Enhancing Quality

Standards and Indicators of Quality Care for Children with Special Health Care Needs

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The New England SERVE Regional Task Force on Quality Assurance was a working group that met extensively over a three-year period from 1986-1989.

Endorsements

The following agencies and organizations endorse **Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs**, and support its use as a tool for improving the quality of health care for children.

State of Connecticut
Department of Health Services
Bureau of Community Health

State of Maine
Department of Human Services
Bureau of Health, Division of Maternal and Child Health

Commonwealth of Massachusetts
Department of Public Health
Bureau of Parent, Child and Adolescent Health

State of New Hampshire
Department of Health and Human Services
Division of Public Health Services

State of Rhode Island and Providence Plantations
Department of Health
Division of Family Health

State of Vermont
Department of Health
Medical Services Division

Children in Hospitals

Connecticut Parent Advocacy Center

Federation for Children with Special Needs

Maine Parent Federation

Massachusetts Spina Bifida Association

New Hampshire Alliance for Children and Youth

New Hampshire Parent Information Center

Parent to Parent of Vermont

Parents Reaching Out of Rhode Island

Connecticut Chapter,
American Academy of Pediatrics
Handicapped Child Committee

Massachusetts Chapter,
American Academy of Pediatrics
Committee on the Child with
Developmental Disabilities

Dedicated to
children with special health care needs
and their families and
to a future where all children
receive quality health care.

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INTRODUCTION

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Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs is a document that identifies key elements contributing to quality health care for children with chronic illness or disability and their families. The health care system and patterns of service delivery are currently changing, with new roles for parents and providers emerging. Concepts such as family-centered and community-based care are promoted nationally by public agencies, providers, and consumer groups. Operational definitions of these ideas and specific indicators of quality are needed in order to support the new directions in health care services for children with special needs. **Enhancing Quality** offers a set of standards that can assist all partners on the health care team to assess the quality of existing service systems.

This document represents the work of an interdisciplinary task force that included representatives of the six New England state health departments, parents of children with special health care needs, as well as health care providers. The task force was established by New England SERVE (See Appendix 1), a regional planning network for children with special health care needs, and supported by the United States Department of Health and Human Services, Bureau of Maternal and Child Health and Resources Development.

The phrase *children with special health care needs*, for the purposes of this document, describes a heterogeneous population of children having in common the need for specialized health services. The definition includes children through age 21 who have any of a broad range of disabilities or chronic illnesses diagnosed at any time during childhood including the prenatal period. Such chronic health conditions may necessitate adaptations for daily functioning, prolonged or periodic hospitalizations, or special services in educational settings.

Enhancing Quality is based upon a critical set of values and assumptions regarding quality health care for children with specialized needs (See Appendix 2). Prominent among these values are family-centered, community-based, and coordinated care, echoing the commitments outlined in the **Surgeon General's Report: Children with Special Health Care Needs, Campaign '87**.

Beginning with the assumption that families of children with special health care needs are both providers and consumers of health care services, **Enhancing Quality** makes a commitment to ensure that family members are partners on a health care team that includes all providers of care. The standards also acknowledge that children with special health care needs require a continuum of services including primary and specialty care and a variety of family support services. Emphasizing the importance of coordination among all providers and reflecting the changing roles of families in the planning and delivery of health care, **Enhancing**

Quality assumes that each family deserves the opportunity to choose a way of becoming involved that is comfortable for family members.

Families and professionals both face barriers to obtaining and delivering quality care, but the burden of quality does not rest on these two groups alone. Effective advocacy on behalf of children demands partnerships that extend beyond parents, relatives, and health professionals, to include educators, administrators, state departments of health, elected officials at all governmental levels, and concerned citizens in society at large. All have an interest in the delivery of quality health care to children. As the United States health care system grows in complexity and cost, so too does the challenge of ensuring quality care for children with specialized needs.

Promoting a responsive health care system requires extensive collaboration and a shared definition of what constitutes quality care. **Enhancing Quality** proposes a working definition, developed with the advice and consent of families and health care professionals. This document is designed to guide collaboration on behalf of children with special health care needs. The standards and indicators offer examples of best practices in the health care field, reflecting what is exemplary in the current system rather than minimal compliance levels of care.

USES OF ENHANCING QUALITY

Enhancing Quality has been developed for a broad range of users including families, physicians and other health professionals, hospitals, community health centers, health maintenance organizations, and state or other public health agencies. Advocates for children's services such as voluntary agencies, parent organizations, and private foundations may use these standards to guide their efforts on behalf of children with special health care needs.

These standards and indicators can be used as an educational tool to define specific characteristics and components of quality care for children with special health care needs. The document provides guidance to families and professionals in selecting care-givers or sites, and defines the rights and responsibilities of parents as partners on the health care team. The standards can form the basis of educational offerings or training for professionals and families who care for children with special health care needs and serve as a catalyst for family-professional discussion of shared concerns in providing care.

Enhancing Quality may be used to conduct self-surveys by health professionals or agencies to assess the quality of care being delivered. The standards support the development of quality assurance systems, which may include monitoring, certification, or reallocation of resources. Third party payors for health services may endorse the standards and utilize them to approve providers and sites. Additional standards for specialty service areas or specific diagnostic groups may be developed using **Enhancing Quality** as a baseline.

The standards and indicators in **Enhancing Quality** support advocacy efforts at all levels and are designed to empower families, health professionals, and agencies to promote effective change in the health care system for children with special health care needs. To strengthen advocacy, **Enhancing Quality** may be used to identify gaps in health care and broader community services for children with special health care needs.

FRAMEWORK AND ORGANIZATION OF ENHANCING QUALITY

The ultimate goal of all health services for children is to ensure that the child grows and develops to optimal levels. However, quality cannot be measured solely on individual health status outcomes. Such an assessment, even if possible, would fail to recognize the many areas of influence and control within the health care system that can and do contribute to quality. Activities of health professionals, whether by individuals or through a team, are often considered as the first and most visible determinant of quality care. However, many health professionals function within an agency whose mission, organization, and policies may or may not facilitate or support their efforts on behalf of children. Although less visible, such agency functions are critical to the delivery of quality care. Both professionals and agencies must also practice within the larger social context of community, state, and nation. Attitudes toward health, allocation of resources, and public policy development all contribute to how health care services are delivered. While this conceptual framework applies to the design and delivery of general health care services, it is perhaps even more critical in an analysis of health services for high risk, high cost populations such as children with special health care needs.

The standards and indicators presented in **Enhancing Quality** have been organized into five sections that parallel the model of the health care system described above.

I. INDIVIDUALIZED SERVICES
II. HEALTH CARE PROFESSIONAL AND TEAM CHARACTERISTICS
III. HEALTH CARE AGENCY OR FACILITY RESPONSIBILITIES
IV. STATE HEALTH DEPARTMENT RESPONSIBILITIES
V. GUIDELINES FOR COMMUNITY AND SOCIETAL SUPPORTS

The first section focuses on services received by the individual child and family. Section II adds the activities of health professionals in delivering those services. Section III expands to include agency responsibilities for supporting and organizing health care services. Section IV addresses the state health department's role in promoting a quality health care system. Section V reaches beyond the interaction of child, provider, and agency to the potential contribution of advocacy groups and communities.

Enhancing Quality is a living document, providing a yardstick for quality as defined today. As expectations for care have grown in the past, they shall continue to grow and change in the future. Definitions of quality and standards for care must reflect such changes and remain responsive to the special health care needs of children and their families.

This edition of **Enhancing Quality** is presented in a workbook style. Layout, margins, and binding choices have been designed to ease note-taking and frequent references. In addition, each set of indicators that follows a standard is considered to be incomplete, offering only a partial list of examples of how a given standard may be implemented. Additional lines are provided to encourage the user to note alternative indicators and acknowledge creative strategies.

I.

INDIVIDUALIZED SERVICES

I. INDIVIDUALIZED SERVICES

The standards in this section are based upon a view of the child as an individual with unique physical, developmental, emotional, social, educational, and cultural needs, as well as legal rights. The standards recognize that the child is a member of a family whose partnership and collaboration with health care professionals are essential to the delivery of quality health care. To be effective, the process of planning and delivering care must reflect both the individuality of the child and the important role of the family.

Throughout this document, *family* refers to persons who consistently serve in care-giving roles for the child. These roles may be filled by a parent, foster parent, guardian, brother, or sister. Other members of the extended family such as an aunt, grandparent, or close friend may represent or substitute for the family. In some cases, family members may require support services to fill these roles.

As the child grows and develops toward independent adulthood, his/her needs will change. Cognitive and emotional development increase a child's ability to understand illness or disability; and with this awareness comes an increased need to be involved in the decision-making process concerning his/her own health care.

An additional assumption underlying the standards for individualized services is that increased participation of children and families will result in more effective care. The standards in this section identify resources and processes for care delivery that will enhance the probability of a collaborative relationship between the child, family, and health professionals.

The process of delivering individualized health care to the child and family involves assessment of health status, needs, and strengths; the development of a health care plan; and determinations regarding the therapeutic interventions and comprehensive services required. These services may include primary and specialty health care, education, developmental therapies, nutrition, family support services, mental health services, and/or care coordination.

The standards in this section are grouped into three major areas that reflect the basic values of family-centered, coordinated, and accessible care.

CHILD AND FAMILY PARTICIPATION

1.0 THE CHILD HAS REPRESENTATION THROUGH FAMILY MEMBERSHIP ON THE HEALTH CARE TEAM.

☐ 1.1 Family members participate in **team decision-making** regarding health care services and the development of the health care plan.

☐ 1.2 **Expectations and roles** of all team members are defined.

☐ 1.3 The family provides **information** regarding the child's strengths, needs, and culture, and **feedback** regarding the services received.

☐ 1.4 **Interpreter** services are available.

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2.0 FAMILIES PROVIDE INFORMED CONSENT FOR ALL TREATMENT, BASED ON INFORMATION REGARDING BENEFITS, RISKS, AND ALTERNATIVE PROCEDURES.

☐ 2.1 The **child is included** in the process of obtaining informed consent as he/she matures.

☐ 2.2 When benefits remain unproven, as in innovative or research procedures, the **implications of the treatment** are fully explained.

