was composed of the milieu within the facility (i.e., facility size; whether the pediatric program was freestanding or a distinct part of an adult facility; the length of time the facility had provided pediatric services; the ages of the children admitted; whether there was a waiting list; the administrator's length of service in the facility and prior experience in pediatrics and long term care; the pediatric program's key staff

person's length of service in the facility and prior experience in pediatrics and long term care; and its sponsoring organization); the milieu within the community (i.e., the facility's location; factors that led to the facility's initiating the pediatric program); and the state's milieu (i.e., sources of funding; the state's licensing requirements for pediatric skilled nursing facilities; the state's pediatric regulations; and the state's interpretation of federal regulations for pediatric skilled nursing facilities.)

Urban locations were defined as sites in communities with populations equal to or greater than 25,000 people; rural locations were sites in communities with fewer than 25,000 people. Suburban locations were defined as sites adjacent to major population centers but not within their city limits.

Facility Effectiveness

The dependent variable for this study was the facility's effectiveness. Skilled nursing facilities are among the most regulated health care environments; they are frequently and aggressively surveyed for compliance with federal and state mandates intended for adult populations. Pediatric facilities are especially challenged in adapting to regulatory and reimbursement edicts. Organizational theorists viewed adaptability to internal and external environmental stress and the ability to regain organizational equilibrium, the capacity to identify and analyze organizational challenges and threats; and a sense of identity, that is, harmony between the organization's mission and actions as elements of organizational effectiveness. Because of the significant impact of licensing rules and reimbursement regulations

on pediatric skilled nursing facilities, effectiveness was defined for this study as the ability of the facility to carry out its mission by adapting and responding to change through (a) meaningful implementation of imposed regulations; (b) a proactive role in the shaping of regulations impacting the facility; and (c) the ability to extract from the environment the resources necessary for the continued viability of the facility. Effectiveness was measured by the facility's recognition of operational problems within the organizational, community, and state milieus; the facility's activities in implementing regulatory and reimbursement changes within the facility and within other organizations as a result of exchanges; the administrator's sense of support and spirit of optimism; and the administrator's vision of the future. See Table 1 for a matrix of effectiveness definition and measurement elements.

Setting and Sample

The setting for this study was the mainland United States and Alaska and the population were all licensed 24-hour pediatric skilled nursing facilities, or pediatric-designated areas of adult skilled nursing facilities. A pediatric skilled nursing facility is defined in this study as a facility licensed by its state as a skilled nursing facility and which admits and provides regular, planned programs of care to individuals 0-21 years of age, either in an exclusively pediatric freestanding building or in a dedicated part of an adult facility. Only facilities which were licensed as skilled nursing facilities were selected because they must implement state and federal regulations according to the skilled nursing facility requirements, and thus have problem areas

Table 1

Effectiveness Definition and Measurement Elements

Study Definition	Measurement Elements		
Effectiveness	Adaptability to Environmental Stress	Identification of Challenges and Threats	Sense of Identity
Meaningful implementation of imposed regulations.	Solved problems, all levels. Solved regulation or funding problems. Facility changes regarding regulations	Unsolved problems, all levels. Unsolved regulation or funding problems.	
Proactive role in shaping regulations.		Effecting change in others regarding regulations.	
Extracting sufficient resources to ensure facility's viability.	Facility adaptation to funding rules. Seeking supplemental funding, material donations, volunteer services.	Effecting change in others regarding funding (Medicaid rates, SSI eligibility, private insurance, etc.	Future services. Sense of support. Spirit of optimism.

in common. It should be noted that federal regulations implemented since this study began eliminated distinctions between skilled and intermediate levels of nursing home care. The term continues to refer to a long term care facility licensed by the state that provides 24-hour licensed nurse care and supervision to children.

Initially, 49 potential facilities were identified in 20 different states through the literature, professional contacts, and a telephone survey to all 50 states. As the study progressed, some facilities were eliminated that did not meet the study's definition of pediatric skilled nursing facility. Other facilities were added to the preliminary list by following up on leads provided by known facilities. Five pediatric skilled nursing facilities were located in this manner: one in Indiana, New Jersey, and California; and two in Ohio.

Basic descriptive information, verification of licensure and patient population, and consent to participate in the study were gathered from all identified facilities through a telephone interview with each facility administrator or designated staff member (see Appendix A). The investigator's address and telephone number were provided so that the administrator could initiate contact to obtain additional information about the study or other facilities.

A purposive sample of 20 facilities was selected in order to maximize representation among the following characteristics:

1. Consent to participate;
2. State of location;
3. Size of facility;

4. Urban and rural setting;

5. Freestanding or dedicated units of adult facilities.

The selection included large and small facilities; urban and rural areas; and freestanding and dedicated units of adult facilities, with at least one from each state having a facility with the exception of Utah. The Utah facility was not available for a site visit due to the administrator's stated reluctance to share information and to a scheduling conflict at the facility for the date on which the site visit could have taken place.

A travel route was finalized to include site visits at one of three facilities in New Jersey, two of six in New York, two of four in Massachusetts, one in Rhode Island, one in Vermont, one in Michigan, one of ten in Illinois, one in Missouri, one in Kentucky, one of three in Ohio, one of two in Alabama, one of two in Louisiana, one in Texas, one in Oklahoma, and one in Iowa. The site visits for the 17 facilities away from the West Coast were scheduled for the five weeks between September 24 and October 26, 1990. The single facilities in Alaska and in California and one facility of seven in Oregon were visited at other times.

Although 20 facilities were included in the site visits and 20 states had pediatric skilled nursing facilities, not all states with pediatric skilled nursing facilities were represented in the interview data. The Utah facility was not available for a site visit and the Indiana facility was identified only after the long-distance trip was completed. Two Massachusetts facilities and two New York facilities were included in the site visits, which totaled 20 facilities in 18 states.

When additional facilities were identified during the course of this study following the site visits, the investigator contacted them to request the same basic demographic data that were obtained for the original facilities. The newly identified facilities were included in Appendix B, the facility directory, which was distributed to each facility.

Procedures and Data Collection Instruments

Appointment arrangements were confirmed by letter, and included the purpose of this study, requests for a tour of the facility and an interview with the administrator, and key points that would be included in the interview. A copy of the interview guide was sent to each administrator prior to the site visit. The administrator was asked to prepare copies of state pediatric licensing regulations, if any, as well as copies of other material the administrator thought would be relevant.

A focused interview guide was used to collect the data (See Appendix C). This investigator developed the interview guide which was reviewed for content by a committee of experts. In addition, it was tested through a pilot application at one pediatric skilled nursing facility site. Data from the pilot site were included in the study. The investigator both tape recorded and took notes during the interview. The tape recordings were used for verification of the written notes.

The investigator then used the interview guide which had four sections. Section I and Questions 16, 17 and 18 in Section II gathered data to measure the contextual variable and included facility demographics, information about state licensing and regulations, and information about funding.

Sections II and IV of the interview guide gathered data to measure the dependent variable, the facilities' effectiveness. While Questions 16, 17 and 18 in Section II related to context, they also elicited problems related to funding. These sections included operational problems solved and not yet solved, the facilities' effectiveness in implementing change as a result of exchanges, and the facilities' future issues.

The third section gathered data to measure the independent variable, support systems, and included questions about the facilities' current networking within their communities, their contact with other pediatric skilled nursing facilities, and types of interactions among the facilities' networks. For recording these responses, the investigator noted the facility's support systems on a network diagram, with the facility as the focal organization and its network organizations surrounding it. There were nine additional questions in the interview guide that relate to the administrators' views on future conference activities; the data from these questions were not part of this study.

Protection of Human Subjects

The investigator followed all guidelines of Oregon Health Sciences University School of Nursing and Office of Research Services regarding protection of human subjects. The investigator reviewed the purpose of the study with each administrator, asked for permission to share their information with other facilities, and asked whether to include the facility in a directory for networking purposes.

The facility's confidentiality was assured by coding the name and location of each facility separately from the interview data. The codes will be destroyed after the data analysis. No names were used on the interview schedules or on taped interviews. No site was described in such detail that it could be identified. Each administrator directed the investigator regarding the degree of information sharing in which he or she wished to participate.

CHAPTER II

Results

This section describes the analysis of the data gathered during the course of telephone interviews of 49 pediatric skilled nursing facilities throughout the United States and site visits of 20 facilities in 18 states. First, the data concerning context, support systems, and effectiveness were described. Secondly, the data were organized to answer the research questions.

The demographic data from the sample facilities were compiled and analyzed utilizing summary statistics such as frequencies, ranges and means. Next, responses to open-ended questions were studied utilizing content analysis, which looked for patterns of similarities and differences. These data were coded into categories that were exhaustive and mutually exclusive. Interrater reliability was tested for the coding of the open-ended responses by having a second rater code for themes in the responses of 5 of the 20 (25%) administrators for all open-ended interview questions. For each set of responses the rater coded a different set of facilities each time. Because of a difference in format for coding the responses to operational problems the second rater was asked to code the responses of 10 (50%) of the 20 administrators. The codes of both raters for each set of responses were compared and a percentage of agreement was obtained based on the ratio of agreements to the total number of responses.

Context

Milieu Within the Facility

Data from telephone interviews. Forty-nine pediatric skilled nursing facilities, located in 20 states, were found during this study. Twenty-seven facilities (55%) were freestanding pediatric facilities and 22 (45%) were dedicated pediatric units within adult facilities. All facilities cared for children newborn through 21 years, although some facilities focused on younger or older children within the range.

The size of the facilities ranged from 2 to 150 pediatric patients (M = 48.84; SD = 33.49). Facility size was multi-modal (12, 50, and 58); the median was 44. Of the freestanding pediatric skilled nursing facilities (n = 27), 18 (67%) had 50 or more patients; 9 (33%) freestanding facilities had fewer than 50 patients. Within dedicated units of adult skilled nursing facilities (n = 22), 4 (18%) facilities had 50 or more children; 18 (82%) facilities had fewer than 50 children.

Data from site visits. The analysis of the data in this section relates to Questions 1-3 and 7-10 in Section I and Questions 16 and 18 in Section II of the interview guide as well as data spontaneously provided by the administrators during the 20 site visits. The sample facilities (N = 20) ranged in size from 12 to 120 patients (Mo = 12; Md = 42.5; M = 51.05; SD = 33.85). Of the freestanding pediatric skilled nursing facilities (n = 15), 9 (60%) had 50 or more patients; 6 (40%) facilities had fewer than 50 patients. Within dedicated units of adult skilled nursing facilities (n = 5), all had fewer than 50 children.

Fifteen (75%) facilities had a waiting list of patients at the time of the site visit. Fourteen (70%) facilities were private, not-for-profit organizations; six (30%) facilities were private proprietary organizations. Of the 14 not-for-profit facilities, 5 were members of vertically-integrated health care systems; none of the proprietary facilities was vertically integrated. Five not-for-profit facilities had religious sponsorship: four were Catholic-sponsored and one was sponsored by an Episcopal religious community of women. Two of the Catholic-sponsored facilities also were members of vertically-integrated health care systems. The length of time the facilities had provided pediatric skilled nursing care ranged from 1 year to 25 years ($\underline{M}$ = 14.28 years; $\underline{SD}$ = 7.37). Nine (45%) facilities provided skilled nursing care to pediatric patients because the need evolved as the acuity level of the patients increased, 6 (30%) developed because of recognized unmet needs in the community, and 5 (25%) were asked by others to provide the service. Ten (50%) facilities provided care to ventilator-dependent children within their patient populations. Nine (45%) facilities provided care to children with tracheostomies but without ventilators. One (5%) facility did not provide care to children with either tracheostomies or ventilators.

Nine (45%) facility administrators were women. In addition to being licensed nursing home administrators, seven (78%) of the nine women were qualified in other health care professions; six (67%) were registered nurses and one (11%) was a physical therapist. Of the 11 (55%) facility administrators who were men, none were registered nurses; 4 (36%) were other health care professionals in addition to

licensed nursing home administrators. Their length of time as administrator of the facility ranged from 0.3 to 17 years (M = 5.3; SD = 4.29). Ten (50%) administrators had no long term care experience prior to their position in the facility, three had 1 to 10 years' prior long term care experience, four had 11 to 20 prior years of experience, and three had "several" years of prior experience in long term care. Thirteen (65%) administrators had no pediatric experience prior to their position in the facility and seven (35%) administrators had prior pediatric experience in fields such as acute care nursing, pediatric rehabilitation, and education.

Some facilities designated a key staff person for the pediatric program. In four (20%) facilities, the administrator retained primary responsibility for the pediatric program. In those facilities in which the administrator was the key pediatric staff person, the mean length of time the administrator had been in the position was 1.3 years (SD = 1.16). A registered nurse was the designee in eight (40%) facilities; the mean length of service was 6.9 years (SD = 4.97). The administrator and a multidisciplinary team carried the pediatric program responsibility in six (30%) facilities. For those teams, the mean length of service was 10.1 years (SD = 6.65). In two (10%) facilities, an assistant administrator was the designee; those individuals had been in their positions for 1 year and 13 years, respectively. No data were available for prior long term care experience for the key staff persons. The responses regarding previous pediatric experience were often descriptive rather than actual numbers. Of the three registered nurse-administrators who retained responsibility for the pediatric program, one had "several years'"

experience in rehabilitation; one had experience in pediatrics and obstetrics; one had no prior pediatric experience; the non-registered nurse administrator had no prior pediatric experience. Of the eight registered nurse designees, two had no prior pediatric experience; two had data missing; one had "several years' experience in pediatric mental health"; and three had 6 years', 20 years', and 25 years' experience, respectively. One assistant administrator had no prior pediatric experience; one had "several years of acute rehabilitation and worked with children with developmental disabilities." Data were not available for prior pediatric experiences of the teams.

