CHILDREN'S PRIMARY HEALTH CARE PLANNING IN ARIZONA

A Strategy Brief

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Children's Primary Health Care Planning In Arizona
A Strategy Brief

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The Child and Adolescent Health Policy Center (CAHPC) at the Johns Hopkins University was established in 1991 by the federal Maternal and Child Health Bureau as one of two Centers to address new challenges found in amendments to Title V of the Social Security Act (MCH Services Block Grant) enacted in the Omnibus Budget Reconciliation Act (OBRA) of 1989. The purpose of the Center is to draw upon the science base of the university setting to help identify and solve key MCH policy issues regarding the development and implementation of comprehensive, community-based systems of health care services for children and adolescents. Projects are conducted to provide information and analytical tools useful to both the federal MCH Bureau and the State Title V Programs as they seek to meet the spirit, intent and content of the Title V legislation and the challenges of addressing the unique needs of MCH populations and programs in health care reform.

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OVERVIEW

In July 1992, the Office of Women's and Children's Health (OWCH), the unit in the Arizona Department of Health Services responsible for needs assessment and planning under requirements of Title V of the Social Security Act (Maternal and Child Health Services Block Grant), convened the Arizona Children's Primary Health Care Task Force. This Task Force was charged with developing a comprehensive plan that would ensure access to primary health care services for all children from birth through 21 years who live in Arizona. To accomplish this assignment, several steps were outlined by the OWCH:

1. define the attributes, or characteristics, of primary care;
2. determine criteria for measuring those attributes at both state and local levels;
3. determine how effectively Arizona's health community is implementing those attributes; and
4. develop strategies to improve current service system policies and programs with the ultimate goal of improved health status.

The Task Force is seen as a broad-based, comprehensive initiative committed to public-private collaboration to improve the health status and well-being of children and adolescents in Arizona. In the initial phase, Task Force meetings were designed to solicit ideas on conceptualizing an ideal system of care, to formulate objectives and action steps, and to build consensus between the public and private sectors for system development. Activities from the Task Force are intended to relate to other efforts occurring in the state and the outcome is intended to form a cohesive, comprehensive plan, as opposed to disparate pieces of a puzzle.

The Task Force met for this initial phase of planning July through December 1992. The first planning phase focused on developing recommendations for an ideal system that would assure accessibility to comprehensive and integrated primary care services for all Arizona children. During 1993-1994, the Task Force is focusing on the second phase, "Planning for Implementation". This second phase involves an in-depth analysis of current system performance, as well as the development of an Action Plan for implementation. The Task Force will analyze current policies and practices and roles and responsibilities for affecting change. Three types of policy and procedure change are anticipated: statewide, organizational, and programmatic. The Action Plan is expected to be completed early in 1994, after which, the final phase of the Task Force planning process, Implementation, is scheduled to begin.

The Task Force planning process in Arizona involves the development of a framework and structure for local needs assessment and planning, as well as the development of strategies for state level agencies to support local efforts with technical assistance and resource development activities. In addition, the Task Force will develop a mechanism for localities to provide information back to state level agencies so that policy, program, and resource needs can be determined. To respond to these needs, the Task Force has been charged with constructing strategies that will generate fiscal and political support.

This process represents one aspect of Arizona's response to federal Maternal and Child Health (MCH) agency guidance on amendments to Title V enacted in the 1989 Omnibus Budget Reconciliation Act (OBRA '89). This guidance calls for state Title V programs to establish a
"statewide network of comprehensive, community-based health care systems that serve women of reproductive age, infants, children, adolescents, and children with special health care needs [that] will assure family-centered, culturally-sensitive, care-coordinated services" (Maternal and Child Health Bureau, 1993). Primary care planning can be addressed by different strategic initiatives: the Arizona Task Force approach represents only one such method.

Task Force staff leading these planning activities in Arizona learned several important lessons about the critical aspects of strategic planning necessary for effective system development efforts. This paper has been developed with the hope that other state Title V programs struggling with the task of planning systems of care for children might benefit from a discussion of Arizona's experiences.

BACKGROUND: INITIAL ASSESSMENT OF THE SYSTEM PROBLEMS IN ARIZONA

In 1988, the Arizona Department of Health Services (ADHS) conducted a survey of health care utilization in the state. The families of Arizona children ages birth to 17 years who were living in a household or family unit with at least one parent or adult caretaker were contacted by telephone. A private survey firm conducted the survey of 2,065 respondents with a completion rate of 87.7 percent. The survey concluded that many Arizona families did not have an identified "medical home," a regular point of contact to receive comprehensive and coordinated primary care services. This survey also found that only 37% of children at all income levels receive preventive services. Various other studies have found Arizona ranks low on measures of child well-being when national comparisons are made (Annie E. Casey Foundation, 1992; ADHS, 1988; Greater Phoenix Affordable Health Care Foundation, 1987; Morrison Institute for Public Policy, 1992). Several system barriers contributing to low primary health care service utilization in Arizona and in turn, low health status, have been identified through these and other studies.

In 1989, 13% of all Arizonans, about 500,000 people, lacked health insurance (Morrison Institute for Public Policy, 1992). As in nearly all states in this country, many families in Arizona lack health insurance or adequate insurance coverage and may not be eligible for programs that provide services at little or no cost (Marquis & Long, 1992). These families often face a financial barrier to appropriate care.

