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IOWA MOBILE AND REGIONAL
CHILD HEALTH SPECIALTY CLINICS

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IOWA CHILD HEALTH SPECIALTY CLINICS
REPORT OF INTENDED USE OF PAYMENTS
1985 - 1986 STATE PLAN

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The Mobile and Regional Child Health Specialty Clinics and Related Programs (CHSC)
(Iowa State Services for Crippled Children)
Specialized Child Health Services (SCHS)
University of Iowa Hospitals and Clinics
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Iowa City, Iowa 52242
August, 1984

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GLOSSARY

AEA	Area Education Agency
CF	Cystic Fibrosis
CHSC	Child Health Specialty Clinics, a division of SCHS (Iowa State Services for Crippled Children)
DHHS	Department of Health and Human Services, formerly HEW
DPI	Iowa Department of Public Instruction
DHS	Iowa Department of Human Services
ENT	Ear, Nose and Throat
EPSDT	Early, Periodic Screening, Diagnosis, and Treatment
HEW	Department of Health, Education and Welfare (now HHS)
ICF-MR/RCF-MR	Intermediate and Residential Care Facilities for Mentally Retarded
IEPC	Integrated Evaluation and Planning Clinics
MCH	Maternal and Child Health Services
NICU	Neonatal Intensive Care Unit
OPP	Iowa Office of Planning and Programming
PNP	Pediatric Nurse Practitioner
RUSP	Residential Unit Service Program
SCHS	Specialized Child Health Services, Department of Pediatrics, UIHC
SHCC	State Health Agency Coordinating Council
SSA	Social Security Administration
SSCC	Iowa State Services for Crippled Children
SSI/DCP	Supplemental Security Income/Disabled Children's Program
Title XIX	Medicaid
UIHC	University of Iowa Hospitals and Clinics
CC	Crippled Children's Services
CSA	Community Services Administration

INTRODUCTION TO CURRENT SERVICES

The purpose of CHSC is to improve the health status and health expectations of Iowa children with chronic handicapping or potentially handicapping problems.

The CHSC achieves this purpose by promoting appropriate health services to all children with chronic handicapping or potentially handicapping conditions and by providing those services not otherwise available or accessible.

Many children are provided services who would not otherwise receive such services because of the family's inability to pay and because specialty services are not available in most communities. Many more children receive services through the private system as a result of promotion activities of the agency.

The services provided by CHSC include preventive, early identification, diagnostic, treatment, care management and follow-up services. These services are provided throughout a variety of activities. A brief summary of CHSC Patient, Family, Provider and Support Systems is included on page v of this section.

Direct patient and family services are provided through a system of regional centers and clinics held at selected sites throughout the state staffed by members of UIHC and CHSC. In support of families, CHSC has a centralized care management program that is responsible for the Supplemental Security Income program for disabled children and for purchase of special care and services.

To fulfill its role as the state program responsible for planning, promoting and providing services for handicapped children, CHSC supports professional training programs and conducts several early identification projects including high-risk follow-up, coronary prevention, scoliosis screening. Finally, CHSC has cooperative arrangements with and/or participates in programs of the University of Iowa Hospitals and Clinics and other state agencies to improve the delivery of services.

This statewide system of regional child health centers and clinics located in Iowa population trade centers provide a method to coordinate services for Iowa children with chronic handicapping or potentially handicapping problems. The CHSC care management program also supports these programs.

The CHSC is heavily involved with a special project that is being conducted to fulfill a mandate of the Iowa Legislature to coordinate a variety of health and health-related services for handicapped children.

The CHSC functions as a modern public service program promoting the specialized services needed by Iowa's handicapped children and providing those services not available from other sources.

SUMMARY OF CHILD HEALTH SPECIALTY CLINICS AND PROGRAMS

PATIENT SERVICES

Evaluation & Intervention Services
 High-Risk Infant Follow-up
 Coronary Prevention
 Integrated Evaluation and Planning Clinics
 Ped/Developmental Clinics
 Adolescent Problems
 Orthopedic Clinics
 Ear, Nose and Throat Clinics
 Cardiac Clinics
 Residential Facility Clinics
 Cystic Fibrosis Clinics
 Muscle Disorder Clinics
 Lead Based Poisoning

FAMILY SUPPORT SERVICES

Care Management Services
 SSI/Disabled Children's Program
 Family Home Care

Financial Support Services
 Transportation
 Sliding Fee Scale
 Purchase of Care

PROVIDER SUPPORT SERVICES

Professional Training
 Audiology and Speech
 Pathology Training Program
 Pediatrician and Pediatric Nurse Practitioner Specialty Training Program
 Student Nurse Training
 Provider Inservice Training Program
 Provider Consultations
 Scoliosis Screeners Training

SYSTEMS SUPPORT SERVICES

Service System
 Regional Centers and Clinics
 Integration of Services Sites, Facilities and Staff
 Networking of Services for Handicapped Children
 Interagency Patient Information System
 Problem Profile

Management System

PATIENT PROBLEMS

Health Risks
 Delayed Development
 Lost Functions
 Early Disabilities
 Premature Death

FAMILY PROBLEMS

Lack of Resources
 Lack of Planning
 Lack of Information

PROVIDER PROBLEMS

Lack of Special Providers
 Maldistribution of Providers
 Provider Information
 Provider Training

SYSTEMS PROBLEMS

Fragmented Resources
 Fragmented Information
 Duplication of Efforts

NOTE: CHSC has cooperative arrangements with and/or participates in related programs of the State Department of Health and University of Iowa Hospitals and Clinics.

BACKGROUND

Iowa State Services for Crippled Children (SSCC) was originally established in 1935 to conduct a statewide program of services "for children who are crippled or who are suffering from conditions which lead to crippling." In 1981 it was deemed important to change the name from State Services for Crippled Children to the Iowa Specialized Child Health Services because the word "crippled" was having a very adverse effect on the acceptability of the program to some families and to many adolescent patients.

In 1983 the name further evolved to Mobile and Regional Child Health Specialty Clinics and Related Programs (CHSC), a division of Specialized Child Health Services (SCHS), Department of Pediatrics, University of Iowa Hospitals and Clinics.

The Iowa CHSC State Plan for 1986 has been prepared and submitted to the U.S. Department of Health and Human Services in accordance with the requirements of the federal Maternal and Child Health Block Grant legislation and the guidelines issued by the Federal Office of Maternal and Child Health. The Plan covers the fiscal year extending from October 1, 1985 through September 30, 1986.

Iowa's State Plan responds to the changes that have occurred in all aspects of the provision of services for handicapped and potentially handicapped children. The major reasons for changes relate to the following.

Changes in Health Problems

The health problems that are recognized as causing handicapping conditions have changed. In 1936, when the CHSC program was started, the major recognized causes of handicapping conditions were life threatening diseases; paralytic poliomyelitis and cerebral palsy. By the 1960's, a number of new life threatening and permanently disabling diseases were identified, including cystic fibrosis, chronic rheumatic heart disease, congenital heart disease and genetically determined diseases. In the 1970's, a large number of growth and development problems that may cause children to be handicapped were identified, including a variety of developmental, behavioral, and educational problems.

Many of these new problems require specialized diagnostic and treatment services that are available only through specialty clinics. Present specialty clinics include pediatric cardiology, pediatric ear nose and throat, muscle disorders, cystic fibrosis, pediatric orthopedics and developmental services covering the full array of problems.

Changes in Family Expectations

Families now expect to take an active role in managing their child's care. Changes have also occurred in family expectations that make clinics more personal. When the CHSC program was initiated, the clinics were conducted as open public pediatric health clinics. No scheduled appointments were given. Children were seen on a first come basis. The clinics are now better organized, patients are given scheduled appointments and reports of the examinations are personalized. Parents are given copies of reports.

Changes in Distribution of Physician Specialists

In addition, changes have occurred in the types of physicians in Iowa who refer children to the program. Historically, Iowa has been a general practice state and now it is predominantly a family practice state. For many years, the number of children per practicing pediatrician was among the highest of all states. This has changed and the number of pediatricians available to provide general pediatric care has greatly increased. Nevertheless, there is now and for the foreseeable future will continue to be a deficit of pediatric subspecialists in many areas of the state.

Changes in Funding Priorities

Title XIX increased public funding for life threatening, disabling and acute conditions for very low income families. Private insurance has increased funding for medical problems.

Changes have also occurred in financing services for handicapped children. The original Title V legislation prohibited the state crippled children's programs from charging parents for diagnostic services; the rationale was that there should be no barrier for any child to enter the medical care system. This policy was changed with passage of the Title V Maternal and Child Health Block Grant legislation that allows states to charge for diagnostic services.

* * * * *

I. DESCRIPTION OF SERVICE NEEDS AND BARRIERS

1. Types of Services Needed by Handicapped Iowa Children

Although it is not possible to determine the precise number of handicapped children who need service, long experience has shown that handicapped children need the following spectrum of services. (Appendix B, page 48 provides information on incidence of diseases and disorders in children.)

Preventive Services

Preventive health services include a broad spectrum of services that are generally credited with being the major factor in determining the health status of the general population.

The major health services that prevent handicapping diseases and disorders are immunization for the well-known childhood contagious diseases whose sequelae have been one of the major causes of handicaps. In this nation and in Iowa, such services are provided as part of usual primary care by private physicians in their offices, and, to a lesser degree, they are provided in publicly supported clinics.

Another type of preventive health service is the health education program. Some health education programs are directed toward the prevention of such potentially handicapping events as accidents, poisonings, burns, etc. Such programs are usually initiated by public or voluntary health agencies and organizations and are primarily conducted through the mass media.

Another type of education program is concerned with personal health behavior and is directed against smoking, improper eating habits, too little exercise, etc. Such programs are fostered by public health agencies.

During recent years, educational programs directed toward early identification of specific diseases such as coronary heart disease, diabetes, and glaucoma have been initiated. Each of these programs require a coordinated public health/private medical sector effort to be effective.

There is widespread public and political support for the concept of providing health services to prevent handicapping conditions. It is clear that it is better to prevent handicapping conditions than to treat them. Nevertheless, few public programs charged with providing services for handicapped children have conducted preventive programs. Although there are many reasons for this omission, the major reason is financial. In the past, when public health programs have considered the development of preventive programs that have long term future effects, they have been confronted with making a choice between providing long-term preventive health services and short-term acute health care services. When confronted with this choice, programs have generally elected to provide

the more immediate direct acute care services. It is important for public health programs to bring more balance into their services, and this may require an administrative decision to designate a portion of the state agency's operating budget to support preventive health services.

Early Identification Services

The original Title V legislation charged the state crippled children's programs with the responsibility for early identification of handicapped children. However, this has proved to be a difficult function for these programs to implement. The great majority of infants and children come from middle class families and receive periodic health supervision examinations, which is the primary means for early identification of handicapping conditions, in private physician offices. Infants and children from poor families receive their care through a variety of public programs. In either case, the children do not receive their primary care from a CC program. As a result, the role of the state CC program has been that of evaluating children who have been identified by primary care examiners as having signs for being handicapped.

Within recent years, a new approach to the early identification of handicapped children has been developed. This new approach is based on the concept of identifying populations of infants and children who are at risk for being handicapped and then providing special follow-up services for them. The best known of these programs are the follow-up programs for infants born at high risk and determined by established guidelines to be at future risk for being handicapped. These programs have proved to be efficient and cost-effective.

There is little doubt that as our knowledge increases about the early identification and the early treatment of the handicapped child, greater emphasis will be given to these programs.

Specialized Diagnosis and Initial Planning Services

Almost all handicapping conditions result in a level of dysmorphology or dysfunction that can be recognized by a physician trained to provide primary care. However, having been identified, the handicapped child requires specialized examinations to determine the cause and to classify the problem. Once this is accomplished, a handicapped child must be provided with a personalized plan of care.

Specialized Treatment Services

Treatment for the various types of handicapping conditions has become complex--sophisticated--and specialized. The day is long past when an individual physician can treat all forms of handicaps. The modern treatment of the handicapped person frequently requires a professional team and special equipment.

2. Types of Services Needed By Families

To achieve its goal for Iowa children who have chronic handicapping or potentially handicapping conditions, CHSC must remove the barriers that limit or restrict Iowa families in obtaining these services. The barriers

that are present in this state are common to all states, but the degree to which each exists is unique to Iowa and influences the design of the CHSC Plan.

Care Management Services

Care management and follow-up services are closely related to initial planning services. They are an important part of any health care, e.g., the patient who has an acute sore throat is examined, diagnosed, given a medication, and requested to return for follow-up examinations to determine the response to the treatment program. Follow-up services become more important for the children who have chronic problems resulting in handicaps. Such children require multiple examinations and multiple treatment by multiple providers over many years. Without such follow-up services, families have great difficulty in maintaining a program of health services for their children over a long period of time.

The provision of care management and follow-up services is essential to the provision of optimal care for handicapped children.

Iowa has addressed this problem by making organized care management services available to all families of children with specialized health care needs.

Coordination of Multiple Problems and Services

The majority of handicapped children have multiple problems that frequently require multiple professional services, involve multiple providers and multiple agencies, and require services over a period of years. Thus, the provision of care for most handicapped children requires coordination of services that exceeds the resources of families and family physicians.

Financial Resources For Care

The greatest barrier that prevents Iowa children from having access to needed specialized child health services is the parents' inability to pay. Low-income families continue to have greater need for health care and are less likely to have a regular source of care than middle and high-income families.¹ In one survey, approximately 70% of all families with a chronically disabled child had significant financial problems as a result of the child's disorder.²

1 Dutton, Diana B., Ph.D. "Children's Health Care: The Myth of Equal Access." Better Health for Our Children; A National Strategy (Report of the Select Panel for the Promotion of Child Health, Volume IV, USDHHS, Publication No. 79-55071, 1981).

2 Pless, I. and Satterwhite, B. "Chronic Illness." In R. Haggerty, K. Roghmann, and I. Pless, Eds., Child Health in the Community. New York: Wiley, 1975.

Costs in addition to treatment include special diets, architectural modifications, home health care, wheelchairs or other devices, psychosocial services, travel to service sites, and days lost from work. There are major gaps in both public and private coverage of health care expenses. For example, Medicaid does not include all services nor does it cover all low-income families. Insurance commonly has exclusions and large deductibles that constitute special barriers to families.

Figure 5 shows the distribution of Iowa families with related children under age 18 and the number of children who are below the poverty level. An estimated 93,900 children lived in 41,014 families with income below the poverty level in 1979.

Figure 6 shows the percent of persons in each county who are below the poverty level and below 150% of the poverty level. One hundred fifty percent of the poverty level corresponds approximately with the lower living standard budget established by the U.S. Labor Department Bureau of Labor Statistics.

The Iowa CHSC addresses the family financial barrier by using a sliding fee scale that results in no charges for services to low-income families (below 150% of poverty level) while more affluent families are charged according to their ability to pay.

Iowa's Medically Needy Program is expected to remove the financial barrier to basic medical services for a large number of children below 100% of poverty.

Available Specialized Health Care Providers

The last three decades of biomedical research has produced major advances in medical science. These advances have led to the growth of medical specialties and subspecialties and to the development of high technology tertiary medical care. However, Iowa is a relatively sparsely populated rural state where the majority of medical care is provided by family practitioners and where the child-to-physician ratio for general practice pediatricians is one of the highest in the nation. This ratio has improved in recent years, but there are still relatively few practicing pediatricians. (Figure 10 shows the distribution of physician specialists in Iowa.) More importantly there are relatively few pediatric subspecialists and related subspecialists throughout the state, and tertiary care is available only at UIHC which is staffed by pediatricians, pediatric subspecialists, and other specialists and subspecialists.

However, because UIHC is located in the southeast corner of the state, there are major problems in making specialized care available to children in all parts of the state.

The distance barrier is addressed by conducting a statewide system of clinics that provide specialized medical services for children with handicapping conditions or potentially handicapping conditions, chronic diseases, and developmental problems.

Available Comprehensive Care Networks

During the last decade, many new public programs have been created to provide new types of services for new problems. This increased specialization has resulted in fragmentation of care. Currently this fragmentation represents a major problem for families as they seek to obtain care for their child.

The Iowa CHSC has addressed this problem of fragmented care through the development of community-based regional child health centers that create a single-entry-site type of care and coordinate the specialized child health services that are provided in the communities.

* * * * *

Thus, the Iowa CHSC provides services that are specially designed to overcome many of the barriers that prevent Iowa children from receiving the specialized child health services that they need.

II. SERVICE GUIDELINES, GOALS AND OBJECTIVES

1. Service Guidelines

Iowa Child Health Specialty Clinics provides and facilitates the provision of specialized health services needed to reduce health risks, chronic illnesses, permanent disabilities, and premature deaths of Iowa children. The following guidelines have been established for the design of CHSC service programs.

Service programs conducted by the Iowa CHSC will, to the extent reasonably possible, assure that specialized health services are:

- a. available and accessible to Iowa children;
- b. targeted to special needs;
- c. cost effective for the patient, the agency, and the state;
- d. coordinated multiprofessional, multi-agency services;
- e. continuing and complete programs of care.

The CHSC statewide child health centers and clinics include:

- a. specialized services and programs provided regionally;
- b. service plans for each child's problems coordinated with other community agencies;
- c. training programs that support graduate-level University students;
- d. inservice training for community service providers.

CHSC programs and systems do not provide:

- a. primary level services for the general population such as those provided by public health, nor,
- b. expensive treatment services, such as renal dialysis, organ transplants, etc. provided by the medical centers.

2. Goals and Objectives

In accordance with the aforementioned guidelines, CHSC has established the following five year goals.

Long-range Programmatic Goals

- a. Patient services will be available within approximately 50 miles of most Iowa children.
- b. Programs will emphasize early identification and intervention.
- c. Care management services will be available to all families served.
- d. Training programs will be targeted to local direct service providers.
- e. Computer patient information will facilitate interagency patient communication.

The following direct service and service system goals and objectives provide direction for FY 1986 agency programs and services.

Patient Service Goal

To increase the health status and health expectations of enrolled Iowa children.

Patient Service Objectives

1. To discharge from service 15% of potentially handicapping conditions as cleared within the first year.
2. To prevent further loss of function for 90% of enrolled children.
3. To increase the functional status of 25% of the enrolled handicapped children after one year of planned services.

