

**Blueprint for a Needs Assessment:
Contributing to a System of Care for
Children with Special Needs & Their Families**

A Technical Resource Brief

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Blueprint for a Needs Assessment: Contributing to a System of Care for Children with Special Needs & Their Families. A Technical Resource Brief

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

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PREFACE

The mission of the Pennsylvania Bureau of Maternal and Child Health is to improve the health status of women, children and their families. This includes, of course, children with special health care needs and their families.

Historically, the Pennsylvania Department of Health has focused its efforts on behalf of children with special health care needs on assuring access to condition/disease-specific specialty medical services. However, as Pennsylvania has expanded medical assistance eligibility and developed other health insurance programs for children, and as the health care environment and family life have grown increasingly complex, the need for new approaches to care for children with special health care needs became obvious.

Our first step in determining what new approaches were appropriate was to determine: who are the children with special needs? what special needs do they and their families have? what resources are available and accessible to meet those needs? and what resources are missing or inaccessible? Pennsylvania, like many other states, could not adequately answer these questions. Clearly, a needs assessment was in order.

Pennsylvania is a large, very diverse state. A one-size-fits-all needs assessment would not yield the information we need. Therefore, we are pursuing a number of strategies to obtain a meaningful picture of our children with special needs and their families to guide the implementation of a community-based, family-focused, culturally-competent and coordinated system of care. Our first step was to work with the University of Pittsburgh, Graduate School of Public Health, to conduct a survey of children with special health care needs enrolled in our Title V programs. This was the first stage of a multistage needs assessment, which includes surveys of children with special needs not enrolled in Title V programs and of health care providers working with these children.

Our next step was to include in our Title V contracts with Pennsylvania's nine county/municipal health departments a needs assessment requirement for children with special health care needs in their respective counties and cities.

The first city health department to begin this assessment was the Philadelphia Department of Health. Philadelphia is Pennsylvania's largest city and has a very complex health and human services political and organizational structure. The Philadelphia Department of Health obtained the consultative assistance of Dr. Henry T. Ireys to work with us and the Public Health Service Region III Office to develop a "Blueprint" to guide and structure the needs assessment. The development of the "Blueprint" was supported by Pennsylvania Title V funds and will be used as a prototype for adaptation by other health departments in the Commonwealth as they initiate their assessments. Because the definitional boundaries for children with special health care needs vary, and because so many categorical systems are involved in surveying these children, we believed it essential to have a "Blueprint" to keep us focused and to facilitate clear communication among all the groups and individuals involved in the assessment process.

We are very grateful to Ms. Susan Lieberman, Acting Director, Maternal and Child Health, Philadelphia Department of Public Health, and her staff for their commitment and dedication to this project. Our next step following completion of the needs assessment will be to provide technical assistance to Philadelphia as they develop an action and implementation plan to continue to build and strengthen systems of care.

As the process is replicated in other county and municipal health departments and integrated into the statewide efforts of the Bureau of Maternal and Child Health, it will continue to guide Pennsylvania in redirecting services and systems which are responsive to the needs defined by the children with chronic and disabling conditions and their families.

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INTRODUCTION

This document develops specifications for a practical, resource-constrained needs assessment pertaining to children with special needs and their families. The document identifies six specific steps in planning and conducting a needs assessment. These steps are:

1. Stating the goal of the needs assessment
2. Defining the population vs defining the focus of the needs assessment
3. Deciding whose needs are being assessed
4. Defining sufficient representativeness of the needs assessment
5. Synthesizing existing and/or collecting new information
6. Developing and disseminating reports

For each step, key decision points are identified and recommendations are made based on previous experiences with states and localities. It is important to stress, however, that this document is a "blueprint" for a set of activities occurring over a period of several months, at a minimum. The blueprint will be revised appropriately in light of information gathered and as progress is made in assessing needs.

Needs assessments occur within a financial and political context. Today, state and local departments of health are struggling to respond to the federal mandate to develop community-based, family-centered, culturally competent, coordinated systems of care for children with special needs and their families. Moreover, major financial and reform-oriented pressures are placing considerable stress on the health and education institutions that provide services to this population. It is important to assure that these institutions contribute to the needs assessment so that their perspectives are taken into account.

