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Assessing the Needs of Children and Youth in New York State

Prepared for:

Bureau of Child & Adolescent Health
New York Department of Health

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Table of Contents

Part I: Initial Site Visit Report

Part II: Summary of a Training Workshop for State and County Officials

Part III: Technical Assistance Follow-Up with Pilot Counties

Forward

The New York State Department of Health, like health departments in many other states, has focused significant effort in recent years on working closely with the state's county health departments to develop more effective community-based systems of care for low-income children and their families. As part of this effort, the Department's Bureau of Child and Adolescent Health (BCAH) launched in 1994 an initiative to strengthen counties' capacity to conduct needs assessments processes for children and youth.

A. Technical Assistance Process

To facilitate this process, BCAH asked for and was selected to receive technical assistance (TA) from Health Systems Research, Inc. (HSR), which is under contract with the federal Maternal and Child Health Bureau (MCHB) to provide technical assistance to states in their effort to develop more comprehensive systems of care for children and their families. Under two separate contracts with the MCHB, HSR is providing such technical assistance to all 50 states, the District of Columbia, the Virgin Islands, and Puerto Rico over a five-year period.

The technical assistance provided by HSR to assist BCAH staff in its effort to design and implement a community-based needs assessment process for children and youth consisted of four major components, as follows:

- In December 1994, HSR Project Director Ian Hill, Senior Associate John O'Brien, Policy Associate Katherine Clayton, and consultant Colleen Monahan of the University of Illinois at Chicago conducted an initial site visit to New York to meet with health department officials to obtain background information regarding New York's existing MCH service delivery system and to plan the technical assistance intervention.
- During the Summer of 1995, Dr. Monahan provided New York officials with a needs assessment training manual entitled, *Focus on Children: Community Planning Manual*, that she had developed to assist Illinois counties with the conduct of their child health needs assessments. New York project staff then adapted the manual for their purposes.

- In November 1995, Katherine Clayton and Dr. Monahan conducted a training workshop for state MCH officials and officials from three pilot counties on performance of community-based needs assessment and planning processes.
- In May 1996, the consultant team provided follow-up technical assistance to the three pilot counties that were implementing their needs assessment and planning processes, providing feedback on planning activities already conducted and advice about how to plan future activities.

B. Structure of this Report

Following each of these technical assistance interventions, HSR produced summary reports highlighting the discussions and conclusions of site visits and workshops. These reports are presented in Parts I, II, and III of this compendium and, together, describe several of the critical steps taken by New York's Bureau of Child and Adolescent Health to design and implement a county-based needs assessment and planning process. It is hoped that other state MCH and Children with Special Health Care Needs programs that are attempting to implement similar processes can obtain insight from New York officials' experience.

Part I: Initial Site Visit Report

Technical Assistance to States Developing Comprehensive Systems of Care for Children New York - Initial Site Visit Report

Prepared for:

Maternal and Child Health Bureau
U.S. Public Health Service
Rockville, M.D.
Contract No. 240-94-0016

Prepared by:

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I. Introduction

In July 1994, Health Systems Research, Inc. was awarded a three-year contract by the Maternal and Child Health Bureau (MCHB) to assist state Title V programs in developing comprehensive systems of services for children and their families. This contract, under which technical assistance (TA) will be provided to 28 states and territories, expanded the scope of an existing contract begun in October 1992 between HSR and the MCHB under which TA is being provided to 25 states over the course of three years. Combined, the two contracts will support technical assistance projects in all 50 states, the District of Columbia, the Virgin Islands, and Puerto Rico. New York was one of the first eight states selected to receive TA under the second contract.

Officials in the Bureau of Child and Adolescent Health of the New York State Department of Health asked HSR for assistance in developing a community needs assessment process for children with special health care needs (CSHCN). This project was noted as particularly relevant to the MCH Block Grant statewide needs assessment and five-year plan, as well for implementing the state's Healthy People 2000 goals.

HSR's initial site visit to New York was conducted on December 15-16, 1994 by HSR Project Director Ian Hill, Senior Associate John O'Brien, and Policy Associate Katherine Clayton. HSR staff were accompanied on this visit by Colleen Monahan, DC, MPH of the Division of Specialized Care for Children at the University of Illinois at Chicago, a nationally recognized expert in needs assessment who agreed to serve as a consultant on this assignment. Dr. Margaret Lee, the Regional Program Consultant for Maternal and Child Health for Region II, also participated in the site visit. The objectives of this initial site visit were as follows:

- To obtain detailed contextual information on existing service delivery systems in the state;
- To review other needs assessment initiatives and determine their relationship and relevance to the technical assistance project;

- Allow state officials responsible for separate, but related, data collection and needs assessment initiatives to identify areas of cooperation and to discuss potential problems; and
- To further define the objectives of the technical assistance assignment and develop a preliminary workplan.

II. Background on New York State

Prior to the visit by the technical assistance team, New York State Department of Health (DOH) officials provided background material on a broad range of issues including: the structure of the Department of Health; DOH's relationship with local health departments; the state's system for delivering services to children with special health care needs; and the state's draft five year plan for instituting a community needs assessment process for children with special health care needs.

The extensive background materials included important contextual information, as summarized below:

- New York's 58 local health departments (57 counties and New York City) are funded by a combination of local, state, and federal funds. Local health departments are highly autonomous and each faces a unique set of challenges; 10 serve urban areas, 12 suburban areas and 36 rural areas. The variety of settings means that the resources available to local health departments also vary widely. The total budget for all local health departments is roughly \$700 million annually of which approximately \$130 million is state matching funds.
- In general, New York does not use Title V CSHCN funds to reimburse medical services. Rather, the Title V CSHCN funds are used for evaluation and diagnoses and to support case management programs in 12 counties. For children with special health care needs who do not qualify for Medicaid, the Physically Handicapped Children's Program (PHCP) provides roughly \$7 million for medical services. The PHCP is not a mandated program, each county determines its own level of support, as well as eligibility and covered services limits.
- In June 1991, New York passed the Managed Care Act, which has accelerated the development of Medicaid managed care. State officials estimate that by the year 2000, 50 percent of the Medicaid-eligible population will be enrolled in

managed care. In response to this growth in managed care, DOH has begun a project to develop practice guidelines and outcomes measures for children with special health care needs enrolled in managed care.

- Since 1988, sections 602 and 603 of Article VI of the New York State Public Health Law have mandated local health departments to prepare a biennial Municipal Public Health Service Plan (MPHSP), usually referred to as Article VI, in order to receive state funds. Each jurisdiction's Article VI plan has four broad topic areas: family health; disease control; community health assessment; and health education. In addition, 34 local health departments also include a section addressing environmental health. State law and regulation define the content and format of the Article VI plans. Plan quality, however, is extremely inconsistent, owing to the variable resources available to the local jurisdictions to prepare the plans. Article VI plans are usually prepared by local health department staff with little community involvement. In ten counties the preparation of the Article VI plan is done by an outside agency under contract.

- The Bureau of Child and Adolescent Health has developed a five-year plan for implementing a process of periodic community needs assessment for CSHCN. Using the leverage afforded by Article VI, the state hopes to institutionalize and integrate the community-based needs assessment process developed for CSHCN with other planning processes. The plan's first year, which has been funded, identified three broad objectives:
 - Provide counties with specific CSHCN needs data to enhance their ability to successfully undertake a community needs assessment process;

 - Provide the training necessary to implement a community needs assessment process in three demonstration counties; and

 - Provide demonstration counties with fiscal resources to conduct community needs assessment. Resources might be used to either provide staff support for the process, or to purchase equipment.

III. Summary of Meetings with New York Officials

Save for the closing meeting, the site visit used a large group format. Presentations by attendees (list attached) were organized by topic area. The format provided the site visit team with a great deal of information and allowed officials from numerous units of DOH to interact and exchange ideas. Summaries of the presentations are presented below.

Thursday, December 15

10:45 a.m. **Health Care Reform Issues in New York and the Role of CSHCN Systems Development: Margaret Lee, Monica Meyer, Chris Kus and Thom Carter.**

During this session the process of developing community-based needs assessment for children with special health care needs was placed in both a state and a national context. On a national level, community needs assessment for children with special health care needs is an integral part of New York's response to the federal Healthy People 2000 objectives. At the state level, the community needs assessment process must be sensitive to the demands that Article VI already places on counties. The growth of Medicaid managed care represents another factor to be considered when assessing and developing services for CSHCN. Finally, for the first time in 12 years, New York is experiencing a change in the Governor's office. This change creates uncertainty for most planning processes, as the priorities of the new administration are as yet unclear.

