



Health Systems Research, Inc.
2021 L Street NW Suite 400
Washington DC 20036
(202) 828.5100
Fax: (202) 728.9469

Enhanced Care for Kids: A Proposed Benefit Package For At-Risk Children in Delaware

Prepared for:

Division of Public Health
Delaware Department of Health and Social Services

Prepared by:

Ian Hill, Beth Zimmerman, John O'Brien and Deanne Pearn
Health Systems Research, Inc.

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Table of Contents

Executive Summary	iii
Chapter I. Introduction	1
A. Delaware’s Request for Technical Assistance	2
B. The Context for Technical Assistance in Delaware	3
C. Technical Assistance Process to Date	5
D. Organization of this Report	7
Chapter II. Model State Programs for At-Risk Children	9
A. Michigan’s Infant Support Services	9
B. Florida’s EPSDT/OBRA-89 Enhancements	12
Chapter III. Design Parameters of Enhanced Services for At-Risk Children	15
A. Eligibility Criteria	15
B. Benefits	17
C. Service Delivery	18
D. Reimbursement	19
Chapter IV. Estimating the Size of the Target Population, Enrollment and Program Costs for the Enhanced Benefit Package	21
A. Estimating the Total Number of Children in Delaware, by Age and Income	23
B. Estimating the Number of “At-Risk” Children in Delaware	26
C. Estimating the Number of “At-Risk” Children Who Would Participate in the Enhanced Services Program	37

D.	Estimating the Costs of Individual Services in the Enhanced Benefit Package	40
E.	Estimating Total Program Costs	45
Chapter V.	Policy Options for Implementing Enhanced Services for At-Risk Children	49
A.	Designing a Risk Assessment Instrument and System	50
B.	Developing Protocols for Enhanced Services	52
C.	Establishing Criteria for Provider Participation and Processes for Certification	53
D.	Obtaining HCFA Approval for Medicaid Coverage of Enhanced Services	56
E.	Designing a Schedule of Sliding Fees	60
F.	Integrating Enhanced Services for Children into Broader Health Care Reform Efforts	61
References		66

Appendix A: Overview of Delaware's Service Delivery System

Executive Summary

In October 1992, the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services awarded a three-year contract to Health Systems Research, Inc. (HSR) to assist 25 states in developing comprehensive service delivery systems for children and their families. Delaware was one of the six states chosen to receive assistance during the first project year.

In its request, the Delaware Department of Health and Social Services, Division of Public Health asked for assistance in developing a package of enhanced services for children at risk of poor growth and development or poor family functioning. As envisioned by Delaware officials, these benefits would be financed through Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and integrated with the State's Part H initiative. The development of such an enhanced benefit package is one of several state-wide initiatives aimed at improving the financing and delivery of health care for all Delaware citizens.

In conducting the technical assistance project, HSR performed three site visits during the summer and fall of 1993 to gain background information and discuss the design of the enhanced benefits package. During the third site visit, HSR facilitated an interagency focus group to discuss and reach consensus on the policy and design parameters of the enhanced services. Based on the input obtained from the interagency focus group, HSR developed during the spring of 1994 the *Enhanced Care for Kids* proposal to address the needs of children at risk of poor growth and development due to psychosocial and environmental factors.

Finally, HSR Associate Director Ian Hill conducted two subsequent site visits to formally brief selected Delaware officials on the *Enhanced Care for Kids* proposal. During these visits, conducted in December 1994 and April 1995, Mr. Hill met with senior Public Health and Medicaid officials, as well as selected additional advisors to the Governor, to discuss various strategies for adopting and implementing the proposal.

A. Design Parameters of Enhanced Services for At-Risk Children

Over the course of the interagency focus group meeting mentioned above, participants identified the key structural components for the program. Decisions were made regarding the eligibility criteria for enhanced services, the benefits to be included in the package, alternative service providers who could deliver enhanced services, and reimbursement issues.

Based on the guidance provided by the focus group, HSR developed a detailed model to estimate the potential costs of a new enhanced benefit program for “at-risk” children. To operationalize the focus group’s recommendations for purposes of developing the estimates, HSR defined the proposed program parameters as follows:

- **Eligibility criteria.** The group established age, income and risk-based eligibility criteria as follows:
 - **Age.** Enhanced services would be available for children up to age 18. However, given that the interagency focus group placed priority on making enhanced services available to the birth to six population, HSR developed the model in such a way that estimates could be presented for both the birth to six population as well as for the birth to 18 group.
 - **Income.** A primary focus in developing the enhanced benefit package was to build off the Medicaid program and maximize federal financing. However, based on input from the interagency group that services should be made available to all at-risk children, regardless of income level, subsidy provisions for families with higher incomes were included in the model.
 - **Risk factors.** Based on input from the group, children demonstrating psychosocial and environmental risk factors (e.g., young maternal age, parental substance abuse, lack of stable housing), rather than children with medical conditions, would be targeted to receive enhanced services.

- **Services.** The interagency group clearly indicated that the package of services should include those of an enabling/supportive nature. In addition, they emphasized the importance of addressing children's, particularly adolescents', limited access to mental health and substance abuse services. Therefore, for the estimation model, HSR assumed that the enhanced service package would include the specific components detailed in Table 1 below:

TABLE 1. ENHANCED SERVICE PACKAGE COMPONENTS

- Care coordination, an intensive, home-based intervention.
- Direct services, a "bundle" of interventions, also provided in the home, including as appropriate:
 - Parenting training;
 - Health education;
 - Nutritional counseling;
 - Psychosocial counseling; and
 - Infant mental health and child development services.
- Outpatient mental health services.
- Outpatient substance abuse services.

- **Service providers.** As proposed by the interagency focus group, enhanced services would be rendered by a multi-disciplinary team of providers; services would be provided in the home whenever possible. The group agreed that enhanced services should initially be delivered primarily by public providers, although private sector providers should be incorporated over time.
- **Reimbursement.** Regarding reimbursement issues, the group agreed that a bundling approach should be used to structure fees for enhanced services. In addition, they decided that there should not be any cost-sharing for recipients beyond an annual premium or enrollment fee.

B. Estimating the Size of the Target Population, Enrollment and Program Costs for the Enhanced Benefit Package

HSR took several steps to develop final cost and utilization estimates. These are described below.

1. Estimating the Number of “At-Risk” Children in Delaware

In determining the size of the target population for the enhanced benefits, HSR undertook the challenging task of pinpointing an overall prevalence rate of at-risk children. To accomplish this, HSR conducted a careful analysis of the prevalence of a broad range of risk criteria that have been identified as important correlates of “at risk” status; these included young maternal age, low maternal education level, lack of stable housing, parental substance abuse, parental mental illness or mental retardation, and family history of child abuse or neglect. Based on these analyses, which drew on national and state prevalence data, experiential data from other state enhanced services programs, and data from Delaware’s Integrated Service Information System,¹ HSR estimated that:

- Twenty percent of children in families with incomes below 185 percent of the federal poverty level would demonstrate sufficient risk factors to qualify as “at risk” under the enhanced services program. As family income rose, HSR estimated that the prevalence of at-risk children would decrease; 15 percent of children in families with income between 185 percent and 260 percent of poverty, and 10 percent of children in families with income above 260 percent of poverty were estimated as being at risk.
- A total of 24,150 children would potentially qualify to receive enhanced services. Forty-six percent of these children would be in families with incomes below 185 percent of poverty, 17 percent would be in families with incomes between 185 percent and 260 percent of poverty, and 36 percent would be in families with incomes greater than 260 percent of poverty.
- A subset of the “at-risk” children would be in need of immediate mental health and substance abuse treatment interventions. Assuming that both mental health and substance abuse services would be targeted to older children (ages six to 19 years), HSR employed national prevalence data to estimate that approximately

¹ Delaware’s Integrated Service Information System is a recently implemented program to track children suffering from a range of high risk conditions. It is described in more detail in Chapter IV.

15 percent of older children would potentially qualify to receive the mental health intervention, and 13 percent of such children would potentially qualify to receive substance abuse intervention.

2. Estimating the Number of Children Who Would Participate in the Enhanced Services Program

The second component of HSR’s cost model allowed for estimating the portion of the at-risk population who would actually receive services. The extent to which families with potentially eligible children would enroll their children in the program will depend upon several factors, including: the degree to which risk screenings are universally administered; the accuracy of the risk-assessment tool; family perceptions regarding the child’s risk status or need for help; the availability of services; the income and insurance status of the families; and the cost of services to the families.

Based on data previously developed by HSR on consumers’ decision-making patterns regarding purchasing insurance products as well as participation data from other state Medicaid programs, the degree to which eligible children would receive enhanced services was estimated. HSR found that, of the total number of “at-risk” children in the state, 23 percent--5,640 children--would participate in the enhanced services program, approximately 45 percent--2,550 children--of whom would be under age six.

3. Estimating the Costs of Individual Services in the Enhanced Services Program

To estimate total program costs for the benefit program, HSR took the preliminary step of developing annual unit cost estimates for each enhanced service within the benefit package. Specifically, by adjusting data from other state enhanced benefit programs to reflect the unique design features of the Delaware program, HSR developed annual unit cost estimates for the care coordination and direct services bundle. Combining these estimates with both national data that indicate that children of different ages utilize services at different rates and actuarial estimates developed by HSR under prior projects, age-adjusted annual per capita costs for these service components were developed. For the purposes of estimating the annual per capita costs of providing “at-risk” children with outpatient mental health and substance abuse services, HSR

relied on Delaware-specific data. Based on these analyses, HSR estimated the costs of the individual service components to be as follows:

- Care coordination services would cost \$400 for infants; \$300 per year for children ages one through five; and \$280 per year for children ages six to 18.
- Providing the direct services bundle would cost \$200 per year for infants, \$150 per year for children ages one through five, and \$140 per year for children ages six to 18.
- The annual per capita cost of providing mental health interventions to children between ages six and 18 would be \$1600.
- The average cost of providing substance abuse services to children between ages six and 18 would be \$960 per child per year.

4. Estimating Total Program Costs

Combining the analyses of the size of the target population, the prevalence of at-risk children, and the annual service-specific per capita cost estimates, HSR developed detailed estimates of the total program costs associated with providing enhanced services to at-risk children in Delaware. Specifically, it is estimated that:

- The total cost of providing enhanced services to all children, from birth to age 18, would be approximately \$4.0 million. Roughly 63 percent of these costs--\$2.5 million--would be associated with the provision of care coordination and the direct services bundle. The remaining 37 percent of costs, totaling just over \$1.5 million, would be associated with the provision of outpatient mental health and substance abuse treatment services.
- If the State of Delaware were to choose to limit enhanced services to children birth to age six, total program costs would drop to approximately \$1.2 million. As outpatient mental health and substance abuse treatment services would not be targeted to these younger children, all costs would be associated with the provision of care coordination and direct services.

Due to the potential availability of matching funds and the requirement that near-poor and higher-income families would pay a portion of service costs, program costs would be distributed between the State of Delaware, the federal Medicaid program, and families with “at-risk” children as follows:

- Of total program costs (\$4.0 million), 40 percent would be paid by the state (approximately \$1.6 million), 19 percent would be paid by the federal contribution to the state’s Medicaid program (approximately \$750,000), and 42 percent would be paid by families (approximately \$1.7 million).
- If Delaware officials were to choose to limit enhanced services to children birth to age six, total costs to the state would equal approximately \$525,000. If, within this age group, state officials were to decide to cover only Medicaid children, total costs to the state would drop to roughly \$311,000.

C. Policy Options for Implementing Enhanced Services for At-Risk Children

Before an enhanced services program for “at-risk” children can be successfully implemented, several important administrative and programmatic issues require exploration and resolution. Specifically, state officials would need to:

- Develop a risk assessment system, including an assessment instrument, to effectively identify “at-risk” children;
- Develop detailed service delivery protocols for the enhanced service package;
- Determine which providers and service delivery systems would be most appropriate for providing enhanced services;
- Obtain approval from the federal Health Care Financing Administration for a state plan amendment that would allow federal Medicaid matching funds to help finance the services for Medicaid-eligible children;
- Design a mechanism to allow families with income above Medicaid eligibility thresholds to purchase enhanced service coverage on either a partially- or non-subsidized basis; and
- Consider how a system for providing enhanced services to “at-risk” children can be merged with the state’s broader efforts to reform health care financing and service delivery systems.

By addressing these issues and implementing the package of enhanced services described in this report, Delaware would assume a leadership role among states by creating a more sophisticated and responsive system of care for children. The development of a program to provide enhanced

services to “at-risk” children is an appropriate strategy for improving the comprehensiveness of Delaware’s system of care either in the presence, or absence, of health care reform.

CHAPTER I

Introduction

With the passage of the Omnibus Budget Reconciliation Act of 1989 (OBRA-89), Congress took a sweeping step to improve health coverage for children on Medicaid. The Act contained numerous provisions designed to improve the delivery of services to low-income children. Specifically, it expanded Medicaid eligibility for pregnant women and children, improved provider participation in Medicaid, and required states to enhance the quality of care provided through Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. In addition, OBRA-89 took a bold and much-needed step to address a traditional shortcoming of EPSDT programs--the lack of attention to treatment services--by requiring states to cover any services needed to treat conditions identified during an EPSDT screening examination, whether or not they normally cover that service through their Medicaid programs.

States have responded to the "treatment services" provision of OBRA-89 in a variety of ways. Believing that their benefits were already quite comprehensive, most states have chosen not to make any significant changes to their programs in terms of broadening benefit coverage. However, a small number of states have taken advantage of the opportunity presented by OBRA-89 to create special benefit packages to meet the unique needs of children (Hill and Breyel, 1991). Delaware is now working to accomplish this task. The state's Division of Public Health is spearheading an effort to improve the comprehensiveness of Delaware's EPSDT program by creating an enhanced benefit package for at-risk children. This report presents a proposed design for this enhanced service package and provides detailed estimates of the costs that might be associated with it.

This report was prepared as part of a project funded by the federal Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services, to assist states in

developing comprehensive service delivery systems for children and their families. In October 1992, the MCHB awarded a three-year contract to Health Systems Research, Inc. (HSR) to provide 25 states with technical assistance (TA) in their systems development efforts. Each project year, states are invited by the MCHB to submit requests for technical assistance to HSR. States' requests are assessed based on a variety of criteria, including the clarity of the request, the degree of support across various sectors for systems change, the readiness of the state to receive TA, and the degree to which other states can learn from the technical assistance effort. During the first project year, 32 states submitted requests for technical assistance. Delaware was one of the six states chosen to receive assistance during this year. (Hill, 1993)

A. Delaware's Request for Technical Assistance

In its request, the Delaware Department of Health and Social Services' Division of Public Health (DPH) asked for assistance in developing a package of enhanced services for "at-risk" children, specifically those children at risk for poor growth and development or poor family functioning due to psychosocial or environmental factors. DPH officials view the establishment of an enhanced service package as an important step in the development of a comprehensive system of care for Delaware's children, particularly for the large numbers of children who are identified by the state's Birth-to-Three Early Intervention Program (Part H of I.D.E.A.) as potentially in need of early intervention services but later determined to be ineligible for Part H. DPH estimates that there are over 3,000 infants and toddlers identified each year in Delaware who are "at-risk" of developmental delay but are not eligible for Part H services.

As envisioned by Delaware officials, the enhanced services package would be financed through Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and integrated with the state's Part H initiative. As well, this new system would be modeled after the Medicaid program's SMART START enhanced prenatal care program for high-risk pregnant women.