Family Service Goal

To align families of enrolled children with acceptable care and services.

Family Service Objectives

1. To implement 90% of recommended/planned health service interventions before annual review.
2. To schedule appropriate professional services for approximately 4,000 enrolled children.
3. To organize multiple-profession and multiple-agency service plans for 1,000 children with multiple problems.

4. To maintain communications with 90% of families of enrolled active patients.

Provider Services Objectives

1. To train health care professionals and students in providing services for handicapping and potentially handicapping problems.
2. To secure appropriate referral of 3,000 children with handicapping and high-risk problems at an appropriately early age/stage.
3. To secure appropriate community staff, facilities and equipment for delivery of service programs.

Service System Objectives

1. To implement computerized patient/client information systems in ten regional locations.
2. To evaluate all program objectives on a semiannual basis.
3. To meet all federal, state and university mandates.

III. DESCRIPTION OF PATIENT SERVICE PROGRAMS AND PROJECTS

1. Introduction

BACKGROUND INFORMATION

To make services available and accessible, the Iowa Child Health Specialty Clinics (CHSC) has over the years, conducted statewide clinics. In these clinics, the staff of CHSC and members of the staff of University of Iowa Hospitals and Clinics (UIHC) provide specialized child health services in or near the home communities of Iowa children who have chronic and handicapping conditions. These specialty services are otherwise unavailable in the local regions, are inaccessible to low-income families or are follow-up to tertiary level services provided at UIHC. They include diagnosis and evaluation, second opinion consultation, care planning and recommendations, follow-up, reevaluations, referrals and arrangements for services.

Future Directions of Patient Services

The following section describes the CHSC service program as it will function at the beginning of the 1985-86 fiscal year. However, a number of changes are now underway and/or planned that will result in improved services to children by the end of the 1985-86 fiscal year:

Services will be provided more frequently on a regional basis.

Services will further utilize local resources: staff, facilities and equipment.

Service information will be more complete; information about previous tests and evaluations will be requested from the referent.

Examiners will be encouraged to directly contact the referring physician about difficult or interesting patients.

Continuity of the medical consultation service will be emphasized.

a. Pediatric Developmental Services - Integrated Evaluation and Planning Clinics - Model 1

Objective: To provide the developmentally-oriented pediatric component to the community educational and social evaluation and planning for Iowa children with health and health-related problems to provide pediatric consultation for medical referrals of these children; and to coordinate multi-agency, multi-discipline services for these children.

Need for the Program: The Iowa CHSC has long been aware that children who are physically disabled and/or educationally handicapped need a community-based medical/educational/social professional team to help them develop to their highest level of independent functioning.

Since 1974, the Area Education Agency (AEA) programs have been required to develop community-based service units for the developmentally and educationally handicapped child. Thus the AEA, as well as CHSC, saw a need to establish a method of providing coordinated community medical/educational/social services for this population.

Staffing: The IEPCs vary in staffing patterns, according to the choice of the respective communities and availability of personnel. The staff generally includes medical personnel provided by CHSC, psychologists and/or speech and audiology personnel from AEA, social workers from district offices of the Department of Human Services (DHS), and other community personnel as needed. The referrals are screened by the CHSC Pediatric Nurse Practitioner (PNP) who is aware of the services available and who channels referrals to the appropriate provider.

b. Pediatric/Developmental Services - Model 2

Objective: To provide pediatric, speech pathology, clinical psychology, physical and occupational therapy services to 400 children in need of definitive recommendations for developmental problems in those areas in which services are not otherwise available.

Need for the Program: The type of problems of children seen in the pediatric clinics is changing to more problems of growth and development, learning and communication.

An increasing number of children are referred to the clinics by the child's physician for problems related to growth and development, difficulties in communication or learning problems. Many of these children have not one but a variety of problems that require examinations by a number of different professionals.

An increasing number of children are also being referred to the clinics by speech pathologists, audiologists, and school psychologists who work in the Area Education Agencies (AEAs). These practitioners provide services that are effective for the majority of the communication and learning problems in the preschool and school-age population. However, as the AEA speech, audiology and psychology practitioners increase in number, they find more severe problems that do not respond or respond poorly to the level of therapy the school personnel supply. Severe problems are usually related to neuropathologies, congenital anomalies and other severe/profound problems.

Since the number of children with severe problems is small, local physicians, speech and audiology clinicians, physical therapy clinicians and psychologists do not gain expertise to recognize and treat these problems. Therefore they refer the children to the clinics staffed by specialists who are experienced in the care of children with severe problems.

Staffing

Pediatric/Developmental clinics are held in the areas of the state where there are few private practicing pediatricians. Staffing includes developmental pediatricians who are members of the Department of Pediatrics, University Hospitals and Clinics and a clinical psychologist, speech and audiology clinician and physical therapist who are members of the CHSC central staff.

Number of Children Served: The number of children served depends on such factors as the number of children in the area, the general economic status of families of the area, the availability of other services, etc.

Plans for the Future: The pediatric/developmental clinics will continue to make specialized services available to handicapped children in the state of Iowa until local specialists are available.

Services will be established in Dubuque, Burlington and Council Bluffs to complete the statewide coverage.

c. Cardiac Services

Objective: To provide pediatric cardiology consultative service for 1,200 children in Iowa who have been determined by their family physician to need definitive recommendations for cardiac problems.

Need for the Program: There are only three specialists providing pediatric cardiology services in the state of Iowa outside of University Hospitals (2 in Des Moines and 1 in Waterloo). Because University Hospitals is located in the southeast part of the state, cardiac evaluation is not geographically accessible to the majority of children in Iowa. The clinics are scheduled so children can receive initial and follow-up examinations as close to home as possible.

Staffing: The cardiac clinics are staffed by a pediatric cardiologist, one or two pediatric-cardiology fellows and/or residents, and a physician assistant from UIHC.

A second model is established in Davenport, which utilizes a single UI pediatric cardiologist and support services from the community hospital and regional child health center to provide monthly consultative services for urgent-acute-complex problems.

Plans for the Future: As clinics become smaller, more frequent and more personal, the number of patients scheduled for each multiple-examiner cardiac clinic is expected to be reduced.

CHSC will continue to extend the single-examiner (Davenport) model as it is determined useful in other locations.

Cardiac services are expected to reduce slowly as a result of increased availability of these services throughout the state.

An estimated 1,200 children will receive services in FY 1986 at multiple-examiner and single-examiner clinics.

Coronary Prevention Project

The coronary heart disease prevention program is conducted in conjunction with the cardiac clinics. The purpose of the program is to identify children who may be at greater risk for future coronary heart disease and to provide counseling, with the intent of reducing the risk of coronary heart disease.

CHSC conducts a coronary heart disease prevention project in collaboration with the cardiology section, Department of Pediatrics, University of Iowa Hospitals and Clinics. This project is an outcome of extensive long-term clinical research conducted in the cardiology section. The research indicated that a significant number of children, whose parents had acute coronary heart disease before age 50 have very high blood lipid levels and are themselves candidates for coronary heart disease. The study also found that it is possible to educate families concerning the need to change their dietary, smoking, and physical fitness habits, and significantly reduce the children's blood lipid levels.

Physicians refer families with a history of early acute coronary heart disease to the program. Blood studies are then conducted to determine if the referred children have high blood lipid levels. Families of children with elevated blood lipid levels are enrolled in the program. Medical counseling is provided by a member of the pediatric cardiology section at the time of a cardiac clinic. Education concerning needed changes and dietary habits and lifestyle is provided by a local nutritionist who has had special training. The children's blood levels are monitored over a period of time to determine the response to the dietary approach. Those few children whose blood lipids do not respond are advised to become involved with medical therapy.

Plans for the Future: The regional child health centers will publicize the availability of the program within the region, particularly to the physicians who are known to provide medical care in the local coronary care units.

d. Orthopedic Services

Objective: To provide orthopedic and physical therapy services to 900 children determined to need definitive recommendations for orthopedic problems.

Need for the Program: There are a number of orthopedists in private practice around the state of Iowa, but many families who attend orthopedic clinics do not have the financial resources for private orthopedic consultations. In addition, many patients lack the financial resources and time necessary to travel the long distances

from many parts of the state to UIHC for orthopedic services. Mobile orthopedic clinics reduce the cost and increase the accessibility of needed services.

The orthopedic service provides specialized examinations and diagnostic services. After examination and diagnosis, certain prescriptive recommendations and decisions regarding intervention procedures are made. CHSC staff provide follow-up services, both pre-intervention and post-intervention, required by conditions such as Legg-Perthes, scoliosis and leg-length discrepancies. Another service of the orthopedic clinics is the education of both families and local physicians about problems such as gait peculiarities. The orthopedic clinics also provide secondary diagnostic service for the statewide scoliosis screening programs.

Staffing: The orthopedic services are staffed by one or two orthopedists and a physical therapist from UIHC in free-standing orthopedic specialty clinics.

Plans for the Future: There are continuing requests for orthopedic consultative services from both medical generalists and specialists. Parent satisfaction with these clinics is also high. Accordingly, these clinics will be continued at approximately the present level.

e. Ear, Nose and Throat Services

Objective: To provide ENT, speech/language, and audiology specialty services for 1,000 children in need of definitive recommendations for ear, nose and throat problems.

Need for the Program: The ENT clinics serve children who exhibit problems such as chronic hearing loss, chronic ear infection, nasal obstruction, voice problems, anomalies of the head and neck and problems of airway obstruction. The state of Iowa has board-certified ear, nose and throat specialists who handle the problems outlined above, but these practitioners are concentrated in a few geographic locations. While eastern and central Iowa are fairly well-covered, southeastern Iowa has only a few practitioners who have quite recently opened offices in that area. West-central and southwest Iowa has an increasing number of practitioners accessible to the population living there.

The excellent program of hearing evaluation in the state of Iowa, administered through the AEA's Department of Public Instruction, has resulted in a discovery of many chronic ear conditions that have not been resolved. Many of these conditions can be remedied if they are appropriately diagnosed and have treatment procedures carried out.

An analysis of families attending ENT clinics revealed that a large proportion of them could not afford the medical cost and/or travel cost for outpatient visits to an ENT specialist for diagnostic and treatment services. Many families in the western part of the state will now have reasonable access to diagnostic and remedial ENT services as a result of the use of private ENT specialists in public clinics.

Staffing: A delivery model has been developed that allows a large number of children to be examined during a one-day clinic. This model is staffed by two otolaryngology examiners from UIHC and five speech pathology and audiology examiners. When the clinics are held in very sparsely populated areas, the above-described team is utilized in two one-half day clinics in two adjacent communities.

A second delivery model utilizes the services of private practice ENT specialists who travel to an area of the state which lacks ENT services, and who, in conjunction with the regional AEA staff, provides secondary level evaluation and treatment services to prevent chronic problems. As ENT specialists increase in number they are becoming interested in serving as examiners in CHSC clinics. During the coming year, arrangements will be made for private ENT specialists to replace UIHC examiners in three additional locations.

Plans for the Future: ENT programs remain one of the most utilized services and will be continued for the foreseeable future. ENT clinics utilizing private practitioners are expected to increase during 1986. A total of approximately 1,200 children are expected to receive ENT clinic services in FY 1986.

f. Muscle Disorder Services

Objective: To provide definitive pediatric, genetic and physical therapy recommendations for follow-up care and appropriate care management for 60 children with genetically determined muscle disease, such as muscular dystrophies and atrophies.

Need for the Program: Once the diagnosis of a genetically determined muscle disease is established in the genetics division, Department of Pediatrics, University of Iowa Hospitals and Clinics, the major part of the ongoing care and counseling can be effectively delivered through the mobile clinic system. A trip to the UIHC three or four times a year over a considerable number of years can be financially and emotionally devastating to a family. In addition, many muscle disease patients become difficult to transport because of increasing size, weight, and loss of muscle tone. Eventually the need to utilize wheelchairs adds to the burden of a long trip. Thus, there is great advantage to the patient and the family to receive ongoing care and counseling through mobile clinics within reasonable driving distance of the child's home.

Staffing: The clinic staff includes a pediatrician, a genetic counselor, and a physical therapist. Services are extended to adults because improved treatment modalities have extended life expectancy into adulthood, and because adult services are otherwise unavailable.

Plans for the Future: Continuation of state funding will enable ongoing clinics in FY 1986. An estimated 60 persons will be served at 5 sites in FY 1986.

g. Cystic Fibrosis Services

Objective: To maintain ongoing services and appropriate care management for 50 children with cystic fibrosis.

Need for the Program: The cystic fibrosis program at UIHC provides specialized care and care management services for children with cystic fibrosis from all areas of the state. It is currently recommended that each patient be seen in the UIHC at least once a year for a comprehensive examination. Clinics provide interim evaluation, care planning, and counseling close to the child's community. The time and financial burdens of the family are reduced and the children receive the needed frequency of services.

Staffing: The clinic staff includes two pediatricians, one or two pediatric nurse practitioners, and one or two respiratory therapists who either are from UIHC or are specially trained personnel in private practice in the region where the clinic is held. Services are extended to adults because improved treatment modalities have extended life expectancy into adulthood and services are not otherwise available.

Plans for the Future: These clinics have decreased in the number of locations because of funding limitations. Services will be restored as funds are available. With the training of local physicians, many patients can now receive follow-up locally. A cystic fibrosis clinic is reinstated in Dubuque. (See Patient Service Statistics)

Number of Children Served: Approximately the same number of children (50) will be served in FY 1986.

h. Residential Unit Service Program (RUSP)

Objective: To provide consultation to residential facility staff in pediatric, pedodontic, speech, physical therapy and developmental services for severely/profoundly handicapped children.

Need for the Program: CHSC was given the responsibility to provide diagnostic and evaluation services for children who are recipients of Supplemental Security Income. After one year of experience in this program, the Iowa CHSC found that the SSI children with the greatest need for service are those who reside in small residential care facilities.

In the past, few severely handicapped children were seen in CHSC mobile clinics, in part because most severely handicapped children were placed in state hospitals and few community services were developed, and in part because the examination of these children at mobile clinics was felt by staff to be unsatisfactory because these children travel poorly and often exhibit atypical behavior in unfamiliar surroundings. Therefore, this alternative method for meeting the needs of the children and care facility staff was developed.

Staffing: The CHSC RUSP team, consisting of a pediatrician, a speech-language consultant, a psychologist and a physical therapist, travels to ICF-MR/RCF-MR facilities upon invitation of the facility staff to design programs for 6 to 8 children per clinic day.

Initially it was planned that each child would be evaluated individually by each discipline. This is the traditional way of assessing severely handicapped children. It became apparent that this method did not provide the optimal examining arrangement for these children. Child care staff who were present during the examinations were being asked the same questions over and over by each discipline. In addition, many of the children could not be assessed with the usual standardized techniques. To resolve this problem, the children are now seen by the psychologist, the speech-language consultant and the physical therapist simultaneously. This allows the examiners to share observations and together arrive at a suggested plan of care.

After the examinations have been completed a case review is held, usually lasting 30-45 minutes for each child, to integrate the team findings and recommendations with the plan of care that the residential unit has prepared for each child. The RUSP team, representatives of the residential unit, designated representatives of other agencies involved with the child (special education, social services, etc.) and parents, if available, participate in the case review. Each review includes a discussion of priorities, scope of services available and short and long-term goals. The major emphasis of the case review is the provision of realistic services from which the child can be expected to profit.

Plans for the Future: The very positive reception of these evaluation and consultation services by facility staff, AEA staff and parents, requires that the agency continue this program in the future.

Number of Children Served: Approximately 60 patients will be served at RUSP clinics in FY 1986.

i. Consultation Services

Objective: To provide single discipline consultation services at the invitation of regional CHSC staff, AEA staff and private physicians.

Speech-Language Consultation: AEA speech-language personnel in those areas who want CHSC consultations for complex communication handicapped children no longer have the clinic services as a resource. At local instigation, a few consultation days were arranged in one AEA and later expanded both there and in two other regions.

Staffing: Children are examined individually by the CHSC speech-language consultant with the local speech-language clinician and at least one parent present. Findings and recommendations are then

jointly discussed and followed up with a written report. Variations on the examining and discussion pattern do occur depending on age of child, presenting problems, parent/child relationships, etc.

Plans for the Future: The speech-language pathology consultation days have been extremely well received and will continue. Service will be expanded to additional areas as time can be made available.

Psychology Consultation Services: Similar consultation is being conducted by the CHSC psychology division. The children are adolescents (12 years and up) who exhibit psychoeducational, and/or psychosomatic problems but are not in categories served by other programs. Psychology services will be increased as staff time allows.

j. High-Risk Infant Follow-up

Objective: A high-risk infant follow-up program is conducted at several of the regional child health centers in association with the research and demonstration project conducted by the UIHC Department of Pediatrics. Plans are being completed to extend the program to other regional centers during the year.

CHSC conducts a service-level high-risk infant follow-up project in the Sioux City, Spencer, Davenport, Carroll, Ottumwa and Waterloo secondary level neonatal intensive care units. Regularly scheduled follow-up developmental assessment examinations are provided for infants who receive perinatal care in Level II neonatal intensive units and who are determined by established criteria to be at risk for being handicapped. The service project is directed by the neonatologist in charge of the local neonatal intensive care unit. The pediatric nurse practitioner employed in the regional child health center serves as the project nurse.

The follow-up program uses criteria established by the research program to determine which children need follow-up examinations. The pediatric nurse practitioner, who has had additional training in developmental assessment, explains the project to parents and, with their approval, enrolls children in the project. The children receive appropriate developmental assessment examinations during the first five years of life. If a child's progress deviates significantly from the anticipated rate of development and/or other physical findings of dysfunction become apparent, the child is referred to appropriate care providers.

The examination protocol utilized in the CHSC project has been developed by the UIHC research and demonstration project. The protocol enables collection of information needed by both the CHSC project and the research and demonstration project.

Plans for the Future: The CHSC projects in Sioux City, Spencer, Carroll, Davenport and Ottumwa have been highly successful. Several other neonatal intensive care units have indicated an interest in establishing high-risk infant follow-up services in conjunction with the regional child health centers.