In addition, there is a lack of primary care resources within the state system to provide all necessary services to those in need. Although Arizona ranks 6th in size of the nation's 50 states, it ranks only 25th in population. The population is estimated to be 3.7 million, 75% of whom are congregated in Phoenix and Tucson, the two urban centers. The remaining 25% of the population is dispersed throughout the state in rural and smaller communities. However, only 12% of Arizona's primary

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1This objective is based on Year 2000 Objective Number 17.20 which calls for "Increas[ing] to 50 the number of States that have service systems for children with or at risk of chronic and disabling conditions, as required by Public Law 101-239 (DHHS, 1990, p. 468)." In addition, "Part H of the Education of the Handicapped Act (P.L.99-457) establishes a discretionary program to build statewide systems for comprehensive, community-based, coordinated, family-centered services for infants and toddlers with, or at risk of, chronic and disabling conditions" (DHHS, 1990, p. 469). States and the federal Maternal and Child Health Bureau have broadened this objective and concept to include all maternal and child health populations.
care providers live in rural and frontier areas (ADHS, 1990). This shortage of providers can be attributed to lower salaries and third party reimbursements, and longer working hours expected of each provider in underserved areas (ADHS, 1990; Stimmel, 1992; Primary Care Task Force, 1992). In rural and isolated areas there is also an unmet demand for linguistically and culturally competent providers (Morrison Institute for Public Policy, 1992). Finally, even those populations living in isolated areas who are able to identify health care services may experience transportation barriers to service sites (The University of Arizona College of Medicine, 1990).

Patient factors may account for additional reasons why people in Arizona do not access health care services. There may be a lack of knowledge about the importance of preventive and primary health care, as well as a dissatisfaction with health care delivery services, such as inconvenient hours, long waiting periods for appointments, and insensitive providers (The University of Arizona College of Medicine, 1990). Certainly, unique subgroups in Arizona, such as the Native American and Hispanic populations may experience linguistic, as well as literacy, barriers to care. The Morrison Institute for Public Policy (1992) has found an unmet demand for linguistically and culturally competent providers in rural and isolated areas. As found nationally, the policies of different categorical programs in Arizona can cause barriers to appropriate and comprehensive care, such as highly variable categorical eligibilities for government funded programs, and a lack of existing and applied standards (Institute of Medicine, 1992).

In addition, the fragmented and discordant health care system creates administrative barriers. Care is often uncoordinated, leading to superfluous administrative costs, an overuse of high technology services, and a lack of follow-up and referral services. Also, prospective clients often endure confusing eligibility policies and cumbersome systems. A study by The University of Arizona College of Medicine (1990) found that lack of knowledge concerning eligibility to the Arizona Health Care Cost Containment System (AHCCCS), Arizona's Medicaid system of health plans, and difficulty with the AHCCCS application process were two key barriers that influence the use of prenatal care services in Arizona. Finally, the use of "gatekeepers" to assure the appropriate management and utilization of services can, in fact, serve as administrative barriers that may hinder people from receiving services.

The need for a broad-based solution to problems of the current system has been acknowledged by various leaders and organizations throughout the state of Arizona (Arizona State University, 1992). Professional and advocacy groups are involved and interested in improving system weaknesses (Children's Action Alliance, 1992). This responsiveness creates an environment that has fostered the success of the Arizona Children's Primary Health Care Task Force planning initiative.
PLANNING CAPACITY: STAFFING AND TASK FORCE PREPARATIONS

The Office of Women's and Children's Health staffed the Task Force with several members of the office:

- the Primary Care Program Manager,
- the Child Health Screening Manager,
- the Planning, Evaluation & Consultation Section Manager,
- the Office Chief, and
- a full time master's level Primary Care Intern.

Collectively, this staff working group included individuals with training in community planning and child health program development and management. In addition, these individuals had significant professional experience in and knowledge of a variety of both state and national child health programs and policies.

In addition, two technical consultants from the Institute for Health Policy Studies at the University of California, San Francisco and a local consultant were employed to assist with Task Force planning strategies and to provide information about other state's activities to plan a rational configuration of child health services. In addition to contracting with consultants, Task Force staff searched for other resources that could provide information about planning activities at both national and state levels.

DEVELOPING OVERALL OBJECTIVES AND AN INITIAL FRAMEWORK

Before the Task Force meetings began, staff spent time determining the overall objectives and framework of the Task Force, defining a timeline for planning steps, selecting and recruiting Task Force participants, as well as preparing the agendas for initial meetings. Staff developed the overall goals and objectives for the Task Force based on those formed by the federal Maternal and Child Health Bureau's Primary Care Workgroup². The goal and objectives for the Arizona Task Force are shown as Figure 1.

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²This workgroup is responsible for the development, dissemination, implementation, and coordination of all primary care systems development initiatives within the Division of Maternal, Infant, Child, and Adolescent Health in the Maternal and Child Health Bureau.
FIGURE 1: TASK FORCE GOAL AND OBJECTIVES

GOAL: All children in Arizona will have access to and utilize primary health care services.

OBJECTIVES:

1. To develop and promote a common understanding (definition) of a primary health care system for all children and adolescents in Arizona.
   1a. To describe the characteristics of a state system.
   1b. To develop process and structure criteria for measuring the characteristics at the state and local levels.
   1c. To determine roles and responsibilities for assuring implementation of the system.

2. To formulate state policy which supports universal access for and appropriate utilization of primary health care services by all children and adolescents.
   2a. To review the current policies that shape the primary health care system for all children and adolescents.
   2b. To determine the current status of primary care services for all children and adolescents.
   2c. To research and present policy options and recommendations related to health services for all children and adolescents.

