SUSTAINABILITY OF PRIMARY CARE
DEMONSTRATION PROJECTS:
END OF YEAR I REPORT

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Mona C. Shediac and Anne Dievler

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CHILD AND ADOLESCENT HEALTH POLICY CENTER

Principal Investigators: Bernard Guyer, MD, MPH
Anne Johansen, PhD

Project Director: Jennifer Harlow, MHS

Address: Department of Maternal and Child Health
The Johns Hopkins University
School of Hygiene & Public Health
624 North Broadway
Baltimore, Maryland 21205

Telephone: (410) 955-0219
Fax: (410) 955-2303

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Sustainability of Primary Care Demonstration Projects: End of Year I Report

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Sustainability of Primary Care Demonstration Projects: End of Year I Report

I. Introduction and study rationale

During the history of the Title V Maternal and Child Health Program, "demonstration projects" have often been funded to test the effectiveness of a particular model or type of program with a limited commitment of funding. Often, there is an underlying intention that these demonstration projects continue to survive beyond the initial grant, sometimes with public funding, sometimes without. It is not well understood why some demonstration projects are sustained, while others are not sustained. The emphasis seems to be on getting programs off the ground rather than on examining how they unfold over time, how they change in response to new environmental demands, their continued appropriateness, and survival. In the case of ineffective or inappropriate projects, one might hope that they do not continue in the long term. But when a project is effective, it is important to understand factors which might help it to survive over the long term. While funding plays a significant role in the sustainability of a project, there are other important factors, including project organization and management, project integration with other programs or services, community participation, and political support.

This research project tells the story of the evolution, survival and demise of a Title V primary care demonstration project which was known as the Children and Youth (C&Y) Project. Established in 1966, the C&Ys provide a valuable model for a case study because there was tremendous variability in their survival across states and within states. With the current interest in primary health care for children, it is also valuable to study a project that was developed nationwide with a substantial amount of initial funding. The C&Y projects, like their counterparts, the Maternal and Infant Care programs, were considered the "boldest and most extensive policy and programmatic initiatives undertaken in the Title V program since its enactment in 1935....they were a significant innovation, therefore, in that they defined and expanded the responsibilities of the Title V program in providing comprehensive health care services for urban, low-income and other high risk populations" (Coburn, 1981).

While the C & Y projects date back to the 1960s and have undergone various legislative changes, they still exist to

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¹The initial authorization for the C&Ys was $15 million in fiscal year 1966, rising to $50 million for fiscal year 1970 (P.L. 89-97).
various degrees and in various forms today. Thus they are still a contemporary and relevant program, although transformed. In Baltimore, all of the C & Y projects which were initiated in the '60s remain today. In Pennsylvania, all six of the original C & Y projects withstood the major policy changes and survived relatively unchanged into the late 1980s. In 1987, when the C & Y system was eliminated and a new CHAPS (Children's Access to Primary Services) program initiated as a way to address fiscal accountability problems with the C & Y program, sites that received funding for CHAPS built on their previous C & Y programs. Thus the current CHAPS program in these sites is an evolution of the previous C & Y.

Given the state-level factors that might have influenced sustainability, the lack of uniform data on the C & Ys nationally, and the relevance of an in-depth case study for this type of theoretical inquiry, this research will examine the C&Ys in one state, the state of Pennsylvania. In the sections that follow, we will: examine the history of the C & Y program, nationally and in Pennsylvania; present the conceptual framework guiding the study; describe the study methodology; present a case study of two C & Y programs in Pennsylvania; conduct a cross-case analysis; and, draw conclusions.

II. History of the C&Y program, nationally and in Pennsylvania

In the mid-1960s, when the government climate supported the development of many different innovative health care demonstration projects, the Bureau of Maternal and Child Health established the Children and Youth Projects (C&Y). The authorizing legislation, P.L. 89-97 amended Title V of the Social Security Act to provide project grants to states, localities and other public and private non-profit organizations to establish comprehensive health services for children living in low income areas. Services included casefinding, preventive health services, diagnosis, treatment and correction of defects, and aftercare, both medical and dental (Lesser, 1985).

C&Ys were similar to community health centers in their approach to health service delivery. They involved the community through activities such as education, outreach and employment. The projects also provided services in a geographically circumscribed area.

Initially, a total of 59 projects were funded across the country, mainly in urban locations. The urban focus of the C&Ys was in contrast to the more rural orientation of the Title V program. Of the project grantees, 34% were medical schools, 24% were hospitals, and 42% were state or local health
departments (Roemer, 1981).

A limited number of studies have documented the effectiveness of the C&Ys, due in part to a limited amount of resources for evaluation and inadequate research tools. There was a federal research grant given to the University of Minnesota for the Systems Development Project which lasted from 1966-1975. However, the results of this project were geared more towards evaluating the process of the C&Ys, rather than documenting effectiveness through changes in health status. Published studies on the C&Ys are summarized in Appendix A. There was a general consensus that the programs were effective in improving access to preventive care, reducing rates of illness and dental disease and decreasing the incidence of hospitalization among children (Lesser, 1985).

Over the course of the history of the C&Ys, two important policy "turning points" affected the survival of the C&Ys on a national level. The first was the transition to the "programs of projects". The second was the transition to the MCH block grant. In 1967, Title V was amended to eliminate the project grants for the MIC and C&Y projects and transfer the funding to their formula MCH grants. This legislation required that the states develop "programs of projects", consisting of five program areas: maternal and infant care (MIC), children and youth (C&Y), dental health, family planning, and infant intensive care. The amendments were aimed at giving states more responsibility and flexibility in administering projects. The transition to programs of projects was supposed to be implemented in 1972, but did not actually go into effect until 1974. In the final regulations, states were only required to develop one of each of the five projects, consequently many states took the opportunity to significantly cut back or eliminate their C&Y projects (Coburn, 1981).

The second major policy turning point was when Congress amended Title V to create the Maternal and Child Health Block grant in 1981. The block grant consolidated the categorical programs and eliminated the requirement that states maintain "programs of projects" (Rosenbaum, 1983a). As a result of this change, and concomitant cutbacks in federal funding of Title V, nearly all states seriously reduced or eliminated services offered by these projects in fiscal year 1982 (Rosenbaum, 1983b).

In Pennsylvania, the original C&Y projects withstood these major policy changes and survived relatively unchanged into the late 1980s. Originally, six C&Y grants were provided to pediatric hospitals or services of the six Pennsylvania medical

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2 See the "Weckwerth Reports".
schools, five in Philadelphia, and one in Pittsburgh. In the 1970s, Children's Hospital (affiliated with the University of Pennsylvania) asked to be relieved of its contract, and Covenant House Health Services, a free standing community health center, was provided a share of C&Y funds. When the Title V funds were folded into the block grant in 1981, Pennsylvania elected to continue the C&Y projects.

One of the first major tests of the C&Y projects in Pennsylvania was in the mid 1980s, when there was growing concern over the accountability of the C&Y grants. The grants started out as operating grants, with a line-item budget, and the money was not tied into the number of children served. During the 1980s, significant numbers of the C&Y client population were receiving Medical Assistance (MA), constituting 93-96% of the project populations in two of the six projects, 80-90% in two projects, and 65% in another project. There was concern by the state Title V program that there was an overlap of funding between the Medical assistance and the C&Y grant. One former Child Health Program director tried to eliminate the sole source payment system for C&Ys and allocate the funds on a competitive RFP basis, but was prevented from doing so because of political pressure (C&Y Project Summary).

In an attempt to improve the C&Y program in a politically acceptable manner, beginning in fiscal year 1986-87, the state implemented a capitated system of financing. Under this system, the C&Ys received a capitation for each non-Medicaid eligible child. The C&Ys also received some line-item funding for other sources, such as social services and nutrition.

In 1987, a new director of Child Health for the state of Pennsylvania, Scott Bucher joined the Department. With an orientation towards community health, Scott conducted an evaluation of the C&Y projects and a needs assessment. It was his conclusion, and that of his boss, Dr. Evelyn Bouden, Director of Maternal and Child Health, that the current C&Ys were not meeting the need for comprehensive health care services for children across the state. Data collected by Lewin and Associates indicated that there was a high rate of uninsurance and underinsurance among Pennsylvania's children. There was particular concern over children in the "grey area," those whose family incomes are above the Medicaid assistance eligibility level, but were too poor to afford the high cost of private insurance or the high out-of-pocket costs for

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3The original projects were: 1) St. Christopher's Hospital for Children (affiliated with Temple Medical School, 2) Jefferson Medical College, 3) Hahneman Medical College, 4) Woman's Medical College of Pennsylvania, 5) Children's Hospital of Philadelphia, and 6) Pittsburgh Children's Hospital.
preventive health care. Also of concern were the Medicaid children who were "on-again-off-again" due to the family's changing economic status (CHAPS RFP).

