National Survey of SSI Children and Families

Deliverable #3.3: Final Options Report

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Glossary of Acronyms

ABS	address-based sample
ACS	American Community Survey
CAPI	computer-assisted personal interview
CATI	computer-assisted telephone interview
CDC	Centers for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CSHCN	National Survey of Children with Special Health Care Needs
CV	coefficient of variation
DEFF	design effect
ED	U.S. Department of Education
ESS	effective sample size
MDD	minimum detectable difference
MEPS	Medical Expenditure Panel Survey
MOE	margin of error
MOS	measure of size
NBS	National Beneficiary Survey
NEILS	National Early Intervention Longitudinal Study
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey-Disability Supplement
NIS	National Immunization Survey
NLSY97	National Longitudinal Survey of Youth 1997
NLTS2	National Longitudinal Transition Study-2
NSAF	National Survey of America's Families
NSCF	National Survey of SSI Children and Families
PEELS	Pre-Elementary Education Longitudinal Study
PUMS	Public Use Microdata Sample
PSU	primary sampling unit
RDD	random digit dialing
SE	standard error
SEELS	Special Education Elementary Longitudinal Study
SIPP	Survey of Income and Program Participation
SLAITS	State and Local Area Integrated Telephone Survey
SRS	simple random sample
SSA	Social Security Administration
SSI	Supplemental Security Income
SSR	Supplemental Security Record
TANF	Temporary Assistance for Needy Families
TTW	Ticket-to-Work
VR	vocational rehabilitation

1. Introduction

The Social Security Administration (SSA) contracted with Westat to develop options for a new National Survey of SSI Children and Families (NSCF). SSA fielded the original NSCF in 2001-02. This survey collected data about the impact of the Supplemental Security Income (SSI) program on children and their families and provided a rich array of information on current and former SSI recipients and applicants (over 8,000 respondents), including their sociodemographic characteristics, experiences, and health care needs, as well as information to evaluate the effects of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-93, also known as welfare reform) on SSI recipients. More than a decade has passed since these data were collected, and SSA has expressed interest in conducting a new NSCF, with the goal of addressing a different set of policy questions. This report presents SSA with options for the new survey and for addressing these policy questions.

SSI Program

The SSI program is a means-tested income assistance program administered by SSA. The program is authorized under Title XVI of the Social Security Act as amended in 1972. SSI provides monthly cash benefits and Medicaid benefits to people who are age 65 or older or blind or have a disability and limited income or assets. With respect to children, the SSI program helps offset the costs of a child's disability for low-income families. For children to be eligible for SSI payments, they must be under the age of 18, be unmarried, and meet the SSI criteria for disability or blindness, citizenship/residency, and income and resources. An individual under age 18 is considered to be disabled if he or she has a medically determinable physical or mental impairment, which:

- results in marked and severe functional limitations; and
- can be expected to result in death; or
- has lasted or can be expected to last for a continuous period of not less than 12 months.

Individuals qualify for SSI benefits if they have limited income and resources. Income includes money earned from work; money received from other sources, such as Social Security, workers compensation, and unemployment benefits; and items received in-kind, such as food and housing. Resources include cash; bank accounts, stocks, savings bonds; land; vehicles; and other personal property. Because only some types of income and resources are counted for the purpose of SSI eligibility, an individual need not be completely without income and resources to qualify for SSI benefits. For children under 18 who live with their parent(s) (or a parent and a stepparent), and at least one parent does not receive SSI, some of the parents' income may be counted when determining the child's SSI benefit. The maximum SSI benefit is paid if the individual has no countable income. Reductions to benefits are made based on a person's countable income.

For children, the disability determination is a three-step sequential evaluation process (SSA 2009) that includes the following:

- Step 1: SSA determines whether the child is working and, if so, whether earnings are below the current substantial gainful activity level. If monthly earnings average less than the substantial gainful activity level, the claim is forwarded to Disability Determination Services.

- Step 2: Disability Determination Services establishes whether the child has a medically determinable impairment (or combination of impairments) and whether it is severe.

- Step 3: Disability Determination Services determines whether the child has an impairment that meets or medically equals one of those on the list of disabling impairments used by SSA. If not, Disability Determination Services determines whether the impairment functionally equals one on the list by assessing the effects of the impairment on the child's ability to function at home, at school, and in his or her community.

SSA examines how much the child is limited in each of six broad domains (i.e., acquiring and using information; attending and completing tasks, interacting and relating with others, moving about and manipulating objects, caring for himself or herself, and maintaining health and physical well-being). A child's impairment is considered functionally equal if it causes limitations in two of the domains or an extreme limitation in one domain.

Purpose of New Survey

According to the *SSI Annual Statistical Report* (2011), over 1.2 million children under age 18 received SSI benefits in 2010. SSA has a wealth of administrative data on these SSI beneficiaries. The administrative data include information about the age of these children, gender, types of disabilities, living arrangements, monthly payments, and income. Although these data are extremely useful, they do not provide a complete picture of the children who receive SSI benefits. Therefore, SSA occasionally develops a special survey. In 2001-02, SSA fielded the NSCF. This was the first national survey of SSI children since 1978, and the data collected by this survey have been analyzed in depth by both SSA staff and researchers.

More than a decade has elapsed, however, since these data were collected, and they are now likely out of date. In addition, SSA has a new set of policy questions that it would like to address about SSI children and their families, and a new survey can better address these questions than administrative data alone. Furthermore, a new survey would provide the up-to-date information SSA needs to serve youth with disabilities in a different economic environment than the one in place at the time of the original NSCF.

Overview of Survey Options Report

This survey options report provides a general framework for a new NSCF. In the chapters that follow, we discuss the options for a new survey of SSI children and families with respect to the sample and the content of a new survey. The content of each of these chapters is detailed below.

- Chapter 2: Discussion of the Original NSCF;

- Chapter 3: SSA Policy Questions for a New NSCF;

- Chapter 4: Data Collection Options;

- Chapter 5: Design Options for a New NSCF;

- Chapter 6: Sampling Options for a New NSCF;

- Chapter 7: Data Analysis and Dissemination Considerations; and
- Chapter 8: Summary and Conclusions.

We also present the following appendices:

- Appendix A: Potential Survey Items;
- Appendix B: Precision Measures;
- Appendix C: Power Analysis for Using the National Survey of Children with Special Heath Care Needs (CSHCN) as a Comparison Group Option.

2. Discussion of Original NSCF

The original NSCF was conducted in 2001-02 to provide information on the characteristics, experiences, and needs of a cross-section of children receiving SSI and their families. It was also designed to evaluate the effects of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193, otherwise known as welfare reform) on SSI children and their families (SSA 2012). In this chapter, we discuss some information from the original NSCF that is relevant to the design of the new NSCF, including the policy questions, sample design, response rates, and the data collection methodology.

Policy Questions

As described in the *NSCF User's Manual for the Public-Use File* (SSA 2012), the NSCF collected data on children and young adults with special health care needs and their families who received or applied for SSI. The specific research questions the NSCF was designed to address were:

- What are the general characteristics of SSI children and their families (demographic, clinical, and family status)?
- What are the patterns of access to and utilization of health care among SSI children? What services do SSI children use?
- What are the costs associated with caring for a child with a disability? What is the impact on the family of having a child with a disability?
- What is the status of young adults with disabilities as they transition to adulthood?
- What is the impact of the 1996 welfare reform legislation on former child recipients in terms of their health, well-being, and transition to adult life?

Sample Design

The sampling frame for the original NSCF consisted of children and young adults in the SSI applicant and beneficiary files at two time points: December 1996 and December 2000 (SSA 2012). The contractor processed the 100% SSI extract files for these two time points and the "children's universe" file of children subject to redetermination as required by welfare reform. The December 1996 100% extract file contained 3,069,383 records and the December 2000 100% extract file contained 4,374,545 records. The children's universe file contained approximately 330,000 records. Children were then classified into one of eight sampling stratum using the criteria described below (see Table 2-1).

Children eligible for the original NSCF included all children who were recipients of SSI at the time of welfare reform (i.e., December 1996) or who were recipients in December 2000.[1] Children were classified as recipients if the current pay status information on the extract record was not a terminated status code. Children who were not recipients at either of these time points were also eligible if the child

[1] For analytic reasons as well as logistical and cost reasons related to data collection, children in Alaska, Hawaii, Puerto Rico, and the United States Trust territories were excluded from the survey population.

either had been a recipient at some time previously or had applied for SSI and had an application date that was after January 1, 1992.

The NSCF used a two-stage probability sample design with the selection of primary sampling units (PSUs) that were formed using counts of children based on the SSI applicant and beneficiary files aggregated to single or multiple county- level units. PSUs, based on single or multiple adjacent counties, were constructed using SSI program files and selected to form a nationally representative sample. PSUs were selected with probability strictly proportional to the size measure and controlling on three factors: (a) whether at least one county in the PSU was rural, (b) SSA region, and (c) state. These controlling factors were used to enhance the representative nature of the sample. The 74 PSUs selected contained more than 916,000 of the 3.5 million children in the survey population.

In the 74 sampled PSUs, the sample of children was allocated across eight sampling strata. These 592 allocations (74 PSUs x 8 sampling strata = 592 allocations) were then inflated to account for nonresponse and ineligible cases. Initially, a larger sample of 27,465 children and young adults was selected and randomly partitioned into waves to control the sample release for reaching the target number of completed interviews. In total, a smaller sample of 11,971 cases was released for interviewing.

Children who were recipients at the time of welfare reform were classified into sampling strata based on redetermination status (subject and not subject to redetermination) and the outcome of the redetermination process (continued on SSI or were denied SSI). For the analysis of welfare reform, there was particular interest paid to the children who were subject to redetermination. Separate sampling strata were formed for children subject to the redetermination process who continued on SSI or for children subject to the redetermination who were denied SSI. These two strata included all children meeting these criteria without regard to the child's age or current recipient status. Because of issues related to transitioning children to the adult eligibility criteria, a separate stratum of children was formed that included SSI recipients who were either 17 or 18 years only in December 1996 and were either on SSI at welfare reform and not subject to redetermination or not on SSI at welfare reform nor currently, but had previously received benefits or had applied after January 1, 1992.

For children who were current recipients (as of December 2000), three sampling strata were defined on the basis of whether the child was on SSI at welfare reform and not subject to redetermination or was not on SSI at welfare reform, and the age of the child. Children under 17 years were classified into two sampling strata. Once again, because of the issues related to the transitioning of children to the adult eligibility criteria, a separate stratum of young adults was formed that included current SSI recipients who were either 17 or 18 years and either were not on SSI at welfare reform or were SSI recipients at welfare reform but were not subject to redetermination.

Table 2-1. Sampling Strata Definitions for Original NSCF

Sampling Strata	Age	Sample
1. Children and young adults who were SSI recipients at welfare reform, were subject to redetermination, and were continued	All ages	2,377
2. Children and young adults who were SSI recipients at welfare reform, were subject to redetermination, and were denied	All ages	2,438
3. Children and young adults who were SSI recipients at welfare reform and not subject to redetermination, but who were not recipients in 2000	Under 17 at welfare reform	1,059
4. Children and young adults who were not SSI recipients at welfare reform and were not SSI recipients in 2000	Under 17 at welfare reform	1,433
5. Young adults who were not SSI recipients in 2000 and were either: A. SSI recipients at welfare reform and not subject to redetermination B. Not SSI recipients at welfare reform	17-18 at welfare reform	935
6. Children who were SSI recipients in 2000 and were SSI recipients at welfare reform, but not subject to redetermination	Under 17 at survey	1,341
7. Children who were SSI recipients in 2000 and were not SSI recipients at welfare reform	Under 17 at survey	1,381
8. Young adults who were SSI recipients in 2000 and were either: A. SSI recipients at welfare reform and not subject to redetermination B. Not SSI recipients at welfare reform	17-18 at survey	1,007
	Total	*11,971*

Source: SSA. 2012. *National Survey of SSI Children and Families (NSCF): User's manual for the public-use file.* Baltimore, MD: SSA.

Response Rates

One major challenge associated with the original NSCF data collection centered on locating sample members (Davies and Rupp 2005/06). Although SSA administrative data were used to identify the sample, the contact information (i.e., addresses or phone numbers) for over 70% of sample members was invalid, even among those sample members who were receiving SSI at the time of the survey.[2] A number of methods were used to locate sample members, including searches of commercially available

[2] For sample members who were receiving SSI at the time of the survey, the percentage with invalid addresses or telephone numbers was around 50%.

databases and NSCF field workers going to sample members' last known neighborhoods. These efforts resulted in about 84% of the NSCF sample being located for interviewing.

As described in the *NSCF User's Manual for the Public-Use File* (SSA 2012), in all, respondents for 8,726 children and young adults who had experience with the SSI program—either as current beneficiaries, former beneficiaries, or applicants who never received benefits—were interviewed. An additional 516 sample members were determined to be ineligible to participate in the survey. The ineligibles included deceased sample members, sample members no longer living in the continental United States or living in Medicaid facilities, and sample members identified as wards of the state.

In order to boost overall response rates, the original NSCF included the use of incentives. Sample members were notified in advance that they would receive a response incentive of $10 once they completed the survey. To explore whether certain types of incentives boosted the completion rates more than others, three types of incentives were used during the NSCF data collection: (1) 70% of respondents were randomly selected to receive a standard check payment, (2) 15% were selected to receive a debit card, and (3) the remaining 15% were selected to receive a prepaid telephone card. Analyses of the completion rates suggested that using the debit card incentive was a good cost-effective option.

In the end, the original NSCF accomplished an overall weighted response rate of 74.4% and an unweighted response rate of 77.2%

Data Collection Methodology

The original NSCF used a mixed-mode data collection (Davies and Rupp 2005/06) consisting of computer-assisted telephone interviews (CATI) and computer-assisted personal interviews (CAPI). Of the 8,726 completed interviews, 7,285 were completed using CATI (83.5%), and 1,441 field interviews were completed using CAPI (16.5%). CAPI interviews were primarily conducted with sample members who could not be reached by telephone (e.g., a correct telephone number could not be found) or who could not complete the interview by telephone (e.g., the respondent's disability prevented him or her from responding by telephone, language barriers).

There were two different versions of the questionnaire: a child version and a young adult version. The versions were similar in content but allowed for differences in living situations, SSI eligibility, and other age-specific issues between children and young adults. The child version asked questions about sample members who were under age 17 at the time of the survey. The young adult version was designed for sample members who were between 17 and 24 at the time of the survey. Both child and young adult questionnaire versions asked about the sample member's health status and functional limitations, health care utilization, health insurance coverage, receipt of services, and SSI experience. In addition, data were collected about the socioeconomic status of the sample members' households, including earned and unearned income, and housing characteristics. Both versions required about 70 minutes to administer. A Spanish version of the questionnaire was also available in CATI and CAPI to ensure representation of Spanish-speaking families (SSA 2012).

More information about the original NSCF, including copies of the questionnaires and a public-use data file and documentation can be found on SSA's website (http://www.ssa.gov/disabilityresearch/nscf.htm).

3. SSA Policy Questions for a New NSCF

SSA has identified a set of policy questions that it would like to address through a new NSCF. These policy questions include topics such as future expectations for SSI children, service utilization, respite care, transition to adulthood, potential effects of the recent economic downturn, sources of care available to youth who lose their benefits, families' knowledge about SSI program rules, needs not being fully addressed, and prescription drug use.

The specific policy questions identified by SSA are:

Policy Question #1: What future expectations do parents have for their children receiving SSI? What future expectations do children have for themselves? Is working and/or leaving SSI viewed as a potential outcome?

Policy Question #2: How accurately do administrative disability diagnosis codes reflect the most significant impairment in the view of the parent or guardian?

Policy Question #3: Of the various resources for children with and without disabilities, which are SSI children using? Are SSI children using more or less than non-SSI children? To what extent are these services coordinated?

Policy Question #4: What is the availability and need for respite care among SSI families?

Policy Question #5: Are older children prepared for the transition to adulthood, particularly an adulthood without SSI? How does this compare to children who do not receive SSI?

Policy Question #6: How has the recent economic downturn affected families with respect to the sources of care for the child, the employment of parents or guardians, and the medical needs of the child? Were families with children on SSI disproportionately affected by the downturn?

Policy Question #7: For youth who lose benefits (at age 18 or at a continuing disability review), what sources of care were subsequently available to them?

Policy Question #8: What needed services do SSI children and their parents think are not offered to them?

Policy Question #9: Do SSI families have accurate information about program rules? From where are they learning about SSI rules? How did the family first learn about the child's potential eligibility for SSI?

Policy Question #10: Are SSI children more or less likely to be taking prescription drugs than children not on the program? For children with mental impairments, are psychiatric services being accessed? What types?

In addition to these questions, Westat suggests another set of questions specifically focused on children with mental impairments. A recent statement by the General Accounting Office (Bertoni 2011) noted that the number of children receiving SSI has continued to rise over the past decade. In addition, there has been an increase in the number of children applying for and receiving SSI because of mental impairments, and these children now make up a growing majority of all child beneficiaries. In particular, Bertoni (2011) noted the increased number of children in the attention deficit disorder/attention deficit hyperactivity disorder, speech and language delay, and autistic disorder and other pervasive development disorders (autism) categories. Therefore, Westat proposes the following additional set of research questions to further explore various topics related to children with mental impairments and their families:

Additional Research Questions: Is there an overrepresentation of children with mental impairments receiving SSI benefits? Are the mental health needs of SSI children being adequately addressed? What services are being used by SSI children with mental impairments and their families? What reasons do SSI families give for not seeking mental health services or for discontinuing mental health services? What kinds of functional limitations do SSI children with mental impairments have?

Potential Subgroups and Comparison Groups

In order to address the SSA policy questions, a new NSCF would need to include a variety of different types of respondents. Many of the policy questions refer to children and families who are currently receiving SSI. Some of these policy questions, however, also identify specific subgroups of SSI children, such as transition-age youth or children with mental impairments. Other policy questions require comparison groups; that is, the policy question discusses SSI children and families in comparison to another group, such as non-SSI children. In this section, we discuss the potential subgroups and comparison groups needed to address each of the SSA policy questions.

Policy Question #1: What future expectations do parents have for their children receiving SSI? What future expectations do children have for themselves? Is working and/or leaving SSI viewed as a potential outcome?

This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI.

(2) Children receiving SSI. Because it is not feasible to survey very young children, this question requires a subgroup of older SSI children. The National Longitudinal Transition Study-2 (NLTS2), a U.S. Department of Education-funded study of children with disabilities, surveyed children with disabilities as young as age 13, so this subgroup could be defined as SSI children who are age 13 or older.

Policy Question #2: How accurately do administrative disability diagnosis codes reflect the most significant impairment in the view of the parent or guardian?

This policy question requires one type of respondent:

(1) Parents (or guardians) of children receiving SSI.

Policy Question #3: Of the various resources for children with and without disabilities, which are SSI children using? Are SSI children using more or less than non-SSI children? To what extent are these services coordinated?

This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI.

(2) A comparison group composed of parents (or guardians) of non-SSI children. The comparison group could be defined in a couple of different ways. First, it could be defined simply as parents of children with disabilities who do not receive SSI. Second, it could be defined as parents of children with disabilities who do not receive SSI and who are low income. We believe that the second option would make a better comparison group for addressing this policy question, as there are many resources that would only be available to low income families (e.g., Temporary Assistance for Needy Families (TANF), Medicaid). However, if SSA is interested in resources that are not income-based, a broader comparison could be made to children with disabilities who do not receive SSI. A comparison such as this one would require a large enough sample of children with disabilities that includes both low-income and higher-income families.

Policy Question #4: What is the availability and need for respite care among SSI families?

This policy question requires one type of respondent:

(1) Parents (or guardians) of children receiving SSI.

Policy Question #5: Are older children prepared for the transition to adulthood, particularly an adulthood without SSI? How does this compare to children who do not receive SSI?

This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI. This policy question requires a subgroup of parents (or guardians) of older SSI children. NLTS2 focused on children ages 13 to 16 in order to follow the children as they transitioned from secondary school to early adulthood. Therefore, similar to Policy Question #1, this subgroup could be defined as parents (or guardians) of SSI children ages 13 or older. Unlike Policy Question #1, this question does not refer specifically to SSI children themselves as respondents. However, it would certainly be reasonable for older SSI children to answer this question. Therefore, another type of respondent might be SSI children, with the subgroup being SSI children who are age 13 or older.

(2) A comparison group composed of parents (or guardians) of non-SSI children. Again, because this policy question refers to older children, it requires a subgroup of parents of non-SSI children ages 13 and older. Similar to Policy Question # 3, the comparison group could be defined as parents of children with disabilities who do not receive SSI and who are low income. Or, a broader comparison could be made to children with disabilities who do not receive SSI with a large enough sample of children with disabilities that includes both low- income and higher-income families.

Policy Question #6: How has the recent economic downturn affected families with respect to the sources of care for the child, the employment of parents or guardians, and the medical needs of the child? Were families with children on SSI disproportionately affected by the downturn?

This policy question requires two types of respondents:

(1) Parents (or guardians) of SSI children.

(2) A comparison group composed of parents (or guardians) of non-SSI children. In this case, the comparison group would be parents (or guardians) of children with disabilities who do not receive SSI but who are low income.

Policy Question #7: For youth who lose benefits (at age 18 or at a continuing disability review), what sources of care were subsequently available to them?

This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI. Because the policy question refers to lost benefits, it requires a subgroup of parents of SSI children who have lost benefits due to a continuing disability review.

(2) Youth receiving SSI. Again, because the policy question refers to lost benefits, it requires a subgroup of youth who lost their SSI benefits at age 18.

Policy Question #8: What needed services do SSI children and their parents think are not offered to them?

This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI.

(2) Children receiving SSI who are age 13 or older.

Policy Question #9: Do SSI families have accurate information about program rules? From where are they learning about SSI rules? How did the family first learn about the child's potential eligibility for SSI?

This policy question requires one type of respondent:

(1) Parents (or guardians) of children receiving SSI.

Policy Question #10: Are SSI children more or less likely to be taking prescription drugs than children not on the program? For children with mental impairments, are psychiatric services being accessed? What types?

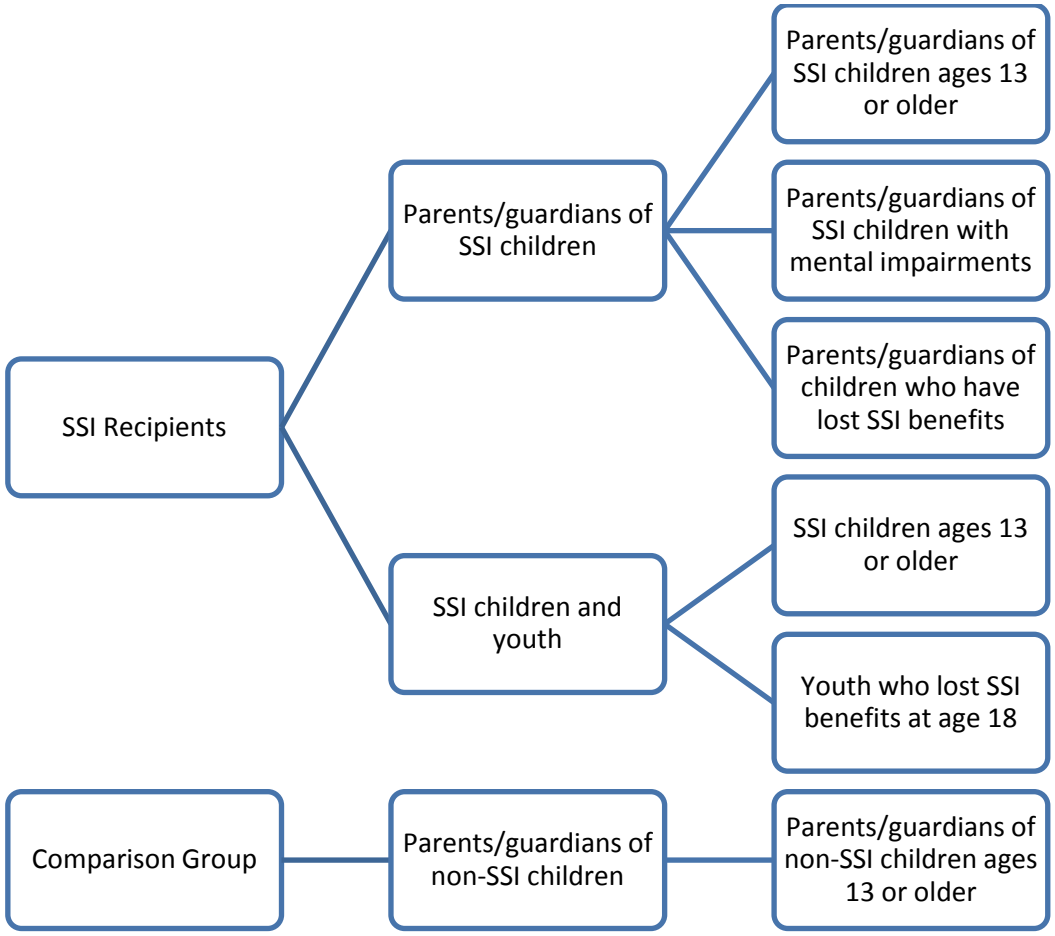
This policy question requires two types of respondents:

(1) Parents (or guardians) of children receiving SSI. In addition, this policy question would require a subgroup of parents (or guardians) of SSI children with mental impairments.

(2) A comparison group composed of parents (or guardians) of non-SSI children, such as parents of children with disabilities who do not receive SSI and who are low income. As with Policy Questions #3 and #5, a broader comparison could also be made to children with disabilities who do not receive SSI with a large enough sample of children with disabilities that includes both low-income and higher-income families.

Figure 3-1 provides a summary of the different types of respondents and subgroups that would be needed to address all of the SSA policy questions.

Figure 3-1. Summary of Categories of Respondents, Respondent Types, and Subgroups Needed for New NSCF



Cross-Sectional Versus Longitudinal Designs

SSA has expressed interest in a variety of different design options for a new NSCF. These include resurveying portions of the original NSCF respondents, surveying a new cross-section of current and former SSI recipients, and surveying a cross-section of recent applicants with the intent of surveying them again in the future. Although SSA wants to explore a number of potential design options, including a possible longitudinal option, the policy questions identified by SSA for the new NSCF typically could be addressed through a cross-sectional design. They are primarily asking SSI children and families (and sometimes comparison groups) about one point in time.

If SSA decides to adopt a longitudinal design, the policy questions could be revised to take maximum advantage of this design option. For example, the policy question related to resources (Policy Question #3) currently reads:

- Of the various resources for children with and without disabilities, which are SSI children using? Are SSI children using more or less than non-SSI children? To what extent are these services coordinated?

This item could be reworked to lend itself to a longitudinal design option:

- Of the various resources for children with and without disabilities, which are SSI children using? Are SSI children using more or less than non-SSI children? To what extent are these services coordinated? *Do the resources used by SSI children and non-SSI children, and the coordination of these services, change over time?*

Likewise, the policy question related to transition-aged youth (Policy Question #5) currently reads:

- Are older children prepared for the transition to adulthood, particularly an adulthood without SSI? How does this compare to children who do not receive SSI?

Again this could be re-written in a way that lends itself to a longitudinal design option, perhaps following youth as they transition into adulthood:

- *How are older children preparing* for the transition to adulthood, particularly an adulthood without SSI? How does this compare to children who do not receive SSI? *When these children reach adulthood, are they still receiving SSI? Are they employed? Are they enrolled in postsecondary education?*

Potential Survey Items to Address Policy Questions

To identify potential items to address the SSA policy questions for a new NSCF, we first reviewed the previous NSCF, since including items from the original NSCF would allow SSA and other researchers to make comparisons and explore trends over time. In addition to items specifically created for the NSCF, the original survey included items from the following sources (SSA 2012), which were reviewed for items potentially relevant to a new NSCF:

- National Survey of CSHCN;
- Primary Care Assessment-Children with Special Health Care Needs;
- FACCT, a screener to identify children with special health care needs;
- Medical Expenditure Panel Survey (MEPS);
- National Early Intervention Longitudinal Study (NEILS);
- National Health Interview Survey (NHIS) and the National Health Interview Survey-Disability Supplement (NHIS-D);

- National Survey of America's Families (NSAF); and
- Survey of Income and Program Participation (SIPP).

