

Twelve Stories: Pediatrician-Led Community Child Health Initiatives

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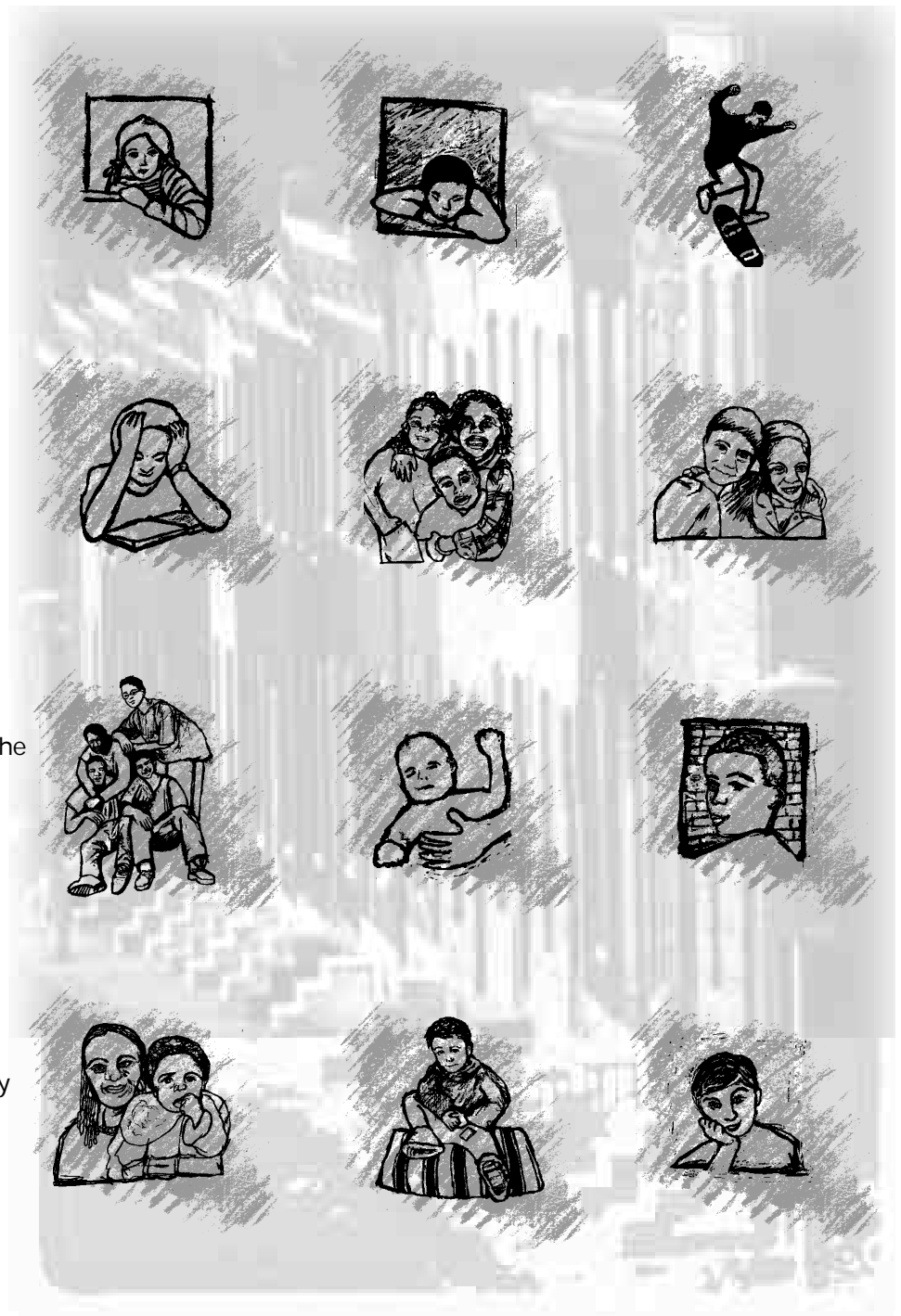
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The Women's and Children's Health Policy Center (WCHPC) at The Johns Hopkins University was established in 1991 to address current policy issues found in national legislative initiatives and evolving health systems reforms impacting on the health of women, children, and adolescents. The mission of the Center—which operated during its first five years as the Child and Adolescent Health Policy Center—is to draw upon the science base of the university setting to conduct and disseminate research to inform maternal and child health policies and programs, and the practice of maternal and child health nationally. Projects are conducted to provide information and analytical tools useful to public and private sector MCH professionals and to elected officials and other policymakers.

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Photography: Gillian B. Silver, MPH. Photograph for Helping Indian Children of Albuquerque from The Center for American Indian and Alaskan Native Health.

Foreword

As the Community Access to Child Health Program (CATCH) of the American Academy of Pediatrics (AAP) approaches its 10-year anniversary as well as the 21st century, it seems an appropriate time to take stock of where the program has been, and thoughtfully consider its future. The recent CATCH Program evaluation undertaken by the Women's and Children's Health Policy Center, Johns Hopkins University in collaboration with the National Center for Education in Maternal and Child Health, Georgetown University, provided an excellent opportunity for critical reflection and strategic visioning.

Daily, we are entrenched in the work of supporting pediatricians who collaborate within communities to provide medical homes for all children and to assure them access to any other needed health care service. The evaluation process helped us to gain insight into, and a broader perspective of, what the pediatricians in the CATCH Program have accomplished and to identify the areas requiring our attention in the future.

For example, the broad array of community-based child health programs initiated during the period of time when The Robert Wood Johnson Foundation funded the CATCH Program is well-represented in these twelve monographs. From programs for children with special health care needs, to school health initiatives, to support for pregnant women and infants, these monographs speak to us about how individual pediatricians work with their communities on behalf of our most vulnerable population—children.

Looking forward, we are excited to participate in a nation-wide call to action on behalf of children through the CATCH Program's commitment to America's Promise. Our commitment, to train 1000 new pediatricians in the concepts of "local people can solve local problems often using local resources" by the year 2000 will help focus our efforts on operationalizing financial access to health care for all children.

We would like to acknowledge all of those who generously contributed their time, effort, and expertise to make the evaluation process a useful and educational one. We look forward to continuing our relationship with you ever mindful of the vision of the CATCH Program: that every child in every community has a medical home and other needed services to reach optimal health and well-being.

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Acknowledgements

By virtue of the very nature of its focus -- Community Pediatrics -- development of this monograph was a highly collaborative effort. Regrettably for the purposes of publicly recognizing and thanking them, we cannot even precisely count or share the name of every individual who contributed to our work over the past two years to better understand the history, elements, challenges, and accomplishments of Community Access to Child Health -- CATCH. The importance of the contributions of each, however, cannot be understated. Scores of individuals and families committed to improved child health and well-being assisted us in this venture. They patiently juggled physician schedules and made meeting and travel arrangements, took time from their work and family commitments to chat with us for hours on end, welcomed us into their homes, drove us around, fed us (well), and told us their personal and professional stories.

While inadequate to address all the appreciation the scores of collaborators are due, we believe it important to recognize the special efforts of the leaders of the initiatives we visited. In addition to contributions of the sort noted above, these individuals reviewed and provided comments and corrections on several drafts of materials generated and granted us permission to share their experiences with a national audience. To this end, we wish to acknowledge: Maria Gomez, Elida Vargas, and Martha Welman (District of Columbia); Alan Kohrt (Pennsylvania); Dexter Cook, Robert Alexander, and Sandra Cato (South Carolina); Ann Botash (New York); Nancy McLaren and Phyllis Schwartz (Georgia); David Tayloe (North Carolina); Arnold Gold (California); Lance Chilton, Paul Avritt, William Green, Roger Gollub, and Katherine Mariano (New Mexico); Chris Johnson (Texas); Kurt Kooyer and Carolyn Newhof (Mississippi); Karen Toker and Jeffrey Goldhagen (Florida); and Mary Carrasco (Pittsburgh). We long will remain in their debt.

Also vitally important to all aspects of our study of CATCH was our Advisory Committee. Their expertise and their commitment to supporting pediatricians in community child health work -- both individually and collectively -- is reflected in all products of the CATCH Evaluation, including this monograph. We thus extend special thanks to Richard Aronson, Peter Boelens, Adrienne Butler, Anne Dyson, Fernando Guerra, and Thomas Tonniges (Ex Officio).

Thomas Tonniges, Director of AAP's Department of Community Pediatrics, and CATCH staff working within the department -- Carol Pandak, Crystal Milazzo, Sherry Z. Lyons, Charlotte O. Zia, Gail Byck, and Yvonne Bluthart have been partners throughout. Their responsiveness to our many and frequent information requests, their candidness, and their energies were critical to our arriving to this point.

We also benefitted throughout from the talents and energy of several members of a staff team at the Johns Hopkins Women's and Children's Health Policy Center (WCHPC). Jacqueline Tyson and Rebecca Newcomer spent numerous hours making arrangements for our visits and meetings, and generally being our communication lifeline. Kristie Susco prepared this monograph for publication. Pictures were taken by Gillian Silver. Document design reflects the fine work of Ben Allen of the Graphic Arts Department at the Johns Hopkins School of Medicine. The project and this publication could not have happened without them, and we are grateful to them all.

We extend our gratitude to the Robert Wood Johnson Foundation for funding the evaluation, and for the time and attention of our Project Officers, Marjorie Gutman and Rush Russell. Our very special thanks also to Robert Wood Johnson's Ruby Hearn, who has supported and watched over the Healthy Children and CATCH programs for many years and who made possible this evaluation.

Introduction

A major theme of the last 70 years has been the need for pediatricians to promote child health in their communities. Expanded roles for pediatricians focus on advocating child health legislation (Berman, 1998), supporting health promotion activities (Micik, 1985), initiating community-based projects (Wilson-Brewer, 1994), and educating peers and the general public regarding important child health issues. These roles recognize the need for pediatricians to concern themselves with the health of "all children in the community: whether or not they appear for medical care" (Haggerty, 1968). The field of Community Pediatrics also espouses a broader social role for pediatrician who must address a range of issues affecting children including behavioral and mental health, chronic conditions, and social health problems (Hutchins, 1994, Green, 1995). These premises reflect growing support for pediatricians' attention to community health needs and environmental and social influences on children's health.

At its first meeting in 1930, the American Academy of Pediatrics (AAP) identified as a fundamental principle of pediatric practice the involvement of pediatricians in the health of the children in their communities. This interest has persisted with increasing organizational focus on the health of children in underserved communities over the past three decades. Increasing commitment to a larger social role for pediatricians is further evidenced in the evolution and growth of the AAP's Community Access to Child Health (CATCH) Program.

In 1989, the AAP began a three-part initiative to help assure access to health care for all children and pregnant women -- the Access to Care Initiative. While the first two components addressed advocacy for child health insurance and public education regarding the health needs of children, the third recognized the power of the community to address child health problems and focused on supporting and developing pediatric leadership at the community level. Building on the work of Dr. Philip Porter's Healthy Children Program and with support from the Robert Wood Johnson Foundation, the Academy brought this third element of the initiative to fruition through the creation of CATCH.

Located in the AAP Department of Community Pediatrics, CATCH identifies the pediatrician as a "major force" in improving child health at the community level and operates on the theory that local people can solve local problems when given the right mix of training, technical assistance, and community involvement (Guyer et al., 1998). Edward Rushton, MD, the first director of the program, described the essence of CATCH as "pediatricians working with others [to] see that all children have access to care (Guyer et al., 1998).

Specific components of the CATCH Program include: training at national and regional meetings; promotion of community involvement through the identification of pediatrician-led models and dissemination of information on these models; and the provision of planning grant funds to pediatricians interested in working in their communities. In addition, the national program office works with the District and Chapter CATCH Facilitators as well as directly with pediatricians in the community to provide support, encouragement, and technical assistance. The CATCH program also established Visiting Professorships at academic centers to provide leadership experience and promote Community Pediatrics. The CATCH program is now supported entirely with AAP funds, private resources, and individual contributions from AAP members.

This document presents brief synopses of activities -- led by pediatricians -- undertaken to improve child health in twelve communities. They were developed from the case study portion of a comprehensive retrospective study of CATCH, conducted between September 1996 and April 1998. These twelve stories do not represent the totality of all such projects underway nationwide, but do, we believe, present a collage reflecting the rich variety of community child health access initiatives across the country. In "telling the story" of these projects, specific attention is given to providing a portrait of the pediatric leaders, highlighting the context of the local health services and political environments in which the projects are undertaken, outlining the specific components of the initiatives and the scope and characteristics of its collaborators, and identifying accomplishments.

very instructive. Most important, we learned that CATCH was, and continues to be, an effective program strategy for stimulating and enhancing community-based child health initiatives. The premise of CATCH that with information, support, and tools, pediatricians can be agents of change in their communities clearly was confirmed by our program review. The CATCH pediatricians with whom we met and many of their colleagues capitalize on their status in the community as physicians, their expertise, and their many programmatic and political connections to create opportunities to promote expanded and improved health and social services for children and families. Moreover, the specific leadership of these pediatricians is often key in overcoming political and cultural barriers to implement system changes.

Over the course of our evaluation work, we also came to understand that exposure to issues of community child health and direct experience in addressing system-wide problems early on in their education and careers are pivotal in promoting pediatricians' ongoing career commitment and activity in this arena. However, pediatricians who are more established in their practices and communities are most available to provide leadership for community child health activity. It appears that prior to adopting leadership responsibilities there may be a period of "dormancy" when pediatricians need most to attend to clinical practice, and to building linkages and credibility with children's agencies and advocates in the community. Different strategies are indicated for meeting the information and support needs of pediatricians interested in community child health at various stages of their careers.

Relationships with local and/or state public health professionals and agencies can be important to catalyzing and supporting the ongoing involvement of pediatricians in addressing child health problems in the community. Ongoing interaction with and support of peers -- primarily, but not exclusively health profession colleagues -- also is an important element in promoting and maintaining the active involvement of pediatricians in community child health activity.

The staff and leadership of the CATCH Program, over the years, provided competent stewardship and professional expertise contributing significantly to the program's success in expanding and enhancing the active involve-

ment of pediatricians in community child health activities, garnering recognition of Community Pediatrics within the AAP organization, and improving care and services for children. They presently are examining and addressing areas uncovered in this and their own evaluation processes in order to strengthen the Academy's support of Community Pediatrics.

Without the CATCH Program funding from the Robert Wood Johnson Foundation, pediatricians interested in community child health activity would not have the visibility and credibility within the American Academy of Pediatrics that they experience today. The evaluation revealed several ways in which CATCH serves as a vehicle for bringing pediatricians interested in community health into the formal structure and processes of the AAP. Today, the CATCH Program is a major unit within a Department of Community Pediatrics (established in 1995). In addition to participation in CATCH-specific functions, pediatricians interested in community child health are routinely appointed membership in all standing committees of the Academy.

While these narratives on community child health projects were developed as a component of a national evaluation of the CATCH Program, we are sharing this information in this more accessible format in the hope of engaging other pediatricians, community leaders, and families across the country in similar important efforts. The team learned a great deal in conducting the evaluation of CATCH and hopes that, in this sharing, the creativity, energy, and commitment of the many individuals and organizations described in the stories are multiplied in years to come.

For more information about the Community Access to Child Health (CATCH) Program, readers are encouraged to contact the national CATCH Program office:

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Overview of Contextual Characteristics of Initiative Sites

Sites	Start Date	Setting
Making Dreams Possible for Hispanic Teens	1993	Urban, Inner City
Educating Physicians in Their Communities	1991	-----
Partnerships for Children	1993	Rural/Suburban
Community-Oriented Advocacy Training Program	1994-95	Urban/Suburban
School Health/Medical Home Project	1995	Urban/Suburban
Wayne County First Steps Program	1994-95	Rural
Yuba-Sutter School-Based Health Clinics	1991-92	Rural
Helping Indian Children of Albuquerque (HICA)	1993	Urban
Children's Association for Maximum Potential and the Village of Hope Center for Children with Disabilities	1980	Urban
Parent Child Program	1978	Rural
Center for Women and Children	1993	Urban
Positive Parenting Program: Drop-In Center	1984	Urban

Geographic Scope	Target Populations	Focus of Services
Local	Hispanic Adolescents	Teen Pregnancy Prevention, STD Prevention, Primary
Statewide	0-5 Children with Special Health Care Needs	Professional Training in Early Intervention
Local to Statewide	Medicaid Eligible Mothers/Infants to age 2	Case Management Primary Care Home Visiting
Local Projects National Training		Advocacy Training for Pediatric Residents
Local	School Age	School Health
Local	0-5	Child Abuse Prevention
Local	School Age -5-11	Primary Care, Asthma Clinic
Local	Urban Indian Population - Children with Special Health Care Needs and their families	Case Management Self-Advocacy Training for Parents Provider Education
Local Projects National Training	Children with Special Health Care Needs	Camping, Respite, Special Medical Care
Local	Pregnant Women / Infants	Parent Education Home Visiting
Local	Children with Special Health Care Needs & their families	Primary Care Case Management
Local	Low Income Mothers and Children	Child Abuse Prevention Services

Making Dreams Possible for Hispanic Teens Project

Mary's Center for Maternal and Child Care, Inc.