11:30 a.m. **State/County Relations and Article VI: Joann Dawson and Carolyn Callner.**

These presentations highlighted the relationships and interactions between DOH and the local health departments. The presentations and discussion raised several issues that may affect the implementation of a community needs assessment process:

- The proposed community needs assessment process needs to be sensitive to the reporting requirements already borne by local health departments. In addition to Article VI, local health departments must also respond to numerous program-specific reporting requirements. Counties often find slight variations in reporting detail and format extremely frustrating. Presenters suggested that, to be successful, counties must perceive any new needs assessment effort as a benefit that will permit them to improve services to their clients, and not as just another reporting requirement.

- Counties have received some training on the how to use and interpret data for Article VI plans. Resource constraints have, however, caused training efforts to be inconsistent.

12:00 noon **State Data Collection and Information System Issues: Michael Medvesky and Susan Bubb.**

These presentations detailed some of the ongoing data collection and dissemination efforts of DOH. Important information included:

- Under a three-year grant from the CDC, New York is in the process of placing all the data sets they maintain onto electronic media. When fully implemented, the system will provide access to a range of information and data, including public health bulletins and vital statistics. By the end of the grant period, the state plans to have all counties directly linked to the central system.
- Since 1985 the Bureau of Child and Adolescent Health has gathered information from both internal and external sources to produce the “Maternal, Child and Adolescent Health Profile.” The profile presents county-level data related to maternal and child health. Data addressing children with special health care needs has been identified as a limitation of the report.

12:30 p.m. **Health Systems Planning Initiatives: Karen Kalaijian, Steve Schreiber, Donna Noyes, and Barbara Frankel.**

This session featured presentations on health system planning and development efforts that are currently underway in New York, as summarized below:

- The “County Comprehensive Planning for Children, Youth and Families” project seeks to integrate local planning activities pertaining to children. Under this project state agencies, including the Department of Health, the Division for Youth, the Department of Labor and the Department of Social Services, jointly developed draft comprehensive planning guidelines and procedures. The comprehensive plans will replace some, or all, of the discrete planning documents currently required by those state agencies. Seven counties have been selected as pilots, however, the change in administration has placed the process on hold.
- New York is one of 10 states to receive a grant through the Robert Wood Johnson Foundation’s “Practice Sites” initiative. The project’s goal is to assist local communities in developing and implementing strategies to improve their primary care systems. The activities funded by the grant are targeted at 40 communities that the state has identified as underserved.
- In the summer of 1994, as part of the Family Preservation/Family Support Initiative, the state issued an RFP for the development or expansion of home visiting programs. A requirement of all applications was a letter of agreement

from all participating local agencies. Local health departments were identified as agencies that must be involved in the project. Grant awards and program implementation are currently on hold pending review by the new administration.

2:00 p.m. Overview of the MCH Technical Assistance Project: Ian Hill.

To give New York officials a perspective on the breadth and scope of the MCH technical assistance projects currently underway at HSR, Ian Hill presented an overview of the range and types of assignments being implemented in the states. In the presentation Mr. Hill outlined the broad categories of projects that states have undertaken, ranging from strategic planning for MCH data systems development, to enhancing states' capacity to conduct community level needs assessment, to helping MCH programs respond to issues relating to the implementation of Medicaid managed care. Mr. Hill stressed the flexibility the project offers states in designing a project tailored to address the state's unique needs.

3:30 p.m. Needs Assessment and Health Surveillance — Issues and Challenges: Colleen Monahan.

In her presentation, Dr. Monahan reviewed issues that states need to be aware of when implementing a process of community needs assessment. Dr. Monahan's presentation focused on the problems that a community needs assessment process will encounter and on the practical solutions that may be used to overcome those problems. Dr. Monahan based her observations on her experience as one of the leaders of community needs assessment process for children with special health care needs in the state of Illinois, and as a consultant in other states. Some of the major issues that Dr. Monahan addressed in her presentation included:

- **Community Needs Assessment Is Part of a Larger, Statewide Process.** Community needs assessment is the local component of a process that also includes an assessment of state needs, state priority setting, and an assessment of the role of state programs in meeting identified needs.
- **Community Needs Assessment Requires the Development of Local Skills and Capacities.** Dr. Monahan stressed that the state has a vital role in assisting local communities to develop the requisite skills to conduct effective community needs assessments. One way that the state can assist communities is by providing a staff person (or persons) who will serve as both a contact and a resource to local communities. The identified staff will be responsible for a

number of different tasks such as, facilitating local meetings, answering community questions, and gathering and interpreting secondary data.

- **Needs Assessment for Children with Special Health Care Needs Presents Unique Data Collection and Interpretation Issues.** Many of the medical problems encountered by children with special health care needs are relatively rare, particularly in sparsely populated rural areas. Data collection and analysis efforts that focus on children with special health care needs, therefore, may be of limited utility to more general needs assessment activities. Conversely, important concerns and deficiencies in the health care system for children with special health care needs may be not be reflected in data that addresses broader children's health issues. Identifying a set of data elements that address both specific CSHCN issues and are useful for broader health planning is a significant challenge to a community needs assessment process focusing on children with special health care needs.

4:30 p.m. **The Primary and Preventive Care Geographic Information System (PPCGIS): Colene Bryne.**

PPCGIS represents another state effort to provide localities with data and the tools to present data. PPCGIS combines data base and mapping software and allows users to manipulate and present data in a variety of aggregations, such as zip code, census tract or county. The state views PPCGIS as a useful tool for local health planning, especially the preparation of the Article VI plans. The first version of PPCGIS is scheduled to be completed in the late spring or early summer of 1995.

Friday, December 16

9:00 a.m. **New York State Multi-Year Plan for CSHCN Needs Assessment — Overview of Concept, Objectives and Budget: Thom Carter.**

Dr. Carter provided an overview of the state's plans and goals for community needs assessment. The needs assessment process is one aspect of the state's long-term effort to improve systems of care for CSHCN. In the presentation, a number of the facets of the plan were examined, including: the definition of CSHCN; the goals for system development; possibilities for integration and linkage across state agencies; and the function of local advisory groups. The year-one objectives and the subcomponents of those objectives were also presented in detail.

The presentation stressed that the Maternal and Child Health Committee of the New York State Association of County Health Officers (NYSACHO) has been involved and regularly briefed during the development of the plan.

11:00 a.m. NYS CSHCN Needs Assessment Plans Issues: Michael Medvesky, Carolyn Callner, Nancy Kehoe, Sandra Birnbaum, and Chris Kus.

In this session presentations focused on some of the major obstacles that the state has encountered in implementing planning initiatives and gathering the data needed to support those initiatives. Major issues that were raised included:

- The state has established a central computerized data base for its Part H/Early Intervention program. Data on children from birth to age two who are at risk for developmental delays are recorded on this data base. The data are entered at the county level according to a standard format.
- Data from the PHCP program are maintained independently by counties according to county-determined formats. Many counties have only paper records for their PHCP programs. The lack of automation and centralization of the PHCP data leads to significant difficulties in presenting complete, accurate summary information on children with special health care needs.
- DOH staff have conducted community focus groups to explore issues relating to the care of children with special health care needs. The intent of the focus groups was to gain insights on how to construct high quality systems of care for CSHCN and to identify current barriers to such systems. Separate focus groups have been held in urban, suburban and rural counties and participants and have included parents and community service providers.

1:30 p.m. Wrap-Up Meeting with DOH Officials: Monica Meyer, Chris Kus, Tom Blake, Thom Carter, Nancy Kehoe, and Mike Medvesky.

The technical assistance team and the RPC, Ms. Lee, conducted a final meeting with the core group of state MCH officials to discuss issues that were raised during the site visit and to develop preliminary objectives and a workplan for the technical assistance project. The year-one objectives as outlined in New York's five-year plan for CSHCN community needs assessment served as the framework for the discussion. The group agreed that HSR's assistance could be most effectively utilized in carrying out the workplan's second objective:

initiating and training community advisory groups in two¹ demonstration counties. This objective will be met through the conduct of community planning group meetings in the selected demonstration counties. The demonstration counties will then use the skills and information gained in the workshop to conduct their own community needs assessment. A number specific issues pertaining to the technical assistance were also discussed, as summarized below:

- Enhancing DOH's capacity to lead and support community needs assessment is a primary goal of the technical assistance. The technical assistance will be structured to train DOH staff in the conduct of community needs assessment. Staff funded through the state's SSDI grant were identified as most appropriate to receive training and provide long-term support for the community needs assessment process. A first step in the technical assistance will be refocusing the state's SSDI project and redefining staff responsibilities.
- The community needs assessment process must not represent, or be perceived as, an additional burden on counties. Providing the demonstration counties some relief from their normal Article VI reporting requirements will greatly improve the project's acceptance and its likelihood for long-term success.
- The demonstration counties should be chosen based upon their capacity to successfully conduct a community needs assessment. By avoiding counties that present complex political and bureaucratic issues, the focus of the technical assistance can be on fine tuning the process and developing DOH staff skills, and not on resolving thorny local issues.
- The community needs assessment process should proceed using the data that are currently available. The group acknowledged that there are problems and limitations with the data on CSHCN currently available, but that these should not delay the conduct of training in the demonstration counties. Existing data are sufficient for a successful community needs assessment. It was also felt that the process itself would lead to a better understanding of the data needed by communities to fully understand and evaluate the needs of children with special health care needs.