We then reviewed other relevant national surveys that had not been the source of items for the previous NSCF. These surveys included:

- National Longitudinal Survey of Youth 1997 (NLSY97),
- National Beneficiary Survey (NBS),
- Pre-Elementary Education Longitudinal Study (PEELS),
- Special Education Elementary Longitudinal Study (SEELS), and
- NLTS2.

Our process for examining the surveys first involved determining which components of the studies were potentially relevant to the SSA policy questions. Several studies, such as PEELS, SEELS and NLTS2, include multiple data collections. Some of these data collections, such as one-on-one assessments or surveys to collect data about the characteristics of the district or school the children attended, are not relevant to the policy questions for the new NSCF. We then thoroughly reviewed the surveys we thought might include items aligned with the policy questions and categorized specific items that could address each of the policy questions. For the proposed research question related to children with mental impairments, in addition to the above surveys, we also reviewed several mental health screeners.

Once we completed reviews of the original NSCF and the other national studies listed above (i.e., NLSY97, NBS, PEELS, SEELS, NLTS2), we assessed the list of potential items. For some policy questions, we noted that only a small number of items from the original NSCF were identified, which was not surprising since SSA is hoping to address new policy questions with the new NSCF. If we did not find relevant items from the original NSCF, then we reviewed some of the original surveys that contributed items, as we thought it was possible that these surveys contained items that might not have been relevant to the original NSCF but that could address the new NSCF policy questions. Any additional items were pulled and added to the list. Table 3-1 provides a brief description of each of the surveys from which we identified items.

The complete list of potential survey items that we identified is included in Appendix A. The items are organized by policy question to facilitate comparison across sources. Several of the policy questions cover similar topical areas (e.g., Policy Question #3: "Of the various resources for children with and without disabilities, which are SSI children using?" and Policy Question #7: "For youth who lose benefits, what sources of care were subsequently available to them?"). Therefore, the same item may be listed for more than one policy question.

Table 3-1. Description of Surveys Examined to Identify Potential Items to Address Policy Questions

Survey	Purpose	Content	Respondents	Time Period	Data Collection Modes
NLSY97	To collect information on respondents' labor market behavior and educational experiences.	Focused on schooling and employment activities, financial characteristics, family background, interaction with nonresident parent(s), social behavior, and health status.	Youth ages 12 to 16 in December 1996 and their parents.	Fifteen annual rounds of data from 1997 to 2011.	CAPI, audio computer-assisted self-interview
NLTS2	To describe the characteristics and school experiences of secondary school youth in special education and their households, to describe the their experiences once they leave secondary school, and to measure their secondary school and postschool outcomes.	Focused on youth and family characteristics, nonschool activities, satisfaction with school programs, and activities after high school. Also several school surveys that asked about additional topics.	Students receiving special education who were ages 13 through 16 and in at least 7th grade on December 1, 2000, their parents and teachers.	Beginning in 2000-01 data collected every other year through 2008-09; youth assessments teacher/school surveys completed in 2001-02 and 2003-04.	CATI, mail/paper survey
PEELS	To collect data on the preschool and early elementary school experiences of a nationally representative sample of children with disabilities and the outcomes they achieve.	Focused on child's health and disability, behavior, school programs and services, and special education and related services, classroom staffing and materials, interaction with peers without disabilities, teachers' philosophies of early childhood education, and children's transitions in and out of their current programs as well as the children's special education programs and related services.	Children with disabilities ages 3-5 in 2003, parents, teachers, and principals/ program directors of the children.	Five waves of data collection in school years 2003-04, 2004-05, 2005-06, 2006-07, 2008-09.	CATI, mail/paper survey

Table 3-1. Description of Surveys Examined to Identify Potential Items to Address Policy Questions (continued)

Survey	Purpose	Content	Respondents	Time Period	Data Collection Modes
SEELS	To understand how special education students are doing, what services schools are providing to students and families, and to what extent special education is helping students and families.	Focused on student and family characteristics, nonschool activities, satisfaction with school programs, students' classroom experiences, instructional goals, assessments, accommodations, social adjustment, programs, placements, and educational progress.	Students in special education who were ages 6 through 12 in 1999, their parents, teachers and principals.	Four rounds of data collection: 1999-00, 2000-01, 2001-02, and 2003-04.	CATI, mail survey
NBS	The NBS is part of SSA's evaluation of the Ticket to Work and Self-Sufficiency program (TTW).	Focused on knowledge of TTW, participation in TTW, program experiences of beneficiaries who use their Tickets, and perceptions about TTW and other SSA programs designed to help beneficiaries with disabilities find and keep jobs. Also collects data on SSA beneficiaries, including their disabilities, interest in work, employment, barriers to work, and use of services.	SSDI and SSI beneficiaries and a sample of TTW participants ages 18 to 64.	First round conducted in 2004, with subsequent rounds in 2005, 2006 and 2010.	Primarily CATI, some CAPI
National Survey of CSHCN	To assess the prevalence and impact of special health care needs among children in the US, and to evaluate change since the survey's inception in 2001.	Focused on whether children with special health care needs have adequate health insurance, access to needed services, adequate care coordination, and that parents are satisfied with their child's care.	Parents of children ages 0 to 17 with special health care needs.	Data were collected in 2000-02, 2005-07, and 2009-11.	CATI

Table 3-1. Description of Surveys Examined to Identify Potential Items to Address Policy Questions (continued)

Survey	Purpose	Content	Respondents	Time Period	Data Collection Modes
NHIS	To monitor the health of the US population through the collection and analysis of data on a broad range of health topics.	The core questions focus on household, family, the sample adult, and the sample child. Supplements are fielded once or may be repeated and have focused on health topics such as cancer screening, complementary and alternative medicine, children's mental health, and healthcare utilization.	For the sample child, information obtained from knowledgeable adult in the household, usually a parent.	Ongoing since 1957.	CAPI
NHIS-D	To collect data that can be used to understand disability, to develop public health policy, to produce simple prevalence estimates of selected health conditions, and to provide descriptive baseline statistics on the effects of disabilities.	Phase I screened for Phase II eligibility, included sections on special health needs of children, special education services for children, and early childhood development. Phase II collected data on utilization and need for services, functional assessment, including emotional and behavioral development, and the impact of the child's disability on the family.	The parent or the adult in the household who knew the most about the selected child's health.	Data were collected in 1994-95.	In-person, telephone, paper
MEPS	To collect data on the health service utilization, the cost of these services, and how they are paid for, as well as data on the cost, scope, and breadth of health insurance held by and available to US workers.	Collects information on demographic characteristics, health conditions, health status, use of medical services, charges and source of payments, access to care, satisfaction with care, health insurance coverage, income, and employment.	Adult household members.	Ongoing since 1996.	CAPI

4. Data Collection Options

In this chapter, we discuss options related to data collection methodologies. First, we review data collection methods that could be used for the new NSCF, such as mail surveys, web surveys, telephone surveys, and in-person surveys/interviews. We then discuss expected response rates for the new NSCF, as well as some ways of enhancing response rates.

Data Collection Options for a New NSCF

The four most common data collection methodologies for large-scale surveys are mail, web, telephone, and in-person surveys/interviews. We believe the length and complexity of the NSCF survey, characteristics of the respondent population, and need for high response rates preclude use of a web or mail survey. Mail surveys are generally unsuitable for questionnaires with complex skip patterns, like the NSCF, because respondents often have trouble navigating from question to question. In addition, because each respondent would answer only a subset of the items in the survey, a mail questionnaire would appear extremely long, dissuading potential respondents and suppressing response rates. While questionnaires can be printed in multiple languages, it can be difficult to ensure that researchers are mailing the right version to the right people, and having questionnaires in the potential respondent's primary language is important for enhancing response rates. In addition, if SSA plans to collect data from children on SSI, the reading level requirements and other issues of accessibility could be problematic.

Web surveys can easily accommodate complex skip patterns and are more suited than mail to long questionnaires. They can also be easily translated and are relatively inexpensive to administer. However, given the income and employment patterns of the target population, access to a computer and the internet may be limited. In addition, potential respondents may not have the necessary computer skills or reading skills to complete the survey without assistance. One additional shortcoming with both mail and web surveys is the inability of the respondent to obtain immediate clarification of survey items, which may also be particularly important if children on SSI are participating as respondents.

As discussed in Chapter 3, the original NSCF used CATI and CAPI, and we believe these two modes are most suitable for the new survey. [3] These modes of data collection can accommodate complex skip patterns, ensure immediate access to a researcher who can clarify questions or record the respondent's verbatim response if he/she is unwilling to select from among the response options available, can easily switch from English to Spanish (or other languages), do not require access to computers or the internet, and have fewer problems than mail or web surveys with item nonresponse or low quality responses to open-ended items. Interviews in which questions are read aloud eliminate the need for respondents to have a specified reading proficiency, which again may be an important consideration, especially if children receiving SSI will be among the respondents.

In the original NSCF, 16.5% of respondents completed in-person surveys; the others completed the interview via remote CATI. The major advantage of a remote CATI over in-person data collection is the reduced cost. Travelling from house to house is an expensive mode of data collection, typically taking

[3] While some in-person data collections use CAPI, many also use CATI. In the former, respondents enter responses on a portable computer, with or without the assistance of the onsite data collector. In the latter, onsite data collectors allow respondents to use their cell phone to complete interviews with remote data collectors. In this report, we use the term CAPI to capture both of these in-person modes of data collection.

several hours of staff time per response.[4] While costs vary considerably, one study found that a case conducted through CATI was 13% of the cost for a CAPI (Radian and Nir nd). Another source cited costs four to eight times as much for CAPI as CATI (Mitchell et al. 2006). CAPI may be preferable to CATI if an interview includes confidential or highly sensitive information that a respondent is unwilling to give to an interviewer. It should be noted that a multi-mode study (such as CATI/CAPI) has the potential to introduce mode effects, which may be especially problematic with sensitive questions. However, research has shown that switching modes or offering respondents a choice of mode can increase response rates (Converse et al. 2008; Dillman et al. 2009; Greenlaw and Brown-Welty 2009), so using CATI as the primary means of data collection and CAPI for nonresponse followup can be expected to enhance response rates. In addition, SSA may wish to have a shortened version of the survey available on paper for hard-core nonrespondents, in addition to offering CATI and CAPI options. This paper survey could be very short—intended to collect only enough data to assess nonresponse bias or provide answers to a small number of critical items. It could be mailed or left for individuals unsuccessfully targeted for in-person data collection.

Table 4-1 shows that the data collection strategy described here (CATI, CAPI, and paper for nonresponse bias analysis) in Spanish and English, for parents and children, would require as many as 12 different data collection instruments. If the in-person data collection is by phone and not hand-held computer (i.e., with the respondent calling in via the data collector's cell phone), the number would be reduced to 10.

Some costs are accrued with each additional version of the survey. For example, there is some added cost for conducting the interview in both Spanish and English, first for translation of the instrument, then for bilingual interviewers who typically demand a higher salary than monolingual ones. Likewise, the cost of programming a CAPI in addition to a CATI should not be overlooked.

Table 4-1. Versions of the Survey Required Based on Modes of Data Collection, Respondents, and Language

Respondents/Languages	Number of Versions			*Total*
	CATI	CAPI[1]	Paper[2]	
Parents				
English	1	1	1	*3*
Spanish	1	1	1	*3*
Children ages 13+				
English	1	1	1	*3*
Spanish	1	1	1	*3*
Total	*4*	*4*	*4*	*12*

[1] CAPI may also be implemented as in-person CATI.

[2] Assumes paper for nonresponse followup only.

[4] As discussed in Chapter 6, clustering PSUs would reduce somewhat the cost of hiring interviewers by limiting the number of areas for data collection or nonresponse followup. However, that sort of clustering also has implication for the efficiency of the sample design.

Response Rates for a New NSCF

While there have been studies suggesting that nonresponse rates are not as strongly related to nonresponse bias as previously thought (e.g., Keeter et al. 2000; Curtin, Presser, and Singer 2000), it is well understood that when response rates are low, there is a greater chance for nonresponse bias. The extent of nonresponse bias depends on many survey conditions, including the differential impact that the likelihood of response has on the bias of each of the survey outcomes. Achieving a high response rate is critical to data quality, in particular in helping to reduce nonresponse bias.

Expected Response Rates

The original NSCF achieved a weighted response rate of 74.4%. We have used an expected 80% response rate throughout this report.[5] However, several factors should be considered in that prediction. We anticipate that much of the contact information in the SSA administrative files will be out of date. Because of direct deposit, beneficiaries have little incentive to update their address and phone records. The prevalence of cell phones and caller-ID also make it increasingly difficult to achieve high response rates on phone questionnaires, in general (Curtin et al. 2005; Lepkowski 2008). In addition, research suggests that response rates on phone interviews have decreased over time, even when similar methods are used (Holbrooke, Krasnick, and Pfent 2008). It appears that the public is simply less willing than they used to be to participate in telephone surveys. Consequently, achieving an 80% response rate will undoubtedly require more tracing, nonresponse followup, and other tactics than were used in the previous administration of the NSCF.

The response rate for the new NSCF can be calculated as the proportion of eligible respondents with whom data collection is completed. However, there are two different aspects of the response rate: contacting potential respondents and gaining their cooperation. For NSCF, the contact rate is the proportion of eligible households in which a household member is reached. The cooperation rate is the proportion of contacted households for which an interview is completed. This distinction is relevant because strategies for enhancing contact rates may be different from those for enhancing cooperation rates. For example, increased call attempts may enhance contact rates but do little to improve cooperation rates. Likewise, incentives may enhance cooperation rates but not contact rates. It is also important to note that surveying both parents and children requires eliciting cooperation from two different respondents.

Enhancing Response Rates

Research suggests a number of ways to enhance contact and/or cooperation rates. For example, experimental studies suggest that people who receive advance letters are more likely to participate in a survey and less likely to refuse than those who do not (Camburn et al. 1995; Hembroff et al. 2005; Link and Mokdad 2005; Traugott, Groves, and Lepkowski 1987). Monetary incentives, especially if they are provided to the respondent in advance, have been shown to substantially increase response rates, sometimes even doubling the response rate (Edwards et al. 2009; Göritz 2006; Holbrooke et al. 2008; Laurie and Lynn 2009; Ryu, Couper, and Marans 2006; Singer 2002; Singer et al. 1999). The amount of the incentive is also a consideration. A sizable body of research has shown that higher incentives are

[5] The estimated 80% response rate is based on the assumption that the denominator will exclude individuals who died, are no longer living in the continental United States or living in Medicaid facilities, and sample members identified as wards of the state. It also assumes that completion of a significant portion of either a parent interview or a corresponding child interview constitutes completion.

associated with higher response rates (Krenzke, Mohadjer, and Hao 2012). Singer and colleagues (1999) found that each dollar of an incentive paid resulted in approximately a third of a percentage point difference in response rate between the no incentive and the incentive conditions. However, while not explicitly forbidden, the Office of Management and Budget tends to require strong justification for the use of incentives (Office of Management and Budget 2006).

In the original NSCF, the contractor conducted an experiment in which it offered three different forms of incentive: a check, a phone card, and a debit card. Response rates for individuals who received the check and debit card were statistically significantly higher than the rates for the sample members receiving phone cards. Of course, in order to provide the incentive prior to the contact attempt requires an advance letter, and, invariably, some proportion of the letters will be discarded without being opened, meaning the incentives are discarded as well.

The length of the field period is another factor that affects the response rate and data collection costs. Longer field periods allow researchers to contact potential respondents who are out of town; let cases 'rest' after multiple unsuccessful call attempts; and trace potential respondents whose contact information is out of date. In a meta-analysis of random digit dialing (RDD) telephone interviews conducted by large-scale survey organizations, Holbrooke and her colleagues (2008) found that one extra day of calling yielded one-tenth of a percentage point increase in response rates, although it is not clear from the analysis that this is a linear trend.

One specific concern about the response rate for the NSCF is the length of the survey, since respondent cooperation is often affected by the length of the interview. For example, in the same study cited above, Holbrooke and her colleagues (2008) found that a 1 minute increase in survey length reduced the response rate by 0.6 of a percentage point. This suggests that a 15-minute increase in the length of an interview would result in a 9% decrease in response rates. Of course, the length of the interview also has implications for the costs of data collection (e.g., interviewer hours per complete) and the subsequent cleaning and processing of the data. Therefore, minimizing the length of the survey is important for a number of reasons.

As noted previously, the original NSCF took, on average, about 70 minutes to complete. If response rates are a concern for the new NSCF, a shorter survey, perhaps averaging between 30 to 40 minutes, could be fielded. A shorter survey, however, would reduce the number of questions that could be asked of SSI children and families. We estimate that approximately 125 questions could be asked in a 40 minute survey.[6] This estimate assumes that not all parents would answer each question due to skip patterns, and that there would be a mixture of different types of questions, but that most questions would be closed ended. The number of policy questions that could be addressed by a 40 minute survey will depend on how broadly or narrowly SSA defines each of the policy questions. For example, the policy question regarding resources used by SSI children and families (Policy Question #3) could be limited to asking about three or four key resources as opposed asking about 10 or 15 different types of resources. If SSA limits the focus of each of the policy questions, we believe that a new NSCF that is 30 or 40 minutes in length could likely address at least 5 or 6 of the policy questions as currently written, perhaps more. The exact number will, of course, depend on the survey design.

[6] This estimate is based on the PEELS parent interview, a CATI survey with many items similar to NSCF. It had approximately 200 questions and took about an hour to complete.

Cost Per Complete

Once the survey is developed and the goal for the response rate is set, consideration must be given to minimizing the cost per complete. In large-scale surveys, the cost per complete typically increases over time. The first slice of the sample can be expected to have up-to-date contact information and will readily agree to participate. The second slice of the sample will include a combination of individuals whose contact information is out of date but who are easily traced, and individuals who are reluctant to participate by phone but agree to do so after multiple calls. The subsequent slice will require extensive tracing and/or refusal conversion. In the final slice of the sample, some individuals will be coded as unlocatable. Given the proposed modes of data collection, others in this slice may be assigned to in-person data collectors or sent shortened versions of the questionnaire on paper. Because in-person data collection is so expensive, one way to control the cost per complete is to maximize the response rate in the first three slices.

5. Design Options for a New NSCF

In this chapter, we present design options for surveying SSI children and families. We discuss three main options, which include re-surveying original NSCF respondents, conducting a cross-sectional survey of a new sample of SSI children and families, and implementing a forward longitudinal design in which a new sample of SSI children and families would be followed for a specified period of time. For the design options, it is assumed that with the new NSCF, SSA would like to be able to: (1) achieve a high-quality sample that limits the potential for bias due to nonresponse, (2) minimize cost, and (3) detect differences among subgroups.

For readers who are unfamiliar with the various measures of precision discussed in this chapter and in Chapter 6, we have included a brief overview of each in Appendix B.

Re-Surveying Previous NSCF Participants

The first design option is to study change among those SSI children/families who participated in the original NSCF by re-surveying former NSCF participants. While the original NSCF did not include conducting multiple waves of data collection, this option would make it a longitudinal panel study. Unlike cross-sectional studies, longitudinal studies provide information about the continuity or discontinuity of individual characteristics or conditions and allow researchers to track trends of development, which is especially pertinent in studies involving children. In addition, because of the long lapse between the original NSCF and the proposed followup, SSA would be able to identify long-term phenomena, such as changes in the nature and severity of children's disabilities, access to health care, educational progress, and household composition. It is important to note that the new NSCF data would not generalize to current SSI participants but to individuals who were receiving SSI in 2001.

The efficiency of such a design depends in part on the expected rate of attrition between the original NSCF and the proposed follow-up as well as the level of effort required to locate the former respondents. For individuals in the original NSCF sample who continue to receive SSI, more recent contact information will be available (although not necessarily up-to-date).

If SSA is interested in acquiring information specific to children on SSI, one limitation of re-surveying NSCF participants involves the number of potential respondents still under age 21. The original NSCF was conducted in 2001 and included children from all different age groups. More than 10 years later, only a proportion of those children will still be under the age of 21. If this option is pursued, items might be added to the survey to capture outcomes suitable for adult respondents.

In the original NSCF, there were 1,316 children who were between the ages of 0-10 and 3,045 between the ages 11-21 who were receiving SSI. We assumed that 30% of the SSI recipients who were ages 0-5 at the time of the survey and 60% of the SSI recipients over age 6 would still be receiving SSI 11 years later, in 2012, as influenced by Davies, Rupp, and Wittenburg (2009). Table 5-1 provides the estimated number of respondents who were between the ages of 0 and 10 and ages 11 to 21 at the time of the original NSCF who would complete the new NSCF in 2013. To be consistent with the response rates for the original NSCF, we assume that about 85% of those who received SSI at the time of the original NSCF and who are still SSI recipients will complete the new NSCF (n = 2,094) and that about 70% of those who received SSI at the time of the original NSCF and are no longer SSI recipients will complete the survey (n

= 1,297). Design effects due to variation in weights and clustering within PSUs in the original NSCF design would reduce the effective sample size (ESS) from 2,094 to 1,047 for SSI recipients and from 1,297 to 649 for non-SSI recipients. With these sample sizes, it would be possible to detect differences of 7 percentage points (e.g., 57% versus 50%) with 80% power. Subgroup analyses may lack the statistical power to detect small or moderate differences between SSI recipients and those no longer on SSI in 2013.

Table 5-1. Estimated Number of Children Receiving SSI at the Time of the Original NSCF Who Would Complete the Follow-Up NSCF, ESS, Margin of Error (MOE), and Minimal Detectable Difference (MDD)

Age in 2013	Estimated number of respondents completing original and follow-up		ESS[1]		MOE for P=50%		MDD[2] for P_1-P_2, SSI vs non-SSI in 2013
	SSI	Non-SSI	SSI	Non-SSI	SSI	Non-SSI	
11-17	163	237	81	118	0.109	0.090	0.20
18-21	378	208	189	104	0.071	0.096	0.17
22 or older	1,553	853	776	426	0.035	0.047	0.08
Total	*2,094*	*1,297*	*1,047*	*649*	*0.030*	*0.038*	*0.07*

[1] Design effects were calculated for the proportion of SSI recipients on Food Stamps using original NSCF data and SUDAAN software for survey data.

[2] For power = 0.80, alpha = 0.05, 2-sided *t*-test of H_0: P_1-P_2 = 0

Re-surveying former NSCF respondents would allow researchers to compare responses on specific items for children who were SSI recipients at the time of the original NSCF and are still SSI recipients. As noted above, we estimate there would be 2,094 respondents in this category, but that the design effects would reduce this to an ESS of approximately 1,047 respondents. We would expect the high overlap in the sample between the original NSCF and the follow-up to induce a positive correlation, so the detectable differences would be smaller, depending on the strength of the correlation between them for the characteristics being analyzed. Comparisons of these 1,047 cases at both points in time would allow MDDs of 6 percentage points for uncorrelated characteristics (ρ = 0), 4 percentage points for a moderately correlated characteristic (ρ = 0.5), and 3 percentage points for a highly correlated characteristic (ρ = 0.8), with 80% power. The much larger group of all SSI recipients who were between ages 0 and 21 at the time of the original NSCF (*n* = 4,317) could also be compared with the subset who are still receiving SSI in 2013 (*n* = 2,094), since there would still be approximately 50% overlap between the two groups, which would increase the power slightly.

Although re-surveying former NSCF respondents would produce findings that would generalize to SSI recipients in 2001 and allow SSA to discuss trends over time, we do not discuss this option in more detail in the next chapter for a couple of reasons. First, we estimate that there would be low ESS for subgroups of interest. For example, for the subgroup of children who would be between the ages of 11-17 in the 2013 survey, the small ESS for SSI recipients (*n* = 81) and non-SSI recipients (*n* = 118) would allow only large MDDs of about 20 percentage points with 80% power. Furthermore, re-surveying former NSCF respondents would not provide SSA with a snapshot of current SSI recipients, including young children (i.e., under age 11), which means that many of the policy questions would not be

addressed by this approach. However, this approach could be used in conjunction with one of the design options discussed below (e.g., a cross-sectional design with a new sample of SSI children).

Cross-Sectional Designs

SSA may wish to consider a cross-sectional design for the new NSCF. The advantage of a cross-sectional design is that it allows researchers to take a snapshot—a detailed picture of current SSI beneficiaries in the specified age range at a particular point in time. By selecting a nationally representative sample and developing appropriate sampling weights, the results of the survey will be generalizable to the entire population of SSI recipients in the same age range at that time. As noted previously, many of the policy questions will be able to be answered by surveying SSI children and families at one point in time. More specifically, the use of a cross-sectional design will allow SSA to address Policy Questions # 1, 2, 4, 7, 8, and 9. Additionally, Policy Questions #3, 5, 6, and 10 could be partially addressed.

The cross-sectional design options could use SSA administrative data for the sampling frame, with oversampling for subpopulations, for example, those who are ages 13-17, those with mental impairments, and those in foster care. The sampling options described in Chapter 6 arrive at the same precision for subgroups, with the exception noted for foster care.

Cross-Sectional Design, with a Comparison Group Sample

Some of the Policy Questions (i.e., #3, 5, 6, and 10) can only be partially answered with a cross-sectional design that focuses solely on a sample of SSI children and families. To answer these Policy Questions fully, researchers will need to collect data from a comparison group of non-SSI children and families. This comparison group could be defined more narrowly as children with disabilities who do not receive SSI and are from low-income families or it could be defined more broadly as children with disabilities who do not receive SSI. A number of options exist for identifying comparison groups. They are introduced briefly here and discussed in more detail in Chapter 6, where we describe sample design options.

The first option is to define the comparison group as those children who have been determined by SSA to be ineligible for SSI. This comparison group would be composed of those children who lost SSI benefits and those who recently applied for SSI but were denied benefits. The second option is to define the comparison group as those children who are potentially eligible for SSI, meaning they have a disability, are from low-income families, and are not currently on SSI. There are a number of approaches that could be used to survey a comparison group of children who are potentially eligible for SSI. One is to use an existing sample from another national survey (e.g., American Community Survey (ACS), National Health and Nutrition Examination Survey (NHANES), NHIS, MEPS, National Survey of CSHCN). A second approach would be to create a new frame, possibly in a limited geographical area. A third approach would involve recruiting school districts and children with disabilities from within those districts. The fourth approach would be to create a new sampling frame through a broad household screening. The final approach would involve using administrative datasets from other federal programs serving low-income families or children with disabilities (e.g., TANF, vocational rehabilitation (VR) services, or Medicaid) to identify a comparison group of potentially SSI-eligible children. All of these options have advantages and disadvantages, which are described in Chapter 6. Because low-income children with disabilities constitute a small portion of the overall US population, locating and surveying a suitable comparison group can be a challenging aspect of the study design.

Longitudinal Designs

Although the policy questions delineated by SSA could be addressed through a cross-sectional design, SSA may wish to consider a forward longitudinal design to assess change over time on some or all of the policy questions. We assume that the longitudinal designs would begin with a nationally representative sample of SSI beneficiaries and therefore would carry forward all the benefits of the cross-sectional designs discussed previously. In addition, as described in the section on re-surveying respondents from the original NSCF, a longitudinal study would allow researchers to track trends in children's development, health, education, employment, and family life.

The simplest longitudinal design would focus solely on SSI children and families; therefore, some of the policy questions would not be fully addressed. With this option, we suggest that the first round of data collection be a cross-sectional survey that includes items to address each of the policy questions. Thus, if for some reason, the additional rounds of data collection do not happen, SSA will still have a rich array of data on SSI children and families from one point in time that would be generalizable to the entire population of SSI recipients in the same age range at that time. For the longitudinal component, SSA may consider following up with all SSI children and families, or just focus on one or more specific subgroups, such as children between the ages 13-17, children with mental impairments, or recent applicants.

Forward Longitudinal Design, with a Comparison Group Sample

A more complex longitudinal design would include a comparison group of non-SSI children and families. One possibility is to include the comparison group sample only as part of the cross-sectional survey in order to fully address the policy questions that compare SSI children and families to non-SSI children and families. Another possibility is to follow the comparison group longitudinally as well in order to assess change over time within this group and as well as compared to the SSI children and families.

Selection of a design option will have implications for sampling, instrumentation, and analysis. The basic designs introduced here are developed more fully as we discuss those additional aspects of the new NSCF.

Benefiting from Related Data Collections

Before discussing various sampling frames for cross-sectional and longitudinal design options for a new NSCF, we briefly mention two ways in which SSA could make use of external data collections to gather information on SSI children and non-SSI children. The first would require collaboration between SSA and other agencies, while the second would mean designing the new NSCF to ensure that it includes questions identical to those used in relevant external surveys on non-SSI children.