Thus in fiscal year 1987, the Pennsylvania Department of Health issued an RFP for the provision of comprehensive primary health services for children. The model promoted in the RFP was a case-coordinated primary health services, under the acronym of "CHAPS" (Children's Access to Primary Services). According to Scott Bucher, all of the six existing C&Y projects were allowed to apply in the RFP, and were even encouraged to apply. The funding mechanism for CHAPS was a fixed monthly capitation fee paid to providers for reimbursement of all required services. Applicants were required to provide primary health care services to at least 100 eligible enrollees (CHAPS RFP).

Of the six original C&Ys, three applied for CHAPS funding and received grants. Two did not apply, and one submitted an unacceptable application. Covenant House did not apply in the RFP. According to Scott Bucher, Jennifer Alcock, the director of Covenant House resigned just prior to the RFP, and perhaps because of the void in leadership, they did not apply. Jefferson also did not apply, for reasons described later in this report. Hahnemann submitted an unacceptable application, and did not try to resubmit or protest the decision not to fund them. In total, 11 CHAPS programs were funded and are currently in operation in Pennsylvania. The state is now in the process of decentralizing its maternal and child health services to the local level. Thus, the state has entered into a contract with the city of Philadelphia to provide MCH services, including administering the CHAPS contracts. According to Harriet Dichter, Director of Maternal and Infant Health for the city of Philadelphia, it is not clear whether the city will continue CHAPS or discontinue it.

III. Conceptual Framework

Considerable resources are spent implementing programs that die soon after initial funding ends. In recent years, the issue of program sustainability has been a growing concern and is likely to assume greater importance, especially as resources dwindle and policy-makers and funders become increasingly concerned with allocating scarce resources effectively and efficiently. Despite the importance of the topic, empirically-based knowledge about its determinants is lacking (Steckler and Goodman, 1989; Lefebvre, 1989).

The concept of sustainability

Several terms have been in use to refer to the phenomenon
of program continuation. Among these are "sustainability", "institutionalization", "incorporation", "integration", and "routinization". The following definitions have been offered:

"**Sustainability** is the capacity to maintain service coverage at a level that will provide continuing control of a health problem" (Claquin, 1989).

"**Project sustainability** is defined by many economists and international development agencies as the capacity of a project to continue to deliver its intended benefits over a long period of time" (World Bank, 1990).

"A development program is **sustainable** when it is able to deliver an appropriate level of benefits for an extended period of time after major financial, managerial, and technical assistance from an external donor is terminated" (A.I.D., 1988).

"The term 'institutionalization' refers to the long-term viability and integration of a new program within an organization" (Steckler and Goodman, 1989).

"Organizational change ultimately involves the process by which new practices become standard business in a local agency. Whether the process is called **routinization, institutionalization, incorporation**, or some other term, it is central to all organizations... ." (Yin, 1979).

While these terms tend to be used interchangeably, they are not synonymous. The study of "institutionalization" is a specific and limited perspective on program continuation referring to integration of a program within an organization. It may carry the connotation of inflexibility and adoption of a program in toto. Furthermore, the focus of the concept of "institutionalization" is on the persistence of the program itself rather than on the benefits it delivers.

In contrast, the term "sustainability" is a broader concept of the continuation process and seems more appropriate to capture the diversity of forms that this process may take. For example, an entire program may be continued under its original or an alternate organizational structure, parts of the program may be institutionalized as individual components, or there may be a transfer of the whole or parts to community ownership. Moreover, as is insightfully suggested by Lefebvre in considering various strategies to maintain the well-known Pawtucket Heart Health Program beyond the initial project period, continuation may occur at levels other than the organizational level, including the individual and network levels. At the individual level, key community members assume a personal commitment to continuing program messages, products,
or services. At the network level, individuals and organizations are brought together to create networks that reinforce program goals and promote coordinated efforts (Lefebvre, 1990). "Sustainability" may better describe the dynamic process necessary for program continuation. Programs survive because they are able to adapt themselves to their environment over a long period of time (Pressman and Wildavsky, 1979). A dictionary definition of the word "sustain" is "to supply with sustenance: nourish," suggesting a living entity with the power to respond and change, just as a program must adjust to new needs and circumstances, if it is to continue. Finally, the definitions of sustainability advanced by leading development agencies emphasize project benefits as being at the heart of the sustainability process.

Conceptual framework and previous research

The study of program sustainability draws on several theoretical perspectives including the theory of organizational innovation (Rogers, 1983), and the developing field of implementation theory and research (Pressman and Wildavsky, 1979; Scheirer, 1981; Goggin, 1987). Most of these models view program sustainability as the final stage of program implementation in a process that occurs over time. Scheirer (1981) has identified three broad levels of analysis for examining program implementation from an organizational perspective:

- the macro level, including the interaction between the program and its environment (e.g., fiscal resources);
- the intermediate level of internal organizational structures and procedures (e.g., program management); and,
- the micro level of individuals' skills, motivations, and cognitions (e.g., commitment to program goals).

Several case studies have appeared in recent years looking at factors that influence the sustainability of health programs. Two notable studies reported in the recent scientific literature have been Bossert (1990) and Steckler and Goodman (1989), both utilizing a multiple-case study design, the first looking at international programs and the latter focusing on domestic programs.

In a multiple-case study of program sustainability, Bossert examined factors influencing the sustainability of 44 projects in Central America and 13 projects in Africa, funded by the US Agency for International Development since the initiation of US government funding to these countries and which had been completed by the time the study began in 1986. Projects were considered as sustained if project activities and benefits continued at least 3 years beyond the life of the project. Bossert categorized the determinants of program
sustainability into: (1) contextual factors, relatively fixed physical, political, sociocultural, and economic conditions and, (2) project characteristics, more amenable to control by project planners and implementors; these include institutional and managerial aspects of the project, project financing, project content, community participation, and project effectiveness.

Another multiple-case study examined factors influencing the institutionalization of ten health promotion programs funded by the Virginia State Health Department for a 3-year grant period and managed by local organizations (Steckler and Goodman, 1989; Goodman and Steckler, 1989). Unlike Bossert's comparative study of programs in different countries, political, economic, and sociocultural factors are relatively constant across the ten Virginia programs; thus Goodman and Steckler's study focused on local-level factors. Goodman and Steckler also used three years beyond the end of the grant to assess sustainability although their conceptualization of sustainability was different. They classified programs into levels of institutionalization, using Yin's concept of routinization as a combination of passages (organizational transitions, e.g., a transition from outside to local funding) and cycles (recurrent organizational events, e.g., annual budget cycles). Goodman and Steckler found that factors that enhanced institutionalization were: existence of a program champion, institutional strength, fit with the mission of the host organization, lack of intermediary organizations, appropriate funding periods, and funding existing programs.

The present study draws from Scheirer's three-level (macro, intermediate, and micro) perspective on the factors influencing program implementation and on previous findings from case studies of program sustainability to identify the dimensions relevant to the study of the sustainability of primary care demonstrations.

IV. Methodology

A. Rationale for site selection

The goal of this study is to examine the history of the Children and Youth (C&Y) projects as a case study in the sustainability of successful child and adolescent health programs. To control for state-level factors, we decided to look at C & Y programs within one state. In order to choose an appropriate state for this analysis, we established several criteria for selection. These criteria included: 1) variability; i.e., within the state not all of the C&Y projects were sustained; 2) original projects; i.e., that C&Y projects were funded in the state during the first year of operation,
1966; and 3) logistical accessibility; i.e., that the state was close to the Center's headquarters, either within Region III of the Public Health Service (PA, VA, W.VA, Del., MD) or nearby (D.C.).

Before proceeding further, we conducted a review of the literature to ascertain the history, purpose, scope, and effectiveness of the C&Y projects. We also looked at the authorizing legislation. From this literature review, we determined that there were 59 original programs implemented in 1966. We then obtained a listing of these original 59 projects.

From the original list, we were able to eliminate Delaware and West Virginia from selection because there were no C&Y projects funded in the state in the first funding cycle. Next, we conducted phone or in-person interviews with key informants, including MCH program directors and former C&Y project directors, to find out more about the programs in MD, PA, VA, and D.C. (Appendix B).

Although we had originally planned to focus on the projects in Maryland because of the obvious accessibility to key informants, we discovered that in Maryland, as well as in Virginia and the District of Columbia, the original C&Y projects were sustained and there has been no distinct variability. In Maryland, there were five original projects. One program was added in the 1970s and the original five projects continue to this day, funded by the MCH block grant, through a competitive bid process.

In Virginia, there were two original projects, one in Norfolk, and the other in Charlottesville at the U. of VA medical center. While the Charlottesville project is no longer funded by the state, it continues to be operated with private funding, and the Norfolk project continues to be run by the local health department with MCH block grant funding. In the District of Columbia, there were two original C&Y projects, one operated by Children's Hospital, the other operated by the D.C. Department of Health. Both projects have been sustained with funding from the District, although they are no longer called C&Y projects.