☐ 2.3 Families are informed if significant disagreements occur among health care professionals regarding the care plan, and understand their option to seek **additional opinions**.

☐ 2.4 A process exists for **resolution of conflict** among health care professionals and/or the family when there are different opinions as to the appropriateness of care.

☐ 2.5 Families are informed of the **legal limits** and requirements for parents and professionals in decision-making regarding the child's care.

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3.0 THE CHILD/FAMILY HAS ACCESS TO THE HEALTH CARE RECORD.

☐ 3.1 Families receive **written information** regarding record-keeping policies, procedures, and their rights to full access to the records.

☐ 3.2 **Copies of information** from the health care record **and explanations** regarding the content of the health care record are provided to the family upon their request.

☐ 3.3 Families have the opportunity to enter **written comments** in the health care record.

☐ 3.4 Family **consent** is obtained when written information from the health care record is shared.

☐ 3.5 Families are encouraged and assisted to establish a **portable record-keeping system** in order to maintain and use information from the health care record.

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4.0 THE CHILD AND FAMILY RECEIVE A SUMMARY OF THE CHILD'S HEALTH CARE RECORD UPON REQUEST.

☐ 4.1 The **summary record** includes, at a minimum, current problems and diagnoses, standing orders, and guidelines for managing specific health crises.

☐ 4.2 Families receive assistance in **translating** the summary record into their primary language.

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PLANNING AND COORDINATION OF CARE

5.0 A COMPREHENSIVE ASSESSMENT PROCESS PRECEDES AND GUIDES THE DEVELOPMENT OF THE HEALTH CARE PLAN.

☐ 5.1 The **family participates** in the assessment process.

☐ 5.2 Child and family reports of **past and current needs** form the basis of the assessment process.

☐ 5.3 The assessment process is **comprehensive** and includes **health and other disciplines**.

☐ 5.4 The assessment process is **periodically updated**.

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6.0 INFORMATION CONCERNING DIAGNOSIS, TREATMENT, PROGNOSIS, AND RESOURCES IS SHARED AMONG ALL MEMBERS OF THE HEALTH CARE TEAM, INCLUDING THE FAMILY.

☐ 6.1 Families receive appropriate **educational materials** concerning the child's specific illness or disability, individual growth and development, and injury prevention.

☐ 6.2 Information and guidance regarding the **potential impact** of the child's health status and treatment on the family are provided.

☐ 6.3 Educational materials are **reviewed** by representative parents for accuracy and relevance.

☐ 6.4 The health care team provides individual families with information on how to obtain a **wide range of services** including education, social, mental health, and self-help and family support groups as needed.

☐ 6.5 The family has access to **written guidelines or standards** of care that are applicable to health care services for their child.

☐ 6.6 Materials for families are written in the **primary languages** of the major population groups served.

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7.0 EACH CHILD HAS A WRITTEN HEALTH CARE PLAN THAT GUIDES ALL TREATMENT AND THERAPEUTIC INTERVENTIONS.

☐ 7.1 The health care plan identifies one member of the team to be **principal contact** for the family to ensure care coordination.

☐ 7.2 Children are assisted in **understanding** the implications of all services and procedures contained in the health care plan.

☐ 7.3 The health care plan is **re-evaluated annually** or more frequently as required by the child's needs.

☐ 7.4 The health care plan contains **up-to-date information** on service needs, resources to be used, and designated professionals who are responsible for providing services.

☐ 7.5 **Community-based health professionals** (e.g., primary care pediatricians, school-based personnel, home care professionals) participate in the development of the health care plan.

☐ 7.6 The health care plan includes services to support the **growth and development** potential of each child regardless of his or her disability or illness.

☐ 7.7 The family is assisted to integrate healing methods practiced in their **culture or religion** into the health care plan.

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8.0 HEALTH CARE SERVICES AND TREATMENT PROCEDURES ARE DESIGNED TO RECOGNIZE THE STRENGTHS AND NEEDS OF THE CHILD AND FAMILY.

☐ 8.1 **Family strengths**, including cultural and ethnic identity are respected and utilized in the delivery of care.

☐ 8.2 **Appointments are coordinated** among service providers in order to limit the family's travel time, waiting time, and loss of work.

☐ 8.3 Services or treatment alternatives delivered in the home accommodate **family life activities.**

☐ 8.4 The unique **contributions of brothers and sisters** are identified and utilized in the development of the health care plan.

☐ 8.5 **On-going training** regarding medical procedures and the use and maintenance of specialized equipment is available to family members and/or the child.

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9.0 THE CHILD/ADOLESCENT'S DEVELOPMENTAL LEVEL IS CONSIDERED IN THE DELIVERY OF CARE.

☐ 9.1 **Anticipatory guidance** regarding developmental issues (e.g., need for mastery, dependence versus independence, sex education) is available to families.

☐ 9.2 Developmentally appropriate **support groups and/or counseling** are available to children and adolescents.

☐ 9.3 Children have opportunities to meet **other children** with similar special health care needs.

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10.0 CONTINUITY OF CARE IS MAINTAINED DESPITE CHANGES IN THE CHILD'S HEALTH CARE DELIVERY SITE, CARE-GIVERS, OR METHOD OF PAYMENT.

☐ 10.1 Comprehensive planning is provided for all **transitions**, such as hospital-to-home, home-to-hospital, and early childhood to school.

☐ 10.2 Planning ensures **linkages** with education, health, and community resources.

☐ 10.3 Continuity of care is not interrupted by changes in **insurance coverage or parental employment**.

☐ 10.4 Planning occurs as the adolescent moves from **pediatric to adult** services.

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11.0 WHEN THE CHILD'S IMPAIRMENT OR PROGRESSION OF HIS/HER ILLNESS IS IRREVERSIBLE, BOTH CHILD AND FAMILY MEMBERS RECEIVE SUPPORT IN COPING WITH THE CONDITION.

☐ 11.1 The design of services **prevents isolation** for the child and family.

☐ 11.2 When death is the anticipated outcome, the child and family are assisted in preparing for this eventuality through the availability of **family support groups** and other services.

☐ 11.3 **Follow-up services** are provided to the family after the death of a child.

☐ 11.4 Families are provided the opportunity to perform **ceremonies or other practices** regarding the death of their child that are in keeping with their traditional cultural or religious beliefs.

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ACCESSIBILITY OF CARE

12.0 SERVICES INCLUDED IN THE HEALTH CARE PLAN ARE DELIVERED WHENEVER POSSIBLE AT THE LOCAL OR COMMUNITY LEVEL.

☐ 12.1 Community-based **primary care** should include health maintenance, management of acute illnesses, and management of some complications of chronic conditions.

☐ 12.2 The child receives primary care from a **community-based physician**.

☐ 12.3 **Care coordination/case management** is provided to support access to community-based services.

☐ 12.4 Delivery of services at the community level is **reviewed by the health care team** whenever the health care plan is re-evaluated.

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13.0 THE FAMILY RECEIVES FULL WRITTEN INFORMATION REGARDING SERVICES OFFERED BY THE HEALTH AGENCY DELIVERING CARE.

☐ 13.1 Program **information and eligibility guidelines** for all services are clearly stated.

☐ 13.2 Procedures or **alternative resources** for obtaining care during hours when the agency is not open are provided.

☐ 13.3 Procedures for patient access to **research studies or innovative therapies** are defined.

☐ 13.4 Information on **financial eligibility**, sources of payment, and processes for appeal is provided.

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14.0 FINANCIAL IMPLICATIONS OF THE HEALTH CARE PLAN ARE ADDRESSED.

☐ 14.1 Families are helped to make maximal use of **insurance benefits, financial assistance, and entitlement** programs for which they are eligible.

☐ 14.2 **Planning for the cost** of home, community-based, and/or hospital care occurs as early as possible and reflects all major transitions including changes in family status.

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II.

HEALTH CARE PROFESSIONAL AND TEAM CHARACTERISTICS

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Children with special health care needs frequently require a comprehensive range of services. A variety of health professionals, sometimes located in different delivery sites, contribute to the child's care over a period of time. This process of care delivery has the advantage of utilizing the knowledge and skills of many qualified professionals to benefit both child and family. However, it also demands close cooperation and coordination among parents and professionals to ensure consistent and continuous care planning.

The standards in this section address resources and activities necessary for professionals to deliver quality care when they are practicing either as individuals or within teams. In addition to their specialized knowledge, these professionals must possess well-developed communication skills for effective collaboration with parents and other providers. Ensuring on-going training of providers in a wide variety of settings presents an additional challenge. As technologies and philosophies of care change, providers require education and training to update knowledge and skills.

The standards in this section are grouped into three areas that focus on maintenance of high levels of training, the health care team's ability to coordinate services, and responsiveness to families.

EDUCATION AND TRAINING

15.0 HEALTH CARE PROFESSIONALS HAVE THE SPECIALIZED EDUCATION, EXPERIENCE, AND CREDENTIALS TO DELIVER QUALITY CARE.

☐ 15.1 Health care professional **qualifications/training** meet existing standards in the specific specialty area (e.g., licensure, board certifications).

☐ 15.2 Health care professionals have specific education and experience with **child/adolescent needs** and developmental issues.

☐ 15.3 The health care team is **familiar with the culture** of the child and family.

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16.0 HEALTH CARE PROFESSIONALS MAINTAIN CURRENT KNOWLEDGE AND SPECIALIZED TRAINING IN ORDER TO DELIVER QUALITY CARE.

☐ 16.1 Providers are knowledgeable about **standards of care** designed specifically for children with special health care needs.

☐ 16.2 **Specialty care providers** participate in continuing education programs specific to services for children.

☐ 16.3 **Primary care providers** utilize up-to-date educational materials and continuing education programs on specific illnesses and disabilities.

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THE ROLE AND FUNCTION OF THE HEALTH CARE TEAM

17.0 THE TEAM CONSISTS OF FAMILY MEMBERS AND PROFESSIONALS WHO SERVE THE CHILD AND FAMILY.

☐ 17.1 Professional team members may have **expertise** in areas such as: audiology, child development, creative arts, dentistry, education, genetics counseling, medicine (primary and specialty care), nursing, nutrition, occupational therapy, physical therapy, psychology, social work, and speech and language therapy.