B. The Context for Technical Assistance in Delaware

Like many other states, Delaware is working hard to improve the financing and delivery of health care to its citizens, particularly to children and their families. A variety of initiatives are underway in the state aimed at achieving different facets of this challenging goal, as described below:

- **Reforming health care.** The Delaware Health Care Commission is currently in the process of developing a comprehensive strategy for reforming health care financing and delivery systems in the state.
- **Establishing pediatric clinics.** The Alfred I. duPont Institute of the Nemours Foundation is in the process of establishing pediatric clinics in twelve medically underserved communities across the state. The clinics will serve uninsured and Medicaid-eligible children under a managed care system.
- **Improving service delivery to families.** In 1993, Governor Thomas Carper created a Family Services Cabinet Council to oversee the development of a statewide strategy for improving the coordination of public and private efforts for families and to ensure that these efforts are focused on providing families with the assistance and support they need to succeed in today's society.
- **Expanding school-based clinics.** Governor Carper has also launched an initiative to greatly expand the availability of school-based health services. He hopes to increase the number of school clinics from four to 30 during his four-year term as Governor.
- **Reducing duplication of services.** The Delaware Health Care Commission and the Interagency Resource Management Committee of the State of Delaware are sponsoring a project to develop a blueprint for improving the delivery of services to children. In particular, the study is intended to identify duplicative efforts as well as gaps in the organization and delivery of services for children, with special attention to programs for children at risk of poor outcomes.

Given the variety of initiatives targeted toward improving services for Delaware's children, DPH officials understood that the technical assistance effort with HSR must be executed in collaboration with the many agencies involved with the initiatives described above. Therefore, as will be described in more detail below, the consulting team spent a considerable amount of time meeting with representatives of the various state agencies that serve children to obtain their input regarding the design of an enhanced benefit package. Together, these meetings served to

clearly demonstrate that, although it was the Maternal and Child Health program within DPH that initiated the request for technical assistance, there is broad governmental support for the development of an enhanced service package for at-risk children. For example:

- **The Department of Children, Youth, and Families**, under the direction of the former Secretary of the Department of Health and Social Services, is interested in creating an integrated system of primary care for children under the care of the Division of Child Protective Services.
- **The Division of Social Services**, within the Delaware Department of Health and Social Services, wants enhanced services to be made available to AFDC families as part of the state's welfare reform program.
- A major focus of the state **Budget Office** is to accrue savings through the provision of care coordination services, a central component of the envisioned enhanced services package.
- The **Part H** program, located in the Division of Public Health, wants to integrate services for infants and toddlers with, or at risk of, developmental delays with the new enhanced services package.

In addition, a recent report by the Center for Assessment and Policy Development developed under the direction of the joint subcommittee of the Delaware Health Care Commission and Interagency Resources Management Committee described above, emphasized the importance of enhanced services in achieving Delaware's vision that all children be healthy, well-developed and raised within strong families. The report recommended that family support and early intervention services, among others, be made available to all families with at-risk children. (McCarthy and Miller, 1994)

The intent of the MCH program is to oversee the development of an enhanced benefit package that meets each state agency's needs and improves integration between the various service systems that collectively serve Delaware's children.

C. Technical Assistance Process to Date

To most effectively assist Delaware officials in developing an enhanced benefit package for at-risk children, HSR assembled a technical assistance team that could draw on the relevant experiences of other state officials. Specifically, HSR bolstered its resources by adding Janet Olszewski of the Michigan Department of Health to the TA team. Ms. Olszewski was one of the key individuals involved with the design of Michigan's Infant Support Services program, an enhanced services program for infants at psychosocial/environmental risk. In addition, HSR consulted with Phyllis Siderits of Florida's Children's Medical Services throughout the development of the report regarding Florida's expansion of services to children with special health care needs. (Both the Michigan and Florida programs are described in detail in Chapter II.)

On 18 May 1993, HSR conducted its initial site visit to Delaware. The objectives of the site visit were to:

- Gather detailed contextual information on the service delivery system for children in the state;
- Discuss optional policy parameters for the enhanced benefit package design with Delaware officials; and
- Develop a work plan for completion of the technical assistance assignment.

To achieve these goals, the consulting team had extensive discussions with both state and local officials of the Division of Public Health, including Maternal and Child Health. These meetings provided the consultants with an overview of Delaware's primary care system for children and a clearer picture of the types of assistance Delaware would need in developing an enhanced benefit package for children. A site visit report describing the content of these discussions was subsequently submitted to Delaware officials and the MCHB on 22 June 1993.

At the conclusion of the initial visit, it was decided that a second site visit was needed to gather additional background information on programs providing primary care to children. Therefore, a subsequent visit was conducted by the HSR technical assistance team on 21 June 1993.

During this trip, meetings were conducted with state officials from several additional agencies, including Medicaid, Child Protective Services, Part H, the Kent/Sussex County Public Health Department, and the state Budget Office. A site visit report summarizing these meetings was submitted on 30 June 1993.

Building on the enthusiastic support voiced by state and local officials during these meetings, DPH officials decided that HSR should facilitate an interagency focus group to reach consensus on the policy and design parameters of the enhanced benefit package. This interagency focus group was held on 15 November 1993 at the Buena Vista Conference Center in New Castle, Delaware. The meeting participants included representatives from the Division of Public Health/Maternal and Child Health, Medicaid, Part H, Division of Family Services (formerly Child Protective Services), Department of Public Instruction, and the A.I. duPont Institute.² The discussions which took place and decisions reached during this meeting are described in detail in Chapter III of this report.

Based on the input obtained from the interagency focus group, HSR developed during the spring of 1994 the *Enhanced Care for Kids* proposal to address the needs of children at risk of poor growth and development due to psychosocial and environmental factors. This report was submitted in draft to Delaware officials in July 1994 and once again in December 1994 after comments from these officials were incorporated.

² An afternoon meeting was also held with a broader range of agency representatives and community organizations, including the Visiting Nurses Association of Delaware and the Association of Delaware Hospitals. During this meeting, the technical assistance project was outlined and outcomes of the morning's focus group were summarized.

Finally, HSR Associate Director Ian Hill conducted two subsequent site visits to formally brief selected Delaware officials on the *Enhanced Care for Kids* proposal. Specifically:

- On 19 December 1994, Mr. Hill met with senior Public Health and Medicaid officials, as well as with representatives of the state's Interagency Resource Management Committee, an executive-level group charged with overseeing an initiative to integrate the funding and operations of Delaware's programs for persons with disabilities; and
- On 20 April 1995, Mr. Hill returned to Delaware to meet with Thomas Eichler, Secretary of the Delaware Department of Services for Children, Youth, and Families as well as with other senior-level officials and consultants to the Department.

During these visits, participants discussed various strategies for adopting and implementing the *Enhanced Care for Kids* proposal. In addition, Delaware officials indicated their support for the methodologies employed by HSR in developing cost and utilization estimates associated with the enhanced benefits.

D. Organization of this Report

The remainder of this report is organized into four sections, as follows:

- To provide examples of potential models for Delaware's enhanced benefit package, Chapter II describes two state programs initiated in the wake of OBRA-89--in Michigan and Florida--to expand the scope and comprehensiveness of Medicaid-financed services for children.
- Chapter III provides a detailed discussion of the decisions reached during the interagency focus group regarding the parameters of the proposed enhanced benefit package. Within each issue area (e.g., eligibility, benefits, etc.), the key policy questions addressed by the group are summarized, followed by the decisions reached by the meeting participants. These decisions formed the foundation for the analyses and policy options presented in subsequent sections of this document.
- Chapter IV presents estimates of the cost and utilization that would be associated with the new services. As well, the methods and data sources used to derive these estimates are described.

- Chapter V presents policy options regarding implementation of the benefit package, including possible service delivery arrangements, strategies for coordinating the new services with existing programs, and options for integrating the enhanced services into broader health care reform efforts in Delaware.
- Finally, an overview of Delaware's service delivery system is provided in Appendix A.

CHAPTER II

Model State Programs for At-Risk Children

As discussed in the introduction to Chapter I, OBRA-89 presented states with a unique opportunity to reevaluate the comprehensiveness of their EPSDT programs and expand the scope of benefits for children. In considering the type of enhanced services package for “at-risk” children that is most appropriate for Delaware, it is instructive to explore the service enhancements that have been implemented in other states.

Two states that have been leaders in significantly expanding the scope of Medicaid-financed benefits for at-risk children are Michigan and Florida. Michigan added a set of support services, much like those provided to Medicaid-eligible pregnant women in the state, for infants with psychosocial risk factors. Florida expanded treatment services for children with special health care needs and is also working to fund Part H services through Medicaid. An overview of each program is provided below.

A. Michigan’s Infant Support Services

Rather than being a direct response to OBRA-89, Infant Support Services (ISS) was originally developed as an extension of the Maternity Support Services program of enhanced prenatal care that was implemented in 1987. Maternity Support Services were developed to help pregnant women, at risk of having poor birth outcomes due to psychosocial and/or nutritional problems, give birth to healthier babies. The program complemented traditional medical prenatal care services by extending a set of nonmedical support services, such as care coordination, nutritional and psychosocial counseling, health education, and transportation, to high-risk women. However, since poverty-related Medicaid coverage for pregnant women expires after

60 days postpartum, Michigan officials believed that they needed to establish a complementary program that would continue to provide special care to the newborns of high-risk mothers.

Like MSS, ISS provides families with a broad set of psychosocial support services. Covered under the plan are:

- Psychosocial and nutritional assessment;
- Professional interventions by a multidisciplinary team of social workers, nutritionists, nurses, and infant mental health specialists;
- Care coordination;
- Parenting education; and
- Transportation.

ISS services are required to be delivered in families' homes or, if the home environment is not safe, in another location. Services cannot be provided in a clinic, hospital, or service agency office.

To qualify for ISS, infants must be referred by a physician, nurse midwife, or family/pediatric nurse practitioner³ because they (or their mother) demonstrate one or more of the following risk factors:

- Alcohol or drug abuse, especially cocaine;
- Mother is less than 18 years of age and has no family supports;
- Family history of child abuse and neglect;
- Failure to thrive;
- Low birthweight;
- Mother with cognitive, emotional or mental impairment;

³ Child protective services workers may also refer families to ISS, as long as a referral from a medical professional is obtained, as well.

- Homeless or dangerous living/home situation; and
- Other conditions placing the infant at risk of death or significant impairment or illness.

Up to nine professional visits are allowed for each infant based on the initial referral; however, up to nine additional visits may be authorized by a medical professional if circumstances indicate that more care is needed. For drug-exposed infants and their families, visits can occur weekly for the baby's first six months of life and biweekly for the subsequent six months. (Michigan Department of Social Services, 1993)

Adoption of ISS did not come easily for Michigan. Three different plan amendments were submitted before HCFA granted approval of the program. In particular, HCFA was concerned that the program was discriminatory by virtue of its focus on newborns--the Medicaid statute prohibits services to be targeted based solely on age. In addition, HCFA officials were concerned that ISS was not really a benefit package for children, since most of the program's interventions were actually directed at newborns' parents. Michigan was finally able to obtain approval of the plan amendment by removing language that restricted the benefits only to children under age one and by convincing federal officials that, by necessity, the psychosocial services contained within the program had to, at least in part, be directed toward the parents of newborns if infant health was to be improved (Personal communication, Janet Olszewski, April 1994). Having learned from their experience in getting HCFA approval for Maternal Support Services, Michigan officials also knew services would need to be demonstrated as medically necessary. Therefore, as with the MSS program, ISS requires a physician referral into the program and reporting by the ISS provider back to the physician throughout the course of services.

B. Florida's EPSDT/OBRA-89 Enhancements

In contrast to Michigan's focus on infants with psychosocial risk factors, Florida's initial response to OBRA-89 was directed to infants and children with complex medical problems. To meet the needs of these populations, Florida used the opportunity presented by OBRA-89 to significantly expand the treatment portion of their EPSDT program.

As was the case in Michigan, case management (or care coordination) is a central feature of the expanded benefit packages in Florida. The state added to its state plan an amendment to provide targeted case management services for children with special health care needs, including children with mental health problems. This plan requires that each family have a single case manager or, at least, does not receive duplicative case management services. These steps were seen as an important part of state efforts to develop a comprehensive and coordinated delivery system. (Personal communication, Phyllis Siderits, 1994)

As with Michigan's ISS program, Florida's expanded benefit package also includes a range of direct services. In addition to the service coordination component, Florida's expanded services for children with complex health care problems include: durable medical equipment and supplies; pharmaceuticals; personal care services; private duty nursing services; nursing facility services; hospitalization; outpatient services; transplantation services; prescribed pediatric extended care services (developmental/medical care); medical foster care; rehabilitation services; and therapy services. Multidisciplinary teams consisting of a pediatrician, social worker and nurse develop care plans for all medically-complex children. If a child needs any of these expanded treatment services, the care coordination team works with a Medicaid service authorization nurse who "prior-authorizes" eligibility for those services. (Personal communication, Phyllis Siderits, 1994)

In addition to expanding treatment services for special needs children, Florida also saw OBRA-89 as an opportunity to maximize funding for its Part H program, as a large number of children eligible for Part H services in Florida are also eligible for Medicaid. Therefore, building on the EPSDT treatment expansions described above, Florida has proposed to the Health Care

Financing Administration (HCFA) that the following early intervention services be covered by Medicaid:

- Interdisciplinary screen;
- Initial psychosocial and developmental evaluation;
- Follow-up psychosocial and developmental evaluation;
- Early intervention (including nutritional, psychological, audiological, nursing, social services or parenting training, as outlined in the child's family support plan) group session;
- Early intervention individual session;
- Early intervention home visiting session;
- Early intervention center-based day program services; and
- Consultation services.

Federal Medicaid funding for the above services, which more closely mirror those envisioned by Delaware officials, have not yet been approved by the Health Care Financing Administration. HCFA staff have indicated that acceptable "medical necessity" criteria for services have not been adequately demonstrated (Personal communication, Phyllis Siderits, April 1994).

As proposed, both children with developmental delay and those at risk for delay would be eligible for early intervention services.⁴ As with the expanded treatment services described earlier, case management services would be extended to Medicaid-eligible Part H recipients through the use of a multidisciplinary planning team. This team is to develop family support (or

⁴ Children with developmental delay include those with cognitive, physical/motor, communication, social/emotional or adaptive impairments. Conditions placing children at-risk for developmental delay include: genetic/metabolic disorders, neurological abnormalities, severe attachment disorder and sensory impairments.

care) plans for each child outlining the recommended early intervention services. Plans are to be updated every six months.⁵

As with the expanded treatment services, children are referred for early intervention services by EPSDT providers, Part H Child Find programs, neonatal intensive care units, schools and Florida's Diagnostic and Learning Resource Centers.

In summary, Florida and Michigan's expanded service programs for at-risk children provide examples of the types of enhanced benefit packages being implemented by states. These programs' experiences also provide insight into some of the issues involved in obtaining federal Medicaid matching funds to support enhanced services, lessons which will be helpful to Delaware officials as they develop their package and plans for implementation.

⁵ The family support plan will serve as the authorizing document for the provision of early intervention services. These services, therefore, will not require approval by Medicaid service authorization nurses as do the expanded treatment services described previously.

