U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

ASSESSMENT OF THE POLICY IMPLICATIONS OF ALTERNATIVE FUNCTIONAL DEFINITIONS OF DISABILITIES FOR CHILDREN:

FINAL REPORT

March 1997

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This report was prepared under a grant by DALTCP to the Albert Einstein College of Medicine. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Michele Adler.

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EXECUTIVE SUMMARY

This project examined the implications of using different definitional elements to identify children with disabilities for research or programmatic purposes. Good data on children with disabilities are needed, but inconsistencies in the way disabilities are defined have made it difficult to interpret available data. For example, prevalence estimates have ranged from a low of 4% to a high of over 30% depending on the definition of disability used to identify children. Functionally-based definitions are beginning to have a more widespread application in public policy arenas, but no single definition has gained universal acceptance. If the consequences of using different identifying criteria can be clarified, the implications for policy and funding decisions for children with disabilities can be elucidated.

Previously, members of this investigative team developed the Questionnaire for Identifying Children with Chronic Conditions (QuICCC), a screening instrument that uses criteria based on consequences of health conditions to identify children with disabilities (Stein, Westbrook and Bauman, in press). The QuICCC assesses three domains of consequences that are intended to be used together: 1) functional limitations, 2) dependency on compensatory devices or assistance, and 3) service use or need over and above routine care. In this project, we used these three components plus the whole definition to represent alternative ways to define disability in children. Limitation of function and extended service use are commonly used in measures of disability. However, the concept of compensatory mechanism to maximize or maintain function has not yet been applied to children.

This study addressed questions in four critical issue areas:

1. definitions and measurement: What proportions of children are identified using the QuICCC definition of disability and its components? How do the groups vary by diagnosis and SSI status?

2. demographic and socioeconomic characteristics: How do age/developmental stage, socioeconomic and racial/ethnic characteristics, and psychological impact on child and caretaker vary by the different definitional elements of disability?

3. service use, expenditures, and effectiveness: How do family needs vary by disability definition? and

4. private cost of care: How do out-of-pocket costs for medical care and other non-medical expenses vary by the alternative definitional elements of disability?

We conducted secondary analyses of three existing data sets that contained the QuICCC:

1. a cross-sectional sample of over 1200 children from a random-digit-dial telephone survey in a Northeastern inner city,

2. a cross-sectional sample of over 1350 children from a random-digit-dial telephone survey conducted across the United States, and

3. a statewide cross-sectional sample of over 4000 children from Arizona.

Each data set was used to answer one or more questions, and was used to replicate and compare findings across the different populations. The State of Arizona also provided data from family needs assessment surveys conducted on two smaller groups: a "probability" sample selected from various Arizona communities and a “quota” sample recruited from families generated through family forum, health providers and other community contacts. These data were used to answer selected questions.

This project builds on the foundation of earlier related work that culminated in the inclusion of the QuICCC as part of the framework used to define children with disabilities in the Disability Supplement of the 1994-1995 National Health Interview Survey (NHIS). The analyses conducted here were intended to lay the groundwork for later analyses of the Disability Supplement data as it becomes available.

I. GOALS, OBJECTIVES, AND POTENTIAL USEFULNESS OF THE PROJECT

A. Project Description

The purpose of this project was to examine the policy implications of using different definitional components to identify children with a wide range of disabilities, chronic conditions, and illnesses for research or programmatic purposes. In this report, we use the term "disability" as it is broadly defined in the language and perspective of the American's with Disabilities Act (ADA) of 1990 (P.L.101-336). Here, disability refers to ongoing conditions that currently have functional consequences, but also includes conditions and illnesses that do not currently cause functional consequences because of accommodation or other type of compensation occurring at the person or environment level. For our purposes, disability includes not only physical conditions, but incorporates cognitive, behavioral, and psychological disorders.

Specifically, we have examined the proportions of children identified using elements of our definition of disability, and describe how pertinent characteristics (including demographics and socioeconomic status, psychological impact on the child and caretaker, service needs, federal program eligibility, and out-of-pocket expenses) of the groups vary when different components of the definition are applied. Four issue areas have been addressed in the analyses: A) Definitions and Measurement, B) Demographic and Socioeconomic Characteristics, C) Service Use, Expenditures and Effectiveness, and D) Private Costs of Care.

We conducted secondary analyses of several existing data sets that contained data from surveys that employed the Questionnaire for Identifying Children with Chronic Conditions (QuICCC), a screening instrument designed to identify children with disabling conditions (Stein et al., in press). The QuICCC was developed in earlier work by members of this investigative team, and is based on three components of disability that are intended to be used together in identifying children: 1) functional limitations, 2) dependency on compensatory devices or assistance, and 3) service use or need over and above routine care for age (Stein et al., 1993).

Three different data sets were used for most analyses:

1. a cross-sectional sample of over 1200 children from a random-digit-dial telephone survey in a Northeastern inner city,
2. a cross-sectional sample of over 1350 children from a random-digit-dial telephone survey conducted across the United States, and
3. a statewide cross-sectional representative sample of more than 4000 children from Arizona. Data on family needs were available from two smaller samples from Arizona: a "probability" sample selected from various Arizona communities and a "quota" sample.

We conducted secondary analyses of these data sets in order to:

1. examine the proportions of children identified by the components of the QuICCC disability definition, alone and together;
2. describe the policy implications of using-alternative functional definitions to identify children for research, benefits, services, and program participation by providing illustrations from the three samples.

In addition, we had originally intended to examine how service needs of children with disabilities and their families might vary depending on how the children are identified by using data collected from the Arizona sample for the purpose of guiding health policy on a statewide level. However, due to the way that the Arizona data were collected we were unable to do this in full and had to modify our objective to analyze how family service needs vary by how children are identified. (NB: This change was a direct result of the State's decision to assess needs on a family unit rather than child-specific level).

B. Significance of the Project

The lack of information on children with disabilities in the United States is well documented (McManus, et al., 1986), especially with regard to their proportion in the population, demographic and socioeconomic characteristics, service needs and use, federal program eligibility, and out-of- pocket expenses. In an era of rapidly changing health care systems, the need to plan services and benefits for these children has increased, and the demand for valid and reliable data on this special population has grown correspondingly.

Prevalence data and descriptive health information typically are derived from national epidemiologic data collected in one of the many large health morbidity surveys conducted by various arms of the federal government. However, with few exceptions, children are not specifically targeted in these surveys with the result that the amount and depth of health information gathered is generally limited. Furthermore, children with disabilities represent such a small minority of the population that they are under-represented in most national sample surveys, even those that specifically target children.

Inconsistencies in the way "disabilities" are defined have contributed to the difficulties in interpreting the data currently available (Newacheck & Taylor, 1992; Patrick, et al., 1981). The predominant method has been to use checklists of disease entities or symptoms to determine status. It is increasingly clear that a disease- or condition-specific method to identify and define children with disabilities is no longer consistent with public policy. Public policy today is characterized by a movement toward broadening the identification and eligibility criteria for children and by a conceptual shift toward an approach that applies noncategorical or generic criteria to define children by examining the consequences of diverse health conditions. Consequence-based definitions have more widespread application in services planning and in reimbursement and program eligibility determinations.

There is no one consequence-based definition. For example, some rely completely on physical criteria, while others include psychological, social, and educational criteria in their definition of disabling conditions. Some definitions are confined to specific impairments, while others are more inclusive. We need to understand the implications of using different definitional components or identifying criteria for children with disabilities. Once the ramifications of these definitional components are elucidated, definitions may be applied appropriately to make policy and funding decisions.

C. Background and Significance

The health of our nation's children continues to be a priority in the decade of the 90's. While mortality rates suggest a marked improvement in children's health during the 1980's, other health status indicators reflect that ever increasing numbers of youngsters are surviving with serious ongoing health conditions and disabilities and a multitude of special health care needs. An estimated 85% of children who are born with a disabling health condition will live to see their 20th birthday (National Center for Youth with Disabilities, 1991). These children continue to represent a challenge to our nation. Documentation of the long-term morbidity associated with disabling conditions in children, and improvement and prevention of these secondary consequences, are important parts of the new health initiatives for the year 2000.

The Healthy People 2000 objectives identify "significant reductions in preventable death and disability, enhanced quality of-life, and greatly reduced disparities in the health status of populations within our society", as a focus for the national health agenda (Public Health Service, OASH; 1990, p.1). Specific goals for children include reducing disabilities, impairments, and limitations in activities associated with chronic conditions, and increasing provider services and service systems for children with special health care needs (Public Health Service, HRSA, MCHB; 1991). Reliable baseline data on the number of children with disabilities, their functional abilities, and their service needs and utilization are a prerequisite for planning local, state, regional, and national programs to improve health status.

With the prospect of a major shift in the way health care is provided in the United States, monitoring service needs, access to care, and impact on the family of children with disabilities is another priority area for research and policy planning. But before the effect of the major national and state health care change can be evaluated for this special population, we must have a baseline against which any change can be measured. That baseline can only be furnished with current quality information on the epidemiology and characteristics of this population of children.

The available national level data are limited and generally unreliable (Health Resources and Services Administration, BHCDA, 1984; McManus et al., 1986; Select Panel on the Promotion of Child Health, 1981; Walker & Richmond, 1984). One of the major reasons for the limited knowledge about children with disabling conditions is that there never has been a survey focusing on this group of youngsters. Much of what is currently known about the epidemiology of disabilities in children in the United States is based on statistics derived from the 1981 and 1988 Child Health Supplements (CHS) -- a special health topic survey appended to the National Health Interview Survey (NHIS). Although the NHIS is one of the best examples of a large-scale, population-based morbidity survey, the available CHS databases depended on a disease-specific checklist method and identified relatively few children with disabilities (National Center for Health Statistics, 1989).