Washington, DC

Maria Gomez, RN, MPH
Executive Director

Elida Vargas, MA
Project Coordinator

Martha Welman, MD, FAAP
Project Pediatrician



by Gillian Silv

Snapshot

The Making Dreams Possible for Hispanic Teens Project (Teen Project) is one of several comprehensive bi-lingual, culturally appropriate programs offered to low-income uninsured women, children, and adolescents at Mary's Center for Maternal and Child Care, Inc. (Mary's Center). Located in the Adams-Morgan section of the District of Columbia (DC), Mary's Center provides prenatal care and pediatric and adolescent services. In addition to providing prenatal and pediatric services to Hispanic teens and their children, the Teen Project offers primary care services to both male and female teens and counseling on family planning, family conflicts, and social and economic problems. The project also provides tutoring, a father mentoring program, and provides teens with community-based services that prevent pregnancy, STDs and other adverse health outcomes.

Setting, People, and Formulative Events

The geographic center of the Adams-Morgan neighborhood is located at 18th Street and Columbia Road in the northwest section of the city. This area, along with the neighboring Mt. Pleasant area, has become "a first stop for (many) immigrants," a permanent and sometimes transient home for immigrating populations--with many health and social needs. The infant and child refugees from the El Salvadoran war years came to Adams-Morgan, sometimes without their parents, and now comprise many of the youth seen in Mary's Center's Teen Project.

The Adams-Morgan neighborhood hosts a series of inter-related and linked community-based programs, personnel, and activities, some of which have a long history in the area.

The Latin American Youth Center (LAYC) was established about 25 years ago, initially to serve individuals from the Dominican Republic and Puerto-Rico with day care for teen parents and education. Central American refugees soon joined the population and services were adapted to meet the differing needs. In the late 1970's, the Goetcheus'--Janelle, a physician, and Allen, a minister--established Christhouse (at Trinity Church) on Columbia

Road in the Adams-Morgan area. Christhouse provided perinatal services in addition to other community services to the homeless and undocumented. Then, in 1981, Family Place was established to provide outreach and community services to the growing Latino population. In the same year, Mary's House, founded by Sharon Murphy, one of the original members of the Committee for Creative Non-Violence in the 1970's, was established to focus on case management, short-term housing, teen education, and interagency cooperation. In the late 1980's Janette Goetcheus identified the need for a community center with a focus on medical services and information on housing and schools. There were no services in the city, for example, which assisted parents in enrolling a child in the school, leading to many 6-8 year old children of immigrants without schooling. In addition, preventive and primary care services were not accessible to many of the immigrants. Ms. Goetcheus wanted to establish such a center and move the prenatal care clinic at Christhouse to the proposed site. When the DC government acknowledged that they were not in a position to create such a center, she joined with Maria Gomez, who had worked in the DC community as a nurse and had just returned from her public health training, to found Mary's Center in 1988. The creation of Mary's Center, with its prenatal care and midwifery services, allowed Christhouse to focus on ambulatory and residential programs for primarily homeless men.

From its inception, Mary's Center has focused on Hispanic teens--their pregnancies, their school-drop-out rate (45%), the lack of support systems, their poverty and abuse, and their isolation. Almost 50% of those presenting for prenatal care were adolescents. The need to address the problems of those under 20 years of age more specifically and differently than those over 20 soon became apparent. The Center received a grant from the federal Office of Adolescent Pregnancy Programs in 1989 to assist with services for the population. Elida Vargas, a psychologist, arrived in the area from the Dominican Republic in 1991. Her interests in teens and Mary's Center's needs coalesced; she joined Mary's Center in 1993 to develop the Teen Project.

Denise Cora-Bramble, MD, FAAP, the current Director of the Community Health Division of George Washington University (GWU), was (and is) a member of Mary's Center's Board and actively involved in developing the Saturday Teen Clinic, a component of the Teen Project which provides primary care services to both male and female adolescents. Dr. Cora-Bramble was a National Health Service Corps pediatrician assigned to DC in the mid-1980s and served in the School Health Division of the Health Department,

splitting her time between Anacostia and Adams-Morgan. She also served as Medical Director of LAYC and received a CATCH Planning Grant to develop a bi-lingual, affordable and accessible health care manual and health education services for Latinos in the District of Columbia. The work supported by the CATCH grant was instrumental in helping Dr. Cora-Bramble develop relationships within the community and collect data on adolescent issues. Dr. Bramble helped to secure the Healthy Tomorrow's funds for Mary's Center and its teen activities.



Components, Activities, and Accomplishments

The goals of the Teen Project are to: 1) develop a system that provides Hispanic adolescents in the community essential bilingual, community-based services that prevent pregnancy, STDs, and other adverse health outcomes; and 2) provide bilingual, comprehensive supportive services to hard-to-reach Hispanic pregnant adolescents and their infants enrolled at Mary's Center. A focus on the prevention of repeated pregnancies and adverse child health outcomes undergirds all project activities.

The Teen Project serves more than 300 low-income, uninsured Hispanic teens. The majority of these teens are recent immigrants from Central and South America ranging in age from 13 to 21. Project staff note their clientele as five "distinct populations"--male and female adolescents seeking primary health care; sexually active female adolescents seeking family planning services; pregnant adolescents needing prenatal care services; infants and children born to teen mothers needing pediatric care; and adolescent mothers needing pregnancy prevention services.

In collaboration with the Latin American Youth Center, the adolescents in the Teen Project receive bilingual, culturally sensitive, family-centered services. The project staff assess each adolescent's needs and enroll them in a variety of appropriate services, including:

- early pre- and post-natal care;
- reproductive health services;
- home visiting;
- STD/HIV screening and counseling;
- primary pediatric care and immunizations;
- intensive case management;
- developmental screening;
- training on child development, stimulation techniques, and the prevention of child abuse and neglect;



- the Peer Educator Program; and
- the Father Mentor Program which trains fathers or fathers-to-be in family related health issues to work with other fathers in the clinic and their community.

Community outreach and education also are provided and focusing on pregnancy prevention, working with schools, churches, and community leadership committees. Teen Project services are provided by dedicated staff, including social workers, case workers, nurses, health educators, home visitors, a nutritionist and child development specialist, physicians, and midwives. All are bilingual and several either come from the community or have recent personal experience with the issues facing the teens in the program.

Project resources include, in order of size (most to least) a five-year federal grant from the Maternal and Child Health Bureau's Healthy Tomorrows Program, a contract with the DC Office on Latino Affairs, funding from the Moriah Fund, the Freddie Mac Foundation, and The Morris and Gwendolyn Cafritz Foundation. In addition, the program receives additional grant monies from a variety of other foundations, the Reading is Fundamental program, and patient fees. GWU funds two pediatric fellows on site for two days a week. Mary's Center and the George Washington University received a grant in 1997 from the National Institutes of Health to participate in research on the importance of families in rearing children. Future funding for the Teen Project is expected to continue to be dependent on a high level of fundraising and project grants.

In addition to working with such community resources as Mary's House, Christhouse, the Latin American Youth Center, and local schools and churches, the Teen Project has a relationship with the public health agency in DC. The DC Department of Health provides funding for the center's pediatrician, participates on the center's Board, and provides monies and/or collaboration with respect to STD, HIV, Substance Abuse, and Tuberculosis services. The DC Office of Latin American Affairs supports the Teen Clinic Patient Coordinator and Health Educator, as well as partial salary support for other personnel. Title X Family Planning funds support the Physician Assistant and Midwife salaries. Mary's Center also works closely with the DC Commission of Mental Health to obtain mental health services for their clients and a representative from the Commission is on the Center's Advisory Board.

Additional members of Mary Center's Advisory Board include representatives from area schools, the Washington Hospital Center, George Washington Hospital, Columbia Road Health Services and DC's Multicultural Services Division. Maria Gomez, the Executive Director of Mary's Center, participates, in turn, on a number of community committees and forums that impact policy in DC, including, among others, the Public Benefits Corporation, Children's Health Coalition, and the Health Policy Council. The public health community, as well as the Center's community partners, describe Mary's Center as a respected and strong voice in community forums.

The Teen Project reports significant impact with respect to most of its goals. The school drop-out rate for participating teens is significantly lower than the average for the area's population in some of the patient categories; many of the adolescents who have dropped out of school have successfully enrolled in alternative programs. The project also boasts a number of health-specific accomplishments: pregnancies were prevented among 94% of the population served; 97% of the babies delivered to participating teens were of normal birthweight, and developmental screening and immunization rates for these children are in the high nineties. A 95% success rate in preventing repeat teen pregnancies was achieved during the first year of project operations, and a 96% rate during the second.

Educating Physicians In Their Communities (EPIC) Program

***Pennsylvania Chapter, American Academy of Pediatrics;
Pennsylvania Departments of Education, Health,
and Public Welfare; and the University of Pittsburgh
School of Medicine***

Alan E Kohrt, MD
Director



by Gillian Silver

Snapshot

Educating Physicians In Their Communities (EPIC) is a continuing education program designed to support pediatricians and other health providers in community settings in the care of young children with chronic illness and developmental delays. Since its inception in 1992, EPIC has become one of the cornerstones of the State of Pennsylvania's commitment to meeting mandates related to early developmental screening and physician involvement in the early intervention component of the Individuals with Disabilities Education Act (IDEA). The program seeks to improve the health care of children by using a train-the-trainers approach to enhancing the skills of community-based primary care providers and other health care personnel in developmental screening, collaborating with families, care coordination, and working within the managed care environment. The program also creates both formal and informal linkages between participating pediatricians and local early intervention program interagency coordinating committees across the state.

Setting, People, and Formulative Events

While the EPIC Program does not focus on generating and supporting child health activities in any one targeted geographic community, the topography of the State of Pennsylvania is pertinent to EPIC's design and implementation. Pennsylvania is a large state: two major metropolitan areas (Philadelphia and Pittsburgh) anchor the east and west ends of the state. The remainder of the state is primarily rural, with large sparsely populated expanses and many pockets of small communities.

Another pertinent characteristic of this state is its commitment to limiting the size and scope of public/government operations. Most public services are provided through contractual arrangements with private sector entities.



Finally, Pennsylvania also is noted for its strong and vigorous organization of pediatricians through the state's chapter of the American Academy of Pediatrics. The Pennsylvania AAP Chapter has been instrumental in creating and maintaining a network of pediatricians, many of whom are very active in community-based child health activities. The Chapter has implemented the nationally-recognized ECEL program (day care provider standards and education), as well as vigorous advocacy related to implementation of the Medicaid EPSDT program and other important child health issues.

This context of extensive networking among pediatricians and government reliance on the private sector to deliver public services provides fertile ground for pediatricians like EPIC Director Alan Kohrt with interests and talents in community health to take on leadership roles in addressing issues of children's access to quality health care. EPIC's conception and evolution stemmed from a confluence of ideas and events in the late 1980s and early 1990s. At the same time that the State's human services agency charged with responsibility for administering the Infants and Toddlers early intervention program under the

IDEA was searching for effective avenues for promoting the participation of pediatricians and family physicians in the program, Alan Kohrt was seeking ideas and avenues for improving community and office-based pediatric services for children in the community where his practice (and family) were located.

Dr. Kohrt's involvement in programs for children with special needs and the statewide early intervention activities intensified in the early years of the decade while he was President of the Pennsylvania AAP Chapter. During that time period, Frank Heron, Public Health Service Region III MCH Program Consultant, encouraged Dr. Kohrt to collaborate with Charlie LaVallee (Pittsburgh) in promoting the Pennsylvania Caring Program for Children, a project designed to expand insurance coverage for low-income children. A partnership was subsequently established through a Healthy Tomorrows project to improve care coordination for children with special health care needs enrolled in the Caring Program. Concurrently, the state's early intervention program was convening a series of meetings to enhance attention to family-centered care and parent participation in early intervention programming. As a participant in those meetings and the Pennsylvania Chapter's 1990 meeting on children with special health care needs, Dr. Kohrt became aware of need to educate local physicians about the concepts of family-centered care and parent participation.

Preliminary planning for EPIC took place in 1991, with informal linkages developed and needs assessment information collected through the Healthy Tomorrows project. In 1992 Dr. Kohrt participated as a fellow in the Children with Special Health Care Needs Continuing Education Institute operated out of Children's Hospital in Columbus, Ohio. Upon Kohrt's return from Institute sessions, he formed a small advisory group charged with the task of developing a format and content for physician training. The Advisory Committee initially was comprised of representatives from the state's Early Intervention Program, the state's AAP Chapter, developmental pediatricians, and general pediatricians in private practice. A broader group which included community pediatricians who were being trained to teach the course and parents was then convened to review program plans. Based on their review, the EPIC training content was "re-oriented" to better address the concerns and practice style of community pediatricians. EPIC was officially launched in 1994 with funding from the Early Intervention Technical Assistance contractor for the Part H early intervention program.

Components, Activities, and Accomplishments

The EPIC Program is designed as a public-private partnership to: 1) develop a cadre of community pediatricians who can present medical education to the health care providers in their communities; 2) provide practicing primary care physicians and other providers with quality, practical education in their own communities; 3) improve the access and quality of health care for children with special health care needs and their families; and to 4) provide primary health care providers for children with linkages to the early childhood and early intervention service providers within their communities.

Training content is organized under three broad topical areas: early intervention services and the community physicians (understanding what works in early intervention, the pediatrician role, improved methods for developmental surveillance); new roles for physicians (collaborating with families, care coordination); and coding, receiving reimbursement for these services, and working with managed care. In addition to general pediatricians and family practitioners on staff at hospitals throughout the state, EPIC is intended to reach hospital nurses, office staff, nurse practitioners, and residency programs.

Beginning in 1994, 24 pediatricians were identified to participate in an intensive training session covering the three core topics, and in contemporary practices promoting adult learning and office based change. Meetings with members of the local early intervention coordinating committees within their designated regions were convened for these Regional Education Coordinators (RECs) to acquaint them with the relevant education, health and human services leadership operating within their respective geographic training areas.

Unique features of the program contributing to its effectiveness include the accessibility of training to improve the attitudes, skills and knowledge of community-based practitioners and their office staff who otherwise would find it difficult to participate in educational sessions of this sort. Continuing medical education credits are offered so that physicians can capitalize on their attendance at EPIC presentations in terms of meeting criteria for state licensure. The strategy of including in the training package information specific to insurance reimbursement and interface with managed care organizations provides EPIC an opportunity to introduce information on developmental assessment and early intervention programming to physicians who otherwise might not participate.

Approximately \$100,000 was budgeted by the Department of Human Resources for implementation of EPIC, supporting materials development, and honoraria and travel costs for the physician trainers. Coordination and communication functions for administration of the statewide program have been performed by Dr. Kohrt, his practice office staff, and the PA AAP Chapter as in-kind contributions. Local Interagency Coordinating Committees contribute to the EPIC program by designating representatives to coordinate and facilitate local EPIC presentations.

Core collaborators in EPIC include the early intervention agency and its contractors, academic pediatricians with an interest in early intervention, faculty of the University of Pittsburgh (as evaluators of EPIC and as the CME credit certifier), family advocate groups, and the state Title V MCH/CSHCN programs. Linkages have more recently been expanded to include also the PA AAP Chapter's Pediatric Office Managers, the state's and CDC Immunization Program, and the state chapter of the American Academy of Family Physicians. Locally, public health nurses, hospital staff, and interagency coordinating councils maintain involvement and support.