3. To develop strategies which assure the implementation of state policy supportive of universal access and utilization of primary health care services for all children and adolescents.
   3a. To enhance partnerships between the public and private sectors that would contribute to strengthening primary health care systems.
   3b. To facilitate better linkages among those concerned with primary care services, to financing, education and research.
   3c. To demonstrate, evaluate and disseminate effective methodologies in assuring primary health care systems for all children and adolescents.
Next, staff outlined necessary time commitments and sequence of issues for discussion during the first phase of planning, as well as a basic framework for subsequent planning phases (see Appendix A for the Task Force Timeline).

**TASK FORCE MEMBER SELECTION AND RECRUITMENT**

After the OW CH staff determined the objectives of the Task Force, potential participants were selected. Under the premise that a diverse representation of organizations facilitates an appropriate and comprehensive planning process, potential members were identified to assure that the many disciplines that impact a child's well-being would be represented. Representatives from educational, business, religious, and health system disciplines at different levels (both public and private organizations at state, community, and local levels) were selected for participation. Individuals also were asked to participate who had demonstrated a familiarity with primary care system issues and barriers in Arizona. Task Force staff from the state Title V unit were well aware of key organizations throughout the state, as well as individuals, involved in or knowledgeable of effective health planning -- these groups and persons were invited to participate as well.

The Arizona Children's Primary Health Care Task Force initiative was intended to create a plan that not only will relate with and expand on other planning efforts going on in the state, but also will establish a mechanism for linkage among key organizations and health system leaders in Arizona. Task Force membership, as well as staff, therefore included individuals who were jointly involved in other planning activities designed to improve the system of primary care and/or related service delivery for children in Arizona. Parallel health systems planning initiatives represented by Task Force members include:

- Partnership for Children -- a project of the Arizona Community Foundation, the Tucson Community Foundation and the Governor's Office for Children designed to restructure Arizona's system of services for "at risk" children and their families;
- the Primary Care Working Partnership -- a statewide project of the Arizona Department of Health Services composed of representatives from public and private agencies and associations who are actively involved in the delivery of primary care;
- the Arizona Partnership for Infant Immunization -- a collaborative effort of public and private organizations to identify barriers, to develop standards for practice, to facilitate partnerships and to educate families on issues relating to childhood immunization; and
- the Prenatal Care Coalition Legislative Prioritization Committee -- an interagency and inter-organizational group designed to identify barriers to prenatal care and to develop recommendations for legislation relating to eligibility and enrollment, availability of providers, services to special populations, education, and services to chemically dependent women and their families.

This strategy of joint appointments was intended to limit duplication in planning and to build upon different efforts.

It also was considered important that community level and private sector organizations be actively engaged in planning, implementing, and evaluating primary care delivery in order to build a
foundation for state-wide acceptance of the model that would be developed. Representatives from communities were considered critical in their roles in educating the Task Force about community problems and needs. Finally, other individuals recommended to staff, as well as persons who asked to be involved, were welcomed to join the Task Force. It was believed that increased cooperation would, in turn, increase personnel resources, political resources, as well as potential financial resources and support for planning (see Appendix C for a list of organizations represented on the Task Force). Staff concerns about the growing membership were resolved by plans to break the full Task Force into three smaller groups for discussion sessions.

Invitations were sent to potential members that described the objectives of the Task Force, and emphasized that a commitment would be needed throughout the entire planning process. These initial letters asked potential members to recommend others who might contribute to the planning and whose interests were not already represented on the Task Force. In addition, persons who believed they would be unable to participate in planning were asked to send a representative. Finally, these invitations included basic background information about primary care and the concept of system development, and asked potential members to consider their personal concept of primary care before the first meeting.

**TASK FORCE PROCEEDINGS AND ISSUE DELIBERATIONS**

After participants were recruited, Task Force staff discussed an agenda for the first meeting. Staff felt it would be necessary to give participants an overview of the need for the Task Force in Arizona and what the Task Force would accomplish. In addition, this first meeting was considered an opportunity for participants to discuss and develop consensus on key terms that would be used in planning, such as primary care, system development, and community. During this first meeting, participants also would have time to discuss their experiences and interests relating to primary care and their key concerns with the primary health care system for children in Arizona. Finally, it was decided that the objectives developed for the Task Force would best be addressed if the full Task Force divided into three working groups to discuss different issues in-depth.

When the Arizona Children's Primary Health Care Task Force first met in July 1992, participants were given proposed Task Force goals and objectives (which participants were asked to review), an agenda for the meeting, and a list of all invited members.

**Developing Consensus on Key Terms and Issues:** The proceedings began with a discussion to help participants develop an understanding of the major concepts to be addressed. First, the full Task Force examined several definitions of what constitutes comprehensive primary care and of what primary care services should entail. Various individuals and organizations have developed their own guidelines as to standards for the content of primary care (American Academy of Pediatrics, 1989; Parker, 1974; Starfield, 1992). Of particular interest to the group was the definition developed by the Maternal and Child Health Bureau (MCHB). In 1992, the MCHB defined primary care as the following:
Primary care for children and adolescents is a personal health care service delivered in the context of the family and community. Primary care is comprehensive in scope and includes services that preserve health, prevent disease and dysfunction, and care for common illnesses and disabilities. Primary care services as the usual entry point to the personal health care system. It shares with the family of the child or adolescent ongoing responsibility for health care, whether illness or injury is present or absent. The primary care provider serves as the integrator of health services by furnishing most health care and counseling and coordinating needed specialty and supportive services. Finally, primary care includes mechanisms that assure the appropriateness, cultural acceptability, and quality of services being provided.