CHAPTER III

Design Parameters of Enhanced Services for At-Risk Children

As mentioned above, on November 15, 1993 at the Buena Vista Conference Center in New Castle, Delaware, HSR facilitated an interagency focus group to reach consensus regarding the policy parameters of the enhanced benefit package. Participants included representatives of the Division of Public Health/Maternal and Child Health, Medicaid, Part H, the Division of Family Services, and the Department of Public Instruction, as well as a spokesperson for the A.I. duPont Institute of the Nemours Foundation.

To provide a framework for discussion, HSR laid out a broad range of policy and design options regarding:

- Possible criteria for determining which children would be eligible for enhanced services;
- Possible benefits to include in the package;
- Alternative service providers who could deliver enhanced services; and
- Optimal approaches for reimbursing providers of these services.

A summary of the decisions that were reached by the interagency focus group regarding the proposed structure of the enhanced benefit package is presented below.

A. Eligibility Criteria

The critical policy questions addressed by meeting participants regarding program eligibility included:

- What risk criteria should be used for determining which children should be eligible for enhanced services?
- Where should the program establish its upper age limit?
- Where should the state apply upper income limits?
- Should the state permit already-insured children to enroll in the plan?

After discussing a range of options, the following eligibility policy decisions were made by the interagency focus group:

- **Enhanced benefits should be targeted to children at environmental and psychosocial risk.** Group participants overwhelmingly agreed that, rather than focusing on children with biological or medical risk factors, enhanced benefits should be targeted to children in families demonstrating environmental and psychosocial risk factors. It was decided that specific risk criteria, such as lack of stable housing, history of child abuse or neglect, being born to a teenage mother, parental substance abuse or parental mental illness should be identified through a formal assessment of risk. The group acknowledged that no single risk assessment instrument was currently being used in the state that fully and adequately identifies such at-risk children. However, the state's Integrated Service Information System (ISIS--currently being implemented to track at-risk children--was noted as being a good foundation upon which to build a risk-assessment strategy for enhanced services.
- **The benefit package should be available to children up to age 19, with priority consideration granted to the birth to six population.** The group expressed a strong interest in extending coverage not only to young children but to adolescents, as well. However, participants acknowledged that there may only be sufficient resources to extend services through the early childhood years. (The consultants underscored the difficulty of obtaining Medicaid financing for an age-limited benefit package, as the Medicaid statute does not permit states to limit coverage by age.)
- **Enhanced benefits should be available to children of all income levels.** Although participants placed a priority on financing enhanced services through Medicaid, they also expressed the belief that all children identified as being "at-risk" should have access to enhanced services. Therefore, participants agreed that children in higher-income families should be allowed to purchase enhanced services on either a partially-subsidized or nonsubsidized basis, depending on their income.

- **Children with private health insurance should not be excluded from receiving enhanced services.** Since the types of services to be included in the proposed enhanced benefit package are not typically covered under traditional private insurance policies, participants decided that already-insured, at-risk children should not be denied access to the enhanced services.

B. Benefits

After reaching several important decisions regarding eligibility criteria, the meeting turned to the issue of benefits. The discussion focused on answering the following design questions:

- What types of services should be included in the benefit package?
- Should the services be center-based or delivered in the home?

The decisions reached by the interagency focus group are summarized below:

- **Service coordination should be a central feature of enhanced services.** The conclusion that service coordination should play a central role in the enhanced services package was determined prior to the interagency meeting. However, it was not clear how this service coordination would be integrated with that to be provided by the Nemours clinics. During the meeting, the A.I. duPont representative clarified that the Nemours clinics would provide only medical case management. Therefore, the group discussed how a complementary service coordination benefit--specifically the Medicaid administrative and targeted case management options under Medicaid--might be designed to provide a more comprehensive approach to service integration. Consensus was not reached regarding which of these approaches would be most appropriate for Delaware's enhanced benefit package. Thus, the consultants were asked to explore this issue further in their final report. (The pros and cons of these options are discussed in Chapter V.)
- **The benefit package should also include a cluster of direct services of a non-medical nature.** As was the case with risk factors, the group agreed that the benefits in the enhanced service package should primarily address psychosocial needs rather than physically debilitating conditions. Specific services identified for inclusion in the benefit package included: early intervention/child development services for young children; parenting training; nutrition counseling; health education; social work services; and outpatient

mental health⁶ and substance abuse services for the adolescent population. The group emphasized the importance of focusing on services of this nature because they are typically not covered, or insufficiently covered, by most health insurance policies.

- **Services should be provided in the home whenever appropriate.** Participants wholeheartedly supported the notion that enhanced services are most appropriately delivered in the home. This approach was felt to be particularly important given the focus of enhanced services on children experiencing social/environmental risk factors.
- **Limits on the amount, duration and scope of services to control costs must be considered.** Officials agreed upon the need to maintain fiscal control over the delivery of enhanced services. Therefore, they noted the importance of exploring ways of monitoring that services are appropriately delivered, such as through periodic reassessments of eligibility.

C. Service Delivery

During this discussion, participants debated several design issues related to service delivery. Specifically, the group considered the following questions:

- What types of providers/practitioners should deliver enhanced services?
- Should public or private provider entities deliver enhanced services?
- Should enhanced service providers be required to undergo a precertification process?

The following decisions were made by the interagency focus group:

- **A multidisciplinary team of providers should be responsible for delivering enhanced services.** Although officials did not reach specific conclusions regarding the most appropriate mix of provider types, all recognized the benefits of, and the need for, encouraging the use of multidisciplinary teams of physician, nursing, social work, nutrition and child development providers. Participants expressed the belief that only this multidisciplinary approach would ensure that children's multiple needs, often primarily of a non-medical nature, would be adequately addressed.

⁶ Since this meeting of the interagency focus group, Delaware has submitted an application for a federal waiver that would significantly expand the availability of mental health services for Medicaid-eligible children. If the waiver is approved, the proposal described in this report will need to be adapted accordingly.

- **Enhanced services will be primarily delivered by public providers, at least initially.** After debating the strengths and weaknesses of both public and private delivery systems, participants concluded that the public system would best serve the program’s needs in the near term. Public sector programs have a long tradition of serving disadvantaged families, already employ significant numbers of non-physician providers, and have extensive experience with the multidisciplinary team approach. However, the group also decided that the delivery system should be flexible enough to allow private sector providers to participate over time and, therefore, allow patients a wider choice of providers.
- **Provider solicitation and certification should take place through a request for proposals process.** Rather than establishing an “open” system through which providers would apply for certification as enhanced care providers, Delaware officials expressed interest in using a request for proposals process similar to that used by the SMART START program.

D. Reimbursement

The questions addressed by the interagency focus group regarding reimbursement for services included:

- How should provider fees be structured?
- Should families of eligible children be required to share costs beyond the annual premium fee?

The decisions reached by the group were as follows:

- **A bundling approach should be used to structure fees for enhanced services.** For reimbursement of direct services, Delaware officials expressed interest in a bundling approach through which a flat rate would be paid for a group of services. This approach would provide multidisciplinary teams with the flexibility to render the most appropriate mix of services to children and their parents. Further, since certain services are likely to be provided in tandem, bundling service fees can be an important strategy for simplifying billing.
- **There should not be any cost-sharing for recipients beyond the annual premium fee.** Officials also decided not to impose a cost-sharing requirement beyond the sliding scale premium for higher-income families primarily for two reasons. First, they did not want imposed user fees, such as copayments and deductibles, to create disincentives for families seeking services. Second, there was a strong desire to minimize the administrative complexity of the program.

Based on this guidance on eligibility, benefit, service delivery and reimbursement policy parameters, HSR's next step was to develop a detailed model for estimating the costs associated with the proposed benefits. This model and HSR's findings are described in detail in the following chapter.

CHAPTER IV

Estimating the Size of the Target Population, Enrollment and Program Costs for the Enhanced Benefit Package

As a next step in the technical assistance process, HSR developed a detailed model to estimate the potential costs of a new enhanced benefit program for “at-risk” children. Specifically, we developed estimates of utilization rates and costs that could be expected to be associated with the enhanced services. As described in Chapter III, the interagency focus group provided HSR with important guidance in defining the features of the new program. However, in order to proceed with the development of our utilization and cost estimates, HSR had to more specifically define the eligibility and service program parameters, as follows:

- **Eligibility criteria.**
 - **Age.** Enhanced services will be available for children up to age 19. However, given that the interagency focus group placed priority on making enhanced services available to the birth to six population, HSR developed the model in such a way that estimates could be broken down by age. Thus, estimates are presented for both the birth to six⁷ population as well as for the birth to 19 group.
 - **Income.** A primary focus in developing the enhanced benefit package was to build off the Medicaid program and maximize federal financing. However, based on input from the interagency group that services should be made available to all at-risk children, regardless of income level, subsidy provisions for families with higher incomes were included in our model. To reflect this, our model is designed to present data relevant to three groups of children: Medicaid eligible; near-poor (non-Medicaid eligible who receive a partial subsidy according to a sliding fee scale); and higher-income (non-Medicaid eligible who purchase services at full cost).

⁷ In fact, the birth to six group is further subdivided in our analysis into two groups--under one year and ages one to six--because differential Medicaid income eligibility thresholds required separate estimation techniques.

- **Risk factors.** Based on input from the group, children demonstrating psychosocial and environmental risk factors (e.g., young maternal age, parental substance abuse, lack of stable housing), rather than children with medical conditions, will be targeted to receive enhanced services.
- **Services.** The interagency group clearly indicated that the package of services should include those of an enabling/supportive nature and should be provided in the home whenever possible. In addition, they emphasized the importance of addressing children's, particularly adolescents', limited access to mental health and substance abuse services. Therefore, for our estimation model, we assumed that the enhanced service package would include the specific components detailed in Table IV-1 below.

TABLE IV-1. ENHANCED SERVICE PACKAGE COMPONENTS	
■	Care coordination, an intensive, home-based intervention.
■	Direct services, a “bundle” of interventions, also provided in the home, including as appropriate: - Parenting training; - Health education; - Nutritional counseling; - Psychosocial counseling; and - Infant mental health and child development services.
■	Outpatient mental health services.
■	Outpatient substance abuse services.

To determine final estimates of total program costs for the enhanced service program, HSR had to develop a range of intermediate estimates. Specifically, HSR calculated:

- The total number of children within the State of Delaware, by age and income;
- The proportion of these children who might be deemed “at-risk” and, therefore, eligible to receive enhanced services;

- The actual number of at-risk children that could be expected to enroll to receive enhanced services; and
- The annual per-person costs for individual services included in the package.

The steps which HSR took to arrive at each of these intermediate estimates, as well as a discussion of how they were combined to develop estimates of total program costs, are described in the following sections.

A. Estimating the Total Number of Children in Delaware, by Age and Income

As noted in Chapter III, the interagency focus group intends for the enhanced benefit package to be available for all at-risk children from birth to age 19 in Delaware. However, the focus group also recognizes that fiscal resource limitations may require that priority be given to children under age six. To maximize resources available for the program, the focus group emphasized the importance of designing the benefit package in such a way that enhanced services may be covered through the state's Medicaid program. Given this guidance, HSR grouped Delaware population data into the following age categories, which correspond to the age-dependent income eligibility groupings of the state's Medicaid program:

- Children under the age of one (Medicaid currently covers these children in families with incomes up to 185 percent of the federal poverty level [FPL]);
- Children ages one through five (Medicaid covers these children up to 133 percent of the FPL); and
- Children ages six through eighteen (Medicaid covers children in this group up to 100 percent of poverty);

While expressing an interest in maximizing federal Medicaid support for enhanced services, the interagency focus group also expressly requested that children in families with too much income to qualify for Medicaid also have access to the enhanced service package. The group agreed that non-Medicaid-eligible families should be able to purchase coverage on a sliding-scale basis. While development of a specific sliding scale subsidy for the enhanced benefit program was beyond the scope of this project, HSR did follow the focus group's recommendation that any

sliding scale that might be adopted should match the sliding scales already being used by existing programs. Therefore, HSR examined several sliding scale payment systems currently in use in Delaware and selected the sliding scale used by the Part H program and other programs within the Department of Health and Social Services, which provides partial subsidies to families with income up to 260 percent of poverty. Based on these decisions, we then grouped the population data into the following three income categories:

- **Medicaid-eligible children:** Children under the age of one with incomes below 185 percent of the FPL; children between the ages of one and six with incomes below 133 percent FPL; and children between the ages of six and 19 with incomes below 100 percent of poverty.⁸
- **Near-poor children:** Children in families with incomes too high to qualify them for Medicaid, but less than 260 percent of the federal poverty level. Following the focus group's recommendations, these children would be eligible to purchase enhanced services with a partial subsidy from the state.
- **Children in higher-income families:** Children in families with incomes above 260 percent of the federal poverty level. Such families with at-risk children would be eligible to purchase enhanced service coverage at full cost, without a subsidy from the state.

Following these decisions, HSR drew upon several data sources to develop its specific estimates of children, including:

- The Delaware 1990 Census;
- The University of Delaware's population projections, based on 1990 Census data, for the year 1993; and

⁸ In estimating the distribution of children by family income, it is important to note that we considered gross, rather than net, family income. That is, we did not employ the Medicaid program's method for counting family income, through which families are permitted to disregard both work and child care expenses when applying for coverage. Such disregards typically reduce families' income by as much as 20 percent. Therefore, our estimates of families in Delaware with children already eligible for Medicaid may undercount the actual number in the state, since income disregards effectively raise the upper income eligibility threshold for Medicaid coverage.

- The Delaware-specific portion of the U.S. Census Bureau’s Current Population Survey⁹.

Specifically, we applied the University of Delaware’s 1993 population growth projections to state 1990 Census data to develop estimates of the total number of children in Delaware, broken out by the age groupings required by our model. Next, we analyzed the 1992-1993 CPS to determine how Delaware children are distributed across income groups. Once again, we determined the percent distribution of children by age group (under one, between one and six, and six and 19); by income group (Medicaid-eligible, near-poor, and higher-income children.) To ensure the validity of our measure, we compared our estimates of the children in poverty to those developed by other sources, including the 1990 Census and the General Accounting Office.

Table IV-2 displays our estimates of the number of children in Delaware, by age and income, who will be potentially eligible to receive enhanced services. As presented in the table, there are a total of 182,160 children under the age of 19 in the State of Delaware. Of these, an estimated 61,050 are under the age of six, while 121,110 are between the ages of six and 19.

Across all age groups, an estimated 26,610 children in the state are eligible for Medicaid, including 12,090 children below age six and 14,520 between six and 19. (Under the enhanced services program, children in this group that are determined to be “at risk” would be eligible to receive fully-subsidized coverage.) An estimated 61,710 children live in families with incomes too high to qualify for Medicaid but below 260 percent of the FPL, including 17,530 below age six and 44,180 between the ages of six and 19. (Under the program, at-risk children in this group would be eligible for partially-subsidized coverage of enhanced services.) Finally, we estimate that 93,840 children currently live in families with incomes above 260 percent FPL, 31,430 of whom are under age six and 62,410 of whom are between the ages of six and 19 (at-risk children in this group would be able to purchase coverage at full cost.)

⁹ To develop as detailed and statistically sound a profile of children as possible, we combined Delaware-specific data from the 1993 CPS with similar data from the 1992 CPS, thereby increasing the number of children included in the sample.

TABLE IV-2. DELAWARE’S CHILD POPULATION BY AGE AND INCOME						
Age	All Children	Income as a Percent of Poverty				
		<100%	100-133%	134-185%	186-260%	>260%
0-1	8,840	2,860			1,430	4,550
1-5	52,210	9,230		16,100		26,880
6-19	121,110	14,520	44,180			62,410
Total	182,160	26,610	61,710			93,840
** Shaded cells indicate Medicaid-eligible populations.						