Medicaid was the primary source of funding for 19 (95%) of the facilities; private insurance was the primary source of funding for the other facility. Patients were occasionally funded through insurance or trust funds in 16 (80%) facilities. Five (25%) facilities had other financial resources, such as Commission for the Blind, a special children's fund, or a private endowment as secondary or occasional sources of funding.

All but three facilities reported some level of activity seeking additional funding. Six (30%) facilities reported formalized development programs, five (25%) facilities reported fund-raising through special events, three (15%) facilities were members of United Way, two (10%) facilities reported seeking funds through grants, and one (5%) facility had a private endowment. The number of fund-raising activities reported in each facility ranged from 0 to 5 ($\underline{M}$ = 1.85; $\underline{SD}$ = 1.46).

Milieu Within the Community

Data in this section were gathered from the telephone survey. Administrators were asked during the telephone survey to identify whether their facilities were in urban or rural locations. Following the site visits, the investigator designated a third category, suburban, to differentiate facilities located adjacent to major population centers but not within their city limits, such as: Voorhees, New Jersey; Bethany, Oklahoma; Johnston, Iowa; and Bountiful, Utah. In the target population ($N = 49$), 28 (57%) facilities were located in urban areas; 8 (16%) facilities were in suburban areas; and 13 (27%) were located in rural areas. In the sample ($n = 20$), 12 (60%) facilities were located in urban locations; 5 (25%) were in suburban locations; and 3 (15%) were in rural locations.

Milieu Within the State

Data in this section were gathered from Questions 4, 5, and 6 in Section I and Question 17 of Section II of the interview guide. The daily Medicaid reimbursement rate to the facilities ranged from $39.42 to $320 ($M = $155.91; $SD = $86.14). Two (10%) facilities reported receiving two Medicaid rates each. In one facility, the state's reimbursement was based on two levels of care; ventilator-dependent patients and non-ventilator-dependent patients. The second facility served children from two states; each state reimbursed at a different rate.

The administrators in four states (Massachusetts, Louisiana, Michigan, and Oklahoma) reported that there were separate licensing regulations for pediatric skilled nursing facilities; administrators in two states (Missouri and Texas) reported

that pediatric skilled nursing facilities regulations were pending. Administrators in 11 (55%) facilities reported that state nursing home surveyors took the needs and differences of pediatric patients into account when interpreting the facility's compliance with regulations.

In summary, 49 facilities in 20 states were located; 20 facilities in 18 states were visited. The facilities varied in size, length of time they provided pediatric care, and professional preparation and experience backgrounds of the administrators and key staff members. Approximately three fourths of the facilities were located in or near urban centers. About half the target population and three fourths of the sample were freestanding facilities caring for children exclusively, as distinct from dedicated pediatric units within adult skilled nursing facilities. Freestanding facilities tended to have larger pediatric populations than did dedicated units within adult nursing facilities. Six (30%) states developed licensing regulations responsive to pediatric needs. Only 11 (55%) administrators believed that state nursing home surveyors were responsive to pediatric differences when interpreting regulations. Although Medicaid was the primary source of funding for nearly all patient care, there was a wide variation in the reimbursement rates.

Support Systems

Network Structural Characteristics

Data about facility network size, composition, and linkages were gathered from the responses to Questions 19, 20, 23, and 24 in Section III of the interview guide. The size of the facility networks was determined by counting the number of

individuals or groups that the administrator identified as part of the facility's support network. Some facilities identified their network members by category. Some identified their members by proper name, for example, "City Center Hospital" rather than "hospital." One facility located in an urban area received referrals from 60 area hospitals. Another facility interacted with seven local school districts in providing educational services for the children in the facility. These entities were identified in the networks as "hospitals" and "school districts." The network sizes for the sample facilities ranged from 9 to 22 members ($\underline{M}$ = 14.9; $\underline{SD}$ = 3.74).

Linkages among members in an organization's network refer to the degree to which members known to the focal organization also know each other. A facility's medical director can be on the staff of its referring hospital and thereby have a relationship separate from either member's relationship with the facility; this is an example of a two-way linkage. The relationships among the Department of Health, the Department of Social Welfare, and the Rate Setting Commission, all of which can be members of a facility's network, is an example of a three-way linkage. The facilities reported linkages among their network members that involved 2 to 6 other members. For 2-way linkages, the mean was 2.3 ($\underline{SD}$ = 1.41); for 3-way linkages, the mean was 0.65 ($\underline{SD}$ = 0.67); for 4-way linkages, the mean was 0.3 ($\underline{SD}$ = 0.44); for 5-way linkages, the mean was 0.4 ($\underline{SD}$ = 0.49); and for 6-way linkages the mean was 0.15 ($\underline{SD}$ = 0.37).

Data on the composition of networks were coded using deductively generated codes derived from an analysis of the interview responses. The following twelve

entities were identified: (a) state agencies; (b) parent groups; (c) students in nursing, rehabilitative therapies, or other health-related fields; (c) legislators, indicating that the facility had developed linkages with policy-makers who could influence state bureaucracies; (e) community volunteers; (f) advisory groups or boards of directors; (g) fund-raisers, indicating a way in which the facility had mobilized advocates in the community; (h) other pediatric skilled nursing facilities, indicating the extent to which linkages among the target population existed; (i) professional organizations; (j) school districts; (k) physicians; and (l) hospitals. The facilities' responses were reviewed to determine the number of key components they included in their networks. Of the 12 key network components, the responses for the facilities ranged from 5 to 10 ($\underline{M}$ = 8.05; $\underline{SD}$ = 1.39). See Table 2 for the frequencies that facilities reported these categories in their networks.

In response to Question 19 as to whether the facility had contact with any other facility providing pediatric skilled nursing care, nine (45%) facilities reported no; nine (45%) identified other pediatric skilled nursing facilities in their own state or geographic region; and two (10%) identified another pediatric skilled nursing facility outside their own state or region (they identified each other). Sixteen facilities reported 40 individuals or groups in response to Question 23, asking whether there were people with whom the facility must interact that it considered not to be supportive. The facilities' responses ranged from 0 to 6 ($\underline{M}$ = 2.0; $\underline{SD}$ = 1.69). Interrater reliability for coding non-supporters was 87%. See Table 3 for frequencies and percentages of the facilities' responses regarding individuals or groups whom the

Table 2

Network Composition of Pediatric Skilled Nursing Facilities (N = 20)

Network Category	Number of Facilities	Percent of Facilities
Community volunteers	20	100
State agencies	19	95
Physicians	19	95
Hospitals	18	90
Boards, advisory or governing	18	90
Students, health-related fields	13	65
Parents	12	60
Legislators	11	55
Professional organizations	9	45
School districts	9	45
Fundraisers	4	20
Other pediatric skilled nursing facilities	2	10

facilities reported as being not supportive. Administrators in 11 (55%) facilities commented throughout the interviews on their sense of an anti-institutional bias as a basis for non-support, expressed by a variety of sources including several state agencies, Associations for Retarded Citizens, discharge planners in hospitals, and local communities.

Table 3

Organizations Viewed by Pediatric Skilled Nursing Facilities as Non-Supportive

(N = 20)

Category	Number of Facilities	Percent of Facilities
State agencies		
Ongoing Medicaid services	8	40
Developmental Disabilities/Mental Health	4	20
Pre-admission authorities	2	10
Licensing and certification	2	10
Rate-setting	2	10
School districts	6	30
Local groups	4	20
Regional Bureaucracy		
Zoning board	1	5
United Way	1	5
Regional referral center	1	5
Pediatric special interest group	1	5
Association for Retarded Citizens	3	15
Sponsors	2	10
Hospitals	2	10
Insurance companies	1	5
No one unsupportive	4	20

Network Exchanges

When asked in Question 22 to identify what factors encouraged the members of their networks to support the facilities' work with children, the administrators gave 72 responses under 16 categories. The number of responses per facility ranged from 0 to 9 (M = 3.4; SD = 2.54). See Table 4 for frequencies and percentages of the

facilities' responses. Interrater reliability for the coding categories was 89%. Four facilities gave one or two responses; eight facilities gave three or four responses; five facilities gave five or six responses; and two facilities each gave nine responses. Data were missing from three facilities.

Table 4

Motivating Factors for Supporters of Pediatric Skilled Nursing Facilities (N = 20)

Category	Number of Facilities	Percent of Facilities
Emotional appeal of the children	9	45
Quality of program	7	35
Being part of something good	4	20
Altruism	3	15
Professionalism of staff	3	15
Environment	2	10
Supporters were helped to help others	2	10
Supporters' own area of interest	2	10
Cost-effective alternative	2	10
Being part of the mission	2	10
Unique characteristics of the facility	1	5
Facility supports families	1	5
Facility is successful	1	5
Supporters want to feel needed	1	5
Public representations made by facility	1	5
Facility's image	1	5
Facility's information base	1	5
Facility's policies	1	5

The data collected by Questions 25 and 26 indicated that 14 (70%) facilities had a facility newsletter as a means of information and support exchanges with members of their networks; an additional 2 (10%) had newsletters that were intended for parents only. Four (20%) facilities did not have newsletters. Twelve (60%) facilities organized parent groups as way of exchanging advocacy and affirmation with members of their support networks.

Questions 27 and 28 asked about professional or advocacy organizations. Memberships in professional organizations ranged from 0 to 7 ($\underline{M}$ = 2.6; $\underline{SD}$ = 1.96). Eighteen (90%) facilities belonged to professional organizations; of those, 10 (50%) facilities belonged to pediatric-oriented professional organizations such as the Association for the Care of Children's Health; 13 (65%) belonged to long term care organizations such as the American Health Care Association; and 8 (40%) belonged to organizations with general health orientation, such as the Catholic Health Association. Twelve (60%) facilities had multiple memberships; of those, the frequency was multi-modal ($\underline{Md}$ = 2, 4, and 5).

Question 29 asked how the professional organizations benefitted the facilities. The number of benefits that the facilities reported they received from their professional organizations ranged from 0 to 6 ($\underline{M}$ = 3.05; $\underline{SD}$ = 2.06). Three (15%) facilities reported that they received no benefits from professional organizations. The types of rewards the facilities received were: information (28%); networking (28%); technical assistance (22%); advocacy (14%); support (4%); and legislative lobbying (4%). Interrater reliability of the coding was 67%.

Question 30 asked what the facilities did to benefit the professional organizations. The number of benefits that facilities provided to the professional organizations ranged from 0 to 5 (M = 1.85; SD = 1.46). Three (15%) facilities reported no exchanges with professional organizations. The types of benefits which the facilities provided to the professional organizations were: working for the organization such as holding office and committee work (66%); giving it a different perspective of pediatric identity and service (11%); keeping it informed of new developments (9%); paying dues (6%); helping its image (2%); being a member (2%); attending meetings (2%); and giving financial support (2%). Interrater reliability of the coding was 100%.

Question 31 asked the cost of organizational membership. For those facilities which belonged to professional organizations, the range of costs was reported to be from $150 to $38,500 annually (M = $5,733.00; SD = $9,663.47).

Question 21 on the interview guide asked what the facility's supporters provided that made the administrator consider them as part of the support network. Most administrators provided answers to this question throughout the course of the interview, particularly when they were identifying the members of their support networks. Because of this, the investigator did not ask the question specifically. In addition, since the data are mixed throughout the interview and would require transcription of the tapes, the data were not analyzed to answer this question. They might be obtained at a later date.

In summary, the sample facilities identified support networks of various sizes, linkages, compositions, and exchanges including costs and benefits. Their support networks were composed of entities within their facilities, their communities, and their states. Except for two facilities with common governance, none of the facilities identified another pediatric skilled nursing facility as part of its support system.

Effectiveness

For the purposes of this study, effectiveness was defined as "the ability of the facility to carry out its mission by adapting and responding to change through (a) meaningful implementation of imposed regulations; (b) a proactive role in the shaping of regulations impacting the facility; and (c) the ability to extract from the environment the necessary resources for the continued viability of the facility." All facilities were considered to have a basic level of effectiveness by the fact that they were in operation. There were varying degrees of effectiveness, however. In order to begin to analyze the facilities' effectiveness, responses to questions in the interview guide were assigned a numerical value and were tabulated.

Meaningful Implementation of Imposed Regulations

Part 1 of the definition was assessed by responses to interview Questions 11, 12, and 13, related to operational problems solved and not yet solved, and to Question 32, related to facility changes regarding regulations due to relationships with others in the network. The analysis of each question follows.

Operational problems. In order to analyze the facilities' operational problems solved and not yet solved, the problems identified by the administrators in Question

11 were scaled according to several levels (see Table 5). Level A related to internal operations, the milieu within the facility. Level B related to the relationship of the facility with its external environment, or milieu, within the community or region. Level C related to the facility in its milieu within the state. Each level was divided into two sublevels. Sublevel 1 indicated that an identified problem was an issue of short-term impact, usually a single instance. Sublevel 2 indicated that an identified problem was a long-term issue. In addition, the operational problems were categorized in Questions 12 and 13 according to whether the administrator considered them solved or not yet solved.