First, SSA could obtain information on SSI children and families by adding an SSI sample to an existing survey that is being conducted by another agency for other purposes. For example, SSA has previously collaborated with the Census Bureau to add a sample of SSI children to the SIPP in order to obtain focused information about SSI children and families. It may also be possible for SSA to collaborate with other agencies to include additional items to be asked of respondents. However, it is likely that this approach would only provide SSA with limited information about SSI children and would not permit SSA to fully address each of the policy questions. The existing surveys are unlikely to include detailed items on each of the policy questions, and adding a sufficient number of items to an existing survey to address

each policy question does not seem feasible since adding this many items would lengthen the existing survey considerably, which could affect response rates. Add-ons might be a better option if SSA decides to focus on a specific policy question instead of a wide range of questions.

Second, SSA could make use of external surveys to obtain information about the comparison group of non-SSI children. This approach would by-pass efforts related to sampling, data collection and weighting for the comparison group. We mention this approach in the design options chapter because in order for this approach to be successful, the new NSCF would need to be designed to include items that are identical to those used in one or more external surveys. As noted in Chapter 3, it is anticipated that many of the survey items for a new NSCF will come from existing surveys. If the exact wording from the existing surveys is kept in the new NSCF, the resulting NSCF estimates for SSI children could be analyzed in conjunction with external survey estimates for non-SSI children in order to make comparisons between these two groups of children. However, this approach can potentially have a number of challenges related to sampling and non-sampling error. Because these challenges are data analysis-related, they are discussed in more detail in Chapter 7.

6. Sampling Options for a New NSCF

SSA has identified a number of policy questions for the new NSCF, which will drive design of the sample. In this chapter, we discuss sampling options available to SSA, beginning with a brief description of the target population. Next, we present sampling frames that are closely knitted to the target population, which include those that are available for the SSI children and their families as well as for comparison groups. Relating to sampling frames, we next discuss the formation of the PSUs and the sample selection process, as we recommend it occur in two stages, first the selection of PSUs, then persons within PSUs. We then provide results of power analyses for both cross-sectional and longitudinal design options. We conclude with a discussion of the relative costs associated with the cross-section and longitudinal design options.

Defining the Target Population

The policy questions dictate the design options and the definition of the target population. As discussed in Chapter 3, the policy questions indicate the need for different types of respondents and subgroups. As an example, answering Policy Question #10 requires a sample of SSI children with mental impairments large enough to determine with some precision whether psychiatric services are being accessed by these children. As another example, answering Policy Question #6 requires researchers to compare the impact of the economic downturn on families of SSI children with the impact on families of non-SSI children.

Because the majority of the policy questions are geared toward SSI recipients, the target population would include the following: "*SSI recipients who are between 0 and 21 years old and reside in the US at the time of interview."* Policy Question #7 has special focus on youth who lost benefits. SSA has also expressed interest in following a sample of recent applicants longitudinally. Therefore, the target population could be expanded to: "*SSI recipients who are between 0 and 21 years old and reside in the US at the time of interview, as well as those who have lost benefits in the past 12 months, or have recently applied in the past 12 months."* Also, a number of policy questions refer to a comparison group of non-SSI recipients. As discussed in Chapter 3, this group could be defined in several ways. One way to think of the comparison group might be those who are potentially eligible to receive SSI; that is, those children who are not currently receiving SSI, who have low income, and who have a disability of a specified level of severity. Here, we offer one possible expansion of the target population in general terms as follows: "*SSI recipients who are between 0 and 21 years old and reside in the US at the time of interview, as well as those who have lost benefits in the past 12 months, or have recently applied in the past 12 months, or other potentially SSI eligible children with low income and a disability with a level of severity similarly defined for SSI recipients."*

Figure 6-1 provides an illustration of these possible groups of interest, namely:

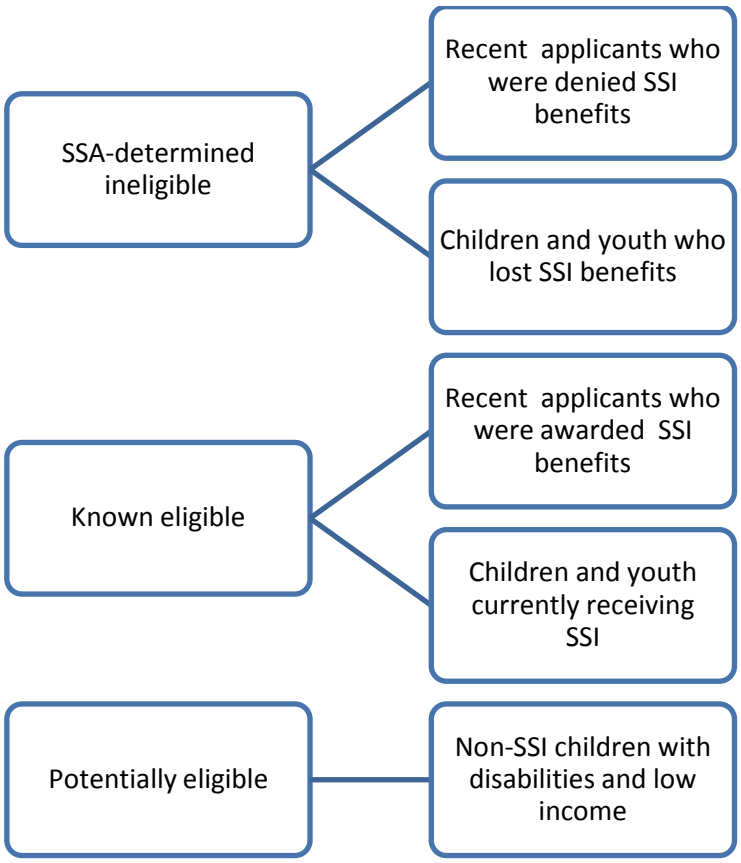
- **SSA-determined ineligible**: SSI recipients who lost benefits (terminated or suspended) for a variety of reasons, including increase in income, and recent applicants who were denied benefits;

- **known eligible**: Current SSI recipients and recent applicants who were awarded benefits. There are additional subgroups within the known eligible category, as some of the Policy Questions focus on transition-aged youth or children with mental disabilities; and

- **potentially eligible**: Children who are not on the SSA administrative records because they have not applied for SSI; they may be eligible for SSI, however, due to a disability and low income.

Later in this chapter, we estimate the size of each major group and the design options for representing these groups. It should be kept in mind, though, that depending upon the design options chosen and how the comparison group is defined, the target population will likely need to be refined further.

Figure 6-1. Major Design Groups of Interest



Note: The status of a small percentage of recent applicants will be left unresolved within the first year.

Sampling Frame for SSI Eligible Children

The SSA administrative data are the sole consideration as the sampling frame for the SSI recipients. The same data source was used for the prior NSCF survey. The Supplemental Security Record (SSR) is the main file used to administer the SSI program and contains information about 1.6 million SSI recipients between the ages of 0 and 21, inclusive. It contains records for every person who has ever filed for SSI benefits. Therefore it contains data for SSI recipients, denied applicants, started application process but did not finish, and those who have lost benefits. The data elements for each record type are provided in

Table 6-1. Other files that may be of use are the 831 and 832/833 Disability Files. The disability diagnoses codes from these files are also included in the SSR.

Table 6-1. Data Elements in the Supplemental Security Record

Group	Data Elements in the Supplemental Security Record
SSI recipients	PSTAT— Payment status. This data element indicates the payment status code. It is an indicator of whether the case is currently being paid, in nonpay, suspended, or terminated status.
Applied, but denied	DENCDE—Denial code (nonblank if denied). This data element indicates the reason the initial claim was denied. It reflects the final denial reason, not just the result of the disability determination, and may be cleared if a claim is allowed on an appeal or reopening (error made on original decision and no appeal is necessary).
Started application process, but did not finish	AP-TYPE—Application type. If blank then a full application was filed, if coded "A" than an abbreviated application was completed. The abbreviated application procedure is used when the applicant is clearly ineligible for payment for certain nonmedical reasons, e.g., excess countable income, not a US resident or failure to pursue the claim. PSTAT— Payment status. This data element indicates the payment status code. It is an indicator of whether the case is currently being paid, in nonpay, suspended, or terminated status.
Lost benefits	PSTAT—Payment status. This data element indicates the payment status code. It is an indicator of whether the case is currently being paid, in nonpay, suspended, or terminated status.

Some contact information among the data elements includes the following:

- PDNAMADR, PD-CITY, PD-STNAME, PDZIP—Mailing address, city, state zip;
- AA-ADDR, AA-CITY, AA-STNAME, AAZIP—Applicant's address if different from mailing address (the SSI Address File has complete mailing/residence address data); and
- TELNO—Recipient's telephone number.

There is also contact information for an authorized representative and representative payee. Some useful variables to help define subgroups include the following:

- TOA and COMP-STAT-TOA—These data elements provide the most recent description of the program category (aged, disabled, or blind) and living arrangement of the eligible person. COMP-STAT-TOA is an update of TOA (Type of Action); this data element is only set when there has been a change since the application was filed;
- BIRTH-JD—Date of birth;
- DIBDIG, DIBDIG2—Primary disability diagnosis code, secondary disability diagnosis code; and

- basic demographics – Amount of earned income (IEAMT), amount of unearned income (IUEAMT), date of birth (BIRTH-JD), race code of applicant/recipient (RACE), sex code (Sex).

The variable LIVF (living arrangement code for federal money) may be used to help define the subgroup of recipients in foster care. While there is no specific code for recipients in foster care, there is a code for "Living in the household of another receiving support and maintenance." This group should include recipients living in foster care, among other types of living arrangements (e.g., recipients living with other family members).

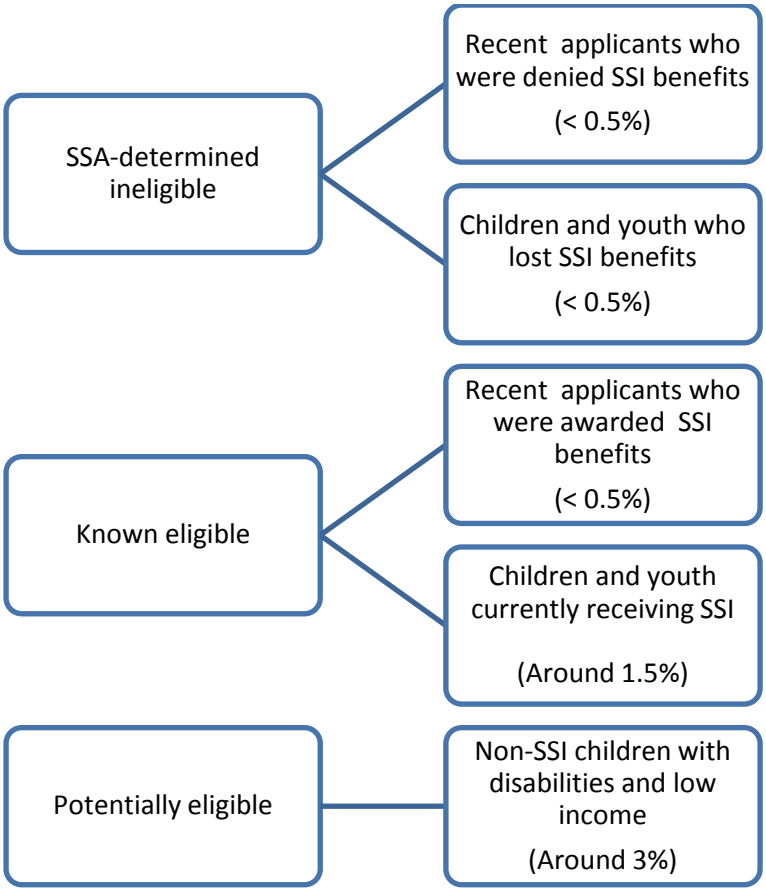
One of the challenges to using the administrative records file is the ability to contact selected persons and families. With regard to the final case dispositions from the prior NSCF (SSA 2012) among those selected in the sample, 16% (unweighted) were non-locatable, even after attempts by phone and in the field. The weighted percentage located in the prior NSCF, according to Davies and Rupp (2005/2006) was 81.5%, including 80.9% for non-SSI recipients. Attempts to contact selected persons from the SSA administrative files will need an extensive vendor-assisted tracing effort for phone numbers and, as in the prior NSCF, on-foot field locating efforts after a vendor-assisted tracing effort for addresses.

Sampling Frame Options for a Non-SSI Comparison Group

A number of the SSA policy questions refer to non-SSI children, which means that a comparison group is needed to fully address these questions. Chapter 3 discussed how this comparison group could be defined more narrowly as children with disabilities who do not receive SSI and are from low-income families or it could be defined more broadly as children with disabilities who do not receive SSI. In this section, we discuss two approaches to identifying this comparison group. The first approach focuses on those children who have been found ineligible for SSI, and the second approach focuses on identifying those children who may be potentially eligible for SSI. The first approach relies on using the SSA administrative data to define the comparison group. For the second approach, we present and describe a number of different options and discuss the advantages and disadvantages of each.

Before discussing each approach, it is important to note the percentage of the population that the comparison group options represent. As shown in Figure 6-2, the known eligible group (i.e., those who are receiving SSI and those who are recent applicants who will eventually receive SSI) make up a relatively small percentage of the population of 0- to 21-year-olds in the US population. Using 2010 data from SSA and the ACS Public Use Microdata Sample (PUMS), we estimate this percentage to be less than 2% of the entire population of 0- to 21-year-olds. The proportions for the SSA-determined ineligible group and the potentially eligible group are also estimated to be relatively small (less than 1% and around 3%, respectively). We discuss the challenges associated with trying to identify such a small proportion of the population in more detail in the next sections.

Figure 6-2. Estimated Population Percentages Among 0- to 21-Year-Olds, by Major Groups



Source: The total population for 0- to 21-year-olds and the population proportions for the potentially eligible group come from the 2010 ACS PUMS. The population proportions for the SSA-determined ineligible and known eligible groups come from 2010 SSA data, using the ACS population total as the base.

SSA-Determined Ineligible Comparison Group

One option is to define the comparison group as those children who have been determined by SSA to be ineligible for SSI. This comparison group would be composed of those children who lost SSI benefits and those who recently applied for SSI but were denied benefits. As shown in Figure 6-2, we estimate that less than 1% of the population of 0 to 21 year olds would fall into this SSA-determined ineligible category.

The main advantages for defining the comparison group in this manner are related to the readily available frame, which comes from SSA administrative files. This comparison group could easily be incorporated into the design options discussed in the previous section. As such, researchers can control the balance of the comparison group and the main sample of SSI recipients for various subgroups of interest. The main disadvantage is the limitations on inferences that can be drawn based on the comparison since these children either did not meet the disability requirements defined by SSA or they did not meet the income requirements.

Potentially Eligible Comparison Group

We estimate that roughly 3% of those 0 to 21 years of age in the population do not receive SSI but are potentially eligible due to low income and disability.[7] The definition that we used to define the potentially eligible comparison group may be too broad, but it is used to help provide a rough determination of the possible size of the group. This definition will need to be refined through future discussions with SSA.

A number of approaches could be used for surveying a comparison group composed of children who are potentially eligible for SSI. One option is to use an existing sample from another national survey. A second is to create a new frame, possibly in a limited geographical area. Table 6-2 provides a summary of these various options. Several of the options require a two-stage data collection: (1) a screener to determine 'potential' eligibility status and (2) a questionnaire to collect the comparison-group information to address the policy questions.

Table 6-2. Sources of Data for a Comparison Group of Children Potentially Eligible for SSI

Sources of Data	Use of Data
Existing sample from national survey	Two-phase sample
School districts	Multi-stage sample—selection of districts/schools/students
New frame	One-stage sample with screener One-stage RDD sample with screener Multi-stage area sample
Non-SSA administrative datasets	Same as SSI recipients.
Low income areas	Multi-stage sample—areas, then households, then persons
Limited number of cities	One-phase sample, with screener

Existing Samples as Screeners. Other national surveys collect data relating to income, disability, and SSI participation. For example, Ireys et al. (2004) compared estimates between the NSCF and three national surveys to gauge the quality of the estimates from the various sources and to gain insights into how estimates from the NSCF align with the other surveys' estimates. The surveys, all of which included samples of SSI children, were the National Survey of CSHCN, SIPP, and NHIS. Such large existing samples may be useful as a screener to help define the sampling frame of children potentially eligible for SSI. The 'screener' questions (i.e., items in the existing sample survey) would need to identify low-income families with a child with a disability (to be defined), who are not already receiving SSI.

[7] The 3% potentially eligible were defined through a definition of low income, presence of a disability, and not receiving SSI. For the 'low-income' component of the definition, we first processed weighted cross-tabulations of SSI x poverty x disability using data from the CSHCN, which covers special needs children ages 0–17, to find the poverty cutoff that includes 90% of the children on SSI. The cumulative percentage distribution of children on SSI by poverty cutoffs are (without regard to disability): 48% less than or equal to the poverty level; 80% less than or equal to two times the poverty level; 90% less than or equal to three times the poverty level; and 95% less than or equal to four times the poverty level. For those on SSI with a disability, the cumulative percentage distribution by poverty level is: 55% less than or equal to the poverty level; 87% less than or equal to two times the poverty level; 96% less than or equal to three times the poverty level; and 98% less than or equal to four times the poverty level. Given the cumulative distributions, the 3 times the poverty level cutoff was used as the surrogate rule for defining 'low income' with the ACS PUMS to get an estimate of potentially eligible for SSI, using the disability variable available.

In this scenario, SSA would collaborate with the agency sponsoring the existing survey to add items necessary for identifying the SSI comparison group and collecting data parallel to that from the new NSCF. We only considered surveys that are ongoing or that will be conducted in the future. The following surveys were among the ones that we considered:

- ACS,
- NHANES,
- NHIS,
- MEPS,
- SIPP, and
- National Survey of CSHCN.

ACS. Looking first at the ACS, we found that the 2010 ACS PUMS has 5,572 records of children who receive SSI and who are between the ages of 0 and 21. Interestingly, 2,506 of these do not report having a disability according to the Census Bureau's disability variable, so there appears to some inconsistency between these two variables. The expected sample size of potentially eligible children would be large enough for an NSCF comparison group. Due to various reasons, it may not be possible to add questions to the ACS to better define and screen for the potentially eligible group; however, it may be possible for SSA to work jointly with the Census Bureau to administer a followup NSCF comparison group survey to the potentially eligible subgroup, or a subsample thereof.

NHANES, NHIS, and MEPS. Due to the low expected sample sizes of potentially SSI eligible children, NHANES, NHIS, and MEPS were not pursued further. (To illustrate the sample size of the potentially eligible, we provide the counts that are on SSI and assume that there are about as many non-SSI potentially eligible cases):

- The 2010 NHIS had 559 families who had at least one child who was receiving SSI.
- NHANES had 231 who were between 0 to 16 years of age on SSI in the 2007-2008 survey.
- The 2009 MEPS had only 187 who were 0 to 18 years old who received SSI, and many would have aged out of the age 0-21 category by 2013.

SIPP. We examined the 2008 SIPP public use files to assess SIPP as a potential source for the comparison group. In the 2008 SIPP, SSA added a supplemental sample of children receiving SSI and special modules that asked child and adult disability questions. In the 2008 SIPP, there were 2,031 children ages 0-21 receiving SSI and 127,195 children ages 0-21 not receiving SSI.[8] Looking at the non-SSI children, there were approximately 1,200 children ages 0-19 who were reported to have a developmental delay or physical, mental, or learning condition that limited ordinary activities or their ability to do regular school work. There were approximately 1,500 children ages 15-21 who were reported to have a physical, mental, or health condition that limited the kind or amount of work they could perform.

[8] In future SIPP data collections, we would not expect the sample size of SSI children to be this large unless SSA again added a supplemental sample to the SIPP.

The number of children who would be potentially eligible for SSI, however, would be smaller than the aforementioned sample sizes because only a portion of them would meet the SSI income requirements. The official poverty level in 2012 is $23,050 for a family of four. Using an annual income of $25,000 as a rough poverty threshold, we found that of those non-SSI children who were reported to have a developmental delay or a physical, mental, or learning condition, the following percentages of children would be classified below this poverty threshold:

- 39% of those ages 0-5,
- 27% of those ages 6-19, and
- 26% to 32% of those ages 15-21 (depending upon the disability items used).

By comparison, the poverty rate for children under age 18 in the 2010 Census is 22%. Although this is only a very rough estimate, it allows us to approximate that the number of sample cases available for the non-SSI comparison group using SIPP 2008 would probably be between 500 and 600 children ages 0-21. The ESS would be less than this, but without the design effects for SIPP, we were unable calculate the ESS. In general, an ESS of at least 400 children per group would allow adequate precision for estimates and comparisons of SSI children and non-SSI children ages 0-21 but would likely not permit subgroup comparisons. It should be noted that the SIPP may not always include child disability questions. The questions that permitted us to estimate the number of children who were reported to have a disability were from one of the SIPP topical modules. Similar questions would need to be included as part of other SIPP modules if it were to be used to identify a comparison group of non-SSI children for the new NSCF.

National Survey of CSHCN. The existing survey with the most potential for providing a comparison group for the NSCF is the State and Local Area Integrated Telephone Survey (SLAITS)/National Survey of CSHCN. The SLAITS, conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC) collects in-depth national, state, and local data on health care in the US. SLAITS provides a mechanism for collecting national data quickly and is funded through sponsorship of specific questionnaire modules by government agencies and nonprofit organizations. SLAITS uses the same random-digit-dial (RDD) telephone interview design and sampling frame as the CDC's National Immunization Survey (NIS), which screens nearly one million households per year to identify eligible respondents. SLAITS can be altered to address issues of interest to specific government agencies or nonprofit organizations through customized questions or series of questions. For example, modules have been added on adoption and the Children's Health Insurance Program (CHIP).

Two alternating studies are currently being conducted on a 4-year cycle using SLAITS, the National Survey of CSHCN and the National Survey of Children's Health. Each survey takes roughly 18 months, and SLAITS is out of the field in the intervening periods. In 2005-06, the SLAITS survey included 40,242 detailed CSHCN interviews nationwide. A SLAITS module might provide a suitable mechanism for collecting data on a comparison group of children who are low income and have disabilities that make them potentially eligible for SSI. Under this scenario, we envision using SLAITS to screen households for children ages birth through 17 who are comparable to those eligible for SSI. Former SSI applicants would be screened out through a series of questions about previous efforts to acquire SSI benefits. A module with new NSCF questions would be added to the SLAITS-based National Survey of CSHCN. A skip pattern would ensure that only non-SSI potentially eligibles received the NSCF questions.

Because the National Survey of CSHCN includes a large sample of children with significant health conditions, it provides the best option to date for creating a comparison group for SSI recipients without the cost of screening millions of households to locate a suitable sample. There are several advantages and disadvantages to using the National Survey of CSHCN in this way. First, it covers many of the topics covered in the NSCF, reducing the number of items in the supplemental NSCF module:

- presence of medical, behavioral, or other health conditions and their expected duration;
- diagnosis of specific conditions, for example, attention deficit disorder, autism, developmental delay, asthma, diabetes, cystic fibrosis, cerebral palsy, Down Syndrome, arthritis, allergies, or other named conditions;
- severity of specific health conditions;
- age at which health conditions were diagnosed;
- affects of health conditions on children, for example, difficulty breathing, seeing, hearing, learning, communicating, feeling anxious or depressed, and other named affects;
- affects of health conditions on children's ability to do things other children his/her age do, such as attend school or participate in recreational activities;
- access to health care;
- coverage by public or private health insurance;
- effects of health care needs on family members, for example, diminished earnings and care requirements;
- household income;
- demographic characteristics;
- special education participation; and
- receipt of SSI.

Second, the survey already generates nationally representative estimates of children ages birth through 17. One disadvantage is that the survey does not include a sample of young adults, like the original NSCF did. As a result, no data will be available about children once they transition to adulthood. In addition, the design effect (DEFF) inherent from the National Survey of CSHCN is fairly high, which affects the ESS. Based on the power analysis shown in Appendix C, we believe that using the National Survey of CSHCN should produce adequate sample sizes for analysis of subgroups (e.g., mental impairments) between those potentially eligible for SSI and SSI recipients. Last, one of the findings by Ireys et al. (2004) is that the National Survey of CSHCN relies on sets of screening items designed to identify children having a special health care need, and these screening items lead to undercoverage of the SSI child population. Here, we want to emphasize that the purpose of using the National Survey of CSHCN would not be to survey the SSI children, but rather to survey a comparison group of non-SSI children. If there are any

concerns about undercoverage of those children who are potentially eligible for SSI, perhaps the set of screening items can be improved to alleviate those concerns.

Samples Through School Districts and Early Intervention Agencies. Over the past 15 years, a number of studies funded by the U.S. Department of Education (ED) have tapped nationally representative samples of infants, toddlers, children, and youth receiving services under the Individuals with Disabilities Education Act through a sample of participating school districts/early intervention agencies. These studies include NEILS, ages birth-2; PEELS, ages 3-5; SEELS, ages 6-9; and NLTS (1 and 2); ages 13-18. Samples for these studies ranged from roughly 3,000 to 15,000. For each study, researchers selected and recruited a nationally representative sample of districts/early intervention agencies. The districts/agencies agreed to recruit families into the study. Family recruitment was a time-consuming undertaking (roughly an hour per family), and ED contractors reimbursed district staff for their work. Only after a family agreed to participate were researchers given access to names, addresses, and telephone numbers. We do not foresee a circumstance in which districts would otherwise release contact information for children with disabilities and their families, so district cooperation would be required in order to achieve access to potential participants.

While the ED-funded studies have a proven method for obtaining a sample of children with disabilities, it presents a number of challenges with respect to generating a comparison group for the NSCF. First, the number of NSCF-eligible children in any given district will be relatively small, so SSA would need to recruit hundreds of districts. Stratifying by district size would facilitate recruitment but increase the effect size, since most districts in the country are small. In the ED-funded studies, recruitment took roughly 12 months. Most districts now have Institutional Review Boards, or the equivalent, that must approve all data collections. Each has its own schedule and paperwork requirements, so recruiting districts has also proven very expensive. To compel districts to participate, ED has invoked regulations stating that, in exchange for Individuals with Disabilities Education Act funds, districts must participate in evaluations of federal education programs. No such regulations would pertain to SSI participation.

Because of these challenges, we do not believe that identifying comparison group children through a representative sample of districts/early intervention programs is a reasonable option.

New Sampling Frames. Another option for identifying a comparison group of children potentially eligible for SSI would be through a separate and independent frame construction effort. Essentially, this option would entail two separate and simultaneous national samples, with more extensive work needed to field the comparison group than the main sample. While a list of SSI recipients exists at SSA, the list for the comparison group would need to be created. As seen in Figure 6-2, we roughly estimate that about 3% of the population of those ages 0 to 21 may be potentially eligible for SSI, which is about 1% of the total US population. Regardless of the definition, children potentially eligible for SSI are a rare group, and extensive household screening efforts would be necessary to identify them.

One option is to conduct a short mail-out screener from an address-based sample (ABS). Using ABS with a mail-out questionnaire provides a viable alternative to RDD. This approach has been used and has attained response rates that exceeded landline RDD response rates while achieving nearly complete coverage (Brick, Williams, and Montaquila 2011). However, as with any data collection approach, ABS has some shortfalls. For any option under the scenario of creating a brand new sampling frame, the screener response rate and eligibility rate would require a very large initial mail-out. Using basic assumptions, suppose a 60% screener response rate is achieved from the mailing, with 1% of the population being eligible, and a 70% completion rate (considers noncontacts as refusals) from those

found to be potentially eligible through phone or mail interviews. In order to arrive at a sample of 5,000 completes, the initial mail-out would need to include well over a million households. With the extensive follow-up needed, and quality checks to ensure acceptable coverage of the target population, this approach may be considered too excessive for the purpose of constructing a comparison group of potentially eligible cases. Selecting an ABS within clusters would reduce the efforts toward a quality frame, however, it does not reduce the screening costs. Also, sampling differentially according to the percentage of households in the census tract having children based on ACS estimates would help reduce the screening a bit.

If the National Study of CSHCN is not available to use to identify the potentially eligible group, and ask survey questions, then a brand new sampling frame and sample design would need to be constructed and developed. The ABS approach would be the best option to produce a nationally representative group of potentially eligible children for the comparison group. The ABS approach has been achieving higher response rates than the option of using RDD for screening. Last, as another option, an area probability sample with in-person interviews was considered by the authors to be too extensive and was not seriously considered.