At Risk Follow-up - Model 2

Follow-up for high risk children is directed towards children who meet the established protocol but is not restricted to these children. Any child who fails the UIHC High Risk Criteria but appears to remain in need of follow-up will, at the discretion of the PNP, continue services but discontinue data collection for the research project.

k. Lead Poisoning Services

In response to an Iowa legislative request to determine if lead poisoning is a significant problem for young Iowa children, the Iowa State Department of Health will screen a sample of 2,000-3,000 children between the ages of two and three. The children will be selected from WIC program participants in all 99 counties. The goal is to screen 50% of the 2-3 year olds enrolled in WIC during the months of May, June, and July, 1985.

Children identified as having elevated serum lead levels will be referred to a regional specialized child health center for further examination.

Each child will receive a complete physical examination by a pediatrician. The purpose of the examination will be to determine the child's health status and to record the presence or absence of disease. Particular attention will be given to evaluating the child's neurological function. A medical reporting form will be used to allow standardized reporting (see attached forms).

Each child will also receive a developmental examination. The purpose of the examination will be to determine the child's development and to record the presence or absence of dysfunction.

- I. WIC - Responsibility for preliminary screening and referral of children with elevated lead levels
1. Screening will be done on 2-3 year olds enrolled in WIC during months of May, June and July.
 2. WIC staff will draw capillary blood for analysis of Free Erythrocyte Porphyrin (FEP) when child is seen for WIC recertification.
 3. If the FEP is elevated, a venous blood lead level will be drawn by WIC staff or lab tech volunteers.
 4. Blood samples will be processed by the Linn County Health Department Lab in Cedar Rapids for FEP and blood lead levels and the written report will be sent to the WIC program within 72 hours of receipt of the blood samples. (The classification of the children based on the blood lead is shown on the attached table.)
 5. Children with elevated lead levels at Class IV will be identified and the results will be phoned to the WIC program immediately with a follow-up written report within 72 hours.
 6. Children with elevated lead levels (Class II, III and IV) will be referred by WIC to the regional clinic of the Child Health Specialty Clinic for further examination.
 7. Children with elevated lead levels (Class II, III, IV) will be referred by WIC to Tom Schlife of the Environmental Health Section for evaluation of their environment for lead contamination.

II. CHSC - Responsibility for medical examinations and health follow-up

1. The CHSC regional secretary will receive the referral and lab test results from WIC. The referral will be made on a WIC Program referral form (see attached) or by telephone if a Class IV child. The regional secretary will notify the central CHSC Patient Management Division (PMS) to initiate a record (Ottumwa will open the record themselves). Enter special program code 014.

The priorities given to scheduling an examination will depend on child's classification.

- a. Class II children are at moderate risk - schedule as time permits.
 - b. Class III children are at high risk - schedule within 1-2 weeks.
 - c. Class IV children are at urgent risk of lead toxicity and should be medically evaluated within 24 hours and in no case later than 48 hours.
2. The CHSC regional secretary will schedule Class II and III children
 - a. with the CHSC regional pediatric nurse practitioner to obtain the history, physical exam and developmental screen. (Creston area will require special arrangements via PMS to obtain.) Use form CH 143-R1.
 - b. with local hospital for CBC, serum iron and iron binding capacity or serum ferritin, flat plate of the abdomen and x-ray of long bones. The CHSC regional secretary will notify PMS to arrange for charges to be paid via Purchase of Care funds (POC).
 - c. with the regional Child Health Clinic pediatrician for complete physical exam, especially the neurologic exam. (Spencer area will require special arrangements via PMS to obtain.). Use form CH-30-R3.
 3. If the child falls within Class IV, ("urgent"). The child will be referred immediately by the pediatric nurse practitioner or secretary to Child Health Specialty Clinic pediatrician; another designated physician; or to University of Iowa Hospitals and Clinics for evaluation. When referring to University of Iowa Hospitals and Clinics for evaluation, the referral should be made to the Pediatric Ambulatory Clinic. The family will be responsible for making arrangements for the cost of the medical care. If the family resources are inadequate, notify PMS to utilize payment via POC funds.
 4. Reports of the clinic evaluation (pediatrician, PNP, lab/x-ray) will be sent to local WIC Project Director, child's family physician, CHSC medical records, and family. A copy will be retained in the regional child health center. WIC will send copies to the MCH Section, Department of Health, Des Moines.

PATIENT SERVICES
EXHIBITS
OCT 1, 1983 — SEPT 30, 1984

Figure 1
AGE GROUPS OF CHILDREN SERVED
ALL CHSC CLINICS
FY 1984

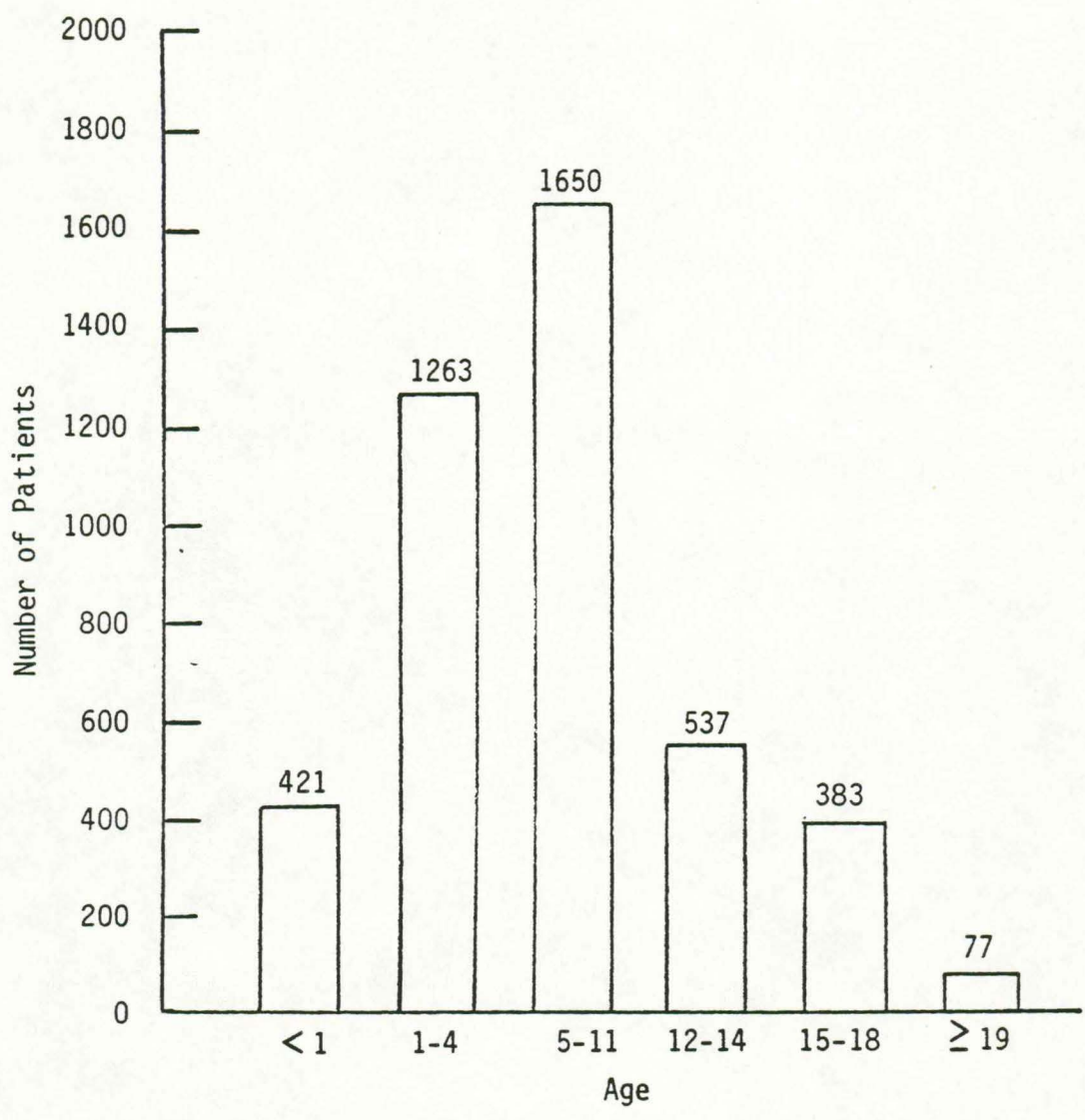


Figure 2

DIAGNOSTIC CONDITIONS SERVED
ALL CHSC CLINICS

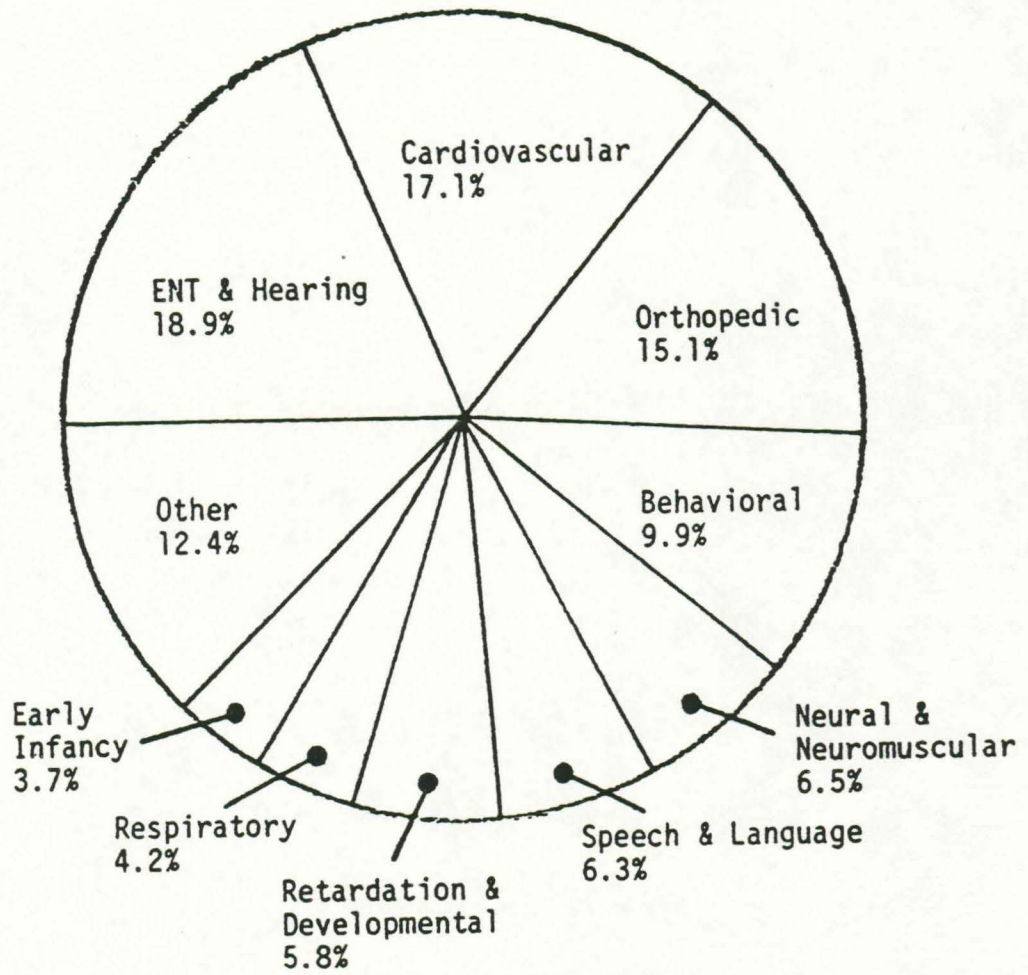


Figure 3

PATIENTS' COUNTIES OF ORIGIN
FY 1984

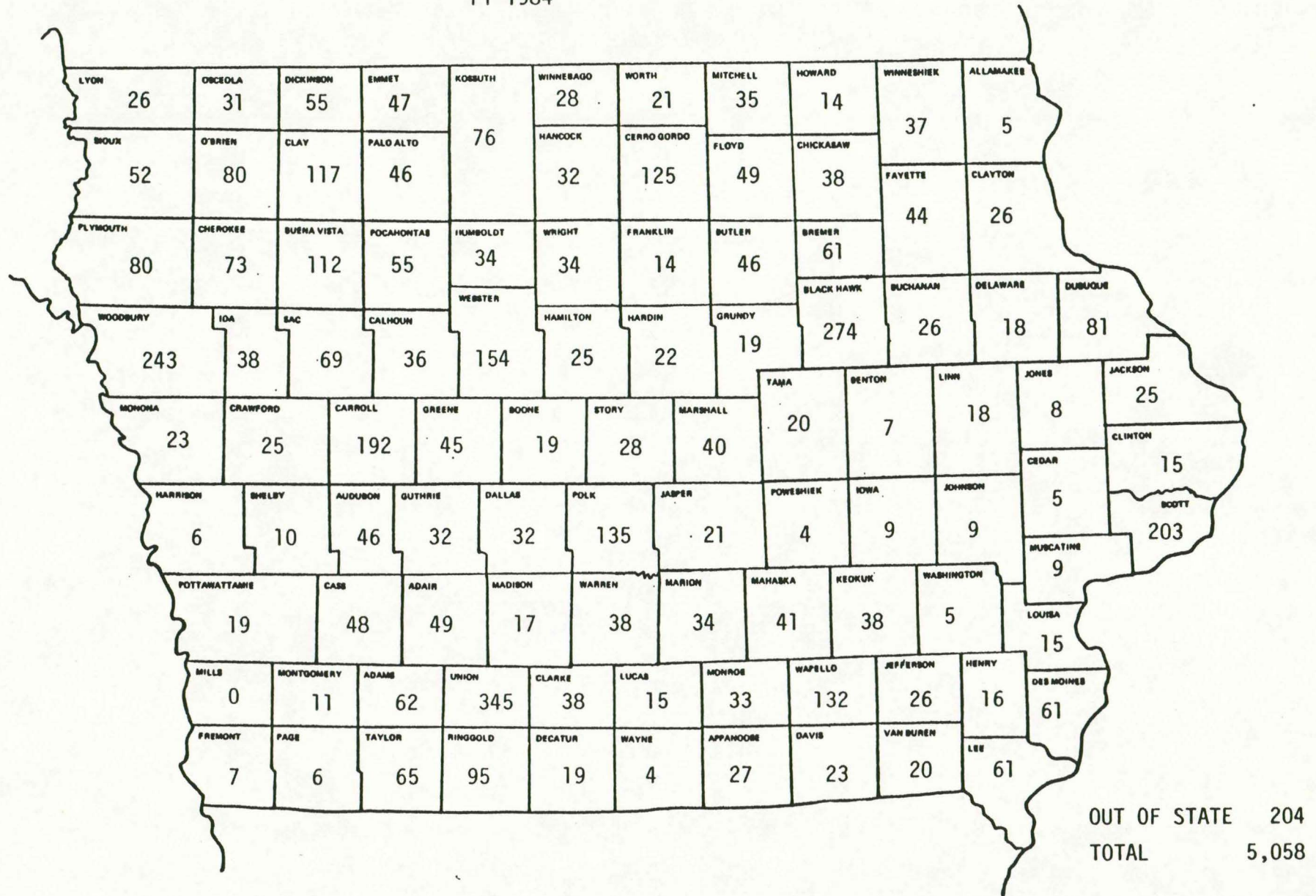
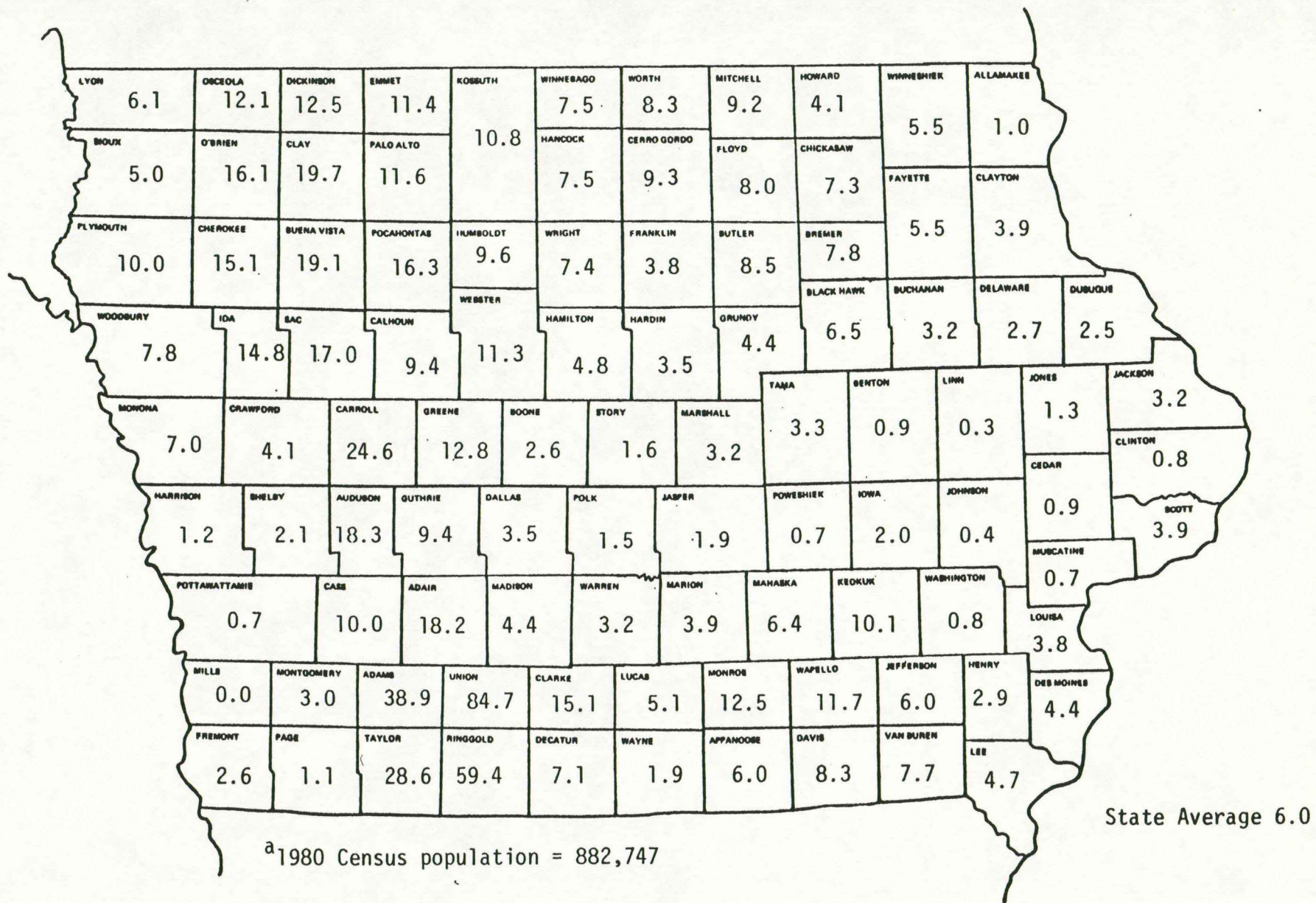


Figure 4

CHSC VISITS PER THOUSAND POPULATION UNDER AGE 19^a



IV. DESCRIPTION OF FAMILY SERVICES

1. Introduction

Historically programs providing services to children with chronic illness or handicapping conditions have provided limited family support services such as counseling, multi-agency planning, referral assistance, follow-up services, anticipatory guidance or access-related facilitations. Yet it is well known that such children and their families frequently are in need of support services to obtain care and to be able to cope with problems as they arise. As a result, CHSC has developed support services to the family as an integral part of the planning and provision of services to their child population.