The number of problems per facility ranged from 0 to 19 ($\underline{M}$ = 5.5; $\underline{SD}$ = 4.07). The total problems solved per facility ranged from 2 to 12 ($\underline{M}$ = 5.7; $\underline{SD}$ = 2.68) and the total problems not solved per facility ranged from 3 to 10 ($\underline{M}$ = 5.7; $\underline{SD}$ = 2.13). Some facilities reported more than one instance of the same category of problem. Nineteen (95%) facilities reported a total of 95 Level A problems; the number of Level A problems per facility ranged from 0 to 19 ($\underline{M}$ = 5.5; $\underline{SD}$ = 16.58). Eighteen (90%) facilities reported 53 Level B problems, relating to the milieu within the community; the number of Level B problems per facility ranged from 0 to 7 ($\underline{M}$ = 2.6; $\underline{SD}$ = 1.82). Eighteen (90%) facilities reported 67 Level C problems, relating to the milieu within the state; the number of Level C problems per facility ranged from 0 to 7 ($\underline{M}$ = 3.4; $\underline{SD}$ = 2.03). Interrater reliability for coding the problems into levels was 85%. See Table 5 for specific examples of operational problems and the frequencies of facility identification of each category.

Table 5

Facilities' Reported Operational Problems by Level (N = 20)

Level	Number of Facilities	Number of Responses	Percent in Category	Solved	Not Solved
Level A-1 (within facility, short-term)					
Individual patient situations	2	3	30	3	0
Legal issues	2	2	20	1	1
Physical plant	1	2	20	0	2
Equipment	1	1	10	0	1
Census-building	1	1	10	0	1
Personnel changes	1	1	10	1	0
Level A-2 (within facility, long-term)					
Staff issues	23	23	27	15	8
Internal organization	17	17	20	16	1
Accommodating patient/family needs	12	17	20	13	4
Written policies/procedures	8	10	12	7	3
Physical environment	8	10	12	1	9
Internal financial issues	5	6	7	0	6
Understanding of program	1	1	1	0	1
Facility growing and viable	1	1	1	1	0
Level B-1 (within community, short-term)					
Individual patient situation involving hospital	1	1	100	0	0
Level B-2 (within community, long-term)					
Multi-level strategic planning	8	13	25	6	7
Competition for staff	9	10	19	0	10
Community perception of program	8	8	15.3	5	3
Relationship with school district	7	7	13.5	4	3
Interagency coordination	6	6	11.5	4	2
Roles and functions of boards	3	5	10	3	2
Vendors' support and service	3	3	5.7	1	2
Level C-1 (within state, short-term)					
None					
Level C-2 (within state, long-term)					
Compliance with regulations	11	14	21.5	4	10
Inconsistent funding systems	8	13	19.5	3	10
Rate negotiations	11	11	16.5	6	5
Working relationships with state agencies	9	9	30	5	4
State/national understanding of pediatric issues	6	7	10	1	6
State pediatric regulations	4	4	6	4	0
Anti-institutional bias	3	3	4.5	0	3
State's unrealistic patient planning	4	4	3	0	4
Research grants	1	1	1.5	1	0
Statewide professional educational programs	1	1	1.5	1	0

Facilities each received one point if they reflected awareness of problems in all three levels: facility, community, and state, whether or not the problems were solved. Then, problems related to regulatory issues were selected from the problem lists. The facility received one point for each regulatory problem that was solved. Because implementation is dependent on funding, problems related to funding issues were selected from the problem lists. The facility received one point for each funding problem that was solved.

Administrators responded to Question 14 by indicating their perceptions about what factors made the difference in problems being solved or not. Eighteen (90%) facilities gave 59 responses under 13 themes (see Table 6). Interrater reliability of the coding was 85%. The number of responses per facility ranged from 0 to 10 ($\underline{M}$ = 3.2; $\underline{SD}$ = 2.49). Eight facilities gave one or two responses; six facilities gave three or four responses; and one facility each gave six, eight, and ten responses. Data were missing from two facilities.

Facility changes. In order to assess implementation of change within the facility itself, the administrators were asked in Question 32 to identify how their facilities had changed following exchanges with members of their networks. Twenty facilities (100%) identified 48 facility changes under 10 themes (see Table 7). Twelve facilities gave one or two responses; seven facilities gave three or four responses; and one facility gave six responses. The number of responses ranged from 1 to 6 ($\underline{M}$ = 2.4; $\underline{SD}$ = 1.27). Interrater reliability of the coding was 75%. The facilities received one point for each regulatory change identified.

Table 6

Factors Affecting Facilities' Ability to Solve Operational Problems (n = 59)

Category	Number of Responses	Percent of Responses
Human resources	12	20
Financial resources	11	18.5
Control	9	16
Perseverance	5	9
Readiness for change	4	7
Timing	4	7
Working collaboratively with others	4	7
Incremental progress	3	5
Sense of support	2	3
Value systems	2	3
Responding to need	1	1.5
Planning	1	1.5
Political influence	1	1.5

Table 7

Regulatory and Reimbursement Changes Effected by Facilities (n = 43)

Category	Number of Responses	Percent of Responses
Reimbursement	14	34
Waivers, exemptions, authorizations	5	12
Licensing or classification	4	9
Improved working relationship with state agencies	4	9
Regulatory issues in process	4	9
State's increased understanding of children's needs	3	7
Regulations	3	7
State regards facility as a model of care	2	5
Increased visibility of children's issues	2	5
Increased appreciation of cost-effective care alternative	1	1.5
Appropriate education program	1	1.5

Proactive Role in Shaping Regulations

Part 2 of the definition was assessed by the facilities' responses to Question 15, influencing change, and Question 33, ways in which the facility had changed others regarding regulations. The analysis of the responses follows.

Effecting regulatory change. Data for the next section were collected from Question 15. All but two facilities reported that they were effective in influencing change in areas of regulations or reimbursement. Eighteen (90%) facilities provided 43 examples under 11 themes of the ways in which they effected change (see Table 8). Fifteen (75%) facilities provided more than one example. Ten facilities gave one or two responses and eight facilities gave three or four responses. Two facilities responded that they had not been effective in making changes in regulations or funding. The numbers of responses ranged from 0 to 4 (M = 2.2; SD = 1.15). Interrater reliability of the coding was 62%. For this part of the definition, facilities were given one point for each regulatory change they effected.

Changing others. Question 33 indicated the extent to which the facility was able to influence others to change following exchanges within the network. Twenty (100%) facilities generated 43 responses under eight themes (see Table 9). The number of responses ranged from 1 to 4 (M = 2; SD = 1.2). Interrater reliability of the coding was 80%. Facilities were given one point for each regulatory change they effected.

Table 8

Facility Changes Resulting from Network Exchanges (n = 48)

Category	Number of Responses	Percent of Responses
New or expanded services	12	25
Improved quality of program	7	14.5
Improved cooperation or coordination with other agencies	6	12.5
Increased patient acuity	5	10
Openness to new ideas	5	10
Planning for the future	4	9
Impact of regulations	4	9
More family involvement	3	6
New or changed physical plant	1	2
Perceiving facility as continuum of care	1	2

Table 9

Changes the Facilities Effected on Others (n = 43)

Category	Number of Responses	Percent of Responses
Changed attitudes or awareness	15	35
Others initiated or modified programs	8	18
Changed standards of care	5	12
Impacted hospital discharges	5	12
Impacted regulations or reimbursements	3	7
Changed others' procedures	3	7
Others providing more support or advocacy	3	7
Changed people's lives	1	2

Extracting Resources

Part 3 of the definition was assessed by considering data which were previously tabulated. These included responses related to funding changes in Question 15, related to influencing change; responses to Questions 17 and 18, related to sources of funding, which also were contextual data; responses to Question 13, related to unsolved funding problems; and responses to Question 34, related to the facility's future.

Effecting funding change. The analysis of data from Question 15 was discussed under part 2 of the definition for effectiveness, on page 54. For this part of the definition, facilities were given one point for each funding change they effected.

Medicaid reimbursement. The analysis of data from Question 17, daily Medicaid rate, was discussed under the contextual variable, on page 38. For this part of the definition, the facilities' Medicaid reimbursement rates were scaled. There were 22 rates because two facilities received two different reimbursement rates. Those rates that fell into the first quartile were designated "low"; one point was given to those facilities. Those in the second or third quartile were designated "medium"; two points were given to those facilities. Rates in the fourth quartile were designated "high"; three points were given those facilities.

Unsolved funding problems. The analysis of data from Question 13 was discussed under part 1 of the definition for effectiveness, organizational problems, on page 49. The facilities' unsolved problems related to reimbursement were scaled. Facilities with no unsolved reimbursement problems received three points. Facilities with 1-2 problems received two points. Facilities with three problems received one point.

Supplemental funding. The analysis of data from Question 18 was discussed under the contextual variable, on page 38. Facilities which were actively seeking supplemental sources of income received one point.

Future visions. Question 34 asked administrators to predict their futures. Twenty administrators generated 78 responses which were coded into 16 themes. The number of responses ranged from 1 to 8 (M = 3.9; SD = 1.92). See Table 10 for specific categories, frequencies, and percentages. Interrater reliability of the coding was 87%. One point was given for each stable, new, or expanded program the administrator mentioned. Necessary resources extracted from the environment to assure facility viability can be material, such as financial aid, or non-material, such as affiliation and affirmation. Where administrators extracted confidence of support and a spirit of optimism, one point was given for each. Fourteen (70%) administrators expressed both confidence of support and a spirit of optimism; 1 (5%) expressed confidence of support but discouragement; 1 (5%) expressed optimism even though doubtful of support; and 4 (20%) did not express either confidence of support nor a spirit of optimism.

In summary, data were reported from interview questions related to facility effectiveness. The assignment of numerical points for relevant responses was described. The analysis of the facilities' effectiveness was begun in this section and will be continued in the following section under the research questions.

Research Questions

The specific purpose of this study was to locate pediatric skilled nursing facilities and to describe characteristics of their support networks. The analysis of data from the interview guide will now be used to answer the four research questions related to the purpose of the study.

Table 10

Administrator's Visions for the Future (N = 20)

Category	Number of Facilities	Percent of Facilities
New/expanding programs	10	50
Expansion of bed capacity	8	40
Increased patient acuity	5	25
Response to unmet needs	4	20
Inpatient rehabilitation	4	20
Day care for medically fragile	3	15
Care of preemies	2	10
Programs for AIDS children	2	10
IV therapy	2	10
Foster care programs	2	10
Parent training	2	10
Home care for medically fragile	1	5
Step-down unit	1	5
Hyperalimentation	1	5
Caring for children with CVPs	1	5
Caring for children with Hickmans	1	5
Community placement	1	5
Fetal alcohol syndrome programs	1	5
Programs related to crack babies	1	5
Before-after school care	1	5
Evaluation center	1	5
Focus on 0-3 population	1	5
Respite care	1	5
Physical plant	4	20
New facility	4	20
Normalizing patient environment	4	20
Long-range planning	14	70
Strategic planning process	3	15
Maintain current number of beds	3	15
Facility as hub of services	3	15
Crossroads: Continue or close	3	15
Operational issues	3	15
Resolve funding issues	2	10
Resolve operational issues	2	10
Continued advocacy	1	5

Research Question #1

What are the structural characteristics of the support networks of the pediatric skilled nursing facilities?

In order to answer research question #1, data from Questions 19, 20, 23, and 24 in Section III of the interview guide related to facility supporters were analyzed. The current networks of the sample facilities were described and summarized according to their size, linkages, and composition in the last section, on pages 41 and 42.

Support network size ranged from 9 to 22 members ($\underline{M}$ = 14.9; $\underline{SD}$ = 3.74); the most prevalent was 16 members. Excluding the focal organizations, there were linkages among the network members that ranged from 2-way to 6-way linkages; the most frequently occurring were 2-way linkages. The 12 key categories of facility network composition were identified in Table 2. Only two (10%) facilities identified another pediatric skilled nursing facility as part of their support networks.

Research Question #2

Do the facilities participate in exchanges within their networks and if so, what are the types of exchanges?

In order to answer research question #2, data from responses to Questions 22 and 25 - 31 in Section III of the interview guide related to network exchanges were analyzed in the last section, on pages 44 and 45. The investigator summarized the types of exchanges that occurred between the facilities and others, and analyzed the facilities' costs and rewards in their exchanges. Facilities participated in

exchanges within their networks through giving up resources which the facility controlled in order to obtain resources which another entity controlled and which the facility desired. The facilities desired various types of support from entities within the facility, their communities, their states, and nationally, such as through professional organizations. Their costs included time, effort, and the commitment of financial resources. For example, of the responses indicating what factors encouraged network members to support the facility, 12% reported that the quality of the program attracted supporters; 12% indicated that the facility provided a setting in which the supporters were able to follow their own areas of interest; and 7% indicated that the facility assists supporters to be able to help. A total of 36.5% of responses to that item indicated that the supporter was realizing a personal reward in exchange for the cost to the facility, as the facility was receiving the reward of the individual's support.