B. Estimating the Number of “At-Risk” Children in Delaware

The next step in developing the cost model was to identify the “target population” for the enhanced benefit program. To achieve this goal, we faced two major challenges. First, we needed to estimate the proportion of children who might be expected to be “at-risk” and, therefore, eligible to receive enhanced services. Second, because the interagency focus group emphasized the need to include discrete mental health and substance abuse services for “at-risk” adolescents, we had to develop additional prevalence rates for the subset of “at-risk” children with mental health and substance abuse problems. Therefore, after estimating the total population of children in Delaware and grouping these children according to various age and income parameters, we then worked to develop each of these prevalence estimates, as described below.

1. Estimating the Overall Prevalence of “At-Risk” Children

The most challenging hurdle we faced was that there is no standard, accepted definition of “at risk.” The interagency focus group concluded that enhanced services should be targeted to children at risk for poor growth and development or poor family functioning. Furthermore, the group indicated that, for the purposes of determining eligibility for benefits, “at-risk” criteria should center around a broad range of psychosocial and environmental risk factors rather than medically-based conditions. Specific risk factors identified during the interagency focus group

meeting as important correlates for “at-risk” status included young maternal age, low maternal education level, lack of stable housing, parental substance abuse, parental mental illness or mental retardation, and family history of child abuse or neglect.

These risk factors, and many others, have been shown in the health services research literature to be highly associated with poor outcomes among children. However, while researchers and policymakers agree that these factors often hinder children’s development, the science of accurately quantifying the number of children who are “at risk” is wrought with “conceptual uncertainties and practical dilemmas” (Blackman, 1986). The difficulty HSR faced in attempting to pinpoint a prevalence rate for “at-risk” children in Delaware was exacerbated by several factors, including:

- **Risk factors are not mutually exclusive.** There is frequently considerable overlap and interaction between various risk criteria. A case in point is poverty. Children in poverty consistently experience higher rates of illness, developmental delay, and other poor outcomes. However, poverty is also strongly correlated with other risk factors known to increase the risk of a poor outcome, such as low educational attainment and lack of stable housing. Thus, the specific risk associated with any single factor is difficult to isolate.
- **There is no universally-accepted risk assessment tool for identifying children at risk for poor outcomes.** While a growing number of states have instituted enhanced services programs for populations experiencing psychosocial and/or environmental risks, especially pregnant women, no single risk assessment tool has emerged as being uniquely effective in identifying at-risk populations.
- **Policy objectives will, ultimately, influence the development of a risk assessment tool and decisions regarding which criteria should define “at-risk” status.** Delaware officials may decide to create a program that is relatively inclusive, or broad in its definition of “at risk.” On the other hand, fiscal constraints may drive the development of a program with tighter, more narrow eligibility criteria. Delaware officials will need to carefully study which factors, or combination of factors, should qualify a child to receive enhanced services. (The challenging task of developing an effective risk assessment tool is discussed in more detail in the next section of this report.)

To address these problems, HSR took a number of steps to develop its estimates of the prevalence of “at-risk” children in Delaware. First, we reviewed the health services research literature on risk assessment. Second, we collected and analyzed risk assessment tools from a

number of other states with enhanced services programs for high-risk and at-risk maternal and child populations. Finally, we carefully examined numerous data sets to help us arrive at our Delaware-specific prevalence estimates. Specifically, we analyzed:

- National and state prevalence data on a broad range of risk factors;
- Data from numerous Medicaid-financed enhanced services programs in other states; and
- Prevalence estimates derived from the Integrated Service Information System (ISIS), Delaware’s recently implemented program to track children suffering from, or at risk of, developmental delay.

Highlights of the outcomes of these analyses are summarized below.

a. National and state data on prevalence of risk

From a broad range of national and state data sources, HSR identified current prevalence rates for a large number of relevant psychosocial and environmental risk factors. Specifically, we found that:

- 28 percent of Delaware’s children live in single-parent families (Center for the Study of Social Policy, 1994);
- 17.1 percent of Delaware births are to mothers with less than a high school education (Delaware Department of Health and Social Services, Health Statistics Center, 1992);
- 12.2 percent of Delaware births are to teenage mothers (Delaware Department of Health and Social Services Health Statistics Center, 1992);
- 11.7 percent of Delaware children live in poverty (Center for the Study of Social Policy, 1994);
- 10 percent of adults nationwide suffer from a substance abuse disorder (Personal Communication, Susan Pfeiffer, 1994);
- 8.1 percent of Delaware children live in poor or overcrowded housing (Center for the Study of Social Policy, 1994);

- 7.9 percent of Delaware births are low birth weight babies (Center for the Study of Social Policy, 1994);
- 2.5 to 3.0 percent of adults nationwide are considered mentally retarded (Fryers, 1993);
- 2.7 percent of Delaware’s families have been reported for child abuse or neglect (Delaware Child Health Task Force, 1992);
- 2.1 percent of women nationwide are considered mentally ill (Center for Mental Health Services and National Institute of Mental Health, 1992); and
- 1.7 percent of Delaware’s children live in severely distressed neighborhoods (Center for the Study of Social Policy, 1994).

As discussed above, the fact that none of these risk factors are mutually exclusive prevented us from employing either a simple additive or multiplicative methodology to arrive at an overall prevalence rate. Nor could we simply select the highest prevalence rate--28 percent of Delaware children live in single-parent families--and assume that all such children are “at risk.” Rather, we analyzed the data to detect whether any patterns of prevalence emerged and to determine whether key individual indicators clustered within a certain range. Further, we analyzed how various individual indicators might interact to create an “at-risk” child; for example, being born into a single-parent family (28 percent of children), to a mother with less than a high-school education (17 percent of children) or who earned income at a level below the federal poverty level (12 percent of children). Combined, we reached the general conclusion that the prevalence of the most critical environmental/psychosocial “at risk” indicators in Delaware clustered between eight percent and 17 percent, after eliminating the highest prevalence rate on the assumption that it was too inclusive (28 percent of children living in single-parent families), and after eliminating the lowest prevalence rates on the assumption that they were too restrictive (prevalence of children in distressed neighborhoods, women with mental illness, adults with mental retardation, and reports of child abuse and/or neglect).

b. Data from other state programs for “at-risk” mothers and children

To further refine our understanding of prevalence rates of “at-risk” populations, we closely examined data from selected states that have had experience operating Medicaid-financed enhanced services programs for such groups. Unfortunately, no program currently exists which precisely targets the population that Delaware wishes to cover. However, we were able to obtain information from two state programs that target similar populations of vulnerable children at risk of poor outcomes: Michigan’s Infant Support Services Program (summarized in Chapter II of this report); and North Carolina’s Children’s Services Coordination Program. In addition, we collected data from three programs that provide Medicaid-eligible pregnant women with enhanced prenatal services because they are designed to target women who are experiencing many of the same environmental and psychosocial risks that have been identified as priorities by Delaware officials. Specifically, we gathered data from: Michigan’s Maternal Support Services Program; Washington’s First Steps Program; and South Carolina’s High Risk Channeling Project and At-Risk Prenatal Program.

From our analyses of these programs, we found that:

- Sixteen percent of all infants born to Medicaid-insured mothers in Michigan have qualified to receive Infant Support Services;
- Between nine and 12 percent of all births in the State of North Carolina have demonstrated risks that qualify them for Children’s Services Coordination;
- Twenty-five percent of all Medicaid-eligible pregnant women in Michigan have qualified to receive Maternal Support Services;
- Twenty-three percent of all Medicaid-eligible pregnant women in Washington have met the risk criteria established by First Steps to qualify for case management services; and
- Fifteen percent of all Medicaid-covered pregnant women in South Carolina are found to qualify for the High Risk Channeling Project.

In four of the five programs mentioned above, data were reported for Medicaid program participants. By definition, therefore, these populations were “poor” and satisfied at least one additional criterion in their respective state’s risk assessment instruments. In these states, prevalence of “at-risk” status ranged from a low of 15 percent to a high of 25 percent. In North Carolina, where program data were reported for the entire population, both low- and high-income “at-risk” prevalence was, as one would expect, a lower 9-12 percent rate.

c. Data from Delaware’s ISIS system

ISIS is a computerized tracking system for children experiencing, or at risk of, developmental delay. Although the system will eventually include children up to age 18, thus far it tracks primarily young children who were identified after the program was implemented in June 1992. From ISIS, HSR obtained data on the overall prevalence of risk in Delaware’s birth to four population, and examined the insurance status of children in the system. Specifically, we found that:

- Twelve percent of Delaware children ages birth to four are in the ISIS system by virtue of having, or being at risk of, developmental delay;
- Forty-one percent of ISIS children ages birth to four are enrolled in Medicaid; and
- By dividing Medicaid-enrolled children in ISIS ages birth to four by all Medicaid children in this age group, 14 percent of all Medicaid children have risks that qualified them for ISIS inclusion. Similarly, by dividing non-Medicaid children in ISIS ages birth to four by all non-Medicaid children in the state in this age group, we found that 10 percent of all non-Medicaid children in the state qualify for ISIS tracking.

From these data, we see risk prevalence ranging from 10 percent for children in higher-income families to 14 percent in lower-income families.

d. Risk prevalence variations by income

As mentioned previously, the health services research has demonstrated a strong link between poverty and the prevalence of various factors that place children at risk of poor

outcomes. To quantify this effect, we analyzed how the prevalence of various individual risk indicators varied by income. Selected findings from our analyses include:

- The prevalence of low birthweight is nearly two times higher in families with income below poverty than it is in higher-income families;
- Children born to mothers with less than a high-school education are almost four times as likely to live in a poor family than in a family with income above the poverty level; and
- Adults living below the poverty level are nearly two and one-half times as likely to suffer from mental illness than non-poor adults.

From findings such as these, we concluded that poor children may be likely to experience poor outcomes at rates two to four times higher than children in higher-income families.

e. Determining a prevalence rate for “at-risk” children in Delaware

Combining our analyses from the above steps (based on national and state-specific data on the prevalence of various risk factors; participation rate data from other state enhanced care programs for at- and high-risk children and mothers; ISIS data; and data on how prevalence of risk varies by poverty status), HSR developed the following three assumptions for its Delaware cost model:

- For children in families with incomes below 185 percent of the federal poverty level, we estimated that 20 percent would qualify as “at risk” and, as a result, be eligible to receive enhanced services.
- For children in families with incomes between 185 percent and 260 percent of poverty, we estimated that 15 percent would qualify as “at risk.”
- For children in families with incomes over 260 percent of poverty, we estimated that 10 percent would demonstrate sufficient factors to qualify as “at risk” under the enhanced services program.

As displayed in Table IV-3, by applying our estimates of the prevalence of “at-risk” children to our estimates of the total child population in the state, we find that there will be a total of

25,570 children who will potentially qualify to receive enhanced services. Thirty-four percent of these children--8,570--are between the ages zero and six, while 66 percent--17,000 children--are between the ages of six and 19. Further, 11,760 are children in families with incomes below 185 percent of poverty, 4,420 are children in families with incomes between 185 percent and 260 percent of poverty, and 9,390 are children in families with incomes greater than 260 percent of poverty.

TABLE IV-3. DELAWARE’S “AT-RISK” CHILDREN, BY AGE AND INCOME				
Income Category	Age	All Children	Prevalence Rate	“At-Risk” Children
Children in Families with Income <185% FPL	0- 1	2,860	20%	570
	1-5	16,910	20%	3,380
	6-19	39,060	20%	7,810
Children in Families with Income between 185-260% FPL	0- 1	1,430	15%	210
	1-5	8,420	15%	1,260
	6-19	19,640	15%	2,950
Children in Families with Income >260 FPL	0- 1	4,550	10%	460
	1-5	26,880	10%	2,690
	6-19	62,410	10%	6,240
Total		182,160		25,570

Table IV-4 illustrates how Delaware’s “at-risk” children are distributed across the three subsidy groups created for the model. Specifically, 5,310 out of 25,570 “at-risk” children--just over 20 percent--live in families with incomes that would qualify them for Medicaid coverage. (Of these, 2,410, or 45 percent, are under age six.) A total of 10,870 “at-risk” children fall into the “near poor” category; that is, they live in families with incomes that are too high to qualify for Medicaid but less than 260 percent of poverty. (Of these, 3,010, or 28 percent are under age six.) Finally, 9,390 children who would qualify as “at risk” live in higher-income families, i.e., families with incomes over 260 percent of poverty. (In this instance, 3,150, or 34 percent, are under age six.)

TABLE IV-4. “AT-RISK” CHILDREN BY AGE AND SUBSIDY GROUP						
Age	“At-Risk” Children	Medicaid-Eligible Children			Near-Poor Children	High-Income Children
		<100%	100-133%	134-185%	186-260%	>260%
0-1	1,240	570			210	460
1-5	7,330	1,840		2,800		2,690
6-19	17,000	2,900	7,860			6,240
Total	25,570	5,310	10,870			9,390
** Shaded cells indicate Medicaid-eligible populations.						

2. Estimating the Prevalence of Children in Need of Mental Health and Substance Abuse Services

After estimating the total number of “at-risk” children in Delaware, we then needed to develop discrete estimates of the subset of these children that are in need of immediate mental health and substance abuse treatment interventions. While perhaps more straightforward a process than that described above for obtaining an overall at-risk prevalence rate, the methods for developing these estimates, nonetheless, posed important challenges due to a paucity of state and national data. The prevalence rates for these conditions were ultimately determined as described below.

a. Estimating the prevalence of children in need of mental health services

As noted previously, the interagency focus group recognized that current systems of care fall far short of serving all children in need of mental health services and, therefore, that such services should be included in the enhanced service package. To meet the most pressing mental health needs of children in Delaware, the focus group suggested that priority for formal outpatient mental health services be given to that population of children with the most severe disorders.¹⁰ Based on this guidance, and due to limited

¹⁰ It is assumed that children with less severe needs who are at risk of emotional disturbance would qualify to receive enhanced care coordination and direct services, but would not receive additional outpatient mental health services.

state data, we utilized a 1992 National Institute of Mental Health estimate that 3.2 percent of children between the ages of nine and 17 have a severe mental disorder (National Institute of Mental Health, 1992). Available data did not permit us to adjust this prevalence rate based on income. Based on national data and program experiences in other states indicating that older children are generally the exclusive users of formal outpatient mental health services, we assigned prevalence rates for mental illness only to population figures for the oldest age category--ages six to 19.

As displayed in Table IV-5, by applying the above prevalence estimate of children's mental illness to our population estimates for the six to 19 age category, we find that there will be approximately 3,870 children who will potentially qualify to receive the mental health intervention. Specifically, 460 are children in Medicaid-eligible families, 1,410 are children in families with incomes between 100 percent and 260 percent of poverty, and 2,000 are children in families with incomes greater than 260 percent of poverty.

b. Estimating the prevalence of children in need of substance abuse services

Once again, Delaware-specific data were not available on the prevalence of children in need of immediate substance abuse treatment. Therefore, we turned to national sources. Data from the federal Substance Abuse and Mental Health Services Administration indicate that 6.1 percent of adolescents between the ages 12 and 17 had misused substances within the last month. This same source found that substance abuse in younger populations was negligible (Substance Abuse and Mental Health Services Administration, October 1993). We applied this rate in our model by adjusting it to reflect our broader age grouping, and arrived at an estimate that 2.8 percent of all children between the ages six and 19 have a substance abuse problem in need of immediate treatment. Based on national data that show that the prevalence of substance abuse among adolescents does not vary significantly by income, we applied this 2.8 percent prevalence rate across all income groups (Substance Abuse and Mental Health Services Administration, December 1993).