Case Management Services

CHSC makes available family support services to increase compliance; assure coordination of care; promote continuity of service; and assist in the removal of barriers to care. The case management staff consists of nurses, pediatric nurse practitioners, and a social worker. Contact with the families is maintained through attendance at clinics and via telephone and mail before and after clinic. Staff is located both in Iowa City and the regional centers.

All children enrolled in CHSC have access to care management services. The number of children contacted at service sites in FY 1985 was approximately 5,000. However, several thousand additional contacts with families were made via phone and mail before or after service provision. This monitoring service is designed to check the child's progress, his status related to the proposed plan of care, and problems related to obtaining care or managing the child. It is estimated that FY 1986 will have similar figures, approximately 5,000 face-to-face contacts and 20-30,000 contacts by phone or mail.

a. Direct Service

It is anticipated that primary responsibility for meeting the needs of the child lies with the family. However, chronically ill or handicapped children frequently have complex social, psychological, educational, and health needs. Even able families may become confused about how to meet these interrelated needs. The direct contact with the family, as part of provision of clinical services, allows face-to-face assessment of barriers, coping skills, understanding of the condition, etc. It also allows the family to establish a personal relationship with a case manager which promotes confidence in the later telephone contacts. The case managers assist the family in mobilizing the community services needed for the child and establishing a realistic plan to implement the recommendations of the examiners.

b. Indirect Service

All new referrals are reviewed by case management staff who schedule the children in appropriate CHSC service settings. When needed services are not available through CHSC, alternative care resources are suggested and direction to those resources are provided to the referrer. No referral is abandoned without redirection.

Once CHSC services have been established the case management staff works with referrers, families, DHS, AEA, and others to promote care appropriate to the individual child's needs. Identification and initial evaluation are only the beginning steps to care. Follow-up contacts are an important element in continuing care as recommendations may change as the child matures. If families are to continue compliance and seek services at appropriate intervals, they may need reinforcement regarding the changing needs as specialty services in Iowa often require travel and related expenses and time loss. Telephone, mail, UI hospital computer and multi-agency reports are all utilized to review and update service plans on a scheduled basis. Staff serve as a liaison among provider, provider agencies, and family. The addition of a CHSC on-line computerized data system has greatly facilitated the tracking and management function with families.

c. Supplemental Security Income/Disabled Children's Program (SSI/DCP)

The case management service unit of CHSC monitors services for children eligible for supplemental security income (see Figure 12 for county distribution of active cases). The Supplemental Security Income, Disabled Children's Program (SSI/DCP) was consolidated with other maternal and child health programs in the MCH block grant. The state crippled children's programs continue to have the responsibility to provide service for eligible children who are identified and referred by the Social Security Administration (SSA). However, the Social Security Administration (SSA) remains charged with enrolling children and notifying CHSC to allow for monitor of status and assistance in obtaining needed services. The CHSC takes very seriously the responsibility that goes with the referral of these children from SSA and continues to fulfill that responsibility.

Functionally, arrangements for this group varies slightly from other CHSC enrolled population. CHSC accepts the determination of eligibility by SSA; assigns staff to monitor this population of children; and informs the family about the program and case management if they desire it.

The SSI/DCP population also is eligible to receive payment for selected health related items requested by medical examiners for which families have no source of payment. This includes special diet supplements, drugs, car seats, cost of transportation to needed services, special strollers and chairs, not covered by Title XIX.

Oversight for SSI/DCP eligible children is carried out as follows. Management of children receiving services from related state-supported programs (UIHC, UI Hospital School, Woodward, Glenwood), is limited to reviewing the records sent to CHSC to be certain that recommended services are being obtained. Management of eligible children who do not receive services in one of these state-supported programs is provided by monitoring on an annual basis to determine the adequacy of the services and to promote the provision of appropriate services.

d. Purchase of Care

Historically, CC programs have paid for services provided certain children enrolled in the program. The Iowa CHSC case management staff determines medical eligibility, scope of service, and the amount of money to be spent in the provision of such services. Purchase of or payment for recommended services in Iowa has been a very limited service of CHSC, related to participation in purchase of Pancrease replacement for children with cystic fibrosis and PKU dietary supplement. Expansion of this service is taking place. The plan is designed to encourage children who receive services in the CHSC clinic to return to their local physician or other referring health providers to obtain the services recommended by CHSC.

A review of the cases of noncompliance revealed that an inability to pay is by far and away the chief reason children do not obtain the services recommended by CHSC.

CHSC does not have the funds to pay for all the services it recommends, so it is necessary to establish criteria to identify those children who would otherwise have the least opportunity of receiving services. Therefore the scope of services needed is restricted to non-inpatient services which meet certain other established criteria.

e. Transportation Demonstration Project

While resources to pay for care have been a chief concern for families, CHSC has also been concerned about verified reports of appointment failures due to lack of access to transportation.

Clinical services presently are provided in communities recognized as the multi-county center for health services. This establishes a network of sites, with few exceptions, within 50 driving miles of the child's home. This distance is reasonable for most families but creates a problem for those without access to a reliable car.

A demonstration project has been designed to address this problem in the southeast region of Iowa, in the counties surrounding Ottumwa (Wapello County), where the number of children served by CHSC is 50% or less than the state average of numbers of children served per 1,000 population.

The plan utilized Department of Human Services volunteers to provide needed transportation to low income families. The Ottumwa regional center will facilitate the project along with the volunteer coordinator in each included county.

It is hoped that by providing transportation and "sitters" if necessary to families with an income less than 200%, it will be possible for children in need of services to be seen in the IEPC, high risk clinics, and mobile clinics held in Ottumwa and Chariton. The results of this demonstration project will determine its extension as part of case management services to other areas of the state.

Home Based Care

Need: Modern medicine has increased dramatically the survival rate of infants and children with multiple and complex health care needs. Medical technology and organization produced a large group of polio survivors in the late 1940's and 50's, some of whom still require life support measures. There have been an increasing number of spinal cord injured patients who are also dependent upon mechanical aids for breathing. Since the 1960's, further developments and technology have produced new groups of patients dependent upon specialized health care service. Today there are many technology dependent survivors of intensive care nurseries who could return to their homes and communities with adequate home and community support systems. Home care could result in large financial savings.

A health care support network system is required for their return to the home which will insure their physical survival, provide for their special needs, and provide the necessary financial and social support to their families. Required is a network of services available to these children and their families. Required is a care manager who will assist families in organizing and overseeing the function of this home and community support system. Therefore, the need in the last half of the 1980's is to develop alternative methods of providing health care for children in need of specialized health care service in the child's home or in a home-like community setting.

In a rural state such as Iowa, with a regionally developed network of special education services, regional Level II hospitals and neonatal intensive care nurseries, and regional child health centers, it is now possible to organize a community/regional network of services required by children who are in need of specialized health care services. Such services can be delivered efficiently and safely to many children in a home setting. Children are not intended to live in intensive care nurseries nor are nurseries intended to become homes for such children.

Target Population: Any child or young person under the age of 19 with the following impairments may be eligible for such services in the future.

- Ventilator dependent--any cause
- Bronchopulmonary dysplasia (BPD)
- Neuromuscular disorders that cause restrictive lung disease
- Sleep apnea
- Tracheostomies
- Cystic fibrosis
- Air passage anomalies
- Asthma
- Other respiratory disabilities (such as those caused by prematurity)
- Severe muscular dystrophy
- Cerebral palsy
- Spina bifida
- Oxygen dependent children

Referral Sources

University Hospitals and Clinics

NICU and PICU

Regional Level II hospitals - NICU and BICU

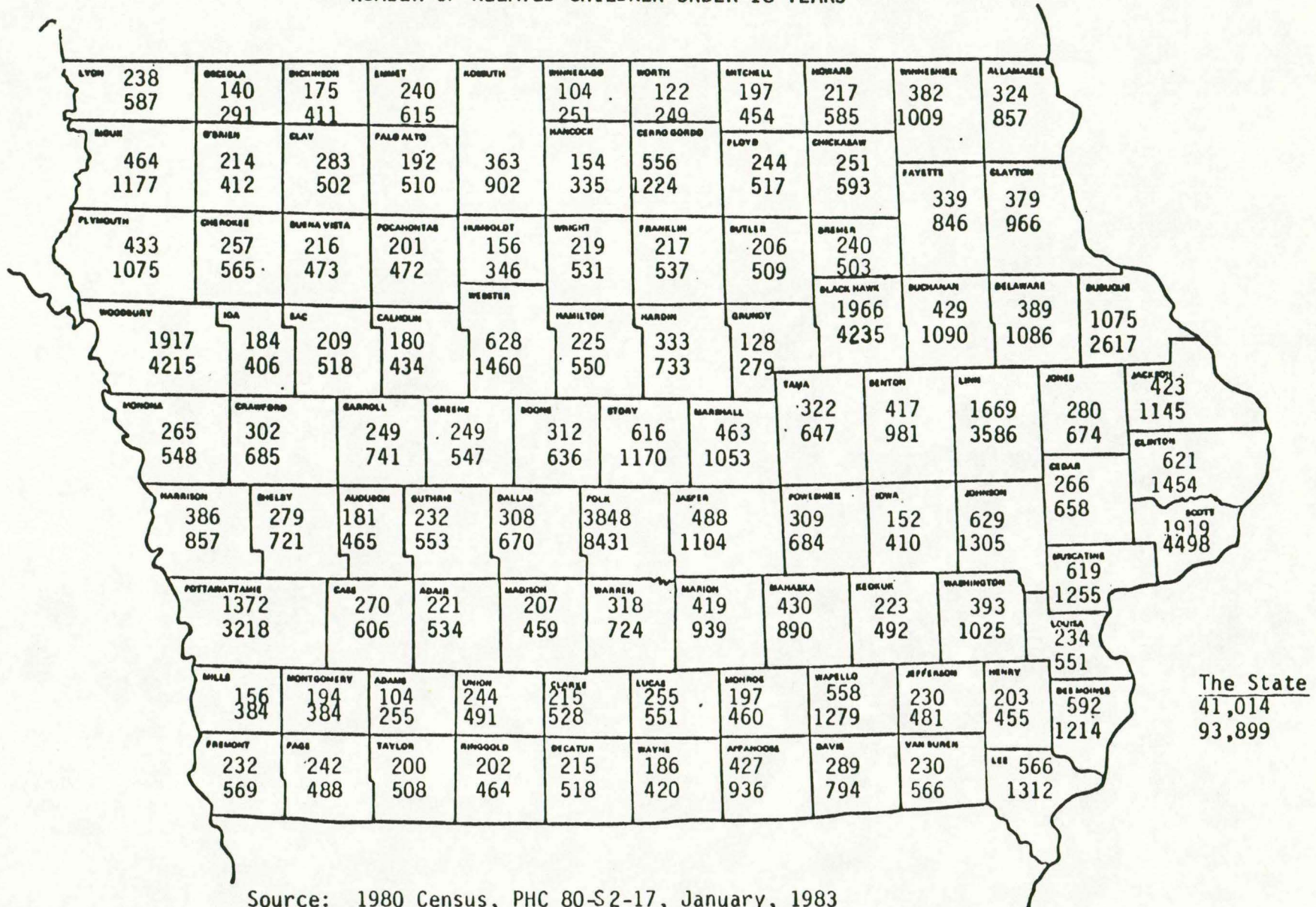
Child Health Specialty Clinics

On referral from local physicians, public health nurses, etc.

FAMILY SERVICES
EXHIBITS
OCT 1, 1983 — SEPT 30, 1984

Figure 5

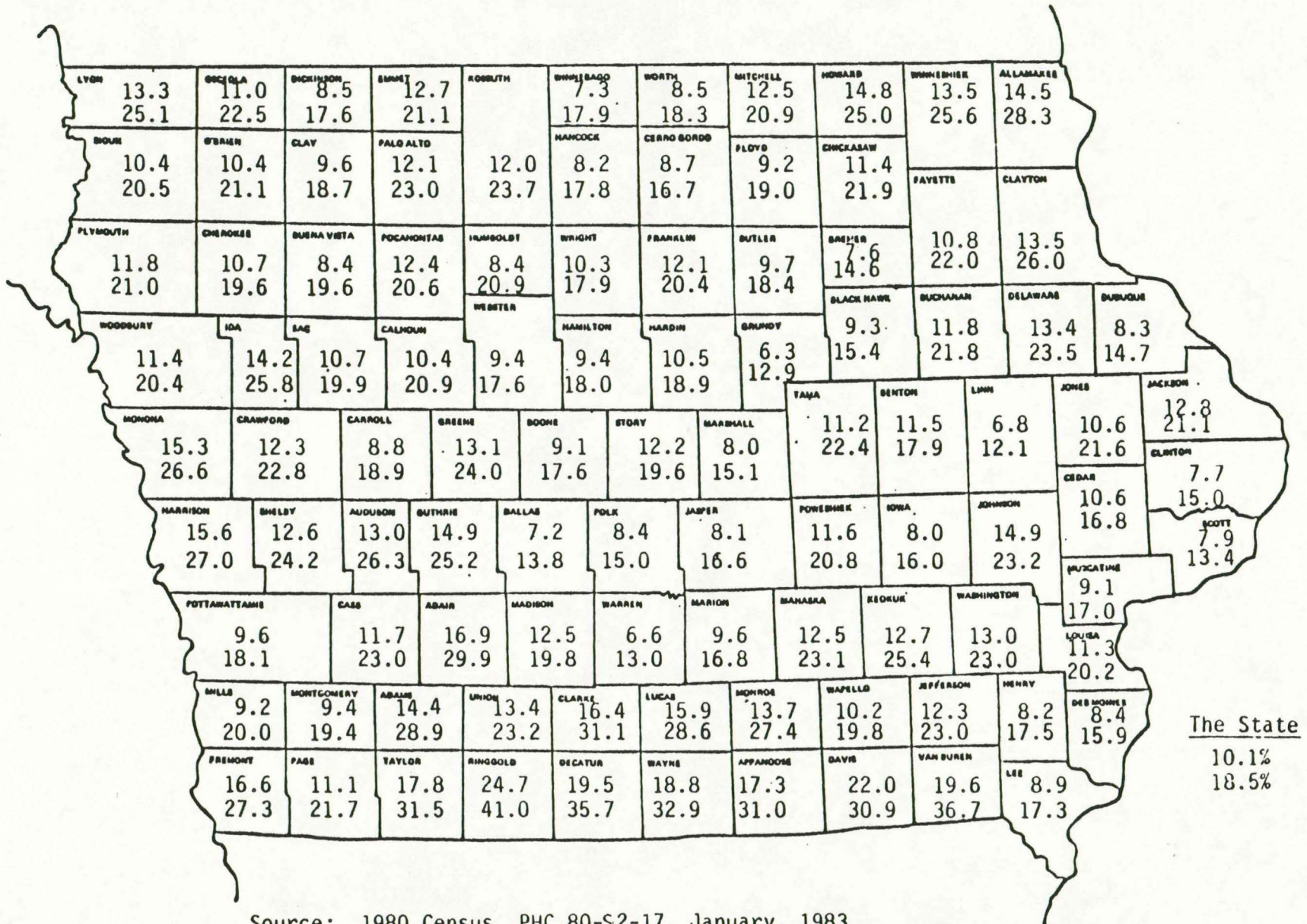
INCOME IN 1979 BELOW POVERTY LEVEL:
 NUMBER OF FAMILIES WITH RELATED CHILDREN
 NUMBER OF RELATED CHILDREN UNDER 18 YEARS



Source: 1980 Census, PHC 80-S2-17, January, 1983
 Advanced Estimates of Social, Economic, and Housing
 Characteristics
 Table P-4

Figure 6

PERCENT OF PERSONS BELOW POVERTY LEVEL
 PERCENT OF PERSONS BELOW 150% OF POVERTY LEVEL



Source: 1980 Census, PHC 80-S2-17, January, 1983
 Advanced Estimates of Social, Economic, and Housing Characteristics
 Table P-4

ACTIVITY STATUS FOLLOWING SERVICE

Activity Status at Last Visit	Total Patients	New in FY 1984	Old ^a	
			Total Old	(Followed More than 3 Years)
Active				
(Future Service Planned at:)				
CHSC Mobile Clinics	1,999	795	1,204	(578)
CHSC Regional Center	683	445	238	(57)
CHSC PMS Follow-up	73	42	31	(17)
University Hospitals	151	62	89	(50)
TOTAL ACTIVE	2,906	1,344	1,562	(702)
Inactive				
(Why No Future Service is Planned)				
Over-age	25	2	23	(22)
Out-of-State	41	21	20	(12)
Deceased	2	1	1	(--)
Lost, No Address	3	3	--	(--)
Well Person	520	391	129	(61)
PRN (Problem Need Not be Followed)	775	420	355	(168)
Patient Withdrew	30	18	12	(5)
Other	29	16	13	(7)
TOTAL INACTIVE	1,425	872	553	(275)
Total Unduplicated Patients	4,331	2,216	2,115	(977)

a - Date of first service is prior to this fiscal year.