In essence, EPIC has been "institutionalized" from the start, as it has been incorporated by the state human services agency as a core activity implementing the IDEA early intervention program mandates. Funds to support EPIC continue to be included in the state agency budget. EPIC is perceived to dovetail with state agency functions and to help meet the needs of pediatricians and families.

As noted above, EPIC's accomplishments include training of 24 Regional Education Coordinator pediatricians to support their leadership activities in early intervention: about 15 of these RECs are reported to maintain active involvement in the program. Over 40 local training sessions were presented during the first three-and-one half years of operation. While precise data collection has been difficult to achieve, those involved in project administration are confident at least 500 pediatricians and other providers received training during this time frame. On a broader scale, EPIC has been used as a replication model for a new project focusing on childhood immunizations. EPIC materials are also being used and disseminated broadly as part of the national AAP's Medical Home project.

Additional evidence of EPIC's accomplishments is found in the reports of the Regional Education Coordinators. One EPIC REC reported that all of the physicians in his "training territory" participated in the sessions. Another reported that she now receives requests for consultation on early intervention-related issues from physicians in nearby communities. A third REC noted that new linkages were established with family practice physicians who previously did not interface with the community's early intervention professionals. Some RECs express concern, however, that because EPIC has already reached a significant proportion of its target audience, and because of pressing issues pediatricians are facing related to major changes in the health care system, that it is time for EPIC to regroup and re-strategize.

South Carolina has an "integrated public health system" with 13 health districts serving 46 counties. All staff are state employees and linked directly to DHEC state offices. This integrated system is described by the department as the mechanism for facilitating the planning and implementation of public health policy statewide, with discussions occurring within and across communities and personnel on the state, district, and local levels.



Partnerships for Children

A Multi-County Public/Private Partnership in South Carolina

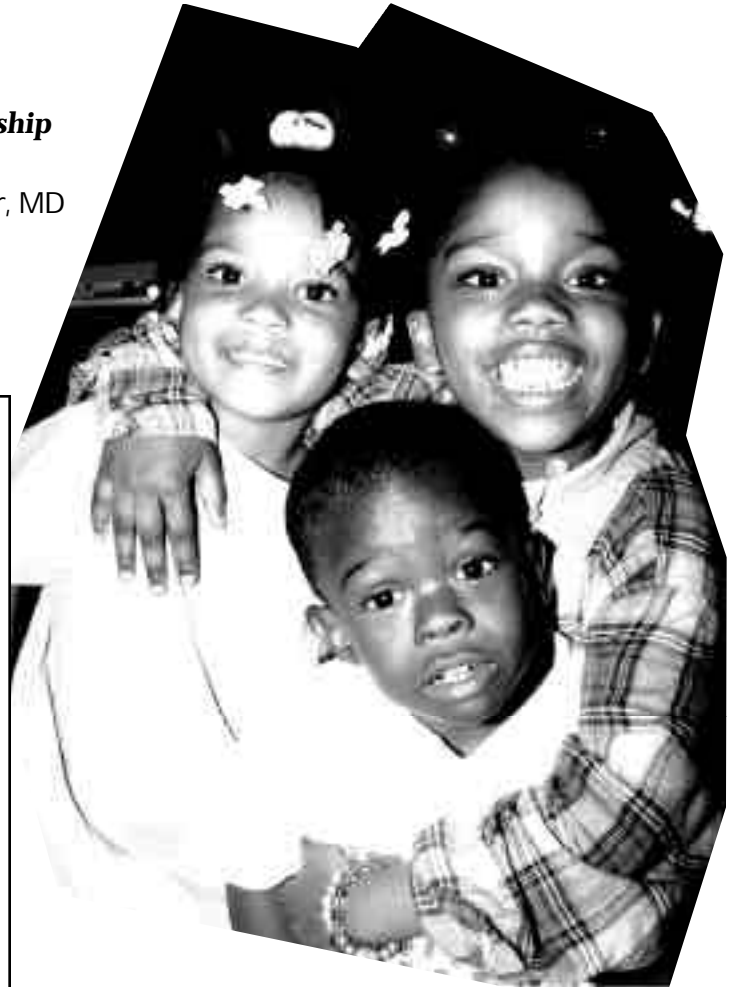
Dexter Cook, MD and Robert Alexander, MD
Pediatricians

Sandra Cato, MD
District Health Officer

Snapshot

Partnerships for Children is a collaborative effort among private practitioners and South Carolina's Department of Health and Environmental Control (DHEC) to decrease mortality and morbidity by improving access to care for children receiving Medicaid. The program is designed to meet the unique needs and resources of each participating community. Although varying by locale, the core principle of the partnership focuses on the use of public health personnel to perform specific functions within the context of private office practice, including, for example, care coordination, in-hospital visits, home visiting, transportation, immunizations, health education, and after-hours call service. The goal is to facilitate and maintain a medical home for children who previously received fragmented care.

The efforts of two participating pediatricians - Dexter Cook, MD, practicing in Lancaster, SC (Lancaster County) and the first pediatrician to join in partnership with DHEC, and Robert Alexander, MD, practicing in neighboring Rock Hill (York County) - are presented here. Since joining the partnership, Dr. Cook has worked actively throughout the state through the State Medical Association (SMA), the CATCH program, and a Robert Wood Johnson Reach Out grant to promote private practitioners' involvement in the effort.



by Gillian Silver

Setting, People, and Formulative Events

More than one in two children in South Carolina are born in poverty. More than half of the infants born are Medicaid eligible and fewer than half see a primary care provider. Acute care is often given in emergency rooms, while EPSDT services are provided in health department clinics. Both York and Lancaster Counties are located in the north central part of South Carolina, approximately 40 to 60 minutes south of Charlotte, North Carolina. Both counties are rural, with a textile-based economy and significant levels of poverty. Rock Hill, with a population of 41,643 (1990), has a slightly higher average income because of its close commuting distance to Charlotte. Lancaster has a population of 54,516 and is a federally designated Health Professional Shortage Area. Infant mortality rates for both counties are higher than the state's rate.

South Carolina has an "integrated public health system" with 13 health districts serving 46 counties. All staff are state employees and linked directly to DHEC state offices. This integrated system is described by the department as the mechanism for facilitating the planning and implementation of public health policy statewide, with discussions occurring within and across communities and personnel on the state, district, and local levels.

In the early 1990's, the SC Chapter of the American Academy of Pediatrics (AAP) explored ways to organize services so more poor children could be seen on a regular basis. They talked to private pediatricians and the health departments in the 13 health districts and determined that "there were better ways for public health and the private community to work together." Representatives of the SCAAP Chapter went to Marie Meglen, CNM, Director of the Bureau of Maternal and Child Health within DHEC, and discussed the possibility of working in partnership. Ms. Meglen developed the concept further and, building on the success of a DHEC-initiated Obstetrical Task Force focused on access to care for pregnant women, convened a Pediatric Task Force in 1992 to address the fragmented care received by children on Medicaid. The task force identified a number of problems, including a limited number of physicians in rural and underserved areas; the inability of overworked physicians to increase their Medicaid case load; the lack of relief from being on "call"; and low Medicaid reimbursement rates and too many Medicaid forms.

In 1993 Ms. Meglen identified a mechanism for funding a partnership "that could assure a medical home for every child in the state." With the assistance of the SC Medical Association and the CATCH leadership in the state, DHEC worked with a select group of pediatricians across the state to discuss how to improve services for underserved children and facilitate medical homes. The pediatricians were asked to work with their respective District Health Officer to design a plan specific to their community's needs and DHEC would provide seed money to support these efforts.

¹ Rushton, Francis. "Innovations in Pediatric Care as Part of Family Support", Report of Proceedings of the Symposium "Effective Pediatric Health Supervision and Family Support in a Changing Environment," January 1996.

Components, Activities, and Accomplishments

Dr. Cook's Partnership (Lancaster County, SC): Dr. Cook and Dr. Cato, the District Health Officer in Lancaster County, devised a plan as they drove home from the 1993 DHEC meeting in Columbus. The plan focused on: 1) responsibility at all levels for tracking all patients back into the practice, 2) the participation of public health nurses in "call" responsibility; 3) intensive "front-end" work by the public health nurse; and 4) the conversion of Dr. Cook's practice into a rural health clinic to become eligible for cost-based reimbursement through Medicaid.

As the only pediatric practice in town, the initial planning decisions were made jointly by the Health Department and Dr. Cook. A protocol was developed and a public health nurse was placed in his office once a week for a one-year period to build relationships and to provide assistance with care and with billing. Dr. Cook and the Health Department worked closely with the local hospital to arrange in-hospital visits and home visits to new mothers on Medicaid, taking care not to compete with the hospital's home health service program. While sharing the goals for the statewide program of reducing infant mortality and service fragmentation by facilitating a medical home for every child on Medicaid, Dr. Cook's specific concerns in serving the children within his community were the high no-show rate of Medicaid patients for their well-child EPSDT visits; the small number of newborns who came in for their first post-natal visit; the financial burden of the low Medicaid reimbursement rate; and the intensity of needs of this population.

Public health nurses now provide care coordination within Dr. Cook's practice, visit Medicaid newborns in the hospital, conduct ongoing home visits, provide immunizations and health and developmental education, provide "call" coverage until 10 o'clock at night for their panel of patients, and provide or arrange transportation and follow-up for office visits. There is an intense "up-front" effort to get these young families off to a good start in terms of their health, parenting education, and knowledge of how and when to access health care for their child. In Dr. Cook's practice, families are followed until the children are one year of age.

The success of the partnership is described by the participants as due to: 1) the inclusion all along the way of the "right" people - health directors, nursing directors, and staff; and 2) support from the highest levels of DHEC and Medicaid. Dr. Cook described the state's health commissioner as a strong child advocate and as instrumental in the project's success.





The Lancaster County community has a history of collaborating on a professional level and with local public health and social service agencies. Dr. Cook himself has a long-standing positive relationship with public health and with Dr. Cato, the District Health Officer. There are a number of coalitions in the community including: a strategic planning committee; a teen pregnancy committee; the Healthy Mothers/Healthy Babies coalition; a Fetal and Infant Mortality Review project; PTAs; and a School Improvement Council.

Community challenges include eliminating the duplication and overlap that exists among agencies, the lack of infrastructure within agencies, and the inability to gain support from school boards for school health clinics. Notwithstanding these challenges, Dr. Cook and the public health nurses report an increase in the numbers served, an improved immunization rate, increase in quality and continuity of care, and improved linkage with other needed services.

Dr. Alexander's Partnership (York County, SC): Dr. Alexander was approached in the Spring of 1995 by Dr. Cook and two representatives from the Lancaster Health District Office and asked to join in partnership with the health department. Dr. Alexander was known by the health department because he assisted them by seeing children on request, was involved in infant mortality reviews, and had articulated his concerns regarding child health issues. By July of that year, a contract was signed between the health department and Dr. Alexander's practice, Rock Hill Pediatric Associates. He and members of the practice reviewed the protocol used by Dr. Cook and amended it to suit their community's needs.

Three public health nurses work with Rock Hill Pediatrics. Home visits are provided for all newborns, with a focus on high risk families. Visits are made once a week for 8 weeks, then once a month or as needed. Nurses are on call until 11 pm each night and each carry a caseload of 65 families. Nurses make sure that families make their appointments, provide education in their home, and help families link with other services such as nutrition, social services, and housing. Families are followed by the public health nurses until the children are one year of age. If a family misses three EPSDT appointments, they are discharged from the practice.

Prior to his involvement in the Partnership, Dr. Alexander's practice experienced a 50-60% no-show rate among Medicaid patients. Dr. Alexander and the public health nurses report significantly fewer no-shows, less calls, prevention of hospitalizations and serious complications; and more mothers comfortable with pediatric care, especially for those leary of the medical system.

The Rock Hill community is described as having a desire to improve child health, but lacking focus for their efforts. In general, the concept of a Medical Home for every child was not traditionally successful in the community among physicians who are not pediatricians. Indigent care is limited by Medicaid issues, as well as by the fact that there are two hospital owned practices which limit indigent care and one large family practice group in town that does not have local hospital privileges. There is a Community Health Center - North Central - which is described as having failed to effectively serve the population because of management.

On the state-wide level, each partnership between public health and a practice is unique, drawing on the needs and characteristics of the community and its providers. Each member of the team providing care to children and families in this project emphasize the unique collaboration between the public and private sector, the quality of care provided, and the professional satisfaction of seeing the positive impact of their efforts. Dr. Cook noted that in a rural area it is very difficult not to serve people in the community; everyone knows everyone else.

This public health-led effort is a strong collaborative between public health and the private sector that draws on historically positive relationships with the community and willingness to solve problems. Prior to this effort only three quarters of children eligible for health care coverage under Medicaid actually received services from any source. Those that were able to access services often received well-child checkups at local health departments and sick care at hospital emergency rooms. The Partnership for Children appears to have eliminated the fragmented care for many of these children. In addition to the initial seed money provided by DHEC, these projects and the state have benefitted from the South Carolina Medical Association's (SCMA) efforts to expand the Partnership for Children model to other private physicians' groups throughout the state. The SCMA recently received a grant from the Robert Wood Johnson Foundation, Reach Out: Physicians' Initiative to Expand Care to Underserved Americans--Dr. Cook is serving as medical director of the project.

Community-Oriented Advocacy Training (COAT) Program

State University of New York Health Sciences Center

Syracuse, New York

Ann S Botash, MD
Director



by Gillian Silver

Snapshot

The Community-Oriented Advocacy Training (COAT) Program, designed and administered in the Department of Pediatrics of the State University of New York (SUNY) Health Sciences Center in Syracuse, represents a CATCH initiative aimed at preparing future pediatricians for their roles as child health leaders in their communities. COAT is based in an academic setting, but reaches beyond the graduate medical training institution to community organizations in order to provide practical experiences in population health problem-solving and community action for physicians in the Pediatric Residency Program. The program seeks to instill values and build skills early on in the careers of pediatricians towards the ultimate goal of promoting life-long community commitment and involvement. COAT seeks to use the special status given physicians by society to improve child health protections and services at the community level.

Setting, People, and Formulative Events

The city of Syracuse and the surrounding Onondaga County community of approximately 656,000 residents provides fertile ground for this program which provides the basic tools, skills and experience in child health advocacy and community program development. This area boasts a long tradition of collaboration among a cadre of committed and talented pediatricians based both in community practice settings and in academia. The Onondaga County community is characterized as a "caring population." The largest employers in the area are the SUNY Hospital, Syracuse University, and Carrier, Inc. Clearly these institutions draw talent to the area, which translates to many community contributions.

Among those physicians noted as having over the years provided leadership and vision for medical sector involvement in community health problems are Julius Richmond, Frank Oski, and Howard Weinberger. Currently, the local health agency is headed by Dr. Lloyd Novick, who has held national and state positions of public health leadership. The Commissioner of the county's Department of Youth and Aging also is reported as a staunch advocate and skilled mobilizer. The professional paths of the COAT project leaders -- Ann Botash, Steven Blatt, Roger Spitzer, and Howard Weinberger -- are similarly representative of this characteristic of the Onondaga community. All four of these physicians have long track records of involvement in the community's health. COAT Program Director, Ann Botash, has developed her pediatric career in the field of child



abuse, and is a member of several regional and statewide task forces and commissions. Similarly, Dr. Blatt is a regional leader in the area of foster care; Dr. Sptizer established and maintains a free primary care clinic in one of the city's housing developments. Finally, Dr. Weinberger is known regionally for his work in lead poisoning prevention.

Community-based coalition initiatives of recent years focused on concerns such as bicycle safety, enhanced services for children in foster care, childhood immunizations, prevention of deaths from SIDS, and teenage pregnancy prevention, among others. The Onondaga community hosts a Success by Six partnership of community businesses and community agencies, led by the United Way. While COAT is not designed to target any predetermined community child health issues, in the past two years it has successfully spawned community activities related to gun safety, parental smoking and asthma, and school-based programming in violence prevention.

The COAT Program evolved from the interest of SUNY Health Science Center pediatric faculty Botash, Blatt, Spitzer, Weinberger in building an advocacy training component into the Residency Program. In 1993 Drs. Botash and Blatt recommended to the faculty that a one month rotation in advocacy be established as a program requirement. This initial proposal, which would have entailed participation of all faculty, was not agreed on due to both logistical and philosophical concerns. Advocacy experiences therefore began to be offered as an elective. A few residents opted to take the advocacy elective. Faculty and residents soon learned, however, that a one-month time frame was inadequate for learning and practicing the skills necessary for effective advocacy.