The attributes, or characteristics, of primary care included in this definition are:

- first contact
- family centered
- continuous
- accessible
- coordinated
- culturally appropriate
- comprehensive
- accountable
- accountable
- community oriented
- culturally appropriate

After evaluating this definition, the Task Force decided that the attributes provided by MCHB were not sufficient to describe characteristics of the ideal system desired in Arizona. The Task Force substituted three attributes identified by MCHB—accessible, culturally appropriate, and accountable—with "universally accessible," "culturally competent," and "quality."

The first meeting also included a discussion of the Task Force's concept of system development. This concept had been presented by Task Force staff as:

"...the long term planning process intended to facilitate appropriate and comprehensive health care service delivery to populations. This process involves more than just an analysis of the functioning of particular organizations or programs. Rather, it involves rational planning to improve the system's capacity for service availability and delivery, as well as increasing collaborative efforts among public and private agencies and organizations so that the "whole system" functions more efficiently (Simpson, 1992).

Staff considered it important to discuss this concept at the first meeting in order that participants better understand the various changes to the health care system needing to take place. This belief was based on the idea that "[t]he best possible health status [for all citizens] can be attained only through a shared commitment at local, state, and national levels (DHHS, 1990, p.1).

After the Task Force recognized that changes to the health care system will need to occur at many levels, including the community level, the next obstacle the group faced was how to define

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3The Arizona Children's Primary Health Care Task Force was using the May 1992 version of the Maternal and Child Health Bureau's Definition of Primary Care. This earlier version did not include "developmentally appropriate" and "accountable" -- concepts that have been incorporated into the February 1994 version. In addition, the concept "culturally appropriate" has been replaced with the term "culturally competent".
"community". "Community" is another term for which definitions vary tremendously: community can be geographically based, culturally based, problem based, service based, among other delineations. The definition of "community" given in the Guidelines for the Title V Maternal and Child Health Services Block Grant Program (p. 64, FY 92) is:

...a group of individuals living in proximity with one another linked conceptually for the purpose of defining and coping with problems or a group of people linked, in fact, through interactions by common geographic and cultural identity.

The model system developed by the Arizona Children's Primary Health Care Task Force assumes that "community" is self defined- it could be a small rural town, a section of a large metropolitan area, a county, a school district, or a culturally unique sub-population of an area. By enabling communities to define themselves, and thus prioritize their own health needs, the local governing body understands which potential changes are most valued in the community.

During this discussion, Task Force members conceded that system development strategies, and therefore the Arizona Task Force, should strive to ensure that each child has and appropriately uses a place, organization, or provider as a regular source of health care services: a medical home. An "ideal" medical home has been described as providing "accessible, continuous, comprehensive, family centered, coordinated, and compassionate [medical care] delivered or directed by a well-trained physician ...[who] should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them" (American Academy of Pediatrics, 1992).

**Working Groups and Model Development:** After discussing key terms, the full Task Force divided into three working groups. The three groups focused on the following:

- **Group 1:** Roles and responsibilities of the major players in a primary health care system. Three levels of functions are addressed in the recommendations relating to a primary health care system: State, Community, and Public-Private Partnerships.
- **Group 2:** Policies and programs influencing access to Primary Care and the development of Primary Care Systems. The recommendations for policies and programs are based on the following premise: All existing and future policies should promote and facilitate a primary health care home for all children.
- **Group 3:** Measures for determining how well the services now in place are meeting the accepted definition of primary care.

The first two groups had the task of describing the specific elements desired in system development. These groups needed a paradigm to systematically evaluate the various components of the health care system. A Health Services System model developed by Barbara Starfield (1992) was used to address multiple issues pertinent to system development (see Figure 2).

The Starfield model divides the health services system into three components: structure, process, and outcome. The **structural components** constitute the resources needed to provide services in a system. **Process components** involve activities of the provider and activities of the recipients of care. The final section that completes the model consists of **outcome components** of care. The flow diagram of
the health services system in Figure 2 illustrates how structural and process elements interact together and with the population and with the social and physical environment to impact health status (Harlow, Starfield, Johansen, & Guyer, 1992, p.6).
FIGURE 2: THE HEALTH SERVICES SYSTEM

- Structure
  - Personnel
  - Facilities and Equipment
  - Range of Services
  - Organization
  - Management and Amenities
  - Continuity/Information Systems
  - Accessibility
  - Financing
  - Population Eligible
  - Governance

- Provision of Care
  - Problem Recognition
  - Diagnosis
  - Management
  - Reassessment

- Process
  - Persons
  - Utilization
  - Acceptance and Satisfaction
  - Understanding
  - Participation

- Outcome
  - Longevity
  - Activity
  - Comfort
  - Perceived Well-Being
  - Disease
  - Achievement
  - Resilience

Source: Starfield, 1992
During Phase 1 of the planning process, development of an ideal system, the Arizona Children's Primary Health Care Task Force utilized the structural components section of the model as the basis for its deliberations. The working groups evaluated each of the structural components separately. Staff developed worksheets for these meetings in order to help members stay focused and on track, and to help facilitate discussions. A chart developed to guide discussion on each of the structural components included the following: 1) a gold standard (what would be ideal); 2) the current situation (where Arizona is now); 3) gaps (in the current system); and 4) recommendations (steps needed in order to reach the gold standard). This chart is provided as Figure 3.

**FIGURE 3: TASK FORCE FRAMEWORK FOR PLANNING**

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<tr>
<th>STRUCTURAL COMPONENT</th>
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Both Group 1 and Group 2 developed gold standards for the structural components. As an example, Groups 1 and 2 decided that the gold standard for the component "Personnel" is:

Public and private agencies and organizations promote accessibility to and availability of culturally competent, family centered, community based primary care providers.

The primary care provider takes responsibility for transferring information to and from other resources, participating in the coordination of treatment plans, and of managing to the limit of his or her capability the physical, psychological, and social aspects of patient care.