Administrative Datasets. If administrative data from other federal agencies serving low-income families and/or individuals with disabilities were available to SSA, those administrative data might serve as a suitable sampling frame for an SSI comparison group. We investigated three types of administrative data: TANF, VR services, and Medicaid. A brief summary of each of these programs is provided below, along with a discussion of the feasibility of using these data.

TANF. The TANF program provides assistance and work opportunities to needy families by granting states the federal funds and wide flexibility to develop and implement their own welfare programs. For TANF, the states provide a data report to the Department of Health and Human Services that contains family-level data collected on TANF recipients according to a standardized layout. However, the data report does not provide contact information. Arrangements for contact information would need to be made with each state. States can report these data for all cases or for a portion of the entire caseload, which is obtained through the use of scientifically acceptable sampling methods. From our review of the data report, data on disability type do not appear to be collected, although there are data on whether family members also receive disability benefits. With these drawbacks, the feasibility of using TANF files in the development of a sampling frame for the comparison group was not pursued further.

VR Services. The VR program, sponsored by federal and state governments, helps people who have physical or mental disabilities prepare for, gain, or retain employment. The limitations of using VR data in the construction of a sampling frame for the comparison group is that only youth 14 to 24 years of age receive VR services. Using the 2009 RSA-911 data file on closed VR cases, we estimate that there are about 130,000 VR recipients ages 14 to 21 who do not receive SSI; of these, about 100,000 do not have Medicaid either. This estimated number is relatively small compared to the total number of children who may be potentially eligible for SSI. However, if SSA were to limit the comparison group to only those youth ages 14-21 who receive VR services, then it may be possible for SSA to make arrangements to pursue these data in the construction of a sampling frame. Although there is a national data file of closed VR cases, it does not contain any contact information; there is not a national database of open VR

cases. As with the TANF data, arrangements for contact information would need to be negotiated with each state, and states may not be willing to share these data without a compelling reason to do so.[9]

Medicaid. Medicaid and CHIP provide health coverage to more than 43 million children, including half of all low-income children in the United States. The federal government sets minimum guidelines for Medicaid eligibility, but states can choose to expand coverage beyond the minimum threshold. Kenney, Ruhter and Selden (2009) estimate that about 2.6% of the children receiving Medicaid also receive SSI. Our analyses of the 2010 ACS PUMS data estimate that less than 30% of the children who are potentially eligible for SSI would be found on the Medicaid data files. As such, the feasibility of using Medicaid files in the development of a sampling frame for the comparison group was not pursued further. However, if the comparison group is to be limited by defining it as 'those non-SSI children on Medicaid,' then it may be possible for SSA to arrange to pursue these data in the construction of a sampling frame. Of the three types of administrative data discussed in this section, we believe the probability of obtaining contact information is likely the highest for Medicaid, as it is our understanding there have been previous collaborations between SSA and Centers for Medicare and Medicaid Services with regard to the sharing of data.

Table 6-3 provides a summary of the advantages and disadvantages for using non-SSA administrative data as a sampling frame for the comparison group. Design options using non-SSA administrative data as a sampling frame were not pursued further for the reasons stated above.

Other Options. In this section, we briefly mention a couple of other options that would provide a comparison group of limited scope. We would expect the potentially eligible cases to be generally hard to reach. Therefore, the target population for the comparison group could be reduced in size to focus on improving the data collection efforts. At the same time, the main sample of SSI recipients would need to be limited during the analysis stage in the same manner to make the groups comparable in definition. We briefly discuss these options with the understanding that SSA is likely not interested in approaches that do not generate nationally representative data.

One possible approach is to use Census or ACS data on small areas to increase the probability of finding those who are potentially eligible. To illustrate, a multi-stage area sample could be selected by first identifying counties, or sub-county areas, with a high percentage of the population in poverty. The target population would be limited to the low poverty areas. A sample of high poverty areas would be selected in the first stage, then households selected in the second stage. The advantage of this approach is to reduce effort and cost in creating the sampling frame for the comparison group. The disadvantages are the limit in scope and the extensive screening that would be needed to identify low-income households with persons 0 to 21 years of age with a disability.

Another option would be to conduct the comparison only within a small number of geographic areas or cities. This option has the advantage of focusing efforts on a small number of locales, where procedures could be used to improve the quality of the sampling frame, as well as more extensive nonresponse followup to improve response rates. The impact on the main sample would be that it would likely require an oversample of SSI recipients within the sample of cities selected for the comparison group.

[9] Confidentiality of the records is addressed in 34 Code of Federal Regulations 361.38, Protection, Use, and Release of Personal Information. Paragraph d of the aforementioned regulation provides an exception allowing the release of information for research and audit purposes.

Table 6-3. Summary of Non-SSA Administrative Data

Administrative data source	Availability of key variables		Age range	Relation to SSI	Access
	Income	Disability type			
TANF	Yes	No	Families with at least one child younger than 18 years old	An estimated 16% of families receiving TANF support in federal fiscal year 2003 included an adult or child SSI recipient (Wamhoff and Wiseman 2005/06).	States maintain the files with contact information
VR	Yes	Yes	Ages 14-24	Based on closed VR cases in 2009, 17% of VR recipients ages 14-21 also received SSI, and 31% also received Medicaid.	States maintain the files on open cases
Medicaid	Yes	Yes	In most states, those receiving SSI are eligible for Medicaid	About 2.6% of children receiving Medicaid receive SSI as well (Kenney, Ruhter and Selden 2009).	Data are protected by the Privacy Act. Process for obtaining data includes a review of research protocol by Privacy Board; for approvals, a data use agreement is required, and a fee will be charged.[1]

[1] Access to the Medicaid data is explained at: http://www.cms.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp#TopofPage

Sampling Frame Options for PSUs

Chapter 4 discussed the data collection approach of conducting CATI and then following up with nonrespondents in person. Therefore, while the previous section discussed issues of person-level sampling frames, this section discusses ways to sample geographic areas for the CAPI follow-up attempts. Clustering the sample will reduce interviewer traveling cost. The Census Bureau provides a list of all counties in the United States. Counties not meeting the minimum measure of size (MOS) criterion, based on the SSI recipient population for the targeted age group, would be combined with adjacent counties, perhaps respecting core-based statistical area definitions, and the travel distance for data collectors, until the minimum size criterion is met. Counties meeting the minimum size criterion would serve as PSUs. In the most common scenario, PSUs are formed and selected, then persons are selected from within PSUs. It is beneficial to form PSUs that have a low between-PSU variance, and then stratify or sort them to minimize the between-PSU variance. The PSUs would consist of single counties or groups of contiguous counties.

An alternative to the traditional approach to PSU formation and selection is to initially select a sample of persons that is stratified, but unclustered, then form and select PSUs after the nonrespondents are

identified. In this scenario, the initial contact with NSCF respondents would be by phone. Selecting an initial sample of persons unclustered reduces the DEFF that would otherwise be caused by clustering. Once the initial set of contacts is completed, the set of nonrespondents would be partitioned into PSUs. Then a subsample of PSUs would be selected for nonresponse followup with in-person interviews. A subsample of areas for nonresponse followup like this is conducted in the ACS. It would reduce the cost of hiring interviewers by limiting the number of areas for the followup. The benefits are dampened, however, if the impact of clustering is expected to be low (to be discussed later). That is, turning to an unclustered design reduces the required sample size only slightly. Also, the subsampling would actually increase the variance due to the differential sample rates that would cause an increase to the variation in the sampling weights. Another disadvantage is that the operational feasibility of waiting to know the nonrespondents, and then hiring the interviewers, would be practically inefficient. Since the ACS data collection is all done in person, there are interviewers already in the field awaiting their assignments. Last, the geographic size of the PSUs necessary for generating a sufficiently large national sample may be too big to accommodate interviews with nonrespondents. For example, suppose the initial sample size is 10,000 persons, and 3,000 of them do not respond initially. If the PSUs are formed as counties or groups of counties and result in a frame of about 1,500 to 2,000 PSUs, there would be about two nonrespondents on average across PSUs of a typical geographic size. The geographic size of the PSUs would need to be increased in order to include more nonrespondents per PSU, which would defeat the purpose of clustering to reduce costs. Therefore, with these disadvantages, this design option for PSUs was not pursued further.

Selecting PSUs and Persons

Regardless of the method used to form the PSUs, the process for selecting PSUs would include PSUs with probabilities proportionate to a measure of size. While not a focus of this report, we note that if a comparison group of non-SSI children and families is involved, it would be beneficial that the set of PSUs for the comparison group be the same as the set of PSUs for the main sample, as this would help to eliminate geographic-specific influences on the outcomes. Also, within the selected PSUs, the SSA administrative data are the sole consideration as the sampling frame for the SSI recipients. The SSR is the main file used to administer the SSI program. It contains records for every person who has ever filed for SSI benefits.

When selecting PSUs, an MOS can be constructed to help ensure that sample sizes are large enough for key subgroups of interest. Oversampling can lead to increased design effects, which in turn reduces the sampling precision for overall estimates. For example, it may be necessary to oversample recent applicants if SSA determines it would like to survey and follow these respondents longitudinally. Other key subgroups for SSI recipients include those who are ages 13-17, those with mental impairments, and those in foster care. In this analysis, we also include recent SSI applicants (i.e., those who have applied within in the past year), of which we estimate about 40% will be awarded SSI benefits (SSA 2011). The subgroups, their proportions, and sources are provided in Table 6-4. The proportions were computed out of the total number of SSI recipients and applicants combined.

Table 6-4. Various Subgroups, their Proportions, and Sources

Subgroup	Proportion among SSI recipients and applicants	Source
Mental impairment, SSI	0.481	2010 SSA data
Mental impairment, applicant	0.106	Original NSCF and 2010 SSA data[1]
Ages 13-17, SSI	0.181	2010 SSA data
Ages 13-17, applicant	0.088	2010 SSA data
Lost Benefits – terminated	0.033	2010 SSA data
Lost Benefits – suspended	0.107	2010 SSA data
Denied applicant	0.166	2010 SSA data
Foster care, SSI	0.005	ACS PUMS
Blind, SSI	0.028	Original NSCF
Blind, applicant	0.007	Original NSCF

[1] The proportion of applicants with a mental impairment from the original NSCF was applied to the total number of applicants (SSA 2011).

PSU Selection

To oversample and provide adequate precision for all subgroups, the sample can be designed by selecting PSUs with an eye toward arriving at required sample sizes for each subgroup. As discussed in Folsom, Potter and Williams (1987), the MOS for PSU selection can be assigned as a linear function of terms represented by mutually exclusive groups, with a sampling factor associated with each term.

The MOS for PSU *i* can be assigned as follows:

$MOS_i = f_1 N_{i1} + f_2 N_{i2} + \ldots + f_j N_{ij}$, for J subgroups of interest.

Where,

f_j = the desired sampling rate for subgroup j, $j = 1, 2, \ldots J$.

$= n_j / N_j$

n_j = the desired sample size for subgroup j

N_j = the number of persons in the target population for subgroup j

N_{ij} = the number of persons in the target population for PSU i and subgroup j.

Then the probability of selection for PSU *i* can be assigned as:

$P_i = m\ MOS_i / \sum MOS_i$

where,

m = the number of PSUs to select, and

$n = \sum MOS_i$.

The above formula assumes that all PSUs are noncertainty ($P_i < 1$). The PSUs could be selected from a sort on geographic region and other related area-level contextual variables or through forming explicit

strata and selecting the PSUs within the strata. Strata are typically formed to ensure representation across geographic areas in terms of the outcome statistics of most interest for subgroups of interest via a nested (Krenzke and Haung 2009), or clustered (Ludington 1992) stratification process.

A property of the approach is that close-to-equal workloads per PSU can be achieved by setting n^* to be the desired sample size from all subgroups for each PSU. Within PSUs, the sample sizes for each subgroup are assigned as follows:

$$n_{ij} = n^* f_j N_{ij} / MOS_i$$

After some algebra, under a simple random sample (SRS) design within strata, then the conditional probability of selection (CP) for respondent k in subgroup j within PSU i becomes:

$$\begin{aligned} CP_{ijk} &= n_{ij} / N_{ij} \\ &= (n^* f_j N_{ij} / MOS_i)/N_{ij} \\ &= n^* f_j / MOS_i \end{aligned}$$

Then the overall probability of selection for respondent k is:

$$\begin{aligned} P_{ijk} &= P_i \, CP_{ijk} \\ &= (m \, MOS_i / \sum MOS_i) \, (n^* f_j / MOS_i) \\ &= m \, n^* f_j / \sum MOS_i \\ &= f_j \end{aligned}$$

Within each subgroup j, the selected persons each have the same probability of selection. A similar application of using a composite measure of size can be found in Mohadjer and Krenzke (2009) as it was applied in the National Assessment for Adult Literacy. To increase the number of Black and Hispanic adults, after PSUs are selected, segments with moderate to high concentrations of Black and Hispanic adults were given a higher selection probability. Another example of a survey that used a composite measure of size is the Study of the Implementation of Research-Based Programs to Prevent Youth Substance Abuse and School Crime, conducted by Westat for the ED's Office of Safe and Drug Free Schools (Crosse et al. 2007). In this study, public school districts were sampled, then schools within sampled districts. Districts were sampled with probability proportional to a composite measure of size that was designed to oversample certain types of schools, but produce a self-weighting sample of schools within strata defined by instructional level, metro status, and percentage minority enrollment.

Sample Size of PSUs

The intracluster correlation (ρ) is a measure of homogeneity within PSUs. If the intracluster correlation is high, then the responses to survey items within the PSUs would be similar, and the responses between PSUs would differ. Using the data from the original NSCF, we computed the intracluster correlation, which was generally low (see Table 6-5). For our computations on design options, we obtained ρ values of 0.0034 for SSI recipients, 0.0172 for SSI applicants, and 0.0040 overall.

Table 6-5. Estimated Intraclass Correlation Coefficient (ρ)

Subgroup	Original NSCF	Proportion on food stamps	ρ
SSI recipient last month (age 0-21)	4,317	0.33	0.0034
SSI applicant (age 0-21)	2,992	0.34	0.0172
Total	7,309	0.33	0.0040

Table 6-6 shows the number of completes needed for attribute proportions ranging from 0.10 to 0.50, to obtain MOEs of 3%, 5%, and 10%, under an SRS design, an equal probability design with 60 PSUs and with 75 PSUs. For example, for an attribute such as food stamps, the true value of p is approximately 0.3. An MOE of 5% would require an overall sample size of 336 completes under simple random sampling, and 342 completes and 341 completes when there are 60 and 75 PSUs, respectively. The table assumes an intra-PSU correlation of 0.004. Values of the sample sizes would be slightly lower for SSI recipients and somewhat higher for SSI applicants (2 to 7% higher than SRS for MOE = 5% and 75 PSUs, and 2 to 10% higher than SRS for MOE = 5% and 60 PSUs. If the intra-PSU correlation values were high, then more PSUs would be necessary to reduce the overall variance in the estimates. Given the low intra-PSU correlation, though, the impact that the sample size of PSUs has on the DEFF is minimal, which then leads to a smaller number of PSUs. However, this needs to be balanced with costs, as shown and discussed in the next chapter.

Table 6-6. Number of Completes Needed by Attribute Proportion to Obtain Select MOEs for SRS and Equal Probability Clustered Designs

	MOE under SRS			MOE with 60 PSUs			MOE with 75 PSUs		
Attribute p	3%	5%	10%	3%	5%	10%	3%	5%	10%
0.10	400	144	36	409	145	36	407	145	36
0.15	567	204	51	586	206	51	582	205	51
0.20	711	256	64	742	259	64	735	258	64
0.25	833	300	75	876	305	75	867	304	75
0.30	933	336	84	987	342	84	976	341	84
0.35	1,011	364	91	1,075	371	91	1,061	370	91
0.40	1,067	384	96	1,139	392	96	1,123	390	96
0.45	1,100	396	99	1,176	405	99	1,160	403	99
0.50	1,111	400	100	1,189	409	100	1,172	407	100

Note: The intra-PSU correlation is assumed to be equal to 0.004.

Power Analysis for Cross-Sectional Designs

In this section, we present an investigation into sampling scenarios for cross-sectional designs. Sample sizes are estimated for different sampling options in order to attain adequate precision levels. A power analysis is conducted to compute sample sizes to attain certain precision levels when comparisons are made between groups. Table 6-7 provides simple estimates of MOE for an SRS of 15,000, 10,000, and 5,000, for an attribute proportion equal to 0.50. For 5,000 completes, there is adequate precision (MOE < 5%) for 6 of the 10 subgroups of interest. However, if comparisons between groups are desired, then a sample size of 10,000 may not be large enough, and if considering a longitudinal component, the sample sizes would need to be increased to account for attrition. With 15,000, 8 of the 10 subgroups would

achieve an MOE < 5%. Oversampling subgroups of interest is an option. The advantages of oversampling are such that one can select an initial sample that, given the assumptions on response rates and eligibility rates, will lead to enough cases to analyze the subgroup by itself and to compare to other subgroups. The disadvantage is that for a fixed sample size, oversampling deviates from an optimal sample design for national estimates, and the impact is an increase in variances, or an increase in sample size (and costs) to offset the loss in precision to national estimates.

Table 6-7. Subgroups, Proportions, and MOEs for Various Sample Sizes Under SRS

Subgroup	Proportion among SSI recipients and applicants	Initial sample size = 15,000		Initial sample size = 10,000		Initial sample size = 5,000	
		n	MOE	*n*	MOE	*n*	MOE
Mental impairment, SSI	0.481	7,219	<3%	4,813	<3%	2,406	<3%
Mental impairment, applicant	0.106	1,587	<3%	1,058	<3%	529	3-5%
Ages 13-17, SSI	0.181	2,722	<3%	1,814	<3%	907	3-5%
Ages 13-17, applicant	0.088	1,319	<3%	879	3-5%	440	3-5%
Lost Benefits—Terminated	0.033	488	3-5%	325	5-10%	163	5-10%
Lost Benefits—Suspended	0.107	1,610	<3%	1,073	<3%	537	3-5%
Denied applicant	0.166	2,491	<3%	1,661	<3%	830	3-5%
Foster care, SSI	0.005	73	>10%	48	>10%	24	>10%
Blind, SSI	0.028	426	3-5%	284	5-10%	142	5-10%
Blind, applicant	0.007	111	5-10%	74	>10%	37	>10%

One option for stratification within PSUs is to partition the sample into eight strata. The stratification would occur after subsetting to the selected PSUs. In one option, foster care was separated out into its own stratum. As noted previously, SSI children in foster care may not be easily identified from the SSA administrative files. An increase to the sample size would account for the fact that less than 100% of the cases selected in the stratum may indeed be in foster care. The amount of the increase could be estimated prior to finalizing the sample sizes. Given the subgroups of interest, Table 6-8 provides a definition of the nine strata (including foster care as a separate stratum) and the approximate population sizes and population proportions.

Table 6-8. Stratum Definitions, Population Sizes, and Proportions

Stratum	Foster care	SSI last month	Age group	Mental impairment[1]	Population size[1]	Population proportion with foster care	Population proportion without foster care
1	Yes	All	All	All	16,264	0.007	N/A
2	No	Applicants	Age 13-17	Yes	92,986	0.040	0.040
3	No	Applicants	Age 13-17	No	111,378	0.048	0.048
4	No	Applicants	Other ages	Yes	153,058	0.066	0.066
5	No	Applicants	Other ages	No	357,134	0.154	0.155
6	No	SSI	Age 13-17	Yes	330,891	0.142	0.143
7	No	SSI	Age 13-17	No	87,097	0.037	0.038
8	No	SSI	Other ages	Yes	776,417	0.334	0.337
9	No	SSI	Other ages	No	398,176	0.171	0.173
Total					*2,323,401*	*1.000*	*1.000*

[1] Calculated using 2010 SSA data and data from the original NSCF.

Using population proportions, the expected sample sizes under proportional-to-size allocation may not be sufficient for all subgroups of interest. Therefore, oversampling can be conducted for strata in order to meet analysis goals. Three oversampling scenarios were compared (see Table 6-9); two that do not include a separate stratum for foster care children (Scenarios 0, 1) and one that does include a foster care stratum (Scenario 2). As mentioned above, the stratum may actually consist of children more likely to be in foster care if it is not possible to identify them on the SSA administrative files. The scenarios assume a sample of 75 PSUs at the first stage, and a sample of age 0-21 persons from the SSA frame within each PSU at the second stage. Solutions for sample size allocations for the three oversampling scenarios were found using nonlinear programming, subject to a different set of constraints for each scenario, ranging from less precise to more precise. Oversampling Scenario 0 is the least expensive, requiring only that MDDs of 10 percentage points between subgroup proportions be detectable, with the exception of the difference between SSI recipients and SSI recipients who have lost their benefits. This comparison was considered of greater interest and was required to have an MDD of six percentage points. Oversampling Scenario 1 requires a larger sample size than Scenario 0 because it requires lower MDDs of six percentage points between two subgroups with the same power. Oversampling Scenario 2 provides the most accurate estimates for subgroups (MDDs of five percentage points, e.g., 50% versus 55%, with a power of .80) but requires the largest sample size and is the most expensive.

Table 6-9. MDDs for Subgroup Comparisons for Oversampling Scenarios

Comparison	Over-sampling Scenario 0	Over-sampling Scenario 1	Over-sampling Scenario 2
SSI recipients vs SSI applicants	10%	6%	5%
SSI recipients age 13-17 vs SSI applicants age 13-17	10%	6%	5%
SSI recipients w/ mental impairment vs SSI applicants w/ mental impairments	10%	6%	5%
SSI recipients vs SSI recipients who lost benefits	6%	6%	5%
SSI recipients vs SSI applicants denied benefits	10%	6%	5%

A subgroup for Blind was also identified to determine the number of completes that would result without oversampling. The sample allocations for the three oversampling scenarios were determined using the Excel Solver tool (Stokes and Plummer 2004). The resulting sample sizes and oversampling factors for each stratum are given in Table 6-10.

Table 6-10. Stratum Sample Sizes for Oversampling Scenarios for 75 PSUs

	Oversampling Scenario 0		Oversampling Scenario 1		Oversampling Scenario 2	
Stratum	Expected initial sample size	Over-sampling factor	Expected initial sample size	Over-sampling factor	Expected initial sample size	Over-sampling factor
1	N/A	N/A	N/A	N/A	1,182	13.18
2	178	0.90	761	2.52	1,185	2.31
3	192	0.81	867	2.40	1,374	2.24
4	163	0.50	625	1.26	1,020	1.21
5	201	0.26	749	0.65	1,240	0.63
6	907	1.28	1,397	1.30	2,175	1.19
7	237	1.27	363	1.29	565	1.18
8	2,043	1.23	1,862	0.74	2,742	0.64
9	1,046	1.23	910	0.70	1,328	0.61
Total	*4,968*		*7,534*		*12,811*	

Table 6-11 provides the ESS and MOE for each subgroup for each oversampling scenario. An 80% completion rate is assumed for SSI recipients, and a 70% completion rate is assumed for non-SSI recipients, which are close to those achieved in the prior NSCF.

For Oversampling Scenario 0, 3,901 completes are needed to satisfy the associated precision requirements in Table 6-11. After taking into account the design effect, the ESS is 2,963. This is sufficient for high quality estimates for an attribute's estimated proportion of 0.50 for SSI recipients, including those ages 13-17, or those with mental impairments. Quality estimates can also be produced for recent applicants and those who lost benefits. By 'high quality,' we refer to an MOE of less than or equal to approximately 0.05. Although not shown, analysis by larger demographic subgroups for the SSI recipients could be conducted. Applicants are considered 'recent' if they applied within the past year. If 'recent' is defined to include the past 2, 3 or more years it would have an impact on required sample sizes as subgroup target sample sizes are trying to be attained.

In Oversampling Scenario 1, the number of completes needed to satisfy the associated precision requirements in Table 6-11 is 5,727. The corresponding ESS of 4,916 is sufficient for high-quality estimates for an attribute's estimated proportion of 0.50 for all major subgroups except foster care, and SSI recipients and recent applicants who are blind.

Table 6-11. ESS and MOEs for Subgroups Under Oversampling Scenarios, 75 PSUs and Precision Requirements

Groups	Oversampling Scenario 0				Oversampling Scenario 1				Oversampling Scenario 2			
	Initial sample size	Completes	ESS	MOE	Initial sample size	Completes	ESS	MOE	Initial sample size	Completes	ESS	MOE
Total	*4,968*	*3,901*	*2,963*	*0.018*	*7,534*	*5,727*	*4,916*	*0.014*	*12,811*	*8,821*	*6,553*	*0.012*
SSI	4,234	3,387	2,944	0.018	4,533	3,626	2,927	0.018	6,810	5,448	4,049	0.016
Applicants	734	514	364	0.052	3,002	2,101	1,045	0.031	4,819	3,373	1,432	0.026
Subgroups												
Age 13-17, SSI	1,144	915	882	0.034	1,761	1,408	1,328	0.027	2,740	2,192	2,000	0.022
Age 13-17, applicants	370	259	248	0.064	1,628	1,139	915	0.033	2,559	1,791	1,285	0.028
Mental impairment, SSI	2,951	2,360	2,138	0.022	3,259	2,608	2,188	0.021	4,917	3,933	3,090	0.018
Mental impairment, applicants	341	239	213	0.069	1,386	970	720	0.037	2,205	1,544	1,047	0.031
Lost benefits	853	683	664	0.039	913	731	665	0.039	1,372	1,098	970	0.032
Foster care	35	25	25	0.202	53	37	28	0.188	1,182	827	800	0.035
Denied benefits	396	277	207	0.070	1,621	1,135	665	0.039	2,602	1,822	970	0.032
Blind, SSI	174	139	121	0.091	186	149	120	0.091	279	223	3,088	0.078
Blind, applicants	18	12	11	0.305	72	50	41	0.157	116	81	3,766	0.129

Note: The MOE is the half-width for a 95% confidence interval and an attribute proportion of $p = 0.5$.

For Oversampling Scenario 2, the number of completes needed to satisfy the associated precision requirements in Table 6-11 is 8,821. The corresponding ESS of 6,553 is sufficient for high-quality estimates for an attribute's estimated proportion of 0.50 for all major subgroups.

Further splits by various subgroups of interest, such as demographics, duration, etc., may require larger sample sizes. For example, suppose Oversampling Scenario 2 is chosen, which would result in about 665 effective completes among those with lost benefits. Suppose that lost benefits by several levels of education attainment is of interest. Then the initial sample for the lost benefits would need to be increased and would need to account for an increase of variance due to oversampling factor on the lost benefits subgroup.

As a general reference table, Table 6-12 provides the effective number of completes for each group in the comparison to detect a difference between estimated attribute proportions p1 and p2, for subgroups 1 and 2, where $\alpha = 0.05$ with 80% power. The value of α represents the probability of rejecting the null hypothesis when the null hypothesis is true, and the power values are the probability of rejecting the null hypothesis when indeed the null hypothesis is false.

Table 6-12. Sample Size for Comparison of p1 and p2 for Each Independent Sample, Two-Sided

	p1										
p2	0	0.05	0.10	0.15	0.20	0.25	0.30	0.35	0.40	0.45	0.50
0	—	150	71	45	32	24	18	15	12	10	8
0.05		—	435	138	73	46	32	24	18	15	12
0.10			—	687	198	97	59	40	29	22	17
0.15				—	908	249	119	70	46	33	24
0.20					—	1,098	292	136	79	52	36
0.25						—	1,256	328	150	86	55
0.30							—	1,383	356	161	91
0.35								—	1,477	375	168
0.40									—	1,541	387
0.45										—	1,572

Note: Cells that are undefined are noted with an "—"; there is no sample size that could detect a difference between two proportions that are equal.

Specific to the design options, Table 6-13 provides the MDDs for the subgroups of interest. The table shows comparison results for five pairs of comparisons, and it essentially demonstrates that the precision constraints were met for each comparison of interest. The power to detect MDDs of 0.05 and 0.10 is also provided in the table.