In 1995 Dr. Thomas DeWitt came to the SUNY HSC as a CATCH Visiting Professor. His visit focused on the theory and tools of Community-Oriented Primary Care (COPC). A number of activities eventually emerged from this event. During DeWitt's visit Drs. Botash and Blatt brainstormed with him about the "advocacy training issue." DeWitt helped them conceptualize a structure for an advocacy training component whereby the four faculty most interested in this topic would serve as the mentors for groups of residents. Under the new plan, each group would work on a single advocacy issue or project throughout the three training years.

Shortly after DeWitt's visit, a CATCH mailing that included Planning Grant application materials arrived on Dr. Botash's desk. She saw this as a "perfect opportunity" to get the program off the ground, and the revised approach was outlined in

the CATCH grant proposal. Being aware that the American Board of Pediatrics' Residency Review Committee was looking towards revising the Residency Program certification requirements to include an advocacy component, the COAT Program therefore began in the summer of 1995, now with the support of the departmental faculty. The peer review/national recognition aspects of the CATCH grant was very important in gaining credibility/legitimacy especially with the Pediatrics Department faculty who were initially skeptical. The year following initiation of COAT, the national adoption of new residency program certification requirements for advocacy training solidified the department's commitment to COAT.

Components, Activities, and Accomplishments

COAT seeks to achieve goals with both national and local impact: 1) to provide a community-based experience in child advocacy for pediatric residents; 2) to develop an advocacy curriculum using a framework of existing advocacy interests of members of the Pediatric Department; and 3) to develop new advocacy programs and new coalitions within the community.

While many physicians training at SUNY continue to reside and begin to practice their profession in the Syracuse area, many move on. Thus, COAT holds potential for building community advocacy and leadership among the cadre of pediatricians nationally. Through interactive workshops dealing with real community problems, current programs and solutions, residents develop and practice advocacy skills. Skills development objectives include learning the role of the pediatrician as advocate, and learning to work in teams to assess needs, set priorities and create meaningful community programs for children.

Each summer in the first week of their residency program new residents begin participating in workshops instructed by SUNY faculty and community leaders, including the Commissioner of Health. The residents are introduced to the GNOME (Goals, Needs, Objectives, Methods, Evaluation) framework for needs assessment and program development, ongoing child-focused initiatives in the community, the range of opportunities for pediatric advocacy, and the characteristics of the Onondaga community related to child health, development, and social environments. Residents are assigned to groups with faculty pediatrician mentors. These groups of between 4 and 6 residents work together over the three years of residency to create, implement, and evaluate their unique projects. In this way, COAT provides

a unifying experience for the residents, and orients them to the challenges and rewards of community advocacy. A COAT Program Advisory Committee comprised of community pediatricians, the county Department of Youth and Aging, the local health department, United Way's Success-by-Six partnership, the Chair of Pediatric Department, and several departmental faculty provides guidance and support to the work of the residents.

The resources supporting the COAT Program come through a number of channels. The 1995 CATCH Planning Grant funds were used to support a half-time program assistant who coordinated the workshops, curriculum materials development and activities of the residents, and assisted the trainees with their needs assessments and communications with community organizations. The Pediatrics Department contributes the salary support for the faculty mentors and residents in this work (approximately \$200,000), and since 1996 has budgeted approximately \$5,000 for supplies and other COAT Program expenses. Without the support for the program assistant, Dr. Botash and her secretary perform all of the coordinating tasks. Funds also were donated for basic support of the program in 1996 and 1997 by the Badge-State Civic Foundation. The gun safety advocacy project has in itself generated approximately \$35,000 in support from the community, including \$10,000 from the SUNY hospital.

COAT's linkages with the community are many, stemming in large part from the child health activism of the program's creators. While each of these faculty and several other COAT faculty mentors have additional individual links with community leaders and activities, the structured program of community advocacy activities provides an organized framework for advocacy linkages between the SUNY hospital and the community. Since each resident group develops a unique project, additional linkages with community-based organizations are established.

The most proud example of the potential of COAT to date is the public awareness campaign developed on the prevention of injuries from handguns. This project began in 1995 with the first-year class of residents, and a multi-faceted public awareness campaign was launched in late summer of 1997. Project components include creation of a coalition, development of educational messages and materials (public service announcements for television and radio, links to a toll-free telephone line, posters and buttons), and in-person presentations of the prevention materials to pediatricians in community practice. Other of the residents' projects include a school-based adolescent support program against violence, a needs assessment examining accident due to

falls from windows, smoking prevention education through development of a school-based curriculum, and an educational program (in collaboration with the Onondaga County Child Care Council) for daycare workers on child nutrition. By virtue of having the trainees develop each project in concert with the community, duplication or overlap of efforts are circumvented. The COAT projects by design thus serve to enhance the ongoing child health efforts of local agencies and organizations.

Overall, COAT's accomplishments include the increased knowledge and skills of the 34 residents involved to date, and development of 5 new local projects related to community child health. Since the initial year of program implementation, several additional faculty began in COAT mentoring roles. In this way COAT (and CATCH) has promoted community orientation among those who might otherwise not participate. Dr. Botash and colleagues continue to refine the advocacy training curriculum, which has been shared with other residency training programs across the country. The COAT Program also has been instrumental in developing a national network of pediatricians interested in advocacy. A Special Interest Group on pediatric advocacy was established in the Ambulatory Pediatrics Association as a result of the workshops presented by COAT residents and mentors in 1996 and 1997.

By building COAT into the Residency Training Program requirements at SUNY, institutionalization was essentially guaranteed from the start. Continued commitment to projects developed by COAT residents who are now in their third year is a problem currently under discussion by the COAT advisory board, mentors and residents. In the specific case of the gun safety/lock campaign, the hospital's Department of Public and Media Relations has pledged to continue their contributions of staff time for getting the awareness and education materials out to the public. Hospital staff also are currently discussing with a manufacturer of gun locks the possibility of making locks available at reduced cost for the community.



School Health/Medical Home Project

City Schools of Decatur

Decatur, Georgia

Nancy McLaren, MD, FAAP

Phyllis Schwartz, MN, MA

Snapshot

In Decatur, Georgia, Dr. Nancy McLaren is leading a CATCH initiative to rebuild the school system's capacity to assure comprehensive health services for enrolled children and adolescents. Begun in 1995, this effort aims to address capacity issues that developed when funds supporting nurse positions were withdrawn from the city school system as a result of re-orientation of school health programming by the DeKalb County Board of Health. The project established an advisory board and undertook a school-specific needs assessment to inform and guide development of a model and plan for implementing school health services which would complement managed care health services delivery strategies. Project participants envision school health services that emphasize linkage between schools and primary care providers, and that provide education and support to families in accessing the full range of health and social services they may need. Also important to this vision is the capacity of the Decatur schools to track and monitor students' health needs and services.



by Gillian Silver

Decatur is described as a magnet area for many families wishing to reside in the region, in particular due to its community spirit as well as the quality of the educational services offered in its public school system. The relatively small size of the municipality's population engenders a "neighborhood feeling," and the pride of Decatur's citizens in their schools prompts significant attention to child-related issues and activities.

With specific regard to health services, Decatur is described as "rich" in medical expertise and capacity. Emory University School of Medicine and its affiliated hospitals and clinics, DeKalb Medical Center, Rainbow Children's Medical Center of Egleston Children's Hospital, and several other medical facilities ensure a provider capacity adequate for the population. Public health leadership and expertise is also nearby, given the state public health agency location in Atlanta, as well as that of the national headquarters of the Centers for Disease Control and Prevention of the U.S. Public Health Service. Decatur's business community boasts a number of active partnerships with the schools. There is a long tradition of community engagement with many successful collaborations among public agencies and between public agencies and the private sector. Community pediatrics has been a long time component of a portion of the private practice community.

Setting, People, and Formulative Events

The City of Decatur, Georgia, borders the City of Atlanta, and sits within DeKalb County. Approximately 17,000 individuals reside in this mixed urban-suburban community. The demographic characteristics of Decatur's population mirror the profile of Atlanta's residents. The City of Decatur elects its own city commissioners, who in turn select a mayor, and levies property taxes to support its school system. Health and social services, however, are provided under the auspices of the DeKalb County government.

For a number of years, the DeKalb Board of Health was the recipient of a sizable annual grant from the State Title V Maternal and Child Health program which supported school health services in Decatur. This grant was awarded through a transfer of funds from the State to the DeKalb County Board of Health. Under the grant, the DeKalb County Board of Health employed school nurses and provided physician consultation. Other services provided by the Board of Health were vision and hearing screening, pregnancy testing and scoliosis screening. In the mid-1990s, however, the DeKalb County public health agency determined that these resources were too narrowly targeted (Decatur and a cluster of schools in DeKalb County were the two major recipients), and that funds would more efficiently enhance school health services region-wide if they were disbursed more broadly to support needs assessment and school-based planning for school health promotion and prevention activities in a greater number of schools. As a result, the DeKalb County Board of Health discontinued physician consultation and some screening services. In 1997, one registered nurse and two nurse aides served the student body of 2,800 children and adolescents in the Decatur school system.

Concurrently, the Georgia Department of Human Resources (GDHR) began implementation of a managed care program and an assigned primary care physician (PCP) for Medicaid beneficiaries. The resultant disruption of health service patterns for families soon began to generate concerns among school personnel (and others) that children had become disassociated with their chosen medical provider and were not utilizing their newly assigned providers. This concern was evident even though part of the planning included an agreement between the State Chapter of the American Academy of Pediatrics and the GDHR to base the plan on enhancing the concept of the "Medical Home." As health concerns would surface in the school setting, school personnel found themselves without both nurse and physician expertise and support.

Dr. Nancy McLaren's awareness of this situation was heightened as she worked in a school based clinic in another part of the metropolitan area, and as she began receiving calls for information and assistance from her own child's school. A community event brought Dr. McLaren and Ms. Phyllis Schwartz -- Director of Human Services for the City Schools of Decatur -- together. A brief communication transpiring at the event subsequently led to a shared commitment to address the problem of inadequate school health services. As their ideas took shape, it was determined that a CATCH Project might get them started.

Together, Dr. McLaren and Ms. Schwartz organized a planning process which brought together school personnel, community physicians and other health care providers, and parents to deliberate an overall approach to the issue of school health. They developed a CATCH grant application for planning funds and also secured resources and technical support from Egleston Children's Hospital and Morehouse School of Medicine. The resultant project proposal included a needs assessment, funding for several school health nurses to maintain data who would be responsible for maintaining health-related data on the student population and linking students with primary care providers (medical home), and providing "wrap-around" support and health care consumer education services for families enrolled in managed care organizations.

Components, Activities, and Accomplishments

The overarching goal of this initiative is to develop and promote partnerships to ensure that students in the City Schools of Decatur are healthy and ready to learn. More specifically, the project seeks to ensure that students are linked to a medical home in their community and to ensure that all children in the schools are able to access their primary care providers to receive preventive health care. The project further seeks to create an infrastructure whereby the CDC Comprehensive School Health Services model can be implemented, and all schools in the system create safe environments, provide health education, and support education staff in caring for children with specific health problems. While all students in the system would benefit from these services, of priority concern are those children and youth in low income families.

MPH students from Emory University on assignment to the Egleston Child Advocacy Center completed an assessment identifying the numbers of students in each Decatur school without a medical home. With resources from Morehouse School of Medicine, focus groups also were conducted with personnel and parents to identify perceived school-health related needs (measured against the CDC model). The Advisory Board crafted a plan that entailed securing additional nursing staff who would produce information in a computer database; provide liaison with the child's private physician (Medical Home) and the parent(s); and, do health teaching. Emphasis is placed on "linkage and family education" roles for school nurses. The initial plan is to start small -- one Pediatric Nurse Practitioner, a health educator, and one clerk -- to coordinate and provide





services for the seven elementary schools, and the Middle and High Schools. If the project in Decatur were to move forward as planned, it would provide a complementary service of linking school personnel with children's medical providers, and would provide the support and education some families need in order to utilize the health and social services system well. Medical training would be more readily available for school personnel -- a high priority for the special education program.

This project boasts many linkages, and potential for shared responsibility within the community for building the health component of services available in the school setting. Members of the initial Advisory Committee for the project included representatives of: the DeKalb County Board of Health and the DeKalb Community Service Board; Grady Health Center; Emory University School of Public Health; Georgia Caring Program for Children; Morehouse School of Medicine; Oakhurst Community Health Center; Rainbow Children's Medical Group; the State Department of Education; the City Schools of Decatur; several pediatricians practicing in the Decatur community; and parents and school personnel from the various schools.

The DeKalb County Board of Health participates on the project advisory board, and many meetings/discussions have taken place with health department personnel on an individual basis to enhance their support. The Superintendent of Schools in Decatur and the Health Commissioner in DeKalb County meet monthly. However, the current Superintendent has only been in Decatur (or even in Georgia) for a few months, and professional relationships have not yet had time to mature. Linkages and partnerships extend well beyond the public agencies. Scottish Rite Hospital, Decatur Hospital, and Georgia Baptist College of Nursing have stepped in to address the gap in screening services created by the DeKalb County Board of Health's discontinuation of these services. Area school system professionals collaborated with the Community Service Board to place mental health counselors in some schools during the school day. The Decatur Board of Education funds social workers in the schools. To ensure adequate connections among the metro services available to children and their families, a school system Networking Committee comprised of representatives of 45 agencies meets three times during each school year to share information on available resources. This group also produces a directory and pursues joint projects (e.g., mental

health, as well as juvenile justice). With specific regard to school health, the efforts of the Networking Committee are complemented by the work of a newly formed Systemwide Health Committee which includes representatives from each of the Decatur schools and the DeKalb Board of Health.

Achievements in Decatur through 1997 included formation of Advisory Board, completion of needs assessment, maintenance of a core working group committed to seeing the project through to implementation. Facilitating factors were expressed as very good collaboration among agencies in the city, much school system support, support from the major universities and medical centers, and an experienced community action administrator -- Phyllis Schwartz.

The Decatur plan was initially presented to the DeKalb County Board of Health in the hopes of re-instituting grant support, however, the proposal was not considered by the health agency administration to be consistent with their school health funding priorities. Dr. McLaren and a core group "shopped the proposal around" and continued seeking funding resources for implementation of the plan. In January, 1998 the DeKalb Medical Center's Foundation unanimously approved the addition of the School Health Project to their fund raising goal. They have committed to raise \$500,000 to fund a 3-year program representing a partnership between DeKalb Medical Center and the City Schools of Decatur. It is hoped that funding for year one will be available for the 1998-99 school year.

Wayne County First Steps Program

Wayne Action Group for Economic Solvency, Inc. (WAGES)

Goldsboro, North Carolina

David T. Tayloe, MD



by Gillian Silver

Setting, People, and Formulative Events

Wayne County is located about 50 miles east of Raleigh, NC. The county has 105,000 residents, with 40,000 living in its county seat, the City of Goldsboro. Wayne is primarily a rural county, with no major industry to speak of. There is an Air Force base, which has some influence on the community. Economic development initiatives are in the planning phase. The population is described as "fairly conservative," though clearly amenable to addressing a range of children's issues.

Snapshot

The Wayne County First Steps Program is a child abuse and neglect prevention initiative aimed at providing support and education to families determined to be at risk for parenting dysfunction. Administered under the auspices of WAGES, the community action agency in Wayne County, North Carolina, First Steps grew out of the concerns and interests of pediatrician Dr. David Tayloe, who, over the years, continued to encounter many vulnerable but well-intentioned families of infants and young children. Inspired by information about the successes of the Hawaii Healthy Start Program and bolstered by the support of a cadre of committed professionals in the community, Dr. Tayloe drew upon his leadership roles in the county and the state to fashion an interdisciplinary intervention that engages both the public and private sectors in this effort to reverse the trend of increasing incidence of child abuse and neglect in the county.

Data for 1994 showed that 2,032 children had been reported abused or neglected in the county. Wayne County's 1993 reported child abuse rate was 102.8 per 1000 children under the age of 18 years; this figure is 43.4 per 1000 higher than the state average for reported cases of child abuse. The Wayne County Department of Social Services was unable to meet the needs of all the abused and neglected children in the county.