¹ The year-one goals outlined in New York's five-year plan for community needs assessment for CSHCN called for conducting community needs assessment in three demonstration counties. During the discussion, however, there was consensus that conducting the needs assessment process in only two demonstration counties would better serve the state's goals. Targeting only two counties for community needs assessment will allow the project to concentrate on refining the needs assessment process as well as developing DOH staff skills to conduct community needs assessment process in future years.

In light of these issues, the group identified a number of tasks that needed to be undertaken, including, for New York officials, refocusing the activities and staff of New York's SSDI grant to reflect the staff's involvement in the community needs assessment process; identifying requirements of Article VI that can be waived or modified for the community needs assessment demonstration counties; selecting the two demonstration counties; and forming community planning groups in the demonstration counties. For HSR, it was agreed that the consultant team would work to provide a draft community needs assessment manual to DOH officials for review and comment; prepare an agenda for the community planning group meetings; complete revisions to community needs assessment manual, tailoring the manual to reflect New York officials' input; and conduct community planning group meetings in the two demonstration counties. The first planning group meeting will be led by HSR staff. The second workshop will be led by DOH staff with HSR in attendance and providing guidance and feedback.

Following the community planning group meetings the demonstration counties will carry out a community needs assessment. The local community needs assessment process will take from nine months to a year. When the demonstration counties have completed their individual assessments, and if the technical assistance budget permits, HSR will review their final products and provide additional comments.

Part II: Summary of a Training Workshop for State and County Officials

Assessing the Needs of Children and Youth In New York State: Summary of a Training Workshop for State and County Officials; 16 November 1995

Prepared for:

Bureau of Child & Adolescent Health
New York Department of Health

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I. Introduction and Background

Under a contract with the federal Maternal and Child Health Bureau (MCHB), Health Systems Research, Inc. (HSR) has worked with the New York State Bureau of Child and Adolescent Health (BCAH) to facilitate the development of comprehensive systems of care for children and their families. New York officials initially asked HSR for assistance in developing a statewide needs assessment process for children with special health care needs (CSHCN) in support of their efforts to meet the MCHB Block Grant requirements to conduct a needs assessment for this population every five years. In particular, state officials sought assistance from HSR in training DOH and county staff in conducting the CSHCN needs assessment. An initial site visit to Albany was conducted on December 15-16, 1994 by HSR Project Director Ian Hill, Senior Associate John O'Brien, and Policy Associate Katherine Clayton. HSR staff were accompanied on this visit by Colleen Monahan, D.C., M.P.H., the Director of Research and Development within the Division of Specialized Care for Children at the University of Illinois at Chicago, who agreed to serve as a consultant on the TA project. Dr. Margaret Lee, the Region II Program Consultant of the U.S. Public Health Service, also accompanied HSR consultants. During the visit, the consultants met with key officials from DOH's Bureau of Child and Adolescent Health as well as selected representatives from other agencies to gather background information on health department programs and develop and discuss the scope of the technical assistance project.

By the close of the two-day visit, New York officials and HSR consultants determined that state and local public health staff would benefit from the receipt of formal training in needs assessment processes and techniques. Before this could occur, however, there were several steps that New York officials needed to complete, including developing a process for selecting two counties to pilot the community needs assessment process and participate in the training,² deciding whether it wanted to expand the scope of the needs assessment training to include all children rather than just CSHCN, and working with the HSR consultants to develop a better

² The number of counties eligible to participate in the training was subsequently increased to three.

understanding of the community needs assessment process so that an appropriate training curriculum could be developed.

In the remainder of this chapter, the events leading up to the conduct of a needs assessment training workshop are discussed. First, information on New York's CSHCN needs assessment proposal and its State System Development Initiative (SSDI) project are presented. Second, a summary of the steps taken to prepare for the workshop, including a site visit made by New York officials and Dr. Monahan to a county in Illinois that was conducting a community-based planning initiative, conference calls between New York officials and the consultant team, and meetings to prepare for the workshop are summarized. The second chapter consists of a detailed summary of the workshop, which was conducted in November, 1995.

A. Overview of New York State's CSHCN Needs Assessment Proposal and SSDI Project

New York decided to use a portion of its 1994 SSDI funding from the MCHB to finance a five-year initiative to enhance communities' capacity to conduct needs assessments for the CSHCN population. As there were already many other youth-focused planning initiatives being conducted by other New York State agencies and local county health departments, BCAH structured its CSHCN needs assessment plan to build off existing state and county projects. To create incentive to participate, BCAH decided to allow counties to substitute the new CSHCN assessment process for that normally required of local health departments under Public Law Article VI, which is used as a basis for determining funding levels from the state.

During Year One of the CSHCN plan, state officials concentrated their efforts on implementing the needs assessment and planning process in three demonstration areas with the goal of expanding the effort statewide in subsequent years. The three areas that were selected to participate were the Orange County Department of Health, the Schenectady County Department of Health, and the Upper Hudson Primary Care Consortium Project which

encompasses Saratoga and Essex counties. In addition, BCAH identified the following goals for the first year of the project:

- Provide demonstration counties with CSHCN-specific data and information to enhance local CSHCN needs assessment and systems planning;
- Initiate and train community advisory groups in the demonstration counties; and
- Provide the counties with the resources and assistance needed to implement a community-based needs assessment process and develop a CSHCN report with plans for meeting identified needs.

B. Preparing for the Workshop

To help meet the SSDI plan objectives described above, MCH officials took several steps to develop a better understanding of community-based planning and needs assessment processes and to develop an appropriate training approach, as described below.

1. Illinois Site Visit

As mentioned previously, HSR retained the services of Colleen Monahan, a nationally recognized expert in community needs assessment for children and families, to assist with the provision of technical assistance. Since 1991, Dr. Monahan has been leading an MCHB-funded effort based out of the University of Illinois at Chicago to develop a model and training guide for communities conducting needs assessment and health planning processes. To date, this model has been implemented in 14 Illinois communities.

To gain a better understanding of Illinois' model, Joan Healey, Rhea Temblador, and Cathy Tucci of BCAH visited the state and participated in a community planning meeting with Dr. Monahan in November 1995 in Vermilion county. Following the meeting, New York staff met with members of the county planning group to discuss critical issues surrounding its efforts to implement a community-based needs assessment project. To provide the New York pilot counties with useful advice, BCAH officials were particularly interested in learning about the challenges the group encountered as it implemented the needs assessment process and the

lessons it learned from the effort. During the second day of the site visit, New York officials met with Dr. Monahan to review the Illinois needs assessment and planning model for children in more detail. Time also was spent identifying the limitations of child health data that are currently collected by NYSDOH and steps state officials needed to take to compile a more complete and useful data set for the pilot counties prior to the conduct of the training workshop. Finally, New York officials were presented with a copy of the Illinois Community Planning Manual and received guidance from Dr. Monahan regarding how to adapt the manual to meet New York's needs.

2. Conference Calls

In the weeks proceeding the workshop, a series of conference calls were held between HSR, Dr. Monahan, and New York officials to discuss adaptations of the Illinois Community Planning Manual and to plan and develop an agenda for the workshop. The group decided that it would be helpful to convene one day prior to the workshop to conduct an informal pre-training session with key state officials, and then conduct a one-day training workshop for state and county officials on community planning and needs assessment processes. During these calls, MCH officials also decided to expand the scope of the workshop to include all children with an emphasis on Children with Special Health Care Needs.

3. Pre-Workshop Meeting

On November 15, Dr. Monahan met with key DOH officials in Albany to attend to final preparations for the workshop. The primary objective of meeting was to review the state and county data sets which had been developed by MCH staff over the preceding months to insert into the Community Planning Manual and to structure data exercises for the afternoon session of the training workshop. Drawing from available data sources, Dr. Monahan and core BCAH staff developed two data sets: one based on statewide data and the other based on data collected from one county which, for the purpose of the exercise, was given a fictitious name ("Catskill County"). These data sets contained approximately 40 elements on demographic information, population risk factors, outcomes, and the service system resources.

Dr. Monahan, with assistance from HSR Policy Associate Katherine Clayton, conducted the workshop on November 16 at the state office building in downtown Albany. The remainder of this report presents a summary of the process and outcomes of the workshop.