Research Question #3

What are the network structural characteristics (i.e., size, linkages, and composition) that correspond with the nursing facilities' effectiveness?

Facility effectiveness. In order to answer research question #3, data from Questions 11 - 15 of Section II and Questions 32 - 34 of Section III of the interview guide related to facility effectiveness were analyzed in the last section, on pages 48-58. Next, facilities were analyzed according to their composite numerical scores on the components of the definition of effectiveness.

Facilities were sorted into groups of those whose administrators summarized their own effectiveness by expressions of both confidence of support and a spirit of optimism, those whose administrators did not, and those with mixed responses. Within these three groups, the facilities' total scores for the components of the definition of effectiveness were examined. There were four facilities in which there were no expressions of confidence and optimism and whose composite scores were among the lowest: 7, 8, 10, and 13, respectively; these were designated as the Less Effective Group. Six facilities whose administrators expressed both confidence of support and a spirit of optimism and whose total scores were the highest, ranging from 18 to 21, were designated as the Most Effective Group. The Moderately Effective Group was composed of 10 facilities whose moderate scores ranged from 13 to 16 and whose administrators may or may not have expressed confidence of support and a spirit of optimism; they included the two facilities which had mixed responses in support and optimism (see Table 11).

The three groups were compared for the components of the definition of effectiveness. In part 1 of the definition, meaningful implementation of imposed regulations, the Less Effective Group ($\underline{n} = 4$) ranged from 4 to 19 problems ($\underline{M} = 9.25$; $\underline{SD} = 6.70$) for level A, milieu within the facility. For level B, milieu within the community, the Less Effective Group ranged from 1 to 2 problems ($\underline{M} = 1.5$; $\underline{SD} = 0.58$). For level C, milieu within the state, the Less Effective Group ranged from 1 to 3 problems ($\underline{M} = 2.0$; $\underline{SD} = 1.15$). For problems related directly to regulations,

Table 11

Effectiveness Groupings by Confidence/Optimism and Composite Scores (N = 20)

	Confidence and Optimism		
Composite Scores	None	Mixed	All
Low (7-13)	Less Effective Group	--	--
Moderate (13-16)	--	Moderately Effective Group	--
High (18-21)	--	--	Most Effective Group

the Less Effective Group ranged from 0 to 1 (M = 0.75; SD = 0.5). For problems related to funding, this group ranged from 0 to 2 (M = 1.25; SD = 0.96).

The Moderately Effective Group (n = 10) ranged from 0 to 12 (M = 4.8; SD = 3.36) for level A problems. For level B problems, this group ranged from 0 to 5 (M = 2.7; SD = 1.70). The group ranged from 0 to 2 (M = 1.2; SD = 0.92) for level C problems. For problems related to regulations, this group ranged from 0 to 5 (M = 2.1; SD = 1.41). The group ranged from 0 to 2 (M = 1.2; SD = 0.92) for problems related to funding.

The Most Effective Group (n = 6) ranged from 3 to 5 (M = 4.0; SD = 0.89) for level A problems. The group ranged from 0 to 7 (M = 3.0; SD = 2.45) for level B problems. For level C problems, the group ranged from 3 to 6 (M = 4.7; SD =

1.51). For problems related to regulations, the Most Effective Group ranged from 1 to 4 (M = 2.7; SD = 1.21). This group ranged from 0 to 3 (M = 1.5; SD = 1.05) for problems related to funding.

The Less Effective Group had one instance of a facility change regarding regulations due to relationships within their networks. The Moderately Effective Group ranged from 0 to 2 (M = 0.80; SD = 0.79) for facility changes. The Most Effective Group ranged from 0 to 1 (M = 1.0; SD = 0.41) for facility changes.

In part 2 of the definition, proactive role in shaping regulations, the Less Effective Group ranged from 1 to 2 (M = 1.5; SD = 0.58) in instances of effecting regulatory change. The Moderately Effective Group ranged from 0 to 2 (M = 0.7; SD = 0.67). The Most Effective Group ranged from 1 to 2 (M = 1.5; SD = 0.55) for instances of effecting regulatory change.

The Less Effective Group had no instances of changing other organizations regarding regulations due to relationships within their networks. The Moderately Effective Group ranged from 0 to 1 (M = 0.1; SD = 0.32) for changing other organizations. The Most Effective Group ranged from 1 to 3 (M = 1.3; SD = 0.82).

In part 3 of the definition, extracting sufficient resources for the facility's viability, the Less Effective Group members had one instance each (M = 1.0; SD = 0.0) of effecting funding changes. The Moderately Effective Group ranged from 0 to 1 (M = 0.5; SD = 0.53). The Most Effective Group ranged from 0 to 2 (M = 1.0; SD = 0.40) for effecting funding changes.

Twenty-five percent of the Less Effective Group's Medicaid reimbursement rates were in the low first quartile of the range of rates; 75% of this group's rates were in the second and third quartiles; none of this group's rates was in the fourth quartile. The group's unsolved reimbursement problems ranged from 0 to 3 ($\underline{M}$ = 1.75; $\underline{SD}$ = 1.26). The Moderately Effective Group had 28% of its facilities' rates in the low quartile, 36% in the second and third quartiles, and 36% in the high fourth quartile. For this variable, $\underline{n}$ = 11 because one state received two rates for levels of care. The Moderately Effective Group ranged from 0 to 3 ($\underline{M}$ = 1.1; $\underline{SD}$ = 1.10) for unsolved reimbursement problems. Forty-three percent of the Most Effective Group's rates were in the high fourth quartile; 57% were in the second or third quartiles; none was in the low first quartile. This group ranged from 0 to 1 ($\underline{M}$ = 0.3; $\underline{SD}$ = 0.27) for unsolved reimbursement problems ($\underline{n}$ = 7 because one facility received two different rates from two states).

Three facilities (75%) in the Less Effective Group sought supplemental funds; the one facility which did not was a not-for-profit organization. Eight (80%) facilities in the Moderately Effective Group sought supplemental funds; of those, four (40%) were proprietary organizations. Of the two (20%) facilities in the Moderately Effective Group which did not seek supplemental funds, one was not-for-profit and one was a proprietary organization. Five (83%) facilities in the Most Effective Group sought supplemental funds. The one (17%) which did not was a proprietary organization.

The number of stable, new, or expanded services envisioned for the future by the Less Effective Group ranged from 0 to 4 (M = 1.0; SD = 4.0). The Moderately Effective Group ranged from 1 to 6 (M = 3.3; SD = 1.57). The Most Effective Group ranged from 2 to 5 (M = 3.7; SD = 1.03) for future services.

None of the Less Effective Group expressed confidence of support or a spirit of optimism in the vision for the future. Ninety percent of the Moderately Effective Group expressed confidence of support and a somewhat different 90% expressed a spirit of optimism. 100% of the Most Effective Group expressed both confidence of support and a spirit of optimism. See Tables 12 and 13 for a comparison of the effectiveness groupings according to the components of the definition.

Network structural characteristics. Next, the facilities' network structural characteristics as analyzed on pages 41 and 42 were considered in relation to the facilities' degrees of effectiveness. The data on the network structural characteristics obtained through this study did not support the investigator's expectations based on the literature review. The network structural characteristics did not correspond to the facilities' degrees of effectiveness according to the way the investigator asked the interview questions (see Table 14).

Research Question #4

Under what contextual circumstances does a facility seem to be effective?

In order to answer research question #4, the investigator compared the contextual circumstances of the facilities in the Most Effective Group with those of the facilities in the Least Effective and Moderately Effective Groups for patterns of

Table 12

Facility Effectiveness by Groupings, Part 1 (N = 20)

Category	Groups		
Effectiveness	Less (n = 4)	Moderate (n = 10)	Most (n = 6)
Part 1: Meaningful implementation of imposed regulations			
Operational Problems A	R = 4-19 M = 9.25 SD = 6.70	R = 0-12 M = 4.8 SD = 3.36	R = 3-5 M = 4.0 SD = 0.89
Operational Problems B	R = 1-2 M = 1.5 SD = 0.58	R = 0-5 M = 2.7 SD = 1.70	R = 0-7 M = 3.0 SD = 2.45
Operational Problems C	R = 1-3 M = 2.0 SD = 1.15	R = 0-2 M = 1.2 SD = 0.92	R = 3-6 M = 4.7 SD = 1.51
Regulatory Problems	R = 0-1 M = 0.75 SD = 0.5	R = 0-5 M = 2.1 SD = 1.41	R = 1-4 M = 2.7 SD = 1.21
Funding Problems	R = 0-2 M = 1.25 SD = 0.96	R = 0-2 M = 1.2 SD = 0.92	R = 0-3 M = 1.5 SD = 1.05
Facility Changes, Regulatory	R = 0-1 M = 0.25 SD = 0.5	R = 0-2 M = 0.80 SD = 0.79	R = 0-1 M = 1.0 SD = 0.41

Table 13

Facility Effectiveness by Groupings, Parts 2 and 3 (N = 20)

Category	Groups		
Effectiveness	Less (n = 4)	Moderate (n = 10)	Most (n = 6)
Part 2: Proactive in shaping regulations			
Effecting regulatory change	R = 1-2 M = 1.5 SD = 0.58	R = 0-2 M = 0.7 SD = 0.67	R = 1-2 M = 1.5 SD = 0.55
Changing others	0	R = 0-1 M = 0.1 SD = 0.32	R = 1-3 M = 1.3 SD = 0.82
Part 3: Extracting necessary resources			
Effecting funding changes	R = 1 M = 1.0 SD = 0.0	R = 0-1 M = 0.5 SD = 0.53	R = 0-2 M = 1.0 SD = 0.40
Medicaid rate	Q1 = 25% Q2&3 = 75% Q4 = 0%	Q1 = 28% Q2&3 = 36% Q4 = 36%	Q1 = 0% Q2&3 = 57% Q4 = 43%
Unsolved reimbursement problems	R = 0-3 M = 1.75 SD = 1.26	R = 0-3 M = 1.1 SD = 1.10	R = 0-1 M = 0.3 SD = 0.27
Seeking supplemental funds	3 (75%)	8 (80%)	4 (83%)
Future services	R = 0-4 M = 1.0 SD = 4.0	R = 1-6 M = 3.3 SD = 1.57	R = 2-5 M = 3.7 SD = 1.03
Confidence of support	0%	90%	100%
Spirit of optimism	0%	90%	100%

Table 14

Network Structural Characteristics by Effectiveness Groups (N = 20)

Effectiveness Groups	Size	Linkages	Composition
Most Effective (n = 6)			
1	9	8	5
2	14	10	6
3	18	10	10
11	20	12	9
12	18	14	7
20	18	14	10
Moderately Effective (n = 10)			
5	12	7	8
6	11	9	7
9	16	9	7
10	22	15	10
13	16	9	9
15	11	4	7
16	10	6	7
17	13	9	8
18	16	11	8
19	14	9	9
Less Effective (n = 4)			
4	9	6	7
7	16	15	9
8	16	12	9
14	19	11	9

similarities and differences. Utilizing the analysis of the contextual data in a previous section, on pages 35-40, the facilities' internal, community, and state environments were summarized (see Table 15).

Milieu within the facility. Five of the six facilities within the Most Effective Group were freestanding pediatric skilled nursing facilities; one was a small (<50) pediatric component of an adult facility. Three of the freestanding facilities had patient populations of 50 or more; two of the three facilities had patient populations near 100. The number of pediatric patients for the six facilities ranged from 12 to 99 (M = 54.3; SD = 35.91). All four of the facilities within the Less Effective Group were freestanding pediatric skilled nursing facilities. Two facilities had patient populations of 50 or more; two had fewer than 50 patients. The number of pediatric patients for the Less Effective facilities ranged from 20 to 80 (M = 50.5; SD = 25.16). Of the 10 facilities within the Moderately Effective Group, 6 were freestanding pediatric skilled nursing facilities; 4 of these had 50 or more patients. The four facilities that were pediatric components of adult skilled nursing facilities had fewer than 50 pediatric patients each. The number of pediatric patients for the facilities in the Moderately Effective Group ranged from 12 to 120 (M = 49.3; SD = 38.47).

Five of the facilities in the Most Effective Group were not-for-profit organizations; the sixth facility was a private, proprietary organization. All four facilities in the Less Effective Group were not-for-profit organizations. The 10

facilities in the Moderately Effective Group were evenly divided between proprietary and non-for-profit organizations.

The facilities in the Most Effective Group ranged from 7 to 25 years for the length of time they provided pediatric skilled nursing care (M = 15.2 years; SD = 8.86). The Less Effective Group facilities ranged from 14 to 19 years (M = 17.5 years; SD = 2.38). The facilities in the Moderately Effective Group ranged from 1 to 22 years (M = 13.6 years; SD = 7.81) of providing pediatric skilled nursing care.

For the Most Effective Group, the administrators' length of time in the position ranged from 1.3 to 8 years (M = 4.6 years; SD = 3.08). The Less Effective Group's administrators ranged from 0.33 to 4.5 years (M = 3.1 years; SD = 1.97) in their positions. The administrators in the Moderately Effective Group ranged from 0.83 to 17 years (M = 6.8 years; SD = 5.18).

Milieu within the community. None of the facilities in the Most Effective Group was located in a rural area; four were in urban locations and two were in suburban locations. One of the facilities in the Less Effective Group was in a rural location; one was in a suburban location; and two were in urban locations. Of the 10 facilities in the Moderately Effective Group, two were in rural locations and two were in suburban locations.