To complete a needs assessment for the purpose of contributing to a system of care, it is necessary to assess the needs of the major components of that system: families, individual and institutional providers, and relevant government entities. An adequate needs assessment, therefore, must identify:

1. what services families say they need and especially what services they say they need and can not find dependably;
2. what individual and institutional providers say they need to provide services that are reliable and of high quality, and what obstacles are interfering with this service-delivery process; and
3. what governmental entities require to monitor the system of care, report progress, and identify emerging issues of concern.

One of the most critical issues in completing a needs assessment is determining the scope and boundaries of the effort. For example, it is possible to interview four to six families with children who have serious ongoing physical health problems (or their providers) and cull from their comments their pressing unmet needs. When legislators hold hearings, essentially they are

doing this kind of a needs assessment. The problem with this approach is that comments from a few families are not "representative" and so the true dimensions of the problem remain vague.

The opposite extreme is to conduct a systematic interview with a random and presumably representative sample of families and providers. This approach can provide substantial and reliable information to guide program development but usually is expensive and time-consuming. One of the most critical decisions that must be made by those who undertake a needs assessment is to identify the stopping point in this continuum of representativeness. What amount of information will be sufficient in light of the larger purposes of the needs assessment?

By definition, needs assessments yield information or data that suggest policy or program directions. Therefore, a second strategic decision involves the questions: 1) how will the data be used? and 2) how should the "stakeholders" (i.e., the persons who will use the data or who have a stake in the outcome of the needs assessment) be involved in the needs assessment? Their involvement is necessary in order to assure that the data from the needs assessment will actually be used productively. On the one hand, the data may serve a limited purpose -- perhaps solely to justify selected programmatic changes. On the other hand, the information may be made available to many diverse groups for purposes of program planning and implementation. Having a detailed, realistic, and accurate understanding of the uses to which the data will be put is pivotal to conducting a successful needs assessment.

The health care system is broad, complex, and changing rapidly. So too are the social and economic pressures on families. Realistically, no single needs assessment can possibly address the full spectrum of "needs," however broadly this term is defined. Moreover, conclusions from a single needs assessment may have a sharply limited "shelf-life" because of the changing conditions in the health care system. Rather than viewing a needs assessment as a single event with clear boundaries in time, it is more useful to consider it as an ongoing process that changes in its form of implementation over time and in response to developments in the field. Moreover, what may be set aside for practical reasons from an immediate needs assessment can become the focus of the next effort.

Many parents have become effective advocates at the policy-making level for children who have disabilities and chronic conditions. Having some of these parents play substantive and leadership roles in a needs assessment process helps to 1) keep the needs assessment focused on matters of importance to families, 2) deflect claims of self-interest that are invariably attached to the participation of providers or administrators, and 3) generate local, consumer support for implementing both the needs assessment and subsequent programmatic changes.

Just as it is important to recognize that most families have many strengths and competencies in responding to a child's chronic health condition, it is imperative to recognize that most communities and elements of the health care system also have many strengths. A needs assessment will be successful to the extent that it recognizes and builds on existing strengths of families, health practitioners, and program administrators who are concerned about improving the health and development of these children.

STEP ONE: STATING THE GOAL OF THE NEEDS ASSESSMENT

It is important first to understand why the needs assessment is being conducted at a specific time, as well as its **primary** purpose. In different settings, needs assessments may serve numerous overlapping purposes, including:

- fulfilling legislative mandates,
- identifying geographical areas that have few medical resources,
- identifying perceived unmet needs of families,
- providing guidance for new service programs,
- providing a rationale for re-allocating service monies,
- justifying politically expedient decisions, or
- helping to establish an agenda for action.

Gaining consensus around the **primary** purpose of the needs assessment, and stating it clearly, is an important first step because it serves as the foundation for future efforts. Clarity of purpose also helps to decide when to stop the needs assessment (i.e., when it has accomplished its main purpose). A clear statement of purpose communicates succinctly the project's intentions. Defining a goal that all key decision makers can endorse is particularly important in gaining support of interested parties, laying the foundation for good public relations, and eventually turning the results of the needs assessments into actions.