V. DESCRIPTION OF PROVIDER SERVICES

Introduction

Services to handicapped children is dependent on the availability of special providers to render the necessary services. In the state of Iowa, the scarcity of subspecialists and the maldistribution of special providers create major problems in provision of services that necessitate special delivery systems and training programs. The extension of the specialists expertise into unserved areas and upgrading of the skills of local professionals are complementary.

Training and Consultation Services

Members of the CHSC staff serve as consultants to professionals throughout the state for both formal and informal training, consultation and information about health care problems and services. Recent information about cause, prevention, and treatment of handicapping conditions is shared so that the handicapped or potentially handicapped may be identified early and receive optimum care. Formal training programs, workshops, conferences and consultations are offered for a variety of professionals who provide services to physically and/or educationally handicapped children. The disciplines involved include medicine, psychology, speech/language pathology, audiology, physical therapy, occupational therapy, nursing, and nutrition. CHSC also conducts training activities directed to University of Iowa graduate students and include supervised observations and assistance at clinics, lectures, grand rounds, seminars, and practica.

Physician and Pediatric Nurse Practitioner Training

CHSC assures that community physicians and pediatric nurse practitioners who serve in regional child health centers receive the training necessary to upgrade their skills in developmental pediatrics. The training programs for both physicians and PNPs are done in collaboration with UIHC Division of Developmental Disabilities.

In FY 1984 special training was reinstated by Telenet and inservice conferences. Training for follow-up of high-risk infants is complete for seven PNPs. As the program is phased into other regional centers, training of PNPs for high-risk infant follow-up will continue in FY 1986.

Audiology and Speech Pathology Training (RB 97-H000040)

A discretionary grant from the federal Office of Maternal and Child Health supports a CHSC training program in which speech and audiology graduate students are given experience in the "real world" in the CHSC clinic system. This training program, in cooperation with the Speech Pathology and Audiology Department, is known internationally for its high quality graduates. If speech and audiology students did not participate in the clinics, their clinical training experience would be limited to seeing patients from the Iowa City area, and they would not observe and work with the wide range of communication problems necessary for top level training. Since graduate students can participate in these clinics without disrupting the clinics, the training program benefits both the students and the clinics.

Student Nurse Orientation

CHSC clinic planners actively recruit student nurses in community college nurse training programs to participate in the various CHSC mobile clinic programs.

Each school receives CHSC-prepared student nursing manuals so that students who are assigned to clinics may acquaint themselves with the history of CHSC, services provided, and the role students are expected to perform.

The clinic provides a unique opportunity for students to see significant child health problems that do not require hospitalization.

Seventeen schools of nursing will provide 250 students to serve as clinic assistants this year.

Professional Inservice Training

In communities where regional child health centers are located, CHSC sponsors continuing education programs designed for those who work for the AEA, the school system, and other community persons. The programs provide information, for example, about health and health-related problems that can delay development, result in physical disability, or result in educational or behavioral handicaps. Sessions are presented by members of the CHSC and UIHC staff.

In FY 1986 CHSC regional staff sponsored or co-sponsored many inservice programs, including programs about child abuse, newborn intensive care, anorexia nervosa and bulimia, Reye's syndrome, emergency care for children, learning disabilities, hyperactivity, and developmental lags.

Such information and training activities are expected to continue in 1986.

Training Scoliosis Screeners

To train scoliosis screeners for children in 16 Iowa counties.

The CHSC scoliosis project is conducted in conjunction with the Iowa Easter Seal Society and the Department of Orthopedics of the University of Iowa Hospitals to complete the statewide network of screening services.

Protocols for conducting the screening examinations and for reporting the children screened have been developed by staff of the Department of Orthopedic Surgery. This assures that the screening examinations will be of high quality and that the reports include standardized information that will allow the CHSC to assess the need for services and to determine the outcome of services.

PNPs who work in the regional centers in Davenport, Ottumwa, Sioux City and Spencer contact the person assigned in the school districts in their area to conduct the annual scoliosis screening of children from 9-13 years of age. The PNP makes arrangements to meet with that person on the

first day they will be conducting screening. While the school person and the PNP screen the first children, the PNP will instruct the school person how to check for scoliosis. The PNP will work with them until they feel comfortable with the assignment. The PNP will also be available at that time to see unusual cases and to assist the school personnel in such matters as making referrals for care.

The children who fail the screening examination (those who have sufficient curvature to require follow-up examinations) are either referred to a CHSC orthopedic clinic or to a local physician.

The CHSC scoliosis program reporting and follow-up system is designed to determine whether the scoliosis is progressive and whether the family have sought follow-up care and the outcome of the scoliosis screening and examination.

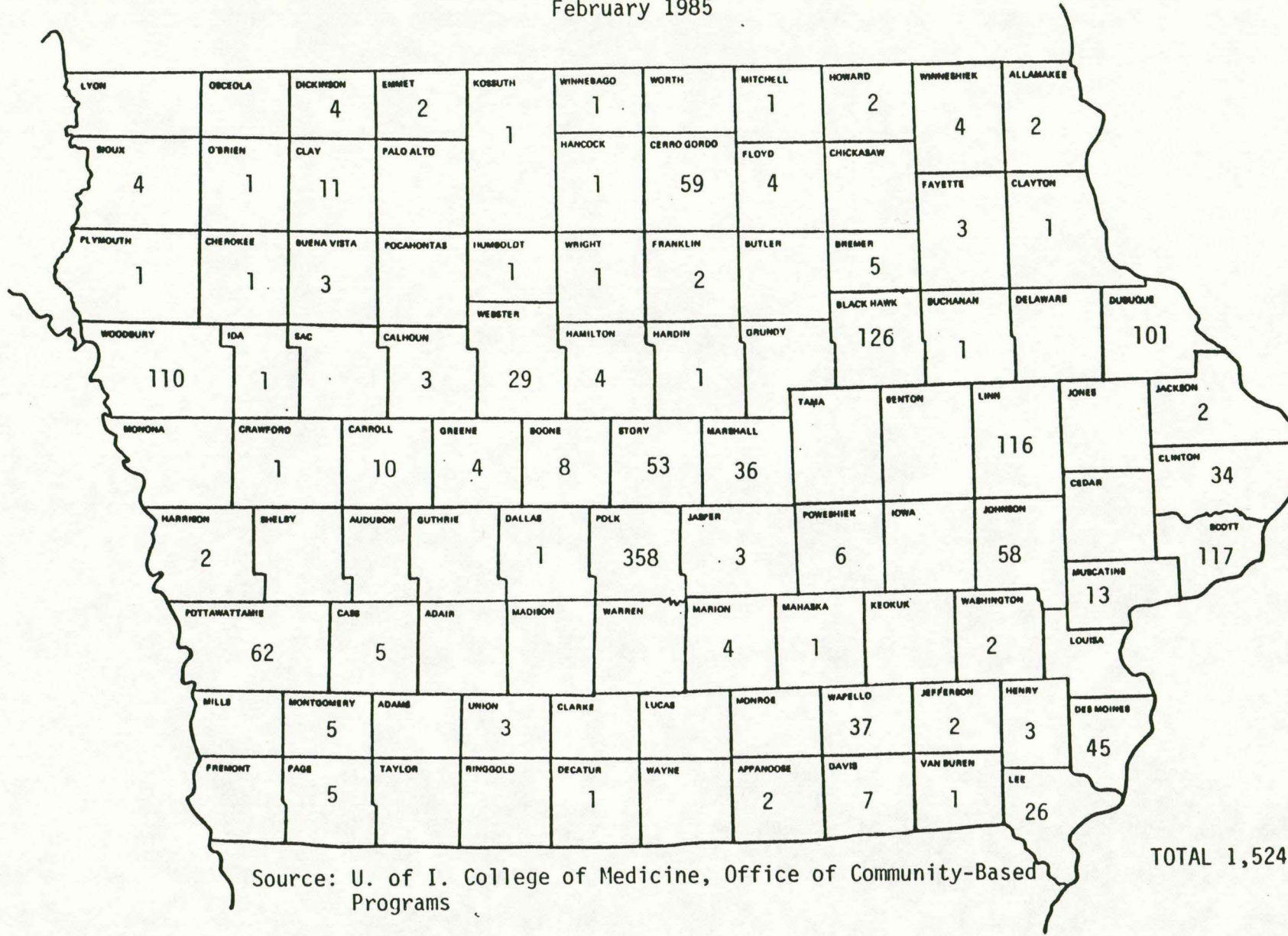
In 1986, all the children in a determined age group of all the school districts in the four regions will be screened for scoliosis and a definite follow-up program will be instituted.

PROVIDER SERVICES
EXHIBITS

Figure 8
 PHYSICIAN SPECIALISTS IN PRIVATE PRACTICE

(does not include Family Practitioners, Pediatricians, Orthopedic Surgeons, or Otolaryngologists)

February 1985



TOTAL 1,524

Source: U. of I. College of Medicine, Office of Community-Based Programs

Figure 9

FAMILY PRACTITIONERS, PEDIATRICIANS, ORTHOPEDIC SURGEONS AND
OTOLARYNGOLOGISTS IN PRIVATE PRACTICE

February 1985

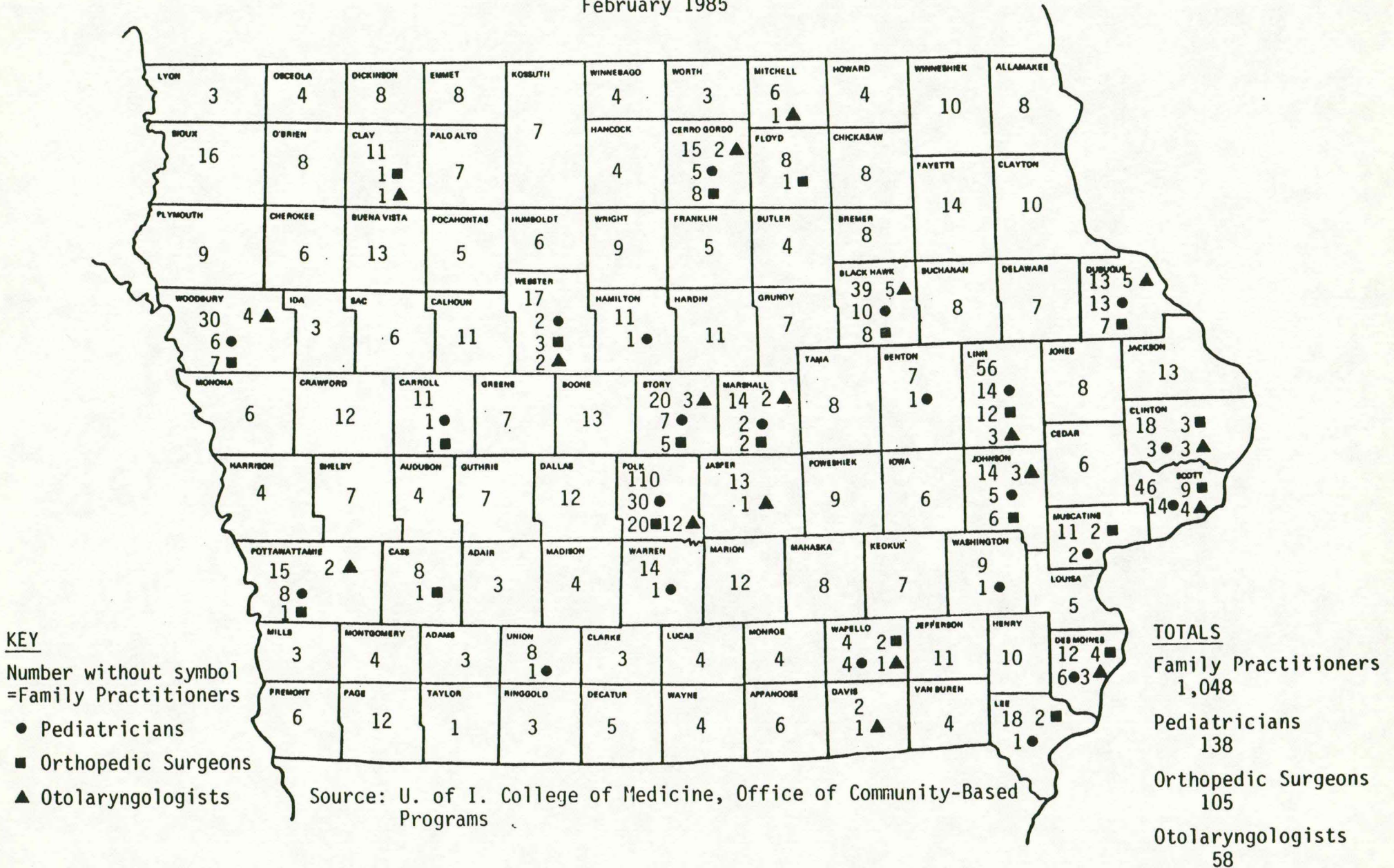


Figure 10

NUMBER OF REFERRALS PER COUNTY.

FY 1984

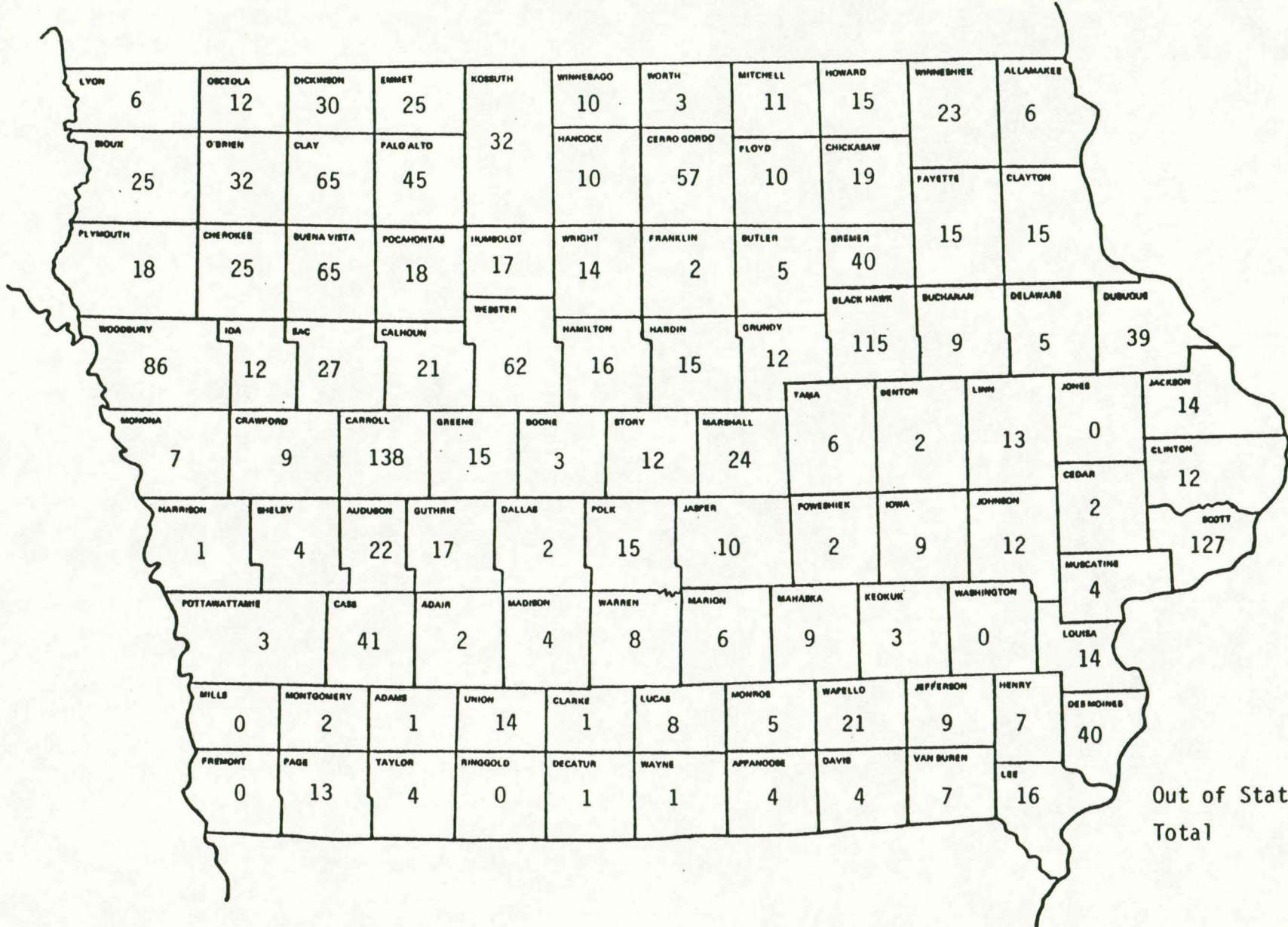
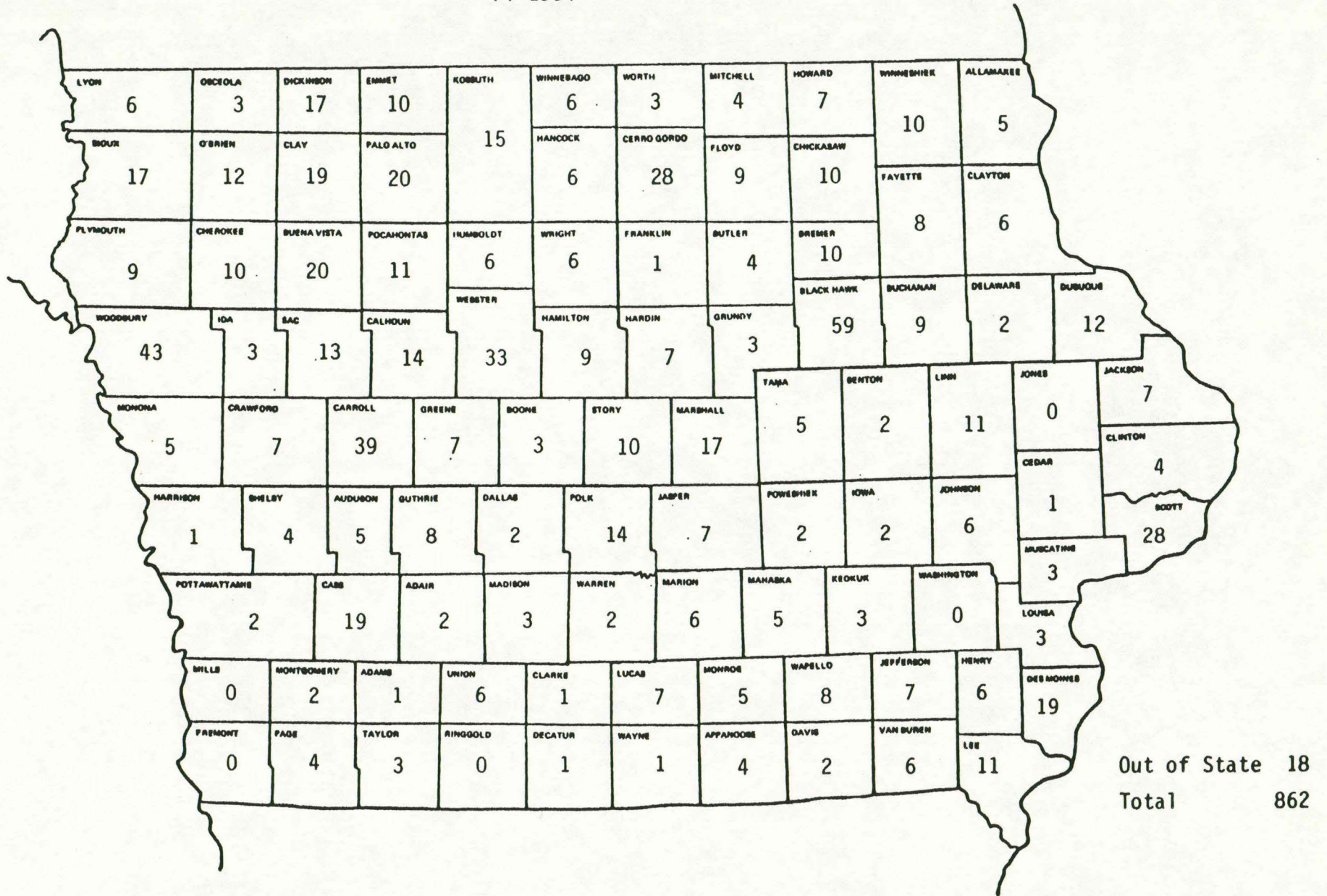