Milieu within the state. Medicaid reimbursement to the facilities was scaled into quartiles in the previous results section, on page 57. Three of the facilities in the Most Effective Group received reimbursement in the high fourth quartile; the three remaining facilities in that group received medium-level reimbursement rates.

In the Less Effective Group, one facility received a rate in the low first quartile; three facilities received reimbursement rates in the medium level. In the Moderately Effective Group, 3 facilities received low-level reimbursement rates; 4 received medium-level rates; 2 received high rates; and 1 received both a low rate and a high rate for different levels of care.

None of the six states represented by facilities in the Most Effective Group adopted separate licensing regulations for pediatric skilled nursing facilities; one state represented had pediatric regulations pending. Three facilities in this group reported that state nursing home surveyors took the needs and differences of pediatric patients into account when interpreting the facility's compliance with regulations. One of the four states represented in the Less Effective Group adopted regulations for pediatric skilled nursing facilities; three facilities in this group reported that nursing home surveyors considered pediatric differences regarding nursing home regulations. Of the 10 states represented in the Moderately Effective Group, 4 adopted separate pediatric regulations; 1 state had regulations pending. The facilities in this group were evenly divided regarding surveyor interpretation of regulations. One state with separate pediatric skilled nursing home regulations was represented by a facility in the Less Effective Group and one in the Moderately Effective Group. A state without separate pediatric regulations was represented by a facility in the Most Effective Group and one in the Less Effective Group.

Three of the six facilities in the Most Effective Group were located in states having more than one pediatric skilled nursing facility in the target population; one

reported some degree of networking among their facilities. In the Less Effective Group, three of the four facilities were located in states having multiple pediatric skilled nursing facilities; none reported active networking among their facilities, although one facility reported that such activities took place in the past. Four of the 10 facilities in the Moderately Effective Group were located in states having multiple pediatric skilled nursing facilities; one reported active networking among their facilities. Two states were represented by two facilities each in the sample; no state was represented by more than one facility in any of the effectiveness groups.

The contextual circumstances of the facilities did not seem to correspond to facility effectiveness. There were no discernible patterns of similarities or differences either between or among the effectiveness groups.

Table 15

Contextual Circumstances by Effectiveness Groups (N = 20)

Effectiveness Groups	Freestanding	Distinct Part	Location	Ownership	Years as PSNF	Administration's Experience in PSNF	Medical Rate	PSNF License
Most Effective (n = 6)								
1		<50	U[1]	NFP[4]	7	7	H	N
2	>50		S_2	P[5]	8	2	H	N
3	>50		U	NFP	25	8	H	N
11	<50		S	NFP	7	7	M	Y
12	<50		U	NFP	19	1.33	M	N
20	>50		U	NFP	25	2	M,M	N
Moderately Effective (n = 10)								
5		<50	U	P	19	4	M	Y
6	<50		U	P	18	7.5	H	N
9		<50	U	NFP	19	6	L	Y
10	>50		U	NFP	18	17	M	N
13		<50	U	P	5	5.5	H	N
15		<50	R[3]	P	1	0.83	L,H	Y
16	>50		R	P	2	2	L	Y
17	>50		S	NFP	15	12	M	Y
18	<50		S	NFP	22	2	M	N
19	>50		U	NFP	17	11	L	N
Less Effective (n = 4)								
4	<50		S	NFP	19	4.5	M	N
7	>50		R	NFP	19	4.5	M	Y
8	<50		U	NFP	18	0.33	M	N
14	>50		U	NFP	14	3	L	N

[1]Urban
[2]Suburban
[3]Rural
[4]Not for profit
[5]Proprietary

CHAPTER IV

Discussion

Context of Pediatric Skilled Nursing Facilities

The literature review revealed a dearth of articles on long term care facilities providing a planned 24-hour nursing care program for medically fragile children who no longer require an acute level of care. There was evidence, however, that there was an increasing need for such type of care with the rising survival rate of health-impaired children. One indication was the majority of facilities with waiting lists. The number of facilities caring for tracheostomy-dependent and ventilator-dependent children was an indication of both the increasing need for pediatric skilled nursing care and the increasing level of acuity of long term pediatric patients; only one facility in the sample did not provide care for children with either tracheostomies or ventilators. The investigator visited pediatric skilled nursing facilities in Ohio in 1979 and in New York in 1987. In those years, neither facility was caring for children even with tracheostomies, although the Oregon facility in which the investigator worked was doing so in 1967. The length of time the facilities provided pediatric skilled nursing care also was indicative of the growing need for this level of care for children. Seven of the sample facilities began providing the care within the last 10 years. Two of those facilities provided care to 99 patients and to 120 patients, respectively. Six of those seven facilities had a waiting list for pediatric patients. The seventh, and newest, program had been in operation for one year and had not yet developed a waiting list.

Freestanding pediatric skilled nursing facilities tended to have larger populations; two-thirds of the facilities had 50 or more patients. Pediatric units of adult nursing facilities, on the other hand, tended to have smaller pediatric programs; 82% of these had fewer than 50 children. The five such facilities included in the sample demonstrated that good care can be provided to children within adult settings. Administrators reported, however, that the pediatric program made up a small proportion of the total patient population and that unique pediatric needs were not always recognized and attended to in as timely a manner as they would wish. It seemed easy at times for the children's issues to get "lost in the shuffle."

The smallest pediatric skilled nursing facility, two pediatric patients within an adult facility, was located in a rural community several hundred miles from any other facility providing pediatric skilled nursing care. Without this facility's planned pediatric program, families would have lacked a needed and appropriate resource. The facility was organizationally related to and received technical assistance from an urban facility that provided pediatric skilled nursing care. While larger pediatric units may be easier to plan for and to staff, facilities were able to provide even very small planned, organized, appropriate pediatric skilled nursing programs, particularly by developing support networks.

Facilities in both urban and rural locations were included in the sample. None of the rural facilities, however, was designated to the Most Effective Group. Although there were some operational problems associated with a rural location, such as difficulty with recruiting staff, the operational problems seemed to be related

more to the facilities' own particular situations rather than to their rural locations. Some examples of situational problems that were probably not related to facilities' rural locations included: the state's policies regarding admissions; the state's requirement for prior approval for purchase of equipment and supplies; the state's severe economic depression; difficult working relationships with local school districts; and philosophical differences with owners.

The financial realities of providing a high level of nursing care to medically complex and unstable children whose source of funding was primarily Medicaid was an impediment to some organizations exploring the feasibility of initiating a pediatric skilled nursing program. There was a wide range of Medicaid reimbursement rates nationwide. Yet, six (30%) of the sample facilities were private, proprietary organizations seeking to earn a profit and half of those six were freestanding pediatric facilities, which limited the amount of cross-subsidization otherwise possible through a mix of payment sources. One of the six proprietary facilities had the highest Medicaid rate of the sample facilities and did not engage in fund-raising activities. The other five proprietary facilities, although limited in their abilities to seek philanthropic support for operations, accepted restricted-use supplemental funds, such as for donations for playground equipment or field trips for the children. The proprietary facilities demonstrated that quality pediatric skilled nursing care can be provided in a cost-effective manner while realizing a return on investment.

Only two of the five facilities that were members of vertically-integrated health care systems were designated to the Most Effective Group. This suggested

several possibilities: that facility effectiveness as measured in this study was attributed to factors other than corporate resource-sharing; that there was insufficient corporate resource-sharing within the other three systems to make a stronger impact on facilities' effectiveness; or that the other three facilities might have been even less effective without the support of their health care systems.

Support Networks

One of the specific purposes of this study was to describe the support networks of pediatric skilled nursing facilities. Networks were described by several authors in the literature review as consisting of sets of individuals or groups whose relationships linked them together in some way. Based on the review, including exchange theory literature, a network was defined for this study as an interrelated web of individuals or groups voluntarily linked by a set of common interests and interdependent on one another for the exchange of information, ideas, advice, resources and moral support, and to effect change. Pediatric skilled nursing facilities lacked organizational linkages with each other. Opportunities to share information and ideas, to strengthen and to be strengthened, to enhance others and to benefit, were lost. In order to assess common areas of interest and concern with a view toward future sharing among the facilities, their current support systems were identified. Network structural characteristics of size, composition, and linkages; and their functional characteristic of exchanges were examined.

Identifying individuals or groups which the administrators considered to be supporters seemed for some to be an unfamiliar line of thought. For some

administrators, it took several probes to stimulate the desired mode of thinking for this open-ended question. There was variation in the administrators' responses. Some administrators named many supporters in each category, for example, several groups of volunteers providing either direct service to the children or working for the organization in such activities as fund-raising. Other administrators listed the aggregate, for example, community volunteers. There was also variation in the amount of probes the investigator initiated. It was apparent from the contents of the full interviews that under other circumstances, for example, more experience in thinking along the required lines, less distraction, and less fatigue factor due to the lengthy interview, all facilities could have identified additional network members.

According to some theories, the greater the size of a network and the more varied the composition, the more reliable and effective the members' support is likely to be. The data gathered in this study did not demonstrate a relationship between network size, composition, or linkages and facility effectiveness. This could be due to the manner in which the data was obtained. At another time, an investigator could identify key network composition and linkages, and use close-ended questions or uniform probes, rather than relying on the administrators' recall or consciousness of certain entities. The lack of a demonstrated relationship between network structural characteristics and facility effectiveness also could be due to the network functional characteristic of exchanges; that is, facilities may have failed to engage in effective, productive exchanges within their support networks.

All facilities identified parents as members of their support networks, yet only 12 (60%) had parent groups. Parent groups can be costly to facilities in terms of staff time and effort, yet effectively mobilized parent power can have persuasive impact on legislators and policy-makers. This readily-available resource seemed to be underdeveloped.

Fourteen (70%) facilities had newsletters. Like parent groups, newsletters can be costly in terms of staff time, effort, and facility money. For several facilities, however, this was a vehicle for networking with volunteers, financial supporters, parents of former patients, legislators and others who had been or in the future could be advocates for the facility. Parent groups and newsletters are tools which promote the enhancement of network size, composition, linkages, and exchanges and, according to network theory, allow facilities to increase the reliability and effectiveness of their support.

In order for individuals or groups to become voluntarily linked and to exchange information, ideas, advice, resources and moral support and to effect change, the individuals or groups must recognize that another controls a resource they desire and they must be willing to pay the cost in exchange. Seven states had more than one pediatric skilled nursing facility: Alabama, two; Illinois, 10; Louisiana, two; Massachusetts, four; New Jersey, three; New York, six; and Oregon, seven. Yet, only New York and Illinois and, on a sporadic basis, Massachusetts, had regular networking among the facilities, which emphasized the facilities' tendency

toward organizational and geographic isolation, lack of recognition of how each facility could be enriched, and the underdeveloped opportunities for exchanges.

In addition to enhancing collaboration within states with more than one facility, networking opportunities could be extended to facilities in adjacent locations. A review of facility locations in the United States revealed regional possibilities. Some combinations could occur fairly easily; some would take more effort on the part of the facilities to find a common meeting place. In the Northeast, Massachusetts' 4 facilities meet sporadically; they could include Rhode Island (1) and Vermont (1) in that region. New York's 6 facilities meet from time to time; they could include New Jersey (3). As an alternative, it is possible that all 15 facilities in the larger geographic region from Vermont to New Jersey could meet together. In the Midwest, Illinois' 10 facilities meet regularly; they could extend an invitation to the surrounding states of Iowa (1), Missouri (1), Kentucky (1), Indiana (1), Michigan (1) and possibly Ohio (3). The South had no current networking opportunities. However, Alabama (2), Louisiana (2), Texas (1), and Oklahoma (1) could begin collaboration efforts. In the West, Oregon's 7 facilities could initiate networking opportunities and include California (1), Utah (1), Alaska (1) and the facility that is anticipated in Washington State in 1992.

Effectiveness

A multi-faceted definition of effectiveness was used for this study. Facilities' responses to an array of factors were used in determining their degrees of effectiveness; no single measurement was used to group the facilities. Although the

results did not support a clear hierarchy, with the Most Effective Group scoring the highest numerical value for each attribute and the Less Effective Group scoring the lowest, nonetheless some generalizations were indicated. Although all facilities were considered to have a basic level of effectiveness, the six facilities designated to the Most Effective Group generally were focused not only inwardly on operational problems but also outwardly toward the community and the state to address interdependent issues; they maximized the exchanges within their networks in order to effect changes within their facilities as well as changes in others. Although the facilities in the Most Effective Group did not all receive the highest Medicaid reimbursement rates, nor did they receive the only high Medicaid rates, that group's percentages of high rates compared with other groups' (see Table 14) indicates that facilities are more likely to be successful when they can access the necessary resources.

Confidence of support and a spirit of optimism, as well as a view of the future, were included in the effectiveness assessment because they are related to the organization's insight about itself and its mission and to the organization's ability to extract resources from the environment. Statements of future facility plans, confidence, and optimism encapsulated the administrator's belief about the balance between the facility's burdens and benefits and its hopes for the future. As one administrator said, "In spite of all that, I feel upbeat!" That administrator went on to list seven positive expectations for the facility's future. As another administrator said, "We will be bigger and better and newer!" Three other administrators,

however, expressed their beliefs that their facilities were at crossroads and that their facilities may or may not continue into the future. One of the facilities whose administrator believed it to be at a crossroads was considered to be a state-of-the-art facility. At another point in its history, its effectiveness probably would have been assessed much higher than in this study. The administrator was severely distressed by the downturn of the economic conditions in the state and their effects on the facility.