For each of the structural components of the health care system, Group 1 identified roles (as appropriate) at the following three levels:

1. State: It is the role of both public and private state-level agencies and organizations to promote broad based system development that supports the primary care needs of communities. This includes issues such
as: the provision of data, technical assistance, decreasing financial barriers, training and education, and establishing and monitoring standards.

2. Community: It is the role of both public and private community level agencies and organizations to assess the primary care system needs of their area and to plan, implement, and monitor community development actions.

3. Public-Private Partnerships: It is the role of both public and private agencies and organizations to promote and facilitate interagency collaboration and cooperation at both a state and local level.

For example, Group 1 made the following specific statements regarding "Personnel":

1. It is the role of the Arizona Department of Health Services (ADHS) to take the lead in the development and implementation of strategies related to educating and/or recruiting upper, mid-, and lower level primary care providers to work in medically underserved areas. The strategies would address broadening/revising scopes of practice, and reimbursement rates.

2. It is the role of the Office of Planning, Evaluation, and Public Health Statistics (OPEPHS)...

   ...to identify Primary Care Areas (PCAs) that reflect primary care service patterns of use.
   ...in collaboration with Arizona Health Education Centers and Universities, to effectively address issues related to:
   a. manpower education  c. manpower recruitment
   b. manpower distribution  d. manpower retention

3. It is the role of public and private state level agencies and organizations...

   ...to provide technical assistance to communities to address primary care systems issues.
   ...to develop incentives for provision of primary health care.

4. It is the role of county health departments to facilitate the availability of physicians in their jurisdiction.

5. It is the role of communities to provide outreach programs and services.

6. It is the role of Area Health Education Centers (AHECs) to monitor the efforts to bring physicians to their particular rural areas.

Concurrently, Group 2 worked to identify policies and programs that facilitate the ideal primary care system. For example, Group 2 developed the following recommendations specifically relating to the structural component "Personnel":
Arizona should have policies that promote and facilitate:

...training of primary care providers.
...an adequate supply of AHCCCS providers, particularly in rural areas.
...an adequate supply of more specialized personnel for referral of AHCCCS patients.
...the development of curricula and training modules for multidisciplinary health care teams.
...an adequate distribution of primary care providers in health underserved areas.
...the expansion of scope of practice for mid-level primary care practitioners.
...the use of alternative practitioners as integral parts of the Primary Care system in Arizona.
...providers who are culturally competent.

Groups 1 and 2 analyzed each of the structural components in this manner\(^4\).

Analysis of the structural components of the health care system is necessary but not sufficient to assure appropriate health service delivery. It is not enough to have the resources in place that provide primary care services, rather these resources need to conform to certain standards. Therefore, the third working group analyzed the qualitative aspects of primary care: the attributes, or characteristics. For each attribute adopted by the full Task Force, Group 3 developed system performance measures.

This group was assisted by the provision of a Primary Care Assessment Tool developed by The Johns Hopkins University Child and Adolescent Health Policy Center\(^5\) for Delaware's Child Health Task Force. The Assessment Tool, as restructured by the Arizona Children's Primary Health Care Task Force, provides for each attribute:

- a concept or definition statement,
- a gold standard of the attribute or an ideal against which all measures should be held, and
- community level self-assessment questions and facility/provider level assessment questions designed to assist in identifying gaps, needs, and current assets within the system.

As an example, the following concept, gold standard, and community level assessment questions were developed by Group 3 for the attribute "First-contact Care":

**Concept:** "First-contact care" refers to the primary care provider being responsible for facilitating entry into the health care system [for each non-referred provision of health care and guiding the client to the most appropriate source of care].

\(^4\) The complete list of Task Force recommendations is included in the report *Primary Care System, Development: A Future for Arizona's Children*. This report is available from the Primary Care Program Manager, Office of Women's and Children's Health, Arizona Department of Health Services.

\(^5\) The Child and Adolescent Health Policy Center, funded under a cooperative agreement from the Department of Health and Human Services, Maternal and Child Health Bureau, and located in the Department of Maternal and Child Health of the Johns Hopkins School of Hygiene and Public Health, works to develop materials and support state initiatives aimed at development of systems of primary care services for all children.
**Gold Standard:** A system of primary care is established in which the primary care provider is contacted for all health care needs so that an informed judgement is made and guidance is given regarding the most appropriate source of care.

**Community Level Self-Assessment Questions:**

1. What mechanisms are in place to encourage the individuals/families to contact a primary care provider for health care needs? Are these mechanisms documented so that trackable data is available for review?
2. What mechanisms are in place to establish the linkages between the individuals/ families and primary care providers?

Figure 4 illustrates some of the areas addressed in the Facility/Provider Level Primary Care Assessment Tool.
FIGURE 4
SAMPLE ISSUES ADDRESSED IN ASSESSING PRIMARY CARE ATTRIBUTES
AT THE FACILITY/PROVIDER LEVEL

First Contact

- Encouraging the use of a primary care provider
- Guiding individuals to the most appropriate source of care
- Improving accessibility and availability through:
  - evening and/or week-end hours
  - transportation assistance or provision
  - shortened waiting times
  - convenient locations
  - telephone consultation
  - educational materials
  - sliding scale fees
  - acceptance of walk-ins
  - child-care

Comprehensive

- Offering different types of services on-site or through referral
- Addressing physical, emotional, developmental and socio-environmental needs as they impinge on the health of client sub-populations
- Using practice standards
- Developing methods to offer a range of services regardless of family's ability to pay