The interview with the Pennsylvania Director of Primary Care Programs revealed that in Pennsylvania there has been some variability of C&Y programs. Originally, there were six C&Y programs in Pennsylvania: five in Philadelphia and one in Pittsburgh. In 1974, the projects were turned over to the state. Although there was a sense that the projects should be competitively bid at this time, the political atmosphere thwarted any change, and the original projects and administrative structures continued to function until 1987. At
this time, a needs assessment was conducted to determine the statewide needs for community based primary health care for children. This needs assessment helped crystallize the support for conducting a competitive RFP of the C&Y projects. Thus in 1988, the contracts with the original providers were terminated and the programs were put out to bid. From this RFP, 11 programs were funded under the title, "Children's Access to Primary Care Services." Of the six original C&Y projects, three were funded in the RFP and three were not. Two of the original providers failed to submit bids in the RFP, and one original provider submitted an unacceptable application.

From this preliminary research, it appeared that Pennsylvania met the criteria for a site to the best possible degree. There was variability in the projects' sustainability, the state had original projects funded in 1966, and the state was close to the Center for logistical accessibility in conducting the case study. In addition, as part of the Child and Adolescent Health Policy Center, there was another project focusing on Pennsylvania. This project was to provide assistance to Pennsylvania in developing systems of primary care and a tool to evaluate the system. We felt that this project would provide important background information for our study of the C&Y program.

B. Definition of sustainability

In this study, we viewed the transition from the C&Y model to the CHAPS model as an evolution of the original program. Thus, we considered the three original C&Ys that received CHAPS funding as "sustained," and the three that did not, as "not sustained."

For the pilot phase of this research project (Year one), we chose one C&Y which was sustained, and one that was not sustained. St. Christopher's Hospital for Children C&Y and the Jefferson C&Y project were selected. St. Christopher's Hospital for Children currently operates a CHAPS model. The Jefferson C&Y no longer exists. These two projects were selected as a pair because 1) they were both sponsored by medical schools, 2) they were both originally located in the community (as opposed to based at the medical school or teaching hospital), and 3) there were knowledgeable key informants available to provide an oral history of the projects since their initiation, more than 25 years ago. Examining matched pairs of programs that vary with respect to implementation outcome but are similar in other respects is a way of dealing with the "too few cases/too many variables" problem enduring in case studies (Goggin, 1986).
C. Interview instrument and approach

Using Goggin's approach to the study of the EPSDT program (Goggin, 1987), we used focused interviews as a way to gather data about each of the Jefferson and St Chris C & Y programs. Respondents were asked broad open-ended questions about each general domain, then more specific questions depending on the answers. The domains we probed in the interviews included: project history and respondent involvement; project organization and management; project staffing; project financing; project leadership; project effectiveness/evaluation; coordination with other programs/agencies; community participation/outreach; support/advocacy for the project; project visibility; political support; and, project role as a model program. The full interview schedule is located in Appendix C.

Study respondents included: one state level official; 6 C & Y program directors (3 at St Chris and 3 at Jefferson); 1 Chair of the Department of Pediatrics at St Christopher; and 2 C & Y pediatricians at St Christopher Hospital (see Appendix D). Five other individuals were approached: two individuals at Jefferson declined to participate; another never returned our calls; two individuals at St Chris stated that they were not familiar with the early history of the C & Y project as they joined St Christopher Hospital after the advent of the CHAPS program.

All interviews except one were conducted by telephone. Individuals were sent an initial letter describing the study, followed by a telephone call to schedule the interview and a second call to conduct the interview after having obtained informed consent.

The first interview was conducted with Dr. Evelyn Boudin and lasted approximately three hours. We realized after completing this interview that the interview was too long and that some of the questions (especially macro-level questions requiring a knowledge of policy that individuals at the local level may not be aware of) were not suitable for all respondents. For the remainder of the respondents, the interview was tailored so that only questions thought to be relevant to the particular respondent were asked.

V. Case 1: The Jefferson C&Y Project - Not sustained

In 1968, the Jefferson Medical College Department of Pediatrics received a grant of $599,913 to establish a Children and Youth Project in a neighborhood in Philadelphia. The first project director, and the author of the grant application was Dr. Edwin Harrington. Over the course of its twenty-one year
history, from 1968-1989, the Jefferson project had six different project directors. The chairman of the Department of Pediatrics during this time period was Dr. Robert Brent who continues to be the chairman of Pediatrics at Jefferson.

The project's first location was in the community, at 13th and Fitzwater street. Children's Hospital had a C&Y project nearby, at 1427 Catherine Street, which was called "Rebound." Between 1979-1980, Children's Hospital pulled out of their project and Jefferson took over, located at the Rebound project on Catherine Street. In 1988, when the state issued an RFP for the CHAPS project, Jefferson did not apply. It is not completely clear why Jefferson did not apply. The state officials did not have a reason. The decision to apply seems to have rested with the Chairman of Pediatrics, and not with the Director of the project, who was Dr. Tapper. Dr. Tapper said he was part-time director at the time of the RFP, and that he was not consulted in the decision not to apply for CHAPS funding. It appears that Jefferson lost interest in the project, perhaps due to declining funding or the change in the approach. There was also a perception that the state was not as supportive of the medical school and wanted more control over the C&Y money, in contrast to the original grants which went directly from the federal government to the medical school.

Project Organization and Management

After the first four years, there were changes in project organization and management. Originally, the theoretical model required 20 hours of professional time. The professional staff, including physicians, social workers, etc. were required to conduct long interviews with patients to compile a comprehensive history. This seemed to inhibit patients from coming in for care. Under Dr. Zeccardi's administration, the emphasis was on a more practical service delivery approach with a focus on providing episodic care or some needed service (e.g., immunizations or WIC), to get people into care; only after patients received this care, did the staff deal with trying to provide comprehensive services.

The interview schedule included a question about correspondence between the mission and goals of the C & Y and the mission and goals of the medical school. On a scale of 1 to 10, with 1 being no correspondence at all and 10 being

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"The project directors were: Dr. Harrington (1968-1972), Dr. Zeccardi (1972-1974), Dr. Mobley (dates not available), Dr. Sewell (dates not available), Dr. Chodoff (1982-1984), and Dr. Tapper (1984-1989)."
perfect correspondence, the correspondence of goals between the project and the medical school was rated at around 5 or 6. The project served as a training ground for physicians, although that was not a major function. There was some integration of the services of the C&Y project and the medical school.

**Staffing**

The quantity and quality of staffing seemed to vary over time. In the early 1970s, according to Dr. Zeccardi, there were 85 staff, mostly full time. In mid 1980s, there were 25-30 staff. The quality of the professional staffing was low in the beginning and then became better.

The project employed members of the community who were paid for their services. Some did good work; however, one director felt that the quality of their work was only average, and that the community staff were probably overpaid.

**Financing**

The grant for the Jefferson C&Y seemed to hover around $600,000 for many years until the mid 1980s when it grew to a little over $1 million, before starting to decline, first to $900,000, then to $600,000, and finally to $200,000.

There were conflicting perspectives on funding: one director said the medical school provided matching funds; another said the medical school took a large proportion of overhead from the grant. This Director felt that taking overhead was inappropriate and not justified, since the project received very little support from the medical school.

**Leadership**

There were conflicting opinions about the level of leadership and commitment of the project's different directors, administrators, and the chairman of pediatrics. One director from the 1970s said that the chairman of pediatrics was a great support and was very committed. He said it was not Dr. Brent's but the project director's role to be a leader. During this time, the project administrator was perceived as not effective at all and somewhat uncommitted.

Towards the end of the project's history, the project director at that time said that Dr. Brent was both not committed at all to the project and not very effective, although the administrator of the project was both committed and also very effective.
Project Effectiveness

There were no formal evaluations of the Jefferson C&Y which showed its effectiveness in terms of health outcomes or quality of service. Overall, it was felt that the project did a good job in meeting the needs of the low income children and youth in the area. It seems that, in the beginning, the community was not very satisfied with the services but that satisfaction increased over time. One director noted that the community either overtly or subconsciously realized that the federal government can establish a program and pull out at any time, so they had low expectations regarding its effect.

Community Participation/Outreach

The Jefferson project had a variable history in involving the community. There was a community board at one time. In the early 1970s, there were active attempts to do outreach in the community but, in later years, outreach was more limited and efforts at working with community groups met with little success. Thus, when the project ended in the late 1980s, there were no vocal community advocates for the project. One C & Y director stated that Jefferson did not have a great deal of commitment to the poor.

Project as a Model

Considering the entire history of the Jefferson C&Y project, from 1968 to the 1988, it served as a successful model of primary care services for children. While one director said the project evolved over time and became more efficient, another director said the project did not adapt as much as it should have to the changing environment.

VI. Case 2: The St Christopher Hospital C & Y project - Sustained

In 1966, St Christopher Hospital for Children received a grant to establish a Children and Youth project in a neighborhood in North Philadelphia, the poorest area in Philadelphia. Dr. Evelyn Bouden was the author of the initial grant proposal and selected the project site. Dr. Bouden served as director of the St Chris C & Y from its inception in 1966 until 1970. Over the course of its long history, St Chris C & Y had six directors.\(^5\)

\(^5\) The project directors were: Dr. Evelyn Bouden (1966-1970), Dr. Jonathan Levitts (dates not available), Dr. Sydney Sussman (dates not available), Dr. Guitty Banaan, acting medical director, (dates not available), Dr. Richard Goldstein (dates not
The federal government's goal was to give C & Y grants to teaching hospitals directly. Dr. Victor Vaughan, Chair of Pediatrics (1966-1976) when the C & Y project began at St Chris, recalls that all five medical schools in Philadelphia who had been recipients of C & Y federal funds were brought together in a structure called "Comp Care" to receive and dispense C & Y funds and to give common direction to each C & Y. The chairmen of Pediatrics at each of the medical schools served on Comp Care. According to Dr. Vaughan, Comp Care was not a very effective structure as each of the C & Ys eventually did what it wanted to do.