Figure 11

NUMBER OF REFERRERS PER COUNTY

FY 1984



VI. DESCRIPTION OF REGIONAL SERVICE SYSTEM

Integrated Service Delivery

Regional child health centers were established to provide a single entry point into the care system for children with multiple kinds of health and health-related problems. Many children with handicapping conditions and/or chronic diseases (e.g. cerebral palsy, cleft lip and palate, epilepsy, muscular dystrophy, and myelomeningocele) require multiple services from multiple agencies and professionals. Children with health-related problems, sometimes called the new morbidity, including psychosocial, behavioral and school problems, also need a multi-disciplinary team approach. While there are a number of federal, state, local and voluntary programs to provide services to children with particular problems, the programs are uncoordinated and frequently constitute a frustrating maze to the families of such children. The centers are designed to integrate and coordinate multiagency, multiprofessional services for children.

Prior to the passage of the state legislation, (Code of Iowa Chapter 281, Education of Children Requiring Special Education, 1974) and the federal legislation (P.L. 94-142, Education for All Handicapped Children Act of 1975) there was no community-based program to provide health services for children disabled because of physical handicaps or educational problems. These two pieces of legislation gave the responsibility for providing nonmedical services to the public school system. Unfortunately, that legislation did not make provision for health-medical care. The regional IEPC clinics create a public forum where the professionals immediately and directly involved with the individual child, including health-medical professionals, can meet to design a personalized program of services for each child.

Location and Organization of Centers

During the 1984 session, the Iowa General Assembly made an appropriation to CHSC that enabled the Spencer and Carroll centers to be opened. In 1985-86 centers are to be opened in Burlington, Dubuque and Council Bluffs (see Figure 13 for the location of regional centers).

Regional advisory committees, consisting of professional care providers and lay people, have the responsibility to advise agencies on services provided in the centers. The CHSC staff based in the centers organize, plan and staff clinics at the centers. The CHSC staff also promote and coordinate other community service programs, provide inservice educational activities for community providers, and participate in other multi-agency service programs such as child abuse councils.

The service delivery system utilizes personnel from CHSC and UIHC (including health specialty teams and support personnel) and from the communities in which clinics are located. Community personnel include staff from the CHSC regional offices and community service personnel (e.g., hospital x-ray and laboratory technicians and student nurse volunteers). Community hospital outpatient facilities are used.

Programs are scheduled statewide, to the extent that funding permits, to provide services within approximately 50 miles of most Iowa children needing services. The financial and time burden on families is reduced by reducing their amount of travel, loss of time from jobs, and number of overnight stays that would be necessary if they traveled to secondary-tertiary care centers.

Locations and frequency of the clinics are planned by the CHSC central office, which also arranges staff travel, facilities, equipment, site preparation, volunteer and support services for the examiners. These preparations are tailored to the needs of each type of specialty clinic, e.g., minimal ambient noise for ENT clinics. Operation of the clinics and patient flow through clinics is assigned to regional staff.

Referrals are received from a variety of sources including private physicians, AEA and school personnel, other health and social services providers, and parents. The CHSC Care Management Unit schedules appropriate services for each patient's problem. The care recommended for children by clinic staff is commonly provided in the community. Children needing further diagnostic or treatment services may be referred to UIHC. The CHSC Care Management Unit and regional staffs assist families who need help in obtaining care.

Plans for the Future

New service patterns, schedules and sliding fee schedules have become understood and accepted, so the number of patients is expected to increase 5-10 percent in FY 1986. Additional regional centers are proposed for Dubuque, Burlington, and Council Bluffs as funding permits in 1986. Computer terminals and printers are to be located in all regional offices to facilitate the transfer of patient information and reporting between professionals and agencies.

In FY 1985-86 the number of clinic days and the number of patients served are expected to increase as a result of increased activities in Spencer, Carroll, Dubuque, Burlington and Council Bluffs.

Legislative Charge to Integrate Service Systems

The Iowa General Assembly assigned the appropriation and oversight responsibility for the Title V Maternal and Child Health Block Grant programs to the Joint Human Resources Appropriation-Subcommittee. In 1982, the Subcommittee charged the State Department of Health, the Iowa Child Health Specialty Clinics, the State Department of Human Services and the University of Iowa Hospitals and Clinics to jointly study and develop recommendations to improve health services for mothers³ and children through the integration and coordination of programs.

³ Journal of the House, April 19, 1982, p. 1354; April 24, 1982, p. 1780.

Based upon this study, a series of recommendations with respect to the integration and coordination of programs were formulated, and an annual report was presented to the Joint Human Resources Appropriation-Subcommittee.

The charges of the subcommittee were as follows:

The state MCH and CHSC programs should co-locate service delivery sites in order to reduce the fragmentation of services, to the extent it is possible without decreasing the efficiency and effectiveness of the services.

The state MCH and CHSC programs should jointly employ personnel working at the regional level, when it is possible, thereby to increase coordination and decrease costs of services.

The state MCH and CHSC programs should develop coordinated administrative policies and procedures with respect to patient record systems in order to further coordinate services and reduce administrative costs.

The state MCH and CHSC programs should formulate, as a goal, the establishment of single-entry points on a regional basis. Such single-entry points will enable families to obtain information about MCH and CHSC services, clinic schedules and appointments, and other related services. The personnel of these sites could also provide case follow-up and coordination of services.^{4, 5}

The charge also recommended that a project to further integrate and coordinate programs providing health and related services to mothers and children should be established in two pilot areas (Ottumwa and Sioux City). The report suggested that the experience in these two areas could be used to test the feasibility of integrating and coordinating services on a statewide basis and that, if the experience in the pilot areas^{6, 7} proved successful, steps should be taken to involve other regions.

The Joint Human Resources Appropriations Subcommittee accepted the January 1985 annual report and charged the involved state agencies to continue to conduct the integration and coordination project in two pilot areas and to report back to the Subcommittee.

4 The Provision of Contemporary Child Health Services Through Community Child Centers, John C. MacQueen, M.D., 1976.

5 Coordinated Medical Services for Physically Disabled and/or Educationally Handicapped Children Under Public Programs, John C. MacQueen, M.D., 1977.

6 A Study of the Health of Iowa's Children and Youth, AAP Iowa Chapter, edited by John C. MacQueen, M.D., and prepared by SCHS (CHSC), 1979.

7 Integration and Coordination of Maternal and Child Health and Crippled Children's Programs in the State of Iowa. Iowa Child Health Specialty Clinics (CHSC) and Iowa Maternal and Child Health (MCH). January 7, 1983. (The "Green Book" plan.)

State Agency Coordinating Committee

CHSC, the State Department of Health's Maternal and Child Health Program, the State Department of Human Services and the State Department of Public Instruction (Special Education Division) formed a State Agency Coordinating Committee to coordinate and facilitate the legislative recommendations. Regional coordinating committees were established in the two designated pilot regions (Ottumwa and Sioux City), and the State Agency

Coordinating Committee provides staff support for these regional coordinating committees. The State Agency Coordinating Committee and the regional coordinating committees have met to develop strategies to carry out the project.

Problems and barriers to integration and coordination have been identified, and the potential for achieving integration and coordination of service programs in other regions of the state has been discussed. The effort to integrate and coordinate public services is ongoing in the Ottumwa and Sioux City areas.

Networking Patient Services Information

Many public, private, and voluntary services are available to children with chronic illnesses and handicapping conditions in Iowa and other states. However, two major communication problems in the service systems reduce the efficiency and effectiveness of services. The two major problems are : 1) individual patient care planning is hindered because of the difficulty of exchanging timely and appropriate information among agencies and professions; 2) regional and statewide planning of services is hindered by a lack of adequate data concerning service needs and outcomes.

Multiagency Information

CHSC has for many years advocated systems for the integration and coordination of services for handicapped children. An integral part of the plan to integrate and coordinate services has been an interagency, inter-professional patient information communication system.

The use of written reports to communicate has proven to be very inefficient and unsatisfactory. CHSC is convinced that the answer to this problem is to be found in new computer technology which makes it possible for agencies to immediately transfer and to share standardized information. Such a system would, in effect, constitute a functional single-entry system, if not a single physical-site entry system.

CHSC's involvement in multiprofessional crippled children's services, multiagency SSI and IEPC programs, and statewide and national planning for services has provided CHSC with an excellent perspective on the problems of communication about patients and planning for services. The CHSC staff has been developing ideas relevant to the problem, including: 1) identification of core patient information needed to communicate among professions; 2) outcome indicators; including the Profile of Problems and Goals; 3) a computerized data/information system, incorporating service and outcome descriptors, and emphasizing the potential for multiagency use.

An automated patient information system has been developed, entitled Information for Assessment, Planning, and Tracking (IAPT). The data base includes information related to patients such as: demographics, diagnoses and problems, care plans and their status, care providers, and outcome indicators. Unique features of the data base include individual service plan summaries, service plan status, status of diagnoses/problems, and ordinal-scale coding of the patient's functional status and prognosis.

Features of the system include: multiagency sharing of demographic information; descriptions of individual agency care plans, care providers, and outcomes of care; automatic tracking and reminders of patient service needs; a capability for providing aggregated multiagency statistical information about the patients, their problems, and the care system; printing of patient information in prescribed formats.

Systems for collecting and processing patient information have been developed for the CHSC clinics, by incorporating limited data items into the professional clinic worksheets and by training clerical, word-processing and data-coding staff to translate the professional worksheets and reports into coded information. Similar systems and training have to be developed for other agencies who participate in the patient information system.

Plans for the Future

The interagency patient information system has been installed in one region. The regional committee has expressed strong support to pilot the proposed system in the Ottumwa area. The MCH Networking grant will provide financial support for this pilot during Fiscal Year 1986.

The remaining activities in the development of an interagency system include: 1) testing and refinement of the information system on a regional basis; 2) development of statistical report formats; 3) evaluation of regional and statewide data; 4) evaluation of the efficiency and effectiveness of the information system.

8 The director of CHSC has participated in many national programs related to services for handicapped children, including the Surgeon General's Workshop and the Select Panel for the Promotion of Child Health.

9 Copyright 1980, Iowa State Services for Crippled Children (CHSC), The University of Iowa. Copyright 1983, Iowa Child Health Specialty Clinics.

While some degree of integration and coordination of these services has been achieved through changes in operating policies and procedures, it is clear that if the project is to be fully implemented additional funding will be required. Additional funding will be needed to develop new services for handicapped children and to purchase computer equipment and services to create an inter-agency modern computerized reporting system. Therefore, CHSC applied for and received a special grant from the U.S. Department of Health and Human Services, Division of Maternal and Child Health to address these problems.

A network of multi-agency services for handicapped children tied together by a modern inter-agency computerized information system is needed to reduce fragmentation. The concept of a network of services for handicapped children is relatively new. It is perhaps best illustrated by the organizational chart showing a number of services that might be included in a network of services and the inter-organizational relationships between service programs.

This concept of a network of services is based upon the experience that CHSC has had during recent years with its Integrated Evaluation and Planning Clinic program which functions as a network of community-based health and related services for children. The success that CHSC has had with this program encourages CHSC to believe that a network of services is not only possible but also that it solves many of the problems created by the existence of several independent agencies which provide services to handicapped children. Community programs participating in such a network are actively involved in the creation of its operating policies and procedures and do not lose their identity.

Networking New Services and Integration of Existing Systems Are Complementary

The Integration Project provided a complete review of existing activities with consolidation where possible. It did not provide new resources for new services or service systems.

The Networking Project provides the necessary resources to hire staff and purchase equipment to implement changes suggested by the integration and coordination effort.

Resources available through the Networking Project will help the regional coordinating committees to develop needed new services, and will also help the regional coordinating committee to establish a computerized multi-agency information system that ties together the network programs for handicapped children.

CHSC will assist the regional coordinating committees through the Networking Project in several ways. CHSC, utilizing the Networking Project, will develop a description of the optimal community services needed for handicapped children. As might be expected, those optimal services include many traditional services that are now generally available, but

also include a number of new services for health problems commonly referred to as the "new morbidity" that are not generally available. In addition, a number of health problems created by new advances in medical technology must be served.

Plans for the Future

The Networking Project will develop and demonstrate new multi-agency services and systems of delivery to the extent of its available resources.

REGIONAL SYSTEM
EXHIBITS

Figure 12

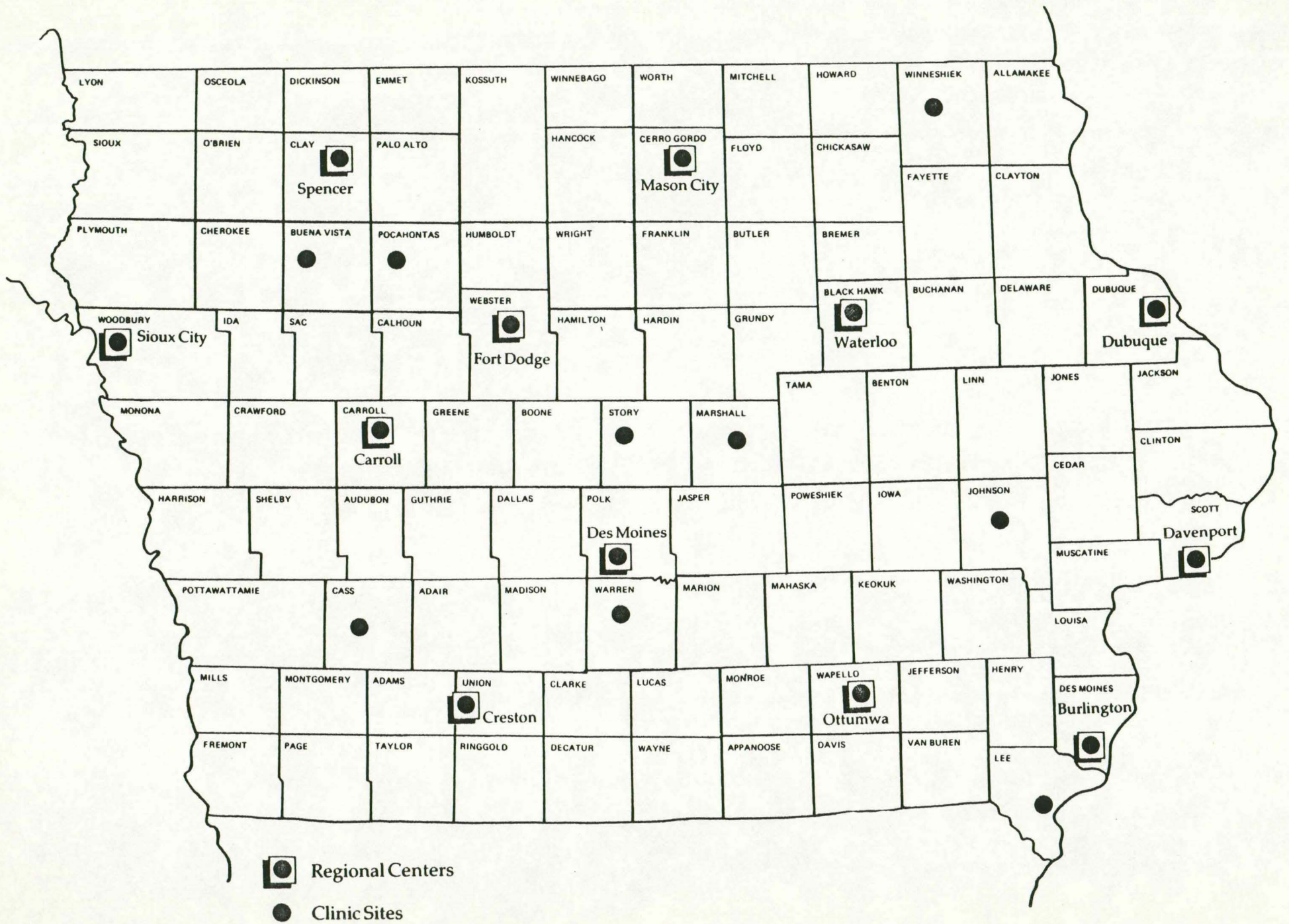
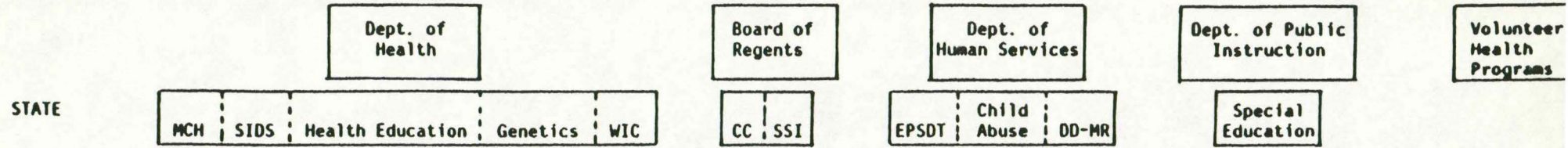