Community-Oriented

- Understanding community needs and health characteristics
- Being involved in community based planning
- Developing programs/services that respond to identified community needs
- Developing community advisory committees

Coordinated

- Developing mechanisms to facilitate information feedback to the primary care provider
- Maintaining follow-up on clients referred to other facilities for services
- Developing mechanisms to facilitate the efficient provision of needed services such as:
  - Case managers/social workers
  - Provider/Staff assistance
  - Information hotlines
  - Community resources directory
  - Handouts/Brochures

Continuous (Longitudinal)

- Maintaining demographic and service information on child client populations
- Developing mechanisms that encourage clients to return to the primary care provider
- Recognition and consideration of reasons for client "drop-out"

Family-Centered

- Having family representatives on Boards or Advisory Committees
- Holding parent/staff meetings
- Understanding family resources, risk factors, social context
- Organizing focus groups

Culturally Sensitive (Culturally Competent)

- Conducting outreach activities
- Training staff in cultural competency
- Being involved with neighborhood groups
- Having diverse representation on Board of Directors
- Having bilingual staff/patient education materials

FUTURE ACTIVITIES OF THE TASK FORCE
The "Planning for Implementation" phase of the Task Force, which began March 1993, involves an in-depth analysis of current system performance, including evaluations using the Primary Care Assessment Tool, as well as the development of an Action Plan for implementation. From each of the recommendations developed by Groups 1 and 2, the Task Force will discuss short- and long-term objectives. Objectives will be prioritized based on seriousness or the extent of the problem, cost and funds available, demonstrated effectiveness of the proposed programs or policies in improving the health of children, and equity issues. Expected strategies to achieve stated objectives will include community development activities, including needs assessment, completed with technical assistance from state level agencies.

Strategies developed by the Task Force will undergo the same scrutiny as objectives so that a systematic prioritization leads towards policy and program change. Several ideas for strategies were discussed during the first planning phase, including:

- "marketing" primary health care to communities
- expanding service system capacity so that all public services include a core set of health care services
- developing a hand-held medical record to improve tracking and follow-up, to provide developmentally appropriate services, and to avoid duplication of services
- developing linkages between providers or hospital systems to provide care through schools for uninsured and underinsured children
- increasing incentives for medical students to pursue a primary care practice rather than a specialty
- developing incentives to providers to practice in medically needy areas
- improving systems of data collection/management
- simplifying eligibility processes for programs
- improving health education

Implementation of the Action Plan in Arizona, scheduled to begin in 1994, will involve policy and practice changes at the state level, as well as community development initiatives. This Action Plan will be the Task Force's agenda for change. Participants are well aware, however, that actual implementation is not a clear cut, separate event from current and near future Arizona activities. Rather, it will entail an ongoing process of incremental efforts to improve the current mechanisms of and means for providing primary health care. Innovative and effective programs that currently exist will be integrated into the Action Plan with consideration for expansion or replication in other parts of the state as appropriate. New initiatives will be cultivated as well.

Although modifications of the "vision" for the primary health care system developed by the Arizona Children's Primary Health Care Task Force are anticipated during implementation (as indicated through continuous monitoring and evaluation efforts), the principal aim of the final Task Force plan is to provide a foundation for broad-based and appropriate primary care system development activities throughout Arizona over time.

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LESSONS LEARNED

Task Force staff in Arizona learned several critical lessons during the process of planning for improved maternal and child health services. As obstacles were confronted and issues deliberated, staff realized important points relating to:

- capacity building, including staffing and resource development;
- preparing for Task Force meetings;
- developing a framework and overall objectives for planning; and
- recruiting participants.

**Capacity Building for Leadership in Planning:** First, staff in the Office of Women's and Children's Health found that the planning required to oversee a Task Force to be more labor intensive than anticipated. OWCH hired a public health graduate student as a full-time planner to coordinate and facilitate the process. This individual was responsible for providing background materials to the participants, developing worksheets and a framework to assist workgroup sessions, synthesizing information shared at meetings into current and cohesive documents, and responding to participant concerns during and between meetings.

In addition, three consultants were utilized to assist with planning. The Arizona Title V program found it very important to articulate, in advance, needs for technical assistance or consultation and to specify and clarify issues needing to be addressed. Without these steps as foundation, communication can be difficult and the potential benefit of the consultant expertise can be compromised. In addition, staff found that before planning begins, contract expenditures and a description of work expected from consultants need to be outlined clearly.

Arizona staff recognized possible disadvantages to using outside consultants for planning, such as the possibility that they are not as aware of the history of the program's Title V planning (including past failed attempts), as well as political and administrative issues in the state. However, staff requested outside technical assistance in the hope that these individuals would have specific training and knowledge in group facilitation, primary care system development, and MCH issues that would benefit the project, as well as the skills to share that knowledge with the group. In addition, it was felt that outside consultants would provide objective insight to the proceedings.

**Meeting Preparations:** Another lesson learned by Arizona Task Force staff is that it is essential to provide participants with background materials to facilitate their understanding of the concept of primary care, concepts of system development and system change, data and arguments supporting the need for change, and information about the emphasis at the national level for addressing primary care concerns. As in most all states, the complexity of various system issues in Arizona required several in-depth discussions to allow members time to process this information.

Obtaining information describing the current situation and articulating the need for change in Arizona was not easy. Although some information was found, there were noticeable information and data gaps. Prior development of a comprehensive information package would have been invaluable to provide participants with an educational foundation on primary care service delivery within Arizona. The lack of data made it hard to develop a situational analysis for the Task Force.
Participants said they found it difficult to determine necessary policy changes, as well as to determine responsibility for program changes, without first examining what currently exists.