☐ 17.2 Team members will include staff from **community-based agencies** when they are providing direct services to the child.

☐ 17.3 When **staff turnover** occurs, a designated team member assumes responsibility for informing the family and orienting new members to the care team.

☐ 17.4 **Interpreters** are available for team meetings to ensure language translation and cross-cultural communication.

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18.0 THE PRIMARY FUNCTION OF THE HEALTH CARE TEAM IS TO DEVELOP AND IMPLEMENT A HEALTH CARE PLAN FOR EACH CHILD.

☐ 18.1 The **team meets** to develop, coordinate, and follow up on a plan of care.

☐ 18.2 A process is established to ensure **communication** among team members such as periodic meetings, telephone conference, and/or sharing of copies of provider notes.

☐ 18.3 **Family contributions** are included in the development of the health care plan.

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19.0 A MEMBER OF THE HEALTH CARE TEAM IS DESIGNATED TO COORDINATE CARE FOR EACH CHILD.

☐ 19.1 The coordinator/case manager facilitates **ongoing communication** among the primary care providers, other team members, across agencies and with the family.

☐ 19.2 The coordinator promotes **consistent care planning** and service delivery among professionals within and across agencies and family.

☐ 19.3 The coordinator assists the family in obtaining financial counseling as needed to develop a **plan for financing care.**

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20.0 COORDINATION OCCURS TO ENSURE SMOOTH INTEGRATION OF THE CHILD INTO EDUCATIONAL SERVICES.

☐ 20.1 Information regarding the child's health condition is provided to the **school nurse** (or other designated school personnel) with the consent of the family.

☐ 20.2 Necessary **training or assistance** is provided to designated school personnel to facilitate the child's integration into the school setting.

☐ 20.3 Special attention is given to **coordinating services** at times of transition in educational settings.

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21.0 PRIMARY AND SPECIALTY CARE PROFESSIONALS COOPERATE TO ENSURE COMPREHENSIVE CARE.

☐ 21.1 A **designated physician** at the local level delivers age-appropriate primary care in coordination with the health team.

☐ 21.2 **Timely contact** (either written or telephone) occurs between the primary and specialty care providers following each patient visit and/or change in treatment protocols.

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RESPONSIVENESS TO SPECIALIZED NEEDS OF CHILD AND FAMILY

22.0 THE CHILD'S HEALTH CARE IS BASED UPON ACCEPTED STANDARDS AND GUIDELINES FOR PRACTICE.

☐ 22.1 **Primary medical care** meets the guidelines of the American Academy of Pediatrics.

☐ 22.2 Services provided by health care professionals meet accepted guidelines for practice as defined by **professional boards and national organizations**.

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23.0 HEALTH CARE PROFESSIONALS OBTAIN AND UTILIZE INFORMATION ABOUT THE CHILD'S DEVELOPMENTAL LEVEL IN THEIR DELIVERY OF CARE.

☐ 23.1 The health care team obtains **information from the family** regarding the child's growth and development.

☐ 23.2 The health care team obtains consultation or makes referrals for **developmental evaluations**.

☐ 23.3 Services and/or treatment protocols are designed to meet the developmental and **age-appropriate needs** of the child.

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24.0 HEALTH CARE PROFESSIONALS INFORM FAMILIES OF AVAILABLE RESOURCES.

☐ 24.1 **Referrals** are made to agencies such as education, recreation, vocational assistance, mental health, and creative arts.

☐ 24.2 Information is provided on **parent-to-parent and support services**, including diagnostic-specific groups.

☐ 24.3 Families are encouraged to identify **informal networks**, (e.g., grandparents, neighbors, friends) and utilize them for support.

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25.0 A HEALTH CARE RECORD IS DEVELOPED AND MAINTAINED FOR EACH CHILD AND IS MADE AVAILABLE TO THE FAMILY.

☐ 25.1 The record includes the **health care plan** and documentation of all delivery of care.

☐ 25.2 The health care record **documents training** received by the child and family in health care procedures.

☐ 25.3 Summaries of **team communication and conferences** are included in the health care record.

☐ 25.4 **Translation services** are available to families.

☐ 25.5 A health care professional **explains the content** of the record for the family upon request.

☐ 25.6 Records are **legible,** and easily used.

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26.0 RECOGNITION IS GIVEN TO COST IN THE DELIVERY OF SERVICES.

☐ 26.1 Providers review appropriateness of treatment **frequency** and eliminate service **duplication** to control cost.

☐ 26.2 Providers consider **cost for families and payors** in selecting services, resources, and equipment.

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III.

HEALTH CARE AGENCY OR FACILITY RESPONSIBILITIES

III. HEALTH CARE AGENCY OR FACILITY RESPONSIBILITIES

The health care agency includes the facility, organizational structure, operating policies, and financial mechanisms that permit professionals to deliver safe, efficient, and effective care to children with special health care needs and their families.

Examples of health care organizations that are included in the definition of *agency* are tertiary care centers, health maintenance organizations, private specialty care clinics or hospitals, neighborhood health centers, publicly operated specialty care programs, and home care agencies. *Agency* may also apply to private specialty care group practices that operate within a formal organizational structure rather than as a loosely affiliated group of professionals.

To be most effective, the health care agency and its operations must guide and assist the staff in the delivery of comprehensive, coordinated, family-centered services. In order to deliver quality care, a health care agency has responsibility for creating a climate that is responsive to child and family needs, supportive to its personnel, and organized in an efficient manner. The agency assumes responsibility for the quality of care delivered under its auspices. It forms collaborative relationships with other agencies to ensure that the health care needs of children are met. The agency may also promote the expansion of knowledge about children with special health care needs via its teaching and research functions.

The standards and indicators in this section are grouped to reflect these three areas: consideration of the needs of children and families, staff supports, and administrative effectiveness.

CONSIDERATION OF THE CHILD AND FAMILY

27.0 THE AGENCY HAS POLICY-MAKING AND/OR ADVISORY BOARDS THAT INCLUDE FAMILY REPRESENTATIVES.

☐ 27.1 Policy-making and/or advisory boards **review agency services** in light of community needs.

☐ 27.2 Policy-making and/or advisory boards ensure that the agency has a mechanism for **families to give feedback** regarding care received.

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28.0 AGENCY OPERATIONS ARE RESPONSIVE TO THE NEEDS OF CHILDREN AND FAMILIES.

☐ 28.1 The agency has a mission statement that includes a **commitment to family participation** at all levels.

☐ 28.2 The agency ensures that all programs and services are available to children and their families **without discrimination** based on race or ethnic identity, primary language, religion, gender, sexual orientation, marital status, medical condition, or method of payment.

☐ 28.3 The agency has a policy for ensuring that children receive care **regardless of the ability to pay**.

☐ 28.4 The agency has a mechanism in place that includes parent representatives to review **ethical issues**.

☐ 28.5 The agency has a procedure for ensuring that families are **well-informed** prior to giving **consent** for any treatment or procedure.

☐ 28.6 The agency maintains **confidentiality of records** and has written procedures for sharing information with others.

☐ 28.7 The agency ensures that the child and/or family has **access to the health care record**.

☐ 28.8 The agency supports its staff in fulfilling their responsibilities for identifying, assisting, and reporting children at risk or potentially at risk for **child neglect or abuse**.

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29.0 THE AGENCY'S PHYSICAL PLANT IS DESIGNED TO MEET THE NEEDS OF CHILDREN AND THEIR FAMILIES.

☐ 29.1 The facility is **accessible** for all users with physical or sensory impairments.

☐ 29.2 Waiting areas and treatment facilities are designed to **accommodate family members** accompanying their child for care, e.g., overnight stays, induction of anesthesia, recovery, radiology.

☐ 29.3 Furniture size, decor, waiting area diversions, and reading materials are **developmentally and age-appropriate** for the children being served.

☐ 29.4 The physical setting is designed to provide **privacy** for the child and family. Space is available for confidential professional/family discussions.

☐ 29.5 Designated **meeting areas** are available to accommodate interdisciplinary team meetings.

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30.0 DIAGNOSTIC AND THERAPEUTIC EQUIPMENT REQUIRED TO MEET THE SPECIAL HEALTH CARE NEEDS OF CHILDREN IS AVAILABLE.

☐ 30.1 Personnel operating the equipment receive **adequate training** including special orientation to issues particular to children.

☐ 30.2 **Adaptations** are made in the equipment to accommodate the smaller size of children and provide for their safety.

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STAFF SUPPORTS

31.0 THE AGENCY PROVIDES SUFFICIENT NUMBERS AND TYPES OF QUALIFIED STAFF TO SERVE CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

☐ 31.1 **Staffing patterns** are documented, equitable, and meet the special needs of the children being treated.

☐ 31.2 Providers are recruited who demonstrate **understanding and sensitivity** as well as knowledge and skills needed to work collaboratively with families and children with special health care needs.

☐ 31.3 Efforts are made to **recruit and retain qualified staff**, including those with chronic illnesses and/or disabling conditions and those from minority or cultural groups being served.

☐ 31.4 **Translation services** are provided for the major populations served by the agency; efforts are made to facilitate translation for population groups that are present in smaller numbers.

☐ 31.5 **Interpreters** are available for hearing-impaired persons.

☐ 31.6 Clerical and administrative **support staff** are available to facilitate record-keeping and communication among professionals and families.

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32.0 THE AGENCY PROVIDES AN ONGOING ORIENTATION AND TRAINING PROGRAM THAT SUPPORTS PROVIDER READINESS TO DELIVER CARE TO THIS POPULATION OF CHILDREN.

☐ 32.1 Staff understand the mission of the agency and the **family-centered approach** to care.

☐ 32.2 Staff have knowledge of **cultural issues** relevant to the population served.

☐ 32.3 Staff have knowledge of the **resources available** in the geographic area served.

☐ 32.4 **Professional books and journals** are available on-site or accessible through agreements with library services.

☐ 32.5 Relevant **quality assurance guidelines** are available on-site.

☐ 32.6 The agency expects and supports staff to receive **on-going education and training**.