The C & Y's intended focus on the community was seen as its main contribution to ambulatory care at St Chris. The project was initially physically located in a row house on Germantown Avenue in the community. The community served by the C & Y had a big Spanish population, approximately 30%. Around 1975, a decision was made to move the C & Y from its location in the community into the outpatient department of the hospital. Physical additions (rooms in trailer attached to the hospital) were made to St Chris that were identified as C & Y. According to one of the study participants, the move from the community to the hospital occurred as a result of pressure to bring the C & Y money to the hospital. But according to Dr. Sussman, chief of Ambulatory Pediatrics at the time of the C & Y move, the C & Y was incorporated into St Chris because it was not viable in the community. When the C & Y project moved to the hospital, there was no longer differentiation between the director of the C & Y and the director of Ambulatory Pediatrics.

Dr. Bouden did not seem to favor the removal of the project's physical location from the community. Others viewed the physical relocation of the C & Y project as having both pros and cons. From the physicians' perspective, the pros included more support for faculty and greater ability to share laboratory and specialty care services with the hospital. Some of the negatives were: the physicians lost their identity as C & Y community physicians; a lesser focus on the family unit as a whole and a greater focus on providing care to the individual patient and on teaching students and residents. Another consequence of the move was the elimination of the van that was available to pick up patients since the beginning of the C & Y project.

The C & Y grant was terminated in 1987. St Christopher Hospital was told that the State Health Department was going to revise the concept behind the C & Y to make it a capitation type system. When the C & Y grant ended, the State Health available), and Dr. Charles Reed (1982-present).
Department notified St. Chris and encouraged the hospital to submit a proposal for the CHAPS program saying that they would be given priority since they had a C & Y. Dr. Reed, chief of Ambulatory Pediatrics at St Christopher since 1982, views the current CHAPS as a spin-off or an evolution of the previous C & Y. In fact, according to one of the physicians, some still refer to the program as C & Y.

Project Organization and Management

The relationship of the C & Y project to the hospital was somewhat uneasy, at least in the early project period. According to one C & Y director, there was a perception that the hospital exploited the C & Y for its own purposes. The C & Y grant was the largest grant the outpatient department had. At the same time, there was resentment from hospital staff about the perceived privileged status of C & Y patients, e.g., regarding the availability of a van to pick up C & Y patients and Family Health Workers (FHWs) to do home visits. The hospital staff wanted these services for their patients too.

In response to the question about correspondence between the mission and goals of the C & Y and the mission and goals of the hospital, participants generally agreed that there was tension between the hospital's mission as a secondary and tertiary care center and the C & Y's status as a satellite primary care unit within the hospital. This tension seems to have lessened over time as the C & Y became more integrated into the hospital. On the other hand, there was correspondence between the C & Y and the hospital with respect to the fact that both were highly committed to serving the needs of the local community.

C & Y services were delivered through a team approach. Each child entering the C & Y program was assigned to one of three teams. Each team was composed of a physician, a nurse practitioner, a social worker, a family health worker (who was recruited from the community, paid and trained to work as a nursing assistant), and a community health worker (who made home visits). The team approach began in 1968 but was gradually discontinued in the early 80's. According to one of the C & Y physicians, this was due to two factors: (1) decreasing funding (e.g., the project could only afford one social worker for all three teams instead of one per team); and (2) increased integration of the C & Y within the ambulatory care department which meant that the C & Y needed to fulfill more and more of the teaching responsibilities of the department. Patients were seen more and more by residents in training and the team concept which stressed continuity of care could no longer be adhered to.

Decisions concerning day-to-day management were done at
the medical director level. In response to the question about any management difficulties that the project staff may have experienced, answers centered around: (1) the difficulty of the Weckwerth reporting system, the challenge posed by the need to deal with all the encounter forms as part of that system and the burden of automating the system; (2) according to Dr. Reed, the biggest management issue in the 80s was how to contend with decreasing funding and still maintain the integrity of the program; and, (3) the desire to meet the community's need for evening and weekend hours was troublesome for the pediatricians because of the project's location in the inner-city.

Integration of the C & Y project with existing services occurred in several ways. During the initial period when the C & Y project was located in the community, the project shared staff with St Chris and space with the Office of Economic Opportunity (OEO) program. In fact, a special feature of the C & Y was its linkage with Temple University's OEO program. Some of the linkages were as follows:

- The community advisory board was one and the same for both OEO and C & Y.
- The C & Y's Family Health Workers received their training through Temple University's OEO program.
- OEO paid for some of the C & Y project's rent because the C & Y project was the first occupant of the building.

**Staffing**

Most participants rated the quality of project staff as excellent (rating of 9 on 10-point scale). All the physicians had academic appointments at Temple. Only one medical director during the earlier C & Y period stated that C & Y providers were not seen as very outstanding doctors. This is probably related to the primary/tertiary care tension noted earlier between the C & Y and the hospital as a whole.

Most participants felt that the C & Y had enough staff or was slightly understaffed during its earlier years. According to Dr. Bouden, the idea was to remain small in order to follow the intent of the C & Y as a replicable model. However, in the 1980s, Dr. Reed noted a worsening problem with understaffing each year because of decreasing funding. As of 1982, family health workers were discontinued and the number of social workers reduced.

Another characteristic of the staff was its stability. The two physicians interviewed in this study, Dr. Guitty Banaan and Dr. Pensri Wanglee, who each headed a team of C & Y providers, spanned the entire C & Y project period since its
inception in 1966. Both continue to serve as providers on the current CHAPS.

Financing

In general, the picture that emerges is one of relatively adequate funding in the early years of the C & Y with gradually increasing funding difficulties in the later years. Even in the early years, however, Dr. Bouden stated that funding was sufficient only because it was augmented by OEO dollars (e.g., payment of rent; payment to improve the entrance to the building and waiting rooms) and in-kind services of the hospital. According to Dr. Vaughan, the C & Y grant was not increased over time to take care of inflation and the institution, which was committed to the local community, had to contribute financial support to the C & Y.

Leadership

As mentioned earlier, there was some resentment from hospital staff directed at the C & Y which, according to some, may have been due to the personality of some of the early directors. Generally, however, the perception was that the C & Y was, on the whole, well served by its leadership over the years. In particular, Dr. Bouden, the first director of the C & Y, was seen as having been the initial force behind the C & Y and very effective in serving the goals of the C & Y, particularly its commitment to the local community.

Project effectiveness/evaluation

Most participants agreed that, overall, the C & Y project did a good to excellent job in meeting the enormous needs of the low-income children and youth in the area it has served in a comprehensive manner, that is by addressing both the medical and social needs. One physician stated that, in contrast, the current CHAPS program is more limited because it addresses only medical needs. However, several participants agreed that the C & Y's contribution to the community was best measured by use of services rather than by impact on the health of the community. Quality of care was assessed by monitoring the number of lab tests done, the number of patients who received immunization or social worker counseling, etc. The impact on health status, however, was not formally scrutinized and was not requested by the government.

Dr. Bouden stated that any reservations she may have about the effectiveness of the C & Y have to do with system issues that the C & Y model could not overcome: inability to totally link up with the emergency care the children received and the lack of provider contractual agreement made tracking and continuity difficult.
The perception was also that, generally, the community itself was very satisfied with C & Y services. The community advisory board and the FHWs helped to give feedback from the community to the project.

Coordination with other programs and agencies

In the later years of the C & Y project, there did not appear to be a great deal of coordination with outside agencies. However, early on, when the C & Y was still in the community, there was, according to Dr. Bouden, a high level of integration, at least with the Department of Public Health, which followed up on children with tuberculosis and lead poisoning and tracked individuals moving from community to community. There were formal agreements and regular meetings with public health department staff and with OEO program staff. The C & Y project also did things with the schools.

Community Participation/Outreach

According to Dr. Bouden, the C & Y project's relationship to the community it was intended to serve was close. At least in the early years of the C & Y, there was, according to Dr. Vaughan, a very earnest attempt to bring the community into planning and evaluation. When the C & Y project first began, it had a community advisory board which met at least monthly and was very vocal. The Chair of the community advisory board when Dr. Bouden was there was Mr. Irish Hamburger, a taxi driver in the community. Since the C & Y project and the OEO program shared the same community advisory board, the board had more than 60% of its members as community members (fulfilling a requirement of the OEO program). There was also faculty representation on the board. According to one of the physicians, the board did not have a role in management but served as a means for the community to communicate certain things, such as requests for night clinics, frequency of visits of FHWs. The community advisory board was discontinued when the C & Y project moved to the hospital.