The following sentence is an example of how to define the purpose of a needs assessment:

The primary goal of this needs assessment is to identify the service and organizational components required to implement and strengthen a community-based, family-centered, culturally competent, coordinated system of care for children with special needs and their families who live in (area) .

This purpose statement implies that an ideal system of care for these children and families has certain attributes. These attributes have been defined in numerous ways. The following statements (adapted from Bronheim, Keefe, & Morgan, 1993) provide a practical approach to defining ideal attributes:

1. **The family can find the system and the system can find the family.** This attribute involves issues related to child find, identification, and outreach.
2. **The services that families need exist in the community and can be easily used by those who need them.** This attribute involves issues of availability, access, and having a medical home.
3. **Families have help coordinating services and the system has help coordinating itself.** This attribute involves interagency collaboration, co-location of services, and strategic planning.

4. **Existing programs and services support families and give them a say in how the system works.** This attribute involves family support, parent-to-parent connections, parent advisory groups, and parent-professional collaboration.
5. **The availability of financing for services supports families' access to care and providers' abilities to make care accessible.** This attribute involves issues of insurance coverage, managed care, rate setting, method for paying providers, malpractice insurance rates, and family out-of-pocket expenses.

For descriptive needs, the needs assessment purpose statement noted above can be amplified as follows:

This needs assessment will account for the perspectives of families, private and institutional providers, and key government agencies because these groups are all needed to assure that a service system is effective and efficient.

This needs assessment is one part of an ongoing process of identifying how the service system can be more responsive to all children with special needs and their families.

The needs assessment will accomplish its primary goal by gathering and synthesizing information on:

- the number of children with special needs in (area) and the extent of services available,
- what services families say they need and especially what services they say they need and can not find dependably,
- what individual and institutional providers say they need to provide services that are reliable and of high quality, and what obstacles are interfering with this service-delivery process, and
- what governmental entities require to monitor the system of care, report progress, and identify emerging issues of concern.

STEP TWO: DEFINING THE POPULATION vs. DEFINING THE FOCUS OF THE NEEDS ASSESSMENT

It is critically important to distinguish between the definition of the population of "children with special needs" and the specific focus of any single needs assessment effort. Financial or other constraints may make it impossible for one needs assessment to cover all children who fall into the population. In Step Two of the needs assessment, the population is defined first, then the specific focus of the needs assessment is defined.

CSHCN agencies often have encountered problems because they have adopted definitions based on lists of diagnoses, rather than cross-cutting issues. A list-based definition is problematic.

There is always one more diagnosis that could be considered; without clear criteria concerning what is "in" versus "out," the debate focuses on the unproductive issue of how similar the "new" group is to the already covered children. Furthermore, the definition of disability included in special education law is only partially relevant to the broader category of "special needs;" many children who have special health needs are not functionally impaired or educationally at risk, yet still require special medical services and an integrated system of care.

An alternative approach has been developed by Ruth Stein and her colleagues (Stein, Coupey, Bauman, Westbrook, & Ireys, 1993). This approach is based on the noncategorical, or generic, perspective. It attempts to identify key, measurable attributes of "ongoing physical health conditions" rather than "special needs." The approach defines ongoing physical health conditions as disorders that:

1. have a biologic, psychologic, or cognitive basis, and
2. have lasted or are virtually certain to last for at least 1 year, and
3. produce one or more of the following sequelae:
 - a. limitation of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development,
 - b. dependency on at least one of the following to compensate for or minimize limitation of function, activities, or social role:
 - medications,
 - special diet,
 - medical technology,
 - assistive device, or
 - personal assistance, or
 - c. need for medical care or related services, psychologic services or educational services over and above the usual for the child's age or for special ongoing treatments, interventions, or accommodations at home or in school.

This definition includes children with diverse diagnoses, including children with autism, biologically-based cognitive and affective disorders, mental retardation, and chronic illnesses. Given a limited budget, however, it may be impossible to accomplish an adequate needs assessment pertaining to **all** types of children who are included in the definition. It does not mean that these children are unimportant. Rather, it means that a different needs assessment effort or additional support will be required.