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ADMINISTRATIVE EFFECTIVENESS

33.0 THE AGENCY HAS WRITTEN POLICIES REGARDING THE HEALTH CARE RECORD.

☐ 33.1 The agency ensures individual **provider access** to the health care record at the time of each patient contact.

☐ 33.2 The agency ensures **family access** to the health care record.

☐ 33.3 The agency ensures the **confidentiality** of the health care record.

☐ 33.4 The agency has written policies to ensure that information from the health care record is released only with **family consent**.

☐ 33.5 The agency provides **long-term storage** of health care records to ensure future access to information for decision-making in areas such as reproductive health.

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34.0 THE AGENCY HAS A MANAGEMENT INFORMATION SYSTEM THAT PROVIDES EFFICIENT DATA AND RECORD UPDATING AND RETRIEVAL.

☐ 34.1 The agency maintains information (e.g., age, diagnosis, residence) on the **population served** while protecting confidentiality of children and families.

☐ 34.2 **Management data** (e.g., budget information, utilization rates) are available to agency administrators and policy and/or advisory boards.

☐ 34.3 The agency has access to **computer capability** to maintain the management information system.

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35.0 ADMINISTRATIVE, PERSONNEL AND ORGANIZATIONAL POLICIES PROMOTE AND FACILITATE INTERAGENCY COORDINATION.

☐ 35.1 Agency personnel participate in **interagency task forces** aimed at coordination of services and program planning.

☐ 35.2 **Collaborative agreements** exist that facilitate joint provision of services, coordination of care/ case management, and the sharing of information and resources.

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36.0 THE AGENCY ASSUMES RESPONSIBILITY FOR REVIEWING THE QUALITY OF CARE ON A PERIODIC BASIS.

☐ 36.1 An interdisciplinary **quality assurance system** is in place to evaluate program effectiveness by identifying problems, developing a plan, and implementing a course of corrective action.

☐ 36.2 The agency has a system of regularly-scheduled **peer review**.

☐ 36.3 The agency has a system for obtaining **family feedback** on a regular basis.

☐ 36.4 The agency promotes new and improved ways to **measure outcomes** so that delivery systems can be modified to better meet the special health care needs of this population of children.

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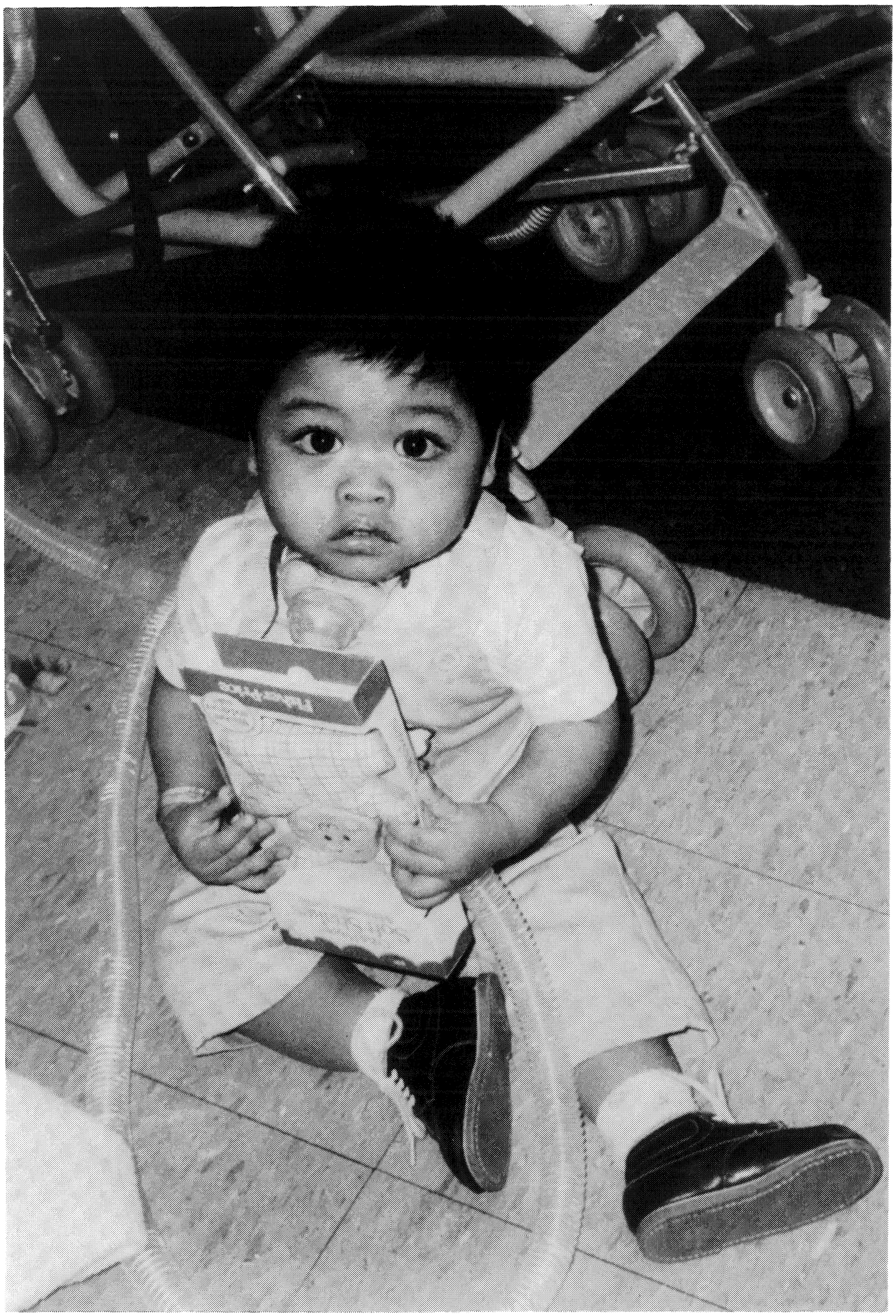
IV.

STATE HEALTH DEPARTMENT RESPONSIBILITIES



IV. STATE HEALTH DEPARTMENT RESPONSIBILITIES

Section IV gives special attention to the role of the state health department. Effective and creative leadership is a key element in guiding the health care system's development on behalf of children. Leadership is needed to support and develop family-centered policies and to anticipate and plan for emerging needs. The state health department, with its history and expertise in services for children with special health care needs, is uniquely qualified to assume this leadership role.

Ensuring adequate numbers of qualified providers to care for children with chronic illness or disability will continue to be a major challenge in the coming years. Anticipated staff shortages coupled with the demand for specialized care at the community level necessitate creative methods of recruitment into the health professions. New and innovative definitions of provider roles may need to be developed. These initiatives require close collaboration among the state health department, institutions of higher education, payors of care, physicians and other health care professionals, child advocacy groups, and families.

Nationwide, Title V of the Social Security Act has served to guide the development of maternal and child health services in the United States including programs for children with special health care needs. State health departments have used the mandates and federal resources of Title V to expand their capacity to develop systems of care for women and children. Across the country these state agencies are providing advocacy and leadership on behalf of children with special health care needs.

Section IV identifies activities necessary for this leadership role. It describes the state health department's responsibilities to anticipate and plan for emerging needs, influence systems development, collaborate with a broad range of public and private agencies serving children, and promote family-centered policies. To fulfill these leadership responsibilities successfully, the state health department must maintain close working partnerships with professionals in both public and private sectors and collaborate with parent representatives from many diverse groups.

The standards and indicators in Section IV describe the role of the state health department in enhancing the quality of the health care delivery system. The major areas of responsibility include state-level planning and resource allocation, health promotion and prevention, collaboration with other agencies on health-related issues, and ensuring quality.

HEALTH CARE SYSTEM DEVELOPMENT AND RESOURCE ALLOCATION

37.0 THE STATE HEALTH DEPARTMENT CONDUCTS AN ONGOING NEEDS ASSESSMENT FOR PLANNING AND POLICY DEVELOPMENT.

☐ 37.1 Multiple strategies for **identifying unmet needs** and gaps in resources are utilized, such as public hearings and surveys of providers, families, and community leaders.

☐ 37.2 **Health status of children** and health service indicators are monitored and made available to the public.

☐ 37.3 Procedures are well-publicized to encourage the **identification and reporting** of clusters of children with specific illnesses to the state health department for investigation into possible causes.

☐ 37.4 Issues and needs related to **cultural differences** are addressed in the planning process, e.g., cultural beliefs and child-rearing practices of target groups should influence the design of early intervention services.

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38.0 THE STATE HEALTH DEPARTMENT HAS A CONFIDENTIAL CHILD HEALTH DATA SYSTEM THAT ASSISTS IN PLANNING FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 38.1 **Families are informed** about purposes of data collection and planned uses.

☐ 38.2 Data systems within the state health department use **common definitions** and are integrated to address issues of incidence, prevalence, and service utilization.

☐ 38.3 The state health department data system has the capacity to **make comparisons** with other local, state, and national data.

☐ 38.4 The state health department data system has the capacity to identify and report potential **environmental hazards** to child health and support prevention efforts.

☐ 38.5 **Other data systems**, such as vital statistics, are periodically reviewed to maximize their usefulness for planning for children with special health care needs.

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39.0 THE STATE HEALTH DEPARTMENT COLLABORATES WITH A BROAD RANGE OF FAMILIES, HEALTH CARE PROFESSIONALS, AND ADVOCACY GROUPS ON BEHALF OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 39.1 On-going departmental **advisory groups** include family representatives, health care professionals, and advocacy groups.

☐ 39.2 **Consultation** is sought in the planning and review of specific programs and policies.

☐ 39.3 Parent **participation is supported** and may include travel and child care reimbursement and training.

☐ 39.4 Parent representatives reflect **diverse** cultural, racial, and socio-economic groups.

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40.0 THE STATE HEALTH DEPARTMENT ASSUMES A LEADERSHIP ROLE IN THE DEVELOPMENT OF INTEGRATED SYSTEMS OF HEALTH CARE.

☐ 40.1 The state health department works in **partnership** with public and private providers in the development of services responsive to children with chronic illness or disability.

☐ 40.2 The state health department **collaborates with primary care providers** to ensure the availability of health care for children with special health care needs at the community level.

☐ 40.3 The state health department ensures **geographic distribution** of services through collaboration with public and private providers.