II. Summary of Workshop

Wednesday, November 16

9:00 a.m. Introductions and Opening Remarks

During the opening session, the BCAH Director, Christopher Kus, M.D., M.P.H., welcomed the group and provided participants with background information on the events leading up to the youth needs assessment workshop. Dr. Kus explained that the following factors stimulated discussions among MCH officials to initiate the assessment and planning process being implemented in the three counties:

- The Omnibus Reconciliation Act of 1989 requires state Title V programs to assume a leadership role in developing community systems of care for children and their families, and conducting a statewide needs assessment every five years based on findings from community assessment processes; and
- Article VI of New York State Public Law requires counties to develop municipal health plans that are based, in part, on an assessment process.

As a first step toward meeting these goals, state officials decided to provide hands-on training to officials from three counties.

Following Dr. Kus' introductory remarks, participants took turns introducing themselves and the programs they represented. HSR Policy Associate Katherine Clayton took this opportunity to describe HSR's technical assistance contract with the MCHB and its role in designing and implementing the workshop.

9:15 a.m. County Updates

At the beginning of the workshop each county was given an opportunity to update the group on planning activities already conducted and their future plans. A summary of issues reported by these three organizations is presented below.

- **Orange County Department of Health.** The Executive Director of the Orange County Youth Bureau, Carol Chichester, presented an update on Orange County activities. Ms. Chichester explained that the state's needs assessment plan fits nicely into existing processes being implemented by the county and the Youth Bureau. To meet the requirements of Article VI, a youth advisory board, whose members were appointed by county executives, had developed a comprehensive community plan for the next three years. Thus far, the advisory board had established committees and assigned tasks to the committee membership, reviewed data sources (e.g., county-specific data and data from the Center for Disease Control and Prevention), and identified health issues that needed to be studied (e.g., exploring adolescent issues and providing prenatal care to children up to age 21).

Ms. Chichester explained that even though some needs assessment work had already been conducted in Orange County, the state initiative presented the county with an opportunity to expand its efforts. For example, state funding had enabled the county to hire a consultant to develop a more complete, up-to-date data set. In addition, the county planned to recruit representatives from a broader range of state and community agencies (e.g., social services, mental health, education, probation, and parks and recreation) to be a part of the needs assessment effort.

- **Upper Hudson Primary Care Consortium Project.** An update on needs assessment and planning activities conducted by the Upper Hudson Primary Care Consortium Project was provided by Peter Whitten, the Director of Planning and Development for the consortium. First, Mr. Whitten explained that the consortium had experienced delays getting started since his staff had to solicit participation from representatives from four counties. Second, Mr. Whitten noted that the primary objective of the consortium was to develop a regional plan based on the examination of health outcomes data for infants, children, and adolescents. To do this, Mr. Whitten explained that the consortium planned to conduct the following activities:

- Recruit into the project all agencies that deal with youth issues;

- Identify ways to collaborate or build off of other community-based, needs assessment initiatives that are being conducted within the four counties represented in the consortium; and
 - Prioritize health needs among infants, children, and adolescents by examining existing health outcomes data.
- **Schenectady County Department of Health.** The Commissioner of the Schenectady County Department of Health, Russell Fricke, M.D., presented an overview of recent needs assessment activities conducted by his staff. Dr. Fricke explained that much of their time, thus far, had been spent sorting through secondary data available on child health and developing a compendium of data for implementing a needs assessment process. He noted that this task had been difficult since available data often are incomplete. With regard to activities conducted under the state-sponsored needs assessment project, Dr. Fricke explained that the county hoped to implement a planning process in one pilot area, look at secondary data, and focus efforts on addressing planning and systems development issues pertaining to *one* child health problem.

9:30 a.m. **Overview of the Needs Assessment Process**

Prior to delivering a formal presentation on the steps involved in conducting a needs assessment, Dr. Monahan reviewed the content of the adapted Community Planning Manuals, one of which was provided to each county group. Dr. Monahan explained that the manual contained specific guidance on the planning and needs assessment process and New York State- and county-specific data on the health status of children. Specifically, the manual was organized into the following chapters:

- Introduction to community-based needs assessment;
- Starting a community-based needs assessment;
- Understanding the target population of children;
- Introduction to data collection and analysis;
- Secondary or existing data;
- Primary data;

- Developing the community health plan; and
- Monitoring and evaluating the community health plan.

After participants had a chance to review their manuals, Dr. Monahan noted that she was going to present a brief historical perspective on needs assessment and then review the various components of the planning and assessment process. A summary of Dr. Monahan's presentation is presented, by section, below.

1. Historical Perspective on Needs Assessments

To provide a context for the discussion, Dr. Monahan presented definitions on health, community, and community needs assessment. First, Dr. Monahan remarked upon how society's definition of health has changed since the turn of the century. She explained that the World Health Organization (WHO) currently defines health as: "not merely the absence of disease, but total physical, social, and psychological health."

Over time, society has moved from measuring health according to a single infectious disease model in the early 1900s; to a model endorsed by WHO in the 1940s and 1950s that accounted for physical, mental, and social well-being; to a holistic model in the 1960s and 1970s that measured how lifestyle, the environment, biology, and the health care system affect a person's well-being; to the current-day philosophy that measures health by examining mind/body relationships, quality, resource allocation, and how social, economic, educational and technological factors affect health.

Second, Dr. Monahan explained that "community" can be defined according to geographic characteristics (e.g., county, city, or township) or functional characteristics (i.e., a group of individuals that live close to one another, have common values or cultural identity, or come together to share common problems).

Third, Dr. Monahan defined “community-based needs assessment” as:

“the involvement of community members in the design and implementation of an assessment of community needs;”

noting that state officials will enhance the quality of their assessment by involving the community in the process.

2. Needs Assessment: Functions and Process

During the next part of her presentation, Dr. Monahan explained that state and local officials may use data collected through needs assessments to support a number of initiatives. To illustrate this point, she identified six uses of a needs analysis, including:

- **Advocacy** (to support funding requests);
- **Budgeting** (to establish program priorities);
- **Descriptive Analysis** (to identify characteristics of a target population);
- **Evaluation** (of an intervention);
- **Planning** (to help with identifying priorities and making decisions); and
- **Testimony** (that heightens community awareness of an issue or satisfies a legislative mandate).

To implement a needs assessment process, sponsors of the effort need to convene a community planning group consisting of a range of individuals and professionals (e.g., education, health, and mental health professionals; consumers, such as parents of CSHCN; and representatives from non-profit and private agencies in the community). Once assembled, the planning group should implement the following steps to conduct an analysis of need:

- **Step 1:** Identify the users and uses of the analysis;
- **Step 2:** Describe the target population to be assessed (e.g., children and families);

- **Step 3:** Identify the needs of the target population (i.e., through collecting data on the health status of the target population);
- **Step 4:** Evaluate and analyze the identified needs; and
- **Step 5:** Communicate results.

3. Definition of Need

First, Dr. Monahan discussed what a “need” is in general terms. She explained that it is a value judgment a person or group makes about another person or group. The assumption that underlies this judgment is that the identified person or group has a problem that, through an intervention, can be solved. Second, Dr. Monahan noted that there are four types of needs and described them in the following manner:

- **Normative Need.** Normative need is derived from expert opinions about appropriate levels of service or health status (e.g., Year 2000 objectives, health indicators) and is often used as the basis for beginning a needs assessment.
- **Perceived Need.** This measurement is defined in terms of what people think their needs are.
- **Expressed Need.** Expressed need is identified by action and does not necessarily reflect what people perceive their needs are. It can be defined through the utilization of services (e.g., Medicaid enrollment or clinic appointments).
- **Relative Need.** This measurement of need is comparative and can be examined by analyzing the needs and resources in one geographic area against those in another area. It can be used to build context for the needs assessment and provide insight into the variance based on resource utilization.

Dr. Monahan encouraged participants to measure all four types of needs in order to develop a complete assessment of their target population’s needs.

4. Common MCH Risk Factors and Indicators

To provide a framework from which workshop participants could begin conducting their own assessment processes, Dr. Monahan next reviewed common MCH risk factors and health indicators. First, Dr. Monahan identified the following risk factors that affect child health:

- **Biological Risk** (e.g., existing health problems, genetic composition, gender);
- **Sociocultural Risk** (e.g., circumstances that develop out of economics, education, family structure);
- **Lack of Health Services** (e.g., lack of a primary care provider, poor access to a health clinic);
- **Behavioral Risk** (e.g., teen parents, substance abuse, diet); and
- **Environmental Risk** (e.g., existence of lead paint).

Dr. Monahan then reviewed common health indicators and child health issues. Specifically, she discussed how these indicators apply to various age categories of children, identified current issues in child health, noted adverse outcomes among poor children, and highlighted CSHCN issues that the groups should consider as they conduct their assessments. Dr. Monahan's comments are summarized, by category, below.