1. Issues of Definition

There are no precise figures on the prevalence of chronic health conditions and disabilities among children in the United States. Most experts believe that the number is somewhere between 10 and 15 percent, or between six and nine million children under the age of 18 years (Gortmaker & Sappenfield, 1984). Estimates have been reported to range from a low of four percent (National Center for Youth with Disabilities, 1991) to a high of over 30 percent (Jessop & Stein, 1995; Mattsson, 1972; Newacheck & Taylor, 1992) depending on the definition and methods used to collect the information (Newacheck & Taylor, 1992). For example, using the most recent data from the 1988 CHS, Newacheck and Taylor (1992) showed how the prevalence of childhood chronic health conditions varied within the same data set depending how it was defined. Overall, 31% of children were estimated to have a chronic condition as defined by a disease-specific checklist. If only children who had a chronic condition with some disability (defined as concomitant bother or activity limitation) were included, this number dropped precipitously to 9%. There were even fewer children (2% of the population) with chronic conditions that resulted in both frequent bother <u>and</u> limitation of activity.

There is such wide variation in severity (as measured by the range in activity limitations that can be associated with any particular disorder) even <u>within</u> the same condition that Newacheck and other leaders in the research field (Perrin, et al., 1993; Stein, et al., 1993) have suggested moving away from a disease-specific approach to defining disabilities. Other problems with diagnostic lists include: 1) the inability to cover every disorder children may have, 2) the inconsistent application of diagnoses across clinicians and settings, 3) that children who have better access to health care may be more likely to be labelled with a diagnosis, 4) that symptoms or consequences may emerge long before a diagnosis is made, and 5) that condition labels alone convey little information about the extent of morbidity for any individual (Perrin, et al., 1993; Stein, et al., 1993). Federal health policy and program rules for children with disabilities have mandated that eligibility criteria for some services and benefits be noncategorical rather than limit qualification to any particular disease category or list of conditions (Ireys & Nelson, 1992).

For example, in Sullivan v Zebley (88-1377 U.S. Supreme Court, 20, Feb 1990), the United States Supreme Court upheld that the Social Security Administration had inappropriately denied Supplemental Security Income (SSI) benefits to certain children with serious disabilities by using condition lists alone. They stated that this was not an adequate means for determining eligibility for the SSI program, and that the consequences of the chronic condition or disability on functioning would be a more equitable way to qualify for program participation and benefits (Parker, 1991; Perrin & Stein, 1991). This decision for the SSI program already has had major implications for other public programs.

2. Preliminary Work

In order to understand the foundation upon which this project was built, it is necessary to summarize some of the work already undertaken by this investigative team in two previously funded projects: the National Child Health Assessment Planning Project (NCHAPP) and the Data Project to Assist States, Children with Special Health Care Needs (CSHCN) Programs in Needs Assessment (State Data Project).

NCHAPP

NCRAPP, conceived of and directed by this investigative team, grew out of the recommendations from a 1987 meeting convened by the leadership of the Maternal and Child Health Bureau (MCHB) to assess the state of affairs with regard to information about children with disabilities. It was concluded that a population-based national morbidity survey was urgently needed to close the gaps in the existing data, and the participants recommended that comprehensive planning for such a project be undertaken promptly. These conclusions and recommendations were paralleled in the concurrent literature of the field (e.g. Hobbs, Perrin, & Ireys, 1985). In addition, there was a growing interest within MCHB, to identify children with disabilities in such a way that federal programs could actually use the definition to target eligible children for services and benefits. MCHB; strongly supported a noncategorical approach to defining the population that incorporated functional status, disability, and service utilization.

The overall purpose of NCHAPP was to develop and pilot an innovative national plan for obtaining these urgently needed data. The plan required three major steps which have each now been accomplished: (a) the development of an operational definition of children with disabilities that was not based on diagnostic labels, (b) the development and field testing of a screening instrument that could be used to identify this population, and (c) the development and pilot testing of a follow-up survey instrument for in-depth descriptive information on identified children.

Questionnaire for Identifying Children with Chronic Conditions (QuICCC). The theoretical framework we developed to define children with disabilities is independent of diagnostic label and etiology. It is based on a noncategorical approach that uses morbidity characteristics and consequences of health conditions with a 12 month expected or actual duration criterion. The consequences of a disability can be measured in a number of ways. we chose to measure three essential dimensions: 1) functional limitations, 2) dependence on compensatory devices or assistance, and 3) service use or need above and beyond routine care for age. We have conceptualized these dimensions as being the essential components to a comprehensive definition of disability in children that relies on consequence-based criteria, not diagnoses, and includes physical, cognitive, behavioral and psychological conditions. Specifically:

- Functional Limitations are conceptualized as 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.

- Compensatory Dependency or Accommodations are conceptualized as dependency on one of the following to compensate for or minimize limitation of function, activities, or social role: (1) medication, (2) special diet, (3) medical technology, (4) assistive device, or (5) personal assistance.

- Service Use Beyond Routine Care is conceptualized as use of or need for medical care or related services, psychologic services or educational services over and above the usual for the child's age, or use of or need for special ongoing treatments, interventions, or accommodations at home or in school.

Functional limitations and utilization of medical and other related services above and beyond what is customary typically are used in measures to identify and describe children with disabilities (Haley, et al., 1991). However, the concept of "compensated" function or accommodation is relatively new (Verbrugge, 1990) and has not before been applied to children (Stein, 1991). When abilities are maximized and symptoms are successfully reduced, many children who have disabilities are indistinguishable from healthy peers (e.g. the child with epilepsy who is seizure free with medication, or the child with phenylketonuria who can live a normal life as long as a special diet is maintained). But in order for successful compensation or accommodation to occur, other consequences are necessarily imposed on these children. These compensatory consequences can be measured (e.g. dependency on medication, special diet, equipment, personal assistance, or ongoing monitoring or treatment).

The three essential concepts in the definitional framework sketched briefly above were operationalized into measurable constructs by this investigative team and other advisers. The QuICCC underwent extensive pilot testing to evaluate prototypes both qualitatively and quantitatively. Additional validity and reliability studies are in press in Pediatrics (stein, et al.). Three levels of field testing were completed in: 1) a local hospital setting, 2) a local community, and 3) a sample of the national population. Testing in the local community and national population samples were accomplished in two separate random-digit-dial (RDD) household telephone surveys. The data collected in these surveys represent two of the data sets we used in the present analyses.

Bronx Inner-city RDD Survey. The first RDD was conducted in a local Northeastern inner-city community (the Bronx). The data were originally analyzed to compare rates of children identified by two conceptually different definitional approaches --- the consequence-based functional approach, of which the QuICCC is a prototype, and the diagnostic approach, of which the condition checklist used in the 1988 Child Health Supplement of the NHIS is a prototype. Therefore, to a large extent, we already have explored a comparison of two alternative definitions of children with disabling conditions (Westbrook, Bauman & Stein, 1994a). Results are summarized below.

Nineteen percent of 1265 inner-city children were identified as having a disability using the functional approach compared to 35% using the diagnostic approach. Fourteen percent of the total sample were identified by both approaches, 21% were identified by the diagnostic approach alone, and 5% were identified by the functional approach alone. Children recognized only by the diagnostic criteria tended to have more disabilities with diagnostic labels, but without functional consequences (e.g., asthma without medication or wheezing, epilepsy without seizures or medication) and had more acute, traumatic, or non-serious conditions (e.g., tonsillitis, hay fever). Children recognized only by the consequences tended to have more disabilities with functional consequences, but without diagnostic labels (e.g., infant who needed to drink special growth formula and took growth hormone, gastrointestinal test results pending on a child who can only eat liquids or soft foods), or conditions that were not included on the diagnostic list (Stein, Westbrook and Bauman, in press).

From these findings it was concluded that the QuICCC appears to respond to criticisms of the disease-specific approach to identifying children with disabilities by shifting the focus from children who carry a diagnostic label to children who have current and significant functional consequences. The critical conceptual difference between the two definitional approaches is epitomized by the illness characteristics of the children who were identified only with one of the approaches.

National RDD Survey. The second RDD survey was a random sample from the national population. The data were ultimately intended to be used as a comparison with the NHIS Disability Supplement to determine how the rates of children with disabilities identified by the NHIS definition might vary with that found using only the QuICCC in a different national sample. We used the national RDD data to compare proportions of children identified in the largely white and middle- class national sample to the largely minority and poor inner-city sample.

In our previous RDD data analysis, we found that despite significant differences in ethnic and sociodemographic composition between the databases, comparable proportions of children in the Bronx inner-city and National samples were defined as having a disability using QuICCC criteria (Westbrook, Bauman & Stein, 1994b). Overall, 19% of Bronx children and 18% of children nationally were identified. We concluded that the results of our analysis support the opinion that variations reported in prevalence rates between minority and non-minority, and between poor and non-poor children may have more to do with the method by which disabilities are defined than true ethnic and sociodemographic differences in rates of occurrence.

Participation in the NHIS Disability Supplement. In 1990, along with three other proposed disability surveys, the QuICCC and a Child Health Survey developed by the NCHAPP project were selected to be incorporated into the Children's Section of the 1994 and 1995 Disability Supplement to the ongoing NHIS. Since that time, we have actively collaborated in every phase of the development and revision of the Children's Section of the Disability Supplement (both Phase I: to identify the children, and Phase II: to provide in-depth descriptive data about them and their families).

The NHIS Disability Supplement promises to remedy the dearth of information by providing quality in-depth data on a large sample of children using state-of-the-art functional and diagnostic criteria. It should prove to be the best source yet available of general population-based epidemiologic data on children who have disabling conditions --- with both the largest sample size and the most detailed descriptive information. Over a two year period, about 60,000 children have been surveyed. The first wave of Phase I data available for analyses by the public have recently been released. The analyses done in this study have laid important groundwork for later analyses of the children's section of the NHIS Disability Supplement.