As displayed in Table IV-5, by applying our estimates of the prevalence of substance abuse disorders in children between ages six and 19 to the population estimates for the older age category in the state, we find that there will be approximately 3,400 children who will potentially qualify to receive substance abuse intervention. Specifically, 410 are children in Medicaid-eligible families, 1,240 are children in families with incomes between 100 percent and 260 percent of poverty, and 1,750 are children in families with incomes greater than 260 percent of poverty.

TABLE IV-5. CHILDREN AGES 6-19 NEEDING, AND ENROLLING IN, OUTPATIENT MENTAL HEALTH AND SUBSTANCE ABUSE SERVICES, BY INCOME				
Income Category	Service Category	All Children	Prevalence Rate	Total Children in Need of Services
Medicaid-Eligible Children	Mental Health	14,520	3.2%	460
	Substance Abuse	14,520	2.8%	410
Near Poor Children	Mental Health	44,180	3.2%	1,410
	Substance Abuse	44,180	2.8%	1,240
Higher-Income Children	Mental Health	62,410	3.2%	2,000
	Substance Abuse	62,410	2.8%	1,750
TOTAL	Mental Health			3,870
	Substance Abuse			3,400

C. Estimating the Number of “At-Risk” Children Who Would Participate in the Enhanced Services Program

The extent to which potentially eligible children would actually participate in the enhanced services program would depend upon several factors. First, Delaware policymakers cannot assume that all “at-risk” children would be successfully identified by whatever risk assessment system is implemented. Further, it cannot be assumed that all families with children who are identified as “at risk” will choose to enroll their children in the program. Rather, it is important to understand that actual participation rates would depend upon such factors as:

- The degree to which risk screenings are universally administered;
- The accuracy of the risk-assessment tool;
- Family perceptions regarding the child’s risk status or need for help;
- The availability of services;
- The income and insurance status of the families; and
- The cost of services to the families.

As a first step in developing our assumptions regarding the likelihood that “at-risk” children would participate in the enhanced services program, we again analyzed the experiences of other states. Nationally, we learned that state Medicaid programs generally experience participation rates of, at best, 75 percent (Congressional Budget Office, 1994). That is, only 75 percent of persons who are estimated to be eligible for the program actually obtain access to Medicaid coverage. Participation rates among pregnant women eligible through the various special expansions enacted by Congress during the late 1980s is generally somewhat higher--between 80 and 90 percent (Congressional Budget Office, 1994). However, in both of these cases, it must be understood that these rates reflect participation levels when a very broad benefit package is offered. Further, in the case of pregnant women, pregnancy provides a very strong incentive for uninsured women to obtain coverage.

When a smaller, less well-understood package of enhanced services is offered, some evidence exists that participation rates are lower. In the State of Washington, for example, even though all Medicaid-eligible pregnant women are eligible for enhanced Maternity Support Services, only 59 percent elect to receive the nutritional and psychosocial counseling, health education, and transportation services the program offers. With enhanced services for children, participation rates may be even lower. In North Carolina, officials estimate that just 35 percent of children eligible for care coordination actually receive services.

Next, we reviewed data developed in prior HSR projects that required us to model consumer decision-making patterns regarding the purchase of special insurance products for pregnant

women and children (Hill, 1992; Butler, 1991). These data, combined with information obtained from federal and state Medicaid sources, permitted us to develop a range of assumptions regarding the likelihood that different types of families would gain access to/participate in the proposed enhanced services program. Specifically, we assumed that:

- Younger children will be more likely to participate in the program than older children, based on the understanding that several systems currently exist that are likely to identify “at-risk” infants and young children, and that public programs such as EPSDT traditionally are more effective in reaching younger children than older children;
- Low-income children will be more likely to participate in the program than children in higher-income families, based on the understanding that state outreach efforts are more likely to inform low-income families with children about the program, and the fact that such families’ existing linkages to public programs such as Medicaid/EPSDT will facilitate enhanced services enrollment;
- The imposition of cost-sharing requirements will negatively impact many “near-poor” and higher-income families’ decision to enroll their children in the program;
- Overall, participation rates will be constrained by the fact that the program, by its nature, offers access to a limited set of benefits--benefits that are not well understood by the broad population;
- At the same time, the program will experience some adverse selection, given that enhanced services are specifically designed to meet the needs of families with children experiencing difficulties; and
- Even when fully implemented, participation in the enhanced services program will never reach 100 percent.¹¹

Combined, these assumptions resulted in the development of participation rates estimates among potentially-eligible children that range, at full implementation, from a high of 60 percent for infants in families with incomes below 185 percent of poverty, to a low of 10 percent for children between the ages of six and 19 in families with incomes above 260 percent of poverty.

¹¹ While participation estimates in our model reflect expected rates at full implementation, Delaware policymakers can assume that participation rates will be lower for the first several years of operation due to several factors, including slow program start-up and clients’ lack of familiarity with the available benefits.

Specific participation rates for children at different ages and income levels are displayed in Table IV-6.

Table IV-6 also presents HSR’s estimates of the number of “at-risk” children who will actually participate in the enhanced services program. These estimates were derived by applying the participation rate factors (described above) to our estimates of the total number of “at-risk” children in the state. Specifically, we estimate that a total of 5,900 children will participate in the enhanced services program. Of these, 2,420 (41 percent) will be children who are currently eligible for the Medicaid program. Children in “near-poor” families, that is, ineligible for Medicaid but in families with incomes below 260 percent of poverty, total 2,500 and make up another 42 percent of all participants. Finally, children in higher-income families (with incomes over 260 percent of poverty) total 980 and constitute just 17 percent of the total participants.

If the state chooses to extend enhanced services only to children up to age six, then total program participation will be 2,550. Of these, 1,260 (just under 50 percent) will be children currently eligible for Medicaid while the remaining 1,290 will be required to purchase enhanced services on either a partially- or non-subsidized basis.

TABLE IV-6. “AT-RISK” PROGRAM PARTICIPANTS, BY AGE AND INCOME				
Income Category	Age	“At-Risk” Children	Participation Rate	Total Enrolled Children
Medicaid-Eligible Children	0- 1	570	60%	340
	1-5	1,840	50%	920
	6-19	2,900	40%	1,160
Near-Poor Children	0- 1	210	40%	90
	1-5	2,800	30%	840
	6-19	7,860	20%	1,570
Higher-Income Children	0- 1	460	20%	90
	1-5	2,690	10%	270
	6-19	6,240	10%	620
Total		25,570		5,900

D. Estimating the Costs of Individual Services in the Enhanced Benefit Package

As noted in Chapter III, the services provided in the enhanced benefit package are not designed to be medical in nature, but instead to provide psychosocial and educational support and to facilitate clients' access to other service delivery systems. It was also noted that the intent of the interagency focus group is for enhanced services to be provided by a multidisciplinary team of professionals with expertise in nursing, social work, child development, nutrition and health education.

1. Defining the Enhanced Services Package

Before developing cost estimates for the enhanced services package, it was necessary to carefully define the individual components of the package and consider how its structure might influence service-specific costs. While the development of complete protocols for enhanced benefits is beyond the scope of this project, HSR developed preliminary service definitions based on the guidance provided by the interagency focus group. Specifically, the benefit definitions used in the cost model were structured in the following manner:

- **Care Coordination.** The central feature of enhanced services, care coordination is designed as an intensive intervention involving frequent and ongoing contacts with the family. Care coordination is further seen as a service that should occur in the family's home as often as possible, rather than by phone or in a clinic setting.

The activities that would constitute care coordination under this model would likely include:

- Conducting a comprehensive risk assessment;
- Developing a plan of care based on the outcomes of the risk assessment;
- Linking clients to health and social service providers in accordance with the plan of care; and
- Monitoring and following up with clients to ensure they receive the care they need.

Since this is a home-based intervention, persons who provide care coordination should also be trained to provide a broad range of direct assistance in such areas as parenting training, health education, and nutritional and psychosocial counseling.

The interagency focus group indicated that care coordination should be reimbursed separately from the other services so as to ensure that it receive appropriate emphasis during implementation of service delivery enhancements.

- **Direct Services.** Beyond the assistance provided by care coordinators, the interagency focus group recognized that “at-risk” children and families may also need considerable, more intensive assistance with various psychosocial needs. Therefore, it was determined that the multidisciplinary service team should also provide, as appropriate, a separate “bundle” of direct services, defined as including parenting training, health education, nutritional counseling, psychosocial counseling, and infant mental health and child development services. Each of these is defined briefly below:
 - **Parenting training** is designed to strengthen and support positive parenting behaviors and modes of interaction with infants and children in a way that facilitates their normal healthy development. Parenting training could be provided through individualized parent education sessions or through observations and discussions of infant-parent interactions. Areas which may be addressed include specific developmental issues, caregiver/parent’s attitude and understanding, and suggestions for change which will result in healthier parent-infant interaction.
 - **Health education** is a service that resists rigid definition and may, in fact, at times interact or overlap with other enhanced interventions such as nutritional or psychosocial counseling. While the specific content of health education may be best left open so as to meet the specific needs of individual clients, several topics are likely to be of importance to families with at-risk children, including: the risks of smoking and alcohol/drug use; the importance of preventive and primary health care and how to use the health care system appropriately; stress management; the importance of exercise; and the risks of environmental and occupational hazards.
 - **Nutritional counseling** includes discussion of the relationship between proper nutrition and good health; promotion of positive changes in food habits; instructions and support for feeding infants (either bottle or breast as selected by the client), toddlers, children and adolescents; and nutritional needs of children at

special risk due to the presence of certain diagnoses or conditions (e.g., diabetes, weight loss). Delaware officials should consider ways of coordinating this benefit with the state's Supplemental Food Program for Women, Infants and Children (WIC).¹²

- **Psychosocial counseling** is designed to assist families in coping with the many stresses of daily life. In particular, low-income families face a range of difficulties that, while not directly related to traditional medical needs, certainly affect health and well being. These include, for example, poor housing, lack of reliable transportation, illiteracy, crime victimization, substance abuse, and disruptions in the family unit. Psychosocial counseling to help families address these stressful challenges may range from advice and guidance on accessing available community resources to specialized counseling to meet more critical needs and problems.
- **Infant mental health and child development services** are designed to strengthen the social, emotional, cognitive and physical well-being of infants within secure and stable caregiving relationships, with the primary goals being security of attachment and stability of infant and family relationships. Strategies for achieving these goals include: providing emotional support; assisting the family in receiving services necessary for meeting basic survival needs; providing guidance to parents about their infant's behavior or how to meet his/her specific care needs; and providing relationship-focused psychotherapy.

Depending on the specific family situation, one or more of these interventions may be brief and focused or it may be necessary to provide them over several months or longer in order to make a significant impact.

Interagency focus group members believed that a single fee should be developed for the direct services bundle for two reasons. First, such a payment methodology would allow the multidisciplinary team maximum flexibility to tailor service delivery to meet the individual needs of children. Second, it would also minimize the administrative burden on team members who will be required to track and bill for rendered services.

- **Outpatient Mental Health and Substance Abuse Services.** The interagency focus group emphasized the importance of including separate outpatient mental

¹² While some nutritional education is provided to all WIC recipients, the extent of this counseling may fall short of meeting all clients' needs due to federal WIC guidelines that require that 80 percent of all funds be spent on food supplements. Therefore, the enhanced service package can provide an important means of supplementing the nutritional counseling and education provided through the WIC program.

health and substance abuse treatment benefits in the enhanced service package because of the large number of children, particularly adolescents, whose needs are not being met under Delaware's current system. As with the existing outpatient mental health and substance abuse benefits covered under Medicaid, the enhanced service package would likely include group and individual counseling services.

Whereas the first two service components--care coordination and direct services--were included because they are not now provided in any formal manner in the current delivery system, the mental health and substance abuse service components were clearly included to build upon, and alleviate deficiencies in, services currently reimbursed by Medicaid. It is important to note, however, that Medicaid has recently begun reimbursing providers for substance abuse services.

2. Estimating the Costs of Care Coordination and Direct Services

To estimate the costs of both care coordination and the direct services bundle, we again conducted extensive analyses of data obtained from other states with enhanced benefit programs (specifically, the States of Michigan, North Carolina, South Carolina, and Washington). First, we assessed the degree to which the other states' programs possessed benefit designs similar to that being developed for Delaware. In so doing, we studied each program's policies and protocols regarding:

- The specific services provided through the program;
- Where and by whom services are provided; and
- The population to which the services are targeted.

After gaining a detailed understanding of the unique design parameters of each state's program, we then analyzed the most current available utilization and cost data from the programs. For each program, we examined:

- The number of clients eligible for the program;
- The proportion of eligible clients who actually receive services;
- Per client utilization rates for individual services;

- Unit costs for individual services;
- Average costs per user per service;
- Reimbursement rates and methodologies for individual services; and
- Total annual program expenditures.

By performing cross-state analyses of these data and making adjustments to reflect the unique design features of the Delaware program, we developed specific annual unit cost estimates for the care coordination and direct services components of the enhanced service package.

As a next step, we gathered national data that indicate that children of different ages utilize services at different rates (Perrin et. al, 1992). Combining these data with actuarial estimates developed by HSR under prior projects, we then developed age-specific utilization adjustments (Hill, 1992; Butler, 1991). Specifically, we assumed that: infants would use the care coordination and direct services most intensively; children ages one through five would utilize these services at a rate 25 percent below that of infants; and children ages six to 19 would utilize these services at a rate 30 percent below that of infants. By applying these adjustments to our unit cost estimates, we arrived at the age-adjusted annual per capita cost displayed in Table IV-7. Specifically, we estimated that providing care coordination services would cost \$400 per year for infants, \$300 per year for children ages one through five, and \$280 per year for children ages six to 19. Further, we estimated that providing the direct services bundle would cost \$200 per year for infants, \$150 per year for children ages one through five, and \$140 per year for children ages six to 19.

TABLE IV-7. Per Capita Costs for Individual Components of the Enhanced Service Package				
Ages	Enhanced Services			
	Care Coordination	Direct Services	O/P Mental Health	O/P Substance Abuse
0-1	\$400	\$200	--	--
1-5	\$300	\$150	--	--
6-19	\$280	\$140	\$1,600	\$960

3. Estimating Costs of Outpatient Mental Health and Substance Abuse Services

For these benefits, HSR was able to obtain Delaware-specific data for the purposes of estimating the annual per capita costs of providing “at-risk” children with outpatient mental health and substance abuse services.

Because the mental health component of the enhanced service package is designed to increase the number of children who receive outpatient services already provided by Medicaid, we based our cost estimates on information obtained from the Delaware Division of Medicaid. Based on the assumption that this service would be targeted to the oldest age group in our model, we asked Medicaid officials to provide us with aggregate data on annual costs and utilization for outpatient mental health services provided to children ages six to 19. Based on our analysis of these data, we estimated the average cost to be \$1,600 per child per year.

The Delaware Division of Medicaid was unable to provide comparable data for outpatient substance abuse services, given that the program only recently began reimbursing for these benefits. However, HSR was able to obtain utilization and cost data from the Delaware Division of Children’s Mental Health. Similar to mental health, we assumed that this service would be targeted to older children. Based on our analysis of these data, we estimated that the annual per capita cost of providing children between the ages of six and 19 is \$960. These figures are also displayed in Table IV-7 above.