- **Common MCH Indicators.** Dr. Monahan noted that low birth weight, inadequate prenatal care, and infant mortality are common indices for infants; that immunization status, population-based growth data, elevated blood lead levels, and non-motor vehicle accident fatalities are common health indices for children; and that births to school-age mothers, suicides, and motor vehicle accident fatalities are common indices for adolescents and young adults.
- **Current Issues in Child Health.** Next, Dr. Monahan referenced the following statistics that indicate that children are at risk of poor outcomes. She noted that:
 - There is a disparity between infant mortality among minority and majority populations;
 - Unintended injuries are responsible for half of deaths among children;
 - There is an increasing incidence of violence against children;

- Chronic diseases, psychological, emotional, and learning disorders are on the rise;
 - Preventable diseases such as infectious diseases are increasing;
 - High-risk behavior among adolescents is on the rise; and
 - Transition to adulthood for CSHCN is increasingly more difficult.
- **Health Outcomes and Poor Children.** Dr. Monahan also referenced statistics that demonstrate that low-income children are at increased risk of poor outcomes. Specifically, Dr. Monahan noted that:
 - Low-income children are 2 to 3 times more likely to be low birth weight, have delayed or incomplete immunizations, be poisoned by lead, have conditions which limit school activity, and lack health insurance if they are chronically ill; and
 - Low income children are 3 to 4 times more likely to have their illness progress to death and develop complications in relation to their illness.
- **Issues for CSHCN.** As a final note, Dr. Monahan identified the special issues CSHCN and their families face, including the inability to access adequate primary and specialty care, finance appropriate services, and plan for transition to adulthood. MCH data also show that a relatively large number of children face these issues, given that:
 - As many as 30 percent of children under age 18 have an ongoing health problem;
 - At least 80 to 90 percent of children with severe chronic illness survive past 20 years of age; and
 - Approximately 4 percent of all children have a limitation in their ability to play or attend school as a result of a chronic condition.

5. Sources of Data

Dr. Monahan briefly reviewed varying techniques that can be employed to obtain information, highlighting secondary and primary data collection strategies. She explained that analyses of existing information (secondary data) as well as new information (primary data) can be used to conduct a needs assessment. Examples of secondary sources that contain valuable data

regarding maternal and child health include vital statistics, morbidity data (e.g., birth defect registries, hospitalizations), U.S. census data, and program administrative data. Techniques for collecting primary data generally fall into one of three categories:

- Those mainly dependent upon observation combined with documentation (e.g., participant observation, case studies);
- Those mainly dependent upon some form of questioning of individuals (e.g., key informant interviews, surveys, the Delphi technique); and
- Those mainly dependent upon some form of gathering information from a group of people (e.g., nominal group exercises, focus groups, community forums).

Dr. Monahan noted that when working with communities it is important for planning groups to have an open mind as to what the community may identify to be important issues. Dr. Monahan noted that she has had the most success in collecting valuable data from communities when she uses the nominal group process or conducts focus groups. She has gathered information from diverse groups of people through the nominal group process and more homogenous groups of people in focus groups.

6. Needs Assessment Plan Development, Implementation, and Evaluation

In closing, Dr. Monahan provided workshop participants with the following tips as they implement the needs assessment process in their communities:

- As the regions *develop* a plan, they should:
 - Select outcomes and objectives;
 - Set reasonable time frames for completion;
 - Assign responsibility for completion;
 - List required resources;
 - Assign priority levels to each objective; and
 - Develop an ongoing means of monitoring and evaluating the effort.

- As the regions *implement* the plan, they should:
 - Find or obtain state support;
 - Look for other sources of financing; and
 - Keep community interest in the effort high.

- As the regions *monitor* and *evaluate* the plan, they should:
 - Set up a permanent community infrastructure; and
 - Set up a schedule to regularly examine objectives and attach it to the plan.

11:00 a.m. Data Overview

The group spent the next hour learning about the range of data sources available to counties through existing state data systems. Time also was spent discussing how state officials could best assist counties in interpreting and using the data in their planning and assessment efforts. The Department’s Director of the Office of Public Health Information, Mike Medvesky, explained that the state had received funding from CDC to implement a system whereby public information, data sets, and a listing of DOH services are placed on electronic media. New York has been developing this “Gopher System” over the past three years. Once fully implemented, the system will provide access to a range of information and data, including public health bulletins and vital statistics. Mr. Medvesky also noted that counties will be able to link up directly to the central system.

Since 1985, county-level maternal and child health data also have been made available through the production of the BCAH’s “Maternal, Child and Adolescent Health Profile.” While this is a great source of information, Mr. Medvesky noted that it, as well as other data sets, have limitations. In particular, none of the existing data sets have sufficient information on children with special health care needs. With this in mind, Mr. Medvesky noted that this project presents the state—via county efforts—with an opportunity to collect more accurate and comprehensive data. Mr. Medvesky also noted that state officials would be available to assist counties in their

efforts by, for example, directing their attention to existing data sets, identifying how to go about collecting new data, and developing useful methods for formatting and presenting data.

Following these introductory remarks, Mr. Medvesky reviewed specific MCH information sources and health indicators available to county officials.

- **State Child/Adolescent Health-Related Information Sources.** Mr. Medvesky reviewed the range of data sets available through DOH, noting some of the strengths and weaknesses of each. Four types of data sets were reviewed, including general data sets (e.g., the U.S. Census, Current Population Survey, birth and death certificates, and Hospital Discharge Survey), registries (e.g., cancer, AIDS, congenital malformations, motor vehicle injury and death, and a central registry on child abuse and maltreatment), surveys (e.g., immunizations, reproductive health, the Behavioral Risk Factor Surveillance System, and Pregnancy Risk Assessment Monitoring System), and program-based data sets (e.g., Medicaid encounters, WIC, family planning, STD, and AFDC).

For each data set, Mr. Medvesky also noted whether it was population- or service-based, at what geographic level the data were available (e.g., state, county, sub-county), the types of sociodemographic information contained in the data set (e.g., age, race, sex, and socioeconomic status), the most recent year for which the data were available, and from what state agency the data could be obtained.

- **Useful Child/Adolescent Health Indicators Available from Existing State Data sets.** Mr. Medvesky then reviewed the health indicators that are available from the various sources of information. Specifically, Mr. Medvesky reviewed which sources were good for finding information on demographics and SES, infant health, causes of mortality and morbidity, health care access, and children with special needs.

Mr. Medvesky closed the session by reviewing several critical issues that county officials should keep in mind as they begin to use the data sources described above. First, he noted that if the counties were interested in conducting trend analyses, they should analyze data sets that contain routinely collected information. Second, Mr. Medvesky stressed that to ensure that data collected from multiple sources were comparable, county officials should be aware of how the data were collected (e.g., active versus passive surveillance), the accuracy and completeness of the information, and the geographical level of the data.

1:00 p.m. Community Planning Group Process

During the afternoon session, participants were given an opportunity to apply many of the needs assessment principles that were reviewed during the morning to state- and county-specific data. As mentioned previously, Dr. Monahan had worked with state MCH officials prior to the workshop to build a data set consisting of key MCH indicators and design exercises that required participants to analyze the data and engage in practice planning effort. Participants were asked to analyze secondary data in the first exercise and primary data in the second exercise. A description of the data set, the two exercises that were conducted, and the results reported from the counties are presented below.

1. The Datasets

Each group was given an abridged data set which consisted of state- and county-specific health data. Data were presented within four categories, including demographics, risk factors and populations at-risk, outcomes, and availability of services. Roughly 40 data elements were presented. Examples of the items presented within each category are presented below.

- **Demographics**, including state- and county-level information on the size of the population, the number of live births, the age distribution and ethnic origin of children, family structure, and median income.
- **Risk Factors and Populations At-Risk**, including information on poverty, fertility rates, prenatal care, immunization, lead screening, children with chronic conditions, and injury.
- **Outcomes**, including standard morbidity and mortality data such as information on deaths, births (e.g., low birth weight, prenatal care, HIV seropositive newborns), hospital discharges, reported child abuse cases, sexually transmitted diseases, malformations, and arrests for violent crimes.
- **Availability of Services**, including information on the number of children enrolled in health and social service programs and descriptive data on the following programs: Medicaid, home relief, Food Stamps, Aid to Families with Dependent Children (AFDC), Supplemental Security Income (SSI), the Infant Health Assessment Program (IHAP), Early Intervention Services, and special education.