Figure 13

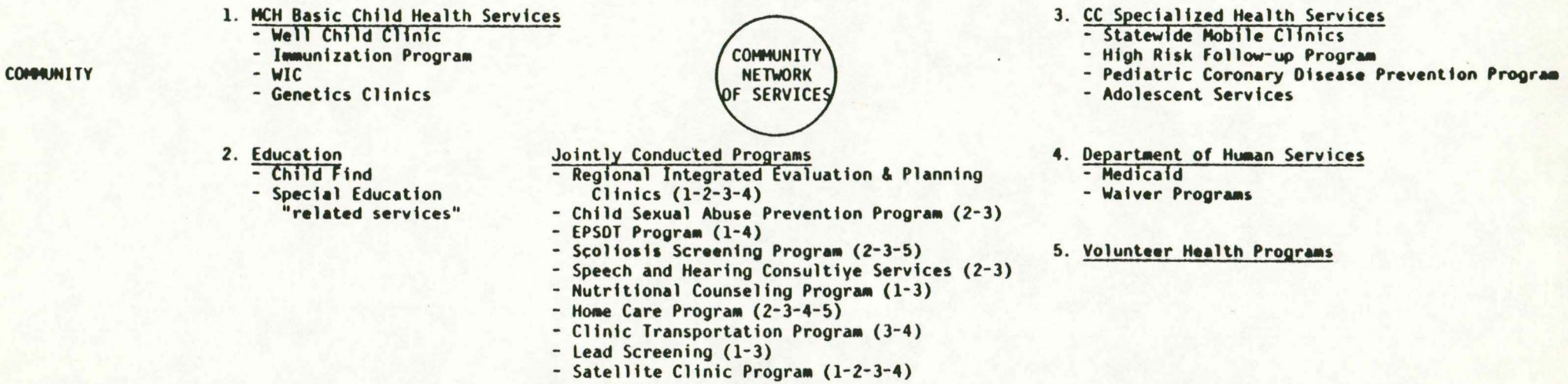
A PROPOSED COMMUNITY BASED SYSTEM TO PROVIDE CONTEMPORARY CHILD HEALTH SERVICES

05



STATE COORDINATING COUNCIL OF CHILD SERVICES

COMMUNITY CHILD COUNCIL



COMMUNITY SYSTEMS PROVIDING CHILD HEALTH CARE

PRIVATE MEDICAL CARE SYSTEM

PUBLIC EDUCATION SYSTEM

PUBLIC SOCIAL SERVICES SYSTEMS

LOCAL HEALTH/HOSPITAL SYSTEMS

SPECIAL EDUCATION
P.L. 94-142

VII. AGENCY ADMINISTRATION AND ASSURANCE ACTIVITIES

1. Statutory Authority

The Iowa State Services for Crippled Children was established under Title V of the Social Security Act in 1936 as an integral part of the Iowa plan for medical care which had been created by the Perkins-Haskell-Klaus Acts of 1915 and 1917. The agency was not established by a specific act of the General Assembly but was placed within the framework of the Board of Regents and The University of Iowa as the result of a 1936 opinion of the Attorney General of the state.¹⁰ Chapter 255 of the Code of Iowa is the authority for receipt of federal funds. The Iowa State Services for Crippled Children is referred to in Section 281.5 of the Code.

On October 1, 1981, federal statutory authority for the Crippled Children's program was changed to Title V-Maternal and Child Health Services Block Grant Act of 1982. This Act consolidated the federal legislative authority for Maternal and Child Health, Crippled Children's, Supplemental Security Income-Disabled Children's Program, Lead-Based Paint Poisoning Prevention, Genetic Diseases, Sudden Infant Death Syndrome, Hemophilia and Adolescent Pregnancy Programs.

In 1983, the name of the Iowa crippled children's program was designated as Mobile and Regional Child Health Specialty Clinics and Related Programs (CHSC), a division of Specialized Child Health Services, Department of Pediatrics, University of Iowa Hospitals and Clinics.

2. Organizational Structure

CHSC is an agency of Iowa government and functions as a state program with consultation from the United States Department of Health and Human Services (previously HEW). All services are planned and conducted in compliance with applicable federal and state laws and regulations. The Iowa Child Health Specialty Clinics (CHSC) operates as a public service unit of The University of Iowa. For University administrative purposes, CHSC and its director function through the chairman of the Department of Pediatrics who is director of Specialized Child Health Services. Day-to-day operations are conducted in compliance with the operations manual of The University of Iowa and the policies of University Hospitals and Clinics.

The organizational units of CHSC are designed to meet the stated purpose of the agency to make needed specialized health services available and accessible to Iowa children with chronic handicapping and potentially handicapping conditions, chronic diseases and developmental and behavioral problems.

¹⁰ Op. Atty. Gen. 1936, pp. 429-434.

Each major unit has primary responsibility for a major group of agency consumers. The professional services unit serves patients and supports providers with training. The case management unit serves patient families and facilitates professional services to providers. The community services unit meets the needs of the local service providers and the administrative unit meets the needs of the program's regulators. Each unit has additional program and staff support activities as assigned.

Professional Services Division

This unit is responsible for the relationship with referents and practicing health professionals. The purpose of the professional service division is to identify the needs of individual health professionals for patient consultation and appropriate health intervention. This unit provides the basis for the agency's existence and the primary services of the agency by defining and recommending appropriate interventions for the many types of special health problems that are presented. This unit includes the agency's consultants of designated regional clinic services programs. This unit provides the service that is not otherwise available or accessible.

The professional service unit is responsible for the quantity and quality of the consultation, education and demonstration services on a regional outreach basis. The unit is a coalition of individual program consultants with outreach clinic service commitments supported by RCHSC. The director of RCHSC and the division director are the chief negotiators with each consultant to facilitate the extension of services through the agency's established regional delivery system.

The professional services division includes regional physician, PNP and clinic examining staff, UIHC program directors and program consultant staff. This division provides direct patient interventions and recommendations, professional education and demonstration services to referents. This unit's major responsibility is satisfying the needs for appropriate diagnoses and recommendations. All other divisions support and facilitate the provision of professional services.

Case Management Division

The case management unit is responsible for agency relationships with patient's families. It works in direct support of the professional services unit to facilitate the provision of professional consultations with patients. This unit interprets and arranges the intervention services with families.

This unit facilitates the initiation and completion of patient service interventions for all children served by advising and counseling families, making patient arrangements, appointments, referrals and by monitoring all intervention plans. This unit assumes the preclinic and postclinic patient service responsibility to assure the families have every opportunity to remain in the appropriate care system for their particular problems. This unit works to successfully complete the recommended intervention plan for each child. The unit supervises the patient service process for each child served by the agency.

The case management division includes the agency's care managers and is responsible for family care compliance. The case management division is also responsible for administering the SSI Disabled Children's Program. The major responsibility of this unit is satisfying the needs of families in securing recommended professional services. This division facilitates and monitors the provision of professional services to all families.

Community Services Division

The community service division is responsible for agency relationships with regional, health, education, social services, regional hospitals and other service organizations involved in the provision of health and health related clinic services. This unit manages agency relationships with competing and cooperative associations.

The community services unit works in direct support of agency professional services and case management services by providing regional clinic and office facilities, equipment and support staff available in each region.

This unit maintains the cooperation and support of public service agencies and organizations in all regions by interpreting the needs for the agency programs and services. This unit maintains a supply of appropriate referrals.

This unit establishes an efficient community support system for each clinic service and initiating and integrating clinic schedules of each region into a statewide delivery system. In addition, the unit is responsible for coordinating and facilitating services in support of examining staff such as transportation, meals, lodging, and ancillary services.

The community services division includes the agency's program representatives to its suppliers. It is responsible for securing clinic referrals from community agencies and organizations for handicapped children. Implementation of clinic operating policies and liaison between the CHSC director and regional organizations are considered the most important duties. This unit arranges the clinic facilities, equipment, and staff support in all regional clinics.

Administrative Services Division

The administrative division includes program managers and central support services for all divisions. It plans and allocates agency resources to plans. The administrative services division also includes the centralized functional support unit responsible for office facilities and equipment, clerical support and accounting and billing services, word processing and program information services for all programs. The program data unit is responsible for operation of patient data systems, for statistical reporting and evaluation for all agency programs.

The administrative division is responsible for relationships with funding and regulatory organizations, including the university administration, H.H.S., state and national legislatures, public state agencies and private organizations. This unit supports the professional services division, case management division and the community services division by providing the statewide plans, reports and central support functions for all staff and programs. Specific functions of the unit include program planning and reporting, staffing, financial services, office support services and other program support services not specifically delegated to divisions.

The four division directors and agency director constitute the basic planning staff of the agency on a continuing basis.

Data Collection and Reporting

The data described in this section will be collected by the Iowa CHSC to prepare required annual statistical reports of its activities, submitted to the secretary of DHS. The data also is used by CHSC administrative services unit to plan and evaluate programs and prepare reports for Iowa officials and the public.

Reports will describe the activities and programs of CHSC and will indicate the degree of success in meeting the goals and objectives listed in Section II of this plan.

Program data will include:

- numbers, types and locations of clinics;
- numbers of children served;
- demographic characteristics of the children and families;
- numbers and types of services provided;
- diagnose/problems of the children;
- status of problems served;
- degree of need for health and medical services by the children;
- functional abilities of the children and families;
- compliance of families with care plans;
- numbers of professionals receiving training by type of training; and
- accounting information concerning the use of Title V and other monies.

CHSC is continuing the process of automating the patient information system to collect and evaluate the above data. The system was completed and operational in FY 1985. A pilot project will be conducted in FY 1986 in one region to test the multiagency capabilities of the system.

The patient data systems unit is responsible for the development and operation of patient information processing systems, for statistical reporting and evaluation systems and for program data.

MCH/CC Advisory Council

A Maternal and Child Health Advisory Council was formed during 1982, composed of health care providers and interested lay people from all regions of the state. CHSC, along with the state MCH program, is working actively with the Council. The Council provides advice to CHSC and MCH concerning maternal and child health programs, goals and objectives, state plans, etc., and serves as advocates for the programs.

Advocacy Activities

The Iowa CHSC has assumed the role of advocate for handicapped children and has espoused causes, legislation, and programs. CHSC staff provide professional and technical information at meetings of a number of professional and lay organizations.

In the past, CHSC had a significant part in enacting in Iowa the PKU legislation, the battered child legislation, and the immunization law; CHSC also had a significant part in the development of the federal Title V MCH Block Grant legislation. In addition the agency staff has had a major role in identifying new service needs and creating new programs: prevention of rheumatic heart disease, follow-up of phenylketonuria, cystic fibrosis care, follow-up services for high risk infants, prevention of myocardial infarction, statewide scoliosis screening, screening of infants at risk for hearing loss, and the regional Integrated Evaluation and Planning Clinics. The agency is also developing a model patient information system that will allow multiple agencies to share patient/client information to promote improved coordination of services and provision of multiagency statistical planning information.

Coordination of State Agency Resources

The Iowa CHSC works cooperatively with many units of state government. Interagency agreements are in effect under Code of Iowa Chapter 28E with the Department of Public Instruction, the Department of Human Services, and the Department of Health.

A commitment to coordination of casefinding and treatment services for identified handicapped children is formalized by these agreements detailing the responsibilities of CHSC and the state programs.

CHSC has agreements with the major state agencies that have been identified as direct service or assistance providers for the agency's target population: Department of Health, Personal and Family Health Division; Department of Human Services, Title XIX; Department of Public Instruction, Special Education Division and Vocational Rehabilitation Education and Services. Agreements will be updated or added to as needed.

Health Planning for Children with A.A.P.

The Iowa CHSC has worked closely with the Iowa Chapter of the American Academy of Pediatrics in its development of the Study of the Health of Iowa's Children and Youth (1979).

The director and staff of the Iowa CHSC have participated in several previous studies of health services in the state of Iowa, and presently have a significant role in the project to further integrate and coordinate maternal and child health and crippled children's services in Iowa.

Rehabilitation Education and Service Branch of the Department of Public Instruction

The Disability Determination Services Division of the Rehabilitation Education and Services Branch of the Department of Public Instruction is the agency responsible for establishing the disability of children in the state for the purpose of qualifying for public assistance programs. Its role includes determining eligibility of children receiving Supplemental Security Income for the services of CHSC. It also becomes involved in rehabilitation of children with severe handicaps.

Department of Human Services

The Department of Human Services (DHS) may establish a lifelong relationship with an individual, while CHSC may have a much shorter term relationship centered around a child's specific medical/health problems, conditions or disabilities. The Department and its staff are recognized as having a special responsibility for the coordination of long-range service plans, particularly those for disabled and low-income persons.

Through its Title XIX Medical Assistance Program, the Department makes available the necessary resources to pay for a comprehensive array of medical and health services for a large number of children, including SSI disabled children under age 16. The expansion of Title XIX to include medically needy families is expected to make many additional services available to the target group.

Coordination of CHSC service plans with DHS takes place as the respective staffs working with families and children identify children with health problems requiring special evaluation and planning services or families in need of social service assistance.

Planning and Programming - Council for Children

In 1967, Governor Hughes introduced in the state government structure an executive planning agency reporting directly to the Governor's office. The Office for Planning and Programming (OPP), is charged to "advise, direct, consult, coordinate and harmonize the planning and programming activities within state government." The Iowa Council for Children, under the direction of OPP, was established in 1976 to identify the needs of Iowa's children and to provide information and coordinate efforts to meet those needs. The Council is currently dealing with problems of reduced funding for consolidated health programs under the MCH Block Grant.

Department of Health

The Department of Health is Iowa's state health planning and development agency. Planning staff of the Department perform this function for the commissioner of health and for the State Agency Coordinating Council (SACC).

CHSC has particularly close ties with the maternal and child health section (MCH) in the Personal and Family Health division of the Department of Health. The professional staff of the Iowa CHSC and the professional staff of the MCH section meet annually to discuss programs and resolve mutual problems. The directors of these programs meet frequently on both a formal and informal basis.

Development of a plan to integrate and coordinate maternal and child health services for all public programs. CHSC and MCH are cooperating with that effort.

University of Iowa Hospitals and Clinics (UIHC)

In addition to functioning within the administrative framework of UIHC and having its central office located at UIHC, CHSC is closely related to UIHC programs. UIHC staff members participate in CHSC specialty clinics and programs primarily by serving as examiners in CHSC mobile clinics; children seen in both mobile clinics and integrated evaluation and planning clinics who require tertiary level diagnostic and treatment services are generally referred to UIHC; and CHSC provides care management and follow-up services for many children served at UIHC who have handicapping or potentially handicapping conditions.

CHSC also has cooperative arrangements with several related child health programs at UIHC, including the High-Risk Infant Follow-up Research and Demonstration program, the PKU Treatment program of the Metabolic Management Clinic, the Rural Comprehensive Care Program for Hemophilia Patients and the Regional Genetics Consultation Service.¹¹

¹¹ The Regional Genetics Consultation Service is part of the Department of Health's Birth Defects Institute and is a collaborative effort of the Department of Health and the Department of Pediatrics, University of Iowa College of Medicine at UIHC.

CHSC Administrative Policies

The following policies of the Iowa CHSC which affect the delivery of patient services are made a part of the State Plan. These policies are in agreement with the guidelines of the Department of Health and Human Services for implementation of P.L. 97-35 and the recommendations of the Iowa Foundation for Medical Care (PSRO).

a. Disclosure of Patient Information

It is the policy of the CHSC that all patient records are maintained confidential in compliance with policies of University of Iowa Hospitals and Clinics. Without a signed release from parent or other responsible person, no one outside the UIHC may receive copies of patient reports or written/verbal information from patient records.

Information about personal facts and circumstances obtained concerning children served and their families constitutes privileged communication and is released only in statistical summary form. This policy conforms to Paragraph 622.10 of the Code of Iowa.

b. Civil Rights

It is the policy of the CHSC to comply with all requirements of Title VI of the Civil Rights Act of 1964. All services are provided by CHSC in a nondiscriminatory manner.

c. Barrier-free Access

It is the policy of the CHSC that all services are made accessible to handicapped persons in compliance with Section 504 of the Rehabilitation Act of 1973. No benefits or services of the program are denied any individual as a result of a handicap. Where necessary, assistance is provided to persons for whom building access is difficult.

d. Protection of Human Subjects

It is the policy of the CHSC to safeguard the rights and welfare of all subjects who participate in the service or research activities of the agency. Procedures established are approved by The University of Iowa's Institutional Review Board (Committee on Research Involving Human Beings - Medicine) and meet the requirements of P.L. 93-348. All activities of the agency are conducted in a manner which preserves the human dignity, rights and safety of the children and families.

e. Program Operation Review

It is the policy of the CHSC to maximize patient services and to minimize cost through continuing review of services and operations. Necessary records and systems are established and maintained. Cost effective solutions are sought for service needs; linkages and agreements are established to prevent duplication and cost containment factors are included in program planning.

f. Consumer Involvement

Volunteers from the community assist in the operation of clinics. By policy, the boards of regional child health centers are encouraged to include a sizable consumer membership.

g. Local Professional Involvement

It is the policy of the CHSC to coordinate its activities with local professionals and service providers and to seek their participation whenever this is in the best interest of the child and of effective service delivery. Local professionals participate in staffings at regional clinics; they are encouraged to attend mobile and regional clinics with a child they have referred. CHSC staff maintain close rapport with persons who are responsible for the continuing care and treatment of a child.

h. Patient Information

It is the policy of the Iowa CHSC to maintain medical records on its patients in a manner suitable for the determination of quality individual service plans. Information from medical records is confidential and divulged only in accordance with the principles of paragraph (a) of this section.

i. Management Information

It is the policy of the CHSC to maintain the necessary and required fiscal records, personnel records, data collection and analysis systems, and evaluation systems to satisfy the statutory requirements of the secretary of HHS, the state of Iowa, the Board of Regents, and the University, as well as to provide information to the agency staff for planning and directing the efforts of the agency, and information for public record and for the MCH/CC Advisory Council.