State Data Project

The Omnibus Budget Reconciliation Act 1989 amendments directly mandate that state CSHCN programs funded under Title V of the Social Security Act must broaden service requirements of state CSHCN programs beyond diagnostic categories so that eligibility of children is based on a noncategorical framework (Hutchins & McPherson, 1991). As a result, state MCH Services Block Grants to CSHCN Programs now require as part of their minimum data reporting requirements that Needs Assessments be made of the populations served by these programs. The deficit of state level information on children with special health care needs is even more extensive than that at the national level (Peoples-Sheps, et al., 1986). While some states are better equipped than others to carry out this level of data collection (Ireys & Eichler, 1988a,b; Walker & Richmond, 1984), many simply do not have the resources or expertise to develop and implement such Needs Assessments.

In 1993 we received a new grant award entitled "Data Project to Assist States' CSHCN Programs in Needs Assessment" to develop analytic models and instruments that could be used to assist several selected state MCH and CSHCN agencies in providing state level data on the populations they serve. The QuICCC and Child Health Survey developed during the NCHAPP project could be modified to meet some of the individual needs of the states as a Needs Assessment Tool (NAT). The tools are consistent with the direction promoted by national MCHB objectives for the states which prescribes that a broadly categorized population of children should be served by service systems that take a generic rather than disease-specific approach to providing health care, and encourages a shift away from the current provider-based data collection system (which only identifies children already in the service system) to a people-oriented data collection system (which could identify children in the general population).

With our assistance, the CSHCN office in the state of Arizona developed a NAT to assess the service and system needs of children with disabilities in their state. The final instrument incorporated the entire QuICCC into a parent survey that was administered in a statewide Needs Assessment Survey. Also included in the Arizona survey were items that examined in detail the unmet service needs of children and their families, (Family Needs Survey) as well as an inventory of current service use. our work with the state of Arizona presents a unique opportunity to illustrate the effects of using different consequence-based definitions, because their data are being collected specifically to provide information for Arizona's health policy and program planning decisions in the near future. In the course of our collaboration, CSHCN leaders in Arizona expressed a desire for our continued assistance in providing a theoretical framework and analytic guidance for these data.

D. Specific Questions Investigated

The current project was developed to enhance overall knowledge about children with disabilities by illustrating the implications of using any one of three different components of a consequence-based definition as well as the definition as a whole to identify children with disability. The primary focus of this investigation has been on A) Definitions and Measurement. From the perspective of alternative definitions, we also addressed issues in the areas of B) Demographic and Socioeconomic Characteristics, C) Service Use, Expenditures, and Effectiveness, and D) Private Costs of Care. Following are the specific questions that have been examined in this project.

1. Definitions and Measurement

1. What proportions of children are identified as disabled using three different components of a consequence-based definition: functional limitations, compensatory dependency, service use beyond routine? How do these proportions compare with estimates based on the whole screen?

2. Are children with different diagnoses and conditions identified by the different components of the disability definition?

3. Are the proportions of children who are
    a. currently receiving SSI,
    b. applied for SSI but been denied for medical reasons, or
    c. applied for SSI but been denied for financial reasons, different within the different components of the disability definition?

2. Demographic and Socioeconomic Characteristics

1. Do children identified by the different components of the disability definition differ in age/developmental stage?

2. Do children identified by the different components of the disability definition differ in socioeconomic status and racial/ethnic group?

3. Do children identified by the different components of the disability definition differ in the psychological impact on the child and the family?

4. Does the impact of the disability on the child and family differ by socioeconomic status or ethnic group?

3. Service Use, Expenditures, and Effectiveness

1. How do service need and use vary by disability (as defined using the different components of the definition), and by characteristics such as age/developmental stage, socioeconomic status, ethnic group, family structure, and insurance coverage?

4. Private Costs of Care

1. How do out-of-pocket costs for <u>medical care</u> and <u>other non-medical expenses</u> vary by disability (as defined using the different components of the disability definition), by receipt of SSI, and by characteristics such as age/developmental stage, socioeconomic status, ethnic group, family structure, and insurance coverage?

II. METHODOLOGY AND DESIGN

A. Data Sources

This project was implemented through secondary analyses of three data sets. Each data set was used to address one or more specific study questions.

1. Samples

Bronx Inner-city Sample. Eligible respondents were English- and Spanish-speaking primary caretakers of children from birth to 18 years old living in the Bronx, New York. Since the data collection for this survey was done through telephone interviews using a random-digit-dial (RDD) procedure, households without telephones were not included in the sample. Households were randomly drawn from a list of phone numbers of residential blocks in the Bronx. A total of 3092 households were contacted. Of these about 10% refused to participate or terminated the interview at some point. Of the remaining 2781, 662 or 25% had children under 18 years of age. We are analyzing data on a total of 1265 children who lived in these 662 households.

The Bronx inner-City RDD survey was dote in two parts. In the first part, the respondent was asked to list all children under 18 living in the household and the QuICCC was administered. QuICCC information was collected on each child in the household. Data on demographic characteristics of the respondent and children also were collected in this section as well as information on the medical condition list from the 1988 Child Health Supplement of the NHIS.

The second part was an in-depth survey conducted on a smaller sample of about 200 children from separate households who were identified as having a disability according to the QuICCC criteria and a comparison group of about 200 children randomly selected from households in which no child had a disability.

National Sample. This study replicated much of the survey content and design of the Bronx study described above on a national sample. Any household with children under the age of I8 with a telephone was eligible to be in the sample. A multi-stage sampling design was used. First, the distribution of households with children by region of the country (New England, Middle Atlantic, East North Central, South Atlantic, East South Central, West South Central, Mountain and Pacific) was calculated using the 1990 Census Population and Housing Summary. The sample was chosen to represent these same proportions. In the next stage, a sample of assigned telephone banks was randomly selected from an enumeration of the Working Residential Hundred Blocks (a block of 100 potential telephone numbers within an exchange that includes 3 or more residential listings). Finally, for each Working Residential Hundreds block chosen, a telephone number was randomly generated to be part of the sample. Since we did not know how many households would need to be contacted in order to achieve the target of 200 children with an ongoing health condition, the sample was drawn in replications of 400 numbers each. All chosen numbers were dialed up to four times before a substitute number was used.

A total of 7998 numbers were dialed. 3639 (69%) of the numbers were households that were successfully contacted and agreed to participate in the survey. Of the participating households 2909 (80%) did not have children under the age of l8, leaving a final sample size of 730 households. Complete data were collected on 712 households representing 1388 children. As with the Bronx RDD, the second part of the survey was completed with selected samples of about 200 children with disabilities and 200 children from households in which no child had a disability. The national data set had sociodemographic information on all households who had a disabled child, but only on a sample of about half the households who did not have a disabled child. We have no reason to believe that those who provided data differed substantially from those who did not, so have based our analysis and discussion on available information.

Arizona Child Health Screen and Family Needs Survey. In 1994, the Arizona Department of Health Services Office for Children with Special Health Care Needs (OCSHCN) conducted a two- part Needs Assessment Survey (NAS) that has provided another important source of data on children with disabilities for this project. Data collection across selected Arizona communities was conducted by the Arizona OCSHCN, with eligible subjects aged 0 to 21 years identified by either of two methods: (1) probability sampling using a two-stage cluster approach or (2) quota sampling among families identified through service providers, family forums, and other community sources. Only one child per household was assessed in these surveys. Although we expected the NAS data would also be gathered from a mostly Native American community in Northern Arizona, data from that sample were not yet available at the time of these analyses. The probability sample yielded data on 255 children in the 0-18 age range. The quota sample had 100 children in the same age group.

In 1995, additional data were gathered from a statewide random sample that included 5160 children ages 0 to 21 years. These were household surveys in which QuICCC data were collected on each individual child. Following the QuICCC, the focus of the survey switched from child-level to household-level questions. Some questions that followed specifically related to needs of households that had children with health conditions, while questions in a subsequent section referred to possible needs of all households with children. We used this dataset for most of the comparative analyses. To be able to compare results to the other RDD samples, we restricted analyses to data on 4831 children under 18 yrs old.

Table 1 shows the sociodemographic characteristics of children in three samples. As anticipated, they were similar in their age distributions but varied in other sociodemographic characteristics. The Bronx sample was primarily nonwhite (85%); the other two samples were about three-quarters white. Respondent educational attainment and household income also were lower in the Bronx than in the other two samples.

2. Measures

Questionnaire for Identifying Children with Chronic Conditions (QuICCC). Children with disabilities were identified using the QUICCC. The respondent is a parent, caregiver, or other adult person who lives in the household and who is the most knowledgeable about the health of the children. Questions generally are structured in four parts, where answer categories are "Yes", "No" or "Don't Know". Each part is asked contingent on whether the preceding part is answered ‘yes’, as illustrated in the following example:

Sample Question:

1. a. Do any of the children [in the household] take medicine or drugs prescribed by a doctor other than regular vitamins?
    1 ( ) Yes
    2 ( ) No (Skip to next question)
    3 ( ) Don’t Know (Skip to next question)

   b. Is this because of a medical, behavioral, or other health condition that the child still has?
    1 ( ) Yes
    2 ( ) No (Skip to next question)
    3 ( ) Don’t Know (Skip to next question)

   c. Has this condition been going on or is it expected to go on for at least one year?
    1 ( ) Yes
    2 ( ) No (Skip to next question)
    3 ( ) Don’t Know (Skip to next question)

Any child is considered to have a disability if any one item from the screen is answered "yes" in all parts. However the entire QuICCC is administered, regardless of the number of items endorsed.

For validation purposes all three surveys employing the QuICCC included a probe administered after each QuICCC item that sought the name or a description of the condition responsible for a "yes" response. Reliability after a two week test-retest was .73 using Cohen's Kappa (p<.001). Content, construct, convergent and criterion-related validity also have been established and are described in Stein et al. (Pediatrics, in press).

Impact on Child and Family. Information on the impact of disability on the child and caretaker was collected in the in-depth survey part of the Bronx inner-city and National RDD surveys.