The Wayne County First Steps Program evolved out of Dr. Tayloe's concern about the stresses families face in the contemporary culture, and the resultant need to ensure stable family life in the community. In 1991, Dr. David Tayloe attended a CATCH session at the annual AAP meeting because the session was one of the few that was being offered without charge. As he recounts the story, as North Carolina chapter chairman he had so many meeting obligations



during the annual meeting that he had not bothered to pre-register for any of the other sessions. The CATCH session that he thus attended, serendipitously, featured Cal Sia, Richard Krugman, and David Olds and discussed the Hawaii Healthy Start Program for the prevention of child abuse. This session provided Dr. Tayloe the kernel of the idea that became the First Steps Program.

Of course, no effort originates from only one source. The Hawaii Healthy Start concept gave David Tayloe the organizing model for a program that had a substantial period of development, involving a group of committed health and social services officials, local agency professionals, and child advocates in Wayne County, North Carolina. The group had long been concerned with the problem of child abuse in this rural part of the state. They had become frustrated with the fact that, despite all of their efforts, child abuse was not declining. The group was ready for a prevention strategy that might reduce the risks of child abuse and neglect among high risk families.

Of additional note in this regard, Wayne County Action Group for Economic Solvency, Inc. (WAGES) is the parent agency for First Steps. WAGES is a community action agency dating back to the civil rights movement. WAGES director, Mr. Bryan Sutton, has been with the agency over that entire time. WAGES has employed most of the child services professionals who came together to plan the child abuse prevention effort. Many of them now work in the County agencies that are responsible for children. It appears that WAGES has been a training ground for community activism.

Components, Activities, and Accomplishments

The mission of the First Steps Program is to significantly decrease the incidence of child abuse and neglect in Wayne County before it starts by using a carefully prescribed prevention program that systematically identifies high risk families of newborns and provides them with community-based family support services and education in parenting skills and child development through intensive long-term in-home visitation. The program is a part of the Healthy Families America initiative. The Wayne County First Steps Program goals are to: 1) systematically assess the strengths and needs of families with newborns in Wayne County; 2) promote positive parent/child interaction; 3) enhance family functioning by developing problem-solving skills, developing trusting relations, and improving

family support systems; and to 4) promote healthy child development.

Anticipated outcomes of the First Steps intervention include reduced incidence of child abuse and neglect, increased immunization rates, early prenatal care in subsequent pregnancies, stronger family systems, and early detection and remediation of developmental delays resulting in improved school readiness.

Screening (through medical records review and structured family interviews) takes place in the maternity unit of Wayne Memorial Hospital -- the only delivery unit in the county. Families are offered services based on a risk assessment done in the hospital. First Steps is currently serving about 90 families with home visiting services. The program reports a "waiting list" of families they are unable to provide home visiting for due to staffing vacancies (2 additional family support workers). The First Steps leadership hopes to ultimately be able to train and employ as family support workers parents who live in the target communities.

All families are offered a pamphlet containing information for parents concerning parenting skills, characteristics of families that need professional help, the names and phone numbers of local organizations that provide parenting education and support services. Dr. Tayloe and his colleagues authored this pamphlet, "Healthy Parents/Healthy Families -- Wayne County Can Afford Nothing Less." Development of this brochure, which preceded inception of the First Steps Program, was a collaborative effort of the consortium: Wayne Memorial Hospital and Goldsboro Pediatrics, P.A., provided funds for its production. All participating agencies and providers continue to disseminate it.

The program is staffed with a project coordinator, a family assessment team leader, and (currently) two family support workers. Staff have participated in training provided by the National Center on Child Abuse and Neglect's (NCCAN) Healthy Families America project. Materials for parenting education component of the program also are purchased from NCCAN for staff use.

The First Steps Program draws on several sponsors for budgetary support, which approximated \$ 292,000 in 1997. The three primary funders since 1996 have been the North Carolina Department of Health & Human Resources (36% from the state's Family Preservation Program); the United Way of Wayne County (9%); and the Duke Endowment (55%). WAGES also contributes to the support of program operations by donation of space and staff support.

The Wayne County First Steps Program (WCFS) receives ongoing guidance and support from the WCFS Consortium, which includes the Department of Social Services, the Wayne County Health Department, Wayne Uplift Resource Association, Wayne County Public Schools, Wayne Community College, Wayne Memorial Hospital, the Mental Health Association of Wayne County, the United Way, and Goldsboro Pediatrics. Each agency participating in the Consortium serves as a referral and services resource, including Goldsboro Pediatrics, which establishes a medical home for each participating family. All reported support for the First Steps effort. The Consortium is transitioning to become a formal Advisory Board, and is planning to engage in strategic planning for long-term outcomes monitoring, and sustainability of the program/funding.

Because the focus of First Steps is on prevention, and as the other home visiting-type services available to county residents are quite limited, those interviewed consider that there is no real overlap of services. The First Steps Program is also seen as a logical complementary aspect of the Early Head Start initiatives now developing in Wayne County. Project Director, Charisse Johnson, however, acknowledges that they must be careful to monitor the potential for duplication of home visiting.

Collaboration on behalf of children in Wayne County appears to be a longstanding tradition. The agency professionals involved with the First Steps Consortium describe themselves as "just learning to work together." It appears, however, that they have a long and deep set of connections. The members of the WCFS Consortium are all mid-level professionals in their organizations, and seem to have the confidence of their superiors to represent the agencies in these collaborative activities. The fact that a number of them worked at one time or another for WAGES may in fact contribute to the cohesion and strength of their efforts. In short, the Wayne County environment seems to be one in which things can get done. This may be the rural/small town nature of the setting where competition among agencies is uncommon. At least one person, however, felt that Wayne County was more progressive and more effective than some of the surrounding counties, who share problems but do not have the same array of programmatic solutions.

Achievements in the project's first year included the development of the program infrastructure, screening of more than 90% of all families in the county with newborns in 1997, and ongoing service provision to approximately 90 families, with a list of families wanting and waiting for services. While highly pleased with these accomplishments, those involved with operating and guiding First Steps are concerned about the need to expand the resource base, and about the long-term sustainability of program resources. At this point, they are primarily looking to foundations for additional support. Ultimately, however, they would like to see First Steps services become part of the Department of Human Resources' core child protection budget.



Yuba-Sutter School-Based Health Clinics

Sutter Health Foundation

Marysville, California

Arnold Gold, MD, FAAP
Pediatric Leader

Snapshot

In Yuba and Sutter Counties in Northern California at the beginning of the 1990s, Dr. Arnold Gold, of Sutter North Medical Group, realized that many local school children had limited or no access to medical care. A significant number of children lacked health care insurance or the funds to obtain needed care. Cultural barriers prevented families from seeking needed help or identifying assistance available to them. In 1992, inspired by the national CATCH program and in partnership with health care professionals, county school districts, health departments, and child protective services, Dr. Gold established school-based health clinics in two elementary schools. These clinics were to provide health services for the children of unemployed and working-poor families in the community. By 1997, the program involved eight schools at six different locations, reaching over 3,000 children each year throughout Yuba and Sutter Counties.



by Gillian Silver

Setting, People, and Formulative Events

Thirty five miles north of Sacramento, separated by the Feather river, are the twin cities of Marysville and Yuba City. These cities are located in a mixed light industry and agriculture valley called the "California Peach Bowl" -- the home of a large number of peach tree orchards and Beale Air Force Base. Yuba County, the site of Marysville (population - 12,706), is one of the 768 counties in the U.S. classified as severely medically underserved. Yuba City (population - 30,303) is in Sutter County. Sutter County, with 36.8% of its population medically underserved, is not classified as underserved due to its concentration of health providers. Founded during the Gold Rush of 1849, the two cities grew with refugees from the Dust Bowl of the mid-30s.

Although the two cities are predominantly white (70%), in recent years they have become more diverse in ethnicity and culture. Among the latest settlers are the Hmongs, African-Americans, Hispanics, and East Indians. The area has a weak economic base and has consistently had one of the highest unemployment rates (around 20%) in the state of California. Many families share common problems in obtaining health care for their children. Many are the cities' working poor -- uninsured and earning too much to qualify for Medi-Cal, but not enough to afford a private physician.

Just over 51% of babies born in Sutter and Yuba Counties are born to parents who can't afford health care. A needs assessment in 1990-92 revealed that almost one-third of all children under 18 years of age in Yuba County and one-fourth of all children in Sutter County lived in poverty. Only 62.6% of women in Sutter County and 57.9% in Yuba County received prenatal care in the first trimester. The rate of child abuse in Yuba County (220.4/1,000) was triple the California rate and over five times the national rate, while the rate in Sutter County (91/1,000) was double the national rate and slightly higher than the state's.



A community leader needs assessment in 1994, listed the following concerns in priority order: 1) education including parenting; 2) access to healthcare; 3) employment and substance abuse; 4) leadership/vision for the future; and 5) affordable dental services.

Before the onset of the project there were few pediatricians and all had reached their limit as to the number of Medi-Cal patients they were willing to accept. Although public health clinics were available, transportation to the clinics was a problem and, once at the clinic, the wait to see a physician was long. As a result, many poor families went without medical care or waited until illness was advanced before seeking care, usually at the emergency room. The delivery of care was ineffective and costly. For many families in Marysville and Yuba City, options were limited. The problem was access to care.

In 1938, four physicians combined their private practices to form a multi-specialty medical group -- The Marysville Medical Clinic, which later became the Marysville Medical Group. When he completed his two years of Air Force duty in 1972, pediatrician Arnold L. Gold joined the group. The Yuba Feather Medical Group, formed in 1974 in Brownsville, expanded and established a branch in Yuba City. In response to the rapidly changing healthcare industry, the Marysville Medical Group and Yuba Feather Medical Group physicians formed a new professional corporation in 1993, the Sutter North Medical Group. The new practice contracted their services to the newly formed, not-for-profit medical foundation, Sutter North Medical Foundation. Sutter North Medical Foundation is affiliated with Sutter Health, one of California's largest integrated healthcare systems. Sutter Health has a medical presence in more than 40 Northern California communities, from Crescent City near the Oregon border to the San Joaquin Valley.

In 1991, because of a high "misery index," the school districts, in collaboration with the social service agencies, began working together around a family learning focus. Technical assistance was sought from and provided by the San Diego school district and a coordinated services program was established that year. Dr. Gold had a vision at the same time of what needed to be done to improve access.

Dr. Arnold Gold read in the 1991 American Academy of Pediatrics (AAP) newsletter about the Community Access to Child Health (CATCH) program and initiated a dialogue with F. Edwards Rushton, MD, the Director of the national program. Dr. Gold, a long time resident and pediatric practitioner in the community, was aware of both the problems of access to health care for most of the poor children in the community and the changes about to occur in the school districts. He formed a

community coalition of the School Districts, Health Departments, interested organizations, and local residents to assist in planning and implementing an approach to the access problems. As a result, school-based health clinics began in October, 1992, in two elementary schools: Cedar Lane in Yuba County; and April Lane in Sutter County. During the planning period, before the school clinics opened, Dr. Gold worked with the coalitions and entities in the community to obtain resources. His knowledge of the community and its residents helped this process. A CATCH planning grant to design an expansion of school clinics was awarded in 1994. Acknowledging the necessity of a needs assessment, he said: "My initial approach was all wrong, I was looking for money and funding support first, and that's not how you do it. You need to go out in the community and see what's needed and then find the necessary resources."

Components, Activities, and Accomplishments

When established, the goal of the school clinics program was, and continues to be, excellent health, academic success, increased parental involvement, and positive interpersonal relationships for all students. This goal is being accomplished by providing access to quality health care, continuity of services, and open communication with parents. The following objectives were identified in 1997: 1) At least 500 children 11 years and younger will be screened between February 1, 1998 and January 31, 1999 at three targeted schools to determine which children will require further education in asthma treatment; 2) At least 1,000 children 11 years and younger will be screened between February 1, 1998 and January 31, 1999 at two targeted schools to determine which children will require dental sealants and/or topical fluoride treatments; and, 3) Extend hours of operation at all clinic sites beginning February 1, 1998 resulting in a goal of 4 hours per site per week by January 31, 1999.

The target population of the program is the elementary school (Grades K-5) population of students of working poor families in targeted communities in the two cities of Marysville and Yuba City. The school boards were initially concerned that a comprehensive program would involve the promotion of condoms and other family planning materials and philosophy. To address these concerns, the decision was made to focus on a more narrow set of services for younger children. Children 11 years and younger are treated for acute illnesses at the school. Younger siblings of the students can also be seen. Parents are required to accompany their children to all clinic visits.



The clinics have been flexible in their operation. The school-based clinics originally were open two hours a day (8-10:00 am), once a week for eleven months of the year. It was found that for the best attendance, they needed to start earlier in the morning. In addition, twilight hours--4:00-6:00 pm--are a success in Marysville. Approximately 57% of the children who come to these clinics are uninsured and another 41% are Medi-Cal eligible. The clinics provide without charge: early intervention, acute and chronic care, health education and detection of child neglect. Medications and immunizations are provided at no cost if the parents are unable to afford them.

Turning to his professional colleagues for support, 14 physicians (family practitioners or pediatricians and both county Health Officers) volunteer their time and services to help staff the clinics. Surgeons see patients without charge and "state tobacco funds" were secured to pay for surgery for uninsured immigrant children. As donations to this community effort, the Sutter North Medical Foundation allows Dr. Gold to spend one day/week of his salaried full-time position in the community, and provides salary support for a clinic coordinator. The county health departments provide vaccines, needles and syringes and Sutter County provides a nurse for the school clinics. The Rotary Club supported the purchase of clinic equipment and supplies. The Kiwanis Club supports a bicycle safety helmet program, and local businesses were invited to donate to the clinics. In 1997, the business community Health Partnership donated \$6,000 for medical care. The community also participates in fund-raisers. Funds are secured as donations and grants from the United Way, local churches, and Foundations, e.g., the Sierra Foundation. The American Lung Association supports the new asthma program.

Local public health agencies are intimately involved in the program: county health departments utilize Title V funds to support health education activities. The state health department has had a more ambiguous role: grant funds provided early on were discontinued after a few years.

The Community Advisory Collaborative Board is comprised of Dr. Gold and sixteen members representing the Yuba City Unified School District, the Marysville Joint Unified School District, the Sutter County School District, the Sutter County Health Department, the Yuba County Health Department, the Fremont-Rideout Health Group, the Sutter North Medical Foundation, the Live Oak School District and the City of Live Oak. The Community Advisory Collaborative Board is a decision making body for the clinics only. Decision making for other issues resides with the School Board and the Board of Supervisors.

The community was described as provincial and territorial with no record of collaboration prior to this effort. One had to break down generations of history, and the work of Dr. Gold and his Collaborative has led to "monumental changes." There are "gifts ungiven in every community" and collaboration started working when agency leaders stepped aside and permitted the "worker bees" of nurses and school principals to continue. "Dr. Gold is successful in finding who is interested and needs to be involved," according to one community resident. Dr. Gold arranges for lunches once a month for the Collaborative to share information and thoughts. "He has made it easy: he schedules, gives advance notice, is accessible, and is a good communicator." In addition, Sutter North Medical Foundation supports a bi-annual retreat for the collaborative and staff.

The program now reaches 8 schools at 6 different locations throughout Yuba and Sutter Counties. Funding was obtained to extend clinics hours at all sites and to add dental screenings and asthma treatment programs in a few select schools. Emergency Room visits have decreased. The problem of asthma among children with no other source of care is being addressed. School attendance has increased by 2%, thus increasing funds for the schools. The clinics have been extremely well received in the community because children with no access to health care now have been found, treated and appropriately referred as needed.

Helping Indian Children of Albuquerque (HICA)

All Indian Pueblo Council, Inc.

Albuquerque, New Mexico

Lance Chilton, MD, Paul Avritt, MD,
William Green, MD, and Roger Gollub, MD

Katherine M. Mariano
Current Project
Director



by The Center for American Indian and Alaskan Native Health

Snapshot

Helping Indian Children of Albuquerque (HICA) is a service coordination project designed to improve access to and utilization of health care and related resources by urban Indian families and their children "with limiting conditions and special needs." Albuquerque is the largest city in New Mexico, with a markedly heterogenous and highly mobile Indian population--a population that feels it is "isolated" within the larger community of Albuquerque and essentially "invisible." Approximately 1000 Albuquerque Indian children between birth and 21 years can be defined as having special health care needs. Due to a number of social, cultural, political, and regulatory issues, these children and their families are often lost in the maze of fragmented services available to the urban Indian population. Many lack a medical home and care coordination has not been accessible. The goal of the HICA project is to provide time-limited care coordination services that focus on empowering the parents to become their own advocates and service coordinators for their children.