2. Secondary Data Exercise

This first exercise presented participants with an opportunity to practice the first two critical steps of conducting a needs analysis: (1) reviewing data; and (2) identifying the gaps and weaknesses of the data. Participants were asked to record issues or additional data that they thought they needed to gain a better understanding of the health status and needs of children on a grid that was included in a handout. This grid was divided into age groups of children and categories of data items. For each age category, participants were asked to identify what additional information they needed on demographics, risk factors, outcomes, and services.

Participants were divided into three groups, according to their county affiliation, and asked to engage in the secondary data exercise. Following the small group exercise, a leader from each group reported their findings. The groups described the process they went through to examine the data, identify gaps, and develop strategies or identify resources to acquire missing data. All three groups approached the exercise in a similar manner by first comparing state and county demographic information on, for example, the number of live births, poverty by ethnic groups, and family size. The groups then concluded that they needed additional information before they could adequately assess the needs of state and county residents, including breakdowns of the data by age categories and geographic locations to identify trends.

Following the group discussion, Dr. Monahan acknowledged that analyzing data can be a very challenging process. To focus their efforts, she encouraged the counties to begin by looking at secondary data (e.g., national, state, and county data) and then develop strategies to obtain primary data by, for example, conducting focus groups. Dr. Monahan also noted that there are a number of existing resources at the state and federal level that help communities enhance their analytical skills. For example, the federal MCHB has entered into cooperative agreements with universities to provide technical assistance in this area. As a faculty member at the University of Illinois at Chicago, Dr. Monahan is leading one of these projects.

3. Primary Data Exercise

The purpose of the second exercise was to encourage participants to think about how to collect primary data to supplement data available through secondary sources. The small groups were asked to select one health indicator from the data set, explain why they needed additional information on the selected issue, and identify a means of collecting additional information. The reports provided by each group are presented below:

- **Upper Hudson Primary Care Consortium Project.** Representatives of the consortium decided that they wanted to collect additional information on reported child abuse cases. Through key informant interviews with Department of Social Service officials, police officers, and school nurses, they planned to gain a better handle on the socioeconomic status and family structure of children who were reported to be abused.
- **Orange County Department of Health.** The second group chose to look at hospital discharge data for children. According to the data presented, there was a relatively high rate of dehydration within Catskill County. To gain a better understanding of this issue, members of the group said they would first examine the hospital discharge data more carefully (i.e., look at how diagnoses were coded), compare data over a three- to four-year period, and obtain information broken down by age and geographic region. Second, the group would conduct key informant interviews with doctors, hospital discharge planners, and social workers to identify possible reasons for the high dehydration rate. The group also mentioned that it would conduct a focus group or town meeting in a geographic region with a high dehydration rate to gain a better understanding of the factors and issues contributing to the problem.
- **Schenectady County Department of Health.** The third group decided to examine fertility data in more depth, as there was a relatively high birth rate among 18 and 19 year olds living in Catskill County. First, the group planned to collect additional primary data on teen pregnancies from Planned Parenthood, school officials and nurses (e.g., how many women completed educational sessions, how many went back to school). Members of the group also noted that they would speak to the teens directly in an effort to identify teen pregnancy risk factors.

Dr. Monahan offered some final remarks on how to implement assessment and analysis processes. As a starting point, she noted that it is helpful to identify the indirect factors contributing to the selected issue, then look at the service needs of the population, and finally

ask the community for input. Dr. Monahan illustrated this point by building off of the teen pregnancy example discussed by Schenectady. First, the group would need to ask what factors contributed to teen pregnancy, then examine what types of services teen mothers needed after they had their babies (e.g., child care, assistance with finding a job and housing) and, finally, learn what the community thought about teen pregnancy (e.g., what does the community not like about it).

4:00 p.m. **Wrap-Up and Next Steps**

Dr. Kus offered some final general remarks about the health department's needs assessment project and outlined next steps that needed to be taken by both state and county officials. He mentioned again that the goal of the project was to enhance the selected counties' capacity to implement a community planning and needs assessment processes. Dr. Kus also reminded the regions that state liaisons within BCAH would be available to provide technical assistance, as needed. In closing, Dr. Kus highlighted the fact that this project gave New York an opportunity to improve the quality and breadth of health data currently available by drawing on input from localities, and that he looked forward to working with the regions on achieving this goal.

Following the workshop, the consultant team met with state officials to debrief and discuss the next steps of the HSR technical assistance project. MCH staff noted that they would be following-up with each region within the next month to gain feedback from them on the quality and utility of the workshop and to assess what types of additional technical assistance they might need. State officials also decided to communicate the findings of these discussions with the consultant team so that the next steps of the TA could be planned.

Part III: Technical Assistance Follow-up with Pilot Counties

**Assessing the Needs of Children and Youth
in New York State:
Technical Assistance Follow-Up with Pilot Counties;
May 6-8, 1996**

Prepared for:

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3 July 1996

I. Background and Overview

In October 1992, the Maternal and Child Health Bureau (MCHB) awarded Health Systems Research, Inc. (HSR) a three-year contract to provide 25 states with technical assistance (TA) in developing comprehensive systems of care for children and their families. The MCHB granted HSR a second three-year contract effective July 1994 to provide TA to an additional 28 states and territories. New York was one of eight states selected to receive assistance in the first year of the second contract.

New York had identified a need for assistance in developing and implementing a statewide needs assessment process for Children with Special Health Care Needs (CSHCN). Specifically, New York requested that HSR conduct workshops for state and county officials on how to conduct community-based needs assessment and planning activities. During an initial site visit in December 1994, HSR Project Director Ian Hill, Senior Associate John O'Brien, and Policy Associate Katherine Clayton met with officials from New York's Bureau of Child and Adolescent Health (BCAH) and other DOH agencies to develop and discuss the scope of the TA project. HSR staff were accompanied by consultant Colleen Monahan of the University of Illinois at Chicago, who is a nationally recognized expert in needs assessment, and Margaret Lee, who is the PHS Regional Program Consultant for New York. At the conclusion of the visit and a series of follow-up conference calls, the consultant team and New York officials made the following decisions regarding the TA project:

- Needs assessment and planning training would be initially provided to officials and community representatives from two pilot counties (this number was raised to three at a later date);
- Although originally intended to target the CSHCN population, the scope of the training would be expanded to include all children ages zero through 18 years;
- Colleen Monahan would work with MCH officials to develop state-and county-specific data and information to enhance the pilot counties' efforts to implement a community planning process;

- The HSR consultant team would conduct a workshop during which the principles of community development would be reviewed and county officials would be provided opportunities to develop skills; and
- Follow-up TA would be provided to each county once they had formed community planning groups and begun implementing the assessment process.

Over the following year, HSR and Dr. Monahan worked with New York officials to plan the workshop. In early November, 1995 key BCAH officials attended a community planning meeting in Vermilion County, Illinois with Dr. Monahan to gain a better understanding of the model of needs assessment that was being undertaken within that state. The HSR consultant team then conducted a second site visit to New York on November 15-16, 1995 to develop final workshop materials and conduct the training workshop for state and county officials. Following this and according to the agreed upon workplan, the team then conducted a third site visit on May 6-8, 1996, during which Dr. Monahan and Ms. Clayton traveled with New York staff to the three pilot counties to attend community planning meetings. The purpose of these visits was to obtain a progress report from each New York county and to respond to and address any problems they had encountered to date in implementing their assessment and planning efforts. This report summarizes the content and outcomes of the third site visit and outlines the final steps of New York's technical assistance project.

II. Meeting Summaries

In preparation for each of the county meetings, officials from Schenectady and Orange counties and the Upper Hudson region submitted progress reports to the consultant team. State officials had asked Dr. Monahan to review the reports prior to her visit, to be prepared to comment on actions taken thus far, and to offer suggestions regarding next steps the groups should consider taking. Per the counties' and state officials' request, Dr. Monahan reviewed background material on the counties' progress in implementing their assessment and planning processes and worked with state officials to develop agendas for the meetings with the counties. Each meeting was structured in the following manner:

- **County Update.** First, the lead agency from each county provided an update on the major planning activities that had occurred since the Youth Needs Assessment Workshop, held in November 1995. Counties described the steps they had taken to collect data on the health status of children living in their jurisdictions and to recruit residents and professionals from their communities to participate in the planning process.
- **Comment Period.** Following the presentations, Dr. Monahan provided each county with feedback on their progress. As appropriate, Dr. Monahan noted how the counties could modify their approaches to subsequent activities to facilitate meeting project goals and highlighted issues to be aware of as they implemented the remaining stages of the planning process.
- **Discussion of next Steps.** Prior to adjourning, Dr. Monahan worked with participants to outline both immediate and long term steps the planning groups should take to meet the goals of the project.

A summary of issues raised at each of the meetings is presented below.