Children's overall adjustment was measured with the 28-item Personal Adjustment and Role Skills Scale III (PARS III) (Stein & Jessop, 1990; Walker, Stein, Perrin, & Jessop, 1990). The PARS III is appropriate for use with minority populations, and it is suitable for children who have a chronic condition or disability in that it does not include somatic items that might inflate an ill child's maladjustment score (Walker et al., 1990).

The PARS III contains six subscales (Dependency, Hostility, Withdrawal, Anxiety-Depression, Productivity, and Peer Relations) and also produces a Total score. The parent rates the frequency of each behavior as "always or almost always," "often," "sometimes," or "never or rarely." Higher PARS III scores indicate better adjustment. Internal consistency coefficients range from .7 to .8 for the subscales and are >.88 for the Total score.

Caretaker adjustment was measured using the Psychiatric Symptom Index (Ilfeld, 1976), a 29-item checklist with good psychometric properties. The PSI was developed on a community sample of 2299 men and women. The internal consistency reliability estimate for the PSI Total score is .91, and its concurrent validity with other criteria indicating emotional distress has been well-established (Ilfeld, 1976). The PSI measures intensity of 29 common symptoms, comprising four dimensions of psychological distress: depression, anxiety, anger, and cognitive disturbance. Respondents are asked to estimate the frequency of each symptom over the past two weeks as "very often," "fairly often," “once in a while,” or "never." Although the PSI is not intended to define psychiatric diagnoses or "caseness," Total scores of 20 or greater are considered to indicate "high" symptoms (Ilfeld, 1976) and Bauman (1994) has shown that scores above 30 are indicative of a high likelihood of diagnosis of major depression an a structured psychiatric interview, the Diagnostic Interview Schedule (Robins et al., 1981)

Family Needs Survey. In the Arizona interviews, family needs were measured by items adapted from the Family Needs Survey (Bailey & Simeonsson, 1985). This scale was developed at the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill in collaboration with Carl J. Dunst, who published a slightly modified later version called the Family Needs Scale (Dunst, Trivette & Deal, 1988). Although psychometric properties for the early version have not been reported, the Family Needs Scale is a widely used tool.

The Family Needs Survey items in the version administered to the Quota and Probability samples from Arizona were used to provide data regarding expressed family needs in a number of specified domains: need for a) information about the condition and health-related services (8 items); b) access to formal and informal support (5 items); c) help in explaining the condition (3 items); d) community services (6 items); e) financial assistance (6 items); f) help with family functioning (6 items); and g) any other identified areas of need (4 items). The survey also asked parents to identify the family's greatest needs at this time.

The Family Needs questions contained in the Arizona Statewide survey were similar and were asked in two sections. Thirteen questions in the first set were specific to needs of parents of children with health conditions, and thus were asked only of respondents in households with at least one identified child. Twenty-five additional questions in the second set referred to possible needs of all parents and were asked of all respondents.

Additional Questions. The version of the Arizona interview used with the Quota and Probability samples obtained information by parent report about the amounts of out-of-pocket monies spent on medical care and other non-medical expenses related to the child with a disability. Questions on the survey also gathered information about health insurance. All of the data sets (Bronx, National, Arizona) had information on selected sociodemographic variables reflecting characteristics of the child, respondent (primary caretaker), and household.

B. Statistical Techniques and Analytic Approaches

To address the study questions we first identified the set of QuICCC items that measured each component of the definition. An affirmative response to any item within a set defined disability for that component.

- Limitation in functioning: measured by items that included being unable to play with other children, being restricted in activities, having difficulty feeding, dressing him/herself, washing, or toileting, and having difficulty hearing, seeing, or communicating. To insure that the activities asked about are age appropriate, there are age or school status restrictions on some of the questions.

- Compensatory dependency: measured by questions on medication use, special diet, and use of special equipment or personal assistance.

- Service use beyond expectation: consists of indicators of hospitalization, doctor visits, nursing care or treatment, physical or speech therapy, psychological services, and need for special arrangements at school (e.g., classroom or schedule modifications, special instruction or services). These items reflect current service use as well as expressed needs for services that are not being met at present.

In the analyses, we divided the samples into subgroups defined by the QuICCC definition of disability and its three components and described the groups in terms of medical, type of condition, sociodemographic and service variables such as age/developmental stage, socioeconomic status, race/ethnic group, family needs, private costs of care, and type of insurance. All sociodemographic outcome variables used were categorical in nature and we collapsed age into groups representing four developmental stages. Thus, we calculated and displayed summary statistics for the identified groups using percentages, and we examined bivariate relationships between disability and the specified dependent variables by cross-tabulation with Chi-square tests used to test for statistical significance.

Analyses of variance (ANOVAs) with post-hoc Student-Newman-Keuls (SNK) tests were used to compare mean values of all continuous variables (e.g., psychological impact, family needs, cost estimates) by disability. For example, information about the child's adjustment (PARS III) and on the caretaker's adjustment (PSI) was available in the subsets of the Bronx and National samples who completed the in-depth surveys. Using each dataset, we calculated and compared mean scores on these two measures for groups of children identified by the disability components and for their caretakers. in the Arizona Probability and Quota samples, we also used ANOVA to compare mean scores for parents' estimates of out-of-pocket expenses and numbers of reported family needs in several domains by number and type of definition component.

We used two-way ANOVAs to compare mean PARS and PSI scores by disability category and by (1) socioeconomic status or (2) ethnic group. We examined the interaction terms in these analyses to determine if disability (defined by the components of the definition) had a different association with impact within some socioeconomic or ethnic groups. Because the sample sizes in some subgroupings were too small for reliable analyses, we were unable to complete certain proposed analyses.

III. RESULTS

The following is a summary of the specific questions we addressed and the results of these analyses.

Question 1. What proportions of children are identified an disabled using three different components of a noncategorical definition of disability based on consequences: functional limitations, compensatory dependency, and service use beyond routine? How do these proportions compare with estimates based on the whole screen?

Table 2 provides information on percentages of children experiencing each number and type of disability consequence, alone and in all possible combinations of components. These data are given separately for each of the three study groups: the Bronx inner-city sample, the National sample, and the Arizona statewide sample. The data in Table 2 are expressed as percentages of the total number of children in each sample and then as the percentage of "disabled" children in each sample, i.e., as a percentage of children identified by at least one component of the QuICCC definition.

The main findings are summarized as follows:

A. Table 2 shows that the overall percentages of children identified as disabled as well as the percentages of children identified by one, two, or all three components were quite similar across the three study samples, despite their very distinct sociodemographic makeups. In addition, the three definitional components, taken alone and in all possible combinations, identified generally similar proportions of children within each of the three different samples. The highest percentage of identified children was in the Bronx; the lowest was found in the Arizona sample. The small difference between samples seemed related, in most part, to differences in percentages of children with functional limitations. This is elaborated below.

B. Table 2 shows that more children were identified as disabled by the service use component than by either functional limitations or compensatory dependency. In addition, approximately half of the disabled children in each sample were identified by a single type of consequence or one component alone. Of note, among children identified by only one component, there were substantial fractions identified by each of the three components alone. Just about one-third were identified by two components across samples, and it was least likely for disabled children to meet criteria for all three types of definitional components.

Nevertheless, some minor differences seemed to emerge when we looked at the composition of the disabled population across samples. In the Bronx sample, disabled children were identified by one component slightly more often than in either the National or Arizona samples, and they were the least likely to be identified by all three components. In particular, disabled children in the Bronx sample were identified more often by functional limitations alone than children in the National or Arizona statewide survey samples, where slightly greater percentages of children with disability were identified by compensatory dependency alone. The Arizona sample also had the greatest percentage of disabled children who experienced consequences in all three definitional components.

Question 2. Are children with different diagnoses and conditions identified by the three definitional components? Now do these proportions compare with estimates based on the whole QuICCC?

We examined whether children identified by different components of the definition had different diagnoses or conditions. This information was obtained from a probe administered after each QuICCC item that asked respondents to name the condition that caused the particular behavior or problem for the child. In some cases we were unable to get specific information because respondents gave descriptions rather than "diagnoses" or said they simply did not know or could not remember the name of the health condition. This underscores one of the advantages of the QuICCC as a tool: children can be identified independent of the respondent's ability to name the condition.

Because there were no apparent differences in the types of conditions in the National, Bronx inner- city, or Arizona statewide samples, we combined the data sets for this discussion. Children who were identified <u>only</u> by functional limitations had conditions such as hearing impairments and deafness, visual impairments and blindness, diabetes, asthma, and epilepsy. In the Arizona statewide sample, some children meeting criteria for this component also had orthopedic conditions or spinal injuries. Children identified <u>only</u> by service use or need beyond routine care had conditions such as behavioral, cognitive, and emotional disorders, multiple sclerosis, sickle cell anemia, asthma, and epilepsy. Children identified <u>only</u> by reliance on compensatory mechanisms had conditions that included heart conditions, high cholesterol, hypertension, sickle cell anemia, asthma, and epilepsy.

There was considerable overlap in the types of conditions found for children identified by the three components of the QuICCC definition of disability. Children with severe conditions were included in each of them. For example, children with asthma and children with epilepsy were reported to have a wide range of different consequences for the same condition. Some children were restricted in their activities or had difficulty performing tasks of daily living. Others were hospitalized, had nursing care or received or needed special school services. And still other children with the same condition were able to compensate and did not experience functional limitations or increased use or need of services, but did require medication, special diets, or assistance devices.

Children identified by all three components of our definition of disability tended to have more pervasive conditions such as Down syndrome and other forms of mental retardation or developmental delay, cerebral palsy, autism, deafness, spina bifida, and a variety of congenital defects. These children also had learning disorders, attention deficit disorder and hyperactivity, or multiple health conditions, most often asthma in combination with some other physical condition.

Question 3. Do the proportions of children who are either currently receiving SSI or applied for SSI but been denied differ within the three definitional components? Now do these proportions compare with estimates based an the whole screen?