Setting, People, and Formulative Events

Located in the center of a largely rural state, Albuquerque has a multi-cultural population of 600,000 people, consisting of Caucasians, Hispanics, and Indians. Native Americans constitute 11% of the state's population. Although there are 19 reservations of Pueblo Indians in the surrounding area, the Indian population within Albuquerque is approximately one-third Navajo, one-third Pueblo, and one-third multi-tribal. The population is highly transient, frequently moving back and forth between the reservation and the city. Families move toward the city for jobs or to

seek health care for their children with special needs. Upon arrival, Indian families often experience isolation and difficulty navigating the system of services.

Albuquerque has been described by the pediatric leadership of this project as primarily a public and private managed care environment, with a great deal of competition among managed care organizations (MCOs). This competition is seen by some as a source of interference with the development of a sense of community and the potential for collaboration. MCOs are not currently working with the Indian Health Service (IHS). Medicaid covers families with incomes up to 185% of poverty and has converted to managed care. Services for special needs children enrolled in Medicaid



must be obtained through MCOs. Although technically, Indians would be eligible for both Medicaid and the IHS or could opt out of managed care and use the IHS exclusively, neither system is perceived by providers and the population served as adequate for children with special health care needs. A common misperception within the community is that the IHS takes care of Indian health needs. In fact, since IHS services were intended and designed for populations living on the reservation, the IHS does not directly fund urban Indian health services, although tribes may contribute funds if they can afford to do so. Coordination and outreach services available to urban Indians are limited.

In addition to the lack of community activism and collaboration noted by the project's leadership, the city is described as not having a strong charitable tradition, due in part to the historical lack of wealth. With the exception of the Levi-Strauss Foundation and United Way, there are no significant local foundations or corporate donors.

A number of organizations and coalitions in Albuquerque address child health issues. Parents Reaching Out, The New Mexico Pediatric Society and the New Mexico Advocates for Children and Families have been strong advocates for children generally and for children with special health care needs. The Albuquerque Indian Health Board represents the needs and issues of the urban Indian population and is beginning to raise awareness within the larger Albuquerque community by working on community task forces and committees. EPICS (Education for Parents of Indian Children with Special Needs) is a national parent training and information center serving Native American families with children with disabilities across the United States. In addition, the State's Maternal and Child Health Bureau, which includes Children's Medical Services (for children with special needs), provides an array of child health services targeted to the community at large, including for example, health promotion, immunization, home visiting, and a developmental education program. The state also has a Healthier Kids Fund for children with no other payment source for primary care. Although some public health activities are directed to special populations, the urban Indian population does not appear to have been specifically targeted for attention.

Although the State Department of Health's Children's Medical Services and the Part H Early Intervention Program provide case management and services for all families with children impacted by disabilities, these services are not viewed as easily accessible to the urban Indian population. The State's CMS program concurs, describing the need for significant outreach to impact the urban Indian population. The staff in the

Albuquerque Health District (District I) is described by the CMS program as not having enough time for the outreach that is needed because of their very large caseloads and recent cutbacks in contract care. Lack of access is also due, in part, to lack of awareness of cultural and resource issues facing the Indian population.

Despite the presence of some strong organizations serving Indian families, the Indian community describes itself as essentially "isolated" and "invisible". Families not only don't know what services are available or how to access these services, but also encounter cultural barriers to receiving care. Self-advocacy is not valued in the Indian culture and, therefore not a skill available to families trying to access care for their children with special needs. Although providers in the community have been aware for a long time that lack of service coordination was an issue, there had been piecemeal action to remedy this problem prior to this project by pediatricians who have made an extra effort.

Four Albuquerque pediatricians, Lance Chilton, Roger Gollub, Paul Avritt, and William Green, spoke frequently together about the lack of coordination confronting their patients with special needs, as well as the fact that many Indian children lack a medical home. They decided in early 1993 to try to work toward remedying this problem. Drs. Gollub, Avritt, and Green work for the Indian Health Service, while Dr. Chilton, formerly of the IHS, works for the Lovelace Medical Center, a managed care organization. Lovelace provided the group a small grant to identify and quantify urban Indian children with special needs. With assistance from the State's CMS programs' Chronic Child Care Registry, they were able to identify 1000 urban Indian children with special needs.

Dr. Chilton, an active member in the AAP, was familiar with Dr. Rushton's work on CATCH and suggested that they apply for a CATCH planning grant. This grant would enable them to begin planning the project and develop a funding proposal for a Healthy Tomorrows grant. They brought in other community leaders, including representatives from Parents Reaching Out (an advocacy group for parents with children with special needs), the All Indian Pueblo Council (AIPC), the Indian Health Service, and EPICS, and began the planning effort. A CATCH planning grant awarded in 1994 enabled the group to hire an experienced grant writer, Michelle Chino, and fund planning meetings that included diverse Indian groups and related organizations. These planning meetings were described as not only key to the success of the project, but also as the foundation for future collaboration. As one member of the Advisory Committee stated, the planning process was the first time representatives from the various organizations representing

Albuquerque's diverse Indian population sat down at the same table and worked together to develop a shared vision and strategy.

Within the Indian community, social workers carry the stigma of the persons who take away their children. The planning group felt it was important to use members from the Indian community as care coordinators and to help those individuals develop new skills themselves. The group also determined that they would not bill for services for two reasons: 1) they did not want to be seen as taking other providers' patients; and 2) they wanted to avoid the Medicaid bureaucracy. The issue of avoiding the bureaucracy was important because Medicaid required that a licensed professional social worker be used for case management services. The project was placed under the administrative umbrella of the All Indian Pueblo Council, Inc., under the direction of Sandra Taft. Although Ms. Taft remains on the project's Advisory Board, she has recently stepped down from position of Project Director.

Components, Activities, and Accomplishments

The goals of the Helping Indian Children of Albuquerque (HICA) project are to: 1) improve access to and utilization of health care and related services by urban Indian children and their families; and 2) improve the health status, functional ability, and developmental capability of urban Indian children with limiting conditions and special needs. In addition to conducting outreach to identify children who need services, the project focuses on providing and improving service coordination, teaching families how to advocate for themselves, facilitating parent-provider partnerships which are culturally appropriate, and identifying a medical home for all client families. The target population includes urban Indian families with children who have special needs and their service providers.

The program provides case management activities for the child as well as support services, education, assistance, and training for the family. In addition, efforts are made to increase cultural awareness about the urban Indian population and special needs children. The specific set of activities include: outreach and case finding; linkage to services and service coordination; establishment of a medical home; development of Individual Family Service Plans (IFSPs); training and education for families; and provider outreach.

Initial project resources included a small grant from the Lovelace Medical Center to conduct a needs assessment and then a CATCH planning grant of \$9,550 to hire a grant writer and conduct planning meetings among a diverse group of community leaders. The CATCH planning grant

enabled the project to apply for and receive a Healthy Tomorrows grant of \$250,000. This required matching funds which came in the form of in-kind support from the All Indian Pueblo Council and other community based-programs. Additional funds have been provided by the Levi-Strauss Foundation, the Indian Health Service (for health and safety promotion), and Parents Reaching Out (to support a parent liaison position), and in-kind donations from a local artist and community agencies.

HICA'S Advisory Committee has representatives from the IHS, the Albuquerque Indian Center, Albuquerque Public Schools, Protection and Advocacy, EPICS, Parents Reaching Out, the All Indian Pueblo Council (the administrative agency for the project), the Albuquerque Indian Development Center, a local law firm, a local artist, and parents from the Albuquerque community. The State's Department of Health's CMS program worked with the pediatric leadership that initiated the HICA project to gather the data necessary to conduct a needs assessment. HICA, itself, helps to link urban Indian Families to the services provided by public health in Albuquerque, as well as services provided by public and private providers and the Indian Health Service. Although invited, public health has not participated in the project in an ongoing advisory or funding capacity.

This project identifies its uniqueness in terms of its work to bring Indian groups together around the same table to forge a common vision and strategy for action on behalf of children. Moreover, HICA has designed its advocacy services for individual families to be time limited, thus enabling families to become self-advocates. The project also developed a very tangible and useful product that can be used in many different settings - an extensive curriculum for parents and for service providers. HICA feels that they have worked effectively with individual families in linking them with appropriate services and in providing training to support families in advocating for themselves. Services are seen as more coordinated and the needs of the population more recognized among providers and community leaders. HICA is very proud of the fact they have developed a comprehensive and culturally appropriate curriculum for parents of children with special needs and the providers that serve them. HICA has been asked to present this curriculum at various professional forums.

The HICA leadership is working hard to look for ongoing funding, and to promote the curriculum it has developed. Support from Healthy Tomorrows ends in September, 1999.



Children's Association for Maximum Potential and the Village of Hope Center for Children with Disabilities

San Antonio, Texas

Chris P Johnson, MEd, MD

Snapshot

Located in San Antonio, Texas, the Children's Association for Maximum Potential (C.A.M.P.) and the Village of Hope are multifaceted community-based service organizations for children with special health care needs and their families. The Village is the center for health care and C.A.M.P. represents a set of linked programs targeted to the highly specialized needs of children with complex medical conditions and severe developmental disabilities for recreation, rehabilitation, respite, and education ("re-orientation") of care providers. C.A.M.P. grew out of a very specific vision of Dr. Chris Johnson for founding a summer camp program designed for medically/developmentally fragile children. Over the years, CAMP has served as a focal point for much of the community involvement around the cause of children with special needs and their families. Thousands of volunteers, primarily locally, but also from across the country, participate in C.A.M.P., and the organization provides the foundation for collaboration between the Air Force and the community. The Village is operated in partnership with the University of Texas Health Science Center. C.A.M.P. and the Village serve as examples of how pediatric leadership can instill and sustain commitment to address the needs of children with special health care needs and their families.



ness interests include tourism, health care, and the U.S. military insurance company, USAA. The University of Texas Health Science Center (UTHSC) medical school is located in San Antonio. The population of San Antonio is segmented socio-economically and ethnically.

Most poor/low-income Spanish speaking (primarily Mexican descent) families reside in two quadrants of the city, and middle-to-upper class households reside in the other two.

San Antonio is described by those interviewed as a "community with a heart," but with few of its own resources, particularly compared to other Texas metropolitan areas such as Dallas or Houston. San Antonio is also described as an activist community -- home of community action groups such as "Communities Organized for Public Service (COPS)." It was noted that little is done without the support of such community groups. This activism is reflected in the development of service agencies such as the Barrio Health Clinic, one of the earliest established 330 Community Health Centers.

Leadership related to child health is frequently attributed to Dr. Fernando Guerra, the current Director of the San Antonio Metropolitan Health District. Even prior to taking his current post, however, Dr. Guerra was involved as a private practicing pediatrician, as Medical Director of the Barrio Health Clinic, and as faculty at UTHSC in stimulating and stewarding initiatives to address the needs of vulnerable populations. Members of the local chapter of the American Academy of Pediatrics organize continuing education functions for San Antonio pediatricians, and provide support to community/coalition initiatives when called upon. It was noted that the UTHSC pediatric faculty often are the physicians who have the most time and latitude to contribute to community child health initiatives and advocacy. San Antonio's churches also are reported to be influential and active in addressing social issues.

Dr. Chris Johnson has been front and center providing leadership in issues related to children with special health care needs for nearly two decades. In fact, her interest and involvement in community social and health services extend back to her years as an undergraduate student, when she headed up a group of volunteers to provide health aid in Central

Setting, People, and Formulative Events

San Antonio is one of the country's 10 largest metropolitan areas, with a current population of 1.2 million. Approximately 60% of the population is of Hispanic origin. San Antonio is the second largest military site nationally, with four Air Force bases, and one army fort. The largest Air Force medical center, Wilford Hall Medical Center, is housed at Lackland Air Force Base -- also the home of C.A.M.P. There is little industry within the area: primary busi-

America, and also became a volunteer at the local United Cerebral Palsy agency. Dr. Marion Sokol, trained in special education and public health, also has been at the forefront of policy and services development for this group of children. She initiated creation of a broad coalition and successfully pursued system changes in respite care policy and resource allocation. Dr. Sokol is currently implementing a federal Title V Community Integrated Services System (CISS) grant which is supporting development of a "Vision for Children."

Examples provided of public sector collaboration include the notable longstanding partnership between the UTHSC and the Bexar County Health District to jointly operate public health clinics, particularly subspecialty services located at the Village of Hope. Targeted campaigns to address immunization rates among children, teenage parenting, and prevention of SIDS were reported to involve numerous private and public sector collaborators. The structure of the public school system, however, is apparently problematic: the metropolitan area has 22 independent school districts with significant variation in resources, policies, and services. Health service initiatives that operate across the district boundaries are challenged in their implementation. This situation is a particular problem for the special needs population where the links between health services and education programming are vitally important. Also, business sector involvement is noted to be limited.

Children's Association for Maximum Potential evolved from Dr. Chris Johnson's personal goal to provide a summer camping experience for children with severe health and/or developmental conditions. Dr. Johnson attributes having this goal to the time when, in college, she was recruited to work at the Lions Camp program for children with disabilities. In the course of her duties that summer, one of the children in her charge was seriously hurt. Dr. Johnson notes that "at that moment, I committed to myself that I would someday have my own camp and do it right." During her residency and while serving as an Air Force pediatrician stationed at Wilford Hall Medical Center (WHMC), Dr. Johnson set about organizing a special one-week camping program that would serve children who were too sick or disabled to qualify for participation in the Lions Camp. She found interest among her patient population, identified a site and volunteer counselors, but had been unable to raise funds to pay the rent on the campsite. Through a serendipitous "connection" between one of the parents of her patients, funds were allocated by the Air Force Aid Society at the special request of the Commander of WHMC and Air Training Command and Air Training Command and Randolph Air Force Base.

The development of C.A.M.P. over the years since 1979 is characterized by Dr. Johnson as a function of requests from families with CSHCN for various services coupled with several unplanned funding oppor-

tunities that were seized to meet the expressed needs of the population. The success of the camping program generated requests from parents for opportunities for respite for themselves and recreation for their children throughout the year. Dr. Johnson's related professional roles in providing subspecialty care for special needs children and in training pediatricians in their care led to a strategy to build a training component into C.A.M.P. This strategy keeps costs low, allowing the program to maximize the number of children served. Several other service programs have been incorporated into the C.A.M.P. portfolio of services over the years. While initially Dr. Johnson was building the program primarily on her own, C.A.M.P. has developed a cadre of community supporters and dedicated staff who continue to push the envelope, and the reach out to the community of families with special needs children.

Components, Activities, and Accomplishments

C.A.M.P.'s overarching goal is to provide children with medical conditions and developmental disabilities and their families the best opportunities to lead a productive life and reach their maximum potential. Central to each of C.A.M.P.'s programs is the provision of high quality medical support so that regardless of the severity of a child's condition, s/he will be able to fully participate in all aspects of the activities offered. Along with this mission, C.A.M.P. seeks to extend its influence by providing training for care providers at all levels, from high school to post-professional education. C.A.M.P.'s four specific goals are to provide opportunities in: 1) recreation -- a chance to enjoy nature, new activities, new friendships and residential camping experiences; 2) rehabilitation -- an opportunity to receive early therapy and adaptive equipment; 3) respite -- a chance for parents to pursue careers, higher education, or to have rest from the daily burdens of caring for their special needs child; and 4) re-orientation -- an opportunity for parents, clients, volunteers and the general public to become better informed about developmental disabilities so that they can become more effective advocates and care providers.

The spectrum of services currently includes: eight one-week sessions of residential summer camp, respite weekends, emergency respite care, parents' nights out (3/month), teens' night out (monthly), a health equipment loan program (HELP), parent conferences (entire families), and a specialized child care center. In addition, integrated with many of these services are a series of training programs, including: child care course, pre-independent living skills course, developmental disabilities review course, community implementation of the Americans with Disabilities Act through Volunteerism course (for college students), Americorps (college students), and special care course (for child care workers).