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41.0 THE STATE HEALTH DEPARTMENT GUIDES THE ALLOCATION OF SCARCE PUBLIC RESOURCES ON BEHALF OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 41.1 The state health department ensures that all families have access to a set of **basic services** that includes primary care, specialty care, respite care, and early intervention services.

☐ 41.2 Objective **eligibility criteria** are applied to the distribution of publicly supported services.

☐ 41.3 Admissions to **public and private pediatric rehabilitation** and nursing homes are determined through an objective and informed process that is monitored by the state health department.

☐ 41.4 The state health department provides information to other public and private agencies regarding **priority needs** of children.

☐ 41.5 The state health department ensures that federal and state training grants respond to the **personnel development needs** as identified by families, providers, and communities.

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42.0 THE STATE HEALTH DEPARTMENT UTILIZES AVAILABLE PUBLIC RESOURCES TO FILL IDENTIFIED GAPS IN THE HEALTH CARE DELIVERY SYSTEM.

☐ 42.1 Special attention is given to **services not adequately supported** in the private sector such as clinical care coordination, housing adaptations, respite care, residential services, nutritional assessment and intervention services, and family support services.

☐ 42.2 The state health department provides or ensures that **service coordination/case management** is available to individual children and families.

☐ 42.3 When state health department funds are used temporarily to fill gaps in services, planning occurs to design **alternative long-term methods** of service delivery.

☐ 42.4 The state health department funds **innovative projects** and encourages replication when efficacy is demonstrated.

☐ 42.5 The state health department supports **transition** services for adolescents as they move into adult health care systems.

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43.0 THE STATE HEALTH DEPARTMENT ENSURES THAT INFORMATION AND REFERRAL SERVICES ARE DEVELOPED TO ASSIST ALL CARE-GIVERS, INCLUDING FAMILIES.

☐ 43.1 The information system is **well-publicized and accessible** in local communities.

☐ 43.2 The information system includes **available health and related services** such as home care programs, parent support groups, medical equipment, and specialty and primary care providers.

☐ 43.3 The information system is **continually updated**.

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44.0 THE STATE HEALTH DEPARTMENT PROVIDES TECHNICAL ASSISTANCE AND TRAINING TO FAMILIES, PROVIDERS, AND EDUCATIONAL INSTITUTIONS.

☐ 44.1 The state health department supports and/or provides training and educational programs for parents and professionals on **new and emerging issues** in the care of children with special health needs.

☐ 44.2 The state health department supports and/or provides education and training to **respite staff and home care providers**, including families.

☐ 44.3 The state health department supports and/or provides ongoing education to **primary care providers**, such as pediatricians, who care for children with special health care needs.

☐ 44.4 The state health department provides technical assistance to **local school systems** concerning children with special health care needs.

☐ 44.5 The state health department encourages professional education institutions and training programs to include content on children with special health care needs in their **curricula**.

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45.0 THE STATE HEALTH DEPARTMENT PERIODICALLY REVIEWS CURRENT AND PROPOSED STATE MANDATES FOR HEALTH SERVICES TO ENSURE THAT THEY ADDRESS THE SPECIAL HEALTH CARE NEEDS OF CHILDREN.

☐ 45.1 State regulations for hospitals, including discharge planning guidelines, support **family-centered care**.

☐ 45.2 State mandated **screening and immunization** programs are periodically reviewed to determine whether they address the unique needs of children with special health care needs.

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HEALTH PROMOTION/PREVENTION

46.0 THE STATE HEALTH DEPARTMENT PROVIDES LEADERSHIP IN ESTABLISHING PROGRAMS TO PREVENT CHRONIC DISEASES OR DISABLING CONDITIONS.

☐ 46.1 The state health department provides or supports a full continuum of modern **intervention and prevention** services.

☐ 46.2 The state health department supports **public education** that reinforces family life education, the importance of prenatal care, and positive health behaviors.

☐ 46.3 The state health department ensures **access to prenatal care**.

☐ 46.4 Standards pertaining to the **quality of prenatal care** are periodically reviewed, revised, and widely disseminated.

☐ 46.5 The state health department ensures **access to newborn screening and genetics services/ counseling**, including information and referral services.

☐ 46.6 An **emergency transport system** for high-risk pregnant women, sick newborns, and children is established to ensure rapid transfer to a facility providing the level of service required.

☐ 46.7 **Educational materials** and programs regarding injury prevention, lead poisoning prevention, communicable diseases, and substance abuse are developed and widely disseminated.

☐ 46.8 Information on **prevention of HIV infection/ AIDS**, including congenital HIV infection, is widely disseminated.

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47.0 THE STATE HEALTH DEPARTMENT PROVIDES LEADERSHIP IN ESTABLISHING PROGRAMS THAT PREVENT COMPLICATIONS OF EXISTING CHRONIC OR DISABLING CONDITIONS IN CHILDREN.

☐ 47.1 The state health department supports the development of models that offer **alternatives to institutional care**, such as home-based services.

☐ 47.2 Standards for assessment, intervention, and monitoring the **nutritional status of children** are developed and disseminated through statewide training and outreach efforts.

☐ 47.3 The state health department supports educational efforts that reinforce the importance of **early intervention** and comprehensive care for children with special health care needs and their families.

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INTERAGENCY COLLABORATION AND CONSULTATION

48.0 THE STATE HEALTH DEPARTMENT PROVIDES CONSULTATION TO A RANGE OF PUBLIC AND PRIVATE AGENCIES ON ISSUES PERTAINING TO CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 48.1 The state health department provides **clinical expertise** to assist agencies in care coordination/case management and service delivery.

☐ 48.2 The state health department assists other agencies and organizations as they address **emerging needs** and plan for services for children.

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49.0 THE STATE HEALTH DEPARTMENT COLLABORATES WITH THE EDUCATIONAL SYSTEM TO SUPPORT THE INTEGRATION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS INTO SCHOOL SETTINGS.

☐ 49.1 Departments of health and education collaborate in the **development of policies** that support the delivery of services to children with chronic illness or disability in school settings.

☐ 49.2 The state health department **provides education and training** to school personnel on the special health care needs of children.

☐ 49.3 The state health department provides **consultation to school personnel** on the special health care needs of individual children.

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50.0 THE STATE HEALTH DEPARTMENT COLLABORATES WITH THIRD PARTY PAYORS IN DEFINING THE UNIQUE CHARACTERISTICS OF QUALITY HEALTH SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 50.1 The state health department improves **access to health insurance** by addressing issues such as ensuring continuity of coverage, benefits for pre-existing conditions, and reimbursement of care delivered across geographic boundaries.

☐ 50.2 The state health department seeks **adequate reimbursement** for a full range of services, including coordination of care for children with special health care needs.

☐ 50.3 The state health department consults with **third party payors**, including Medicaid, on the need for comprehensive benefits to include coverage for: home care, long-term and school-based care, mental health services, nutritional services and products, and rehabilitative and adaptive equipment and services.

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QUALITY ASSURANCE

51.0 THE STATE HEALTH DEPARTMENT USES STANDARDS AND GUIDELINES TO PROMOTE QUALITY CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

☐ 51.1 The state health department **develops and/or utilizes** existing standards and guidelines that promote individualized, family-centered, community-based services for children with special health care needs.

☐ 51.2 Procedures exist for **disseminating** the standards to a broad range of people, including families, professionals, and advocacy groups.

☐ 51.3 Standards and guidelines are periodically **reviewed and revised** by a broad range of users including families.

☐ 51.4 **Public acknowledgement** is given to those professionals, teams, centers, or programs that meet identified standards or guidelines.

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52.0 THE STATE HEALTH DEPARTMENT CONDUCTS INTERNAL MONITORING TO ENSURE THAT PUBLICLY FUNDED SERVICES ARE RESPONSIVE TO CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES.

☐ 52.1 The state health department has a **quality assurance system** in place to evaluate its own performance.

☐ 52.2 The state health department monitors the attainment of its own identified **goals and objectives**.

☐ 52.3 The state health department has an **internal audit system** for monitoring the use of funds in purchased or contracted services.

☐ 52.4 The state health department **monitors compliance** of publicly funded programs with existing standards or guidelines.

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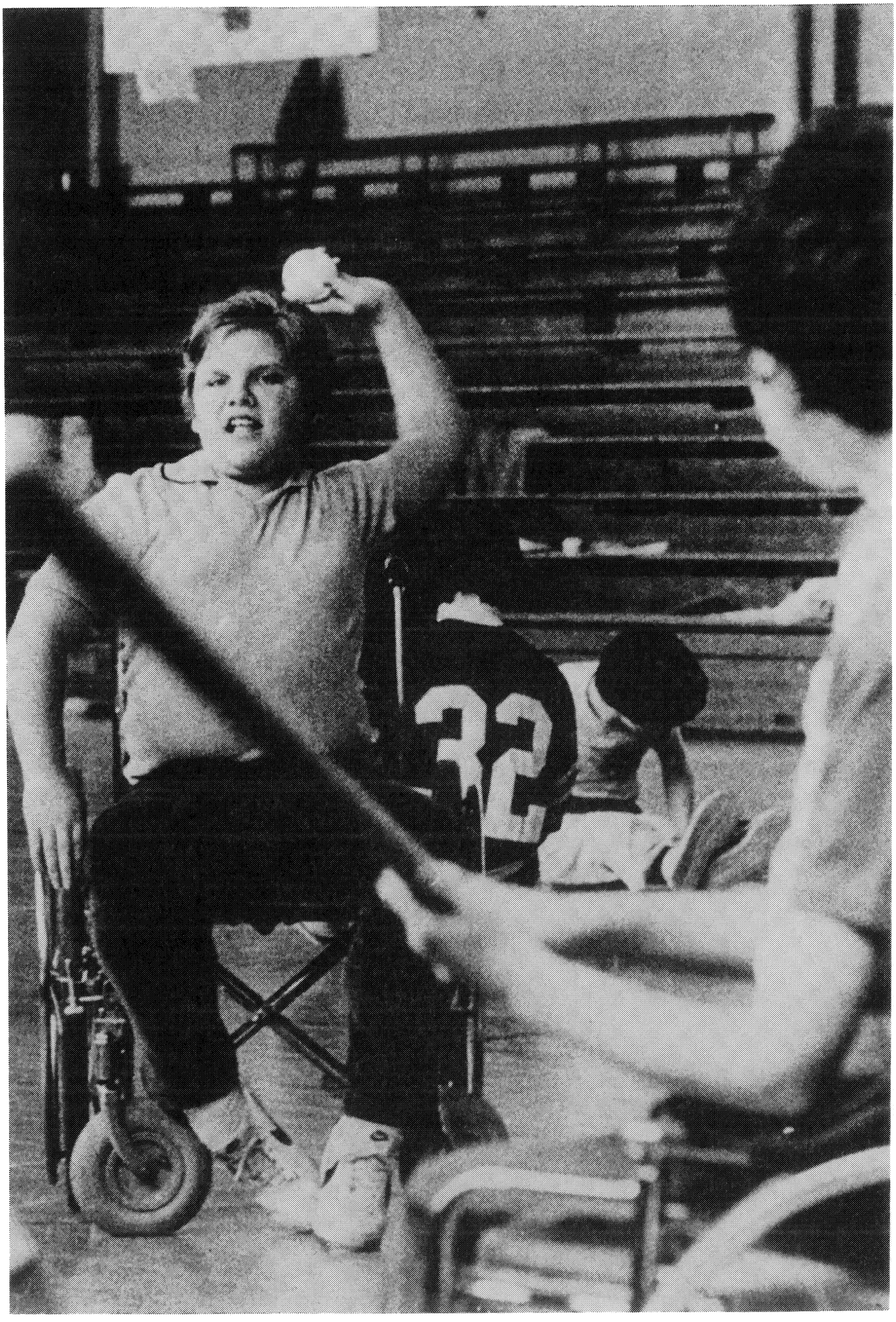
V.