Information about the primary care system development initiatives of other states was also difficult to obtain. Materials about the ways other states have overcome barriers or have affected system change greatly would have facilitated the planning efforts in Arizona. Because program staff were continually discovering better approaches to planning, the Task Force strategy was modified several times, causing frustration among some participants. The significance of providing members a situational analysis and background information on primary care planning cannot be overemphasized.

Staff also found that a clear framework for Task Force activities notably facilitates achievement of project goals. It was therefore found necessary to present participants with a description of how the Task Force will work, its intended accomplishments (or a mission statement), and the anticipated time commitment. Planning staff also needed to develop their own workplan goals and objectives, and a realistic timeframe for achievements (see Appendix B for a descriptive timeline of Phases II and III).

**Planning Framework:** Use of the Starfield model of the Health Services System (see Figure 2) as a framework for planning, greatly assisted planning because participants felt comfortable that they were conducting a comprehensive examination of all aspects of health care.

Arizona staff also learned that a long range vision, supported by sufficient background research, is critical to articulate before convening the group (see Figure 1 for Arizona's list of goals and objectives). After this vision is articulated, it is easier to explore with participants in a concrete manner the anticipated outcomes for the initiative. Because staff in Arizona struggled to articulate specific desired end products, Task Force participants initially had difficulty conceptualizing the process. Members asked for a concrete illustration of what an "ideal" primary care system might entail. It was necessary for planning staff to identify a metaphor to describe the system model. Because program staff were committed to the notion that primary care must be tailored to meet unique population needs, the "ideal" system would need to vary depending on locale. Therefore, the model being developed for the whole state would constitute only a "blueprint" for system development.

The Task Force was charged with identifying an outline for the types of policies and programs needed, the roles and responsibilities of various players in developing these, and methods by which various systems and programs can assess performance in relation to "gold standards" for primary care attributes. Task Force participants were told their charge was to identify what needs to be in place in order to create an optimal system for children, and communities would then determine how the structure of the system would look. For example, although the state level Task Force might agree that primary care providers need to be available in an area, a local level governing body would be responsible for determining the types and number of primary care providers that would best serve the community.

**Membership and Recruitment:** Membership on the Arizona Children's Primary Health Care Task Force was intended to reflect the diversity of the state's population, and the different aspects of social
and physical well-being of children and adolescents. However, it was evident as planning progressed that cultural and consumer representation on the Task Force was not sufficiently inclusive. Although staff thoughtfully selected membership, representatives from some consumer and ethnic groups were notably absent. For example, there were no members participating solely as parents, although membership included the Publisher/Editor of a parenting magazine, and certainly there were many parents in the group. In addition, although members came from diverse cultural and ethnic backgrounds, Task Force membership did not include representatives for all cultural and ethnic groups living in Arizona. Staff also found it important to select subgroup membership carefully to assure diversity. Multidisciplinary representation within each group was similarly noted as key to promoting comprehensive analysis of the broad spectrum of issues impacting children's health. Finally, staff found it important to choose members willing and able to make a commitment to ongoing planning because when people come and go, planning groups significantly change focus and often, momentum.

Several additional conditions were identified by Task Force staff and members as important to maintaining and bolstering the effectiveness of future Task Force planning activities. These include the following:

- Timely and thorough minutes provided between meetings: Participants commented that minutes presented within a matrix or framework simplified their review of materials.
- Continued support from the organizations represented in Task Force membership. These organizations throughout the state need to promote Task Force ideas to communities as well as they are able.
- General political and environmental enthusiasm, as evidenced by interagency Task Force participation and commitment, supported with financial resources. In-depth planning of objectives and strategies must include a discussion of financial issues.
- A statewide system of data management as well as a central repository for maintaining the primary care information/data, including a network system among states that describes primary care system development initiatives.
- A plan to market to communities the recommended system changes (including formal mechanisms to obtain community feedback).
- An assertive legislative agenda.
- A plan for designating technical assistance responsibilities for community development initiatives.
CONCLUDING COMMENTS

The initiative to develop a system of primary care for all children in Arizona was given high priority within the Arizona Department of Health Services, as well as by organizations throughout the state. Many different organizations including state agencies, professional groups, and community groups showed support through active participation on the Task Force. Members of the Task Force provided expertise and enthusiasm to the project. The Task Force was considered to be both purposeful and necessary to address the primary health care needs of children.

There is strong support within the Task Force, as well as within the Arizona Department of Health Services to implement this system model. Participants as well as Task Force staff stated several times that they didn't want the plan to be just a "document that gathers dust on the shelf". Participants and staff are aware of the commitment needed as well as the time required to fulfill the goal of Task Force. Planning for the new Arizona system is intended to be flexible enough to adjust to other changes occurring in the health care system, including national health system reforms. It is comprehensive in that it is intended to provide and assure services for all children, and is designed to generate long term change. In addition, the interagency structure of the Task Force provides a good foundation for establishing connections with other primary care efforts in the state. Finally, the Arizona Children's Primary Care Task Force was based on a sound program philosophy: Universal access to basic primary care services is essential to improving child health in Arizona.

Several times throughout this planning initiative, staff struggled with the various process issues presented in this report. A better understanding of the issues and concerns about primary care system development might have allowed for more efficient and effective planning. It is hoped that this report of Arizona's experience will provide some guidance for similar primary care system development activities in other states to avert problems encountered.