C.A.M.P.'s longstanding policy is to serve children with special health care needs regardless of the degree of severity of their condition. That is, children are never turned away from services due to the complexity of their problems. Technically, any child from 6 months of age through 21 years is eligible to participate in C.A.M.P. irrespective of residence. The only program area where this is not the case is the TLC Child Care Center, which serves only military dependents. The large majority of children/families served are from the San Antonio area, although children from around the country attend the summer camping programs. Individuals participating in the training programs also drawn from a national pool (particularly those involved in graduate and post-graduate training).

Agency resources in 1996 totaled approximately \$ 1.14 million. Primary sources of this funding included Combined Federal Campaign/United Way contributions, a grant from the Air Force Aid Society, a Corporation for National Service (AmeriCorp) grant, government fees and grants, client fee income, and contributions from local foundations. In addition, C.A.M.P.'s programs generate approximately 184,000 volunteer service hours/year, valued at about \$ 625,000. The United Way is considered to be particularly important to C.A.M.P., not only in terms of funds, but also in relation to opportunities (requirements) to work with other agencies/programs undertaking similar activities. Meetings convened by United Way staff have opened doors to linkages, ideas, and support for Chris Johnson and C.A.M.P.

Extensive linkages with the community generally and the health system specifically have been established. C.A.M.P.'s Board of Directors includes military personnel, the church community, advocacy and service organizations for persons with disabilities, USAA, the UTHSC, and a local attorney. Other supporting individuals include agency representatives from the San Antonio Metropolitan Health District, three school districts, and the Bexar County Health District. Pediatricians in private practice are not highly involved. Discussions are underway, however, aimed at developing new strategies for drawing them into the organization.

C.A.M.P. has evolved with the express purpose of filling gaps in the service system for children with special health care needs and their families. Dr. Johnson and her staff take great care not to duplicate services. In cases where such potential exists, they develop formal and/or informal organizational partnerships for program planning and joint service ventures. Examples include significant collaboration with the area's early intervention programs, and with Any Baby Can, which is currently developing a home visiting case management and counseling program.

Approximately 5,400 persons received at least one C.A.M.P. service in 1996. In addition, slightly over 600 individuals participated that year in some aspect of C.A.M.P.'s training and education programming. Using these figures, the impact of C.A.M.P. in the nineteen years since its inception can be extrapolated to many more thousand, its reach extending beyond San Antonio to state, national and international participants.

The Village of Hope is a younger and smaller program than C.A.M.P. The Village grew out of the UTHS Center's Program for Children with Disabilities, which since 1986 had been providing multi-disciplinary care to urban and primarily indigent Hispanic children in its large tertiary care county health facility. In an effort to provide these services in a more community-based, family-friendly environment nearer to the area of San Antonio where most of the program clients live, in 1992 Dr. Johnson took on the task of moving these specialty health services to a set of adobe cottages at the south end of the city. Developmental, School Functioning, Pediatric Rehabilitation, Neuro-Developmental, and Psycho-Developmental clinics operate out of the Village, where over 75% of the families served live within a two mile radius. Since additional space was gained by moving the children with disabilities program to the Village, she also was able to work with a number of community agencies to locate support services at the Village site. These services include two parent-training and advocacy programs, an early intervention and day care program, an equipment loan program, and respite services.

Dr. Johnson is a clever manager and strategic planner of services. The entire array of programs at C.A.M.P. and the Village of Hope has been pieced together with multiple sources of funding from both private and public sectors, involving sources as diverse as the Air Force and the University Medical Center. In addition, Dr. Johnson's strong personal relationship with her colleagues and constituents has resulted in a large number of volunteers providing extensive services to the families under care. Although Dr. Johnson and others at the Village of Hope originally opposed the construction of a modern new chronic care facility on the grounds, they are clearly thinking about how to further the work of the Village through linkages with the center and unique services to be available through it. She and her colleagues are always looking for new ways to fund more and better services to their population. CATCH funds are being sought to support a formal needs assessment, primarily for planning Village of Hope services. Remarkably, \$2.5 million was built into the FFY 1996 federal Defense budget to fund construction of a new facility for C.A.M.P.

Parent Child Program

Cary Christian Center
Cary, Mississippi

Kurt Kooyer, MD
Carolyn Newhof, MS



by Gillian Silver

Snapshot

The Parent Child Program in Cary, Mississippi represents an outgrowth of several pediatricians' and colleague health professionals' commitment to bring health care, and social and spiritual support services to the residents of this impoverished area of the Mississippi Delta. Established in 1971 by pediatrician Peter Boelens, the Cary Christian Center today provides a broad umbrella for two rural health centers, and a number of programs aimed at reducing the burdens of poverty and isolation. The Parent Child Program, among the longest operating services sponsored by the center, provides prenatal and parenting classes and home visiting for pregnant women and new mothers, and classes for mothers with toddlers. Over the years, Cary Christian Center has drawn physicians such as Dr. Kurt Kooyer as well as related health professionals such as Parent Child Program Director, Carolyn "Care" Newhof to the area to reach out to the residents of Sharkey and Issaquena counties. The center further has engaged thousands of volunteers from the community, the surrounding area, and nationally in its cause and service programs.

Setting, People, and Formulative Events

Sharkey and Issaquena Counties are located in West Central Mississippi. The combined population of these two counties is approximately 10,000: the majority of residents live in poverty. Large tracts of property in this highly rural area are owned by relatively few individuals. These tracts, where cotton, soybeans, and corn are the major harvests are referred to by area residents as plantations. No industry of significance exists. Cary, the town in which the center sits, has 400 residents. Its nearest neighboring town, Rolling Fork, has a population of 2,000.

Rolling Fork hosts a community hospital with a total of 29 beds, approximately 20 of which constitute a geriatric facility. The hospital has an emergency room, however does not have a delivery suite, therefore women living in Sharkey and

Issaquena Counties must travel to either Vicksburg or Greenville, each approximately 45 miles from Cary/Rolling Fork. Public and private resources for vulnerable families are very limited: local health department services operate inconsistently, and are closed down entirely from time to time. Both Sharkey and Issaquena Counties are listed among the state's ten counties with the highest rate of teen births (1993), and Issaquena County is reported to have the highest percentage of low birthweight births among all counties in the state (19.2 % in 1993). School drop out rates in these counties were reported by those we interviewed to be quite high.

In general the population is not well-educated, and local leadership for community action is scarce. Recruitment and retention of a stable core of health, education, and human services professionals is a challenge in this area.



The Cary Christian Center was founded and health services commenced in 1971 when pediatrician Dr. Peter Boelens arrived in the area from Minnesota. The town had been recruiting a physician at that time, however Dr. Boelens' arrival in Cary was related instead to his personal goal to provide missionary health services in an area of need in the United States. He had been touring the delta with his family in search of such a place, when he happened upon the town of Cary and its expressed needs and interests. Dr. Boelens immediately set up a health clinic, and brought several health professionals into the service of the Cary community by recruiting staff and volunteers from the upper mid-west states and schools where he had previously worked and trained. Over the years, college students, medical students, and residents were drawn to the area during and after their education to gain experience in the field. Peter Boelens served as formal and informal mentor to most of these individuals. Such was the process by which Kurt Kooyer came to be associated with the Cary Christian Center, and ultimately establish a rural health center (DeltaCare) in nearby Rolling Fork.

Carolyn Newhof, whose sister worked as a nurse at the health clinic at Cary Christian Center throughout the early 1970s, learned of the needs for support for pregnant women and young mothers. Armed with a degree in home economics, she arrived from Michigan in 1978 and began an early stimulation program which included prenatal classes, parenting education, and home visiting. Within a few years as the needs of the women she served became more apparent and demand grew she could no longer continue with her practice of home visiting. Funds to re-initiate the home visiting component of the program became available in 1989 through a five-year Healthy Tomorrows grant. Funds available from the Healthy Tomorrows grant also allowed the Parent Child Program to support the involvement of a social worker (part-time) in teen pregnancy, and child abuse prevention efforts. Among the objectives of the Healthy Tomorrows project also was the development of a Health Alliance.

Components, Activities, and Accomplishments

With its mission to provide parents with the support, knowledge, attitudes and skills they need to nurture their children, goals of the Parent Child Program are: 1) to promote the safe birth of all children through encouraging early entry into prenatal care, networking with health professionals providing prenatal care, providing prenatal education classes, and providing assistance and caring support for expectant mothers (transporta-

tion assistance, home visiting, referrals); and 2) to enhance the ability of parents to nurture their children through parenting education classes parenting support (home visits through the first year of life, mailing of parenting materials, and referrals), Biblical guidelines for parenting, and through encouraging mothers to finish high school or complete their GED. The program further seeks to share its Christian message to participating individuals.

Any expectant mom or new mother is welcomed into the program: the majority, however, are very young, low-income women receiving public assistance. Referrals are received through local obstetric and pediatric providers (including the public health department), word-of-mouth (prior program participants and family members), and outreach mailings.

Central to the program is the role of the lay home visitors, who are women from the community. The home visitors make monthly home visits to enrolled women, and share in the teaching of the parenting classes. Training for the home visitors is provided by the health professionals affiliated with the Cary Christian Center (child development -- Care Newhof, pediatrics -- Kurt Kooyer, Andrew George, and Debra Schout) and by Linda Sweezer from the Vicksburg Family Development Center. Standard guidelines for the content of home visits and for the classes were developed by Carolyn Newhof during the Healthy Tomorrows funding period, and continue to be conscientiously adhered to by the workers and monitored by professional staff.

The current home visitors -- Irma Johnson, Hattie Lewis, and Barbara Williams -- are reported and observed to be well-accepted by their clientele. These women grew up in the community, and two were at one time enrolled in the Parent Child Program. They feel and express strong commitment to the overall Christian mission of the program and the Cary Christian Center. As such, they are able to communicate and "connect" with the women who come to the program for services in a manner that otherwise might not be possible.

Similarly, the professionals who lead and supervise the home visitors -- Grace Tazelaar, Debra Schout, Care Newhof, Brian Kruis, and Kurt Kooyer -- are highly committed to the clients, staff, and mission of the Parent Child Program based on their personal goals realized through Christian service to society.

The total costs for the Parent Child Program as currently constituted approximates \$93,000/year. In 1997, the Center was able to secure a grant from the state supported by federal Family Support Services funds. These resources were utilized to cover the salaries of the home visitors. The state discontinued these funds, however, after one year.

The participation of a licensed social worker on staff was discontinued when the Healthy Tomorrows grant funding ceased. The Parent Child Program operating budget now relies exclusively on donations to the Cary Christian Center. The program Director and home visitors, however, essentially donate many hours each week to the ongoing effort. In addition, staff work with area volunteers from all over the country to secure contributions of baby supplies which are given out at classes (e.g., baby bottles, home safety devices). They are further able to utilize Cary Christian Center volunteers for contributions of time and services (e.g., baby sitting during group educational sessions, homemade bibs). Program leaders and staff are now considering potential strategies for garnering external support for program services.

Staff of the Parent Child Program are in routine contact with the area's public health agency, located in Rolling Fork. Referrals are received from the public health department for prenatal/parenting classes and/or home visiting, and are made to the health department by program staff for prenatal care where necessary and possible. Public health resources, however, are very limited: they primarily consist of some nurse practitioner and nurse midwife-provided prenatal care. Both the Cary Christian Center and the public health department are WIC providers, and collaborate in that effort. Dr. Kooyer interacts with Health Director, Dr. Grillo, in the context of general public health concerns as they arise.

While there appears to be strong connections between the community and the program/Cary Christian Center, there is no organized support from the professional community for the services provided by the Parent Child Program. In fact, no local organized support for children's services generally is apparent. The two rural health centers -- situated at Cary Christian Center, and in Rolling Fork (DeltaCare) -- are housed under the organizational umbrella of the Center, and thus routinely work with the Parent Child Program. Program staff work with individual obstetric clinicians located in Vicksburg and Greenville, but feel that the important role of the educational and home visiting services they provide is not recognized by these area health professionals.

Attempts to bring the health and social services community together have not been successful. During the time frame of the Healthy Tomorrows grant, a Health Alliance was established to address infant mortality and teen pregnancy issues on a systems level. However, beyond discussions around improving the availability of transportation services, little interest or participation was generated. The Alliance disbanded after one year. The effort to bring health education programming into the schools (also a component of the Healthy Tomorrows project) also met with resistance and was ultimately abandoned. The

staff and leadership are somewhat more encouraged about the potential for success in this regard with a new effort underway.

The Parent Child Program faces little "competition" in its efforts. While a few similar programs have started up in Sharkey and/or Issaquena Counties over the years, they have not been sustained as have those of the Parent Child Program for the past twenty years.

Program impact includes training of 12 community health advisors (home visitors), a number of which have pursued additional educational and professional opportunities. Two of these women went on to become licensed practical nurses. Although a rigorous evaluation has not been possible and despite the difficulty in computing rates in this small population, some statistical evidence exists to support assertions that the Parent Child Program has contributed to reductions in non-white infant mortality. Further, maternal satisfaction, early recognition of potential child abuse/neglect, and enhanced parenting practices are anecdotally reported by the program. Finally, Dr. Boelens and Grace Tazelaar have used the story and success of the Parent Child Program as a model for HIV/AIDS programming, replicated in ten US communities and abroad. In another vein, through Kurt Kooyer's association with the CCC, a family contact is building a cement tile manufacturing plant, which will begin operations in the summer of 1998. The plant will eventually employ about 200 individuals. This business venture holds significant potential for enhancing the community's economic base, improving the socioeconomic status of families living in and around Cary, and thus positively influencing health and education levels in the community.

In 1998 the program leaders are hoping that the Cary Christian Center can maintain some level of support for the Parent Child Program and that staff and others can continue to commit significant "volunteer" time and effort until alternative and more stable funding resources can be identified and secured.



Center for Women and Children

Access to Child Health including Medical Home for Special Needs Children Duval County Health Department

Jacksonville, Florida

Karen H. Toker, MD
Medical Director

Snapshot

The Center for Women and Children, formerly Pearl Plaza Pediatrics, a unit of the Duval County Health Department (DCPHD), provides comprehensive primary care to children from all socio-economic groups, many with or at risk for chronic medical or psycho-social problems. The philosophy of the practice and their teaching is a holistic view of the child in the context of family, school and community. The Nemours Foundation founded this clinic for children with special needs in 1993 as part of a larger effort that began in the late '80's to establish satellite clinics in rural and urban areas. Nemours established Pearl Plaza Pediatrics to provide primary care for disadvantaged children with multiple handicaps, as well as for generally healthy children. Pediatrician Karen H. Toker was recruited to serve as Medical Director. In July of 1995, the clinic moved to, and came under the supervision of, the Duval County Health Department. The clinic, presently known as the Center for Women and Children, serves approximately 1,600 children annually.

Setting, People, and Formulative Events

Located in northeast Florida, Duval County is coterminous with the city of Jacksonville, geographically the largest city in America with 840 square miles. The population of the metro area (Duval, and the primarily rural counties of Baker, Clay, Nassau and St. Johns) is just over one million; the population of Jacksonville is 728,437 (1995 est.) with an anticipated growth to 805,500 by the year 2005. This rapidly growing city ranks 15th in population in the U.S. and has a minority popula-



by Gillian Silver

tion of 30%, mostly African-American. Twenty percent of its families live below the poverty line and 40% of its school children receive free or reduced cost lunch programs.

In almost every category during the 1990s, Jacksonville has demonstrated substantive improvement in community health indicators: births per 1000 women aged 15-19 decreased from 87.6 to 75.6 since 1990; repeat births to this age group declined from 19.1 to 15.2 during the same time period; the infant mortality rate dropped from 12.3 to 7.4 in the past ten years; primary and secondary syphilis cases decreased since 1990 from 65.2 to 9.8 cases per 100,000 population; and, the percent of high risk infants beginning immunizations increased from 72.5% to 98% in the past decade.