GUIDELINES FOR COMMUNITY AND SOCIETAL SUPPORTS



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V. GUIDELINES FOR COMMUNITY AND SOCIETAL SUPPORTS

The standards and indicators in the four previous sections focus on the delivery of and support for high quality care to children with special health care needs. However, successful implementation of these standards depends on factors extending beyond the health care providers and agencies to the larger society in which the health care system exists. Section V is designed to recognize this social context. This section asks the users to expand their thinking to consider community and cultural characteristics and values that shape family life, affect health status, influence the integration of children with special needs into community activities, and ultimately impact the delivery of health care services. This section acknowledges the many spheres of influence in child and family life: education, leisure activities, housing, and employment. Section V challenges everyone to identify activities where they may join with others to enhance the daily lives of children with special health care needs and their families.

Individuals define *community* in many ways. Definitions often shift to accommodate differing needs or purposes. Families may define their communities based on the type, intensity, and frequency of their needs. For example, a family's *educational community* may correspond to the local school district, whereas the community from which health care services are received may cover a wider geographic area. For some families, their *health community* may extend a considerable distance to include sites where specialty services are delivered, or it may be defined by the vast array of informal resources utilized in rural settings.

Families have differing expectations of what services need to be present in their immediate community. Generally considered important and included are the following: primary care, dental services, information and referral, care coordination/case management, a school system responsive to children with special health care needs, recreation, respite care, family supports, public awareness efforts, and effective advocacy.

Culturally-specific values may also influence how a family defines their community. Such values may include the importance of sharing a common language, respect for religious beliefs, or a shared concept of family roles and responsibilities. In some instances these values may supersede geographic proximity in defining community, and these families will seek critical services from a broader area or region.

Section V is organized into three major areas where activities must take place in order to support a system of quality health care and community integration for children with special health care needs and their families. The areas include: 1) public awareness and family support, 2) community program planning, and 3) advocacy.

Responsibility for implementation of these activities will vary. It may rest solely within local municipalities or voluntary organizations, or may require collaborative actions across many levels of society. Because of the shared nature of responsibility for these activities, the goal of this section is to provide guidance to groups and individuals rather than establish standards. This section is designed to assist families, professionals, agencies, and advocates for children in addressing the broader influences on the availability of quality child health services.

PUBLIC AWARENESS AND FAMILY SUPPORT

Children with special health care needs and their families are a part of every community. Communities, however, vary widely in the degree to which they support and integrate children with chronic illness or disability and their families. A key strategy for strengthening community support is to increase public awareness of: 1) the developmental needs of children, 2) the specific needs of children with chronic illness or disability and their families, and 3) the mutual rewards of integrating every child and family into community life.

Parent groups have played a significant role in increasing community awareness about children with special health care needs. Many of these groups originated when families facing similar issues reached out to others for understanding, support, and information. In recent years parent groups have expanded in size and political action. While mutual support and information sharing remain the core of their mission, parent groups have also increased their activities in the areas of child advocacy and public education.

Effective public awareness and family support efforts increase community sensitivity to and acceptance of children with special health care needs. The following guidelines define the components of a quality public awareness and family support system.

53.0 PUBLIC AND PRIVATE ORGANIZATIONS SPONSOR AND SUPPORT ACTIVITIES THAT INCREASE PUBLIC AWARENESS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN THE COMMUNITY.

☐ 53.1 Public institutions such as schools, libraries, and museums initiate **disability awareness programming** for children and adults and include appropriate and updated educational materials in their permanent collections.

☐ 53.2 Members of the community are **recruited and trained** as volunteers to assist in programs that serve children with special health care needs.

☐ 53.3 **Volunteers** are identified and recognized.

☐ 53.4 Exemplary **public education programs** are recognized.

☐ 53.5 Public service announcements, community cable television programs, and cultural events (e.g., films, art exhibitions, and theatrical productions) are utilized to increase **public awareness**.

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54.0 COMMUNITY SERVICES AND PROGRAMS SERVE CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND REFLECT RESPECT FOR FAMILY DIFFERENCES.

☐ 54.1 **Barriers** to children's participation in community programs are identified and addressed.

☐ 54.2 Public and private **recreational programs** integrate children with special health care needs into regular programming and develop specialized services as needed.

☐ 54.3 **Religious organizations** include children with special health care needs in education, worship, and recreational activities.

☐ 54.4 **Transportation services** are available to facilitate participation in community programs.

☐ 54.5 **Accessible housing** is available to families in the community.

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55.0 COMMUNITY SERVICES, EDUCATIONAL INSTITUTIONS, MUSEUMS, AND LIBRARIES ENSURE ACCESSIBILITY FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 55.1 Physical facilities are **barrier-free** for all users with physical or sensory impairments.

☐ 55.2 Alternative **communication resources** are available to support use by children with visual or auditory impairments.

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56.0 PERSONS WHO WORK WITH OR SERVE CHILDREN IN THE COMMUNITY ARE SENSITIZED TO THE SPECIAL HEALTH CARE NEEDS OF CHILDREN WITH CHRONIC ILLNESS OR DISABILITY.

☐ 56.1 Local **police and fire department** personnel have specific knowledge of children with chronic illness or disability in their community who may require their assistance.

☐ 56.2 Local **community organizations** or facilities that provide services to children (e.g., day care, recreation, youth groups, libraries) prepare personnel to serve children with special health care needs.

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57.0 LOCAL EMPLOYERS, BUSINESSES, AND CIVIC ORGANIZATIONS DEVELOP POLICIES THAT SUPPORT CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES AND PROVIDE LEADERSHIP TO INCREASE PUBLIC AWARENESS.

☐ 57.1 **Youth employment** opportunities include children with special health care needs.

☐ 57.2 **Corporate giving** and voluntary contributions benefit children with special health care needs.

☐ 57.3 **Private organizations** and charities recognize and address disability issues.

☐ 57.4 Personnel policies are supportive and **provide flexibility to families** caring for a child with special health care needs.

☐ 57.5 Employment practices **do not discriminate** based on the special health care needs of employees or their family members.

☐ 57.6 Employer sponsored **health insurance plans** are responsive to the needs of children with special health care needs.

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58.0 FAMILY SUPPORT PROGRAMS AND PARENT NETWORKS ARE PROMOTED AND FINANCED.

☐ 58.1 A full range of family support services are **available in the community**, e.g., babysitting/day care, adaptive equipment exchanges, transportation, and advocacy services.

☐ 58.2 Parent networks are encouraged and **widely publicized**.

☐ 58.3 Support programs for parents and for brothers and sisters receive **public and private funding**.

☐ 58.4 Families receive **respite care services** so that they may participate in community life.

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59.0 FAMILIES HAVE ACCESS IN THEIR COMMUNITY TO UPDATED INFORMATION AND REFERRAL SERVICES.

☐ 59.1 Information and referral services are **widely publicized**.

☐ 59.2 Information and referral services are accessible at **no cost**.

☐ 59.3 A **comprehensive range** of child health and family support services are included.

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COMMUNITY PROGRAM PLANNING

Many public and private organizations provide services to children. While some of these groups address the needs of children in general, more often they focus on specific areas such as medical care, education, mental health, or social services.

Definitions for target populations, operating procedures, geographic organization, data bases, and information systems vary among service providers. These differences also occur across public agencies such as departments of health, education, and social service and contribute additional barriers to effective needs assessment and planning at the community level.

Because the needs of children with chronic illness and disability fall within the purview of many agencies, families face the often difficult task of integrating services. Coordinated planning and program development are needed at the community level to facilitate delivery of care. These activities require close collaboration, on-going consumer and professional involvement, and open communication as described in the following guidelines.

60.0 FAMILIES AND PROVIDERS ARE REPRESENTED ON A BROAD RANGE OF COMMUNITY PLANNING AND POLICY BOARDS AT THE LOCAL LEVEL.

☐ 60.1 Community organizations such as hospitals, recreation commissions, United Way, mental health centers, YMCA, and arts centers **recruit family and provider representatives**.

☐ 60.2 **Family representatives** are drawn from a variety of child/family advocacy and support groups.

☐ 60.3 Provider representatives are drawn from a **range of disciplines** and professional groups.

☐ 60.4 Community planning and policy boards provide **training** to family representatives and providers to build partnership skills.

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61.0 NEEDS ASSESSMENT ACTIVITIES OCCUR AT THE COMMUNITY LEVEL TO IMPROVE PROGRAM PLANNING FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 61.1 Multiple strategies for **identifying unmet needs** and gaps in resources are utilized, such as public hearings and surveys of providers, families, and community leaders.