Given that boundaries have to be drawn around a particular needs assessment effort, it is reasonable to specifically exclude certain categories of children. Many mental health diagnoses (e.g., childhood schizophrenia) have clear biomedical bases and therefore, children with these

diagnoses would fall into the group based on the definition above. Children with these diagnoses, however, may be specifically excluded from consideration because they are the primary responsibility of mental health agencies. A similar case can be made for children who have learning disabilities with no other physical impairments. These children, while strictly fitting the definition, can be excluded from consideration because they are the responsibility of the special education authorities and have minimal involvement with health agencies.

A particularly important issue in defining the target population group for the needs assessment is consideration of whether to include those children who are "at risk" for developing serious ongoing physical health conditions. This is becoming an increasingly important issue because of the growing capacity to detect children who will develop disease in the future based on analyses of their genetic make-up. A second group of children are at risk because of environmental factors. Research on environmental risk suggests that these factors may significantly increase the likelihood of learning disabilities and other "soft" neurological problems, but are unlikely to increase the risk for other serious ongoing physical health conditions.

Moreover, children who are either genetically or environmentally at risk are different in numerous respects from those who actually have a serious physical health condition; as a result, they require a somewhat different set of services. A strong argument can be made that this group of children and their families are sufficiently distinct as to warrant a separate needs assessment effort.

In summary, Step 2 involves the following set of decisions:

1. Adopt a definition of children with special needs.
2. Decide whether a needs assessment will focus on all or only part of the children who fall within this definition, and explain the rationale for this decision.
3. Decide whether to include "at risk" children in a particular needs assessment.

STEP THREE: DECIDING WHOSE NEEDS ARE BEING ASSESSED

At the foundation of this needs assessment plan is the process of gathering information that will contribute to improving the **system** of care for children with special needs and their families. A system includes distinct components with separate roles and functions that communicate with each other to achieve a common purpose. It is necessary, therefore, to determine what each component of the system "needs" to accomplish its respective tasks effectively, and what the system "needs" as a whole to function effectively. Information may be gathered from each component in a different way, but there should be an effort to gather as much parallel information as possible from each component.

For children with special needs, the system components include the children, families, private providers, educational and health institutions, communities, and governmental agencies. As a result, it is important to ask the following questions:

- What does a family need to maintain its central role as primary caretaker of the child, assuring that it has 1) the information it needs to make informed judgments concerning the child's care and 2) access to needed health services in an appropriate setting?
- What do private and institutional providers need to assure that health services are delivered in an appropriate and timely fashion?
- What do government agencies need to monitor the system of care and identify existing or emerging problems?
- What communication "channels" are necessary to assure that the components can work together?

From a somewhat different perspective, the same issues can be addressed by gathering information on the questions adapted from Bronheim, Keefe, & Morgan (1993) noted previously. Again, these questions are:

- Can the family find the system and the system find the family?
- Do the services that families need exist in the community and can they be easily used by those who need them?
- Do families have help coordinating services and does the system have help coordinating itself?
- Do existing programs and services support families and give them a say in how the system works?
- How does availability of financing influence families' access to care and the system's ability to make care accessible?

Organizing a needs assessment report around these themes will convey the strengths and weaknesses of the current system of care and may suggest where additional attention is needed.

STEP FOUR: DEFINING SUFFICIENT REPRESENTATIVENESS OF THE NEEDS ASSESSMENT

In general, the more a needs assessment can involve a statistically representative sample of children, families, and providers, the more accurate it will be. However, as noted above, the closer a needs assessment is to being statistically representative, the more expensive it becomes.

An alternative approach involves the concept of strategic representativeness. This concept entails selecting subgroups that represent points along a continuum. A continuum may involve issues related to biological severity, need for services, or social urgency.

For example, at one end of a service-use continuum are children who are dependent on ventilators or other sophisticated medical technologies. These children represent the extremely high-cost segment of this group because of their extensive use of technology and home care services; although there are comparatively few of these children, they consume a vastly disproportionate amount of health care resources. At a mid-point in this service-use continuum might be children who need ongoing medication or various replacement therapies, such as children with idiopathic seizures, intractable asthma, or hemophilia. Finally, there are children who have a condition that may be life-threatening at certain times but which do not necessarily entail ongoing or daily intervention; children with certain types of asthma are illustrations of this group. The policy importance of this subgroup comes through its size; there tend to be comparatively more children in this subgroup.