Table 3 shows the percentages of children identified as disabled in each of the three samples who currently receive SSI benefits distributed according to the number and types of definition components met. That is, in Table 3, we provided data on the number of children who qualified in each component or set of components and the percentage within that group who were reported to be receiving SSI benefits. Table 3 also includes data from the Arizona "Quota" sample (see Methods for further description).

The percentage of identified children receiving SSI was higher in the Bronx inner-city sample than in either the National or Arizona statewide samples (9% vs 4% and 3%, respectively). This was not an unexpected finding since eligibility for SSI benefits is based on financial requirements as well as on disability. In all of the samples, children identified by all three components were significantly more likely to receive SSI than children identified by one or two components. However, in the Bronx inner-city sample, differences in SSI among children identified as disabled by one, two, and three components appeared to be less substantial than in the other groups, primarily because of the comparatively high rates of SSI in Bronx children identified by only one or two components. Whether this reflects differences in poverty status or in the application of SSI criteria is beyond the scope of the data. Nearly one quarter of the children in the Arizona Quota sample received SSI. This was the highest proportion of all the samples, and was not unexpected because the Quota sample consisted primarily of children who were already known to be receiving services for health conditions and disabilities, while the other samples were all population-based.

For exploratory purposes, we also examined the percentages of identified children who had ever applied for and were denied SSI. (These data are not included in Table 3). The Arizona “Quota” sample also had the highest proportion of children who had applied for and were denied SSI (13%), followed by the Bronx (8%), Arizona statewide (5%), and National samples (2%).

We also found that, except for four children in the Bronx sample and one in the National sample who were identified by the service use component only, all of the identified children in the three study samples who received SSI had functional limitations (either alone or in combination with another component). This is consistent with the criteria for determining disability in children as described in Sullivan v Zebley. Conversely, no child in any of these three samples who was identified only by the compensatory dependency component received SSI benefits. We believe this may reflect current regulations that specify that when the disability is fully compensated, an individual does not qualify for SSI assistance.

Question 4. Do children identified by the three definitional components differ in age/developmental stage?

A. Table 4 shows the proportions of children in each of four age groups (0-3, 4-6, 7-11, 12-17) by number and type of definitional component. These age groupings were selected because they reflect the organization of many types of services and therefore are policy-relevant. Looking across samples, one sees that 0-3 year olds appear to be under-represented in the identified population; that is, there are fewer 0-3 year olds in the disabled groups relative to the representation of their age group among the non-identified children in each of the samples. Generally, at least for the National and Arizona statewide samples, children identified as disabled tended to be from the two oldest groups, suggesting that children may be more likely to be identified as disabled by the QuICCC criteria the older they get. In the Bronx sample, the pattern for children over three years was slightly different. There were slightly more 4-6 year olds and 7-11 year olds among the identified children than would be expected based on the age distribution of the non-identified children, and the proportions of 12-17 year olds were the same among identified and non-identified children.

B. The smaller than expected percentages of 0-3 year olds were most likely to be found among children identified by functional limitations. This observation seemed to hold up across samples, and suggests that a certain proportion of 0-3 year olds who are disabled might be missed if functional limitations were the only criteria used to identify children with disability. Nevertheless, the age distribution among disabled children with and without functional limitations differed significantly only in the Arizona sample ($P<.05$), where the age distribution seemed to be shifted more toward adolescents. Although slightly more young children (0-3 years old) than expected were included in the groups identified by compensatory dependency across the samples, these differences were not significant. In addition, there were no statistically significant differences in age by number of definitional components used to identify children with disabilities in any of the three samples we examined.

Question 5. Do children identified by the three definitional components differ in race/ethnicity or socioeconomic status (as measured by household income level and education of respondent)?

A. Race/Ethnicity (Table 5)

A. The Bronx inner-city sample had a racial breakdown of about 85% nonwhite to 15% white, while the National and Arizona statewide samples had many more white than nonwhite children (76% vs 24% and 72% vs 28%, respectively). In the Bronx sample, race/ethnicity was not related to meeting the QuICCC criteria for disability: there were almost exactly the same proportions of whites and nonwhites in the groups identified as disabled and not disabled. In the National sample, however, somewhat fewer white children and more nonwhite children were identified as disabled compared with their proportions in the sample (p<.02). Conversely, there were slightly more whites and slightly fewer nonwhites identified as disabled than expected by their representation in the Arizona sample (p<.02).

B. Race/ethnicity distributions across the samples by type and number of definitional components could be compared only in a preliminary way. Although these distributions sometimes appeared to differ within samples, the numbers in most subgroups typically were too small to conclude that these represented reliable or stable patterns and therefore could not allow much in the way of their interpretation.

For example, there were slightly more white children among those meeting criteria for compensatory dependency in the National and Arizona samples; this was a significant difference in the Arizona sample (p<.001), and it also approached significance in the National sample (p=.10), but was not found in the Bronx. There also were significant differences in race/ethnicity by number of components in all groups. There were more white children among those identified by all three components in the National samples (p<.01), and more whites among those identified by two or more components in the Arizona statewide sample (p<.01). In the Bronx sample, however, there was a different and somewhat irregular pattern, with more nonwhites among children identified by two components vs only one or all three (p<.05).

B. Socioeconomic Status (Table 6)

A. As expected, the Bronx inner-city sample had proportionately more low income families (reported as below $15,000/year) than were found the other two samples. Compared with their expected distribution based on comparison with the non disabled children, there were proportionately more children from the poorest families (<$15,000) among those identified as disabled in both the Bronx (p<.05) and National samples (p<.001). This suggests that poverty may be a risk factor for disability in children. However, **there was much missing data on this question** and this fact needs to be taken into consideration while interpreting the results. In addition, disabled children in the Arizona sample were somewhat over-represented on <u>both</u> ends of the income distribution (p=.07); that is, there were more children than expected in the lowest (<$15,000) <u>and</u> in the highest (>$45,000) family income categories.

B. Within the disabled population, the relationship of different components to income bracket varied from sample to sample. Again, patterns were difficult to discern or interpret in a meaningful way due to the very small subgroups.

For example, in the Bronx, there was a significant relationship between income and number of components (p<.05), such that children identified by all three components were more likely to be from families at the lowest income level (<$15,000). In the National and Arizona samples, family income was not significantly associated with number of components, but appeared to differ significantly by the type of consequences experienced. Specifically, among children identified by functional limitations, there were fewer children than expected from the highest income group (>$45,000) in both the National (p<.05) and Arizona samples (p<.001). The Arizona sample also had more children than expected from the two highest income groups ($30,000-45,000 and >$45,000) among children identified by compensatory dependency (p<.01).

C. Respondent Education Level (Table 7)

A. Parents reported less education in the Bronx compared with the other two samples. In the Bronx, nearly one-third of respondents had less than a high school education, but in the National and Arizona samples, they were more likely to be at least high school graduates and nearly half of the parents who responded said they had gone beyond that. Comparing the children identified as disabled to the non-disabled groups within each sample, we found that their distributions were fairly consistent with regard to education level of the respondent. Although there were slightly more children from families with a parent who went beyond high school in the disabled groups across samples, this difference was significant only in the Arizona sample (p<.001). It is unclear whether this represents a real difference or an increase in the report of health related difficulties by parents with higher educational attainment.

B. When we looked at disability by number and type of components, the patterns that emerged for education essentially paralleled those already reported for household income. Generally, the National and Arizona samples were consistent with each other. There were more children from highest education group (>HS) among those identified by compensatory dependency in the National (p<.05) and Arizona samples (p<.01), and fewer than expected from the same group (>HS) among the children identified by functional limitations in both samples as well (p<.01). In the Bronx sample, which is clearly a different population overall in terms of education, no statistically significant relationship with number or type of definition component was detected; however, the pattern of higher parental education being related to compensatory dependency that was found in the other samples still emerged (p<.07).

Question 6. Do children identified by the three different definitional components vary in the impact on the child and the family?

Data by which to evaluate the impact of disability on the child's adjustment and parent's adjustment were available for subsets of both the Bronx inner-city and National samples. one of the goals of the larger study that provided these data sets was to collect in-depth information on the health status and adjustment of approximately 200 children from separate households who were identified as having a health condition based on the responses to the inventory and an 200 healthy children randomly selected from households where no child had a condition. Data also were collected on the physical and mental health of the adult respondents in these selected households.

In the in-depth interview, information about caretakers' psychological distress was assessed by the Psychiatric Symptom Index (PSI; Ilfeld, 1976). The Bronx inner-city sample yielded adjustment data from 417 adult respondents. of these, 88% (n=366) were biological parents, 3% (n=14) were stepparents, adoptive parents, or foster parents, and 9% (n=37) were grandparents or other relatives; 92% of caretakers were female. In the National data set, the subsample included a total of 398 parents whose data were used in the present analyses. These were primarily biological parents (95%), with only small percentages of stepparents, adoptive parents, or foster parents; 83% of the parents were female.

Psychological effects an children were assessed by the Personal Adjustment and Role Skills Scale (PARS III.) (Walker, et al., 1990; Stein, et al., 1990). The PARS III was analyzed only for children in the in-depth subsamples who were 5-12 years old, inclusive. For the purpose of these analyses, we also excluded any child who was identified as disabled based only on a mental or emotional condition because we wanted to assess the mental health correlates of physical health conditions. The sample sizes for these analyses were 164 children in the Bronx inner-city sample and 168 in the National sample.