The FHWs who lived in the community also gave feedback to the project staff. That was very good but there was great concern over confidentiality of records. A system of grievance was also in place whereby clients put grievances into boxes which went to the pediatricians who then tried to address them.

Project visibility

There was some advertising about the C & Y project in its early years. According to Dr. Bouden, newspaper stories and brochures went out to the community.
Project as a model

Generally, participants agreed that the C & Y model was a successful model for the delivery of comprehensive health services to children and youth. According to Dr. Bouden, the provision of health services to low income families must emphasize community outreach. The C & Y project must be out in the community; as long as it is in the hospital, it is not a model. Ideally, pediatricians should have an academic home in the teaching hospital but serve in the community. One physician noted that since health care is not a priority for this population, extra effort is needed to provide such care. FHWs were a great help because they knew the families in the community and their problems. Dr. Reed stated that the C & Y model was a good model, at least early on, because it permitted the provision of services to a low-income population who would otherwise not receive comprehensive services. These youths, he said, need more than physical exams. They need psychologists, nutritionists, and social services.

Participants stressed the support of the hospital, its contribution of in-kind services to the C & Y, and the commitment to primary care as key to the success of the C & Y. One participant, however, suggested that in-kind support from the hospital was not enough and that C & Y funding was not adequate for growth.

Several participants suggested that St Chris' commitment to the community was greater than other medical schools' commitment to their local community, and attributed this partly to the fact that St. Christopher is embedded in the worst poverty area of Philadelphia.

Dr. Reed mentioned three things that would make the C & Y program better: (1) realistic funding; (2) objective parameters to measure impact. This caveat was also stressed by Dr. Sussman who felt that we cannot legitimately estimate the effectiveness of the C & Y program as the impact on the health of the community has not been adequately studied; and, (3) the C & Y program should have been better tailored to suit local community needs. Social services, nutrition services, and CHWs were the first things to go with funding cuts. St. Chris saw a great need to have CHWs and lost something very vital when it could no longer afford CHWs. Dr. Reed stated that, in other communities, CHWs may play less of a vital role, but at St. Chris the loss of CHWs was a vital loss.

Dr. Reed stated that the current CHAPS program has been a great disappointment to St Chris, so much so that they have seriously considered not renewing their contract. He cited three drawbacks of the current CHAPS program: (1) too much paperwork and administration; (2) difficulty in identifying the
right patients eligible under CHAPS (those eligible for CHAPS must be not eligible for Medicaid); and, (3) the fact that CHAPS does not provide comprehensive care. One physician stated that the team approach is no longer a feature of the current CHAPS program. There is only one social worker for four physicians and no more family health workers.

Among other factors identified by the physicians as influencing the long-term survival of the St Christopher Hospital C & Y was the stability of the staff. As was mentioned earlier, two of the physicians interviewed in this study, Dr. Guitty Banaan and Dr. Pensri Wanglee, spanned the entire C & Y project period and both continue to serve as providers on the current CHAPS. One of the physicians stated that smallness, a lot of money, and the best staff are the three factors that everybody mentions as key to the success of the C & Y program at St Chris.

According to Dr. Sussman, political considerations account for why the C & Y program was in place for such a long time. "We were very concerned about doing something for poor people during the early years of the C & Y." But, he said, times have changed. Finally, Dr. Vaughan talked about the lack of commitment to children in the United States and wanted to go on record as saying that "anything dealing with children doesn't get strong commitment in the Nation. Even children's librarians earn less than librarians for adults."

VII. Cross-case analysis and study implications

The above descriptions of each of the C & Y programs tell the "story" of each of the programs. Since the logic of comparative case studies is to focus on the differences between the programs, and not the similarities, uncovering some of the differences between the two projects may serve to identify some explanatory themes and generate hypotheses about factors influencing sustainability that could be tested in future research.

A number of hypotheses about factors influencing sustainability are suggested when the two programs are compared:

1. Funding

Funding is a clear factor in program continuation. St Chris received CHAPS funding to continue delivering primary care services to children in low-income families in the target community, albeit with different eligibility criteria and a different mode of service delivery; thus, primary care services are still being delivered to the community. In contrast,
Jefferson did not receive comparable funding as it did not apply for it. As mentioned earlier, Jefferson may have lost interest in the project. This loss of interest may be a reflection of other factors, including those discussed below.

2. Integration of the C & Y program into the hospital may enhance its sustainability.

The St Chris project relocated from the community to the hospital approximately five years after its inception. While respondents identified certain negative effects of the move, the contribution of in-kind services by the hospital and the hospital's assistance with resources as the C & Y funding declined suggests that the St Chris program was integrated into a mature resourceful organization which contributed to its survival.

In contrast, the Jefferson project was continuously located out in the community in a free-standing manner and thus may not have had the benefit of the hospital or another parent organization contributing resources to supplement declining funds or providing a supportive and nurturing organizational niche for the program.

3. Supportive leadership may enhance sustainability

While some individuals at Jefferson noted problems with program leaders who were unsupportive of the C & Y, there was no such active opposition to the C & Y at St Chris.

4. Commitment to the local community may enhance program sustainability

Almost all respondents noted the strong support of the St Christopher Hospital to the local surrounding community which its C & Y program was intended to serve. The goals of the C & Y and those of the hospital were seen to converge in so far as both were strongly committed to the community. Thus the degree to which program mission corresponds with institutional mission may enhance sustainability.

Another feature of the St Chris C & Y which may have served to reinforce its community orientation and commitment was its linkages with Temple University's OEO program. These linkages consisted of: shared space (before the program moved to the hospital); a common community advisory board; and training of C & Y Family Health Workers through Temple University's OEO program.

In contrast to the strong commitment to the local community evidenced at St Christopher, at least one individual affiliated with the Jefferson project noted that Jefferson did
not have a big commitment to the poor and was not particularly interested in the project itself, seeing it merely as a form of public relations with the community.

5. Stability of staff may enhance program sustainability

Two individuals at St Chris mentioned stability of staff as one of the reasons for program viability. It is not clear how stable Jefferson staff were.

Study limitations

The St Christopher C & Y "story" may be more complete than the Jefferson "story" as more respondents contributed to the description of the St Chris program. There was also a great deal of convergence in what the respondents at St Chris told about the program which lends greater validity to the observations about the program (Yin, 1989). Such convergence could not be observed in the case of the Jefferson program because of the more limited number of respondents available to provide information about that project.

None of the St Chris contacts declined to participate while three of the Jefferson contacts either refused to participate or made no effort to return repeated telephone messages. This may be due to two factors that are likely to be enduring limitations in sustainability studies: (1) greater willingness to participate in the sustained compared to the non-sustained project because the sustained project may be viewed as more "successful" than the non-sustained project by virtue of having survived; thus sustainability may be equated with a positive outcome while a non-sustained project may be viewed as a bad outcome; 2) Jefferson staff appeared to have been less stable than the St Chris staff. Finding project staff is likely to pose some difficulty whenever the study of a noncontemporary project is attempted.

The definition of sustainability in this study is less than ideal. Both programs studied in this pilot effort were sustained for more than twenty years as funding was renewed each year. Thus, even the non-sustained program at Jefferson survived for a long period of time before it ended. Future studies of the sustainability of primary care demonstration projects may examine programs closer to the end of their demonstration period.

Next steps

Having completed a study of two C & Y programs in Philadelphia, one defined as "sustained" and one considered "not sustained", we suggest the following points for consideration in planning the future scope of work:
1. The study conducted in year I was a useful pilot study of the sustainability of primary care demonstration programs. We accomplished at least the following: (1) tested the feasibility of conducting this kind of study; (2) pilot tested an instrument for assessing the determinants of program sustainability; and, (3) generated some hypotheses to be explored more fully in future work on this topic.

However, our definition of sustainability was not ideal. Both programs studied survived for over 20 years before one of them (the non-sustained) program ended. Both programs experienced and survived many changes, e.g., in funding source, type of funding (project grant then block grant) and amount of funding. Thus, this study was, in a sense, more a study of program evolution over time than program sustainability. A more persuasive definition of sustainability would be one where the survival of a program is examined closer in time to the end of the initial funding period. In the scant literature on program sustainability, the specification of an acceptable time frame for assessing project sustainability has been limited to vague suggestions but has usually translated, in practice, to three and five years post-project period as cut-off points.

2. Studying the remaining 4 C & Y programs in Philadelphia in year II, as was initially suggested, may not yield any significant new information. We will still be limited in terms of power to draw broad-based conclusions on the determinants of the sustainability of primary care demonstration programs. We therefore propose abandoning initial plans to continue the study of C & Y programs in year II.

3. Instead, we propose to consider another set of programs for the analysis of sustainability. This new set of programs would be selected in such a way that: (1) the definition of sustainability would be more satisfactory (see point 1 above); and, (2) we would attempt to examine a greater number of programs (to increase power) and a more representative set of programs (e.g., more variability in program site - C & Y programs in Philadelphia were primarily hospital-based).