E. Estimating Total Program Costs

Based upon our analysis of the size of the target population, our assumptions regarding prevalence and participation rates, and our annual service-specific per capita cost estimates, we have developed detailed estimates of the total program costs associated with providing enhanced services to “at-risk” children in Delaware. The estimated costs of providing coverage to children in various age groups and income categories are displayed in Table IV-8.

As shown in Table IV-8, the total cost of providing enhanced services to all children, from birth through age 18, is approximately \$4.3 million. Roughly 62 percent of these costs--\$2.6 million--are associated with the provision of care coordination and the direct services bundle. The remaining 38 percent of costs, totalling just over \$1.6 million, are associated with the provision of outpatient mental health and substance abuse treatment services. If the State of Delaware were to choose to limit enhanced services to children birth to age six, total program costs would drop to approximately \$1.2 million. As outpatient mental health and substance abuse treatment services are not targeted to these younger children, all costs would be associated with the provision of care coordination and direct services.

TABLE IV-8 TOTAL PROGRAM COSTS, BY AGE, INCOME, AND SERVICE						
Age	Total Enrolled Children	Cost of Care Coordination	Cost of Direct Services	Cost of O/P Mental Health Svcs	Cost of O/P Substance Abuse Svcs	TOTAL COST
<i>Children < 1</i>	520	\$208,090	\$104,040	na	na	\$312,130
Medicaid Eligible	340	\$137,450	\$68,730	na	na	\$206,180
Near Poor	90	\$34,230	\$17,110	na	na	\$51,340
Higher Income	90	\$36,410	\$18,200	na	na	\$54,610
<i>Children 1-5</i>	2,030	\$609,450	\$304,730	na	na	\$914,180
Medicaid Eligible	920	\$276,910	\$138,450	na	na	\$415,360
Near Poor	840	\$251,920	\$125,960	na	na	\$377,880
Higher Income	270	\$80,630	\$40,310	na	na	\$120,940
<i>Children 6-19</i>	3,360	\$939,830	\$469,920	\$1,069,330	\$569,420	\$3,048,490
Medicaid Eligible	1,160	\$325,270	\$162,640	\$297,390	\$158,360	\$943,660
Near Poor	1,570	\$439,820	\$219,910	\$452,410	\$240,910	\$1,353,050
Higher Income	620	\$174,740	\$87,370	\$319,520	\$170,150	\$751,780
TOTAL	5,910	\$1,757,370	\$878,690	\$1,069,330	\$569,420	\$4,274,800

When reviewing Table IV-8, however, it is important to remember that the State of Delaware will not be fully responsible for paying all program costs for two reasons: (1) federal Medicaid

matching funds would be made available to finance care for Medicaid-eligible children; and (2) near-poor and higher-income families would be required to pay a portion, or all, of the costs associated with enhanced services coverage. In analyzing total program costs, it is reasonable to make the following assumptions to calculate the portion of costs that would be borne by the state:

- For children eligible for Medicaid, 50 percent of total costs would be borne by the state, while 50 percent would be paid with federal Medicaid matching funds (given Delaware's current Federal Financial Participation Rate);
- For "near-poor" children, i.e., children ineligible for Medicaid in families with incomes below 260 percent of poverty, 50 percent of total costs would be borne by the state, while the remaining 50 percent would be paid by families with "at-risk" children (assuming a smooth sliding fee scale that evenly distributes costs between the state and families); and
- For higher-income families, i.e., children in families with incomes over 260 percent of poverty, all costs would be born by families with "at-risk" children.

Table IV-9 illustrates how total estimated program costs would be distributed between the State of Delaware, the federal Medicaid program, and families with "at-risk" children. Specifically, of total program costs (\$4.3 million) 40 percent would be paid by the state (approximately \$1.7 million), 18 percent would be paid by the federal contribution to the state's Medicaid program (approximately \$780,000), and 42 percent would be paid by families (approximately \$1.8 million). If the State of Delaware were to choose to extend enhanced services only to Medicaid-eligible children, total state costs would amount to approximately \$782,000.

If Delaware officials were to choose to limit enhanced services to children birth to age six, total costs to the state would equal approximately \$525,000. If, within this age group, state officials were to decide to cover only Medicaid children, total costs to the state would drop to roughly \$311,000.

TABLE IV-9 DISTRIBUTION OF COSTS BY PAYOR SOURCE							
Ages	Total Program Costs	Medicaid-Eligible Children		Near-Poor Children		Higher- Income Children	Total State Costs
		Federal	State	Family	State	Family	
0-1	\$312,130	\$103,090	\$103,090	\$25,670	\$25,670	\$54,610	\$128,760
1-5	\$914,180	\$207,680	\$207,680	\$188,940	\$188,940	\$120,940	\$396,620
6-19	\$3,048,490	\$471,830	\$471,830	\$676,530	\$676,530	\$751,780	\$1,148,360
TOTAL	\$4,274,800	\$782,600	\$782,600	\$891,130	\$891,130	\$927,340	\$1,673,730

CHAPTER V

Policy Options for Implementing Enhanced Services for At-Risk Children

By implementing the package of enhanced services described in this report, Delaware would assume a leadership role among states by creating a more sophisticated and responsive system of care for children. In particular, the state would build upon already well-established primary and tertiary care systems by adding the capacity to provide specialized care to children experiencing environmental and psychosocial disadvantages. As discussed throughout this paper, very few states have taken this step, one that many believe is needed to establish a system of care that is truly comprehensive.

However, before enhanced services for “at-risk” children can become a reality, several important preparatory steps first must be taken. Obviously, the state would need to pass legislation authorizing funding for the program. But, beyond this legislative and budgetary hurdle, there are several administrative and programmatic issues that would require exploration and resolution. Specifically, state officials would need to:

- Develop a risk assessment system, including an assessment instrument, to effectively identify “at-risk” children;
- Develop detailed service delivery protocols for the enhanced services package;
- Determine which providers and service delivery systems would be most appropriate for providing enhanced services;
- Obtain approval from the federal Health Care Financing Administration for a state plan amendment that would allow federal Medicaid matching funds to help finance the services for Medicaid-eligible children;
- Design a mechanism to allow families with income above Medicaid eligibility thresholds to purchase enhanced service coverage on either a partially- or non-subsidized basis; and

- Consider how a system for providing enhanced services to “at-risk” children can be merged with the state’s broader efforts to reform health care financing and service delivery systems.

Each of these issues is discussed in more detail below.

A. Designing a Risk Assessment Instrument and System

As discussed in detail in Chapter IV of this report, two of the most challenging and complex tasks that would confront Delaware officials in implementing an enhanced services program would be designing a risk assessment instrument that accurately identifies children at risk of poor health and developmental outcomes, and establishing a system that effectively screens the universe of children who may be at risk. Once again, while the development of a risk assessment instrument and system was beyond the scope of this project, HSR has worked closely with Delaware officials to identify the general risk criteria that should guide decisions regarding whether a given child is eligible for enhanced services.

The health services research literature provides a starting point for a study of the current “state of the art” in risk assessment strategies and approaches. In addition, Delaware officials should closely study the risk assessment instruments used by other states that have implemented enhanced services programs. Unfortunately, as was discussed previously, the science of predicting which children will suffer poor outcomes as a result of experiencing environmental and psychosocial risks is inexact. Therefore, while these sources may be helpful, they will fall short of providing Delaware officials with a definitive instrument for identifying at-risk children.

In developing a risk assessment system, Delaware officials should also note that design decisions are driven as much by policy and budget considerations as scientific principles. For example:

- **A risk assessment system may be either inclusive or restrictive.** Fiscal realities may drive policymakers to design a risk assessment instrument that is relatively restrictive in its definition of “at-risk” status in order to limit the number of children who qualify for enhanced services. Conversely, the tool may be designed to provide relatively easy initial access to enhanced services, but

include protocols that require frequent reassessments to determine whether continued provision of enhanced services is warranted.

- **A risk assessment tool may be complex or simple.** To make the risk assessment process simple, policymakers may design a relatively straightforward instrument that could be administered by a broad range of professional and lay health and social services providers. Such an instrument might present a checklist of specific risk factors, and any child exhibiting one or more of the risks could be deemed eligible for enhanced services. Conversely, officials may want to design a more sophisticated instrument that, for example, prioritizes certain risk conditions, assigns points for the presence of various risks, and establishes a scoring system for identifying which children have sufficient risk to warrant receipt of enhanced services. (Remember that a simple instrument is not necessarily more inclusive than a sophisticated one; a simple checklist tool could be very restrictive if the list of criteria that qualify children for eligibility is small and/or targeted to a limited number of circumstances.)
- **Risk assessment “intake” points could be created throughout the system of care or, alternatively, be in certain target locations only.** Ideally, program designers would want their risk assessment system to be universal; that is, they would implement a system through which every child in the state would be assessed for the presence of risk factors. A universal system would establish points of intake in a broad array of health, education, and social service sites, including physicians’ offices, hospitals, clinics, schools, social services agencies, community mental health centers, etc. However, given the diversity of these sites and the range of professional and lay personnel working in them, the capacity to perform accurate and consistent risk assessments across the system may be difficult to build. Therefore, in an effort to assure consistent assessment, a universal system might use a relatively simple screening instrument with the attendant problems of reduced ability to distinguish degree of risk. A strategy to achieve higher quality assessments might involve providing assessors with specialized training and placing them in a limited number of appropriate, centralized sites. Limiting the number of sites where children can be assessed for risk carries with it, however, obvious trade-offs with regard to universality.
- **The assessment of risk can occur in stages, rather than at a single point.** One strategy for mitigating the trade-offs discussed above would be to implement a staged risk assessment system. Under such a system, a simple pre-screening form could be distributed to multiple agencies and providers who would be instructed to screen all children. Those exhibiting potential risks, broadly defined, could then be referred to enhanced services multidisciplinary teams for a more thorough, comprehensive assessment. Under this approach, the risk assessment process could directly feed into the process of developing individualized plans of care for “at-risk” children, thereby leading to more effective and efficient delivery of services.

Once a system for risk assessment is established, Delaware officials will need to develop detailed protocols for structuring the delivery of enhanced services, as described below.

B. Developing Protocols for Enhanced Services

In Chapter IV, following the guidance of the interagency focus group and our study of the designs of enhanced service programs in other states, HSR established a basic structure and definitions for the proposed enhanced service package for children. The development of detailed protocols describing the content and rules for providing enhanced services, however, was beyond the scope of this project. Therefore, one important task facing Delaware officials would be the development of such protocols.

In establishing service protocols, Delaware officials, with consultation from appropriate health care and developmental providers, would need to develop a consolidated document that specifies:

- The purpose, goals and objectives for the benefits package, as a whole, as well as the individual service components;
- The criteria defining eligibility for receipt of enhanced services;
- The precise content of each service intervention;
- Rules regarding what professional(s) are permitted to render individual components of the service package;
- A step-by-step description of the process to be followed when providing enhanced services, including the initial receipt of a referral, the conduct of a comprehensive risk assessment, the development of a plan of care, the provision of individual interventions, referral to other health care and social services providers (both within and outside of the multidisciplinary team), and the closing of cases when service delivery has accomplished its objectives;
- Rules describing when and where enhanced services providers should go to obtain service authorization (if applicable);
- Rules regarding where enhanced services should be provided and under what circumstances;

- The frequency with which enhanced services should be delivered;
- Criteria for determining how long children should receive enhanced services;
- Requirements for coordinating the delivery of enhanced services with children’s primary care providers (as well as other individuals, entities, or agencies in the delivery system);
- Requirements for documenting service delivery activities and reporting such activities to appropriate state agencies;
- Service limitations for individual components of the package (if applicable); and
- Instructions for billing and collecting family contributions to the cost of care.

As a starting point, Delaware officials may wish to structure their protocols after those developed for the state’s SMART START program for high-risk pregnant women. In addition, it would be instructive to study the protocols developed for other states’ enhanced services programs.

C. Establishing Criteria for Provider Participation and Processes for Certification

As discussed in Chapter III of this report, the interagency focus group provided critical input regarding the types of providers who should deliver enhanced services. Specifically, the group agreed that enhanced services should be provided by a multidisciplinary team of physician, nursing, social work, nutrition, education, and child development providers. The group also concluded that public sector programs were the most logical place to set up enhanced service systems, at least initially, given their experience with delivering services through a multidisciplinary model and their expertise in providing care to low-income and disadvantaged families.

At this time, the group that most readily possesses the experience to serve as enhanced service providers is the state agency staff based in the 15 State Service Centers run by the Delaware Department of Health and Social Services. These centers essentially represent “one-stop shopping” sites where services from numerous divisions of the Department of Social and Health

Services (the Divisions of Public Health, Family Services, Child Mental Health, Alcohol, Drug Abuse and Mental Health, and Mental Retardation) are available. The State Service Centers have long provided Delaware families with a range of preventive and public health services including dental examinations, immunizations, health education and, to a more limited degree, sick child care. In addition, centers are also sites where families can receive social, mental health, and mental retardation services (Delaware Child Health Task Force, 1992). The nurses, social workers, nutritionists, health educators, and mental health providers who staff the Centers also have extensive experience conducting risk assessments. Finally, DPH has served, since 1989, as a major SMART START provider (along with the Visiting Nurse Association of Delaware) in the state and are, therefore, uniquely familiar with the purposes and processes of providing enhanced service in support of medical care.

While the interagency focus group indicated that public providers should initially deliver enhanced services, they also indicated that, over time, the enhanced services program should permit a broader range of qualified providers to participate. Providers that already possess, or perhaps could develop the capacity to provide enhanced services in the future, include the state's three Federally Qualified Health Centers, community-based family service agencies, any of the newly developed Nemours clinics, and school-based health centers.

In any event, state officials will need to establish formal criteria, as well as a process for certifying providers, for participation in the enhanced services program. The certification process could occur through either an "open" application or a competitive request-for-proposals process. Through both of these processes, Delaware officials will want to establish criteria that demonstrate providers' capacity to deliver enhanced services in a high quality manner. Specific provider participation criteria that state officials may want to consider include, but are not limited to, requiring providers to:

- Participate in Medicaid's EPSDT program;
- Demonstrate experience serving disadvantaged children and an understanding of the concept and process for delivering enhanced support services;

- Demonstrate the capacity to provide enhanced services according to the protocols established by the state, including the ability to provide extensive home visitation services;
- Possess appropriate multidisciplinary staff with the qualifications necessary to provide enhanced services, as laid out in the state's service protocols;
- Have in place formal arrangements (e.g., subcontracts, memoranda of understanding, etc.) to refer for services that cannot be provided on site;
- Demonstrate linkages to relevant social, health, educational and other service providers in their communities;
- Demonstrate a capacity to perform outreach activities to the target population, as well as to providers and agencies in the community that may serve disadvantaged children;
- Possess physical facilities that are comfortable, safe, clean, accessible, and meet legal requirements; and
- Generally, provide assurances that they will respond promptly to referrals for enhanced services, provide for weekend and after-hours emergencies, arrange for bilingual services if indicated, arrange for transportation if indicated, maintain a confidential recipient records system, and conduct ongoing communication with each eligible child's primary care physician.

A provider application or bid could serve as the sole basis upon which a decision is rendered regarding whether or not a provider qualifies to participate in the enhanced services program. Alternatively, written applications or bids from providers that appear capable of rendering enhanced services could be followed up with a site visit by appropriate state officials to ensure that a provider has adequate service delivery capacity.