Table 6-13. ESS, MDD, and Necessary Power for Subgroup Comparisons, by Oversampling Scenario

Scenario	Group 1	Group 2	ESS		MDD for power = 0.80, P1=0.50	Power to detect	
			Group 1	Group 2		P1-P2 = D[1]	P1-P2 = 0.10
Oversampling Scenario 0	Applicants	SSI	364	2,944	0.077	0.58	0.95
	Applicants, ages 13-17	SSI, ages 13-17	248	882	0.100	0.39	0.80
	Applicants, mental impairment	SSI, mental impairment	213	2,138	0.100	0.39	0.80
	Lost benefits	SSI	664	2,944	0.060	0.80	1.00
	Denied benefits	SSI	207	2,944	0.100	0.39	0.80
Oversampling Scenario 1	Applicants	SSI	1,045	2,927	0.050	0.92	1.00
	Applicants, ages 13-17	SSI, ages 13-17	915	1,328	0.060	0.80	1.00
	Applicants, mental impairment	SSI, mental impairment	720	2,188	0.060	0.80	1.00
	Lost benefits	SSI	665	2,927	0.060	0.80	1.00
	Denied benefits	SSI	665	2,927	0.060	0.80	1.00
Oversampling Scenario 2	Applicants	SSI	1,432	4,049	0.043	0.90	1.00
	Applicants, ages 13-17	SSI, ages 13-17	1,285	2,000	0.050	0.80	1.00
	Applicants, mental impairment	SSI, mental impairment	1,047	3,090	0.050	0.80	1.00
	Lost benefits	SSI	970	4,049	0.050	0.80	1.00
	Denied benefits	SSI	970	4,049	0.050	0.80	1.00

[1] D = 0.10 for Oversampling Scenario 0, except for the lost benefits versus SSI comparison, where D = 0.06; D = 0.06 for Oversampling Scenario 1; D = 0.05 for Oversampling Scenario 2.

Power Analysis for Longitudinal Designs

Next we present power analyses for the forward longitudinal design option for surveying SSI children and families for a new NSCF.

The difference between proportions from two waves for subgroup j is defined as follows:

$d_j = p_{1j} - p_{2j}$

The variance of the difference between two proportions is:

$$Var(p_{1j} - p_{2j}) = var(p_{1j}) + var(p_{2j}) - 2\rho P\sqrt{var(p_{1j})var(p_{2j})}$$

Where,

$var(p_{1j})$ is the variance of p_{1j} at Wave 1,

$var(p_{2j})$ is the variance of p_{2j} at Wave 2,

ρ is the correlation between Waves 1 and 2, and

P is the proportion of overlap in the sample between Waves 1 and 2. As an example, p_{1j} could be the proportion of SSI recipients receiving food stamps at Wave 1.

Given that they have already responded in the first wave, we assume the completion rate for Wave 2 to be five percentage points higher than Wave 1. The attrition rate could be lower than that between waves. The biggest loss is after Wave 1, but if there are further follow-up attempts after Wave 2, the attrition is usually small percentages. In Wave 2, we assume that only respondents are followed up; however, this assumption should be re-evaluated after Wave 1 since it depends on the response rate and the data needs. If only data from Wave 1 are needed, then the focus may be on those who responded to Wave 1.

Table 6-14 provides the resulting MOEs for Wave 2 for Oversampling Scenario 0. For an attribute proportion equal to 0.50, the MOEs range from 0.02 for SSI recipients to 0.07 for recent applicants with a mental impairment. Those in foster care would have an MOE of an unreliable 0.233. Table 6-15 provides the power analysis results showing MDDs for unit correlations between responses at time 1 and time 2 varying from 0 (higher MDDs), 0.5 and 0.8 (lower MDDs). For a unit correlation of 0.8, the MDD with 80% power ranges from 0.02 for SSI recipients to 0.08 for recent applicants with a mental impairment and those who were denied benefits. Those in foster care would have an MDD of an unreliable 0.26.

Table 6-16 provides the resulting MOEs for Wave 2 for Oversampling Scenario 1. For an attribute proportion equal to 0.50, the MOEs are less than 0.045 for all subgroups except those in foster care, which would have an MOE of an unreliable 0.22. Table 6-17 provides the power analysis results for comparisons between waves for Oversampling Scenario 1. For a unit correlation of 0.8, the MDDs with 80% power are less than 0.05 for all subgroups, except those in foster care, which would have an MDD of an unreliable 0.24. Table 6-18 provides the resulting MOEs for Wave 2 for Oversampling Scenario 2. Table 6-19 provides the power analysis results for comparisons between waves for Oversampling

Scenario 2. For an attribute proportion equal to 0.50, the MOEs are less than 0.041 for all subgroups including those in foster care.

Table 6-14. MOE Results for Wave 2 for Oversampling Scenario 0

	Wave 1		Wave 2		
Subgroups	**Completes**	**ESS**	**Completes**	**ESS**	**MOE**
SSI	3,387	2,944	2,879	2,502	0.020
Applicants	514	364	385	273	0.060
Total	*3,901*	*2,963*	*3,264*	*1,947*	*0.023*
Ages 13-17					
SSI	973	882	827	796	0.035
Applicants	277	248	208	199	0.071
Total	*1,250*	*1,145*	*1,035*	*948*	*0.032*
Mental impairments					
SSI	2,508	2,138	2,132	1,931	0.023
Applicants	256	213	192	171	0.077
Total	*2,764*	*2,270*	*2,324*	*1,909*	*0.023*
Lost benefits	683	664	512	498	0.045
Foster care	25	25	18	18	0.233
Denied benefits	277	207	208	155	0.080

Table 6-15. Power Analysis Results for Comparisons Between Waves for Oversampling Scenario 0, Wave 1 vs. Wave 2

	MDD P1-P2, $\rho = 0$	MDD P1-P2, $\rho = 0.5$	MDD P1-P2, $\rho = 0.8$	Power to detect P1-P2 = 0.06, $\rho = 0$	Power to detect P1-P2=0.10, $\rho = 0$	Power to detect P1-P2 = 0.06, $\rho = 0.5$	Power to detect P1-P2 = 0.06, $\rho = 0.8$
SSI	0.038	0.028	0.021	0.99	1.00	1.00	1.00
Applicants	0.111	0.079	0.060	0.32	0.71	0.48	0.72
Total	0.041	0.028	0.021	0.98	1.00	1.00	1.00
Ages 13-17							
SSI	0.068	0.052	0.040	0.69	0.98	0.90	0.99
Applicants	0.132	0.102	0.077	0.24	0.56	0.37	0.58
Total	0.061	0.046	0.035	0.78	1.00	0.94	1.00
Mental impairments							
SSI	0.044	0.033	0.025	0.97	1.00	1.00	1.00
Applicants	0.142	0.108	0.081	0.21	0.50	0.33	0.52
Total	0.043	0.032	0.024	0.97	1.00	1.00	1.00
Lost benefits	0.083	0.064	0.048	0.53	0.92	0.74	0.93
Foster care	0.380	0.335	0.255	0.06	0.10	0.07	0.09
Denied benefits	0.146	0.106	0.080	0.20	0.47	0.30	0.48

Table 6-16. MOE Results for Wave 2 for Oversampling Scenario 1

Subgroups	Wave 1		Wave 2		MOE
	Completes	ESS	Completes	ESS	
SSI	3,626	2,927	3,082	2,488	0.020
Applicants	2,101	1,045	1,576	784	0.036
Total	5,727	4,916	4,658	3,039	0.018
Ages 13-17					
SSI	1,408	1,328	1,197	1,129	0.030
Applicants	1,139	915	854	686	0.038
Total	2,548	2,096	2,052	1,688	0.024
Mental impairments					
SSI	2,608	2,188	2,216	1,860	0.023
Applicants	970	720	728	540	0.043
Total	3,578	2,700	2,944	2,222	0.021
Lost benefits	731	665	548	499	0.045
Foster care	37	28	28	21	0.217
Denied benefits	1,135	665	851	499	0.045

Table 6-17. Power Analysis Results for Comparisons Between Waves for Oversampling Scenario 1, Wave 1 vs. Wave 2

Subgroups	MDD P1-P2, $\rho = 0$	MDD P1-P2, $\rho = 0.5$	MDD P1-P2, $\rho = 0.8$	Power to detect P1-P2 = 0.06, $\rho = 0$	Power to detect P1-P2 = 0.10, $\rho = 0$	Power to detect P1-P2 = 0.06, $\rho = 0.5$	Power to detect P1-P2 = 0.06, $\rho = 0.8$
SSI	0.038	0.030	0.022	0.99	1.00	1.00	1.00
Applicants	0.066	0.051	0.039	0.72	0.99	0.91	0.99
Total	0.032	0.025	0.019	1.00	1.00	1.00	1.00
Ages 13-17							
SSI	0.057	0.044	0.033	0.84	1.00	0.97	1.00
Applicants	0.070	0.055	0.042	0.66	0.98	0.87	0.98
Total	0.046	0.036	0.027	0.96	1.00	1.00	1.00
Mental impairments							
SSI	0.044	0.034	0.026	0.97	1.00	1.00	1.00
Applicants	0.079	0.062	0.047	0.56	0.94	0.78	0.95
Total	0.040	0.031	0.024	0.99	1.00	1.00	1.00
Lost benefits	0.083	0.064	0.049	0.53	0.92	0.74	0.93
Foster care	0.360	0.312	0.237	0.06	0.10	0.08	0.10
Denied benefits	0.083	0.064	0.049	0.53	0.92	0.74	0.93

Table 6-18. MOE Results for Wave 2 for Oversampling Scenario 2

Subgroups	Wave 1		Wave 2		MOE
	Completes	ESS	Completes	ESS	
SSI	5,448	4,049	4,631	3,442	0.017
Applicants	3,373	1,432	2,530	1,074	0.031
Total	8,821	6,553	7,161	3,663	0.017
Ages 13-17					
SSI	2,192	2,000	1,863	1,700	0.024
Applicants	1,791	1,285	1,343	964	0.032
Total	3,983	3,088	3,206	2,486	0.020
Mental impairments					
SSI	3,933	3,090	3,343	2,626	0.020
Applicants	1,544	1,047	1,158	786	0.036
Total	5,477	3,766	4,501	3,095	0.018
Lost benefits	1,098	970	823	727	0.037
Foster care	827	800	620	600	0.041
Denied benefits	1,822	970	1,366	727	0.037

Table 6-19. Power Analysis Results for Comparisons between Waves for Oversampling Scenario 2, Wave 1 vs. Wave 2

Subgroups	MDD P1-P2, $\rho = 0$	MDD P1-P2, $\rho = 0.5$	MDD P1-P2, $\rho = 0.8$	Power to detect P1-P2 = 0.05, $\rho = 0$	Power to detect P1-P2 = 0.10, $\rho = 0$	Power to detect P1-P2 = 0.05, $\rho = 0.5$	Power to detect P1-P2 = 0.05, $\rho = 0.8$
SSI	0.032	0.025	0.019	0.99	1.00	1.00	1.00
Applicants	0.056	0.044	0.033	0.70	1.00	0.96	1.00
Total	0.029	0.023	0.018	1.00	1.00	1.00	1.00
Ages 13-17							
SSI	0.046	0.036	0.027	0.86	1.00	0.98	1.00
Applicants	0.060	0.046	0.035	0.65	1.00	0.92	0.99
Total	0.038	0.029	0.022	0.96	1.00	1.00	1.00
Mental impairments							
SSI	0.037	0.029	0.022	0.97	1.00	1.00	1.00
Applicants	0.066	0.051	0.039	0.56	0.99	0.85	0.97
Total	0.034	0.026	0.020	0.98	1.00	1.00	1.00
Lost benefits	0.068	0.053	0.040	0.53	0.98	0.76	0.94
Foster care	0.075	0.059	0.045	0.46	0.96	0.68	0.89
Denied benefits	0.068	0.053	0.040	0.53	0.98	0.84	0.97

It should be noted that the sample sizes were not boosted from the cross-sectional sample sizes shown in Table 6-10 to account for the attrition between Waves 1 and 2 (85% completion rate for SSI recipients and 75% for applicants).

As noted previously, to reduce the costs, the followup could be conducted only with 13- through 17-year-olds. For example, under Scenario 2, if limited to 13- through 17-year-olds, the initial sample size decreases from 7,161 to 3,206. Further reduction to SSI recipients 13- through 17-year-olds decreases the sample size from 4,631 to 1,863. When limiting to SSI recipients, the SSI status could either be based on their responses to Wave 1 or based on administrative records at the time of data collection for Wave 2. Nonetheless, there would be a proportion of newly awarded SSI cases and a proportion over the year that would have lost benefits. Certainly the redetermination at age 18 comes in effect for a portion of the sample if followups are done after age 18.

Relative Costs of Design Options

In this section, we discuss the relative costs associated with the various design options. Because we did not have access to direct cost information for some of the comparison group options (e.g., a SLAITS module), our discussion of relative costs concentrates primarily on cross-sectional and forward longitudinal design options for surveying SSI children and families.

The following cost-variance model draws from points made in Kish (1965). The total cost is a function of the fixed cost (C_0) and the variable cost (C_v).

$C = C_0 + C_v$

Where,

C_0 = fixed costs, which may include materials prep and in-house labor related to questionnaire development, sampling activities, hiring interviewers, training, systems development, and post-processing tasks related to producing datasets and reports.

And where the variable cost is estimated as:

$$C_v = DEFF_{clu} \times DEFF_{sr} \times\{ n_{ceff,\ CATI}\ [(r_{\ CATI}\ c_{CATI} + c_{contact,CATI})+(1-r_{CATI})(r_{CAPI}\ c_{CAPI} + c_{locate,CAPI})] + a\ c_{psu}\}$$

Where,

$DEFF_{clu}$ = the DEFF due to clustering

$DEFF_{sr}$ = the DEFF due to differential sampling rates

$n_{ceff,\ CATI}$ = ESS for CATI

r_{CATI} = response rate for CATI

c_{CATI} = cost of conducting the interview using CATI

r_{CAPI} = response rate for CAPI, given followup is needed

c_{CAPI} = cost of conducting the interview using CAPI

$c_{locate,CAPI}$ = cost of finding addresses

a = number of PSUs

c_{psu} = cost per cluster

The variable cost is a function of the DEFF since the sample design has a direct impact on the size of the initial sample in order to arrive at an ESS that meets a certain criteria. Another component of the variable cost is the cost of finding the sample case in the field, and then conducting the CAPI, and also the cost of the CATI. Last, a term is added to bring in the cost of adding PSUs to the sample.[10]

Table 6-20 provides the rough variable costs (C_v) of the design options, relative to the variable cost of a SRS sample leading to 5,000 completed CATI cases, assuming a 70% completion rate. A 70% completion rate is assumed since this scenario does not include in-person nonresponse followup attempts. The cost estimates that underlie the computations are rough and are used to show a general picture of how the costs of the various designs relate to one another in general. The costs in the tables are relative *variable* costs, which for the cross-sectional (cs) design is computed as follows:

$RelC_{v,cs} = C_{v,cs}/C_{v,SRS}$

Where

$C_{v,cs}$ = variable cost for the cross-sectional oversampling design option, and

$C_{v,SRS}$ = variable cost for the SRS design.

In the table, by Forward Longitudinal we refer to a cross-sectional design in Wave 1 with a longitudinal followup of Wave 1 respondents in Wave 2. The variable costs shown in the table for Wave 2 only for the cross-sectional forward longitudinal (csfl) design options are computed as follows:

$RelC_{v,csfl} = C_{v,csfl}/C_{v,SRS}$

Where

$C_{v,csfl}$ = variable cost for the cross-sectional forward longitudinal design option, and

$C_{v,SRS}$ = variable cost for the SRS design.

Then, the "Relative variable cost," as given as the column header in the table, for Wave 1 and Wave 2, is equal to $RelC_{v,cs} + RelC_{v,csfl.}$

Among the cross-sectional designs, Oversampling Scenario 0 with 60 or 75 PSUs is the most cost efficient, at 1.4 times the rate of the SRS low-sample-size option. The forward longitudinal component

[10] About the last term, Kish (1965) says the following: "*For example, in a sample of n dwellings of a city taken in a sample of blocks, the main cost factor, beyond the cost of interviewing, could be the listing of dwellings; this would be c_{psu} per sample block. Another example could be sample of cities, in each of which a sample is drawn from a list (of housing construction, or retail stores, or school teachers); the cost per city consists of obtaining a field worker, cooperation from the city government, access to the list, and ancillary information about the city*." For the original NSCF design, with the sample selected from a listing of records for administrative files, the cost per additional PSU is minimal. Adding a PSU in our design options does not mean another field worker is added, or cooperation from the area is needed, or access to the list is needed. There may be some small relative cost due to producing maps and ancillary information about the area, and the need to travel interviewers for training. We do not provide the components of the cost function, but rather report the relative difference between a design and a base design for the variable cost (C_v).

would have a CATI component only, and therefore costs decrease substantially in Wave 2. Furthermore, when following up with 13- through 17-year-olds only, the variable costs decrease substantially (e.g., for Oversampling Scenario 0 from 0.6 to 0.2 times the SRS costs). However, with the longitudinal component, the fixed costs for Wave 2 would need to be considered. In the table, by Forward Longitudinal we refer to a cross-sectional sample in Wave 1, with an additional one wave of follow-up with Wave 1 respondents. The initial sample sizes in the table come from Table 6-11 for the cross-sectional design for 75 PSUs. Initial sample sizes that involve a 60 PSU design were computed in the same manner as those computed for the 75 PSU design in Table 6-11. The initial sample sizes for the forward longitudinal approach are the estimated number of completes from the cross-sectional design from Table 6-11 for 75 PSUs, while initial sample sizes under a 60 PSU design were computed in the same manner. Using the aforementioned initial sample sizes in the computations is the same as using the DEFF in the formula for C_v, since the initial sample size accounted for the DEFF.

Table 6-20. Relative Variable Costs and Initial Sample Sizes for Featured Design Options

Design option	Number of PSUs	Initial sample size	Relative variable cost (C_v)	Wave 2 only
SRS		7,143	1	
Cross-sectional				
Oversampling Scenario 0	60	5,035	1.4	
Oversampling Scenario 1	60	7,816	2.2	
Oversampling Scenario 2	60	13,544	3.8	
Oversampling Scenario 0	75	4,968	1.4	
Oversampling Scenario 1	75	7,534	2.2	
Oversampling Scenario 2	75	12,811	3.6	
Forward longitudinal				
Oversampling Scenario 0	60	3,954	2.0	0.6
Oversampling Scenario 1	60	5,934	3.1	0.9
Oversampling Scenario 2	60	9,351	5.2	1.4
Oversampling Scenario 0	75	3,901	2.0	0.6
Oversampling Scenario 1	75	5,727	3.0	0.9
Oversampling Scenario 2	75	8,821	5.0	1.3
Forward longitudinal, subgroup of ages 13-17				
Oversampling Scenario 0	60	1,264	1.6	0.2
Oversampling Scenario 1	60	2,662	2.6	0.4
Oversampling Scenario 2	60	4,270	4.5	0.6
Oversampling Scenario 0	75	1,250	1.6	0.2
Oversampling Scenario 1	75	2,548	2.5	0.4
Oversampling Scenario 2	75	3,983	4.2	0.6

Note. The initial sample sizes shown in the table for the forward longitudinal designs are for Wave 2 only, and they are the number of completed cases from Wave 1.

The cost results indicate that it would be beneficial in terms of both cost and precision to use a PSU sample of 75 rather than 60. In general, the four options provide a wide array of opportunities to address the policy questions. A larger sample, if within budget constraints, could also facilitate a need for unforeseen analysis interests. For example, a demographic that may be of little or no interest at this time may not have a large enough sample for analysis in Oversampling Scenario 1, but would have enough from Oversampling Scenario 2, or from a general increase in sample size. The design options provide a variety of ways to reduce costs. For example, if a forward longitudinal design is desired, it could be limited to the 13-17 age group. A decision on which of the four major design options to use will need to take into account the priorities of SSA.

7. Data Analysis and Dissemination Considerations

In this chapter, we discuss some data analysis considerations that are closely related to the design options. Specifically, we discuss sample weighting procedures with respect to handling key aspects of the sample design options that affect analysis. We also briefly note some approaches to conducting analyses with data such as those that might be collected by a new NSCF, including analyses between the main sample (SSI children) and the comparison group (non-SSI children), as well as analyses that pertain to longitudinal designs. We conclude with some thoughts about data dissemination.

Weighting and Variance Estimation

The purpose of calculating sampling weights for sample persons is to permit inferences to the population from which they were drawn, for instance, to have the tabulations reflect estimates of the population totals. Sampling weights can be considered as estimated measures of the number of units in the target population that a sampled case represents. Weighting incorporates several features of the survey, including the probabilities of selection of units in the sample and accounting for nonresponse and any known differences between the selected sample and the total target population. Differences between the sample and the population may arise because of sampling variability, differential response rates or coverage rates among subgroups of the population, and other types of response errors, such as misclassification errors.

In summary, sample weighting in surveys is carried out to accomplish the following objectives:

- to permit unbiased estimates by compensating for disproportionate sampling of various subgroups in the sample;
- to minimize bias arising from differences between respondents and nonrespondents;
- to compensate for undercoverage in the sample due to inadequacies in the sampling frame or other reasons;
- to bring data up to the dimensions of the population totals; and
- to reduce sampling errors by using auxiliary data on population characteristics that are known with a high degree of accuracy.

Several weighting approaches are used to meet the above objectives of reducing nonresponse and coverage bias. Kalton and Flores-Cervantes (2003) discuss the use of cell weighting, raking, generalized regression models, logistic regression weighting (sometimes referred to as propensity score weighting), mixture of methods, and methods to restrict the range of adjustments.

Cross-Sectional and Longitudinal Weights

Cross-sectional weights are used in an analysis of one wave of the survey data. We refer to the first wave of data collection as the baseline sample. Weights that are constructed for follow-up waves are referred to as longitudinal weights. Longitudinal weights for the follow-up survey are created by adjusting the final baseline weights to account for nonresponse. A calibration process can be executed

at the end of the follow-up sample weighting process to bring the final weights into alignment with control totals. With more than one follow-up sample (wave), the possible patterns for unit nonresponse in the waves are illustrated in Table 7-1.

Table 7-1. Patterns of Unit Nonresponse in Baseline and Two Followups

Pattern	Baseline	1st followup	2nd followup
1	R	R	R
2	R	NR	R
3	R	R	NR
4	R	NR	NR

Note: R = Respondent, NR = Nonrespondent.

Pattern 1 corresponds to those who participate in all three waves of the survey. Pattern 2 includes the baseline respondents who missed the first followup but who will return to the survey in the second followup. Patterns 3 and 4 are dropouts who permanently leave the survey after the first follow-up or baseline, respectively. The response patterns affect the longitudinal sets of weights that are created. For example, the longitudinal weights LW1 of Table 7-2 apply to analyses that use the set of respondents who complete both the baseline and the two followups. The longitudinal weights LW2, which are the cross-sectional weights from the second followup, apply to analyses of respondents respond to the second followup but not the first follow-up interview. The longitudinal weights LW3, which are equivalent to the cross-sectional weights from the first followup, can be used in analyses based on the respondents who responded to the first followup but did not complete the second follow-up interview.

Table 7-2. Longitudinal Weights for Baseline and Two Followups

Longitudinal weights	Baseline	1st followup	2nd followup
LW1	R	R	R
LW2: 2nd follow-up cross-sectional weights	R	R/NR	R
LW3: 1st follow-up cross-sectional weights	R	R	R/NR

Note: R = Respondent, R/NR = either Respondent or Nonrespondent.

Variance Estimation

The usual estimation and testing procedures are not appropriate for the design options discussed above since the sample design includes departures from assumptions that are made in standard statistical textbooks. Even if unbiased weights are used to compensate for unequal probabilities of selection, inferences will not be valid unless the corresponding variance estimators appropriately reflect all of the complex features of the sample design, such as stratification and clustering.

Two approaches are commonly used for estimating variances for complex surveys: replication and Taylor Series Linearization. Several replication approaches will capture the variation due to the complex sampling and weighting approaches, including:

- Delete-one jackknife;
- Paired jackknife;

- Balanced repeated replication; or
- Fay's method.

The delete-one jackknife is also referred to as delete-a-group jackknife, random groups approach, and JK1. The paired jackknife is also referred to as JK2. The JK2 approach, with two variance units per stratum, is appropriate for sample designs where PSUs are stratified or selected with systematic sampling from a sorted list. The balanced repeated replication approach is also commonly used when strata are involved, and Fay's method is a variant of the balanced repeated replication approach.

Replication methods are applied to surveys by dividing the sample into specially designed replicate subsamples that mirror the design of the full sample. To form the replicate subsamples, variance strata and variance units are defined. Each subsample is re-weighted to account for the subsampling that occurred. An estimate is then calculated for the full sample and each of the replicate subsamples. The variance of the full sample estimate is computed as the sum of squared deviations between each replicate subsample estimate and the full sample estimate. The general replication formula is:

$$Var(\hat{\theta}) = c\sum_{i}(\hat{\theta}_i - \hat{\theta}_0)^2$$

Where,

c = 1, for the paired jackknife (JK2)
= (g-1)/g, for the random groups (delete-one) approach (JK1)
= 1 / g for the BRR approach
= $1/[g(1-k)^2]$ for Fay's method

g = number of replicates

k = weighting factor for Fay's method

$\hat{\theta}_0$ = full sample estimate

$\hat{\theta}_i$ = estimate for replicate *i*

Approaches to Analysis

The data collected from a new NSCF will need to be analyzed using a variety of analytic techniques in order to address the SSA policy questions. This section provides a general overview of some of the possible techniques. We also discuss the possibility of comparing to estimates of other national surveys, using administrative data, and linking the NSCF data to other datasets.

Addressing the Policy Questions

A number of the policy questions are purely descriptive in nature (e.g., Policy Question #5: What is the availability of and need for respite care among SSI families?). The descriptive questions may be answered largely with estimated percentage distributions or measures of central tendency and corresponding variance estimates. Although the policy questions typically do not reference specific

subgroups of SSI children, SSA may wish to calculate cross-tabulations for major subgroups, for example, looking at type of impairment (e.g., mental, physical, other), gender, age, and race/ethnicity, and living arrangements. As appropriate, significance tests such as chi-squares, *t*-tests, or ANOVAs, with appropriate post-hoc tests could be conducted to identify significant differences across subgroups.

A number of the Policy Questions involve comparisons between SSI children and non-SSI children (e.g., Policy Question #3: Are SSI children using more or less (resources) than non-SSI children?). If SSA opts to include a comparison group in the new NSCF, then additional descriptive and cross-tab analyses would need to be conducted, focusing on SSI children and non-SSI children.

Once the descriptive and bivariate analyses have been completed, SSA may wish to conduct statistical modeling to help explain the variation in the outcome variables in terms of auxiliary (independent) variables for some policy questions, particularly those focused on determining whether the comparison group of non-SSI children is different from the SSI children. For example, using weighted regression models (e.g., linear, logistic, multi-level) might be appropriate to address the policy question looking at economic downturn (Policy Question #6: How has the economic downturn affected families with respect to the sources of care for the child, the employment of the parents or guardians, and the medical needs of the child? Were families with children on SSI disproportionately affected by the downturn?). Multi-level models allow researchers to predict the outcomes of interest while taking into account the clustering of the data due to sampling persons within PSUs; in addition, covariates can be adjusted at various levels of aggregation, yielding results that are more easily interpreted.

If SSA opts for a longitudinal design, then additional analyses would need to be conducted to explore change over time. For example, SSA may be interested in exploring services utilization at two points in time for all SSI children or how children's prescription drug use may change over time for those SSI children with mental impairments. Statistical tests, such as *t*-tests, or more sophisticated procedures like analysis of covariance or generalized estimating equations, could be conducted to further examine these types of issues and questions.

Added Value of SSI

SSA may also wish to conduct additional analyses to better understand the added value of receiving SSI. These analyses will allow SSA to explore the relationship between the added income that families of children with disabilities receive through the SSI program and access to and use of various services (i.e., health care, mental health, and educational services) and how this might affect outcomes for these children as compared to children who do not receive SSI. Although we recognize that the NSCF would not be an experimental design, weights that incorporate sampling selection probabilities and propensity scores, such as the counterfactual projection weights described in Judkins et al. (2007), may be helpful in exploring the NSCF data in this manner. As discussed in Wang (2009), the propensity score is the conditional probability of a subject's receiving the treatment of interest given a set of covariates. The use of a propensity scores in nonexperimental studies has been increasing as a way to control for confounding differences between comparison groups. That is, it could be used to reduce the impact from any differences in characteristics (e.g., demographics) between SSI recipients and non-SSI recipients.