☐ 61.2 Needs assessment strategies identify child and family service needs in **multiple areas** such as education, recreation, social service, and health.

☐ 61.3 Needs assessment activities include **outreach efforts** to identify individual children in need of services.

☐ 61.4 Communities initiate **recruitment of professionals** to meet identified needs, including providers of primary care and dental services.

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62.0 PUBLIC, PRIVATE, AND VOLUNTARY ORGANIZATIONS COORDINATE THEIR PROGRAM PLANNING EFFORTS TO ENSURE INTEGRATION OF SERVICES.

☐ 62.1 Planning for children with special health care needs is **integrated** into the overall planning for health services.

☐ 62.2 Planning for health care services reflects the **specialized needs of children**.

☐ 62.3 Community organizations, including schools, coordinate planning for major transitions in services to ensure **continuity of care**.

☐ 62.4 Community organizations such as schools, day care, and social service providers coordinate **transportation services**.

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63.0 PUBLIC AND PRIVATE AGENCIES COLLABORATE IN THE IMPLEMENTATION OF PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS TO AVOID DUPLICATION OF SERVICES.

☐ 63.1 Services that fall under the purview of each agency are clearly **identified and publicized**.

☐ 63.2 **Collaborative agreements** are developed to implement joint programs.

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64.0 LOCAL BOARDS OF EDUCATION FULLY IMPLEMENT FEDERAL AND STATE MANDATES CONCERNING THE RIGHTS OF ALL CHILDREN TO A PUBLIC EDUCATION IN THE LEAST RESTRICTIVE ENVIRONMENT.

☐ 64.1 **Individual education plans** ensure attention to health needs that have an impact on learning.

☐ 64.2 Local **parent councils** are established to identify program needs and monitor compliance.

☐ 64.3 Public schools provide programs enabling staff to acquire skills to support the **educational and social integration** of children with special health care needs.

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65.0 LOCAL BOARDS OF EDUCATION ENSURE THAT CHILDREN WITH CHRONIC ILLNESSES OR DISABLING CONDITIONS RECEIVE THE NECESSARY HEALTH SUPPORTS TO PARTICIPATE IN SCHOOLS, WHETHER OR NOT THEY REQUIRE SPECIAL EDUCATION.

☐ 65.1 Children requiring intermittent hospitalization receive timely and age-appropriate **home or hospital-based** education.

☐ 65.2 Policies are in place to ensure that needed **health services** are delivered **in the school**.

☐ 65.3 Local boards of education ensure that **school personnel** receive necessary **training** or assistance.

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ADVOCACY EFFORTS

Advocating for children is a special responsibility. Children, because of their age, developmental level, and legal definition, require others to speak for them, especially when their rights or interests are at risk. Traditionally, parents, guardians, public officials, and interested citizens at large have assumed the child advocacy role. These advocacy efforts have often stemmed from the needs of a specific child and family and broadened to collective efforts on behalf of many children with similar needs.

Parents who advocate for groups of children add these unpaid activities to their on-going parenting responsibilities. Advocacy requires skills that are effective in the public arena as well as financial resources for implementation. Fortunately, recent legislative mandates in the field of education have encouraged and supported the development of such skills, which may be transferred to health care. The broad range of available activities permits advocates to choose a comfortable level of participation. Some may write letters of support to legislators, others may wish to serve on local, state, or national policy-making committees.

Professionals, like family members, have in-depth knowledge of the issues relating to children with special health care needs. This knowledge must be transmitted to a broader audience in order to contribute to effective advocacy. Professionals are encouraged to join with parents in analyzing public policy issues that relate to children with special health care needs.

Parents, professionals, and other interested citizens have often formed organizations along disorder-specific lines. While these groups do perform important mutual support and education activities, they also advocate for a relatively small population of children and families. Coalitions among these groups can strengthen advocacy on behalf of all children with special health care needs.

The following guidelines identify ways in which advocacy efforts can be organized to ensure that the interests of children with special health care needs are represented.

66.0 INDIVIDUAL CHILD ADVOCACY SERVICES ARE AVAILABLE IN THE COMMUNITY.

☐ 66.1 Public and private agencies have clear procedures to assist **individual children** in obtaining services.

☐ 66.2 Agencies **publicize resources** for individual child advocacy.

☐ 66.3 Individual child needs are aggregated to assist in identifying areas for **collective advocacy**.

☐ 66.4 Advocates for children monitor and report on **compliance with mandated services**, regulations, and standards of care.

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67.0 CHILD ADVOCACY GROUPS, INCLUDING PARENTS, PROFESSIONALS, AND OTHER INTERESTED CITIZENS, ARE SUPPORTED IN THEIR EFFORTS ON BEHALF OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS.

☐ 67.1 Child advocacy groups have opportunities to **access funding** through grants, private foundations, and/or public resources.

☐ 67.2 Child advocacy groups have **access to data** regarding needs and utilization of resources.

☐ 67.3 Advocates have opportunities for **training** to develop effective advocacy skills.

☐ 67.4 Advocates use opportunities for **communication with officials** in public agencies and legislative bodies.

☐ 67.5 **Input from families** and/or child advocates is actively sought on proposed legislation; parents and professionals present testimony at public hearings.

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68.0 COALITIONS BETWEEN PARENT, PROFESSIONAL, COMMUNITY AND OTHER ADVOCACY GROUPS ARE FORMED TO PROMOTE COLLECTIVE ACTION.

☐ 68.1 Communication systems are developed and maintained among the various advocacy and professional organizations to assist **information exchange**.

☐ 68.2 Advocacy groups **form coalitions** with professional organizations to lobby for needed policy changes relating to children with special health care needs.

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EPILOGUE


People love our parks.

EPILOGUE

Enhancing Quality describes resources, activities and collaborative roles that are necessary to build a system of quality health care for children with special health care needs and their families.

These standards and indicators provide an operational definition of the concepts of family-centered, community-based, coordinated care. They are organized into a framework that focuses attention on differing levels within the health care system: the individualized service, the provider and team, the health care agency, the state department of health, and the local community.

Successful implementation of these standards will support beneficial outcomes for children, families, and communities. Many of these outcomes, though long-term and difficult to measure, are no less important or real. This presents a significant challenge when documenting the relationship between services and outcomes in health care.

The following list of anticipated outcomes reflects the values and philosophy of care that are central to **Enhancing Quality**. These statements summarize desired outcomes for each of the following: the individual child and family, health professionals and teams, health care agencies, the state health department, and communities.

The child

- grows and develops toward independent adulthood;
- develops a positive self-image;
- is knowledgeable about his/her illness or disability;
- develops ways of managing the impact of his/her illness or disability; and
- gives feedback indicating that he/she is satisfied with the care received.

The family

- is knowledgeable about the child's condition, prognosis, treatment plan, and available resources;
- feels comfortable in caring for the child's special health care needs;
- effectively uses a range of resources to meet the needs of the child and other family members;
- maintains social integrity;
- maintains financial integrity; and
- gives feedback indicating satisfaction with the availability of resources, the process used in the delivery of care, and their involvement in decision making.

The health care professional or team

- delivers care resulting in health status outcomes consistent with optimal expectations for children with special health care needs;
- maintains a high level of education and training;
- responds to the needs of families as defined by families;
- coordinates care with others delivering services to children; and
- derives professional satisfaction and growth in delivering care to children and families.

The health care agency or facility

- delivers, and/or collaborates in delivering, a wide range of services;
- facilitates family-centered care through its administrative practices;
- supports providers in their delivery of care to children with special health care needs;
- delivers care in a cost effective manner; and
- ensures safe care within its physical facility.

The state health department

- provides leadership in the development of the health care system;
- utilizes standards of care to promote quality;
- establishes a health data and information system;
- guides the allocation of public resources to meet the special health care needs of children;
- initiates statewide efforts in the primary and secondary prevention of chronic illnesses and disabling conditions; and
- collaborates with public and private agencies and providers on behalf of children with special health care needs.

The community

- values all children;
- integrates children with special health care needs into all aspects of community life;
- recognizes that its life is enriched by the integration of children with special health care needs;
- supports and engages in broad advocacy efforts by agencies, parents, and professionals;
- provides a coordinated system of care responsive to children with special health care needs; and
- supports services to children with special health care needs through public and private funding.

This document has been developed as a tool for families, health care providers, and policy-makers to use to build more effective partnerships to enhance the quality of health care for children with special health care needs. **Enhancing Quality** is a blueprint for action on behalf of children.

USE OF TERMS

The following words or phrases are explained or defined below as they are used in this document.

Accessibility	The degree to which health care is available to individuals; the absence of geographic, attitudinal, cultural, physical, architectural, or financial barriers to care.
Administrative effectiveness	Application of sound management techniques, including those pertaining to the mission, organizational structure, human resource development, information systems, policies, procedures, and quality assurance systems, to deliver care effectively and efficiently.
Advocacy	The process of speaking for, or on behalf of, an individual, group, or cause, especially when rights or interests are at risk.
Age-appropriate care	The recognition and/or reinforcement of the individual as a person of a certain chronological age in the design and delivery of health care.
Agency	The facility, organizational structure, operating policies, and financial mechanisms that permit professionals to deliver safe, efficient, and effective care to children with special health care needs and their families. Health care agencies may include tertiary care centers, health maintenance organizations, private specialty care clinics or hospitals, neighborhood health centers, publicly operated specialty care programs, and home care agencies. The term agency may also apply to private specialty care group practices that operate within a formal organizational structure rather than as a loosely affiliated group of professionals.
Assessment	The process of identifying the health status of an individual including present developmental and functional levels, strengths and needs, conditions that may impede development and, where possible, the causes of disability or disease.