Certain groups of children can be identified as representative or "markers" of the whole group. If this strategy is selected, it is important to acknowledge that true representativeness is not possible and that, as a result, certain problems or needs may be under- or over-identified. Furthermore, in the reports that are generated from data using this approach, specific links to the entire group of children with special needs will have to be drawn out clearly.

The issue of representativeness tends to be more important to academically oriented professionals than to legislators, government agencies, or family organizations. Statistically representative research findings or needs assessments rarely have been the basis for public policy development or reform. Nonetheless, it is important to identify the limitations in the sources of data and information used in the needs assessment report, and to acknowledge frankly that the report's conclusions reflect "critical issues" rather than scientifically representative findings.

STEP FIVE: SYNTHESIZING EXISTING AND/OR COLLECTING NEW INFORMATION

To answer the questions listed in Step 3, it is necessary to inventory existing components of the service system and identify what is known about them. Data must be gathered from several sources including published reports, surveillance systems, claims or encounter data, families, pediatricians, other health providers, insurers, and officials in public programs. Different data gathering methods may be needed to gather information from or about different components of the system, but similar questions should be asked to allow for overlapping data as much as possible.

There are four standard methods for gathering data:

1. review existing reports and/or surveillance systems to determine what already exists,
2. gather expert testimony from parents, pediatricians, etc.,
3. hold focus, nominal, or community groups, panels or forums, and
4. implement systematic surveys, gathering qualitative or quantitative data (or both).

Gathering data typically consumes a significant portion of resources dedicated to the needs assessment process as a whole. For this reason, it is extremely important to determine what information will be gathered, and equally important, to determine **how** that information will be presented to and used by others. Moreover, it is important that each piece of data be related to the overall goal of the needs assessment. A useful question to keep asking is: "Are these data going to contribute to improving the system of care, and if so, how?" Financial constraints will have their greatest impact on this step. With extremely limited funds, a report that simply reviews existing or published data is all that can be expected. Additional funds can be used to gather expert testimony or hold community panels.

If focus groups or community panels are held, it is important to structure them in a way that will provide information pertinent to the goals of the needs assessment. For example, parents can be asked about system issues such as how they found the services they use, what financial obstacles they encounter, and what kinds of assistance they have had in coordinating services. Providers can be asked about how they make their services "family centered," what financial obstacles they encounter in providing care of high quality, and their experiences in communicating with families and other professionals.

Regardless of the methods chosen, it is strongly recommended that the final needs assessment report be outlined before any data are gathered. This exercise can be extremely helpful in 1) assuring that gaps in existing data are known ahead of time, 2) defining how the different data elements will be organized so as to build convincingly toward suggestions for improving the system of care, and 3) preparing the dissemination plans.

STEP SIX: DEVELOPING AND DISSEMINATING REPORTS

It is a truism that individuals will act on recommendations if they have had a role in developing them. Considerations for disseminating the results of the needs assessment, therefore, have to begin in the early stages of the project. This step will assure that those who will act on or be influenced by the recommendations have substantive and on-going roles in the needs assessment process. It is an extremely useful exercise to draft the table of contents for the final report early in the stages of a needs assessment and to consider what different venues and summaries will be required to disseminate the findings broadly.

A partial list of persons who may be influential in disseminating and/or acting on the recommendations include:

- the news media
- community groups and organizations
- family advocacy organizations
- disease oriented voluntary associations
- legal rights advocacy groups
- general pediatric associations

- specialty pediatric associations
- other provider associations
- special education advocacy groups
- tertiary care medical centers
- developmental centers
- insurance groups
- government program offices (i.e., IDEA, Head Start, Medicaid, Social Security)

Specific details need to be worked out to assure that these groups 1) know about the needs assessment, 2) have appropriate input, and 3) are informed of its results in a timely manner. It is recommended that the needs assessment strategy include identification of a key contact person in each group. These individuals should be kept informed of the activities through periodic mailings and early drafts for review. These individuals can then be invited to contact the office that is conducting the needs assessment with any additional input or comments. The effective dissemination of the results of the needs assessment will provide the foundation for implementing new programs or initiatives.

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