Monday, May 6, 1996

1:30-3:00 p.m. **Meeting at the Schenectady County Department of Health,
Schenectady, New York**

Schenectady County Deputy Commissioner Carolyn Callner facilitated this meeting, which was attended by approximately 15 people, including the HSR consultants and state officials. Dr. Callner explained that during the Fall of 1995 county staff had focused on sorting through secondary data available on child health and in developing a compendium of data for implementing a needs assessment process. In addition, Dr. Callner explained that following the November workshop the county spent several months recruiting providers from the community to participate in the planning efforts. Dr. Callner noted that the county redirected its efforts in this manner given the importance Dr. Monahan had placed on building community participation. Dr. Callner further noted that the county had succeeded in involving providers from the community, as evidenced by their attendance at the meeting.

Dr. Callner also reported that the county-led planning group had built off previous needs assessment efforts by analyzing available secondary data on the health status of children and

youth living in Schenectady County. Having compared its county data to that of the state and other counties, the planning group decided to focus its needs assessment on the following two issues:

- **Spontaneous Fetal Deaths.** Upon analysis, the planning group noticed that there were a greater number of spontaneous fetal deaths in Schenectady as compared to other counties in New York and the state as a whole. The group decided to research this issue further.
- **Early Intervention Activities.** The planning group also decided to study the state-operated Early Intervention program for children ages 0 to 3 since it felt that there was a dearth of information available on children participating in the program. The group specifically wanted to take a closer look at participants' diagnoses, outcome data, and draw conclusions regarding the effectiveness of the program.

The county formed two committees to study each issue and developed an action plan. As of this site visit, Dr. Callner reported that each of the committees had met once and had developed a list of questions, both of which are presented as Attachment A. A representative from each committee summarized the issues raised by their groups upon which Dr. Monahan commented. The concerns identified by each committee and Dr. Monahan's response are discussed separately below.

A. Spontaneous Fetal Deaths

1. Issues Identified by the Committee

As described by the chair of the committee, the members decided to focus their efforts on the following two tasks: (1) substantiating whether the number of fetal deaths in Schenectady County is indeed increasing by conducting a trend analysis, and (2) determining if the difference between the number of spontaneous fetal deaths in Schenectady County is statistically significant from other counties, New York State, and the country on the whole. The chair noted that, thus far, the committee had had difficulty focusing these efforts. Members debated how to define the population to be studied (i.e., whether to research every women's pregnancy or only those women who make it past the first trimester), how to identify the factors that put

women at-risk of spontaneous fetal death (i.e., examining the types of assessment tools that are being used by providers), and how to identify the best methods for obtaining input from providers (i.e., to determine if the providers view spontaneous fetal death as a problem in their community).

Dr. Callner explained that once the committee addressed these issues, it would examine the data on spontaneous fetal deaths and discuss the range of possible interventions that the group could implement to mitigate the problem.

2. Comments from Dr. Monahan

Dr. Monahan offered the following comments on the planning group's effort to date:

- As members of the committee begin examining the risk assessment tools used by providers, Dr. Monahan urged them to keep the goals of the project in mind. For example, if the committee determines that private providers do not use risk assessment tools, does the planning group want to set providing preventive technical assistance to these providers as a goal?
- Dr. Monahan also urged the committee to not spend too much time discussing the risk factors related to poor pregnancy outcomes, as they are well documented in the research literature. Rather, Dr. Monahan suggested that the committee focus on how to improve pregnancy outcomes among the target population. For example, the committee should focus on which areas within the community the committee can have the biggest impact.
- Dr. Monahan concluded by reminding the committee that its ultimate goal is to implement an intervention that changes behavior, noting that many planning groups get overwhelmed with collecting and analyzing data and forget about identifying and implementing interventions to solve problems.

3. Next Steps

The following tasks were identified by the consultant team and meeting participants to be possible next steps to be taken by the committee:

- Assess interventions already in place (e.g., early prenatal care, eating healthy, SIDS studies) that are geared toward improving pregnancy outcomes; and

- Conduct a series of focus groups with program administrators, providers, and managed care plans to obtain their views on spontaneous fetal deaths.

B. Early Intervention Program

1. Issues Identified by the Early Intervention Committee

Funded by the State DOH, New York's Early Intervention (EI) program provides health and social support services to children 0 to 3 years of age that are determined to be developmentally delayed or at-risk of having developmental problems. Dr. Callner explained that the planning group decided to study the EI program since state funding for the services may be reduced over the next few years and the program has never been evaluated.

The committee that was formed decided to conduct the following tasks: (1) to complete a demographic profile on the EI population in Schenectady County and (2) to examine service utilization patterns of the EI population (e.g., determine if the goals of the Individual Family Service Plans are being met). As a first step, the chair of the committee explained that committee members have encountered problems developing an estimate of the percent of children with special needs in the county and the percent unserved by the EI program. Second, the chair reported that the committee has conducted chart reviews of a sample of children referred to the EI program to develop a profile of the EI population. Upon reviewing a sample of charts, the committee noticed that a large percentage of children (35 of 92) were being referred for drug and alcohol abuse or related problems. Finally, in an effort to develop a better understanding of the EI population, the committee plans to include providers from the community in their assessment efforts.

2. Comments from Dr. Monahan

In response to the EI committee's report, Dr. Monahan suggested that the committee engage in an exercise to identify the range of issues it plans to address within the final months of the first year of the project. Dr. Monahan suggested that the committee save developing a strategic plan

until the second year of the project, and concentrate instead on conducting the following steps within the remaining months of Year One:

- **Step One:** Take a look at what children are being served by the EI program, noting who provides them with services, the source and type of referral, and where children served by the program live. Dr. Monahan noted that the committee should examine national prevalence estimates of children with disabilities to ascertain the unmet need in their county.
- **Step Two:** Identify where imbalances in service delivery may exist (i.e., maybe the referrals are coming from one area of the county).
- **Step Three:** Step outside the EI program and ask other providers to describe the populations they serve and the range of services they render to these populations. Also obtain their perception about service delivery and, specifically, the EI program.

3. Next Steps

Dr. Monahan and members of the planning group agreed that the committee should examine the list of questions identified by the group (see Attachment B) and prioritize which issues the committee will address by the end of the first year. To the extent possible, Dr. Monahan encouraged the committee to involve providers from the community in a nominal group process exercise to prioritize these issues. Dr. Callner agreed; however, she anticipated waiting to involve providers until the committee had developed a more clear direction.

Tuesday, May 7, 1996

10:30 a.m.-1:30 p.m. **Meeting at the Orange County Youth Bureau, Goshen, New York**

As noted in the second site visit report (Attachment A), the Orange County Department of Health decided to use BCAH funding to contract with the county Youth Bureau to conduct a needs assessment on children and youth. In addition, the county also used funding available through its grant to hire a consultant, Margery Josephson, to facilitate this process. This

meeting was chaired by Dr. Josephson and was attended by Orange county officials, the HSR consultants, BCAH staff, and approximately 20 providers from the community.

1. County Update and Discussion

Dr. Josephson began the meeting by providing the consultant team and BCAH staff with an update on recent activities conducted by the community planning group. Dr. Josephson reported that members of the group had been given assignments, which included conducting key informant interviews with Department of Social Service officials, school administrators, parents, and teenagers to identify the needs of children and youth living in Orange County. A summary of the health issues identified through these interviews is presented as Attachment B. Dr. Josephson noted that the focus of this meeting was to begin prioritizing the health issues raised during the interviews.

Prior to obtaining feedback from Dr. Monahan on their progress and mapping out future steps to be taken, the group spent time discussing how the findings from this process will be incorporated into the needs assessment component of Public Law Article VI, which the county is required to submit to the state. County officials attending the meeting expressed concern over whether the county health department was required to include all of the needs identified by the planning group in its strategic plan (i.e., Article VI plan). Dr. Monahan offered two solutions to this problem: (1) the county health department does not have to include every issue identified by the planning group in its plan, and (2) although the county should be involved in addressing the identified needs, it does not have to take the lead (i.e., it may be more appropriate for the mental health agency to assume the lead if the planning group identifies a need for more mental health treatment services). Joan Healey of BCAH said that she would look at the Article VI regulations and clarify the county health department's role in managing and implementing the strategic plan.

2. Prioritizing Exercise led by Dr. Monahan

Next, Dr. Monahan led the group through an exercise to prioritize the needs identified thus far through the key informant interviews. Dr. Monahan employed a nominal group process to permit the group to identify which needs were high-priority and then facilitated a discussion on identifying strategies to address the identified needs. The five areas of need and strategies to address the needs identified by the group are presented below.

- Expand Mental Health Services by:
 - providing treatment services (not just evaluation);
 - providing long-term counseling;
 - recruiting more specialized providers (including bilingual providers) for children and families into the service delivery system;
 - expanding prevention and school-based services such as early intervention programs, conflict resolution and self-esteem classes;
 - providing crisis services;
 - treating drug use; and
 - offering support services to children of parents with HIV/AIDS.