The effectiveness scoring did not reflect the impact of changing circumstances within the facility's milieu, such as those experienced by the above facility. In addition, the numbers of internal, community and state problems per facility did not reflect that some facilities were actively working on problems while others were not and yet others had resolved them. Some facilities were in adversarial atmospheres related to certain problems and others were not. Some of the solved problems could be tied to the effects of networking and outreach but unsolved problems could not be said exclusively to be caused by lack of networking. The data gathered in this study did not demonstrate a relationship between gender, professional preparation, or prior pediatric experience of the administrators and facility effectiveness.

Facility effectiveness incorporated the results of network exchanges including coalition activities, which are a type of network function. The facilities were dependent upon the states' interpretation of regulations which, except where states developed separate pediatric regulations, were intended for a different patient population. Should the state surveyor declare the facility to be out of compliance

with regulations in a situation in which the facility implemented a regulation in a way that addressed a unique pediatric need, the facility and the state must resolve their differences. Failing successful resolution of the issue, the state can invoke a number of sanctions, including facility closure. Yet, only about half the facilities reported that the state nursing home surveyors considered pediatric differences and needs when determining the facility's compliance with regulations, and only 30% of the states had developed regulations specific to pediatric concerns. The facilities were challenged to implement regulations meaningfully for their patient populations while complying with state and federal requirements; they also were challenged to promote understanding of pediatric needs within their state bureaucracies.

CHAPTER V

Summary

This study developed out of a concern for children who need 24-hour skilled nursing care and their families, and the facilities who struggle in geographic and organizational isolation to provide the care. The identities of a few pediatric skilled nursing facilities were known; others were unknown but believed to exist.

The literature review examined the definition and incidence of medically fragile children; the impact on their families; the types of residential care settings in which the children might receive services; network literature, particularly that relating to the structural characteristics of size, linkages, and composition and the functional characteristic of exchanges; and literature on organizational effectiveness.

The conceptual framework for this study was based on network theory from an exchange perspective. Each facility must weigh the balance of rewards and costs for its own exchanges. Networks provide the means for the facilities to move from geographic and organizational isolation to positions of solidarity with each other.

A three-phase process was conceptualized for this study that envisioned the facilities evolving from isolated, unorganized entities through network organization to political activism and cohesiveness as a coalition. The entire process takes place within the context of the facilities individually and as an aggregate. This study was restricted to the first phase of the process.

Forty-nine pediatric skilled nursing facilities in 20 states were identified through this study. They were freestanding facilities and distinct parts of adult

facilities; proprietary and not-for-profit; in urban and rural locations; and they provided an increasingly needed level of care to children and families.

The facilities' support networks were analyzed for size, linkages, composition, and exchanges. With a few exceptions, the facilities were geographically and organizationally isolated and unaware of the others' existence.

The facilities' effectiveness was assessed using an array of factors that related to a three-part definition of effectiveness. The facilities in the Most Effective Group were judged to be balanced in the internal, community and state levels of problems with which they were concerned; successful in resolving both regulatory and reimbursement problems; successful in effecting changes particularly regarding regulations and funding; successful in effecting change in others regarding regulatory issues; successful in negotiating an adequate Medicaid reimbursement rate and in seeking supplemental funding; successful in envisioning a future with stable, new, or expanding services; confident of others' support into the future; and evidencing a spirit of optimism.

Strengths and Limitations

There were several strengths as well as several limitations to this study. Truly, this was uncharted territory. The number of facilities located was beyond the investigator's initial imaginings. A directory of facilities was developed which will facilitate the facilities' networking among themselves. Copies were provided to all facilities in appreciation for their participation in the study. The directory is

available at cost to other interested health care providers such as health planners and hospital discharge coordinators.

The method selected for this study allowed human contact with facility administrators who were isolated and many of whom, until the initial telephone call, did not know they had a peer group. The warmth and enthusiasm with which the investigator was welcomed helped to establish a bond that reflected the kind of moral support that can be enjoyed through networking. The investigator provided an opportunity for the administrators to catharse with another pediatric nursing home administrator, which in some instances added considerably to the length of the site visit. The physical visit to the facilities, seeing and hearing their successes and challenges, and moving on to the next facility stimulated networking among the facilities by the second site visit. Each facility gave permission to share its demographic information, and several facilities needed the information before the site visits were completed. The felt need for networking and for technical assistance was made evident by the telephone contacts to the investigator initiated by individuals throughout the United States since this study began.

The methods selected for this study were necessary and appropriate but also were limitations. Administrators' responses were dependent on several factors, including the rapport that the investigator and the administrator established. The investigator was a nursing home administrator whom the facility administrator did not know. Although most of the administrators seemed to give candid comments,

responses may have been slanted toward the facility administrator's perception of social acceptability and desire to appear knowledgeable to a peer.

The site visits were long and the administrators were busy. Some interviews were made lengthier by interruptions and distractions from staff or telephone calls. Responses to the interview items may have been restricted by the degree that the administrator previewed the interview guidelines, the amount of effort put into the interview, and the administrator's degree of articulateness. In addition, the investigator varied somewhat in the number and types of cues and probes given to stimulate the administrators' thinking. The investigator's fatigue and the varying degrees of pressure to get to the next appointment were also limitations for some facilities.

There was considerable variation in the facilities' problem lists, one of the factors used to assess effectiveness. The administrators' responses were limited to the problems that came to their minds during the interviews. Some may have dealt with a particular problem but not have thought of it during the interview. The internal state of the facility influenced the amount of attention some administrators gave to community or state concerns.

Although the interview guide was tested through a pilot application, repeated administration of the interview questions showed that some subject areas were covered in several questions, and that the administrators began to omit items that had already been discussed and to respond only with new information. The fatigue factor was a limitation in some instances.

Implications for Future Research

Identification of potential network members enhanced the first element of network theory, that of identification of potential members of one's network, by describing the characteristics of the pediatric facilities. An analysis of each facility's existing network enhanced the understanding of network theory as applied to geographically and organizationally isolated, specialized health care facilities. Through the investigator's providing information to facilities about each other during the site visits and by the compiled directory, future studies can analyze the second phase of the conceptual framework, the network relationships that develop, or do not develop, among the facilities and the reasons. Further research is needed to test network theory after the introduction of an intervention, that of communication of problems and strategies among the facilities.

The third phase of the conceptual framework, coalition-building and political activities with state and federal governments, also should be studied. Previous work on exchange theory has concentrated on rewards and costs between entities that compete for limited resources, such as patient populations. This group of facilities is not competing among each other for the same patients; further studies could analyze the differences and similarities of their exchanges with those in previous research.

Facilities' effectiveness could have been measured in other ways, for example, by Nursing Home Survey results; this was not a management study, however, but a study focusing on networks. Future research could focus on other measures of

facilities' effectiveness and use a format to obtain data that would tend toward more predictive correlations.

Implications for Practice

Nurses whose specialty area is community health care systems are concerned not only with individual patients and families but also with the systems that provide their care. Nurses in newborn nurseries, pediatric acute care and intensive care units, pediatricians' offices, and community-based clinics meet medically fragile children and their families for whom caring for the child at home is not an option or is no longer an option. The dearth of alternatives for the child can be anguishing for the family as well as for the concerned nurse. The results of this study will be disseminated to health care professionals, to affirm out-of-home nursing care as a legitimate component in the continuum of pediatric health care, to provide a list of facilities to assist families and health care providers with locating pediatric skilled nursing care, and to stimulate public and private planners to develop additional facilities. The large number of facilities that reported anti-institutional bias, and the small number of facilities whose state surveyors take pediatric differences into account when interpreting regulations indicate great need for nurses to intervene through teaching. The struggle is likely to be long and hard; intellectual knowledge alone does not overcome emotional prejudices.

The results of this study will be shared among the nation's pediatric skilled nursing facilities and can guide the development of approaches to enhance the facilities' strengths and to neutralize, change, or eliminate their weaknesses. The

facilities will be able to become acquainted with others providing the same type of care and to network with others to share information, to problem-solve, to gain negotiating strength within their states, and to be models for new facilities. Perhaps the most important results of this study will be bondedness and hope.

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APPENDIX A

Pediatric Skilled Nursing Facilities

Telephone Survey

1. Facility Name: _____

2. Address: _____

   City, State, Zip: _____

3. Phone: _____ 4. Location: ☐ Urban ☐ Rural

5. Administrator: _____

6. Telephone Contact Person: _____

7. License Category: ☐ Skilled ☐ Intermediate ☐ ICF/MR ☐ Other

   (If not skilled, thank them for their time and information, and do not gather further information).

8. Does your facility routinely provide 24-hour nursing care to infants and children 0-21 years? ☐ Yes (*go to #9*) ☐ No (*go to #10*)

9. If yes, is your facility exclusively pediatric? ☐ Yes ☐ No

   Comments _____

10. If not exclusively pediatric, are the children cared for in a specific section of your facility? _____

11. What are the ages of the children for whom you provide care?

    _____

12. Total number patients: _____ Total number pediatric patients: _____

13. How long has your facility provided pediatric skilled nursing care?

_____

14. Do you have contact with any other facility providing pediatric skilled nursing care? ☐ Yes ☐ No If yes, what is its (their) name(s) and location(s)?

_____

15. Would you be willing to participate in a site visit and spend 2-3 hours with a researcher, touring your facility and describing various characteristics of your program? The site visit would be this fall, sometime between mid-September and mid-October. ☐ Yes ☐ No Comments _____

_____

16. Do you think that a network of pediatric skilled nursing facilities would benefit your facility? ☐ Yes ☐ No Comments _____

_____

17. Would you be willing to have your facility listed in a directory of pediatric skilled nursing facilities? ☐ Yes ☐ No Comments _____

_____

18. Would you like to talk with the researcher directly, either during the study or after the information about pediatric skilled nursing facilities is compiled?

☐ Yes, during study ☐ Yes, after compilation ☐ Not necessary

Comments _____

APPENDIX B

PEDIATRIC SKILLED NURSING FACILITIES IN THE UNITED STATES

First Edition

Identifying Information as of December, 1991

Facility names were provided by the Medicaid Agency in each state or through networking information.
Please provide additions, deletions, or corrections to:

Sister Katherine Smith, RN, NHA
29 S.E. 52nd Ave.
Portland, Oregon 97215
(503) 235-8215

Alabama

*1. Father Purcell Exceptional Children's Center
2048 W. Fairview
Montgomery, Alabama 36100
(205) 834-5590
Sponsoring Organization: City of St. Jude; Catholic Archdiocese of Mobile;
Not-For-Profit.
Frank May, Administrator
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1976 (31-year-old organization).
58 children ages 6 months - 21 years.

2. Father Walter Memorial Child Care Center
2815 Forbes Drive
Montgomery, Alabama 36110
(205) 262-6421
Sponsoring Organization: Resurrectionist Fathers;
Not-For-Profit.
Audrey Wright, Administrator
Dahl Moore, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
30 -year-old organization.
44 children ages 1 year - 18 years.

Alaska

*3. Our Lady of Compassion Care Center
4900 Eagle Street
Anchorage, Alaska 99503
(907) 562-2281
Sponsoring Organization: Sisters of Providence Corporations; Not-For-Profit.
Thomas Boling, Administrator
Lynn Towner, RN, Director of Nursing
12-bed pediatric unit within adult facility (total 216 patients); Urban location.
Has provided pediatric SNF care since prior to 1983 purchase.
12 children ages 0 - 10 years.
Ventilator-dependent children.

Arizona

No facilities located.

Arkansas

No facilities located.

California

*4. Children's Convalescent Hospital
8022 Burmingham Drive
San Diego, California 92123
(619) 576-5833
Sponsoring Organization: Children's Hospital of San Diego; Not-For-Profit.
Joyce Turner, Administrator
Debi Jennings, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1973 (became "Distinct Part SNF" on 1/1/91).
59 children ages 0 - 22 years.

Colorado

No facilities located.

Connecticut

No facilities located.

Delaware

No facilities located.

Florida

5. Tender Care
1821 S.E. 4th Ave.
Ft. Lauderdale, Florida 33316
(305) 763-6270
Sponsoring Organization: Steven Dietz, Owner;
Proprietary.
Stephen Dietz, Administrator
JoAnn Guinta, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care on 12-hour basis since 1988; on 24-hour basis since mid-1990.
18 children ages 1 week - 6 years.
N.B.: THIS FACILITY IS NOT LICENSED ACCORDING TO SNF REGULATIONS BECAUSE FLORIDA DOES NOT LICENSE NURSING HOMES FOR CHILDREN. IT IS, HOWEVER, PROVIDING THE SAME TYPE OF CARE AS PEDIATRIC SKILLED NURSING FACILITIES.

Georgia

No facilities located.

Hawaii

No facilities located.

Idaho

No facilities located.