The status of children with special needs is less optimistic. The Jacksonville Community Council, Inc. (JCCI) was created in 1975 with the goal of improving the quality of life in Jacksonville through informed citizen participation in public affairs. It is a non-profit, nonpartisan, broad-based civic organization which produces an annual report and selects two issues per year for in-depth community study. Many of these studies focus on child health issues. The number of children in the county with special needs, as estimated by JCCI, is 26,000. This number represents 11.5% of the approximately 225,000 young people ages birth through 20 who live in Duval County. The 1997 JCCI study also noted: 1) "...fragmentation and lack of coordination exists among

service providers in Duval County; 2) ...a significantly higher ratio of children with special needs to staff; 3) ...gaps in services; 4) ...absence of a comprehensive source of information for families and caregivers that is kept current and is easily accessible; 5) ...poor communication ...between service providers and families and care givers because of the complexity of the system and the existence of multiple case managers from several agencies for some and (none) for others; and that 6) ...the long-term, chronic-care needs of some children with special needs may be inadequately met because of managed care's focus on acute and preventive care, and cost containment."

Over the years, activities to improve the health of children and families frequently followed release of JCCI studies. A referendum to add a penny sales tax, designated specifically for children's services in Duval County, was defeated several years ago. Subsequently, the Mayor and City Council created the Jacksonville Children's Commission in 1994 to fund services for children. Four years ago, the Children's Health Partnership was formed to work together for the betterment of children. The members of the Partnership, representing academia, subspecialists, hospitals, community medical centers and public health, are the Nemour's Foundation, the University of Florida Medical School in Jacksonville, the University of Florida Medical Center and Wolfson Children's Hospital. Their agreement is due for review and renewal in 1999.

A critical element of the history of the Center for Women and Children is the strategic partnership that developed between academia and public health with the arrival of Jeffrey Goldhagen, MD, MPH in Jacksonville as the Director of the Duval County Health Department (DCHD) in late 1991. Dr. Goldhagen was recruited from Case Western Reserve in Cleveland. His career in both domestic and foreign fields has been devoted to the interface between academia and public health. He worked with Ed Rushton from the national CATCH office in the late 1980's and early 1990's; organized one of the first regional CATCH meetings; received one of the first CATCH awards; and, in 1997, was a CATCH Visiting Professor to the University of Pittsburgh. The DCHD, the Jacksonville campus of the University of Florida (UF) Department of Pediatrics, and the University Medical Center (UMC) merged their general pediatrics and adolescent medicine programs. All physicians in DCHD are now full-time UF faculty and are "leased" back to DCHD. Clinical services are delivered in the network of health centers. Pediatric resident education, including continuity of care clinics, is decentralized into the network of DCHD pediatric practices.

Components, Activities, and Accomplishments

Against this backdrop, Pearl Plaza Pediatrics was founded and then evolved under the leadership of Karen H. Toker, MD.

Pearl Plaza Pediatrics was started by the Nemours Foundation to provide a private-like practice. Because it served children with special needs, it attracted families from all over the city. In the area surrounding Jacksonville in the late 1980's, Nemours started rural clinics, with physicians and pediatric nurse practitioners in a private practice-like settings that would be attractive to poor families of children in these areas. The rural clinics were administratively tied to the subspecialists at the Nemours Clinic. Karen Toker was originally recruited to develop an urban clinic in Jacksonville similar to these rural clinics. Because of some administrative delays, she first staffed one of the rural clinics in 1991 and then began providing general pediatric consultative services at the main Nemours Children's Clinic in mid-1992. She also served as the pediatrician on the Cleft Palate, Spina Bifida, and Cerebral Palsy multi-disciplinary teams. Nemours established an urban primary care site, the Nemours Children's Clinic at Pearl Plaza, in 1993 and Dr. Toker was appointed medical director.

This clinic provided comprehensive pediatric care primarily to socially disadvantaged children with multiple handicaps. In mid-1995, as Nemours found their satellite clinic system more expensive than anticipated, they gradually closed or transferred the clinics to other auspices. The urban clinic at Pearl Plaza moved organizationally from Nemours to DCHD and became Pearl Plaza Pediatrics. Later, it expanded to become the Center for Women and Children. Ancillary services, such as WIC, are more convenient and transportation is more accessible at the new location. The Center for Women and Children has since served as primary site for comprehensive care for DCHD's children with special health care needs.

Approximately 1,600 patients are registered in the Center for Women and Children's pediatric section. While most are enrolled in Medicaid, a large number of children are covered by Florida's Healthy Kids program. A small proportion of the pediatric caseload are privately insured, and 10% have no source of health care coverage.

Dr. Toker has built and expanded services based on her personal philosophies. Although administered within a governmental agency, the clinic is run like a private practice with total pediatric involvement. Providing comprehensive services, it serves as a medical home for children with special health care needs. Dr. Toker stated that she has been providing comprehensive services all of her professional life, but only recently has it





been called a "medical home" to correspond with the term used by the American Academy of Pediatrics. "The clinic is a unique combination of academic, public health and private practice," she explains, which helps "to move the families to a better understanding of what they can manage and a higher level of general health."

Some of the quality elements of a comprehensive primary care site as identified and implemented under Dr. Toker's leadership include:

- One patient/family and one provider; Dr. Toker stresses that "there must be development of trust first before all else can be accomplished;"
- Developmental testing on standardized test (PDQ) at every well-child visit;
- Quality vision and hearing testing;
- Charting including problem list, plan, data base, immunization record, growth data and specialized data tracking. The chart should read like a book and describe the course of the child's medical history in a connected fashion;
- Use of The Injury Prevention Program (TIPP) and extensive health education handouts - placed in waiting and examining rooms, given out at each well visit, and with the ability to be ordered via the nurse if not regularly given out;
- Teaching residents;
- Case management and comprehensive care of chronic disease by generalist physicians;
- Moderately complex laboratory services;
- Outreach via public health nurses and community workers;
- Team approach, goal setting and monthly review of goal progress;
- Accurate billing, monthly statistical reports and budget comparisons.

Pearl Plaza Pediatrics has strong links with other public health services, such as STD and HIV counseling. It also has strong links with the professional community. Drs. Toker and Goldhagen, as the other DCHD physicians, are faculty members of the Pediatric Department of the Medical School. The physicians at Nemour's Children's Clinic provide specialty consultation and backup as needed. Strong alliances are reported with Children's Medical Services, Healthy Kids, Healthy Start, Healthy Families, the Early Intervention (0-3 years) program, Child Find (0-5 years) and the school system. The program does not formally solicit advice and input from the non-professional community, although Dr. Toker and her staff rely on their many informal contacts within the community for ideas and guidance.

Goals are set and revised regularly based on 1) patient satisfaction surveys; 2) key quality characteristics determined for the practice; 3) chart reviews; and, 4) budget/production goals. Although there is a desire on Dr. Toker's part to do outcome evaluation, to date none has been conducted. The nursing staff do report, however, decreased Emergency room use by patients that are part of the practice.

The continuation and sustainability of the Center for Women and Children appear solid, and plans are underway to institutionalize this comprehensive approach to pediatric care for children with special needs and their families.

Positive Parenting Program: Drop-In Center

Sto-Rox Neighborhood Family Health Center

Stowe Township and McKees Rocks Borough, Pennsylvania

Mary Carrasco, MD



by Gillian Silver

Setting, People, and Formulative Events

Pittsburgh (population-369,900), the nation's largest inland port and the seat of Allegheny County, sits in southwest Pennsylvania at the confluence of the Allegheny and Monongahela rivers which there form the Ohio river. The terrain of the area is a mix of plateaus and hillsides, narrow valleys, tunnels and rivers spanned by many bridges. In Pittsburgh, no fewer than 90 neighborhoods are recognized by the city's Planning Department. With a population of 1.3 million, Allegheny County has approximately 130 small towns outside of Pittsburgh.

The Positive Parenting Program is located in McKees Rocks (population- 7,500), and serves the borough of McKees Rocks and Stowe Township (population-7,500) in Allegheny County. Stowe Township is incorporated and its governance is through a nine member Council; McKees Rocks has a mayoral government. The area, with ethnic neighborhoods settled mostly by Eastern Europeans, was a railroad town that began its economic decline with the discontinuance of the railroads in the late 1950's, 30 years before the second contribution to the decline, the closing of the steel mills 15 years ago.

Snapshot

Positive Parenting Program, a child prevention project developed in 1981, is located at the Sto-Rox Health Center in McKees Rocks Borough, Allegheny County, Pennsylvania. The program provides family support services through social workers and lay parent educators who coordinate their work with the health center and numerous community agencies. In 1981, pediatrician Mary Carrasco began working part-time at Sto-Rox, the health center developed by the community coalition, Focus on Renewal.

Recognizing the isolation in the community, especially among women subject to poverty, domestic violence, or other barriers to care, she sought and secured resources and a staff to support vulnerable families.

In the late 1960's, under the aegis of the federal Office of Economic Opportunity (OEO), Don Fisher, a Roman Catholic priest, organized the Focus on Renewal (F.O.R.) coalition in the community. The organizing effort was stimulated by opposition to the mayor of McKees Rocks who had been in office for over 30 years and wouldn't allow federal funds into the community because of his fear of setting up local community boards. Individuals from twenty-one natural neighborhoods became part of the community organization effort. The mayor was defeated and in 1969, the diocese gave the coalition a small amount of seed money to enable Focus on Renewal (F.O.R.), Sto-Rox Neighborhood Corporation, to open a storefront office and attempt to address the needs in the economically impoverished neighborhoods of McKees Rocks Borough and Stowe Township.



Four housing projects (800 units) in McKees Rocks were a focus of the project - one was primarily African-American, two were white and one was mixed. This high risk population suffered from poverty, unemployment (22-25% in the general area), drug and alcohol abuse, single parent and adolescent pregnancies, and domestic violence. The first service offered was the establishment of a credit union in 1970. Gradually an adult drop-in center, a weekday lunch program for the elderly, a food bank, transportation services, crisis care, and legal aid were added. Ambulatory health services in the neighborhood were difficult to obtain and, in response, a store front pediatric clinic opened in the fall of 1971 as part of the F.O.R. With funding from OEO, this effort evolved into the Sto-Rox Neighborhood Family Health Center. The relationship between the Neighborhood Center (F.O.R.) and the Health Center encouraged a comprehensive approach to health and well-being, with an initial emphasis on health care for the large elderly population. The Health Center eventually received Section 330 funds and National Health Service Corps placements.

Mary M. Carrasco, MD, came to Pittsburgh in 1977 to enter an Ambulatory and Community Pediatrics Fellowship in the Department of Pediatrics at the University of Pittsburgh. After completing the fellowship and taking a year off to care for her young child, Dr. Carrasco began working as a part time pediatrician with the Allegheny County Health Department. In 1981, she was recruited as a part time pediatrician by the Sto-Rox Health Center. Dr. Carrasco found that the problems of the high risk population were not being met. She became Medical Director of the Sto-Rox Health Center in 1983, and focusing on domestic abuse, initiated a series of Parents Anonymous meetings at the Community Center.

In mid-1984, Dr. Carrasco attended a Section 330 (Community Health Center funding) conference in Philadelphia and in a conversation with the federal Regional Health Administrator, Will Lassek, MD, recounted her work and some of the problems in Sto-Rox. Lassek said: "You know about child abuse...design a project and we'll fund it." She did and it was funded by the Regional Office with discretionary 330 funding.

The next few years were devoted to developing the Drop-In Center model. In 1988, Dr. Carrasco joined Children's Hospital of Pittsburgh as Director of the Section of Community Health. Diane Perkins succeeded her as director of Sto-Rox's Positive Parenting Program and then two years later, Amy Celtrone. In 1989, Carrasco was awarded a 5 year, one million dollar grant from the National Center on Child Abuse and Neglect (NCCAN) to expand to other sites the original family support program that she had built in Sto-Rox.

Components, Activities, and Accomplishments

When she arrived at Sto-Rox, Mary Carrasco realized that traditional medical care was not sufficient for children from the poor families the Center was serving. Treating their illnesses in a clinical setting was doing little to prevent their health problems and virtually nothing to impact the crucial parent-child relationship. She reasoned that true health care extends beyond the clinic and that child development, parenting education, substance abuse counseling, respite care for children, and housing assistance are the family support services that improve family life and health.

Her vision was the outline for the first drop-in center in Sto-Rox. While the idea was new to Center staff and young families in the area, the concept would have been familiar to the immigrants who preceded them in the Pittsburgh area as the drop-in center was similar in many ways to the Settlement Houses of previous years that helped thousands of young families find homes, employment, food and medical care. The goals of the program are to: 1) prevent abuse in families diagnosed as high-risk; 2) improve parenting skills in the target population; and 3) provide emotional support and crisis intervention for parents unable to cope with the daily stresses of child rearing.

The target population includes the residents of four county housing projects in the service area. The high-risk population of these projects reflects increased percentages of very mobile transitional families, single parent families, adolescent pregnancies, alcoholism and drug abuse, and unemployment. Beyond the housing projects, unemployment in the general area (estimated at 22-25%) contributes greatly to the stress and tension which constantly add to the problem of child abuse. At the time of the program's inception, 70% of all the prenatal patients at Sto-Rox were unmarried. Ninety percent of the young women were described as high risk due to drug and alcohol abuse, histories of abusive families, previous abortions, and unstable and emotionally disturbed family life.

Services provided through the Positive Parenting Program include: the drop-in center with child care facilities (Time Together); in-home visits by the parent Educator/Aide, social worker and nurse; daily well child telephone advice; an Infant and Toddler car seat program; individual counseling; support groups and educational meetings; and a literacy program.

The Time Together drop-in center for parents and children is located in the basement of an old bank building which previously housed the

Health Center. The play area is organized into several distinct and well-equipped play and learning areas. Two additional small rooms provide space for art play, and a nursery. Separate from the playroom, but close enough for easy intervention when needed, is a homey living room. The room is open to parents at all times, and always has a pot of coffee brewing. Parents need little encouragement to use this room for socializing, talking privately with a staff member, or for enjoying a few quiet moments alone. This room is also the site for group sessions.

Children cannot come to the walk-in center alone nor can they be left in the center without a caretaker. While some free time for the parent is provided within the center, interaction between parent and child/children is the main focus. Parents are encouraged to participate in play, reading or craft projects. It is hoped that through subtle encouragement, intervention and role-modeling by staff members, parents and children will adopt positive behaviors and enriched family interactions.

Though F.O.R., the Credit Union, and the Health Center had Boards whose members came from the local community, the Positive Parenting Program initially did not. Dr. Carrasco was concerned that many Boards don't pay attention to what clients say and sometimes don't include on the Board the poorer and more vulnerable in the community. She and her staff therefore listened carefully to their clients on a daily basis and made concerted efforts to continually modify their program to meet expressed needs. Three years after the program began, however, Dr. Carrasco and the staff determined that an advisory board was needed to help raise funds and educate the community about needs and services. She established an Advisory Board that had as its members community leaders from throughout the larger Pittsburgh area.

The program works extensively with other agencies, including Mental Health, Children and Youth Services, Americorps, Healthy Start and WIC. In addition, the Local Interactive Network for children and Families (LINC), composed of 23 agencies, meets monthly and provides advice for Family Support groups for the school district, and the United Way's Early Childhood Initiative supports activities to have children ready to learn at entry to Kindergarten.

The Positive Parenting Program has been a mustard seed to attract other funding, such as federal Healthy Start support. In 1989, after Dr. Carrasco moved to Children's Hospital, the National Center on Child Abuse and Neglect provided \$1 million over five years to expand the Family Care Connection (FCC). Matching funds of \$760,000 were provided by the Scaife Family Foundation, the Howard Heinz Foundation and the Hearst Foundation. Using the Sto-Rox model, comprehensive programs to prevent child abuse and neglect were developed in four additional Allegheny County communities -- Rankin, Braddock, Wilkinsburg and Turtle Creek/East Pittsburgh.

The four centers are located within walking distance of most families in the communities and are the hubs for services. Each drop-in center is located within a well-established community agency that provides free space and links its program and staff with those of the FCC program and staff. The host agencies provide families with an array of services including food banks, energy assistance offices, job training and literacy programs, and recreation programs for older children in the families. The FCC now serves between 800-1,000 families each year.

In the ten years since Mary Carrasco began at Children's Hospital, she has brought over \$6.5 million into these communities. These funds have come from foundations and local, state and federal sources, including a Healthy Tomorrows grant for a Foster Care and Homeless Health Care Program. All of these projects have built on each other with the original Positive Parenting Program in Sto-Rox as the seed program. The substantial amount of funding for these programs that began as demonstration grants now is embedded in local and state agency annual budgets.



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