Responsibility for provider certification could be assigned to a single state agency or, alternatively, could be shared by a combination of appropriate state agencies. In Delaware, the state Medicaid, Maternal and Child Health, Part H, Child Mental Health, and Substance Abuse agencies all represent viable options for consideration.

D. Obtaining HCFA Approval for Medicaid Coverage of Enhanced Services

Medicaid financing will be a critical underpinning for the enhanced services program. Capturing federal financial support, however, will require the Delaware Division of Medicaid to develop, submit, and receive approval from the federal Health Care Financing Administration of an amendment to its Medicaid State Plan to add coverage of enhanced services.

The authority to develop enhanced services for children was extended to states by the Omnibus Budget Reconciliation Act of 1989 (OBRA-89). As discussed in Chapter I of this report, OBRA-89 required states to cover any service needed by a child to treat a condition identified during an EPSDT screen, even if that service is not normally covered under the state's Medicaid plan. This provision is important because it provides states with a vehicle for working around the Medicaid statute's prohibition of discrimination against any recipient group on the basis of age or medical condition. In other words, OBRA-89 cleared the way for states to offer new, specialized services for children without having to offer the same services to all other Medicaid recipient groups.

In contrast to the process required to gain approval of a waiver to the Medicaid statute, the state plan amendment process is relatively straightforward. Furthermore, the components of the benefit package designed by HSR and the interagency focus group were identified with an eye toward Medicaid financing. That is, each of the services included in the package have been approved for federal Medicaid funding in one state or another in the past. In spite of these advantages, Delaware officials should be aware of several issues that may complicate the approval process. These issues are discussed in detail below.

- **Meeting the Definition of Medical Necessity.** The Medicaid statute requires that, in order to qualify for federal financial participation, services must be demonstrated to be *medically* necessary. This requirement can be traced to the program's roots as a health insurance program. Enhanced services for children, because they are intended to address psychosocial, environmental, and developmental problems, may be scrutinized closely by HCFA officials and judged as not meeting the statute's definition of medical necessity. For example, some states have encountered this problem when attempting to obtain Medicaid financing for early intervention services. Further, the State of Michigan originally

had its amendment to add Infant Support Services denied, in part due to the fact that services were not judged to be medically indicated.

To overcome this hurdle, Delaware officials will need to incorporate into their plan amendment a strong rationale that the preventive interventions embodied in the service package will address a host of needs, nearly all of which have implications for child health. For example, the amendment should discuss how enhanced services could reduce Medicaid expenditures for medical care and hospitalization for sick and neglected infants and children. In addition, state Medicaid officials may want to build in a formal process for determining medical necessity as part of the protocol for rendering enhanced services. In Florida, state officials have proposed that certain enhanced services be subject to a “service authorization” review by the state Medicaid agency before they can be provided. In Michigan, officials successfully addressed HCFA concerns by requiring a physician referral before Infant Support Services can be provided, as well as ongoing reporting by the ISS provider back to the physician during the period that ISS services are being delivered.

- **Not Discriminating by Age.** As stated above, the Medicaid statute normally prohibits states from discriminating against any recipient group on the basis of age. OBRA-89 permitted states to disregard this prohibition and develop unique coverage rules for children. The law did not, however, extend states the authority to further discriminate by age *within* the broader group of children. That is, any service included in the state plan for children must be equally available to all Medicaid-eligible children, regardless of age.

This issue is moot if Delaware officials choose to provide enhanced services to all children up to the age of 19. However, if it is decided that fiscal constraints dictate that children from birth to six receive priority treatment (as discussed with the interagency focus group), then state officials can expect to encounter difficulties with HCFA. In fact, the plan amendment would certainly be rejected if it explicitly stated that enhanced services will be targeted only to children under age six. That was the response from HCFA’s Region V office when Michigan originally proposed Infant Support Services as a unique intervention for children under age one. Michigan officials, however, overcame this problem by removing the explicit language regarding age. Today, while ISS services are theoretically available to all children, the program’s protocols and service definitions effectively target the interventions only to the youngest children. Delaware officials will need to explore a similar strategy if they hope to limit enhanced services to a subset of all children in the state.

- **Serving Children, not Parents.** While enhanced services are designed to promote the health and well-being of children, the individual interventions included in the package are often directed at the parents of eligible children. For example, parenting training, health education, and nutritional counseling would, most likely, be provided to parents more often than they would to children.

HCFA officials may raise concerns over whether Delaware's enhanced service program really represents a benefit package for children if so many of the program's interventions are actually directed at parents.

This issue has been raised by HCFA with other states attempting to add coverage of enhanced services. Once again, the State of Michigan succeeded in convincing HCFA officials that, by necessity, the support services contained in ISS had to, at least in part, be directed toward the parents of newborns if infant health was to be improved. Delaware officials would need to prepare similar arguments and rationales so that they could effectively respond to such challenges, should they arise.

■ **Determining the Optimal Approach for Covering Care Coordination.**

Delaware officials have three options for covering care coordination under the enhanced service program.

- First, they could consider care coordination to be one component of the broad benefit package, and submit a single state plan amendment to gain approval of the entire package.
- Second, they could split out the service and submit a separate, second plan amendment for Targeted Case Management, under authority granted by the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA).
- Finally, state officials could sidestep the plan amendment process and implement case management as an administrative activity (although a plan amendment would still be required to add coverage of the remaining components of the package).

If care coordination is to be classified as a service, then there is no inherent advantage to splitting it out from the broader package, from either a financing or service delivery perspective. Either as part of the package, or separate from the package as targeted case management, state officials would retain the flexibility to develop protocols that would dictate who was to receive the assistance, under what circumstances, and how the service was to be carried out. In both cases, as well, the state would receive federal matching funds at Delaware's current 50 percent level. At the margin, the visibility of care coordination as the central feature of the benefit package might be higher if the service were covered under a separate plan amendment. Simplicity might argue, however, against the development of a separate amendment if this were the only advantage.

Covering care coordination as an administrative activity offers one distinct advantage over covering it as a service: in cases where care coordination requires the expertise of a skilled medical professional (e.g., a nurse), the state could earn federal match at the enhanced rate of 75 percent. This option also

carries with it, however, one serious disadvantage: by definition, administrative case management is only matchable to the degree that activities performed are “necessary for the efficient administration of the state plan.” According to HCFA, therefore, activities for which a match is available “...must be limited to those activities necessary for the proper and efficient administration of Medicaid covered services.” Therefore, for example, Medicaid administrative match would not be available for the time spent by a nurse linking a child to WIC, Head Start, Part H, or any other services not covered by the Medicaid program.

Targeted case management, on the other hand, permits coverage of a broader range of activities. Specifically, the Medicaid statute defines targeted case management as “services which will assist individuals eligible under the plan in gaining access to needed medical, social, education, and other services.” Based on the experiences of other states, this same broad definition of care coordination could be employed as well if Delaware were to bundle the service into the broader enhanced service package.

Delaware officials will need to carefully weigh the pros and cons of these alternatives as it prepares to seek HCFA approval for coverage of enhanced services.

- **Expanding Coverage of Outpatient Mental Health and Substance Abuse Treatment Services.** Separate plan amendments will also, perhaps, be required to add expanded coverage of outpatient mental health and substance abuse treatment services. Depending on the nature and scope of existing coverage, and how the specifications of expanded coverage take shape during the development of service protocols, Medicaid officials may need to modify their state plan to reflect changes made under this initiative.
- **Developing Additional Aspects of the Enhanced Service Package.** Once again, this report has only taken the first steps in defining the precise structure for the enhanced services package. In order to gain federal approval of a state plan amendment, state officials will need to provide additional detail on the components of the plan, including the criteria under which children will qualify to receive services, the criteria under which providers can qualify to render services, and the content of, and processes for, delivering enhanced services. Most of these definitions will be resolved during the processes of developing risk assessment systems and protocols for service delivery (as described above).

An additional component of the program that will need to be designed prior to the submission of a plan amendment is the program’s reimbursement methodology. As discussed in Chapter III of this report, the interagency focus group expressed its desire that at least two separate fees be created; one for care

coordination, and one for the bundle of direct services.¹³ Beyond this guidance, however, numerous questions remain regarding the definition of units of service and the development of specific fees. For services like care coordination, many states choose to reimburse capitated rates for specified periods of time (e.g., paying providers a monthly fee for each child they are responsible for serving). Other states, however, have chosen to reimburse either much smaller units of service (e.g., 15-minute blocks of time spent conducting case management on behalf of a client), or individual fees for discrete activities (e.g., one fee for performance of a risk assessment, one fee for developing a plan of care, and one fee for ongoing management). Similarly, several different methodologies could be employed to reimburse providers of Direct Services. Monthly capitations represent one option. However, Michigan officials have been pleased with their approach, which involves the payment of a consolidated fee for a generic “professional visit.” As discussed in Chapter III, Michigan will pay ISS providers for up to nine professional visits during a year, leaving the multidisciplinary team to determine for each child what combination of education, counseling, and developmental services are needed.

Once again, before submitting a plan amendment to HCFA for approval, state officials will need to develop fees, methods, and a rationale for their payment approach.

E. Designing a Schedule of Sliding Fees

As discussed in Chapter III, the interagency focus group did not want to limit access to enhanced services to Medicaid-eligible children. Rather, they indicated that the program should institute a sliding fee scale that would allow higher-income families to purchase services either on an at-cost or a partially-subsidized basis. Since the design of a sliding scale was beyond the scope of this project, this additional task needs to be completed before enhanced services can be implemented in Delaware.

As laid out in HSR’s model, fully-subsidized coverage of enhanced services ends at the current upper income eligibility thresholds of the Medicaid program. These upper limits vary by age group: 185 percent of the federal poverty level for children under age one; 133 percent of poverty for children ages one through five; and 100 percent of poverty for children ages six to

¹³ New reimbursement methods may not be required for expanded outpatient mental health and substance abuse services, depending on the scope and content of existing coverage.

19. Based on HSR's desire to integrate the sliding scale system for enhanced services with that used by other existing DPH programs, the upper limit for partially-subsidized coverage was made uniform across all age groups--260 percent of poverty. Therefore, since the income range for partially-subsidized coverage varies by these age groupings, Delaware may need to develop three distinct sliding fee scales, one for each of the age groups.

The question remains, however, as to how to design the sliding scale. One approach would be to base fees on the costs of individual services, and to require families to pay (and providers to collect) fees each time they receive a service. The advantage to such an approach is that it could be designed to keep individual fees low and, therefore, minimize disincentives to purchase care. An alternative approach would be to charge a single annual enrollment fee based on the estimated average total cost of care. While this approach would be much simpler administratively, it could also impose relatively higher one-time, up-front costs on families and might create disincentives to purchase.

In either case, Delaware officials should design a sliding scale with two goals in mind. First, fees for families at the lower end of the scale (e.g., 100 percent to 150 percent of poverty) should be kept as low as possible to help maintain affordability. Second, the sliding scale should provide a smooth transition between the fully-subsidized Medicaid thresholds and the non-subsidized upper income threshold. This will be relatively more difficult to achieve in the case of infants, for example, than for children ages six to 19 because the income gap between fully- and non-subsidized coverage is much narrower for infants (185 to 260 percent of poverty) as compared to the oldest age group (100 to 260 percent of poverty).

F. Integrating Enhanced Services for Children into Broader Health Care Reform Efforts

As discussed in Chapter I of this report, the State of Delaware has been actively considering alternatives for health care reform. The lead agency in the state, the Delaware Health Care Commission, released in May 1994 its final report presenting a recommended strategy for achieving comprehensive health care reform (Health Systems Research, Inc., 1994). More

recently, the state Medicaid agency submitted to HCFA in July 1994 an application for a statewide Section 1115 Research and Demonstration waiver, entitled The Diamond State Health Plan. Under the proposed waiver, the state would expand coverage under Medicaid to all persons with incomes below 100 percent of the federal poverty level. Comprehensive medical and mental health benefits would be provided through a statewide system of managed care. The target date for implementing the Diamond State Health Plan is October 1995.

Given this development, it is appropriate that Delaware officials begin considering how an enhanced service program for “at-risk” children can be integrated with this broader health care reform effort.

In Delaware, as is the case across the nation, reform has identified several underlying principles for a restructured health care system. Two of the most important are: 1) providing all citizens with access to a basic package of health care benefits; and 2) increasing the use of managed care systems, both as a cost-containment measure and as a means for improving the integration of service delivery.

However, as important as these principles are to the goal of improving overall access to health care, they also raise critical questions regarding how a reformed health care system can meet the needs of vulnerable and disadvantaged populations and persons with special health care needs. Questions that have yet to be answered include, but are not limited to:

- What should be the scope of services included in a “basic” benefits package?
- Should “basic” benefits be defined as including psychosocial support and enabling services that have been proven effective in meeting the needs of at-risk populations?
- What should be the role of traditional public health providers relative to managed care systems?
- Can managed care providers be expected to: 1) effectively serve low-income, disadvantaged populations that have traditionally been the charge of public systems; and/or 2) build the capacity to provide support services such as care

coordination, home visiting, parenting training, nutrition and psychosocial counseling?

- How will systems effectively integrate the delivery of primary, specialty, and support services?

Nationally, proposals being put forth at both the federal and state levels have begun to address these concerns. Increasingly, proposals like President Clinton's Health Security Act discuss the concept of "wrap-around" services that provide special needs populations with care beyond that included in a basic benefit package. Additionally, they describe the importance of maintaining a network of "essential community providers" whose traditional mission has been to provide services to poor and disenfranchised individuals and families who would, but for these providers, lack access to care. Finally, these proposals suggest alternatives for financing the delivery of "wrap-around" services, ranging from the development of risk-adjusted capitations and/or supplemental payments to health plans, to the creation of separate categorical programs that will pay for enhanced services.

In Delaware, the Diamond State Health Plan proposes to address some of these concerns through a variety of strategies. First, the waiver would require managed health care plans to offer all Federally Qualified Health Centers (clinics that are often considered "essential community providers") and rural health clinics the opportunity to participate in their provider networks. Second, children would be able to receive their services through either the new managed care plans or the A.I. duPont Children's Clinics, and plans would be required to offer the Children's Clinics the opportunity to participate in their provider networks. Third, managed care plans would be required to coordinate their delivery of services with that of School Based Health Centers serving children. Finally, the waiver includes a proposal that the Division of Child Mental Health Services within the Department of Services for Children, Youth, and Their Families would operate a single integrated system of mental health services for children, "carved out" from the Plan's basic benefits package and financed through a separate capitation rate.

However, because the fate of the Diamond State Health Plan will not be decided for some time, Delaware officials may wish to move forward with plans to implement an enhanced services

program for at-risk children. Indeed, the lessons that could be learned by implementing such a program in an evolving managed care environment could offer Delaware officials valuable insight into viable solutions to the questions raised above. For example:

- In the new term, Delaware could implement enhanced services under its traditional Medicaid programs. Services could be provided through the network of State Service Centers and financed through a combination of federal and state Medicaid funds, and family contributions.
- Over time, as the state moves toward health care reform, the Department of Health and Social Services would gain valuable experience operating the enhanced services program, devising strategies for integrating the delivery of enhanced services with the delivery of primary care, and developing firm data on program costs.
- At the same time, additional providers in the state may explore the feasibility of participating as enhanced service providers, including the Nemours clinics, Federally-Qualified Health Centers, the Visiting Nurses Association and, perhaps, private managed care entities.
- By the time comprehensive systems reforms are ready to be enacted, through either the 1115 waiver or some other initiative, Delaware may find itself in a strong position to formulate an effective strategy for integrating enhanced services into its broader health care financing and delivery system. Experience gained through the development and implementation of enhanced services may provide the state with sufficient information to decide:
 - Whether enhanced services should be incorporated into a basic benefits package, or carved out into a separate “wrap-around” package;
 - Whether managed care plans can effectively render enhanced services to at-risk children, or whether State Services Centers should be maintained as the primary provider of such care; and
 - Whether prepaid capitated rates can reasonably be adjusted to cover the additional costs of providing enhanced services, or if a separate categorical financing mechanism is needed to continue funding these services outside of the prepaid structure.