D. Impact on Caretakers

Caretakers were classified into groups according to the consequences of disability experienced by their children. Comparisons of mean PSI Total scores among the groups were made first using one-way ANOVA. Caretakers of non-disabled children were included in these analyses. Table 8 shows that the overall difference in parents' self-reported psychological distress based on the types of consequences experienced by their children was significant in both samples, p<.01. Distress, as indicated by higher mean PSI Total scores, appeared to be greatest in those subgroups of caretakers whose children had functional limitations. This seemed true whether the child's health condition was defined by a single domain of consequences or by multiple domains. However, the very small within-group sample sizes made it quite difficult to compare subgroups and achieve paired differences that were statistically significant in order to determine more specifically how consequences related to distress. Therefore, we also examined the impact of each component on PSI scores using-three-way ANOVAs, with presence or absence of each component used as the independent variables. Again, the analyses also included caretakers of nondisabled children. These analyses, conducted separately for the two samples, demonstrated main effects only for presence of functional limitations in each sample (p<.01). There were no statistically significant main effects for compensatory mechanisms or service use, and no two-way or three-way interaction effects were found in either sample. However, in the Bronx sample only, the main effects for service use approached significance (p=.10).

Next, we limited the three-way ANOVAs of PSI by component to the caretakers of children identified as disabled by the QuICCC. In these analyses, slightly different patterns in caretaker distress by type of consequences emerged in the two samples. In analyzing the Bronx data set, we found that caretaker PSI scores did **not** differ significantly by type of consequence. Thus, the significant effects reported above were primarily the result of higher scores in caretakers of children with any type of disability compared with those caretakers whose children were not identified as disabled. However, in the National sample differences in caretaker PSI score by type of consequence remained significant when we restricted the analyses to parents of children identified by the QuICCC; again, functional limitations had a main effect on caretaker distress (p<.01). That is, significant differences were found between caretakers of disabled children with and without functional limitations. However, in this sample we also noted that the mean PSI scores found for caretakers of disabled children without functional limitations did not differ significantly from scores found for caretakers of healthy children. Number of components was not related to caretaker distress in either the Bronx or National sample.

The difference in these two samples is intriguing and further study is needed to determine what accounts for these differences in level of parental distress.

E. Impact on Children

Comparisons of mean PARS III Total scores by component were made using oneway ANOVA. Children with and without disabilities were included. Scores for the subgroups in the Bronx and National samples are shown in Table 9. For both samples, the overall F-statistic was significant, indicating that there was a significant relationship between children's adjustment and disability. As with the caretaker analyses, adjustment seemed to be poorer (lower PARS scores) in those subgroups of children who had functional limitations, and the three-way ANOVAs of PARS III score by component showed a main effect for functional limitations (p<.01) in both samples. Main effects for compensatory dependency were found only in the Bronx data set (p<.05). Interestingly, however, the relationship of compensatory dependency to child adjustment seemed "reversed" in the Bronx sample in that children with compensatory dependency had better adjustment than other children. There were no significant main effects for service use, and no two-way or three-way interaction effects were found in either sample.

Next, three-way comparisons of PARS III scores by types of consequence were conducted only among identified children. These ANOVAs continued to yield main effects for functional limitations in both samples (p<.01). That is, identified children with functional limitations had poorer adjustment than identified children without functional limitations. Service use had a borderline effect in these analyses in the National sample only (p=.07); identified children with service use above routine had poorer adjustment than other disabled children. Service use had no significant effect in the Bronx data set. Among identified children only, the relationship of compensatory dependency to child adjustment was again "reversed" in the Bronx sample, although this relationship only approached significance (p=.10). Children with compensatory dependency tended to have better adjustment than other disabled children. In contrast, compensatory dependency was not related to adjustment among identified children in the National sample. PARS III scores decreased (adjustment was worse) as the number of components increased in both samples; however, the only significant difference found was between children meeting all three components and those meeting one or two components in the National sample (P<.05).

Question 7. Does the impact of the disability on the child and family differ by socioeconomic status or race/ethnic group?

We examined whether the relationships of child and caretaker mental health to the disability definition and its components varied by socioeconomic status as measured by household income or by racial/ethnic background. We divided households in each of the Bronx and National samples into two groups based on annual family income: 1) under $30,000 and 2) $30,000 and above. We first examined caretaker PSI scores and children's PARS III scores in each sample (Bronx and National) using two-way ANOVA and looked for interactions of disability with household income in the entire subsample (i.e., everyone with in-depth data). Next, we looked for interactions of income with each disability component only among the identified children and their caretakers in each sample to see if the effects of different components varied by socioeconomic status. Equivalent analyses then were conducted by disability and by white vs nonwhite race/ethnic group within each sample. Unfortunately, the small size of subgroups prevented us from examining effects of both income and race/ethnicity simultaneously.

No statistically significant interactions of disability with race/ethnicity were found for caretaker PSI scores in either the Bronx or National samples. This suggests that presence of disability has a main effect on caretaker PSI score that is independent of racial/ethnic background. in addition, we continued to find a relationship of functional limitations to parent distress that we previously reported for the National sample only. This effect occurred in both white and nonwhite racial groups, although the borderline significance of this interaction term (p=.08) and pattern of means suggested that the impact of functional limitations on caretaker mental health may be greater in nonwhite respondents in this sample. In conducting these analyses among caretakers of identified children only, the interaction term was not significant, although the pattern of means still suggested greater impact on adjustment for nonwhite caretakers. We were unable to determine whether this is related to their relatively poorer socioeconomic status.

In contrast, socioeconomic status appeared to affect the relationship of disability to caretaker distress only in the Bronx sample. A significant interaction effect was found (p<.01), such that caretakers of identified children in the lower income category (<$30,000) had higher mean PSI scores (24.7) than caretakers of unidentified lower income children (15.6) or caretakers of children with (13.2) or without (14.9) disability in the higher income group. No interaction of income with disability was found in the National sample and no interaction of income with type of consequences was found among caretakers of identified children in either sample.

In looking at child's mental health, we first used two-way ANOVAs of PARS III scores by disability and race/ethnic group. These analyses yielded no significant interaction terms for either sample overall or for any definition component. Similarly, the relationships of disability to PARS III reported above were maintained in two-way ANOVA and did not differ by family income.

Question 8. How do service NEED AND USE vary by the different definitional components of disability? How do service NEED AND USE vary by age/developmental stage? Socioeconomic status? and Ethnic group?

To answer the first question, we examined data obtained from the Family Needs Survey that was included in the interviews conducted in Arizona with the "Probability" and "Quota" samples. As noted in the Measures section, the Family Needs Survey provided data on expressed family needs in the following domains: (1) information about the condition and health-related services; (2) accessing formal and informal support; (3) help in explaining the condition; (4) community services; (5) financial; and (6) help with family functioning. We compared numbers of needs in each of these domains and the total number of needs expressed overall only by the number of definition components that identified disabled children in each of these two samples. These results are given in Table 10. Number of needs expressed was not analyzed by specific type of consequences experienced because of small group sizes. The Family Needs data from the statewide survey could not be used for this purpose since the QuICCC data were obtained on a child-level, but the family needs items were asked on a household level. As a result, needs data could not be matched with a particular child's disability characteristics. In addition, actual "use" data were not obtained for any of the Arizona samples and, therefore, we could not address this portion of the question.

In the "Probability" the sample, number of definition components on which a child was identified as disabled was significantly related to responses in two domains: community services ($p<.0l$) and financial ($p<.05$); as well as to overall number of needs expressed ($p<.05$). In all cases, parents of children meeting all three components expressed more needs. In the "Quota" sample, we could only compare children meeting all three components to those meeting one or two. A similar pattern occurred for community service, financial and overall needs by number of definition components. However, none of these differences achieved statistical significance in this sample.
The second question, which asked about the relationships of service need to sociodemographic characteristics, could not be answered with the available data sets. Both the Arizona Quota and Probability samples were too small to form subgroups that would support this level of analysis.

Question 9. How do out-of-pocket costs for medical care and for other non-medical expenses vary by disability (as defined using the three definitional components)? How do out-of-pocket expenses vary by characteristics such as age/developmental stage? Socioeconomic status? Ethnic group? Family structure? Insurance coverage?

Data on out-of-pocket expenses were collected in the surveys done with the Arizona "Quota" and "Probability" samples only. Out-of-pocket expenses were defined as the estimated dollar amounts of monies spent for "medical care" for the child and for "other expenses" related to the child (non- medical costs). There were two questions an the survey, so parents were asked about each type of expenses separately. In both samples there were **high proportions of missing data** for both questions; effects of this, if any, on our findings is unknown.

Out-of-pocket medical expenses reported by families with disabled children in the Probability sample (n=83 of a potential 104 provided this information) ranged from 0 to $10,000 in the past year; mean=$788, SD=$1,612, Median=$300. The range for families in the Quota sample (n=44 of a potential 100),was from 0 to $20,000; mean=$1879, SD=$4422, Median=$200. Thus, while the range of expenses was greater and the estimated mean costs were higher for families in the Quota sample, the median cost was lower than for families in the Probability sample. More than one-third of families in the Quota sample (34%) and one-quarter of families in the Probability sample experienced no out-of-pocket medical expenses.

By comparison, out-of-pocket <u>non</u>medical expenses were less for families in both samples. The range for families with disabled children in the Probability Sample (n=76) was 0 to $7700; mean=$684, SD=$1480, Median=$100. For families in the Quota sample (n=41)), the range of <u>non</u>medical expenses paid out-of-pocket was 0-$3000; mean=$534, SD=4904, Median=$0. Although medical expenses were greater in the Quota sample, these families reported fewer <u>non</u>medical costs than families in the Probability sample. More than half (56%) of the Quota sample families, compared with less than one-third (30%) of Probability sample families said they had no out-of-pocket costs for non-medical expenses.

Within each sample, we also examined whether out-of-pocket expenses varied by the number and type of definitional components that identified the child as disabled. No statistical difference was apparent for the number of definitional components, likely due to the small number of children that could be included in this analysis. However, a pattern was very clear: the more disability components that identified the child, the greater the out-of-pocket expenses. The pattern holds over both samples and for both medical and <u>non</u>medical expenses. Controlling for insurance status (have it or not) did not change this pattern (tested in the Probability sample only), although expenses for the uninsured were considerably less than for the insured. When we examined the type of component, we found no discernible pattern, but found that families whose children were identified by all three definitional components reported greater out-of-pocket expenses.