Illinois

6. St. Luke Health Care Center
Rural Route 3, Box 446
Beardstown, Illinois 67618
(217) 323-2720
Sponsoring Organization: Lutheran Social Services of Illinois;
Not-For-Profit.
Gerald Owen, Administrator
Barbara Gordon, RN, Director of Nursing
50-bed pediatric unit within adult facility (total 129 patients);
Rural location.
Established as "Skilled Care Under Age 22" (Illinois pediatric SNF) in January, 1989.
50 children ages 0 - 21 years.

7. Marklund Children's Home
164 South Prairie Ave.
Bloomingdale, Illinois 60108
(708) 529-2871
Sponsoring Organization: Healthcorp Affiliates;
Not-For-Profit.
Patricia Pearce, President
70-bed pediatric unit within a "lifetime care" facility (total 98 patients);
Urban location.
Has provided pediatric SNF care for 36 years.
70 children ages 1 week - 21 years.

8. Nursing Center of Canton
1675 East Ash Street
Canton, Illinois 61520
(309) 647-5631
Sponsoring Organization: Signature Corporation;
Proprietary.
Michael Frawley, Administrator
Beverly Biswell, RN, Director of Nursing
32-bed pediatric unit within adult facility (total 194 patients);
Rural location.
Has provided pediatric SNF care for 12 years.
32 children ages 0 - 22 years.

9. Champaign Children's Home
109 Kenwood Road
Champaign, Illinois 61820
(217) 356-5164
Sponsoring Organization: Hoosier Care, Incorporated;
Not-For-Profit.
Terry Ellis, Administrator
Kathy Schmidt, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1975.
87 children ages 0 - 22 years.

10. Augustana Center for Developmentally Delayed Child
7464 North Sheridan Road
Chicago, Illinois 60626
Sponsoring Organization: Lutheran Social Services of Illinois;
Not-For-Profit.
Thomas Sullivan, Administrator
Donna Fahrenbach, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care for 12 years.
150 children ages 0 - 21 years.

*11. Misericordia Home
2916 W. 47th Street
Chicago, Illinois 60632
(312) 254-9595
Sponsoring Organization: Catholic Charities, Archdiocese of Chicago; Sisters of Mercy;
Not-For-Profit.
Betty Flynn, RN, Administrator
Deborah Ryan, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1972 (41-year-old organization).
110 children ages 0 - 22 years.

12. Little Angels Nursing Home, Inc.
Rte. 4, Box 304, Rte 58
Elgin, Illinois 60120
(708) 741-1609
Sponsoring Organization: Private Corporation;
Proprietary.
Shelley Wasmond, Administrator
Susan Bagherpour, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care for 26 years.
50 children ages 0 - 22 years.

13. Children's Habilitation Center
121 West 154th Street
Harvey, Illinois 60426
(708) 596-2220
Sponsoring Organization: Private Corporation;
Proprietary.
Daniel Westlake, Administrator
Helga Wostl, RN, Director of Nursing
Freestanding pediatric facility with waivers for patients over 22 years of age;
Urban location.
Has provided pediatric SNF care since 1975.
60 children ages 2 months - 21 years.

14. Walter Lawson Children's Home
1820 Walter Lawson Drive
Rockford, Illinois 61111
(815) 633-6636
Sponsoring Organization: Hoosier Care, Incorporated;
Not-For-Profit.
Theo Brandel, Administrator
Jan Primuth, RN, Director of Nursing
Freestanding pediatric facility with waivers for patients over 22 years of age;
Urban location.
Has provided pediatric SNF care since 1971.
85 children ages 0 - 21 years.

15. Exceptional Care and Training Center
2601 Woodlawn Rd.
Sterling, Illinois 61081
(815) 626-5820
Sponsoring Organization: Hoosier Care, Incorporated;
Not-For-Profit.
Jerry Fyhrlund, Administrator
Anna Carroll, RN, Director of Nursing
Freestanding pediatric facility with waivers for patients over 21 years of age;
Rural location.
Has provided pediatric SNF care since 1979.
50 children ages 0 - 21 years.

Indiana

16. Vernon Manor
1955 S. Vernon St.
Wabash, Indiana 46992
(219) 563-8438
Sponsoring Organization: Hoosier Care, Incorporated;
Not-For-Profit.
Jocylyn Ravenscroft, Administrator
Claudia Fleck, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric skilled nursing care since 1968.
96 children 0 - 21 years; approx. 40 individuals 21 - 30 years (total 136 patients).

Iowa

*17. Children's Habilitation Center
5900 Pioneer Parkway
Johnston, Iowa 50131
(515) 270-2205
Sponsoring Organization: Convalescent Home for Children; Not-For-Profit.
Jack Vogt, Administrator
Connie Sue Hoffman, RN, Director of Nursing
Mary Goodrich, Social Worker
Freestanding pediatric facility;
Suburban location.
Has provided pediatric SNF care since late 1960s (63-year-old organization).
28 children ages 0 - 22 years.
4 ventilator-dependent patients.

Kansas

No facilities located.

Kentucky

*18. Home of the Innocents
Pediatric Convalescent Center
485 E. Gray
Louisville, Kentucky 40202
(502) 561-6600
Sponsoring Organization: Home of the Innocents;
Not-For-Profit.
Sandy Schmidt Leach, RN, Administrator and Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1971.
40 children ages 0 - 21 years.

Louisiana (N.B.: Louisiana has approved Pediatric Skilled Nursing Facility regulations.)

19. South Down Care Center
1395 West Tunnel Blvd.
Houma, Louisiana 70360
(504) 872-4553
Sponsoring Organization: Private Corporation;
Proprietary.
Patty Fruge, Administrator
23-bed pediatric unit within adult facility (total 138 patients);
Rural location.
Has provided pediatric SNF care for 7 years.
23 children ages 0 -21 years;
Ventilator-dependent children.

*20. Iberville Living Center
1601 River West Drive
Plaquemine, Louisiana 70764
(504) 687-0240
Sponsoring Organization: ARA Living Centers; Proprietary.
Madeline Giroir, Administrator
22-bed pediatric unit within adult facility (total 180 patients);
Rural location.
Has provided pediatric SNF care since October, 1989. 22 children ages 0 - 21 years;
2 ventilator-dependent children.

Maine

No facilities located.

Maryland

No facilities located.

Massachusetts

(N.B.: Massachusetts has approved Pediatric Skilled Nursing Facility regulations.)

*21. New England Pediatric Care
78 Boston Road
North Billerica, Massachusetts 01862
(508) 667-5123
Sponsoring Organization: New England Medical Center; Not-For-Profit.
Joyce McDonald Shannon, RN, Administrator
Sharon Chiary, RN, Director of Nursing
Freestanding pediatric facility;
Rural location.
Has provided pediatric SNF care since early 1970s.
80 children ages 0 - 21 years;
2 ventilator-dependent children.

22. Children's Extended Care
22 Hillside Ave.
Groton, Massachusetts 01450
(508) 448-3388
Sponsoring Organization: Children's Hospital of Boston; Not-For-Profit.
Dr. Elsbeth Kalenderian, MD, Administrator
Debra Willard, RN, Director of Nursing
Freestanding pediatric facility;
Rural location.
Has provided pediatric SNF care for 21 years.
58 children ages 0 -21 years.

*23. Northampton Nursing Home
737 Bridge Road
Northampton, Massachusetts 01060
(413) 586-3300
Sponsoring Organization: Harold Lash, Owner; Proprietary.
John Mahoney, Administrator
Ellen Miller, RN, Director of Nursing
41-bed pediatric unit within adult facility (total 164 patients);
Urban location.
Has provided pediatric SNF care since 1972. 43 children ages 0 - 21 years;
4 ventilator-dependent children.

24. Mayflower House
123 South Street
Plymouth, Massachusetts 02360
(508) 746-4343
Sponsoring Organization: Oakwood Living Centers;
Proprietary; Soon to be Not-For-Profit, sponsored by American Health Foundation, Incorporated.
Keith Lombardi, Administrator
Virginia Robinson, RN, Director of Nursing
62-bed pediatric unit within adult facility (total 186 patients);
Rural location.
Has provided pediatric SNF care since mid-1970s.
62 children ages 18 months - 21 years.

Michigan (N.B.: Michigan has approved Pediatric Skilled Nursing Facility regulations.)

*25. Grand Valley Health Center
4118 Kalamazoo Ave. S.E.
Grand Rapids, Michigan 49508
(616) 455-7300
Sponsoring Organization: Butterworth Health Care System; Not-For-Profit.
Roy Eichman, Administrator
Lynn Brouwers, Director, Child Care Program
12-bed pediatric unit within adult facility (total 165 patients);
Urban location.
Has provided pediatric SNF care since early 1970s.
12 children ages 0 - 21 years.
PSNF combined with pediatric rehab services.

Minnesota

No facilities located.

Mississippi

No facilities located.

Missouri (N.B.: Missouri has approved Pediatric Skilled Nursing Facility [Pediatric Long Term Care] regulations.)

*26. Ranken Jordan Children's Rehabilitation Center
10621 Ladue Road
St. Louis, Missouri 63141
(314) 993-1207
Sponsoring Organization: Ranken Jordan Corporation;
Not-For-Profit.
Jo Ellerbrake, RPT, Administrator
Ann Young, RN, Director of Nursing
Freestanding pediatric facility;
Suburban location.
Has provided pediatric SNF care since April, 1983 (50-year-old organization).
26 children ages 2 weeks - 16 years.
PSNF combined with pediatric rehab services.

Montana

No facilities located.

Nebraska

No facilities located.

Nevada

No facilities located.

New Hampshire

No facilities located.

New Jersey

27. Children's Specialized Hospital
150 New Providence Road
Mountainside, New Jersey 07092
(201) 233-3720
Sponsoring Organization: Children's Specialized Hospital;
Not-For-Profit.
Jim Pascuiti, Administrator
Karen DeWitt, RN, Director of Nursing
Warren West, V.P. for Administrative Services
25-bed pediatric SNF in same building as 60-bed pediatric rehabilitation;
Urban location.
Has provided pediatric SNF care since 1988 (100-year-old organization).
25 children ages 0 - 22 years.
Ventilator-dependent children within rehab program only.

*28. Voorhees Pediatric Facility
1304 Laurel Oak Road
Voorhees, New Jersey 08043
(609) 346-3300
Sponsoring Organization: HBA Management;
Proprietary.
Carl Underland, Administrator
Bonnie MacNew, RN, Director of Nursing
Susan Muracco, Admissions Director
JCAHO Accreditation;
Freestanding pediatric facility;
Suburban location.
Has provided pediatric SNF care for 9 years.
99 children ages 6 weeks - 21 years.
24 ventilator-dependent children.

29. Wanaque Convalescent Center
1433 Ringwood Ave.
Haskell, New Jersey 07420
(201) 839-2119
Sponsoring Organization: Private Partnership;
Proprietary.
Robert Mondrone, Administrator
Marian Rizzo, RN, Director of Nursing
60-bed pediatric unit within adult facility (total 240 patients);
Rural location.
Has provided pediatric SNF care for 5 years.
60 children ages 0 -19 years.
4 ventilator-dependent children.

New Mexico

No facilities located.

New York

30. Coler Memorial Hospital SNF Unit
Roosevelt Island, New York 10044
(212) 848-6000, Ext. 6031
Sponsoring Organization: Coler Memorial Hospital;
Not-For-Profit.
Norman Hellman, Coordinator of Pediatric Unit
29-bed pediatric unit within adult facility (total 1000 patients);
Urban location.
Has provided pediatric SNF care since 1952.
29 children ages 2 years - 18 years.

*31. Friedman Rehabilitation Institute for Children
(Formerly Asthmatic Children's Foundation of New York)
P.O. Box 568 Spring Valley Road
Ossining, New York 10562
(914) 762-2110
Sponsoring Organization: Israel Friedman Foundation;
Not-For-Profit.
Dennis Conway, Administrator
John Greenwood, RN, Director of Nursing
Freestanding pediatric facility;
Suburban location.
Has provided pediatric SNF care since 1971.
44 children ages 1 month - 16 years.

32. New York Foundling Hospital for Parent & Child Development
1175 Third Ave.
New York, New York 10021
(212) 633-9300
Sponsoring Organization: Sisters of Charity;
Not-For-Profit.
Ruth Muller, Administrator
Rose Santi, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since September, 1988.
100 children ages 0 - 18 years.

33. Rutland Nursing Home Co., Inc.
585 Schenectady Ave.
Brooklyn, New York 11203
(718) 604-5291
Dr. Chen, MD, Director of Pediatrics
32-bed pediatric unit within adult facility (total 500 patients);
Urban location.
Has provided pediatric SNF care since 1976.
32 children ages "few months" - 16th Birthday.

34. St. Margaret's Center for Children
27 Hackett Blvd.
Albany, New York 12208
(518) 465-2461
Sponsoring Organization: Episcopal Diocese of Albany; Not-For-Profit.
James Hamil, Administrator
Kristin Armstrong-Ross, RN, Director of Nursing
Eloisa LeConte Walker, Social Worker
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1962 (100-year-old organization).
58 children ages 0 - 16 years.

*35. St. Mary's Hospital for Children, Inc.
29-01 216th Street
Bayside, New York 11360
(718) 990-8800
Sponsoring Organization: Sisters of St. Mary (Episcopal); Not-For-Profit.
Stuart Kaplan, Administrator
Nancy Boccuzzi, RN, Director of Nursing
JCAHO Accredited.
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1965 (121-year-old organization).
95 children ages 0 - 16 years.