Care coordination	The act of providing assistance necessary to ensure the effective and efficient organization of and access to services and resources that are appropriate to meet child and family needs. Care coordination includes a process of negotiating, facilitating, and advocating for the delivery of services that are included in the health care plan.
Case management	A variety of case management models and programs have been developed that offer a continuum of services, reflecting differing levels of service intensity. For the purposes of this document, the terms case management and care coordination are used synonymously.
Children with special health care needs	A heterogeneous population having in common the need for specialized health services. The definition includes children through age 21 who have any one of a broad range of disabilities or chronic illnesses diagnosed at any time during childhood including the prenatal period. Examples include diabetes, asthma, cystic fibrosis, arthritis, sickle-cell anemia, HIV infection, cerebral palsy, myelodysplasia, etc. Such chronic health conditions may necessitate adaptations for daily functioning, prolonged or periodic hospitalizations, or special services in educational settings.
Chronic illness	An illness marked by long duration or frequent recurrence.
Collaboration	The establishment and maintenance of open, cooperative communication and working relationships among care-givers and the family in identifying goals and delivering care to individuals.
Community	An interacting population of various kinds of individuals in a common location. Families may define their communities in different ways depending on the type, intensity, and frequency of their needs and their culturally-specific values. A community may exist at local, regional, or national levels.

Community-based care	Services delivered at a local level or as close to the child's home as possible; the major responsibility for planning, designing, and implementing the services rests within the community as defined by the family.
Community program planning	The process by which agencies that address the generic needs of children collaborate to plan and design services that can effectively meet the special health care needs of children.
Comprehensive	The inclusion of a broad range of health, educational, social, and related services in delivering care.
Continuous	Care that is maintained without interruption despite changes in the child's health care delivery site, caregivers, or method of payment.
Coordinated	Care that is planned and implemented so as to form a cohesive therapeutic program.
Culturally-sensitive	Care that is responsive to the values, beliefs, social norms, and behaviors of the individuals or population being served. Recognition of the values of different population groups.
Developmentally-oriented	Care that is based on the individual's functional level and chronological age. Functional level includes physical, cognitive, psychosocial, and communications development.
Disabling condition	Any condition that interferes significantly with normal functioning and development.
Documented care	All aspects of care (assessment, problem-identification, ongoing interventions, and outcomes) are periodically recorded in a system that is easily accessible to the family, providers, and authorized monitors/evaluators of health care.

Education and training	The preparation of family members or health care providers to deliver care by increasing their knowledge base, skill level, and/or sensitivity to issues relevant to children with special health care needs.
Efficacious care	Care that is based on acceptable scientific evidence and practices, achieving the anticipated outcomes in health status.
Family	The basic unit of society having as its nucleus one or more persons consistently serving in the care-giving role for a child. This role may be filled by a parent, foster parent, guardian, brother, or sister. In some cases, other members of the extended family such as an aunt, grandparent, or close friend may represent or substitute for the family.
Family-centered	Care that recognizes and respects the pivotal role of the family in the lives of children. It supports families in their natural care-giving roles, promotes normal patterns of living, and ensures family collaboration and choice in the provision of services to the child.
Family participation	The process by which the child and family work collaboratively with health professionals in decision-making, planning, and delivering care.
Family supports	A range of services that respond to needs as identified by family members. Such services may include parent networks, babysitting/day care, equipment exchanges, advocacy services, respite care, and any other assistance that facilitates family life activities and participation in the community.
Geographically-available care	Care that is accessible to all children regardless of place of residence.
Habilitation	Procedures and interventions designed to assist the individual to greater mental, physical, and social development.

Health	A state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.
Health care delivery system	The network of public and private health care professionals, services, and administrative structures that support and/or deliver in-patient, ambulatory, and community-based care to meet the health needs of individuals or groups. The network includes tertiary care centers, health maintenance organizations, private specialty care providers, hospitals, publicly operated specialty care clinics, neighborhood health centers, home care and community health agencies, and all payors of care.
Health care plan	A written plan of services and therapeutic interventions based on a comprehensive assessment of an individual child's developmental and health status, strengths, and needs that is designed and periodically updated by the health care team.
Health care team	An interdisciplinary group of professionals and family members who collaborate in planning, delivering, and evaluating health care services for an individual child with special health care needs.
Health care professional	A provider who meets the educational and/or licensure requirements to deliver certain services. Health care professionals may have expertise in areas such as: audiology, child development, creative arts, dentistry, education, genetics counseling, medicine (primary and specialty care), nursing, nutrition, occupational therapy, orthotics, physical therapy, psychology, social work, and speech and language therapy.
Health promotion	The process of enhancing the development of positive health behaviors or outcomes for specific or general populations. Strategies may include health education and/or health care interventions.
Indicator	Specific example of how a standard may be implemented or operationalized.

Individualized care	Care that reflects the unique physical, developmental, emotional, social, educational, and cultural needs of the individual within the context of the family.
Integrated care	Care that includes a system for communication and advocacy in order to ensure that the individual and his/her family participate fully in all aspects of society.
Interagency collaboration	Cooperative efforts between or among agencies to maximize resources on behalf of children with special health care needs and their families.
Interdisciplinary process	A process of communication and interaction among persons who bring a variety of diagnostic, therapeutic, and habilitative skills and knowledge to bear upon the development and implementation of a health care plan.
Needs assessment	The process of identifying and documenting unmet needs and gaps in services for children with special health care needs. Information is gathered from families, providers, and service agencies and may be aggregated on a community, regional, or state level. Indicators of the health status of children and service utilization measures are monitored as part of a comprehensive needs assessment process.
Non-discriminatory	Care that is available to all individuals and their families regardless of race or ethnic identity, primary language, religion, gender, sexual orientation, marital status, medical condition, or method of payment.
Payment-assured	The cost of health services provided to the child are paid for while protecting the financial integrity of the family.
Primary care	Health care for children that includes health maintenance, management of acute illnesses and some complications of chronic conditions, routine physical examinations, and immunizations.

Public awareness	Increased consciousness and/or understanding within a community or broader society about the special health care needs of children and their families.
Quality assurance	A system of ensuring that health care service providers, facilities, and agencies have the capability and resources necessary to deliver an acceptable level of service consistent with established beliefs regarding good practice. Strategies for quality assurance may include the setting of standards, monitoring, auditing, certification, program evaluation, training and technical assistance, and reallocation of resources.
Resource allocation	The process of apportioning funds, staff, equipment, facilities, or anything of value to fulfill a specified objective.
Safe care	Care that is free from unnecessary risk by ensuring use of adequate facilities, staff, procedures, and equipment.
Staff supports	Agency policies, programs, and climate that facilitate staff members to perform in a sensitive, knowledgeable, skilled, and efficient manner when delivering health care services for children with special health care needs and their families.
Specialty/specialized care	Health care that is differentiated according to body system or diagnosis and requires specific professional education, knowledge, and skills to be delivered. Access to specific resources such as medications, therapies, and procedures is usually required.
Standards	Pre-established objective criteria or benchmarks that define goals for performance in health care. Standards are derived from current knowledge, proven practice, laws, and policies that identify the required components of care and are endorsed by both providers and recipients of care. Standards may be minimum compliance thresholds or may offer model targets for increasing quality and infusing the health care system with new practices. **Enhancing Quality** is an example of a set of model standards.

State health department	The organizational unit at the state governmental level that has the responsibility to promote, administer, and/or provide health services to children.
Tertiary care	The most specialized level of health care services characterized by highly trained specialists and access to sophisticated technologies.

Many of these definitions have been adapted from the following sources:

Accreditation Council on Services for People with Developmental Disabilities.
Standards for Services for People with Developmental Disabilities, 1987.

Association for the Care of Children's Health.
Family-Centered Care for Children with Special Health Care Needs, 1987.

International Dictionary of Medicine and Biology, 1988.

National Maternal and Child Health Resource Center.
Community-based Systems of Comprehensive Services for Children with Special Health Care Needs and Their Families, 1988.

Project SERVE, Massachusetts Health Research Institute, Inc.
New Directions: Serving Children with Special Health Care Needs in Massachusetts, 1985.

Webster's Ninth New Collegiate Dictionary, 1985.

APPENDICES

New England SERVE

A Planning Network for Children with Special Health Care Needs

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VALUES

The New England SERVE Regional Task Force on Quality Assurance began its work by reviewing and defining core beliefs and values regarding health care for children with specialized needs. These values formed the philosophical base for the development of the standards contained in **Enhancing Quality**. The following values adopted by the Task Force focus on the rights of the child and his/her family to have access to and receive appropriate care.

All care for children with special health care needs shall be:

Community-based	Services delivered at a local level or as close to the child's home as possible; the major responsibility for planning, designing, and implementing the services rests within the community as defined by the family.
Comprehensive	The inclusion of a broad range of health, educational, social, and related services in delivering care.
Continuous	Care that is maintained without interruption despite changes in the child's health care delivery site, caregivers, or method of payment.
Coordinated	Care that is planned and implemented so as to form a cohesive therapeutic program.
Developmentally-oriented	Care that is based on the individual's functional level and chronological age. Functional level includes physical, cognitive, psychosocial, and communications development.
Documented	All aspects of care (assessment, problem-identification, ongoing interventions, and outcomes) are periodically recorded in a system that is easily accessible to the family, providers, and authorized monitors/evaluators of health care.
Efficacious	Care that is based on acceptable scientific evidence and practices, achieving the anticipated outcomes in health status.

Family-centered	Care that recognizes and respects the pivotal role of the family in the lives of children. It supports families in their natural care-giving roles, promotes normal patterns of living, and ensures family collaboration and choice in the provision of services to the child.
Geographically-available	Care that is accessible to all children regardless of place of residence.
Individualized	Care that reflects the unique physical, developmental, emotional, social, educational, and cultural needs of the individual within the context of the family.
Integrated	Care that includes a system for communication and advocacy in order to ensure that the individual and his/her family participate fully in all aspects of society.
Interdisciplinary	A process of communication and interaction among persons who bring a variety of diagnostic, therapeutic, and habilitative skills and knowledge to bear upon the development and implementation of a health care plan.
Non-discriminatory	Care that is available to all individuals and their families regardless of race or ethnic identity, primary language, religion, gender, sexual orientation, marital status, medical condition, or method of payment.
Payment-assured	The cost of health services provided to the child are paid for while protecting the financial integrity of the family.
Safe	Care that is free from unnecessary risk by ensuring use of adequate facilities, staff, procedures, and equipment.

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Please note: *Numerals correspond to standard or indicator numbers; numbers in italics indicate page numbers for narrative sections.*

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