To determine whether health insurance status varied by disability, we first compared the insurance status of families in the Probability sample who had a disabled child with families who did not have a disabled child. We found that families were not likely to be uninsured if they had a child who was disabled according to the QuICCC, as

86% said they had insurance. However, out of 49 children who did not have insurance, 14 or 28% were disabled. When disability was broken out into its different components, children who had functional limitations were all insured. Otherwise, no other pattern could be detected. There was no relationship between insurance and number of components.

We also examined the insurance status of families in the Arizona Quota sample, all of whom met the QuICCC definition. We found that 63% of the children who were identified by only one definitional component (i.e., service only) were not insured. In contrast, those identified by two or three components were very likely to be insured (87%). The explanation for this is unclear. Insurance status also varied according to the different definitional components: service only (38%), compensatory reliance and service (71%), functional limitations and service (83%), all components (90%); p<.01. It appeared that children with functional limitations were more likely to be insured. Whether this reflects greater support from the functionally based SSI payments or greater ability to qualify for Title V or for Medicaid as medically needy remains an open question.

Although we had planned to ask how out-of-pocket costs vary by receipt of SSI, we found that there were too few disabled children who received SSI to attempt this level of analysis. The additional questions related to differences in costs by sociodemographic variables also could not be answered with the available data sets as both samples were too small to form subgroups for this level of analysis.

F. Discussion and Conclusion

The results of these analyses suggest that different definitions of disability in children may substantially affect prevalence estimates and may differentially identify children with particular characteristics. Several broad implications for program and service funding, and for health policy for children with disabilities, can be drawn from the data.

First, the policy implications of using a particular definition of disability may extend beyond the effects on prevalence. As fiscal planning of programs and services depends heavily on available prevalence estimates, the ways in which disability is defined also can ultimately affect the number of children served. One definition of disability may be more suitable than another to identify children with certain types of conditions (e.g., those with pervasive disorders effecting physical, cognitive and emotional arenas). Likewise, some definition may be more tailored to identify children in certain age groups and developmental periods than others, and perhaps even in certain sociodemographic groups, although our findings here can only be considered suggestive.

Second, any definition of disability based on a single conceptual element brings significant risk of under-identification of disabled children. Only a small proportion of the children in this study met criteria for all three types of consequences (20%). The majority of children were identified by one or two operational components of disability and thus may be missed depending on which conceptual components are tapped by the definition used.

Although the conceptual Zeitgeist in defining disability for children has been on functional limitations and service use or need, we would argue that the dimension of compensatory accommodation is a critical component to definitions of disability. Although it is not currently incorporated into many of the existing definitions of disability, reliance on compensatory mechanisms represents a new and increasingly accepted concept in the disability field. Children who rely on mechanisms or assistance (such as medications, special diets, assistive devices or help from another person) to maintain daily functioning or to minimize or compensate for illness consequences may be a strategic group to highlight for several reasons. Doing so would be consistent with disability policy as reflected in recent legislation relating to the American's with Disabilities Act of 1990 that mandates a broader perspective with regard to the disabled community and includes not only people who have ongoing health conditions with consequences, but also those not directly experiencing disability in the classic sense. Additionally, as health care technology improves, there are more and varied options for children to decrease the functional limitations associated with chronic and disabling diseases that cannot be cured. we may anticipate that compensatory dependencies may play an important role in the future epidemiology of chronic and disabling conditions in childhood.

Finally, with the prospect of a major shift in the way health care is provided in this country, it may be useful to identify, count, and assess this population of disabled children for health planning and monitoring. From the perspective of our changing health care system, children who rely on compensatory mechanisms or assistance may be extremely vulnerable to the effects of funding cuts on medical and related services and to the provisions of managed care programs. Should compensatory mechanisms be taken away from a child due to lack of funding, for instance, the number of disabled youngsters exhibiting functional impairments might increase as might the number eligible for services and programs for the disabled. It could reveal much about the quality of health care to compare over time the relative proportions of those who have functional limitations to those who rely on compensatory mechanisms.

The results of this secondary analysis can only be suggestive of how different definitions of disability may affect prevalence estimates and the descriptive characteristics of the disabled children. We used three types of consequences or components of a noncategorical definition of disability that we developed to simulate three conceptually-distinct domains that comprise many definitions. We were only able to approximate the two major definitional types extant in the disability arena: functional limitations and service use. Due to the relatively small sample sizes, we also were restricted in the level of subgroup analysis we could conduct and still maintain the integrity of the statistical analysis performed. The numbers available for some of the subgroup analyses on sociodemographic characteristics were especially small as these data were not collected on the full sample. Based on the selection procedures employed in these surveys we had no reason to suspect that those households who provided sociodemographic data differed substantially form those who did not. However, it would be premature to conclude that any patterns revealed in the analyses regarding socioeconomic status, race and education were reliable or stable.

To follow this preliminary work, we plan to conduct a similar secondary analysis of data form the Children's Section of the 1994-1995 Children's Disability Supplement of the National Health Interview Survey. This data set represents the largest and richest source of information that currently exists on our nation's disabled children, and will provide critical information toward elucidating the full scope of conceptual, methodological and definitional issues around disability.

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TABLE 1. Sociodemographic Characteristics of Children and Caretakers in the Bronx, National, and Arizona Statewide Samples

	Bronx N=1265	National N=1388*	Arizona Statewide N=4831
CHILD AGE			
0-3 years	29%	22%	20%
4-6 years	18%	18%	18%
7-11 years	26%	29%	29%
12-17 years	28%	31%	34%
CHILD RACE			
White, non Hispanic	15%	76%	72%
Non White	85%	24%	28%
RESPONDENT EDUCATION			
< High School	30%	12%	17%
HS graduate	31%	38%	34%
> High School	39%	50%	49%
HOUSEHOLD INCOME			
< $15,000	36%	18%	15%
$15-30,000	32%	27%	25%
$30-45,000	16%	24%	27%
$45,000+	17%	32%	33%

* Race, education and income data for National sample based were based on an approximate 50% subsample of these respondents (see Methods).

TABLE 2. Percentages of Children Identified by QuICCC According to Types and Numbers of Consequences Experienced (Percent of Total/Percent of Identified Children)			
	Bronx	**National**	**Arizona**
Not Identified	81% n=1029	82% n=1132	85% n=4099
Total Identified	19% n=236	18% n=256	15% n=732
ANY FUNC*	10%/35% n=125	9%/49% n=125	7%/46% n=333
ANY COMP*	8%/45% n=105	10%/55% n=140	9%/59% n=432
ANY SERV*	13%/70% n=164	13%/72% n=185	11%/76% n=553
One Component	9%/50% n=118	8%/44% n=113	7%/43% n=312
FUNC ONLY	3%/15% n=36	2%/10% n=25	1%/9% n=62
COMP ONLY	2%/10% n=23	2%/13% n=34	2%/14% n=105
SERV ONLY	5%/25% n=59	4%/21% n=54	3%/20% n=145
Two Components	6%/33% n=78	7%/36% n=92	5%/36% n=254
FUNC & COMP	1%/6% n=13	1%/5% n=12	<1%/2% n=12
FUNC & SERV	3%/15% n=36	3%/15% n=37	2%/13% n=93
COMP & SERV	2%/12% n=29	3%/17% n=43	3%/20% n=149
Three Components FUNC, COMP, SERV	3%/17% n=40	4%/20% n=51	3%/23% n=166
KEY: FUNC = Functional limitations; COMP = compensatory dependency; SERV = service use above routine care. *These categories are not mutually exclusive			

TABLE 3. Percentages of Children with Disability Receiving SSI Benefits According to Type and Number of Consequences Experienced in the Bronx, National, and Arizona Statewide and Quota Samples

	Bronx	National	Arizona Statewide	Arizona Quota
Total Identified % Receive SSI	n=236 9%	n=256 4%	n=731 3%	n=98 25%
ANY FUNC % Receive SSI	n=125 13%	n=125 8%	n=333 6%	n=83 29%
ANY COMP % Receive SSI	n=105 7%	n=140 6%	n=431 3%	n=66 27%
ANY SERV % Receive SSI	n=164 10%	n=185 5%	n=552 3%	n=98 25%
One Component % Receive SSI	n=118 7%	n=112 2%	n=312 <1%	n=9 0
FUNC ONLY % Receive SSI	n=36 11%	n=25 4%	n=62 3%	n=0 NA*
COMP ONLY % Receive SSI	n=23 0	n=34 0	n=105 0	n=0 NA
SERV ONLY % Receive SSI	n=59 7%	n=54 2%	n=145 0	n=9 0
Two Components % Receive SSI	n=78 6%	n=92 1%	n=253 2%	n=29 21%
FUNC & COMP % Receive SSI	n=13 0	n=12 0	n=12 0	n=0 NA
FUNC & SERV % Receive SSI	n=36 14%	n=37 3%	n=93 5%	n=23 26%
COMP & SERV % Receive SSI	n=29 0	n=43 0	n=148 0	n=6 0
Three Components % Receive SSI	n=40 18%	n=51 16%	n=166 7%	n=60 30%

KEY: FUNC = functional limitations; COMP = compensatory dependency; SERV = services above routine care; * in the AZ Quota sample, there were no children in categories that omitted service use

TABLE 4. Child Age Group by Type and Number of Consequences Experienced in Bronx, National, and Arizona Sample