One potential fruitful avenue to take this research is to work with the Robert Wood Johnson Foundation (RWJF) to explore the feasibility of examining some RWJF-funded demonstration programs. This may be worthwhile pursuing for two reasons: (1) Dr. Guyer has recently completed a study of RWJF-funded maternal and child health programs; one of the conclusions of this study was that sustainability was an important issue in these programs and that very little was known about what has been sustained; (2) Dr. Shediac submitted a grant to RWJF in September 1990 to conduct an analysis of program sustainability. The grant proposal was not funded but received an enthusiastic response and an encouragement to resubmit.
Potential programs that we may examine for sustainability include "Healthy Tomorrows" funded by RWJF with the American Academy of Pediatrics or "Healthy Children". In the latter program, for example, there are no data on which of the 25 communities that received funding for this program sustained the programs after RWJF funding ceased.

VIII. References


C&Y Project Summary, Pennsylvania Department of Health (undated)


IX. APPENDICES
Appendix A

Summary of C & Y studies

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<thead>
<tr>
<th>CITATION</th>
<th>MEASURE</th>
<th>RESULTS</th>
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<tr>
<td>Becker, M.H., et al. 1974. A field experiment to evaluate various outcomes of continuity of physician care. AJPH. 64:1062-1070.</td>
<td>Continuity of physician care.</td>
<td>Patient families and medical staff of a large C&amp;Y project were randomly assigned to a conventional &quot;sequential&quot; clinic, or to a &quot;panel&quot; clinic, with an assigned pediatrician for each patient. The physician continuity of the panel clinic produced greater patient and staff satisfaction and had a positive effect on mother's health beliefs and behaviors.</td>
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<td>Davis, K. and Schoen, C. Medical Care for mothers and children: the MCH program. In: Health and the War on Poverty, Washington, D.C.: The Brookings Institution, 1978, pp.120-161.</td>
<td>Hospitalization; preventive care.</td>
<td>In 1972, 59 C&amp;Y projects served 500,000 children. The projects have been successful in meeting the needs of the children they serve. Days of Hospitalization declined from 101 per 1,000 registrants in 1968 to 42 per 1,000 in 1972. The annual cost per registrant also declined, from $201 in 1968 to $131 in 1972. The C&amp;Ys have also been effective in reducing the high incidence of correctable defects, particularly dental caries and hearing and visual defects.</td>
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<td>De Geyndt, W., Sprague, L.M. 1972. Differential patterns in comprehensive health care delivery for children and youth: health department, medical school, teaching hospital. <em>AJPH.</em> 60:331-335.</td>
<td>Delivery patterns and organizational differences in C&amp;Ys.</td>
<td>C&amp;Y projects managed by health departments exhibited greater outreach and extensive cooperation with existing community resources and were more effective in recruiting and registering children. Projects managed by teaching hospitals and medical schools drew patients from the OPD and ER as a referral source. They were less effective in cooperating with community agencies.</td>
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<td>Gordis, L. 1973. Effectiveness of comprehensive-care programs in preventing rheumatic fever. <em>NEJM.</em> 289:331-335.</td>
<td>Incidence of disease.</td>
<td>Children eligible for care at one of the comprehensive care (C&amp;Y or OEO) projects in Baltimore had a lower rate of rheumatic fever than a similar comparison group ineligible for care at the projects. Moreover, the rate of rheumatic fever decreased 60% between 1960-64 to 1968-70 in census tracts with comprehensive care projects, but was unchanged in the rest of the city.</td>
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<td>Kaplan, R.S., et. al., 1972. The efficacy of a comprehensive health care project: an empirical analysis. <em>AJPH.</em> 62:924-930.</td>
<td>School Attendance.</td>
<td>A C&amp;Y project in Pittsburgh produced an improvement in school attendance; however, other variables, such as the proximity of the school, race, sex &amp; socioeconomic conditions exhibited an even greater effect.</td>
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<td>Kotch, J.B. et. al., 1988. Productivity and selected indicators of care in maternity and infant care and children and youth projects according to sponsorship. <em>Journal of Medical Systems.</em> 12:294.</td>
<td>Productive and type of care.</td>
<td>C&amp;Ys sponsored by health departments served a larger proportion of infants and preschool children, had more nonmedical encounters and employed fewer physicians and more health educators, social workers, etc. These programs generated fewer third party reimbursements and more state and local funding. In nonhealth department C&amp;Ys, x-ray, lab and pharmacy represented a larger proportion of total costs. In terms of health service measures (eg. immunization rates, anemia screening, and utilization of family planning services, the projects were similar).</td>
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<td>Morehead, M.A. et. al. 1971. Comparisons between OEO neighborhood health centers and other health care providers of ratings of the quality of health care. <em>AJPH.</em> 61:1294-1306.</td>
<td>Quality of care.</td>
<td>Audits of the quality of care provided to patients by hospital OPDs, OEO NHCs, Children's bureau programs (MIC &amp; C&amp;Y), well-baby clinics, group practice programs and rural private practitioners produced high performance ratings for C&amp;Y projects. The C&amp;Ys were rated 60% higher than the average of the hospital outpatient departments in providing pediatric care.</td>
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<td>Owen, G.M. et. al. 1975. Changes in levels of hemoglobin and hematocrits among children and youth registrants between 1968 and 1971. Clinical Pediatrics. 14:445-448.</td>
<td>Hemoglobin and hematocrit levels.</td>
<td>Tests of hemoglobin and hematocrit levels were made on children in C&amp;Y projects in two time periods, March--April 1968 and December 1970--1971. Results showed that median hemoglobin and hematocrit values were higher in 1971 than in 1968. The authors attribute the improvement to increased consumption of iron-fortified formulas and foods, wider prescription of medicinal iron, and more widespread benefits from comprehensive health care, including monitoring and detection of anemia.</td>
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Appendix B
PRELIMINARY INTERVIEWS

Region III, Philadelphia Office:
1. Frank Herron, Regional Program Consultant

Maryland:
1. Dr. S.S. Huang, Program Director, C&Y project at GBMC
2. Dr. Bob Drackman, former Program Director, C&Y project at JHU

Virginia:
1. Joyce Berra, MCH Nurse Consultant
2. Dr. Linyear, Division Director, MCH

District of Columbia:
1. Dr. Fred Green, formerly with Children's Hospital
2. Dr. Swoboda, Chief of Child Health for the District

Pennsylvania:
1. Scott Bucher, Director of Primary Care Programs
Appendix C

SUSTAINABILITY OF PRIMARY CARE DEMONSTRATION PROGRAMS

INTERVIEW QUESTIONNAIRE

Name and site of C & Y being investigated:

Name, address and telephone no. of interviewee:

Interviewer name:

Date of interview:
INTRODUCTION

The purpose of my interview with you today is to learn about the [NAME SITE] C & Y/CHAPS program in order to understand how the program evolved over the years and what factors shaped its evolution and survival. I will be asking you questions in several areas: the nature and extent of your involvement in the program over the years; your perspective on how the program was/is operating; and the role of individuals, other than yourself, and organizations in shaping the program. Before we begin, do you have any questions?

SECTION I. MICRO-LEVEL FACTORS

HISTORY (10 minutes)

First, I would like to ask you a few questions about the history of the [NAME SITE] C & Y / CHAPS program and your involvement in it.

1. As a start, could you briefly summarize what happened to the [NAME SITE] C & Y/CHAPS program since its beginning in the mid-1960s (or as far back as you can recall) and through its various turning points (project grant/program of projects/block grant/competitive RFP) up to the present. RECORD ANSWER

PROBE:

o Who was the recipient of the original grant?

o Date of original grant receipt.

o Where was the project physically located?

o Project dates (Beginning and end; name changes; site/address changes).

o Who was the first director of the C & Y?

o Who were subsequent directors?

o Who was the first project administrator?

o Who were subsequent project administrators?

o What structure was set up for the program?
2. What has been your involvement with the C & Y? More specifically, could you tell me when, how and why you became involved with the C & Y?

RECORD ANSWER with beginning and end dates of employment/involvement with the C & Y and position.

PROJECT ORGANIZATION AND MANAGEMENT (10 minutes)

Now I would like to ask you a few questions about the way in which the program has been administered and implemented.

3. Was the relationship of the project to the medical school of which it was a part? RECORD ANSWER

a) Did the C&Y project appear on the organizational chart of the medical school? 1 = YES (ASK a)
   2 = NO

b) Where? RECORD ANSWER

4. On a scale of 1 to 10, with 1 being no correspondence at all and 10 being perfect correspondence, how well did the goals of the C & Y correspond with the mission and goals of the medical school within which it was housed?