Comparing to Existing Survey Estimates

As discussed in Chapter 5, analyses could also focus on data from the new NSCF in conjunction with external surveys in order to make comparisons between SSI children and non-SSI children. For these

analyses, the SSI group mean estimate would be based on the new NSCF survey results, and the comparison group mean estimate would be based on the external survey results. These kinds of analyses can be made if the questions in the new NSCF are identical to those in one or more external surveys. However, this analysis approach would need to take into account potential challenges related to sampling and non-sampling error.

With regard to sampling error, the complex sample designs impact variances and therefore design effects need to be taken into account to ensure estimates of adequate precision if SSA opts to depend on an external survey for the non-SSI comparison group. In addition, SSA likely would have no control over the sample sizes for non-SSI children, as well as any subgroups of interest. With small sample sizes, the variances may be too large to detect significant differences.

For non-sampling error, there are several problematic issues. First, this analysis approach is limited to those questions that already appear in the external surveys, unless it can be negotiated with the survey sponsor to add a topical module to their data collection, as in the National Survey of CSHCN. The estimates for the comparison group can conceptually come from more than one survey. A major problem for some analyses is that the external surveys may not contain the set of items needed for the comparison of domains or for multivariate analysis. For example, if only one of the external surveys contains data on family relationships, then the comparisons within the domains defined by relationships are restricted to that survey and its other measures.

In addition, for the items of interest for the analysis, it is important that the questions are asked with the exact same wording; otherwise, the results may be influenced by the way the question was asked. A review of the items of interest from surveys will be important so that the same wording is used in the NSCF. In addition to wording effects, context effects are likely to be an issue. In a survey dedicated to other topics (like a survey on employment), the context may result in potentially different estimates.

Also, if more than one external survey is used to generate comparison group estimates, the definition of the comparison group will likely vary from survey to survey. That is, each survey may not carry the same questions on disability and income that allow a standard formulation of the comparison group across the external surveys. There will need to be careful consideration of the scope of each external survey, as was done in Ireys et al. (2004), which compared the NSCF and three national surveys: National Survey of CSHCN, SIPP, and NHIS. As discussed in Ireys et al. (2004, p. 45), "The surveys are quite different from each other in terms of survey objectives, sampling frame, sample design, sample size, and procedural and operational issues. The NSCF offers the distinct advantage of using a sampling frame—the SSI program files—that offers excellent representation of the survey's target population. In contrast, the National Survey of CSHCN relies on sets of screening items designed to identify children having special health care needs, and these screening items lead to undercoverage of the SSI child population." Coverage of the population is a source of bias that would impact the ability to make good comparisons between the NSCF and the comparison group estimates from the external surveys. For example, if NSCF data is compared to results from a school-based sample, there may be problems with defining a comparison group that includes young children and dropouts.

Last, the timing of the external survey is also an issue and becomes more of an issue when multiple external surveys are used for different comparison group estimates. This is most often a concern when economic conditions change as they recently have with the downturn in 2008-09.

To the extent that these issues are addressed and their effects minimized, this analysis approach may be considered as a possibility.

Administrative Data Analysis

Data from the administrative files could be analyzed to determine how the sample of SSI recipients from the original NSCF has changed with respect to available characteristics in the SSA administrative data. The analysis would be limited to the extent that the data are maintained for terminated or suspended beneficiaries. The administrative data analysis option has been conducted in the past at SSA, as discussed in Rupp et al. (2005/2006). While valuable information exists for characteristics such as receipt of SSI, age, and sex, data on other characteristics such as race/ethnicity, education, and household composition, are unavailable or incomplete in the administrative records.

Possibility of Linking to Other Datasets

Since the Social Security number of the subjects is available, other datasets, such as the ones mentioned above (TANF, VR services, Medicaid), and from other sources, could be linked with the SSA administrative data and attached to the new survey data to enhance the data fields for analysis. However, this approach is limited in that the population to which results could be generalized would be defined by the scope of the administrative data. For instance, if VR data are used, the analysis results could only be generalized to SSI recipients receiving VR services.

Data Dissemination

Data disclosure risk will need to be addressed for any data dissemination tool. Several options are available for disseminating data, including:

- public-use micro data file,
- public access to public-use data through on-line system,
- restricted-use micro data file,
- public access to restricted-use data through on-line system,
- restricted access to data (e.g., password protected on-line system, research data center), and
- set of tables for a publication report or research paper.

An initial risk analysis can be conducted to determine the disclosure risks. Statistical disclosure control treatments, such as data coarsening, suppression, data perturbation, can be applied to reduce the risk of disclosure. Limiting the access to the data, as mentioned in the list above, can also lead to a reduction in disclosure risk. Special attention should be given if longitudinal data exist in data dissemination products. This is because the extra wave of data provides much more information about individuals and brings more confidence to a data intruder's attack to identify individuals in the data.

8. Summary and Conclusions

The original NSCF was conducted over a decade ago to explore issues such as the general characteristics of SSI children and their families, health care access and utilization, the costs and family impacts associated with caring for a child with a disability, SSI children's transition to adulthood, and the impact of the 1996 welfare reform legislation on former SSI children. Recently, SSA has expressed interest in conducting a new NSCF to address a different set of policy questions. In this design options report, we reviewed a variety of issues related to conducting a new NSCF.

In **Chapter 2**, we noted some key features of the previous NSCF that could affect the design of the new NSCF, including the sample design and the response rates.

In **Chapter 3**, we discussed the new NSCF policy questions. For each of the policy questions, we outlined the types of respondents needed to address fully the questions and noted whether any particular subgroups of respondents are necessary. We identified three major types of respondents: (1) parents or guardians of SSI children; (2) SSI children and youth; and (3) parents or guardians of non-SSI children. Key subgroups include parents or guardians of SSI children ages 13 or older, parents or guardians of SSI children with mental impairments, parents or guardians of children who lost their SSI benefits due to a continuing disability review, SSI children who are ages 13 or older, youth who lost their lost their SSI benefits after redetermination at age 18, and parents or guardians of non-SSI children ages 13 or older. Also in Chapter 3, we described our review of national surveys to identify potential items for the NSCF. Appendix A provides a list of those items.

Chapter 4 discussed data collection methodologies and concluded that the two modes most suitable for a new NSCF are CATI and CAPI. We also noted expected response rates and options for enhancing those rates, including the use of incentives.

Chapter 5 provided specific design options related to surveying SSI children and families and possibly a comparison group of non-SSI children and families. These options included re-surveying original NSCF children and families, cross-sectional survey designs, and forward longitudinal designs.

- Re-surveying former NSCF respondents would produce findings that would generalize to SSI recipients in 2001 and allow SSA to discuss trends over time. However, we estimated that there would be low ESS for subgroups of interest. In addition, re-surveying former NSCF respondents would not provide SSA with a snapshot of current SSI recipients, which means that many of the policy questions would not be addressed by this approach. However, this approach could be used in conjunction with other design options.

- Use of a cross-sectional design will allow SSA to address each of the policy questions by collecting data from a nationally representative sample of respondents on the key variables at a particular point in time.

- If SSA opts for a longitudinal design, one option would be to follow the entire NSCF sample, including all of the various subgroups, which would provide rich insights into change over time on key variables related to the SSA policy questions. However, another approach might be to follow only one or more particular subgroups of interest, for example, recent applicants, SSI children ages 13 to 17, or SSI children with mental impairments.

In **Chapter 6**, we reviewed possible sampling frames for SSI children and families and non-SSI children and families. For SSI children and families, the sampling frame will be the SSA administrative data files. For the non-SSI children and families, we reviewed two approaches. The first approach focused on those children who have been found ineligible for SSI and relies on using the SSA administrative data to define the comparison group. Although this approach might be cost-effective since the sampling frame relies solely on administrative data, it may not be the best option since these children are not eligible to receive SSI for one or more reasons, and therefore, may not be comparable to SSI children. The second approach focused on identifying those children who may be potentially eligible for SSI; that is identifying those children who have a disability and low-income but have not applied for SSI. If SSA wishes to include such a comparison group in a new NSCF, a plausible option is to negotiate with CDC to incorporate questions into the National Survey of CSHCN screener and the interview itself. Our analyses and investigation showed that the survey could yield a large enough sample size to provide adequate power on comparisons between SSI recipients and the potentially eligible comparison group.

Also, in Chapter 6, we discussed sampling frames for PSUs and options for sampling PSUs and children and families. We also provided the results of power analyses for both cross-sectional and longitudinal design options. For the cross-sectional design options, we noted that SSA's priorities and analysis objectives will affect the estimates of the initial sample sizes required for a new NSCF. For point estimates for major subgroups, SSA could consider a cross-sectional survey that assumes 5,000 completed cases or less. However, if more precise estimates with low potential for bias due to nonresponse are needed, the design of the new NSCF would likely need to include a sample of PSUs to conduct tracing and followup of nonlocatable and nonresponse cases. Likewise, if comparisons among subgroups are a priority for SSA, then a much larger initial sample would be required, with initial sample sizes ranging from less than 5,000 cases to about 15,000 cases, depending upon the subgroups of focus. Chapter 6 provided a number of tables designed to assist SSA with determining the impact of a variety of different options on sample size and precision when considering a new NSCF, for both cross-sectional designs and longitudinal designs.

At the end of Chapter 6, we discussed how the priorities for a new NSCF need to be balanced with the costs involved in conducting such a survey. We compared variable costs for three oversampling options for a cross-sectional survey with a range of precision constraints (and therefore a range of relative variable costs) and for a forward longitudinal design comparing following-up with all respondents or just SSI children ages 13-17.

Last, in **Chapter 7**, we briefly discussed some data analysis considerations that are closely related to the design options, including sample weighting procedures and approaches to conducting analyses with data such as those that might be collected by the NSCF.

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Appendix A. Potential Survey Items

As discussed in Chapter 3, we reviewed a number of existing national surveys to identify items that may address the SSA policy questions for a new NSCF. Our review included the following surveys:

- original NSCF;
- NLSY97;
- NLTS2;
- PEELS;
- SEELS;
- NBS;
- National Survey of CSHCN;
- NHIS and NHIS-D; and
- MEPS.

The remainder of this appendix presents the results of that review. The items are organized by policy question to facilitate comparison across sources.

Policy Question #1 Topic Area:

Future Expectations

Employment	
NBS	B4. Please tell me how much you agree with the following statements. Would you say you strongly agree, agree, disagree, or strongly disagree? a. You see {yourself/NAME} {(IF B24=01) continuing to work/ (IF B24=00,d,r) working} for pay in the next year b. You see {yourself/NAME} working and earning enough to stop receiving disability benefits in the next year c. You see {yourself/NAME} {(IF B24=01) continuing to work/ (IF B24=00,d,r) working} for pay in the next five years d. You see {yourself/NAME} working and earning enough to stop receiving disability benefits in the next five years
NLTS2, Parent Interview, Wave 1 (PI-1)	J9(J8). How likely do you think it is that {YOUTH} eventually will get a paid job? Do you think {he/she} …
SEELS, Parent Interview (PI)	K7. How likely do you think it is that CHILD eventually will get a paid job? Do you think s/he…
NSCF	E33. When (NAME) turns 18, how likely is it that (HE/SHE) will work at a job? Would you say…
Education	
NLTS2 (PI-1)	D1T(D5A). Do you expect that {YOUTH} will be enrolled in school or receiving instruction in the fall? [IF NEEDED, "That is the 2001-2002 school year."] J1. How likely do you think it is that {YOUTH} will get a regular high school diploma? Do you think {he/she} … J2. How likely do you think it is that {he/she} will attend school after high school? Do you think {he/she} J3. How likely do you think it is that {he/she} will complete a technical or trade school program? Do you think {he/she}… J4. How likely do you think it is that {he/she} will graduate from a 2-year or community college? Do think {he/she} … J5(J3). How likely do you think it is that {he/she} will graduate from a 4-year college? Do you think {he/she} …
NLTS2, School Program Survey, Wave 1 (SP-1)	E4. For the period following high school, the primary goal of this student's educational program is to prepare him/her to…

SEELS (PI)	K2. How likely do you think it is that CHILD will graduate from high school and get a regular high school diploma? Do you think s/he… K3. How likely do you think it is that CHILD will attend school after high school? Do you think sh/e... K4. How likely do you think it is that CHILD will graduate from a 4-year college? Do you think s/he… K5. How likely do you think it is that CHILD will graduate from a 2-year or junior college? Do you think s/he…
SEELS, School Program Survey (SP)	SS8. Which of the following best describes the primary goal of this student's educational program for the period immediately following high school…
NSCF	E32. After (NAME) turns 18, how likely is it that (HE/SHE) will attend school or some type of training program? Would you say…
Living Arrangements	
NLTS2 (PI-1)	J6(J5). How likely do you think it is that {YOUTH} will get a driver's license? Do you think {he/she} … J7(J6). How likely do you think it is that {he/she} eventually will live away from home on {his/her} own without supervision? Do you think {he/she} … J8(J7). How likely do you think it is that {he/she} eventually will live away on {his/her} own with supervision? Do you think {he/she} … J10. How likely do you think it is that {YOUTH} will earn enough to support {him/her}self without financial help from {his/her} family or government benefit programs? Do you think {he/she}…
SEELS (PI)	K6. How likely do you think it is that CHILD eventually will live away from home on (his/her) own without supervision? Do you think s/he…
NSCF	E34. After (NAME) turns 18, how likely is it that (HE/SHE) could live independently if (HE/SHE) wanted to? Would you say… G15. Before (NAME) turns 25 years old, how likely is it that (HE/SHE) will be able to live independently. By that, I mean away from you and your family. Would you say…

Policy Question #2 Topic Area:

Accuracy of Administrative Disability Code According to Parent

Administrative Codes	
NSCF	B37. Considering everything you just told me about, what do you consider (FILL "NAME'S" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) main health condition or problem to be?

Policy Question #3 Topic Area:

Resources for Children

Government Assistance	
NLSY97 Youth Questionnaire, round 15 (YQ15)	YINC-6400A. During 2010, did [you/you or your spouse/you or your partner] receive any other benefits from government programs, for example, assistance with child care, transportation, energy, or housing? YINC-6500A. Approximately what do you think was the total cash value of all these other benefits that [you/you and your spouse/you and your partner] received in 2010? YPRGA-1100. Since [LINTDATE~X] have [you/you or your spouse/you or your partner] ever lived in a public housing project or receiving rental certificates or vouchers from a public agency? YPRGA-1200. Since [LINTDATE~X] have [you/you or your spouse/you or your partner] received any of the following kinds of assistance from a government program? - Transportation assistance, such as gas vouchers, bus passes, help registering, repairing, or insuring car - Child care services or assistance so you could go to work or school or training - Help paying energy bills - Food assistance from the Women, Infants, and Children (WIC) program - Cash assistance from Supplemental Security Income or SSI - Cash assistance from TANF, AFDC, or other government programs to help low-income families - Other non-cash assistance from the government because you had income that was too low to meet needs YPRG-16410_UPD. Are [you or your spouse/you or your partner/you] currently receiving Food Stamp benefits? YPRG-20700_UPD. Thinking about the Food Stamp benefits [you or your spouse/you or your partner/you] received [between (date) and (current/stop date)([loop])], on average, how much did [you or your spouse/you or your partner/you] receive per MONTH during this period? YPRG-21430_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving WIC benefits? YPRG-29130_UPD. Are [you or your spouse/you or your partner/you] currently living in a public housing project as a leaseholder or tenant or receiving rental certificates or vouchers? YPRG-35100_UPD. Thinking about the rental assistance you received [between (date) and (current/stop date)([loop])], on average, how much did you receive per MONTH during this period in rental certificates or vouchers? YPRG-35740_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving any AFDC, TANF, or other government assistance payments to low-income families?

	YPRG-35900_UPD. Thinking about these payments that [your or your spouse or children/you or your partner or children/you or your children] received [between (date) and (current/stop date)([loop])], on average, how much did [you or your spouse/you or your partner/you] receive per MONTH during this period? YPRG-35971_UPD. Since [LINTDATE~X] did [you or your spouse/you or your partner/you] receive any kind of non-cash government assistance? YPRG-35972_UPD. Since [LINTDATE~X] which of the following kinds of non-cash assistance did you receive? - Transportation assistance, such as gas vouchers, bus passes, help registering, repairing, or insuring car - Help from energy assistance program - Child care services or assistance so you could go to work or school or training - Other non-cash assistance from the government because you had income that was too low to meet needs YPRG-35973_UPD. Since [LINTDATE~X] did [you or your spouse/you or your partner/you] receive any kind of short term cash assistance to tide you over when you need it? YPRG-35974_UPD. What was the total amount of short term cash assistance that you received? YPRG-36120_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving any other welfare payments, such as general assistance payments, emergency assistance payments, or Cuban/Haitian or Indian assistance payments? YPRG-32300_UPD. Thinking about the other welfare payments [you or your spouse/you or your partner/you] received [between (date) and (current/stop date)([loop])], on average, how much did you receive per MONTH during this period?
NBS	J2. There is a program called Medicaid that pays for health care for persons in need. {Are you/Is NAME} currently covered by Medicaid? OTHERWISE USE: There is a program called Medicaid that pays for health care for persons in need. In {your/NAME'S} state, you may also hear it called {STATEMED FROM {NAME'S} CURRENT STATE}. {Are you/Is NAME} currently covered by Medicaid? PROBE: Medicaid is a state medical assistance program that serves low-income people and Social Security Income recipients with disabilities K6. Last month did {you/NAME} receive any income from… a. Private disability insurance (sometimes called long-term care disability insurance) b. Workers' compensation? c. Veterans' benefits? d. Public assistance or welfare payments? e. Unemployment benefits? f. Private pensions or government employee pensions? g. Other sources on a regular basis but not from jobs or Social Security?

	K7. How much income did {you/NAME} receive last month from {SOURCE FROM K6}? K11. Did {you/NAME} receive any food stamps last month? Please include only food stamps {you/NAME} received for {you/NAME} and {your/NAME's} family. Do not include food stamps received separately by other members of [your/NAME's} household. K12. What was the dollar value of the food stamps {you/NAME} received last month? Please include only food stamps {you/NAME} received by {you/NAME} for {your/NAME's} family. K13. Did {you/NAME} receive assistance from any other government program last month? For example, housing or energy assistance. K14. What other assistance did {you/NAME} receive? K15. How much income did {you/NAME} receive last month from the assistance you just told me about?
NLTS2 (PI-1)	K12B (K14B). Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? K13B (K15). Do you, or anyone in the household, receive food stamps now?
PEELS Parent Interview, Wave 1 (PI-1)	B31. Is (child) covered by (state's) government-assisted health insurance, such as (Medicaid) (or) (CHIP)? D3. Head Start is a federally-sponsored preschool program primarily for children from low-income families. Is (prog1/prog2) a Head Start program? H24a. My next questions are about government benefits you or others in your household may receive. Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? H24b. Did you or anyone in the household get any of these welfare benefits anytime in the last year? H25. Do you, or anyone in the household, receive food stamps now? H26. Do you now get food or food vouchers from WIC (or the Women, Infants, and Children's program)?
PEELS - Elementary School Teacher/ Kindergarten Teacher Questionnaire (ELT/KT Quex)	A9 (ELT)/A11 (KT). Does this child participate in the following? b. Title I e. Free/reduced-price lunch program

SEELS (PI)	C2. Is [CHILD] covered by government-assisted health insurance, such as _____, (fill in state names for Medicaid and other low-income insurance programs)? J14a. My next questions are about government benefits you or others in your household may receive. Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? J14b. Did you or anyone in the household receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program anytime in the past 2 years? J14c. Who got these welfare benefits? Was it… J15. Do you or anyone in the household receive food stamps now?
SEELS (SP)	A4. Does this student participate in any of the following? Free/reduced-price lunch program Program for gifted and talented students Chapter 1 Bilingual education or instruction for English-language learners Summer school during the previous summer
NSCF	D1. The next questions are about all types of health insurance and health care coverage that (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) may have. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by Medicaid, a health insurance program for persons with certain income levels and persons with disabilities? In this state, the program is sometimes called (FILL STATE MEDICAID NAME). D4. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by the State Children's Health Insurance Program, or S-CHIP? (FILL IF S-CHIP NAME IS DIFFERENT THAN STATE MEDICAID NAME) In this state, the program is sometimes called (FILL S-CHIP NAME). D8. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by military health care, TRICARE, CHAMPUS, OR CHAMP-V.A.? D10. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) enrolled in a Title 5 program? Title 5 programs are state level programs that usually provide maternal and child health services. D11. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by any other kind of health insurance or health care plan that pays for services obtained from hospitals, doctors, and other health professionals? D12. What kind of health plan is it? K2. In addition to earnings from work, families often receive other income from the government, from private institutions, or from their own savings. I would like to ask you a few questions about all other sources of income received in (LAST MONTH) by members of your family, including (INSERT NAMES OF HOUSEHOLD MEMBERS FROM A42). In (LAST MONTH) did anybody receive payments from the welfare office, including Emergency Assistance?

	K6. In (LAST MONTH) did anybody in your household receive any other kind of welfare assistance, such as help with getting a job, placement in education or training programs, or help with transportation or child care? K8. In (LAST MONTH) did anybody in your household receive any payments from your state's general assistance program? K11. In (LAST MONTH) did anybody in your household receive any Food Stamps? K25. In (LAST MONTH) did anyone in the household receive any social security payments? These include retirement benefits, survivor's benefits, or social security disability insurance, also known as SSDI. K53. Now I'd like you to think about the past 12 months. In the past 12 months, were you or anyone in this household on WIC, the Women, Infants, and Children's nutrition program? K54. In the past 12 months, did this household receive any energy assistance from the federal, state, or local government? K55. In the past 12 months, did any of the children living with you receive free or reduced price school lunches because they qualified for the Federal School Lunch Program? K76. In (LAST MONTH) did (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) (FILL "OR ANYBODY IN NAME'S HOUSEHOLD" IF K71=01 AND RTYPE=03; "OR ANYBODY IN YOUR HOUSEHOLD" IF K71=01 AND RTYPE=02; ELSE BLANK) receive any OTHER kind of welfare assistance, such as help with getting a job, placement in education or training programs, or help with transportation or child care? L15. (FILL "IS YOUR FAMILY" IF RTYPE=01; "ARE YOU" IF RTYPE=02; "IS NAME" IF RTYPE=03) paying lower rent because the federal, state, or local government is paying part of the rent?
Education	
NSCF	E11. These next questions are about special education. Special education is a program designed to meet the individual needs of children with special needs. It is paid for by the public school system and may take place at a school, at home, or at a hospital. During the past 12 months, has (NAME) received any type of special education services or benefits? Do not include gifted or talented programs. E19. Early intervention is a program designed to meet the individual needs of infants and very young children who have special needs. It is provided free and may include services at home, at a hospital, or somewhere else. During the past 12 months, has (NAME) received any type of early intervention services?
SEELS (PI)	D13a. Our records show that CHILD received special education services at the beginning of 1999-2000 school year. Is she/he in special education now? D13e. Does CHILD now have a 504 plan for accommodations because of his/her special needs?
SEELS (SP)	B6. Which of the following services has this student received from or through the school system during the current school year, including services contracted from other agencies?

NLTS2 (PI-1)	D8a (D13A).Our records show that {YOUTH} received special education services and had an IEP at the beginning of the 2000-2001 school year. {Does {he/she} still receive special education services and have an IEP?}
PEELS (PI-1)	E7. Does (child) get any of (his/her) special education or therapy services through the public schools? E20a. Now I'd like to ask you about any services (child) may be receiving that are not paid for by the public schools. Is (child) receiving any special education or therapy services that are paid for by any other source such as your family, your insurance, or another public program?
PEELS ELT/KT/Early Childhood Teacher (ECT) Quex	B8 (ELT)/B5 (KT)/D3 (ECT). Were any of the following services provided to this child through the school system during the current school year?
Employment/Training Services	
NLSY97 (YQ15)	YTRN-700. Other than high school, college, or university degree programs you may have told me about earlier, since [LINTDATE~X], have you attended any schooling, courses or training programs designed to help people find a job, improve their job skills, or learn a new job? YTRN-3700. {TRNA_W} Were any of the costs of this school or training program paid for or provided directly by a government program? TRN-4100. Did you receive a training allowance or additional money besides public assistance or unemployment insurance because of your participation in this training program? YTRN-4200. How much was the allowance or additional money? YTRN-4600. Did you receive any student financial aid or did you take out a student loan to help pay for this training? YTRN-6100. Did any of your employers provide or help pay for this training program?
SEELS (SP)	SS6. Please indicate which of the following services this student received from or through the school system during this school year. *PLEASE CIRCLE ALL THAT APPLY.* 1 A formal assessment of career skills or interests 2 Career counseling 3 Job readiness or prevocational training 4 Work exploration 5 Work experience 6 Specific job skills training 7 Referrals to potential employers 8 Instruction in looking for jobs 9 School staff worked with employer to modify jobs for this student 10 School staff contacted student or employer to monitor performance on the job 11 None of these

NBS	G1. Next, I will ask about different types of services that people with disabilities sometimes get in order to improve their ability to work or live independently. First, I will ask about employment services {you/NAME} may have received. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any employment services to help {you/him/her} get a job? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any employment services to help {you/him/her} get a job? G10. Sometimes people get training to help them learn new skills so they can get a new job or change careers. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers?
NLTS2 (PI-1)	H1A. During the past 12 months, has {YOUTH} received any of the following services? H1AP p. Career counseling, help in finding a job, training in job skills or vocational education? H1B. Was any of that from or through {his/her} school or district? H1BP P. CAREER COUNSELING, HELP IN FINDING A JOB, TRAINING IN JOB SKILLS OR VOCATIONAL EDUCATION
NSCF	E25. Is (NAME) now receiving any training in job skills, vocational education, career counseling, or help in finding a job? E26. What kinds of training or help is (NAME) now receiving or has (HE/SHE) received in the past? Has (HE/SHE) received… E52a. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training in specific job skills, for example, car repair, food service, or training for another kind of job? E52b. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training to find out (FILL “HIS/HER” if RTYPE=01, 03; “YOUR” if RTYPE=02) work interests or abilities? E52c. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training in basic skills needed for work, like counting change, telling time, or using transportation to get to work? E52d. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received career counseling, like help in figuring out jobs (FILL “HE/SHE” if RTYPE=01, 03; “YOU” if RTYPE=02) might be suited for? E52e. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received help in finding a job or learning to look for one? E52f. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received any other training or counseling? E54. About how much training in job skills, vocational education, career counseling, or help in finding a job did (FILL “HE/SHE” IF RTYPE=01,03; “YOU” IF RTYPE=02) get during the past 12 months? Would you say…

	E58. The Social Security Administration sometimes refers beneficiaries to state vocational rehabilitation agencies for services. Has the Social Security Administration ever referred (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) for vocational rehabilitation services?
Service Coordination	
NLTS2 (PI-1)	H2A. Does {YOUTH} have a case manager or someone who coordinates the services {he/she} receives? (also asked in Student's School Program Survey item D7)
PEELS (ELT/KT/ECT Quex)	B8. (ELT)/D3 (ECT)/B5 (KT). Were any of the following services provided to this child through the school system during the current school year? p. Service coordination/case management
SEELS (PI)	B9a. During this school year has CHILD received any of the following services? p. Service coordination or case management
CSHCN	C5Q12. Does anyone help you arrange or coordinate [S.C.]'s care among the different doctors or services that [he/she] uses? C5Q17. [During the past 12 months/ Since [his/her] birth], have you felt that you could have used extra help arranging or coordinating [S.C.]'s care among these different health care providers or services? C5Q09. [During the past 12 months/ Since [his/her] birth], how often did you get as much help as you wanted with arranging or coordinating [S.C.]'s care? Would you say never, sometimes, or usually?
Other Sources	
NLSY97 (YQ15)	YEMP-INJ-15. Have you collected any worker's compensation benefits for this [injury/illness]? YEMP-VET-18. Did you attend any of the Transition Assistance Program workshops, known as TAP or A-CAP? INTERVIEWER: READ IF NECESSARY: These workshops provide information about finding civilian jobs, obtaining training, securing Veterans' benefits, and obtaining other services available to veterans. YFER-5160. These next few questions concern child support. Child support payments can be specified in written or verbal child support agreements. Have child support payments ever been agreed to or awarded for [name of child([loop])]? YEMP-100300. I'm going to refer to a list of benefits which employers sometimes make available to their employees. [At this time/At the time you left], which of the benefits on this list would it [be/have been] possible for you to receive as part of your [job_assignment] [as/with] [employer name([(loop)])]? 1 Medical, surgical or hospitalization insurance which covers injuries or major illnesses off the job 2 Life insurance that would cover your death for reasons not connected with your job 3 Dental benefits 4 Paid maternity or paternity leave 5 Unpaid maternity or paternity leave which would allow you to return to the same job, or one similar to it 6 A retirement plan other than Social Security 7 A flexible work schedule

	8 Tuition reimbursement for certain types of schooling 9 Company provided or subsidized childcare 10 Employee Stock Ownership Plan(s)
NSCF	G41. In (LAST MONTH), did (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) receive financial assistance from members of (FILL "YOUR" IF RTYPE=02; "HIS/HER" IF RTYPE=03) family not living with (FILL "YOU" IF RTYPE=02; "HIM/HER" IF RTYPE=03)? For example, to pay medical bills or other living expenses? Do not include money received to pay for school. K15. In (LAST MONTH) did anybody receive any child support payments? K19. In (LAST MONTH) did anybody receive any foster care payments? K29. In (LAST MONTH) did anybody in your household receive any kind of pension or annuity payment? K32. In (LAST MONTH) did anybody in your household receive payments from any other sources not mentioned, such as alimony, contributions from family or friends, VA payments, worker's compensation, or unemployment compensation?