Age Group (YRS)	Bronx Sample					National Sample					Arizona Sample				
	n	0-3	4-6	7-11	12-17	n	0-3	4-6	7-11	12-17	n	0-3	4-6	7-11	12-17
All Children	1265	29%	18%	26%	28%	1385	22%	18%	29%	31%	4831	20%	18%	29%	34%
Not Identified	1029	31%	17%	25%	28%	1129	25%	19%	27%	30%	4099	22%	18%	28%	33%
Total Identified	236	19%	21%	32%	31%	256	11%	13%	38%	38%	732	12%	14%	33%	41%
ANY FUNC	125	16%	25%	31%	28%	125	8%	16%	43%	33%	333	9%	13%	32%	46%
ANY COMP	105	21%	22%	30%	29%	140	14%	11%	41%	34%	432	12%	13%	33%	43%
ANY SERV	164	18%	21%	34%	27%	185	11%	13%	37%	38%	553	12%	15%	34%	40%
One Component	118	20%	16%	35%	29%	101	12%	11%	37%	41%	312	14%	15%	32%	39%
FUNC ONLY	36	22%	25%	28%	25%	25	0%	20%	44%	36%	62	10%	10%	34%	47%
COMP ONLY	23	26%	17%	30%	26%	34	18%	6%	38%	38%	105	14%	14%	28%	44%
SERV ONLY	59	17%	10%	41%	32%	54	13%	9%	33%	44%	145	15%	18%	35%	32%
Two Components	78	19%	27%	23%	31%	92	12%	16%	33%	39%	254	11%	14%	35%	40%
FUNC & COMP	13	8%	15%	23%	54%	12	17%	17%	42%	25%	12	8%	8%	33%	50%
FUNC & SERV	36	14%	31%	28%	28%	37	8%	19%	32%	41%	93	7%	17%	32%	44%
COMP & SERV	29	31%	28%	17%	24%	43	14%	14%	30%	42%	149	13%	12%	37%	37%
Three Components	40	15%	23%	40%	23%	51	10%	12%	51%	28%	166	10%	11%	32%	46%

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine.

TABLE 5. Child Race by Type and Number of Consequences Experienced in Bronx, National, and Arizona Sample

Race	Bronx Sample			National Sample*			Arizona Sample		
	n	White	Non-White	n	White	Non-White	n	White	Non-White
All Children	1235	15%	85%	811	76%	24%	4830	72%	28%
Not Identified	1003	15%	85%	558	78%	22%	3477	71%	29%
Total Identified	232	14%	86%	253	70%	30%	1353	76%	24%
ANY FUNC	121	11%	89%	124	67%	33%	333	78%	22%
ANY COMP	103	14%	86%	138	75%	25%	432	80%	20%
ANY SERV	161	13%	87%	182	71%	29%	553	77%	23%
One Component	117	20%	80%	112	69%	21%	312	71%	29%
FUNC ONLY	35	11%	89%	25	60%	40%	67	71%	29%
COMP ONLY	23	22%	78%	34	71%	29%	105	77%	23%
SERV ONLY	59	24%	76%	53	71%	29%	145	66%	34%
Two Components	77	7%	94%	91	64%	27%	254	76%	24%
FUNC & COMP	13	23%	77%	12	75%	25%	12	42%	58%
FUNC & SERV	35	3%	97%	37	60%	41%	93	73%	27%
COMP & SERV	29	3%	97%	42	79%	21%	149	73%	27%
Three Components	38	13%	87%	50	74%	26%	166	86%	15%

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine.

* Data for National sample based on 50% subsample

TABLE 6. Household Income by Type and Number of Consequences in Bronx, National, and Arizona Samples

Income Group	Bronx Sample					National Sample*					Arizona Sample				
	n	<15000	15000-30000	30000-45000	45000+	n	<15000	15000-30000	30000-45000	45000+	n	<15000	15000-30000	30000-45000	45000+
All Children	1057	36%	32%	16%	17%	770	18%	27%	24%	32%	3712	15%	25%	27%	33%
Not Identified	856	34%	33%	17%	17%	531	14%	27%	26%	33%	3116	14%	26%	27%	33%
Total Identified	201	45%	27%	13%	14%	239	26%	26%	19%	29%	596	17%	22%	26%	36%
ANY FUNC	105	46%	26%	13%	15%	117	28%	31%	21%	21%	273	22%	23%	24%	30%
ANY COMP	90	52%	21%	9%	18%	128	26%	20%	21%	33%	246	12%	20%	28%	40%
ANY SERV	137	47%	26%	12%	15%	173	25%	31%	16%	27%	465	16%	24%	26%	34%
One Component	104	41%	30%	17%	12%	108	27%	22%	18%	33%	244	17%	21%	25%	37%
FUNC ONLY	33	33%	33%	21%	12%	24	33%	21%	17%	29%	47	28%	21%	23%	28%
COMP ONLY	20	55%	20%	15%	10%	31	19%	13%	29%	39%	77	8%	10%	26%	56%
SERV ONLY	51	41%	31%	16%	12%	53	28%	28%	11%	32%	120	18%	28%	25%	28%
Two Components	63	38%	35%	11%	16%	83	18%	31%	22%	29%	216	16%	19%	26%	40%
FUNC & COMP	11	27%	46%	9%	18%	11	27%	9%	36%	27%	7	57%	0%	14%	29%
FUNC & SERV	27	41%	33%	15%	11%	34	15%	50%	24%	12%	83	25%	21%	19%	35%
COMP & SERV	25	40%	32%	8%	20%	38	18%	21%	16%	45%	126	8%	18%	30%	44%
Three Components	34	68%	6%	6%	21%	48	35%	27%	17%	21%	136	17%	27%	27%	29%

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine.
*NOTE: Data for National sample based on 50% subsample

TABLE 7. Caretaker Education by Type and Number of Consequences in Bronx, National, and Arizona Samples

Education	Bronx Sample				National Sample*				Arizona Sample			
	n	<HS	HS	>HS	n	<HS	HS	>HS	n	<HS	HS	>HS
All Children	1258	30%	31%	39%	813	12%	38%	50%	4777	17%	34%	49%
Not Identified	721	30%	32%	38%	558	12%	39%	49%	4047	18%	35%	47%
Total Identified	236	31%	26%	42%	255	13%	35%	53%	730	15%	30%	55%
ANY FUNC	125	36%	33%	56%	124	15%	43%	42%	333	16%	35%	39%
ANY COMP	105	28%	22%	51%	139	7%	36%	57%	430	12%	28%	61%
ANY SERV	164	35%	27%	38%	184	11%	38%	51%	553	13%	31%	56%
One Component	118	30%	31%	40%	113	18%	27%	56%	310	17%	28%	55%
FUNC ONLY	36	22%	28%	52%	25	28%	28%	44%	62%	26%	39%	36%
COMP ONLY	23	26%	22%	52%	34	12%	21%	68%	103	13%	23%	64%
SERV ONLY	59	36%	36%	29%	54	17%	30%	54%	145	17%	28%	56%
Two Components	78	37%	18%	45%	92	8%	34%	59%	254	15%	31%	55%
FUNC & COMP	13	15%	23%	62%	12	0%	33%	67%	12%	42%	17%	42%
FUNC & SERV	36	445	22%	33%	37	16%	41%	43%	93	17%	39%	44%
COMP & SERV	29	38%	10%	52%	43	2%	28%	70%	145	11%	27%	62%
Three Components	40	25%	30%	45%	50	10%	54%	36%	166	10%	33%	58%

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine.
<HS = Less than high school; HS = High school graduate; >HS = More than high school
*NOTE: Data for National sample based on 50% subsample

TABLE 8. Mean Psychiatric Symptom Index (PSI) Total Scores of Caretakers by Type and Number of Consequences Experienced by Children in the Bronx and National Subsamples*

	Bronx Sample		National Sample*	
	n	Mean	n	Mean
Not Identified	237	15.3	193	13.5
Total Identified	180	21.8	189	17.0
One Component	89	20.8	91	15.3
FUNC ONLY	26	23.2	21	19.7
COMP ONLY	18	20.0	29	13.5
SERV ONLY	45	19.8	40	14.0
Two Components	57	23.2	65	18.7
FUNC & COMP	12	23.1	9	25.7
FUNC & SERV	26	24.2	24	24.8
COMP & SERV	19	21.9	32	12.7
Three Components FUNC, COMP, SERV	34	22.2	34	18.2

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine; * Analysis of subsamples of caretakers of disabled and nondisabled children (see Methods)

TABLE 9. Mean Personal Adjustment and Role Skills (PARS) Total Scores by Type and Number of Consequences Experienced by Children in the Bronx and National Subsamples*

	Bronx Sample		National Sample*	
	n	Mean	n	Mean
Not Identified	87	96.2	82	97.2
Total Identified	77	91.3	86	93.2
One Component	36	93.5	45	96.4
FUNC ONLY	7	82.4	13	93.8
COMP ONLY	7	100.1	11	97.7
SERV ONLY	22	95.0	21	97.2
Two Components	24	90.6	22	93.6
FUNC & COMP	4	92.8	4	95.0
FUNC & SERV	10	83.3	8	87.5
COMP & SERV	10	97.1	10	97.9
Three Components FUNC, COMP, SERV	17	87.6	19	85.3

KEY: FUNC = Functional limitations; COMP = Compensatory dependency; SERV = Service use above routine; * Analysis of subsamples of disabled and nondisabled children (see Methods). In addition: 1) PARS analyses were restricted to children 5-12 years, and 2) Children with mental/emotional problems only were excluded

TABLE 10. Mean Family Needs Reported By Caretakers According to Number of Consequences Experienced by Children in Arizona Probability & Quota Samples

N Components	Probability Sample			Quota Sample	
	One (N=31)	Two (N=31)	Three (N=42)	1-2 (N=39)	All 3 (N=61)
FAMILY NEEDS DOMAIN					
Information (8)	1.4	1.7	1.8	4.1	4.9
Accessing Support (5)	1.2	1.2	1.7	2.0	2.3
Help to Explain (3)	0.3	0.3	0.4	0.7	0.8
Community Services (6)	0.2	0.5	1.1	1.1	1.6
Financial (6)	0.7	0.7	1.4	1.5	2.1
Family Functioning (6)	0.5	0.6	0.8	1.0	1.3
Total	2.8	3.4	5.7	6.6	8.5

N of items per domain shown in parentheses