1 2 3 4 5 6 7 8 9 10

5. The original 1965 C & Y grant guidelines specified that "in planning comprehensive health services for children and youth, the organization of services is a key element on the program". Could you briefly describe how services were organized? RECORD ANSWER

6. At what level were most of the decisions regarding the C & Y project made? RECORD ANSWER

7. What kinds of management problems, if any, have there been in the administration of the C & Y / CHAPS project and how have they affected the operation of these projects? RECORD ANSWER

8. How well integrated was the C & Y project to the remaining services and activities at the medical school?

1 = HIGHLY INTEGRATED
2 = MODERATELY INTEGRATED
3 = LITTLE INTEGRATION
4 = NO INTEGRATION AT ALL

PROBE:
- To what extent was there sharing of resources (i.e. staff, space) between the C & Y project and other services delivered at the medical school? RECORD ANSWER
a) Were there any formal and/or written agreements? 1 = YES 2 = NO

PROJECT STAFFING (5 minutes)

Now I would like to ask you some questions about project staffing.

9. On a scale of 1 to 10, how would you rate:
   A) the quality of project staff? 1 2 3 4 5 6 7 8 9 10
   B) the quantity of project staff? 1 2 3 4 5 6 7 8 9 10

10. Was there any inservice or continuing education for project staff? 1 = YES 2 = NO

11. Who have been the most influential doctors staffing the C & Y? RECORD ANSWER

12. What were the various levels of personnel (in terms of training and education) staffing the project? RECORD ANSWER

13. Were community members recruited as project staff (e.g. as nonprofessional community health workers or community health educators)?
   1 = YES (ask a) 2 = NO
   a) Were they paid? 1=YES 2=NO

PROJECT FINANCING (5 minutes)

Now I would like to ask you some questions about project financing.

14. How adequate was the funding (federal and state) for the C & Y project over the years?
   1 = VERY ADEQUATE
   2 = SOMEWHAT ADEQUATE
   3 = SOMEWHAT INADEQUATE
   4 = VERY INADEQUATE

15. Where there any problems at any time as a result of deficiencies in funding? 1 = YES (ask a) 2 = NO
   a) What kinds of problems? RECORD ANSWER
16. Were there sources of funds for the project other than the federal/state grant?
   1 = YES (ask a) 2 = NO

   a) Where were these funds from? RECORD ANSWER

17. Did funding levels change over time (e.g. at transition points from federal grant to state-level funding)?
   1 = YES (ask a) 2 = NO

   a) What was the impact of changes in funding levels?

PROJECT LEADERSHIP (5 minutes)

Now I have some questions about project leadership.

18. How effective was the chairman of pediatrics as a leader?
   1 = VERY EFFECTIVE 2 = SOMEWHAT EFFECTIVE 3 = SOMEWHAT INEFFECTIVE 4 = NOT EFFECTIVE AT ALL

   a) How committed was he/she to the C & Y project?
   1 = VERY COMMITTED 2 = SOMEWHAT COMMITTED 3 = SOMEWHAT UNCOMMITTED 4 = NOT COMMITTED AT ALL

19. How effective was the project director as a leader?
   1 = VERY EFFECTIVE 2 = SOMEWHAT EFFECTIVE 3 = SOMEWHAT INEFFECTIVE 4 = NOT EFFECTIVE AT ALL

   a) How committed was he/she to the C & Y project?
   1 = VERY COMMITTED 2 = SOMEWHAT COMMITTED 3 = SOMEWHAT UNCOMMITTED 4 = NOT COMMITTED AT ALL

20. How effective was the project administrator?
   1 = VERY EFFECTIVE 2 = SOMEWHAT EFFECTIVE 3 = SOMEWHAT INEFFECTIVE 4 = NOT EFFECTIVE AT ALL
a) How committed was he/she to the C & Y project?

1 = VERY COMMITTED
2 = SOMewhat COMMITTED
3 = SOMEWHAT UNCOMMitted
4 = NOT COMMITTED AT ALL

21. Overall, did the C & Y project experience stability and continuity of leadership over its history or did it experience high turnover and instability?

1 = HIGHLY STABLE
2 = SOMEWHAT STABLE
3 = NEITHER PARTICULARLY STABLE NOR PARTICULARLY UNSTABLE
4 = SOMEWHAT UNSTABLE
5 = HIGHLY UNSTABLE
6 = DON'T KNOW

PROJECT EFFECTIVENESS/EVALUATION (5 minutes)

Now I would like to ask you some questions about the performance of the program.

22. What kind of information and data do you routinely collect and keep to evaluate:

a) the level and quality of services provided?
b) impact on the health status of the population served by the C & Y?

RECORD ANSWER

PROBE:
o How is this data collected?
o How is it used?

23. How effective has the project been according to these measures?
RECORD ANSWER

24. Were there improvements in health outcomes?
RECORD ANSWER

25. Overall, how good a job do you feel the C & Y project did in meeting the health needs of the low-income children and youth in the area it has served?

1 = EXCELLENT
2 = GOOD
3 = FAIR
4 = POOR
26. Overall, how satisfied do you think the recipient community has been with the services provided by the C & Y?

1 = COMPLETELY SATISFIED
2 = SOMewhat SATISFIED
3 = SOMewhat DISSATISFIED
4 = NOT SATISFIED AT ALL

COORDINATION WITH OTHER PROGRAMS AND AGENCIES (10 minutes)

Now I would like to ask you some questions about the coordination of the [NAME SITE] C & Y program with existing services and programs in the community.

27. How much coordination and integration of activities and services was there between the C & Y project and other State or local health, welfare and education agencies or programs for children (e.g. other hospitals, community health agencies, schools)?

1= HIGH LEVEL OF INTEGRATION
2= MODERATE INTEGRATION
3= LITTLE INTEGRATION
4= NO INTEGRATION AT ALL

a) Were there any formal agreements/arrangements? YES NO

28. In your opinion, how did the coordination with existing community agencies and staff influence the evolution and/or sustainability of the program? RECORD ANSWER

29. Did the project have a central role in the overall system of primary health services to children and youth at the city level, state level, both levels, or did it only have a peripheral role?

1 = CENTRAL ROLE AT CITY LEVEL
2 = CENTRAL ROLE AT STATE LEVEL
3 = CENTRAL ROLE AT BOTH LEVELS
4 = PERIPHERAL ROLE

30. On a 10-point scale, with 1 being not harmonious at all and 10 being very harmonious, how harmonious has been the relationship between the project and any other outside agencies with which the project was involved?

1 2 3 4 5 6 7 8 9 10

a) To your knowledge, were there any interagency rivalries? YES NO

PROBE:
 o What was the nature of the rivalries?
 o How have they affected program performance?
COMMUNITY PARTICIPATION/OUTREACH (10 minutes)

Now I would like to ask you some questions about the project's relationship to the community it was intended to serve.

31. How would you describe this relationship? RECORD ANSWER

32. Did the [NAME SITE] C & Y have a community advisory board? YES NO
   a) What was the composition of the community advisory board? RECORD ANSWER

PROBE:
   b) What was the percent of community members? RECORD ANSWER
   c) How frequently did the advisory board meet? RECORD ANSWER
   d) How much decision-making authority over the project activities and services did it have?

1=only suggestion/advice/recommendation with no real influence
2=can influence direction somewhat
3=a great deal of control

33. Were there other methods of community involvement/community input in the planning and delivery of C & Y services other than the community advisory board? RECORD ANSWER

SUPPORT/ADVOCACY FOR THE PROJECT (10 minutes)

Now I would like to ask you some questions about your perspective on individuals who acted as advocates for the project at various levels.

34. Was there an advocate for the project from within the community (e.g. consumer advocates or community leaders)? YES NO

PROBE:
   a) Who was it and how did they advocate for the project? RECORD ANSWER

35. Was there an advocate for the project from within the project staff?

PROBE:
   a) Who was it and how did they advocate for the project? RECORD ANSWER
36. Was there an advocate for the project from within the medical school?

PROBE:
  o Who was it and how did they advocate for the project?
  RECORD ANSWER

37. Where were any other individuals who acted as advocates for the project?

PROBE:
  o Who and How? RECORD ANSWER

38. Who have been the major opponents of the C & Y at the project level?

39. What provider groups (e.g., state medical association), if any, became involved with the C & Y?
a) What impact did they have on the project? RECORD ANSWER

40. What "consumer" advocacy groups, if any, became involved with the C & Y?
a) What impact did they have on the project? RECORD ANSWER

41. What impact, if any, do you feel the participation or involvement of any of these individuals or groups had on the evolution or survival of the C & Y project? RECORD ANSWER

PROJECT VISIBILITY (1 or 2 minutes)

42. How was the project promoted or advertised? RECORD ANSWER

PROBE:
  o Were there any newspaper stories/TV or radio announcements about the project?
  o Pamphlets/flyers/poster/newsletters distributed or mailed?
  o Project staff or community members speaking about the project?
SECTION II. MACRO-LEVEL FACTORS

The next set of questions has to do with factors operating at the city, state or federal levels that may have influenced C & Y activities or services.

LEGISLATIVE CHANGES (10 minutes)

43. What impact did the transition of the C & Y project through its various legislative turning points (federal grant/program of projects/block grant/competitive RFP) have on:

a) funding level
b) services offered
c) population served
d) management
e) other?

RECORD ANSWER

44. What was the impact on the [NAME SITE] C & Y of the transition to state administration due to the 1974 change from grant funding to formula funding?

45. What was the impact on the [NAME SITE] C & Y of the advent of the block grant in 1981 in terms of greater state discretion in the administration of the C & Y?