Policy Question #4 Topic Area:

Respite Care

Respite Care	
NLTS2 (PI-1)	H1A. During the past 12 months, has {YOUTH} received any of the following services? H1AO o. Respite care? H1B. Was any of that from or through {his/her} school or district? H1BO O. RESPITE CARE H6B. Which services is {he/she} on a waiting list for? H6B_15 15. RESPITE CARE
NSCF	F49. During the past 12 months, did your family receive any respite care? Respite care is a service provided to families so the family caregivers can go on vacation or take a break. It can be provided by a person or organization at your home or somewhere else. F50. During the past 12 months, did your family need any respite care services? F51. Why did your family not receive any respite care services?

Policy Question #5 Topic Area:

Transition to Adulthood

Employment Services	
NLSY97 (YQ15)	YTRN-700. Other than high school, college, or university degree programs you may have told me about earlier, since [LINTDATE~X], have you attended any schooling, courses or training programs designed to help people find a job, improve their job skills, or learn a new job?
NBS	G1. Next, I will ask about different types of services that people with disabilities sometimes get in order to improve their ability to work or live independently. First, I will ask about employment services {you/NAME} may have received. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any employment services to help {you/him/her} get a job? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any employment services to help {you/him/her} get a job? G10. Sometimes people get training to help them learn new skills so they can get a new job or change careers. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers?
NLTS2 (PI-1)	H1A. During the past 12 months, has {YOUTH} received any of the following services? H1AP p. Career counseling, help in finding a job, training in job skills or vocational education?
NLTS2, School Survey, Wave 1 (SS-1)	C13. What percentage of this student's school day currently is spent in the two activities below (please do not include after-school employment)? a. School sponsored work experience on the school campus b. School sponsored work experience off campus C14. Since starting high school, which of the following classes or services has this student received from or through the school system? Career counseling, job readiness or prevocational skills, instruction in looking for jobs, job shadowing or work exploration, internship or apprenticeship, tech-prep program, entrepreneurship program, specific job skills training, referrals to potential employers, other job placement support, job coach E10. Has any of the following been contacted by the school or school system regarding programs or employment for this student when s/he leaves high school?
SEELS (SP)	SS7. What percentage of this student's school day currently is spent in the two activities below (please do not include after-school employment)? School sponsored work experience on the school campus

	School sponsored work experience off campus SS6. Please indicate which of the following services this student received from or through the school system during this school year. *PLEASE CIRCLE ALL THAT APPLY.* 1 A formal assessment of career skills or interests 2 Career counseling 3 Job readiness or prevocational training 4 Work exploration 5 Work experience 6 Specific job skills training 7 Referrals to potential employers 8 Instruction in looking for jobs 9 School staff worked with employer to modify jobs for this student 10 School staff contacted student or employer to monitor performance on the job 11 None of these
NSCF	E25. Is (NAME) now receiving any training in job skills, vocational education, career counseling, or help in finding a job? E26. What kinds of training or help is (NAME) now receiving or has (HE/SHE) received in the past? Has (HE/SHE) received… E52a. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received training in specific job skills, for example, car repair, food service, or training for another kind of job? E52b. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received training to find out (FILL "HIS/HER" if RTYPE=01, 03; "YOUR" if RTYPE=02) work interests or abilities? E52c. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received training in basic skills needed for work, like counting change, telling time, or using transportation to get to work? E52d. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received career counseling, like help in figuring out jobs (FILL "HE/SHE" if RTYPE=01, 03; "YOU" if RTYPE=02) might be suited for? E52e. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received help in finding a job or learning to look for one? E52f. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) received any other training or counseling? E54. About how much training in job skills, vocational education, career counseling, or help in finding a job did (FILL "HE/SHE" IF RTYPE=01,03; "YOU" IF RTYPE=02) get during the past 12 months? Would you say… E58. The Social Security Administration sometimes refers beneficiaries to state vocational rehabilitation agencies for services. Has the Social Security Administration ever referred (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) for vocational rehabilitation services?

Education	
NBS	G23. (IF DISABLED BEFORE AGE 16 (C_DISAGE <16)) Since age 16, {have you/has NAME} enrolled in school or taken any classes to help {you/him/her} get a new job or change careers? Please do not include any training you have already told me about. (IF DISABLED AT AGE 16 OR LATER (C_DISAGE ≥ 16)) Since becoming disabled, {have you/has NAME} enrolled in school or taken any classes to help {you/him/her} get a new job or change careers? Please do not include any training you have already told me about. PROBE 1: This could include vocational training in high school, college classes, or other instructional programs. G26. {Are you/Is NAME} currently enrolled in school or taking any classes? G27. {Are you/Is NAME} working toward a degree, a certificate or license, or {are you/is (he/she)} just taking classes? G28. PROGRAMMER: IF G27=01 USE "DEGREE" AND IF G27=02 USE "CERTIFICATE OR LICENSE" Toward what type of {degree/certificate or license} {are you/is NAME} working?
Life Skills	
NSCF	E31. Has (NAME) ever received any training in how to do things like manage money, cook, or keep house, or any other life skills training? Do not include instruction from family members or friends.
Transition Planning	
NLTS2 (PI-1)	E2C. Have you or another adult in the household met with teachers to set goals for what {YOUTH} will do after high school and make a plan for how {he/she} will achieve them? Sometimes this is called a transition plan? (Similar to Youth Survey – Wave 2 #8c) E2D. Has {YOUTH} met with teachers to set goals for what {he/she} will do after high school and make a plan for how {he/she} will achieve them? E4B. Has the school done any planning for what {YOUTH} will do after high school? E4C. How useful has this planning been in helping {YOUTH} prepare for life after high school? Would you say it has been…
NLTS2, Parent Interview, Wave 2 (PI-2)	E3a. Did the school mostly come up with the goals on [his/her] IEP [IF E2c=1 ADD: and transition plan] or was it mostly you and/or YOUTH who came up with the goals? (Similar to Youth Interview Part 2b – Wave 2 #8d – amount of choice youth had about transition plan goals) E3b. Which of the following best describes YOUTH's role in [his/her] [IF E2b=1 ADD: IEP] [IF E2d=1 ADD: and] transition planning? E3c. How do you feel about your family's involvement in the decisions about [YOUTH'S] IEP [IF E2c=1 ADD: and transition plan]? Do you feel you ... (Similar to Youth interview Part 2b– Wave 2 #8e – amount of involvement youth had in transition planning)
NLTS2 (SS-1)	E1. Has there been planning for transition to adult life for this student? E2. At what age or grade level was this student when transition planning first started for him or her?

	E3. Has this student received instruction specifically focused on transition planning? E4. For the period following high school, the primary goal of this student's educational program is to prepare him/her to… E6. How much progress do you believe this student is making toward each kind of goal for the transition to adulthood? E7. How well suited do you believe this student's school program is for preparing him or her to achieve his or her transition goals? E11. Has information about services available after high school related to this student's kind of disability been provided his or her parents or guardians by the school system? E12. What service or program needs were identified for this student after high school in his or her IEP or transition plan?
NLTS2, Youth Interview, Wave 2 (YI-2)	R7e. How much do you think your IEP [IF R7b = 1: or transition] goals are challenging and right for you. Are they...."
NLTS2, Assessment, Wave 2 (A-2)	Self Determination Scale (SDS). Selected items - Student is asked a series of questions relating to planning for the future, self-advocacy, and perspectives on the transition process.
SEELS (SP)	SS10. Has anyone at the school done postsecondary transition planning for this student during this school year? SS10b. Is the student's transition plan written? c. Who has actively participated in the transition planning for this student during this school year (for example, by being involved in discussions on choosing services or goals)?
NSCF	E63. (FILL "DOES NAME" IF RTYPE=01, 03; "DO YOU" IF RTYPE=02) now have an Individual Written Rehabilitation Plan or IWRP? This is also known as an Individual Written Vocational Plan or IWVP. E64. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) ever had an Individual Written Rehabilitation Plan or IWRP? This is also known as an Individual Written Vocational Plan or IWVP.

Policy Question #6 Topic Area:

Effect of Economic Downturn

Financial Situation/Employment	
NLSY97 (YQ15)	YINC-7990. Which of the following best describes [yours/yours and your spouse's/yours and your partner's] financial condition? YINC-7970. During the past 12 months, have [you/you or your spouse/you or your partner] been late in paying your rent or your mortgage by more than 60 days?
NSCF	G21. Now I'd like you to think back over the past (FILL NUMBER OF YEARS SINCE 1996) years, from 1996, (FILL "WHEN (NAME) WAS AROUND (INSERT NAME'S AGE IN 1996)"; IF NOT BORN IN 1996 THEN BLANK) to the present time. Since 1996, did you or any member of your household do any of the following, even if just for a short while… A. Move in with someone in order to save money or lower housing costs B. Add a boarder or roommate to your household C. Cut-back on buying things for (NAME's) care D. Cut back on other household purchases and expenses E. Go into debt or increase your debt to pay for (NAME's) care G22. Since 1996, did you or any adult member of your household, (FILL IF AGE=14+ "NOT COUNTING NAME"; ELSE BLANK), do any of the following… A. Get a job, a second job, or a better paying job B. Enter a job training program or go back to school G23. Since 1996, have you and your family lived in an emergency shelter or domestic violence shelter at any time? G24. Since 1996, have you and your family ever been homeless or living on the street? G25. Since 1996, have you and your family ever received help from a food pantry, a soup kitchen, a community center, or a church? (IF YES) Which ones? G27. How would you compare your standard of living now with your standard of living in 1996, (FILL "WHEN (NAME) WAS AROUND (INSERT NAME'S AGE IN 1996)"; IF NOT BORN IN 1996 THEN BLANK)? Would you say that now you are… G29. Now I'd like to ask some questions about (FILL "YOUR" IF RTYPE=02; "NAME'S" IF RTYPE=03) daily living. I'm going to read you some statements that people have made about their food situation. The first statement is "I worried whether my food would run out before I got money to buy more." Was that often, sometimes, or never true for (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) in the last 12 months? G30. "The food I bought just didn't last, and I didn't have money to get any more." Was that often, sometimes, or never true for (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) in the last 12 months? G31. In the last 12 months, did (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) ever cut the size of (FILL "YOUR" IF RTYPE=02; "HIS/HER" IF RTYPE=03) meals or skip meals because there wasn't enough money for food?

	G32. How often did this happen? Was it… G33. During the last 12 months, was there a time when (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) were not able to pay (FILL "YOUR" IF RTYPE=02; "HIS/HER" IF RTYPE=03) rent, mortgage, or utility bills? G34. How often did this happen? Was it… I31. Now I'd like you to think back to (LAST MONTH) 1996, (FILL "WHEN (NAME) WAS (INSERT NAME'S AGE IN 1996)"; IF NOT BORN IN 1996 THEN BLANK). Were you employed at a job or business in (LAST MONTH) 1996? I32. What is the main reason you were not working in (LAST MONTH) 1996?
NHIS	AAU.113_00.020. In regard to your health insurance or health care coverage, how does it compare to a year ago? Is it better, worse, or about the same? CAU.133_00.010 - CAU.135_04.000. DURING THE PAST 12 MONTHS, was there any time when [fill: alias] NEEDED any of the following, but didn't get it because you couldn't afford it... To see a specialist, Follow up care, Prescription medicines, Mental health care or counseling, Dental care, Eyeglasses? FDMED12M. DURING THE PAST 12 MONTHS, [fill: have you delayed seeking medical care/has medical care been delayed for anyone in the family] because of worry about the cost?
MEPS	RJ04. During our last interview on {PREV RD INTV DT}, we recorded that (PERSON) worked {full-time/part-time} at (ESTABLISHMENT). {(Do/Does)/Did} (PERSON) still work {35 hours or more/less than 35 hours} per week at (ESTABLISHMENT) {on {END DATE OF REFERENCE PERIOD}}? RJ05. What is the main reason (PERSON) changed from {full-time/ part-time} to {part-time/full-time} at (ESTABLISHMENT)?
Receipt of Government Assistance (Prior and Current)	
NLTS2 (PI-1)	K12A (K14A). Did you or anyone in the household receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program anytime in the past 2 years? K12B (K14B). Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? K13A.Did you, or anyone in the household, receive food stamps in the past 2 years? K13B (K15). Do you, or anyone in the household, receive food stamps now?
SEELS (PI)	J14a. My next questions are about government benefits you or others in your household may receive. Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? J14b. Did you or anyone in the household receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program anytime in the past 2 years? J16a. Does the household receive money for [CHILD] from the Supplemental Security Income or SSI program? J16b. Did the household get money for [CHILD] from the Supplemental Security Income or SSI program in the past 2 years?

NSCF	K44. As best you can remember, in 1996, (FILL "WHEN (NAME) WAS AROUND (INSERT NAME'S AGE IN 1996)"; IF NOT BORN IN 1996, THEN BLANK) did anybody in your household receive payments from the welfare office, including Emergency Assistance? I'm not going to ask you the amount, just whether or not anybody received it. K45. In 1996, did anybody in your household receive any payments from your state's general assistance program? K46. In 1996, did anybody in your household receive any food stamps? K47. In 1996, did anybody in your household receive any child support payments? K48. In 1996, did anybody in your household receive any foster care payments? K49. In 1996, did anybody in your household (IF (NAME) BORN BEFORE 1996, FILL "BESIDES (NAME)"; ELSE BLANK) receive any Supplemental Security Income, or SSI payments? K50. In 1996, did anybody in your household receive any other social security payments? These include retirement benefits, survivor's benefits, or social security disability insurance, also known as SSDI. K51. In 1996, did anybody in your household receive any other kind of pension or annuity? K52. In 1996, did anybody in your household receive any payments from any other sources not mentioned, such as alimony, contributions from family or friends, VA payments, worker's compensation, or unemployment compensation?
PEELS (PI-1)	H27a. Do you now receive money for (child) from the Supplemental Security Income or SSI program? H27b. Did you ever get money for (child) from the Supplemental Security Income or SSI program?

Policy Question #7 Topic Area:

Sources of Care for Youth Who Lose Benefits

Government Assistance	
NLSY97 Youth Questionnaire, round 15 (YQ15)	YINC-6400A. During 2010, did [you/you or your spouse/you or your partner] receive any other benefits from government programs, for example, assistance with child care, transportation, energy, or housing? YINC-6500A. Approximately what do you think was the total cash value of all these other benefits that [you/you and your spouse/you and your partner] received in 2010? YPRGA-1100. Since [LINTDATE~X] have [you/you or your spouse/you or your partner] ever lived in a public housing project or receiving rental certificates or vouchers from a public agency? YPRGA-1200. Since [LINTDATE~X] have [you/you or your spouse/you or your partner] received any of the following kinds of assistance from a government program? - Transportation assistance, such as gas vouchers, bus passes, help registering, repairing, or insuring car - Child care services or assistance so you could go to work or school or training - Help paying energy bills - Food assistance from the Women, Infants, and Children (WIC) program - Cash assistance from Supplemental Security Income or SSI - Cash assistance from TANF, AFDC, or other government programs to help low-income families - Other non-cash assistance from the government because you had income that was too low to meet needs YPRG-16410_UPD. Are [you or your spouse/you or your partner/you] currently receiving Food Stamp benefits? YPRG-20700_UPD. Thinking about the Food Stamp benefits [you or your spouse/you or your partner/you] received [between (date) and (current/stop date)([loop])], on average, how much did [you or your spouse/you or your partner/you] receive per MONTH during this period? YPRG-21430_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving WIC benefits? YPRG-29130_UPD. Are [you or your spouse/you or your partner/you] currently living in a public housing project as a leaseholder or tenant or receiving rental certificates or vouchers? YPRG-35100_UPD. Thinking about the rental assistance you received [between (date) and (current/stop date)([loop])], on average, how much did you receive per MONTH during this period in rental certificates or vouchers? YPRG-35740_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving any AFDC, TANF, or other government assistance payments to low-income families?

	YPRG-35900_UPD. Thinking about these payments that [your or your spouse or children/you or your partner or children/you or your children] received [between (date) and (current/stop date)([loop])], on average, how much did [you or your spouse/you or your partner/you] receive per MONTH during this period? YPRG-35971_UPD. Since [LINTDATE~X] did [you or your spouse/you or your partner/you] receive any kind of non-cash government assistance? YPRG-35972_UPD. Since [LINTDATE~X] which of the following kinds of non-cash assistance did you receive? - Transportation assistance, such as gas vouchers, bus passes, help registering, repairing, or insuring car - Help from energy assistance program - Child care services or assistance so you could go to work or school or training - Other non-cash assistance from the government because you had income that was too low to meet needs YPRG-35973_UPD. Since [LINTDATE~X] did [you or your spouse/you or your partner/you] receive any kind of short term cash assistance to tide you over when you need it? YPRG-35974_UPD. What was the total amount of short term cash assistance that you received? YPRG-36120_UPD. Are [your or your spouse or children/you or your partner or children/you or your children] currently receiving any other welfare payments, such as general assistance payments, emergency assistance payments, or Cuban/Haitian or Indian assistance payments? YPRG-32300_UPD. Thinking about the other welfare payments [you or your spouse/you or your partner/you] received [between (date) and (current/stop date)([loop])], on average, how much did you receive per MONTH during this period?
NBS	J2. There is a program called Medicaid that pays for health care for persons in need. {Are you/Is NAME} currently covered by Medicaid? OTHERWISE USE: There is a program called Medicaid that pays for health care for persons in need. In {your/NAME'S} state, you may also hear it called {STATEMED FROM {NAME'S} CURRENT STATE}. {Are you/Is NAME} currently covered by Medicaid? PROBE: Medicaid is a state medical assistance program that serves low-income people and Social Security Income recipients with disabilities K6. Last month did {you/NAME} receive any income from… a. Private disability insurance (sometimes called long-term care disability insurance) b. Workers' compensation? c. Veterans' benefits? d. Public assistance or welfare payments? e. Unemployment benefits? f. Private pensions or government employee pensions? g. Other sources on a regular basis but not from jobs or Social Security?

	K7. How much income did {you/NAME} receive last month from {SOURCE FROM K6}? K11. Did {you/NAME} receive any food stamps last month? Please include only food stamps {you/NAME} received for {you/NAME} and {your/NAME's} family. Do not include food stamps received separately by other members of [your/NAME's} household. K12. What was the dollar value of the food stamps {you/NAME} received last month? Please include only food stamps {you/NAME} received by {you/NAME} for {your/NAME's} family. K13. Did {you/NAME} receive assistance from any other government program last month? For example, housing or energy assistance. K14. What other assistance did {you/NAME} receive? K15. How much income did {you/NAME} receive last month from the assistance you just told me about?
NLTS2 (PI-1)	K12B (K14B). Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? K13B (K15). Do you, or anyone in the household, receive food stamps now?
PEELS - Parent Interview, Wave 1 (PI-1)	B31. Is (child) covered by (state's) government-assisted health insurance, such as (Medicaid) (or) (CHIP)? D3. Head Start is a federally-sponsored preschool program primarily for children from low-income families. Is (prog1/prog2) a Head Start program? H24a. My next questions are about government benefits you or others in your household may receive. Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? H24b. Did you or anyone in the household get any of these welfare benefits anytime in the last year? H25. Do you, or anyone in the household, receive food stamps now? H26. Do you now get food or food vouchers from WIC (or the Women, Infants, and Children's program)?
PEELS - Elementary School Teacher/ Kindergarten Teacher Questionnaire (ELT/KT Quex)	A9 (ELT)/A11 (KT). Does this child participate in the following? b. Title I e. Free/reduced-price lunch program

SEELS (PI)	C2. Is [CHILD] covered by government-assisted health insurance, such as _____, (fill in state names for Medicaid and other low-income insurance programs)? J14a. My next questions are about government benefits you or others in your household may receive. Do you or anyone in the household now receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program? J14b. Did you or anyone in the household receive money from TANF (Temporary Assistance to Needy Families) or the state welfare program anytime in the past 2 years? J14c. Who got these welfare benefits? Was it… J15. Do you or anyone in the household receive food stamps now?
SEELS (SP)	A4. Does this student participate in any of the following? 5. Free/reduced price lunch program
NSCF	D1. The next questions are about all types of health insurance and health care coverage that (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) may have. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by Medicaid, a health insurance program for persons with certain income levels and persons with disabilities? In this state, the program is sometimes called (FILL STATE MEDICAID NAME). D4. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by the State Children's Health Insurance Program, or S-CHIP? (FILL IF S-CHIP NAME IS DIFFERENT THAN STATE MEDICAID NAME) In this state, the program is sometimes called (FILL S-CHIP NAME). D8. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by military health care, TRICARE, CHAMPUS, OR CHAMP-V.A.? D10. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) enrolled in a Title 5 program? Title 5 programs are state level programs that usually provide maternal and child health services. D11. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) covered by any other kind of health insurance or health care plan that pays for services obtained from hospitals, doctors, and other health professionals? D12. What kind of health plan is it? K2. In addition to earnings from work, families often receive other income from the government, from private institutions, or from their own savings. I would like to ask you a few questions about all other sources of income received in (LAST MONTH) by members of your family, including (INSERT NAMES OF HOUSEHOLD MEMBERS FROM A42). In (LAST MONTH) did anybody receive payments from the welfare office, including Emergency Assistance? K6. In (LAST MONTH) did anybody in your household receive any other kind of welfare assistance, such as help with getting a job, placement in education or training programs, or help with transportation or child care? K8. In (LAST MONTH) did anybody in your household receive any payments from your state's general assistance program?

	K11. In (LAST MONTH) did anybody in your household receive any Food Stamps? K25. In (LAST MONTH) did anyone in the household receive any social security payments? These include retirement benefits, survivor's benefits, or social security disability insurance, also known as SSDI. K53. Now I'd like you to think about the past 12 months. In the past 12 months, were you or anyone in this household on WIC, the Women, Infants, and Children's nutrition program? K54. In the past 12 months, did this household receive any energy assistance from the federal, state, or local government? K55. In the past 12 months, did any of the children living with you receive free or reduced price school lunches because they qualified for the Federal School Lunch Program? K76. In (LAST MONTH) did (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) (FILL "OR ANYBODY IN NAME'S HOUSEHOLD" IF K71=01 AND RTYPE=03; "OR ANYBODY IN YOUR HOUSEHOLD" IF K71=01 AND RTYPE=02; ELSE BLANK) receive any OTHER kind of welfare assistance, such as help with getting a job, placement in education or training programs, or help with transportation or child care? L15. (FILL "IS YOUR FAMILY" IF RTYPE=01; "ARE YOU" IF RTYPE=02; "IS NAME" IF RTYPE=03) paying lower rent because the federal, state, or local government is paying part of the rent?
Education	
NSCF	E11. These next questions are about special education. Special education is a program designed to meet the individual needs of children with special needs. It is paid for by the public school system and may take place at a school, at home, or at a hospital. During the past 12 months, has (NAME) received any type of special education services or benefits? Do not include gifted or talented programs. E19. Early intervention is a program designed to meet the individual needs of infants and very young children who have special needs. It is provided free and may include services at home, at a hospital, or somewhere else. During the past 12 months, has (NAME) received any type of early intervention services?
SEELS (PI)	D13a. Our records show that CHILD received special education services at the beginning of 1999-2000 school year. Is she/he in special education now? D13e. Does CHILD now have a 504 plan for accommodations because of his/her special needs?
SEELS (SP)	B6. Which of the following services has this student received from or through the school system during the <u>current</u> school year, including services contracted from other agencies?
NLTS2 (PI-1)	D8a (D13A).Our records show that {YOUTH} received special education services and had an IEP at the beginning of the 2000-2001 school year. {Does {he/she} still receive special education services and have an IEP?}

PEELS (PI-1)	E7. Does (child) get any of (his/her) special education or therapy services through the public schools? E20a. Now I'd like to ask you about any services (child) may be receiving that are not paid for by the public schools. Is (child) receiving any special education or therapy services that are paid for by any other source such as your family, your insurance, or another public program?
PEELS ELT/KT/Early Childhood Teacher (ECT) Quex	B8 (ELT)/B5 (KT)/D3 (ECT). Were any of the following services provided to this child through the school system during the current school year?
Employment/Training Services	
NLSY97 (YQ15)	YTRN-700. Other than high school, college, or university degree programs you may have told me about earlier, since [LINTDATE~X], have you attended any schooling, courses or training programs designed to help people find a job, improve their job skills, or learn a new job? YTRN-3700. {TRNA_W} any of the costs of this school or training program paid for or provided directly by a government program? TRN-4100. Did you receive a training allowance or additional money besides public assistance or unemployment insurance because of your participation in this training program? YTRN-4200. How much was the allowance or additional money? YTRN-4600. Did you receive any student financial aid or did you take out a student loan to help pay for this training? YTRN-6100. Did any of your employers provide or help pay for this training program?
SEELS (SP)	SS6. Please indicate which of the following services this student received from or through the school system during this school year. *PLEASE CIRCLE ALL THAT APPLY.* 1 A formal assessment of career skills or interests 2 Career counseling 3 Job readiness or prevocational training 4 Work exploration 5 Work experience 6 Specific job skills training 7 Referrals to potential employers 8 Instruction in looking for jobs 9 School staff worked with employer to modify jobs for this student 10 School staff contacted student or employer to monitor performance on the job 11 None of these

NBS	G1. Next, I will ask about different types of services that people with disabilities sometimes get in order to improve their ability to work or live independently. First, I will ask about employment services {you/NAME} may have received. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any employment services to help {you/him/her} get a job? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any employment services to help {you/him/her} get a job? G10. Sometimes people get training to help them learn new skills so they can get a new job or change careers. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any training to help {you/him/her} get a new job or change careers?
NLTS2 (PI-1)	H1A. During the past 12 months, has {YOUTH} received any of the following services? H1AP p. Career counseling, help in finding a job, training in job skills or vocational education? H1B. Was any of that from or through {his/her} school or district? H1BP P. CAREER COUNSELING, HELP IN FINDING A JOB, TRAINING IN JOB SKILLS OR VOCATIONAL EDUCATION
NSCF	E25. Is (NAME) now receiving any training in job skills, vocational education, career counseling, or help in finding a job? E26. What kinds of training or help is (NAME) now receiving or has (HE/SHE) received in the past? Has (HE/SHE) received… E52a. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training in specific job skills, for example, car repair, food service, or training for another kind of job? E52b. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training to find out (FILL “HIS/HER” if RTYPE=01, 03; “YOUR” if RTYPE=02) work interests or abilities? E52c. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received training in basic skills needed for work, like counting change, telling time, or using transportation to get to work? E52d. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received career counseling, like help in figuring out jobs (FILL “HE/SHE” if RTYPE=01, 03; “YOU” if RTYPE=02) might be suited for? E52e. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received help in finding a job or learning to look for one? E52f. (FILL “HAS NAME” IF RTYPE=01, 03; “HAVE YOU” IF RTYPE=02) received any other training or counseling?