North Carolina

No facilities located.

North Dakota

No facilities located.

Ohio

36. Aristocrat Berea
255 Front St.
Berea, Ohio 44017
(216) 243-8330
Sponsoring Organization: Koury Family;
Proprietary.
Michael Koury, Administrator
Rose Uberstein, RN, Director of Nursing
Campus model: Freestanding pediatric facility on campus with adult facilities (total 200 patients);
Suburban location.
Has provided pediatric skilled nursing care for 15 years (25-year-old organization).
60 children ages 2 weeks - 14 years.
3 ventilator-dependent children.

*37. Northland Terrace
5700 Karl Road
Columbus, Ohio 43229
(614) 846-5420
Sponsoring Organization: Northland Terrace Nursing & Rehabilitation Center;
Proprietary.
Sharon Reynolds, Administrator
Sue Longhenry, RN, Director of Nursing
16-bed pediatric unit within adult facility (Total 260 patients);
Urban location.
Has provided pediatric SNF care since 1985.
16 children ages 3 months - 10 years.
All 16 children are ventilator-dependent.

38. Ashley Place
5291 Ashley Circle P.O. Box 4240
Youngstown, Ohio 44515
(216) 793-3010
Sponsoring Organization: Private Corporation; Proprietary.
Patricia Macejko, Administrator
Gayle Greier, RN, Acting Director of Nursing
14-bed pediatric unit within adult facility;
Urban location.
Has provided pediatric skilled nursing care since 1986 (10-year-old organization).
14 children ages 0 - 16 years.
Up to 14 ventilator-dependent children.
Subacute care.

Oklahoma

(N.B.: Oklahoma has Pediatric Skilled Nursing Facility Regulations pending.)

*39. The Children's Center
6800 N.W. 39th Expressway
Bethany, Oklahoma 73008
(405) 789-6711
Sponsoring Organization: Children's Convalescent Center, Inc.;
Not-For-Profit.
Albert Gray, Administrator
Carol Gray, Assistant Administrator
Donna Truitt, RN, Director of Nursing
Freestanding pediatric facility;
Suburban location.
Has provided pediatric SNF care since 1975 (84-year-old organization).
82 children ages 0 - 21 years.
4 ventilator-dependent children.

Oregon

*40. Providence Children's Nursing Center
830 N.E. 47th Ave.
Portland, Oregon 97213
(503) 234-9991
Sponsoring Organization: Sisters of Providence Corporations; Not-For-Profit.
Ethelyn Pankratz, Administrator
Jody Carson, RN, Director of Nursing
Donna Abbott, Social Worker
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care since 1965 (46-year-old organization).
54 children ages 0 - 14 years.

41. Hearthside Care Center
2625 Koosbay Blvd.
Coos Bay, Oregon 97420
(503) 267-2161
Sponsoring Organization: Volunteer Hospital Association; Proprietary.
Don Chan, Administrator
Marilyn Wright, RN, Director of Nursing
6-bed pediatric unit within adult facility (total 92 patients);
Urban location.
Has provided pediatric SNF care since 1989.
6 children ages 0 - 21 years.

42. Oak Villa Care Center
650 E. Oak
Hillsboro, Oregon 97123
(503) 648-8588
Sponsoring Organization: Achievements in Health Care; Proprietary.
Dan Wellman, Administrator
Judy Gettmann, RN, Director of Nursing
10-bed pediatric unit within adult facility (total 104 patients);
Urban location.
Has provided pediatric SNF care since 1989.
10 children ages 6-7 years - 21 years.
1 ventilator-dependent child.
Focus on care of closed head trauma.

43. Portland Adventist Convalescent Center
6040 S.E. Belmont
Portland, Oregon 97215
(503) 231-7168
Sponsoring Organization: Portland Adventist Medical Center; Not-For-Profit.
Harley Clendenon, Administrator
Annette Lofftus, RN, Director of Nursing
12-bed pediatric unit within adult facility (total 175 patients); Urban location.
Has provided pediatric SNF care since 1983.
12 children ages 0 - 21 years.

44. Rest Harbor Extended Care Center
5905 E. Powell Blvd.
Gresham, Oregon 97030
(503) 665-1151
Sponsoring Organization: Dempsey Family; Proprietary.
Greg Dempsey, Administrator
Ruth Ann Eaton, RN, Director of Nursing
10-bed pediatric unit within adult facility (total 128 patients); Suburban location.
Has provided pediatric skilled nursing care since 1981.
19 children ages 0 - 21 years.
1 ventilator-dependent child.
Focus on closed head injuries.

45. South Hills Care Center
1166 E. 28th Ave.
Eugene, Oregon 97403
Mailing Address: P.O. Box 5051, Eugene 97405
(503) 345-0534
Sponsoring Organization: Garber Enterprises, Inc.; Proprietary.
Lee Garber, Administrator
Wanda Matthews, RN, Director of Nursing
10-bed pediatric unit within adult facility (total 110 patients); Urban location.
Has provided pediatric SNF care since 1986 (22-year-old organization).
10 children ages 0 - 21 years.

46. Valley View Care Center
103 Adams Ave.
La Grande, Oregon 97850
(503) 963-4184
Sponsoring Organization: Achievements in Health Care; Proprietary.
Rick Miller, Administrator
Kathy Barber, RN, Director of Nursing
2-bed pediatric unit within adult facility (83 total patients);
Rural location.
Has provided pediatric skilled nursing care since 1989 (20-year-old organization).
2 children ages 0 - 21 years.
Ventilator-dependent care.

Pennsylvania

No facilities located.

Rhode Island

*47. Tavares Pediatric Center
101 Plain Street
Providence, Rhode Island 02903
(401) 272-7127
Sponsoring Organization: Eugene and Vivian Tavares; Proprietary.
Eugene Tavares, Administrator
Alice Turner, RN, Director of Nursing
Complete pediatric top floor leased in a multi-story adult facility;
Urban location.
Has provided pediatric SNF care for 9 years.
24 children ages 2 - 21 years.
5 ventilator-dependent children.

South Carolina

No facilities located.

South Dakota

No facilities located.

Tennessee

No facilities located.

Texas (N.B.: Texas has Pediatric Skilled Nursing Facility regulations pending.)

*48. Truman W. Smith Children's Center
2200 Highway 80 W.
Gladewater, Texas 75647
(214) 845-2181
Sponsoring Organization: Truco Properties;
Proprietary.
Al Shirley, Administrator
Carla Shirley, RN, Director of Nursing
Freestanding pediatric facility;
Rural location.
Has provided pediatric SNF care since October, 1988.
120 children ages 0 -21 years.

Utah

49. South Davis Community Hospital
401 S. 400 E.
Bountiful, Utah 84010
(801) 295-2361
Sponsoring Organization: Not Available;
Not-For-Profit.
Gordon Bennett, Administrator
Michelle Nielsen, RN, Director of Nursing
30-bed pediatric unit within adult facility (total 44 patients);
Suburban location.
Has provided pediatric SNF care since 1982.
30 children ages "few months" - 21 years.
14 ventilator-dependent children.

Vermont

*50. Vermont Achievement Center
88 Park Street
Rutland, Vermont 05701
(802) 775-2398
Sponsoring Organization: Vermont Achievement Center;
Not-For-Profit.
Faith Brothers, RN, Administrator
Joan Dupre, RN, Director of Nursing
Freestanding pediatric facility;
Urban location.
Has provided pediatric SNF care for 19 years (53-year-old organization).
20 children ages 0 -22 years.
PSNF combined with pediatric rehab services.

Virginia

No facilities located.

Washington

51. Mother Joseph Care Center
3333 Ensign Road Northeast
Olympia, Washington 98506
(206) 493-4900
Sponsoring Organization: Sisters of Providence Corporations;
Not-For-Profit.
Robert Wildenhaus, Administrator
Janice Wilder, RN, Director of Nursing
6-bed pediatric unit within adult facility (total 152 patients) planned for Summer, 1992;
Suburban location.

West Virginia

No facilities located.

Wisconsin

No facilities located.

Wyoming

No facilities located.

***Denotes site visit**

Readers are encouraged to share this information but please credit the Master's Research Project of Sister Katherine Smith.

This project was supported in part by a grant from Sigma Theta Tau, Beta Psi Chapter.

Sister Katherine Smith, RN, NHA
29 S.E. 52nd Avenue
Portland, Oregon 97215
(503) 235-8215

Please mail me ______________ copy(s) of *PEDIATRIC SKILLED NURSING FACILITIES IN THE UNITED STATES: DIRECTORY* at $15.00 per copy.

Enclosed is a check or money order for $______________ payable to: SISTER KATHERINE SMITH.

Send check and order form to:

Pediatric Skilled Nursing Facilities Directory
Sister Katherine Smith
29 S.E. 52nd Ave.
Portland, Oregon 97215

Name:____

Address:____

City, State, Zip:______________________________________

Please indicate: ☐ PSNF ☐ Parent ☐ Hospital ☐ MD ☐ Nurse

☐ Other____

- -

Please mail me ______________ copy(s) of *PEDIATRIC SKILLED NURSING FACILITIES IN THE UNITED STATES: DIRECTORY* at $15.00 per copy.

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Sister Katherine Smith
29 S.E. 52nd Ave.
Portland, Oregon 97215

Name:____

Address:____

City, State, Zip:______________________________________

Please indicate: ☐ PSNF ☐ Parent ☐ Hospital ☐ MD ☐ Nurse

☐ Other____

APPENDIX C

Interview Guide

State Purpose of Study

Explain purpose of tape recording, and request permission to record.

Request permission to share information with other facilities. Request identification during interview of information facility *doesn't* wish shared.

Section I

1. Facility ID #:_____
2. Sponsoring Organization:_____
3. # Patients: _____ # Pediatric Patients: _____ # Waiting: _____
4. Does this state have a separate licensing category for pediatric facilities?

   _____
5. Does this state have separate pediatric regulations? ☐ Yes ☐ No

   (If yes, get copy) _____
6. Does this state interpret federal regulations differently for pediatric skilled nursing facilities? _____

   _____
7. What is the length of time the facility has provided pediatric skilled nursing facility care? _____

8. What led to this facility's beginning to provide pediatric SNF care?

_____

9. How long have you been administrator here and what kinds of prior experiences have you had, in pediatrics and long term care?

_____

10. Who is the key staff person in the pediatric program? How long has this individual been in the position and what kinds of prior experiences has he/she had in pediatrics and in long term care? _____

_____

Section II

11. Think of 2-3 problems your facility has with ongoing operations (such as problems with federal, state, local regulations, funding regulations, other); describe: _____

_____

_____

_____

_____

12. Are there problems you consider solved? _____

_____

_____

13. Are there problems you consider not yet solved? _____

_____

_____

14. What do you think made the difference? _____

_____

15. Have you been able to influence change in such areas as licensing, regulations, or funding of pediatric skilled nursing care?

_____

_____

_____

16. What are the primary sources of funding for the children in your care?

_____

17. What is your current daily Medicaid rate? _____

18. Do you have additional sources of funding or material contributions? Would you share what those are? _____

_____

Section III

19. Do you have contact with any other facility providing pediatric skilled nursing care? If yes, what are the name(s) and location(s)?

_____

_____

20. In your community and in your state, whom do you consider your greatest supporters? _____

21. What do these people or groups provide that makes you consider them part of your support system? _____

22. Can you identify what factors encouraged them to support your work with children? _____

23. Are there individuals or groups with whom your facility must interact whom you do *not* consider supporters? _____

24. To your knowledge, is there interaction between members of your network? What types of interactions? _____

25. Do you have a facility newsletter? To whom is it distributed?

_____

26. Do you have a parent group? What are their activities? _____

_____

27. Are you a member of any professional/advocacy organization related to your program? Identify: _____

_____

28. Is the professional/advocacy organization specific to pediatrics, or to general long term care? _____

29. What does this organization do for you? _____

_____

30. What do you do for it? (sharing information . . . mutual support)

_____

_____

31. What is the cost of organizational membership? _____

_____

Section IV

32. In what ways has your service changed because of your relationship with others in your network? _____

_____

_____

_____

33. In what ways have other organizations changed because of their relationship with your facility? _____

_____

_____

_____

34. What do you see in the future for your pediatric program?

_____

_____

Section V

1. Would you see a network or coalition of pediatric skilled nursing facilities of benefit? _____

_____

2. What sorts of benefits would you like to derive? _____

_____

3. If a politically active Pediatric SNF coalition were developed, do you have a preference about whether it should be under the umbrella of a larger organization or on its own? If yes, which organization?

_____

_____

4. Would a conference of pediatric SNFs be of benefit to you?

_____

5. What kinds of topics would you like to see addressed? (E.g., successful strategies, patient care issues, adaptive equipment, P.L. 94-142, etc...)

_____

_____

_____

6. If this conference were on the West Coast, would you/your staff be likely to attend? _____

7. If you made the selection, where would you locate a conference?

_____

8. What do you think the ideal conference length should be?

_____

9. Are there any additional issues pertinent to your pediatric SNF program that you think would be helpful to include in a study of pediatric SNFs and/or helpful in developing a network? _____

_____

Section VI

1. Would you like to have a summary copy of this study when it is completed?

_____

2. May I call you if the need for additional information comes up during the course of this study, and have I given you my card so that you may contact me if you wish? _____