46. The most recent critical turning point in the history of the C & Y projects has been the competitive RFP. What happened? Why did the [NAME SITE] project respond/not respond to RFP? Or why was the [NAME SITE] project turned down for funding?

PROJECT MANAGEMENT

47. To what extent were the federal and state Title V programs involved in the decision-making about the C&Ys over the years?

o How much consultation or technical assistance did they provide and with what impact?

POLITICAL SUPPORT

48. How intensely committed were federal officials to the C & Y project?

1 = VERY COMMITTED
2 = SOMewhat COMMITTED
3 = SOMewhat UNCOMMITTED
4 = NOT COMMITTED AT ALL
o Who have been the most influential federal officials supporting the project?

o Who have been the biggest opponents?

49. How intensely committed were state officials to the C & Y project?

1 = VERY COMMITTED
2 = SOMEWHAT COMMITTED
3 = SOMEWHAT UNCOMMITTED
4 = NOT COMMITTED AT ALL

o Who have been the most influential state officials supporting the project?

o Who were the biggest opponents?

50. How intensely committed were city officials to the C & Y project?

1 = VERY COMMITTED
2 = SOMEWHAT COMMITTED
3 = SOMEWHAT UNCOMMITTED
4 = NOT COMMITTED AT ALL

o Who have been the most influential city officials supporting the project?

o Who were the biggest opponents?

51. What role did the regional office play in supporting the C&Ys?

SECTION III. PROJECT ROLE AS MODEL PROGRAM (10 minutes)

52. Historically, the C & Y program was developed as a demonstration program to test a model of providing comprehensive primary health services to children and youth in low-income families. Do you think the C&Y project has served as a successful model for the delivery of health services to children and youth?

1 = YES, DEFINITELY
2 = YES, TO SOME EXTENT
3 = MAY BE, NOT SURE
4 = NOT REALLY
5 = DEFINITELY NOT
53. Did the project adapt to a changing environment over the years?  
   YES       NO

54. When, at the origin of the project, the medical school received the C&Y grant, what were the expectations regarding the lifespan of the project? RECORD ANSWER

55. As the projects became part of the "programs of projects" and then the block grant, to what extent was there planning for sustainability? RECORD ANSWER

56. What, in your opinion, could be done/could have been done to make the program work better? RECORD ANSWER

57. Now, reflect back on all that we have discussed so far. Are there any other observations that you would want to make concerning factors that influenced the evolution/survival of the C & Y from its inception in 1965 up to the present (or up to its end) that we have not addressed? RECORD ANSWER

Finally, I would like to ask you a few questions about yourself.

58. Position held previous to C & Y:

59. Present position and agency:

60. Highest degree obtained and major subject:

That concludes the interview. Thank you very much for your cooperation and patience. Now that you have seen the kinds of questions I have asked, are there state officials, key consumer or provider spokespersons whom, in your opinion, I should definitely contact to get a complete picture of the C & Y program? What are their names, addresses and telephone numbers?

We would sincerely appreciate receiving any documents that may help us better understand the activities of the [ NAME SITE ] C & Y program (e.g. progress or final reports). Would you mind if I called you back to clarify any answers if I felt unsure about some answers or needed more information? Thank you very much.
## Appendix D

### C&Y Project Key Informants/Contacts

<table>
<thead>
<tr>
<th>NAME/ADDRESS</th>
<th>AFFILIATION</th>
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<tbody>
<tr>
<td><strong>1. Arthur Lesser, M.D.</strong>&lt;br&gt;2924 Rittenhouse St., N.W.&lt;br&gt;Washington, D.C. 20015&lt;br&gt;(202) 244-5332</td>
<td>Former Director of Children's Bureau; Retired; see descriptive article by Lesser;</td>
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<td><strong>2. Vince Hutchins, M.D.</strong>&lt;br&gt;1316 Woodside Parkway&lt;br&gt;Silver Spring, MD 20910&lt;br&gt;(301) 585-9308</td>
<td>Former Director of Med. College of PA C&amp;Y; Former Director of federal Maternal &amp; Child Health Bureau - recently retired;</td>
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<td><strong>3. Evelyn Bouden, M.D.</strong>&lt;br&gt;*&lt;br&gt;604 Washington Square South&lt;br&gt;Apartment 2417&lt;br&gt;Philadelphia, PA 19106-4115&lt;br&gt;(215) 574-1262</td>
<td>Former Director of MCH for the state of Pennsylvania; Former Director of the Temple/St. Christopher's Hospital C&amp;Y Project; Recently retired;</td>
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<tr>
<td><strong>4. Frank Herron</strong>&lt;br&gt; DHHS/PHS/DFHRD/MCH&lt;br&gt;P.O. Box 13716&lt;br&gt;Mail Stop 14&lt;br&gt;Room 10410&lt;br&gt;Philadelphia, PA 19101&lt;br&gt;(215) 596-6686</td>
<td>Regional Program Consultant in Region III Office;</td>
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<tr>
<td><strong>5. Scott Bucher</strong>&lt;br&gt;*&lt;br&gt;Director of Primary Health Programs for Children&lt;br&gt;Pennsylvania Department of Health&lt;br&gt;P.O. Box 90&lt;br&gt;Room 714&lt;br&gt;Harrisburg, PA 17108&lt;br&gt;(717) 787-7440&lt;br&gt;(717) 783-1414</td>
<td>Current Director of primary health programs for children in Pennsylvania - CHAPS projects; Developed RFP for CHAPS in late 1980s.</td>
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<td><strong>6. Harriet Dichter</strong>&lt;br&gt;Director of Maternal &amp; Infant Health&lt;br&gt;Philadelphia Dept of Public Health&lt;br&gt;500 S. Broad Street&lt;br&gt;Philadelphia, PA 19146&lt;br&gt;(215) 875-5927</td>
<td>Current Director of MCH in Philadelphia</td>
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<td>No.</td>
<td>Name</td>
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<td>7</td>
<td>Victor C. Vaughan *</td>
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<td></td>
<td>Clinical Prof. of Pediatrics</td>
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<td>Dr. Charles Reed *</td>
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<td>General Pediatrics</td>
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<td>Jorge Melendez</td>
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<td>Pensri Wanglee M.D. *</td>
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<td>Ambulatory Pediatrics</td>
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<td>11</td>
<td>Guitty Banaan M.D. *</td>
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<td>Same address as Wanglee</td>
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<td>12</td>
<td>Jerry Aronson, M.D.</td>
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<td>216 North Broad Street</td>
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<td>13</td>
<td>Ted Tapper, M.D. *</td>
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<td>1400 South 5th Street</td>
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<td>Philadelphia, PA 19147</td>
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<td>(215) 755-2652</td>
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<td>14</td>
<td>Kwan Lee, M.D.</td>
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<td>Jefferson Community Health</td>
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<td>Care Center</td>
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<td>1427 Catherine St.</td>
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<td>(215) 546-7700</td>
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<td>15</td>
<td>Bill Chodoff, M.D.</td>
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<td>Hospital? HMO?</td>
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<td>3550 Market Street</td>
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<td>4th Floor, Pediatrics</td>
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<td>Philadelphia, PA 19104</td>
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<td>(215) 823-8643/8640</td>
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<td>16</td>
<td>Dr. Robert Brent</td>
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<td></td>
<td>Chairman</td>
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<td>Department of Pediatrics</td>
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<td>Jefferson Medical College</td>
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<td>700 College Building</td>
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<td>1025 Walnut Street</td>
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<td>Philadelphia, PA 19107</td>
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<td>(215) 955-6966 (1 day/week)</td>
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<td>(302) 651-6880</td>
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<td>17</td>
<td>Sue Robbins, M.D.</td>
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<td>18</td>
<td>Senator Schweiker</td>
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<td>19</td>
<td>Dr. Sylvester Mobley</td>
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<td>215- 955-6520</td>
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<td>Department of Pediatrics</td>
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<td>1025 Walnut Street</td>
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<td>Philadelphia, PA 19107</td>
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<tr>
<td><strong>20. Dr. Joseph Zeccardi</strong></td>
<td><strong>Director of C &amp; Y before Mobley; currently head of ER</strong></td>
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<td>Emergency Medicine</td>
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<td>215-955-6844</td>
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| **21. Dr. Tony Luberti**    |                                                          |
| Director of Ambulatory      |                                                          |
| Pediatrics                  |                                                          |
| St. Christopher's Hospital   |                                                          |
| for Children                |                                                          |
| Erie Avenue and Front Street|                                                          |
| Philadelphia, PA 19134-1095 |                                                          |

| **22. Dr. Sydney Sussman**  | **Director of C & Y and Chief of Ambulatory Pediatrics at St Chris 1968-1979** |
| Department of Pediatrics    |                                                          |
| UMDNJ                       |                                                          |
| Education and Research      |                                                          |
| Bldg                        |                                                          |
| 401 Haddon Ave., 3rd Floor  |                                                          |
| Camden, N.J. 08103          |                                                          |
| (609) 757-7817              |                                                          |

* interviewed in pilot study