In conclusion, it seems clear that the development of a program to provide enhanced services to “at-risk” children is an appropriate strategy to improve the comprehensiveness of Delaware’s system of care either in the presence, or absence, of health care reform. In either event,

exploration of the feasibility, affordability, and potential benefits of enhanced services need not, nor should not, be delayed while larger health care reform issues are debated.

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Appendix A: Overview of Delaware's Service Delivery System

I. Introduction¹

The current system of primary care in Delaware is complex. Care is provided to children and adolescents by a variety of individuals and institutions and financed through a combination of public appropriations, private funds for special programs and populations, insurance plans, and out-of-pocket payments. The major source of health insurance for low-income children is Medicaid.

This overview presents a cross-sectional "snapshot" of primary care in Delaware including descriptions of: the specific elements of a comprehensive system; the diverse primary providers; the consultative providers and support services; some aspects of the financing of the system; the distribution of providers across the state; cooperative and collaborative programs in primary care; new initiatives; and opinions of selected providers on the system.

Delaware MCH officials have defined primary care as including: preventive health supervision; health promotion; health education; early detection of medical, sensory, communication, dental, developmental, and emotional disorders; and care of acute and chronic illness. The frequency and content of children's health supervision visits to the provider required to accommodate all of these elements are prescribed by the American Academy of Pediatrics.

Primary care also includes coordinated access via the health care home to secondary-level services. These include consultation with appropriate pediatric, behavioral science and surgical specialists, when indicated, and referral to appropriate support professionals such as child psychologists, speech pathologists, occupational and physical therapists. Special services such as these are regularly required by children or their families. Twenty percent of children can be expected to benefit at some time from such referrals, while another 15 percent of children have a chronic illness or condition requiring frequent specialist visits.

II. The Providers

This section provides an overview of the various public- and private-sector providers serving Delaware's children. An overview table is provided in Table B-1.

A. Physicians in Private Practice

Pediatricians and family practitioners in private practice provide primary care for a large majority of Delaware children and are, therefore, at the center of the primary care infrastructure.

¹ This Appendix is adapted from a report that was originally prepared for the Delaware Child Health Task Force, Division of Public Health, October 1992.

Ideally, their practices are based on the attributes of primary care identified by Delaware's Child Health Task Force.²

However, the distribution of private physicians is not equal across the state, and in a number of areas there are inadequate numbers of private physicians. Furthermore, many private physicians, while they accept payment from private insurers and from private managed care health plans, decline to accept Medicaid, making them inaccessible to children and families on Medicaid. As shown in Figure B-1, there are many areas of the state with large numbers of Medicaid clients but few or no doctors. In a recent study conducted by the Delaware Medicaid Program, only 54 percent of Medicaid-enrolled physicians provided services to *any* Medicaid recipients. Of those, 15 percent served one to 10 Medicaid recipients, and only 28 percent served more than 31 recipients.

The infrastructure of physicians in private practice is supplemented by federal, state, and community-based programs which target services to families without access to private sources of care. Figure B-2 shows the distribution of many of these providers across Delaware.

B. Public Health

In Delaware, the Division of Public Health (DPH) offers services at 15 locations distributed across the state. Services available at these locations include preventive health, dental health, immunizations, health education, limited pediatric sick care, and home visiting. Although services are available to all children regardless of ability to pay, low-income families who are on Medicaid or who have no insurance are the primary recipients of DPH services. In collaboration with pediatric specialists at the A.I. duPont Institute and the Medical Center of Delaware, DPH also provides secondary-level specialty diagnostic services for children in Kent and Sussex Counties. Public health services provided by DPH are not, however, available 24 hours a day.

C. Federally Qualified Health Centers,

Primary care services are provided at federally-supported Community and Migrant Health Centers in medically-underserved areas. These centers are referred to as Federally Qualified Health Centers (FQHCs). FQHCs in Delaware include the Henrietta Johnson Medical Center and the West Side Health Service in Wilmington, and Delmarva Rural Ministries Migrant Health Services in Kent/Sussex Counties. FQHCs are located in the community, provide services to families, have a variety of services on site, have access to state services, accept all insurance including Medicaid, utilize a sliding scale for uninsured families, offer 24-hour coverage, and are governed by a board of consumers and community leaders. The federal government offers

² The 11 attributes of primary care identified by the Task Force are: first contact, accessible, longitudinal, comprehensive, coordinated, family-centered, culturally appropriate, community-based, accountable, developmentally appropriate, and empowering.

financial incentives to encourage the development and continuation of FQHCs. Some states have responded to the offered incentives by converting existing public health centers into FQHCs.

D. School Nursing

Delaware has an organized and effective system of school nurses managed by the Department of Public Instruction. For many school-age children, the school nurse is the first source of care for acute illness and health supervision. School nurse services by their very nature are neither comprehensive nor longitudinal and are only accessible during school hours. School nurse services are expected to be developmentally and culturally appropriate and are financially accessible.

E. School-Based Health Centers

There are school-based health centers in four high schools in Delaware. These have been developed through the collaborative efforts of DPI, DPH, the schools, and contract providers. School-based health centers are generally staffed by a nurse practitioner and supported by a physician. Since they are on-site, school-based health centers are accessible by day. Adolescents frequently make poor use, or have no regular source, of coordinated primary care even though they are at risk for a broad range of developmentally-determined medical, behavioral, and emotional problems. These include substance abuse, motor vehicle injuries, failure in school performance, attempted suicide, homicide, sexually transmitted diseases including AIDS, and unplanned pregnancies.

F. Hospitals

Virtually all general hospitals offer primary care, or at least some elements of primary care. The large multispecialty hospitals and some community hospitals have on-site and off-site outpatient care centers. For example, many children from the city of Wilmington without access to private physicians receive (and have received for many years) comprehensive, accessible, longitudinal care at the Wilmington Hospital Pediatric Clinic. This clinic also serves as a primary care training site for pediatric, emergency medicine, and family practice residents who can learn under the supervision of board-certified pediatricians with interest and skill in primary care.

However, families without an independent source of primary care often present at hospital emergency departments for diagnosis and treatment of acute, relatively minor illnesses. Emergency departments can provide adequate, even excellent, acute care but they are not comprehensive and, by definition, do not provide longitudinal service. Emergency rooms are also costly, and children brought to the emergency room tend to be brought there relatively late in the course of an illness. Hospitals, of course, have an essential role in the comprehensive, coordinated primary care system as the site for inpatient and specialized outpatient services.

G. Pediatric Consultants

While pediatric subspecialty care is not strictly within the definition of primary care, accessibility to appropriate consultants through the primary health care home is implied if care is to be comprehensive. Communication between the primary care provider, the family, and the specialist is critical to assure continuous and coordinated care. Delaware has what appears to be adequate numbers of pediatric surgical and subspecialty providers. In Delaware, there are pediatricians in the practice of allergy, cardiology, developmental medicine, endocrinology, gastroenterology, genetics, hematology/oncology, infectious disease, intensive care, neonatology, neurology, and rheumatology. In addition, there are several pediatric surgeons, pediatric ophthalmologists, a pediatric neurosurgeon, pediatric urologist, pediatric orthopedists, and general surgeons who also serve children. Pediatric subspecialists are in private practice in the community, or are full-time employees of the various general hospitals, or are full-time employees of the Alfred I. duPont Institute.

With a few exceptions (a neonatologist, a neurologist, and a developmentalist), all of the subspecialists are located in New Castle County in Greater Wilmington. Some of the subspecialty services are offered in Kent and Sussex County through occasional outreach clinics (genetics, ophthalmology, neurology, cardiology, and orthopedics) which are extensions of the Medical Center of Delaware (MCD) or the A.I. duPont Institute in collaboration with the Division of Public Health. Subspecialists in Delaware generally accept Medicaid patients and most are willing to see a limited number of uninsured without fee. However, lack of transportation and inadequate insurance are barriers restricting access for some children to appropriate consultant services.

H. Child Mental Health

According to a recent report sponsored by the Delaware Division of Child Mental Health Services (DCMHS), about 18 percent of the child and adolescent population can be expected to display some maladaptive behavior of sufficient intensity to require some level of intervention. Another 10 percent could be considered to be at substantial risk for emotional disturbance.

DCMHS estimates that about 50 percent of children with serious pathology will be helped to overcome the less severe aspects of their problem by professionals such as teachers, nurses, clergy, and guidance counselors. Of those children seen by mental health professionals, a substantial percentage will receive services through private providers; the services are totally or partially paid for by private insurance. This leaves a relatively large number of children who will need to be served by the Division of Child Mental Health which will almost certainly require expanded resources to meet this challenge.

I. Dental Health

There are a number of pediatric dentists in Delaware and many (probably most) general dentists treat children. However, dental services are expensive and no dentists accept Medicaid. The

Division of Public Health (DPH), through public health dental clinics, provides diagnostic and primary treatment services. These clinics are the only providers of Medicaid EPSDT dental services. DPH provides some dental health education advice to schools but preventive dental services such as fluoride and sealant applications, and dental hygiene exams are not yet provided. Emergency dental treatment for children is available on a limited "first come, first serve basis" through the MCD dental clinic and the Dental Health Teaching Center at the Wilmington Branch of Delaware Technical & Community College.

J. Other Providers

Some selected aspects of primary care to children are provided through programs such as Head Start and at child care centers. Other services are available at residential and outpatient facilities for children with special health needs and from private organizations such as Easter Seals, Delaware Curative Workshop, Visiting Nurses Association, etc. Many children spend a large part of the day at Head Start or at day care. Currently health services at these facilities are not well coordinated with services of the primary care physician, and personnel at these facilities are not prepared to care for children with special health needs. Establishing a support system of technical assistance to these agencies is important to assure quality and coordination of care.

III. Public/Private Partnerships

It is frequently stated that access to health care could be substantially expanded if there were more public/private collaborations. Public/private joint ventures strengthen Delaware's health care system by sharing resources and expertise across agencies who also join forces to assure future growth and quality. There are a number of public/private cooperative efforts in Delaware relevant to comprehensive primary care for children and their families.

A. WATCH Program

The Perinatal WATCH and Child Development WATCH programs are cooperative, collaborative ventures among the Medical Center of Delaware, the A.I. duPont Institute, DPH and the Division of Mental Retardation. In southern Delaware, the Delaware Early Childhood program and the Easter Seal Society are additional partners. The multidisciplinary WATCH teams conduct a range of activities including: conducting risk assessment and team care for high-risk pregnant women and developmental assessments for infants and toddlers; conducting home visiting and evaluations; communicating regularly with the primary health care providers; and arranging for and providing treatment services for children at risk for developmental delay and their families.

B. Specialty Clinics

Pediatric and surgical specialty clinics in Kent and Sussex Counties are joint efforts involving DPH, the A.I. duPont Institute, the Medical Center of Delaware, and private specialty physicians. These multidisciplinary specialty teams offer specialty services to children at various State Service Centers (see below), particularly in Kent and Sussex Counties. Orthopedics, neurology, cardiology, genetics, orofacial surgery, ophthalmology, and otorhinolaryngology are among the specialties represented. In these clinics, collaboration and outreach make specialty services accessible to individual children and more generally to the primary care system.

C. Other Collaboration

West End Neighborhood House, the Birth Center of Delaware, St. Francis Hospital, and DPH are collaborating to provide comprehensive maternity care services to women in Wilmington. Private obstetricians, Kent General Hospital, and DPH collaborate in Dover to make maternity care available to all Kent County pregnant women. The A.I. duPont Institute and the Department of Public Instruction cooperate in a scoliosis screening program. These are examples of numerous collaborative efforts in the state.

D. State Service Centers

The system of 15 State Service Centers operated by DHSS are a unique system of co-located social, public health, mental retardation, mental health, child protective and juvenile justice services. These state facilities are accessible to families throughout Delaware. For families with multiple needs, the existing State Service Centers are a major strength of Delaware's primary care infrastructure. Strategies to improve and strengthen coordination among the State Service Centers, hospitals, and the private physicians in each community are a priority for Delaware's primary care system for children. Examples of such coordination already exist for provision of prenatal services in several communities and should be extended to children.

E. Nemours Foundation CHILD Project

A major new effort initiated by Governor Castle and The A.I. duPont Institute (AIDI) in 1992 is improving access to primary health care for children. AIDI's Children's Health Improvement Linkage of Delaware (CHILD) Project is establishing pediatric practices in 12 medically underserved communities across the state. The DHSS, including DPH and the Division of Social Services (DSS) (specifically Medicaid), collaborates with AIDI in identifying underserved areas, determining target population, estimating cost share, and developing a service plan. As of December 1994, seven clinics are opened and serving children. Three more are expected to open in the spring of 1995. These clinics serve low-income families with Medicaid and those without health insurance. DPH and DSS assign a liaison public health nurse and social worker to each clinic to assist with home-based services, care coordination, and outreach.

F. Other Initiatives

Other Delaware initiatives include the award of several federal grants to Delaware which help strengthen components of primary care services, including:

- ***Disabilities Prevention Grant*** (1991-95) is a five-year award from the Centers for Disease Control to the Division of Public Health, DHSS, for the purposes of: (1) primary prevention of mild mental retardation; (2) tracking of children with sickle cell disease; and (3) prevention of head and spinal cord injuries. Establishing a surveillance system to track these disorders is an essential component.
- ***Childhood Lead Poisoning Prevention Grant*** (1992-97) is also a five-year award from the Centers for Disease Control to the DPH, DHSS, for the purposes of: (1) expansion of screening; (2) increasing public and provider awareness; (3) establishing a surveillance system; and (4) establishing community-based coalitions. Screening for lead poisoning is a new requirement under the EPSDT program.
- ***Immunization Action Plan*** is a five-year cooperative agreement between the CDC and the DPH for improving the immunization status of two-year-old children in the state.
- ***PROJECT: CAN DO IT*** is a federal grant to the Division of Child Protective Services, DSCYF, to develop an interdisciplinary training model to assist professionals working with families experiencing substance abuse and child abuse and neglect.

Table B-1 DELAWARE'S PRIMARY CARE SYSTEM								
Provider	Preventive Care	Immunization	Illness Care	Emergency Care	Health Education	WIC	Home Visits	Service Coordination
Private Physician	A	L	A	A	L	NA	NA	L
Public Health	A	A	L	NA	A	A	A	A
FQHCs	A	A	A	NA	A	L	L	A
Hospital Primary Care Centers	A	A	A	A	A	NA	NA	L
School Nursing	A	NA	L	NA	A	NA	NA	L
School-Based Health Centers	A	NA	L	L	L	NA	NA	L
Emergency Departments	NA	NA	A	A	NA	NA	NA	NA

Key	
Available	A
Not Available	NA
Limited	L