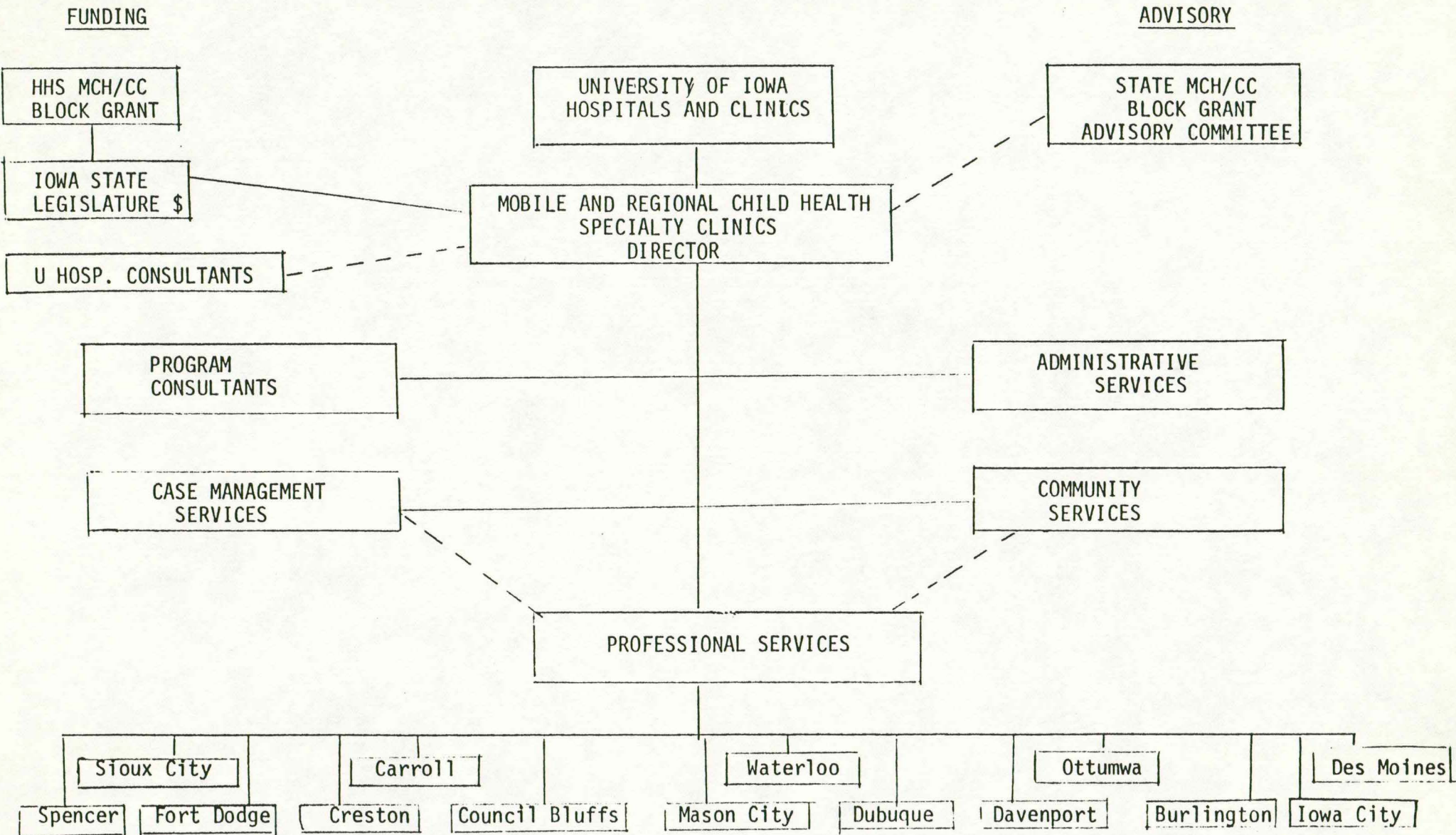
j. Family Charges According to Sliding Scale

Individuals and families at or below 150% of the CSA poverty guidelines and without third party resources are considered to have no resources available for care and have all charges for agency services waived. Individuals with income above 150% of the poverty guidelines will be charged a percent of the usual fee based on the gross income and number of persons in the family. Insurance and third party payments are collected before the sliding scale is applied to any charges to families. Families with unusual circumstances such as unemployment, or catastrophic medical costs may have family charges waived.

CENTRAL ADMINISTRATION
EXHIBITS

Figure 14

FUNDING AND OPERATIONAL STRUCTURE
MOBILE AND REGIONAL CHILD HEALTH SPECIALTY CLINICS



APPENDIX A
STATEMENT OF ASSURANCES

This annual plan includes the information required in Section 505 of the Title V Maternal and Child Health Block Grant Act.

- (1) A report describing the intended use of payment.
- (A) A description of those populations, areas, and localities which the state has identified as needing child health services.

The information is to be found in Sections I (Services Needed by Handicapped Children) and III (Description of CHSC Patient Service Programs and Projects) of this annual plan.

- (B) A statement of goals and objectives for meeting those needs.

The Child Health Specialty Services goals and objectives are listed in Section II (Service Guidelines, Goals and Objectives).

- (C) Information on the types of services to be provided

The types of services the agency will provide and the characteristics of the individuals to be served are described in Section III (Description of CHSC Patient Services, Programs and Projects).

- (D) Data the state intends to collect respecting activities conducted with such payments.

A description of the agency's data collecting and reporting system is to be found in Section VII (Agency Management and Assurance Activities).

- (2) A statement of assurances.

- (A) The state (agency) will provide a fair method for allocating funds allotted to the State under this title among such individuals, areas, and localities as identified under paragraph (1)(A) as needing maternal and child health services, and the State will identify and apply guidelines for the appropriate frequency and content of, and appropriate referral and follow-up with respect to health care assessment and services financially assisted by the State under this title.

The method used to determine a fair method for allocating funds is as follows: The services are widely publicized throughout the state. The size of the program in each of the clinics (the number of personnel, equipment, etc.) is determined by the number of referrals received. In this way the clinics respond to the demand for service.

- (B) Funds allotted to the State under this title will only be used, consistent with section 508, to carry out the purposes of this title or to continue activities previously conducted under the consolidated health programs (described in section 502(bX1)).

The CHSC will use the funds received to carry out the purposes of this title or to continue activities previously conducted under the consolidated program.

Methods for assuring quality assessments and services.

See Section VII (Data the CHSC Intends to Collect Respecting Title V Activities) and (Administrative Policies).

- (C) the State will use --

- (i) a substantial proportion of the sums expended by the State for carrying out this title for the provision of health services to mothers and children, with special consideration given (where appropriate) to the continuation of the funding of special projects in the State previously funded under this title (as in effect before the date of the enactment of the Maternal and Child Health Services Block Grant Act),

The major program activities of CHSC involve the provision of health services to handicapped children and children with potentially handicapping conditions. The Program of Projects is administered by the State Maternal and Child Health Section, and is a separate activity.

- (ii) a reasonable proportion (based upon the State's previous use of funds under this title) of such sums will be used to carry out the purpose described in paragraphs (1) through (3) of Section 501(a).
- (1) The statewide programs of CHSC make quality services available to all children in the State. Low income families will not be charged for services, and charges to other families will be adjusted to reflect income, resources, and family size.

- (2) CHSC conducts a follow-up program for infants born under high risk conditions (Section II). CHSC services help to reduce the incidence of handicapping conditions and the need for inpatient and long term care services Appendix A.
 - (3) CHSC conducts an SSI Disabled Children's Program, described in Section III.
- (D) If the state imposes any charges for the provision of health services assisted by the state under this title, such charges (i) will be pursuant to a public schedule of charges, (ii) will not be imposed with respect to services provided to low income mothers or children, and (iii) will be adjusted to reflect the income, resources, and family size of the individual provided the services.

A new method of charging is described in Section IV (Description of Family Services). The system has been developed to conform to the requirements stated in the legislation.

- (E) The State agency will participate.

- (i) In the coordination of activities between such programs and the Early and Periodic Screening, Diagnostic and Treatment Program under Title XIX to insure that such programs are carried out without duplication.

The Iowa Child Health Specialty Clinics accepts by referral patients who fail the screening tests provided by nurses in the state EPSDT centers.

- (ii) In the arrangement and carrying out of coordinated agreements described in section 1902(a)(11) relating to coordination of care and services available under this title and Title XIX.

The Iowa Child Health Specialty Clinics has a very comprehensive interagency agreement with the Department of Human Services.

- (iii) The coordination of activities within the state with programs carried out under this title and related to federal grant programs.

This agency has an interagency agreement with the state Maternal Child Health program. The administrative staff of MCH and CC meet regularly to discuss methods to integrate staff services, sites and activities.

The annual plan of the state Maternal Child Health program and the state Child Health Specialty Clinics program are developed in close cooperation.

APPENDIX B

Assessment of the Incidence of Diseases and Disorders
that Cause Iowa Children to be Handicapped

Unfortunately, there is no way to accurately determine the number of handicapped children in Iowa, or the area in which they live, much less the type or severity of their problem, and certainly not the services they need. There are many reasons for this lack of information. There is no agreed-upon single definition of what constitutes a handicap and, therefore, the meaning of available data is uncertain. Moreover, there is no one state agency charged with collecting and compiling this information.

In an effort to obtain better information about the handicapped children in the state of Iowa, the Iowa Child Health Specialty Clinics (then Iowa SSCC) and the Department of Public Instruction (DPI) conducted an in-depth survey of a six-county area around Mason City in 1965. The survey was designed to determine the numbers and types of handicapped children in the study area and their need for services. One important finding of the survey was that the number and types of services needed varied greatly among the children with the same diagnostic condition. The results of the survey were very helpful and have been used by the Iowa CHSC in health planning. However, ongoing and extensive surveys of this kind are not a feasible method of obtaining information about the prevalence and incidence rates of handicapping conditions because of the cost and the personnel time they require.

The Area Education Agencies (AEA) have become a new potential source of information about handicapped children because the Education for All Handicapped Children Act of 1975 (P.L. 94-142) gave the state the responsibility "to insure that all handicapped children have available to them a free appropriate public education which includes special education and related services to meet their unique needs."² This charge has made it necessary for the schools to collect information about the handicapped, and the DPI now maintains an extensive registry and data base about the

1 Iowa State Services for Crippled Children. Planning Comprehensive Services for Handicapped Children and Youth. Iowa City, Iowa, 1972.

2 Implementation of Part B of the Education for All Handicapped Children Act. 45 CFR Part 121a. Subpart A Sec. 121a.1(a). Federal Register, August 23, 1977.

(Underlining added.)

handicapped children it serves. However, even this potential source of information does not provide useful needs assessment statistics concerning handicapped children because the children are classified as to their educational problems, and the AEAs do not collect medical and health information about the children.

Other state agencies have limited data systems for handicapped children. The Department of Human Services (DHS) collects data concerning developmentally disabled persons who are receiving DHS services and the Iowa CHSC collects data concerning those children with handicapping or potentially handicapping conditions who are referred to them for services.

In conclusion, there is no single source of information about handicapped children in Iowa that can be used to assess the incidence or prevalence of the handicapped in the state. Therefore, such an assessment must be attempted by using the information available from a number of sources. The most significant information follows.

Incidence Rates of Handicapped Children as Reported by Various Sources

The Rand Corporation Report³ (rates applied to 1980 Iowa child population⁴)

<u>Handicap</u>	<u>Rate per 1,000 Children</u>	<u>Number of Children</u>
Mental Retardation	33.4	31,500
Learning Disability	8.8	8,300
Emotional Disturbance	17.9	16,900
Crippling or other Health Impairment	20.0	18,800
Visual Impairment	2.3	2,200
Hearing Impairment	5.8	5,500
Speech Impairment	26.3	24,800
Multiple Handicap	0.6	600
Total	114.0	107,400

³ Rand Corporation. Services for Handicapped Youth: A Program Overview R-1220-HEW, May 1973.

⁴ The U.S. census for Iowa, April 1, 1980 showed 941,885 persons under age 20.

The University of Iowa and the State Department of Health Report⁵ about congenital/inherited abnormalities (based on 40,000 live births per year)

Birth defects due to chromosomal abnormalities (about 230-250)*

Down syndrome	50 births/year
Trisomies 13 & 18	20
Trisomy X	20
Trisomies XXY & XYY	80
Turner syndrome	10
Other chromosomal abnormalities	50-70

Birth defects most often due to multifactorial inheritance

Cleft lip or cleft lip and palate	60 births/year
Cleft palate alone	20
Spina bifida, meningomyelocele	100
Congenital heart disease	250
Familial mental retardation	600

Birth defects due to single gene (single gene pair) inheritance

Neurofibromatosis	10 births/year
Duchenne muscular dystrophy	7-12**
Other types of muscular dystrophy	4
PKU (phenylketonuria)	4***
Myotonic dystrophy	10 or more
Cystic fibrosis	20
Sickle cell anemia	3
Retinitis pigmentosa	10-20
Hemophilia	2
Huntington's chorea	2
Other hemoglobinopathies (including thalassemia)	3
Dysautonomia	1
Tay Sachs disease	1
Galactosemia	1
Histidinemia	1
Homocystinuria	1
Tyrosinemia	1
Maple syrup urine disease	1

* about 1/3 are preventable

** about 1/6 are preventable if newborn screening becomes available *** can be treated effectively if detected at birth

5 Compiled by James Hanson, M.D., The University of Iowa, based upon recent Iowa population and birth data and upon rates available from the U.S. Center for Disease Control and from the literature. The Department of Health reported live births in Iowa in 1983 (Provisional occurrence data).

Other SourcesScoliosis⁶

4 per 100 children ages 10-13 7,800 children/year
manifest scoliosis

1 per 800 children ages 10-13 240
require treatment

Cerebral Palsy⁷

Cerebral palsy occurs at a rate of 70-140 births/year
(1.5 to 3.0 per 1,000 live births)

Certified count of handicapped children receiving special education and related services

The DPI certified count of handicapped children being served by special education programs as of December 1, 1981 indicates 56,112 children between ages 3 and 21. The count by category of handicap is as follows:

Mental Disability	11,933 children/year
Learning Disability	22,347
Emotional Disability	4,197
Severe/Profound Mental Retardation	656
Physically Impaired	794
Visually Impaired	188
Hearing Impaired	779
Speech, Language and Communication Impaired	15,218
Deaf-Blind	24
Total	56,112

Number of newborns in neonatal intensive care units who have a high potential for handicapping conditions

According to the Department of Health annual hospital survey report for 1979, the number of infants who received care in the 12 Iowa neonatal intensive care units in 1979 was 3,104. The level II units are distributed statewide. At this time, four of the level II units have follow-up programs for early identification of consequent handicaps. The level III unit is located at the University of Iowa Hospitals and Clinics (UIHC) and also has a follow-up program.

6 Communication from Ignacio V. Ponseti, M.D., The University of Iowa.

7 Cruickshank, William M., Ed., Cerebral Palsy, A Developmental Disability. 3rd ed. Syracuse: Syracuse University Press, 1976. pp. 7-15.

The number of children with handicapping or potentially handicapping conditions referred to the CHSC

In FY 1983, 4,107 children received services from Iowa CHSC in its specialty clinics. This figure represents the total number of visits by children to CHSC specialty clinics. It should be noted that this figure does not represent an unduplicated count of children because some children receive services at more than one clinic. It should also be noted that this figure does not represent the total number of examinations since many children receive multiple examinations during a clinic visit. University of Iowa Hospitals and Clinics (UIHC) provided services to patients enrolled in the CHSC program, including 6,434 outpatient visits and 1,529 inpatient visits. CHSC and/or UIHC also provided case management services or planned future clinic services for a total of 11,723 active cases.

Note: The above figures do not represent the total number of Iowa handicapped children receiving services because many handicapped children received services from other sources.

Diagnostic conditions for the 8,949 CHSC children (unduplicated count) served by the Iowa CHSC and UIHC in 1983 include the following major categories. (Detailed information is available in the annual report.)

- Down syndrome
- Mental retardation
- Developmental retardation
- Learning problem
- Behavioral problem
- Hearing deficit
- Speech problem
- Muscular dystrophy
- Cerebral palsy
- Congenital heart disease
- Cystic fibrosis
- PKU
- Cleft lip and/or palate
- Scoliosis
- Spina bifida and meningocele
- Sickle cell anemia
- Other multiple congenital anomalies
- Hemophilia
- Neurofibromatosis
- Retinitis pigmentosa

Review of available data illustrates several problems in trying to use the information from the several sources to assess the current incidence of handicapped children. For example, comparison of the Rand rates and the DPI count shows considerable discrepancy both in the estimated total count of handicapped children in the state (107,000 versus 56,100) and in the number of handicapped children in each category (e.g., physically impaired, 18,800 versus 800; learning disability, 8,300 versus 22,300; hearing impaired, 5,500 versus 800; etc.). The obvious reason for these discrepancies is that different definitions and methods were used in developing the data.

The data concerning incidence rates of birth defects was obtained from public health sources and is probably relatively accurate. However, the expected rates of birth defects are not reflected in the rates of live birth congenital malformations reported by the Iowa Department of Health, indicating a deficiency in reporting systems.

Because of these and similar problems, it is unrealistic to use any current data system to determine the number of handicapped children in Iowa to plan for the services they require. Hence, it is important to develop a coordinated single data collection system in order to accurately assess the need for services.

Further data about handicapped children served by various public and private health programs is to be found in A Study of the Health of Iowa's Children and Youth.

8 American Academy of Pediatrics, Iowa Chapter. A Study of the Health of Iowa's Children and Youth. Iowa City, Iowa. September, 1979.

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