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## Arizona Children's Primary Health Care Task Force Timeline

<table>
<thead>
<tr>
<th>TASK</th>
<th>DATE</th>
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<tbody>
<tr>
<td><strong>PHASE 1: DEVELOPMENT OF A MODEL PRIMARY CARE SYSTEM</strong></td>
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<tr>
<td>Develop recommendations for policies and programs in Arizona.</td>
<td>July-December 1992</td>
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<tr>
<td>Develop recommendations for roles and responsibilities in system development.</td>
<td>July-December 1992</td>
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<tr>
<td>Develop system performance measures.</td>
<td>July-December 1992</td>
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<tr>
<td>Define a model that will assure all children in Arizona have access to a comprehensive primary health care system.</td>
<td>December 1992</td>
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<tr>
<td><strong>PHASE 2: PLANNING FOR IMPLEMENTATION</strong></td>
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<tr>
<td>Determine current system performance in relation to Task Force Recommendations from Phase 1.</td>
<td>March 1993</td>
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<tr>
<td>Define plan objectives derived from Task Force Recommendations.</td>
<td>April-May 1993</td>
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<tr>
<td>Prioritize objectives.</td>
<td>June-July 1993</td>
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<tr>
<td>Develop strategies for each objective.</td>
<td>August-September 1993</td>
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<tr>
<td>Prioritize strategies.</td>
<td>October-November 1993</td>
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<tr>
<td><strong>PHASE 3: IMPLEMENTATION BEGINS</strong></td>
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APPENDIX B: Descriptive Timeline for Phases II and III

Phase II: Planning for implementation: Analysis of recommendations from Phase I and the development of an Action Plan

(Timeframe: March 1993 - March 1994)

I. Analysis of how we are meeting recommendations
   A. System strengths- policies and practices currently functioning
   B. System gaps- areas that need to be addressed for change

II. Development of objectives (based on Task Force recommendations for change) including:
   - time frame
   - desired effect
   - target population
   - measurable process or outcome criteria

III. Prioritization of objectives based on:
   A. Seriousness or extent of problem
   B. Cost and funds available
   C. Demonstrated effectiveness of the proposed programs in improving the health of children
   D. Demonstrated costs of not doing proposed programs
   E. Equity issues- equivalent services for equivalent needs

IV. Development of strategies (based on objectives) including:
   - year to be completed/ time frame
   - responsible parties
   - short, medium, and long term activities

   C. State level planning strategies including:
      - interagency collaboration
      - policy changes
      - providing technical assistance (manuals, models, worksheets, etc.) to communities
      - providing financial assistance to communities

   D. Community level planning strategies including:
      - marketing strategies
      - coalition building
      - community forums, focus groups, etc.
      - identification of barriers
      - identification of community leaders
      - needs assessment
V. Prioritization of strategies

VI. Development of an Action Plan including:
   • minimum standards for service delivery
   • a plan for a data management system
   • a plan for monitoring progress and evaluating the new system

   **Phase III: Implementation**

   *(Timeframe: 1994-1999)*

I. The actual execution of policy and practice changes

II. The coordination of programs and activities

III. Pilot demonstration sites of system changes

IV. Develop system and service measurement methodology, including both health outcome and service/system process measures

V. Primary care resource development process and methodology
APPENDIX C

Organizations Represented on the Arizona Children's Primary Health Care Task Force

Arizona Academy of Family Physicians, Phoenix, AZ
Arizona Association of Community Health Centers, Nogales
Arizona Association of Industries, Phoenix
Arizona Chapter of the American Academy of Pediatrics, Phoenix
Arizona Department of Education, Phoenix
Arizona Department of Health Services (ADHS), Phoenix
Office of Children's Rehabilitative
Office of Local and Border Health
Office of Infectious Disease
Office of Planning, Evaluation, & Public Health Statistics
Office of Women's and Children's Health
Arizona Family Care, Douglas
Arizona Health Care Cost Containment System, Phoenix
Arizona House of Representatives, Phoenix
Arizona Physicians IPA, Phoenix
Blair & Associates (Local Consulting Firm), Glendale
Centro De Amistad, Guadalupe
Children's Action Alliance, Phoenix
Cigna Healthplan of Arizona, Phoenix
City of Phoenix Human Services
Coconino County Health Department, Flagstaff
El Rio Community Health Center, Flagstaff
Governor's Office for Children, Phoenix
Greater Phoenix Affordable Health Care Foundation (GPAHCF), Phoenix
Health Choice Arizona, Mesa
Institute for Health Policy Studies, University of California, San Francisco, CA (Consultants)
Intergroup Health Care Corporation, Phoenix
Maricopa Area Health Education Center, Phoenix
Maricopa County Dental Clinic, Phoenix
Maricopa County Health Care Agency, Phoenix
Maricopa County Medical Center, Phoenix
Motorola, Phoenix
Northern Arizona Area Health Education Center, Yuma
Phoenix Area Indian Health Service, Maternal Child Health Branch, Phoenix
Pilot Parent Partnership, Phoenix
Pueblo Pediatrics, Chandler
Raising Arizona Kids Magazine, Phoenix
University of Arizona College of Medicine, Department of Pediatrics, Tucson
University of Arizona, Office of Rural Health, Tucson
Valley Christian Center, Phoenix
Valley of the Sun Association For The Education of Young Children (VSAEYC), Phoenix
Western Arizona Area Health Education Center, Yuma
Young Families Can, Phoenix
REFERENCES


The University of Arizona College of Medicine, Rural Health Office. (1990). Study of the availability of obstetrical and other primary care services in underserved Arizona: Report submitted to the President of the Arizona State Senate, Speaker of the Arizona State House of Representatives, and the Governor of Arizona. Funding for this project was provided through the Office of the Dean and the Southwest Border Rural Health Research Center (Government Contract HA-R-000020-02): Tucson.