- Increase Health Education and Prevention and Healthy Lifestyle Services for Children 0 to 21 Years in the following areas:
 - human sexuality;
 - adolescent pregnancy;
 - drug, alcohol, and tobacco use;
 - nutrition counseling;
 - parenting skills;
 - hygiene (including dental);
 - family planning;

- appropriate use of health services;
 - lead poisoning;
 - respiratory problems; and
 - recreational services.
- Refine/Tailor Services for Sexually Active, Pregnant, and Parenting Teens by:
 - Improving access to WIC;
 - Sponsoring parenting classes for teens; and
 - Addressing the high “drop out” rate.
- Reduce Violence in the following areas:
 - battering relationships;
 - abuse by adults/parents (physical, sexual, and emotional);
 - domestic violence;
 - gangs; and
 - schools.
- Expand Specialized Pediatric Health Services in the following areas:
 - dental;
 - orthopedics;
 - CSHCN;
 - ophthalmology;
 - neurology;
 - pediatrics;
 - infectious diseases; and
 - support services.

3. Next Steps

Dr. Monahan noted that Orange county's next step should be to develop a document summarizing the issues identified in the above section, using information from the key informant interviews to substantiate each need. Once this document is written, Dr. Monahan suggested that the group could ask agencies in the community to comment on its findings and then engage in a more in-depth process of prioritizing the issues. As a final step, Dr. Monahan suggested that the committee develop a strategic plan to address the issues presented in the document. However, she suggested that the group make this a goal of the second year of its project.

Wednesday, May 8, 1996

10:00 a.m.-12:00 p.m. **Meeting with the Upper Hudson Primary Care Consortium Project, Upper Hudson, New York**

The final meeting with the Upper Hudson Primary Care Consortium project was less formal than the previous meetings with the other two counties and did not follow the same format; the site visit was not coordinated with a planning group meeting. Rather, Dr. Monahan and BCAH staff met with Peter Whitten, the Director of Planning and Development for the Consortium to learn about the activities conducted by the consortium.

During the meeting, Mr. Whitten reviewed the structure of the Upper Hudson Primary Care Consortium and explained that the Youth Needs Assessment and Planning Initiative encompassed four counties: Warren, Washington, Saratoga, and Essex. Mr. Whitten explained that, since the November workshop, the consortium had refined the structure of the community planning group (CPG) in an effort to best facilitate participation from the counties. The CPG is composed of a core group of eight members, including the Directors of Public Health and Youth Bureaus from each county, who are responsible for region-wide decision making. To ensure that the planning group obtained input from agencies and providers within the four-county area, Mr. Whitten explained that sub-groups in each county were created. These sub-groups report to their respective Youth Bureau Director and are responsible for obtaining input from community providers and youth agencies on issues identified by the consortium to be a

priority. The UHPCC's decision to convene county-by-county groups was motivated by two factors. First, it was recognized that each county perceives itself as unique and UHPCC did not want competition to be a disruptive factor in the early stages of decision making. Second, it was felt that the process might be unwieldy if all of the prospective participants from four counties were involved in a single group from the outset.

In addition, Mr. Whitten noted that the following needs assessment activities had been conducted by the CPG:

- The CPG referred to national, state, and regional data sources to develop a health status profile children living in the target region;
- The core group of the CPG then reviewed the health profile, identified which issues to analyze further, and developed a list of causative factors for each health priority; and
- Based on the identified risk factors, the CPG developed a youth risk behavior survey, which was administered to children in 10th through 12th grades at 22 schools in the four-county region.

In closing, Mr. Whitten mentioned that attendance at CPG meetings had been sporadic and he discussed with Dr. Monahan possible methods for ensuring continued participation in the planning activities. Dr. Monahan suggested that the consortium develop a paper summarizing the needs of youth living in the target region and devise a method of promoting the CPG's plan to providers and agencies from the community.

III. Next Steps

This follow-up technical assistance represented the final intervention to be funded under HSR's MCHB-funded project. To document the stages of technical assistance provided to New York and create a product from which other states could learn about strategies for implementing a successful child health needs assessment and planning process, Ms. Clayton agreed to develop a

compendium of reports written by HSR, describing the progress BCAH officials have made in designing and implementing their needs assessment initiative.

Attachment A: Questions Developed by Schenectady County Committees

Questions Developed by the Committee on Spontaneous Fetal Death (SFD)

1. Are the differences in SFD between Schenectady County and the rest of New York State (excluding New York City) statistically significant?
2. How are spontaneous fetal deaths reported?
3. Does the change in terminology influence reporting?
4. Are there environmental factors relating to certain geographical areas?
5. Are there any socioeconomic factors when looking at geographical areas?
6. Do we have a high number of women coming to Schenectady (from New York City) for treatment for alcoholism (drug treatment)?
7. Do we have a high number of women coming to Schenectady (from New York City) for treatment for recidivism of drug use and then subsequent pregnancy?
8. Do we have a high number of women coming to Schenectady (from New York City) for access to mental health services?
9. Do we have a high number of women coming to Schenectady (from New York City) for access to shelters for domestic violence?
10. Do we have a high number of women coming into Schenectady from other counties (Fulton/Montgomery) to deliver high-risk babies?
11. Is Schenectady a service-rich area?
12. Is data reflective of other county residents delivering at Schenectady County hospitals?
13. Can we get SFD data according to census tracts?
14. What about environmental risk? (What's buried in the County?)
15. What are the sources of water for each locality (e.g., aquifer, well)?
16. Are there differences over time (i.e., from 20 to 30 years ago)?
17. Information given by mother on death certificate may not be reliable. Are there biases based on race?
18. There is a need for more information regarding entry into care for both ends of the age spectrum (risk factors).

19. Are we sure that death certificate information is based on county of residence, not place of death?
20. Do health precursors affect SFD rates among migrant populations? Is this significant in the county?
21. How is the mother's area of residence recorded? How long do they have to be living in Schenectady County for it to be recorded as their resident county? What if they are living in a shelter or halfway house?
22. How does Schenectady's SFD rate compare with national rates?

Questions Developed By the Early Intervention Committee:

1. Why were the children who were identified to be at-risk, screened and referred to EI originally in ICHAP.
2. How are disabilities manifested as a result of drug and alcohol abuse?
3. How are disabilities manifested as a result of parenting problems?
4. How are disabilities manifested as a result of environmental problems?
5. What happens to the children whose parents refuse ICHAP? What percentage of parents refuse these services?
6. Are there familial traits or disorders?
7. How involved are the parents with interventions of their own child's program?
8. How does ICHAP/EI involve parents in children's service plans?
9. Is there an increased need for mental health services for children?
10. Are there any drug rehabilitation programs for children in the community?
11. What are the categories of delays that are being serviced in the EI program?
12. What is the largest category of delay?
13. What are the characteristics/demographics of children/families serviced by the EI program?
14. Are there significant commonalities among the risk factors?
15. What kind of variables influence entry into the EI program?
16. What kind of variables influence the outcomes of children in the EI program?
17. What are some proxy measurements that can act as indicators for the EI program?
18. What are the variables if groups compared are: (a) children who are discharged from the program before age 3 because they no longer need services, (b) children who go into the 3-5 program but leave before kindergarten because they no longer need services, and (c) children who start regular school program services.

Attachment B: Health Issues Identified by the Orange County Youth Bureau

Health Needs Assessment of Children and Youth in Orange County

Summary of Health Issues

- Access to medical specialists
- Additional pediatricians in county
- Access to dental services
- Mental health treatment services
- Increasing prevalence of asthma
- Location/scheduling of immunization services
- Transportation services
- Information on existing agencies, on HMOs, on providers who accept Medicaid
- Education on parenting skills, dental hygiene, appropriate use of health services, family planning
- Bilingual services for various languages and signing
- Expansion of school health screenings/services/staff
- Additional STD services
- Need for increased flexibility in hours and shorter waiting periods for the WIC program
- The need for information sharing between agencies, providers, and hospitals
- Sports medicine centers
- Increased confidentiality of services for teenagers
- Poor nutritional habits leading to both obesity and bulimia
- Portable dental operatories to take to schools or other locations
- Violence/aggression
- Mental health treatment (beyond evaluation) in schools
- Improved school accommodations for disabled of all types
- Support groups for children with chronic conditions
- Adolescent pregnancy
- Adolescent drug use
- Sensitivity training for providers with regard to young mothers, teenagers, minorities, and the disabled
- Expand health education curriculum
- Additional satellite health centers in more isolated areas
- Services for the non-insured
- Services to children of parents with AIDS
- Health oriented recreation and social activities