	E54. About how much training in job skills, vocational education, career counseling, or help in finding a job did (FILL "HE/SHE" IF RTYPE=01,03; "YOU" IF RTYPE=02) get during the past 12 months? Would you say… E58. The Social Security Administration sometimes refers beneficiaries to state vocational rehabilitation agencies for services. Has the Social Security Administration ever referred (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) for vocational rehabilitation services?
Service Coordination	
NLTS2 (PI-1)	H2A. Does {YOUTH} have a case manager or someone who coordinates the services {he/she} receives? (also asked in Student's School Program Survey item D7)
PEELS (ELT/KT/ECT Quex)	B8 (ELT)/D3 (ECT)/B5 (KT). Were any of the following services provided to this child through the school system during the current school year? p. Service coordination/case management
SEELS (PI)	B9a. During this school year has CHILD received any of the following services? p. Service coordination or case management
Other Sources	
NLSY97 (YQ15)	YEMP-INJ-15. Have you collected any worker's compensation benefits for this [injury/illness]? YEMP-VET-18. Did you attend any of the Transition Assistance Program workshops, known as TAP or A-CAP? INTERVIEWER: READ IF NECESSARY: These workshops provide information about finding civilian jobs, obtaining training, securing Veterans' benefits, and obtaining other services available to veterans. YFER-5160. These next few questions concern child support. Child support payments can be specified in written or verbal child support agreements. Have child support payments ever been agreed to or awarded for [name of child([loop])]? YEMP-100300. I'm going to refer to a list of benefits which employers sometimes make available to their employees. [At this time/At the time you left], which of the benefits on this list would it [be/have been] possible for you to receive as part of your [job_assignment] [as/with] [employer name([(loop)])]? 1 Medical, surgical or hospitalization insurance which covers injuries or major illnesses off the job 2 Life insurance that would cover your death for reasons not connected with your job 3 Dental benefits 4 Paid maternity or paternity leave 5 Unpaid maternity or paternity leave which would allow you to return to the same job, or one similar to it 6 A retirement plan other than Social Security 7 A flexible work schedule 8 Tuition reimbursement for certain types of schooling 9 Company provided or subsidized childcare 10 Employee Stock Ownership Plan(s)

NSCF	G41. In (LAST MONTH), did (FILL "YOU" IF RTYPE=02; "NAME" IF RTYPE=03) receive financial assistance from members of (FILL "YOUR" IF RTYPE=02; "HIS/HER" IF RTYPE=03) family not living with (FILL "YOU" IF RTYPE=02; "HIM/HER" IF RTYPE=03)? For example, to pay medical bills or other living expenses? Do not include money received to pay for school. K15. In (LAST MONTH) did anybody receive any child support payments? K19. In (LAST MONTH) did anybody receive any foster care payments? K29. In (LAST MONTH) did anybody in your household receive any kind of pension or annuity payment? K32. In (LAST MONTH) did anybody in your household receive payments from any other sources not mentioned, such as alimony, contributions from family or friends, VA payments, worker's compensation, or unemployment compensation?
Regular Medical Care/Doctor	
NSCF	C5. During the past 12 months, how many times, if any, (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) seen a doctor or other health professional about (FILL "HIS/HER" IF RTYPE=01,03; "YOUR" IF RTYPE=02) health at a doctor's office, a clinic, or some other place?
NBS	G15. Sometimes people with disabilities receive medical services to improve their ability to work or help them live independently. Some examples of these services are physical therapy, surgery, and help getting special equipment or devices. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received any medical services to improve {your /his/her} ability to work or live independently? (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received any medical services to improve {your/his/her} ability to work or live independently? I12. Since {THIS MONTH, LAST YEAR}, {have you/has NAME} received any treatment for a mental or emotional condition at a hospital, clinic, or doctor's office?
NLSY97 (YQ15)	YHEA-1880A. During the past 12 months, how many times were you *physically* injured or ill and had to be treated by a doctor or nurse? YHEA-1940A. In the past 12 months, have you visited a doctor for a routine checkup?
PEELS (PI-1)	B29. Does (child) have a place to go for regular medical care where they know (him/her) and (his/her) medical history?

Policy Question #8 Topic Area:

Needed Services Children Not Getting

Services Needed	
NBS	G1. G60. In 2009, were there any services, equipment, or other supports that {you/NAME} needed but did not receive that would have improved {your/his/her} ability to work or live independently? G61. Why {were you/was NAME} unable to get these services?
NLTS2 (PI-1)	H3. Overall do you think {YOUTH} is getting enough services?
NLTS2 (PI-2)	F10a. Do you think YOUTH needs any [IF F8a=1 YES TO JOB TRAINING SINCE HS. OR NOW, SAY: other] job training or help now? F10b. What [other] kinds of job training or help do you think YOUTH needs? F13a. Do you think YOUTH needs any [IF F12a=1 (GETTING HELP NOW) ADD: other] training in or help with independent living skills now? F13b. What [IF F12a=1, ADD: other] kinds of training in or help with independent living skills do you think YOUTH needs? F14e. Do you think [he/she needs] any services [IF ANY YESES IN F14b ADD: besides the ones (he/she) receives] now? F14f. What services do you think [he/she] needs? F16d. Do you think YOUTH is getting enough case management services? F16e. Do you feel your family or YOUTH needs a case manager or someone who coordinates the services [he /she] receives?
PEELS (PI-1)	E17a. Are there any special education services or therapies that (child) is now getting through the school system that you think (he/she) needs more of? E17b. What therapy or services do you think (he/she) needs more of? Would you say (he/she) needs more… E18a. Are there any special education services or therapies that you think (child) should be getting through the school system, but isn't? E18b. What therapy or services do you think (he/she) needs, but isn't getting?
NSCF	E16. During the past 12 months, have you tried to get any (additional) special education services for (NAME)? E21. During the past 12 months, have you tried to get any (FILL "ADDITIONAL" IF E19=01) early intervention services for (NAME)? E29. During the past 12 months, have you tried to get any (FILL "ADDITIONAL" IF E24=01) job training, vocational education, career counseling, or help in finding a job for (NAME)? F4. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need any physical, occupational, or speech therapy? F5. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not receive any physical, occupational, or speech therapy?

	F10. During the past 12 months, did (NAME) need any respiratory therapy? F11. Why did (NAME) not receive any respiratory therapy? F15. During the past 12 months, did (NAME) need any recreational therapy? F16 Why did (NAME) not receive any recreational therapy? F20. During the past 12 months, did (NAME) need any audiology services? F21. Why did (NAME) not receive any audiology services? F27. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need any other type of therapy? F28. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not receive any other type of therapy? F32. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need any special transportation services? F33. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not receive any special transportation services? F39. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need any services from a personal care attendant? F40. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not receive any services from a personal care attendant? F44. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need any services from an adult day care center or day activity center? F45. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not receive any services from an adult day care center or day activity center? F50. During the past 12 months, did your family need any respite care services? F51. Why did your family not receive any respite care services? F56. During the past 12 months, did you or other family members need any mental health care or counseling because of (NAME's) health? F57. Why did you or other family members not receive any mental health care or counseling? F64. Are there any services that (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) now need(s) but (FILL "IS" IF RTYPE=01, 03; "ARE" IF RTYPE=02) not receiving that we haven't yet talked about? F65. What are these services? F66. Why (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) not receiving (THIS SERVICE/THESE SERVICES)? F68. Are there any other health care items that (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) need(s) now but (FILL "IS" IF RTYPE=01, 03; "ARE" IF RTYPE=02) not receiving? F69. What items are these?
Services on Wait List For	
NLTS2 (PI-1)	H6A. Is {YOUTH} on the waiting list for any services? H6B. Which services is {he/she} on a waiting list for?

NLTS2 (PI-2)	F10d. Is YOUTH on the waiting list anywhere to get [IF F9a=1 ADD: other] job training or help? F13d. Is YOUTH on the waiting list anywhere to get [IF F12a=1, ADD: other] training in or help with independent living skills?
NSCF	E17. Are you now on a waiting list for these services (special education services)? E22. Are you now on a waiting list for these services (early intervention services)? E30. Is (NAME) now on a waiting list for these services (job training, vocational education, career counseling or help in finding a job)?

Policy Question #9 Topic Area:

Accuracy of Information on Program Rules

Accuracy of Information on Program Rules	
NBS	C5A. Beneficiaries do not always know that they should report a change in work status to Social Security. Around that time did {you/NAME} let Social Security know that {you were/ (he/she) was} working? C5B. How soon after {you/NAME} started this job did {you/NAME} tell Social Security {you were/(he/she) was} working? E12. {Have you/Has NAME} ever heard of the student earned-income exclusion? This is a Social Security incentive where if {you are/a beneficiary is} in school, up to $1,340 of earnings per month are not counted when Social Security figures {your/the} benefit. E13. {Have you/Has NAME} ever used the student earned-income exclusion?
NSCF	H44. The Social Security Administration has a number of work incentives for SSI recipients. Some can help a person with a disability go to work. Others let disabled people keep cash or Medicaid benefits after they go to work until they become self-supporting. (FILL "HAVE YOU" IF RTYPE=01, 02; "HAS NAME" IF RTYPE=03) ever heard of these work incentives or discussed them with a Social Security representative? H46. Which of the following work incentive programs have ("HAVE YOU" IF RTYPE=01, 02; "HAS NAME" IF RTYPE=03) heard of? Have ("HAVE YOU" IF RTYPE=01, 02; "HAS NAME" IF RTYPE=03) heard of … A. A plan for achieving self-support, or PASS? B. An individual development account, or IDA? C. The general earned-income exclusion? D. The student earned-income exclusion? E. The exclusion for property essential to self-support (PESS)? F. The exclusions for impairment-related work expenses (IRWE) and blind work expenses (BWE)? G. Continued eligibility for Medicaid after SSI benefits end? H47. (FILL "HAS NAME" IF RTYPE=01, 03; "HAVE YOU" IF RTYPE=02) ever used any of these work incentives? H48. Which ones?
CSHCN	C6Q0A_E. Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as (S.C.) becomes an adult?

Policy Question #10 Topic Area:

Prescription Drug Usage

Prescription Drug Use for Health Conditions	
NBS	I10. {Do you/Does NAME} take any prescription medications for any ongoing physical health conditions? PROBE: Please do not include over the counter medication such as cold or headache medication. I11. {Do you/Does NAME} take any prescription medications for any ongoing mental or emotional conditions?
NLTS2 (PI-1)	B7B (B8B). Is {he/she} now taking any prescription medicine for a condition or problem related to {his/her} disability or special need? B7C (B8B1). Is {he/she} taking any prescription medicine that controls {his/her} attention, behavior, or activity level, or changes {his/her} mood, such as Ritalin or an antidepressant? B7E (B8C3). Was the medicine prescribed to control…[B7E_1 1. Attention, behavior or activity level? B7E_2 2. Emotions, such as depression or anxiety? B7E_3 3. Mood? B7E_4 4. Anything else?
PEELS (PI-1)	B37a. Now I'm going to ask you some questions about any prescription drugs (child) is currently taking. Please do not include over-the-counter medications or a single round of prescription medication to treat an episodic illness, such as antibiotics for a one-time illness. Is (child) now regularly taking any prescription medicine for a specific condition or problem? B37b. Is (he/she) taking any prescription medicine that controls (his/her) behavior or changes (his/her) mood, such as Ritalin or an antidepressant?
SEELS (PI)	B8b. Is CHILD now taking any prescription medicine for a condition or problem related to his/her disability?
NSCF	B7. (FILL "DOES NAME" IF RTYPE=01, 03; "DO YOU" IF RTYPE=02) currently need or use medicine prescribed by a doctor, other than vitamins? C15. During the past 12 months, was there any time when (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) needed prescription medicines but didn't get them? C16. Why did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) not get the prescription medicines that (FILL "HE/SHE" IF RTYPE=01,03; "YOU" IF RTYPE=02) needed? F67A.In (LAST MONTH) did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) use any medications for (FILL "HIS/HER" IF RTYPE=01,03; YOUR" IF RTYPE=02) health care needs?
CSHCN	CSHCN1. ('Does your child'/ 'Do any of your children') currently need or use *medicine prescribed by a doctor*, other than vitamins? CSHCN1_A_X. Is (AGEID)'s need for prescription medicine because of ANY medical, behavioral, or other health condition?

	CSHCN1_C_X. Has (AGEID)'s need for prescription medication lasted or is it expected to last 12 months or longer? C4Q05_4. [During the past 12 months/ Since [his/her] birth,] was there any time when [S.C.] needed…) Prescription medications? C4Q05_4A. Did [S.C.] receive *all* the prescription medications that [he/she] needed? C4Q05_4B. Why did [S.C.] not get *all* the prescription medications [he/she] needed?
NHIS	ALT.534_00.000. Did you receive any of the following medical treatments for [fill1: condition from TP1_CMST]? Prescription medications? CHS.311_00.000. Does [fill1: SC name] NOW have a problem for which [fill2: he/she] has regularly taken prescription medication for at least three months? CAU.130_00.000. DURING THE PAST 12 MONTHS, was there any time when [fill: alias] NEEDED any of the following, but didn't get it because you couldn't afford it... Prescription medicines? CMS.010_00.000. DURING THE PAST 6 MONTHS, was [fill1: S.C. name] prescribed medication or taking prescription medication for difficulties with emotions, concentration, behavior, or being able to get along with others? DEP_2. Do you take medication for depression?
NHIS-D	3a (Child's questionnaire). Do (names of persons under 18) NOW have a physical, mental, or emotional problem for which they regularly take prescription medication? 9 (Adult questionnaire). How many different prescription medicines are you supposed to use? Please count ones you should use each day and those that you use regularly but not every day.
MEPS	CSW03. Does (PERSON) currently need or use medicine prescribed by a doctor, other than vitamins?
Type of Prescription Drugs Used	
NLTS2 (PI-1)	B7D (B8C).What is the name of the prescription medicine {YOUTH} takes to control {his/her} behavior, or change {his/her} mood? [IF NEEDED: "You may give us either the brand name or the generic name." REFER TO HARD COPY LIST OF PRESCRIPTION MEDICINES, LOCATE NAME OF DRUG GIVEN BY RESPONDENT AND ENTER CORRESPONDING CODE. PROBE FOR ANY OTHER MEDICINES UNTIL RESPONDENT SAYS NO. CODE ALL THAT APPLY.
PEELS (PI-1)	What is the name of the prescription medicine (child) is taking to control (his/her) behavior or change (his/her) mood? [If needed: You may give us either the brand name or the generic name.]
SEELS (PI)	B8c. Is CHILD taking Ritalin?
MEPS	PM02. While we were talking about (PERSON)'s medical care, we listed the following prescription(s) as purchased or received {since (START DATE)/between (START DATE) and (END DATE)}. (READ MEDICINES BELOW.) PM08. Is (MEDICINE) used for a specific health problem? PM08. What health problem is (MEDICINE) prescribed for?

Research Question #1 Topic Area:

Children's Mental Health

Treatment for Mental Health Condition	
NLSY97 (YQ15)	YHEA-1891. During the past 12 months, how many times did you have an emotional, mental or psychiatric problem and were treated by a mental health professional?
NBS	G19. Sometimes people go to a mental health professional to get therapy or counseling to improve their ability to work or live independently. (IF DISABLED BEFORE AGE 16 (B18_AGE < 16 OR IF BIRTHYEAR – B18_YEAR <16)) Since age 16, {have you/has NAME} received mental health therapy or counseling to improve {your/his/her} ability to work or live independently? This could include treatment for alcohol or drug abuse. (IF DISABLED AT AGE 16 OR LATER (B18_AGE ≥ 16 OR IF BIRTHYEAR - B18_YEAR ≥ 16)) Since becoming disabled, {have you/has NAME} received mental health therapy or counseling to improve {your/his/her} ability to work or live independently? This could include treatment for alcohol or drug abuse. I11. {Do you/Does NAME} take any prescription medications for any ongoing mental or emotional conditions? I12. Since {THIS MONTH, LAST YEAR}, {have you/has NAME} received any treatment for a mental or emotional condition at a hospital, clinic, or doctor's office?
NLTS2 (PI-1)	H1A. During the past 12 months, has {YOUTH} received any of the following services? H1AC c. Psychological or mental health services or counseling?
NLTS2 (SS-I)	D7. Which of the following services has been provided this student from or through the school system during this school year? h. Mental health services, personal/group counseling, therapy, or psychiatric care
PEELS (ECT/KT/ELT Quex)	B8 (ELT)/D3 (ECT)/B5 (KT). Were any of the following services provided to this child through the school system during the current school year? e/k. Mental health services, personal/group counseling, therapy, or psychiatric care provided for this child
SEELS (PI)	B9a. During this school year has CHILD received any of the following services? a. Psychological or mental health services or counseling
SEELS (SP)	B6. Which of the following services has this student received from or through the school system during the current school year, including services contracted from other agencies? f. Mental health services, personal/group counseling, therapy, or psychiatric care

NSCF	B16. (FILL "DOES NAME" IF RTYPE=01, 03; "DO YOU" IF RTYPE=02) need or get treatment or counseling for any kind of emotional, developmental, or behavioral problem? C18. Now I'd like to ask about any mental health care (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) may have received. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) stay overnight in a hospital or other place to receive services for mental health or substance abuse? C19. Was this for mental health, substance abuse or both? C20. Altogether how many times (FILL "WAS NAME" IF RTYPE=01,03; "WERE YOU" IF RTYPE=02) hospitalized to receive treatment for (FILL "MENTAL HEALTH" IF C19=01; FILL "SUBSTANCE ABUSE" IF C19=02; FILL "MENTAL HEALTH AND SUBSTANCE ABUSE" IF C19=03, D, R) during the past 12 months? C21. During the past 12 months, did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) receive any outpatient mental health or substance abuse services? This includes services from a psychiatrist, psychologist, psychiatric social worker, or other health professional. By outpatient, we mean that (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) did not stay overnight in a hospital or other place. C23. Was this for mental health, substance abuse or both? C24. How many times did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) receive (FILL "MENTAL HEALTH" IF C23=01, "SUBSTANCE ABUSE" IF C23=02, "MENTAL HEALTH AND SUBSTANCE ABUSE" IF C23=03, D, R) outpatient services during the past 12 months? F55. During the past 12 months, did you or other family members receive any mental health care or counseling because of (NAME's) health?
Effect of Mental Health Condition	
NBS	B3. {Do you/Does NAME} have any other physical or mental conditions that limit the kind or amount of work or other daily activities {you/he/she} can do? B4. What are those conditions? I6. During the past 4 weeks, how much did {your/NAME's} physical health or emotional problems limit {your/his/her} usual social activities with family or friends? I7. During the past 4 weeks, how much {have you/has NAME} been bothered by emotional problems (such as feeling anxious, depressed or irritable?) I8. During the past 4 weeks, how much did personal or emotional problems keep {you/NAME} from doing {your/his/her} usual work, school or other daily activities?
NLSY97 (YQ15)	YHEA-1892. Some conditions are not treated by a professional. During the past 12 months, how many times *did you have an emotional, mental or psychiatric problem* so that you missed at least one full day of usual activities such as work or school, but were not treated by a professional? YHEA-1893. How many times did you miss work because you were just not feeling right – for example, you were 'too blue' to get up in the morning, or feeling too anxious to conduct your usual activities? Please do not include times that you missed work that you've already told me about. YHEA29-260. During the past 4 weeks, have you accomplished less than you would like with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	YHEA29-265. Did you not do work or other activities as carefully as usual as a result of any emotional problems (such as feeling depressed or anxious)? YHEA29-280. How often during the past 4 weeks have you felt down-hearted and blue? YHEA29-290. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
NLTS2 Youth Survey, Wave 2 (YS-2)	12. In the last month, how often did a health or emotional problem cause you to miss a social or recreational activity?
NSCF	B17. Has (FILL "NAME'S" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) emotional, developmental or behavioral problem lasted or is it expected to last 12 months or longer? B20. Does a medical, behavioral, or other health condition now prevent (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) from working at a job or business, or attending school? B21. (FILL "IS NAME" IF RTYPE=01, 03; "ARE YOU" IF RTYPE=02) limited in the kind or amount of work or school (FILL "HE/SHE" IF RTYPE=01, 03; "YOU" IF RTYPE=02) can do because of a medical, behavioral, or other health condition? B23. (FILL "IS NAME" IF RTYPE=01 OR 03; "ARE YOU" IF RTYPE=02) now limited in any way in any activities because of a medical, behavioral, or other health condition? B27. The next questions are about any physical, mental, learning, or developmental conditions or problems that (FILL "NAME HAS" IF RTYPE=01, 03; "YOU HAVE" IF RTYPE=02). (FILL "IN THE PAST 12 MONTHS" IF AGE 1+; "SINCE BIRTH" IF AGE <1), how often has (FILL "NAME'S" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) health condition or problem affected (FILL "HIS/HER" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) ability to do things other (FILL "CHILDREN" IF AGE <17; "YOUNG PEOPLE" IF AGE=17+) do? Would you say: B28. Does (FILL "NAME'S" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) health condition or problem affect (FILL "HIS/HER" IF RTYPE=01, 03; "YOUR" IF RTYPE=02) ability to do things a great deal, some, or very little? G9. I'm going to read a list of items that sometimes describe children. For each statement please tell me if it has been almost always true, sometimes true, not often true, or never true for (NAME) during the past 12 months. c. (HE/SHE) has been unhappy, sad, or depressed. Is that… G53. During the past 12 months, how often did (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) feel sad or depressed. Would (FILL "NAME" IF RTYPE=01, 03; "YOU" IF RTYPE=02) say (FILL "HE/SHE WAS" IF RTYPE=01, 03; "YOU WERE" IF RTYPE=02) sad or depressed…
Reasons for Not Receiving Mental Health Services	
NSCF	F57. Why did you or other family members not receive any mental health care or counseling?

Mental Health Screeners and Assessments of Child Behavior	
Other	- The Psychological Screening Inventory - Selected subtests from the Social Skills Rating Scale, Problem Behaviors Subscale (SSRS, Gresham & Elliott 1990), Child Behavior Checklist (Achenbach & Edelbrock 1983), or the Children's Depressive Inventory (Kovacs 1985). - Child Mental Health Brief Questionnaire included in the NHIS

Appendix B. Precision Measures

This appendix provides an overview of the measures of precision used for evaluating the utility of the various design options. We also present a series of tables showing precision levels associated with the sample design and overall sample size for the original NSCF.

Standard Error (SE)

SE is a basic measure of the sampling error. Under SRS, for an estimate of a proportion p, the SE is computed as SE(p) = $\sqrt{p(1-p)/n}$, where n is the sample size. The SE formula given above is for SRS, but in practice, large-scale national surveys, such as the NSCF, typically use complex sample designs.

Design Effect (DEFF)

The SE formula for SRS needs to be multiplied by the square root of the DEFF to give the SE under the complex design. The DEFF is a useful quantity to examine when comparing alternative designs. Since the NSCF design may include PSUs for nonresponse followup, the SE is larger than under an SRS. One typical interpretation of DEFF says that if DEFF = 2, the sample size needs to be doubled in order to achieve the same precision as from an SRS. In general, the overall DEFF is sometimes approximately expressed as the product of two components: $DEFF_{CLU}$, which is due to clustering and the $DEFF_{SR}$, which is due to differential sampling rates (or unequal weighting). That is, DEFF = $DEFF_{CLU}$ * $DEFF_{SR}$.

In a two-stage design such as that for the original NSCF survey (see Chapter 2 for a description), the DEFF due to clustering may be expressed approximately as:

$$DEFF_{CLU} = 1 + (\bar{b} - 1)\rho$$

Where $\bar{b}$ is the average number of sampled persons per PSU, and ρ is the intracluster correlation that measures the homogeneity of the characteristic being measured for persons within the PSUs. See Hanson, Hurwitz, and Madow (1953, volume 1, section 17) for more details.

The DEFF due to differential sampling rates by stratum, as given in Kish (1965) can be expressed as:

$$DEFF_{SR} = (\sum W_B / k_B)(\sum W_B k_B)$$

Where $W_B = N_B / N$, where N is the total population size, N_B is population size for stratum B, and k_B is the ratio of the sampling rate for stratum B to the smallest of the stratum sampling rates.

Effective Sample Size (ESS)

ESS (n_{eff}) is the sample size that would be needed for an SRS to achieve the same precision as the complex design. It is computed as:

$$n_{eff} = n/DEFF$$

Margin of Error (MOE)

The MOE is a multiple of the SE that represents the half-width of a confidence interval. For a 95% confidence interval, one can be 95% confident that the true proportion is within the interval defined by p ± MOE. The MOE is generally computed as MOE = 1.96 × SE(p), where 1.96 is the value taken from the normal distribution to give 95% coverage for the interval. However, when the SE estimate is based on few degrees of freedom, the normal distribution value should be replaced by a corresponding value for the t distribution with the given degrees of freedom. With a clustered sample design, the number of degrees of freedom for the estimate of the standard error of a proportion depends on the number of sampled PSUs. For example, with eight degrees of freedom, the 95% t value is 2.31 in place of 1.96. It should also be noted that the confidence interval computed as p ± MOE is based on the approximation that the sampling distribution of p is a normal distribution. The validity of that approximation depends on the sample size *n* and the value of *p*. Cochran (1977, p. 58) suggests that for an SRS, a sample size of 30 is adequate if p =0.05 but much larger sample sizes are needed if p is small. For example, the sample sizes needed for the approximation to hold reasonably well are 200 for *p* = 0.2, 600 for *p* = 0.1, and 1,400 for *p* = 0.05. When the approximation is inadequate, asymmetrical confidence intervals are needed.

Coefficient of Variation (CV)

The CV is the SE relative to the estimated proportion. The CV is commonly presented as a percentage, that is, CV = 100 × SE(p) / p. In general, a CV of 5% is considered to indicate a high level of precision for the estimate, with 10% being widely viewed as acceptable. In contrast, a CV of 30% is generally considered imprecise. However, for low rates, an assessment of the MOE may give the better guidance than the CV on what is an acceptable level of precision.

To illustrate the relationship between given values of estimated proportions (p) and CVs, MOEs, and the corresponding 95% confidence intervals, Table 5-1 assumes a random sample of *n* = 2,000 cases with a complex design having an overall DEFF = 2. The CV of 22% associated with a proportion 0.02 (2%) may seem inadequate. However, in terms of the MOE of 0.9 and the confidence interval ranging from 1.1 to 2.9%, the precision may be considered adequate. Note that when the CV = 5% for an attribute's estimated percentage of 50%, then that is about the same as an MOE = 5%.

Table B-1. Percentages and Their CVs, MOEs and Confidence Intervals for a Random Sample of Size 2,000 with DEFF = 2

Estimated percentage	CV (percent)	MOE	95% Confidence interval	
			Lower bound	Upper bound
0.5	45	0.4	0.1	0.9
1.0	31	0.6	0.4	1.6
2.0	22	0.9	1.1	2.9
5.0	14	1.4	3.6	6.4
10.0	9	1.9	8.1	11.9
20.0	6	2.5	17.5	22.5

Power

Power is the probability of a statistical test to find a difference to be statistically significant when in fact there is a true difference.

Minimum Detectable Difference (MDD)

When comparing the difference between two groups, a useful measure is the MDD that can be claimed for a statistical test under certain test parameters. The MDD is the smallest difference or change that would be statistically significant for a specified test, power and Type I error rate. In this report, we give the MDDs for a t-test of the hypothesis H_0: $P_1 - P_2 = 0$ vs H_a: $P_1 - P_2 \neq 0$ for Type I error rate $\alpha = 0.05$ and power = 0.80. A power of 0.80 is an acceptable and commonly used standard in planning many studies. Alpha is the probability the test will find a difference to be statistically significant when in fact it is not a true difference.

Precision From Published Reports Using Original NSCF Data

The following tables (Tables B-2, B-3, and B-4) are provided to give indications of the precision levels associated with the sample design and overall sample size for the original NSCF. Sample sizes and precision measures are two main measures that we present when comparing sample design options for the new NSCF. Tables B-2 through B-4 help to indicate which subgroups may result in smaller sample sizes that may require oversampling, if so desired by SSA.

In their overview of the NSCF, Davies and Rupp (2005/06) discussed the demographic data presented in Table B-2.

Table B-2. Percentages or Means, Standard Errors, and Coefficient of Variation for Selected Variables for Children and Young Adults Receiving SSI in December 2000 and Children and Young Adults Receiving SSI in December 2006

Variable	Percent or mean	Standard error	Coefficient of variation
Children and young adults receiving SSI in December 2000			
Black	43.9	2.9	0.066
Hispanic	15.7	1.8	0.115
Earnings of parent or guardian in previous month (mean)	$1,073.83	45.59	0.042
Household receipt of food stamps last month	30.8	1.3	0.042
Health insurance coverage	97.6	0.3	0.003
Children and young adults receiving SSI in December 1996			
Black	43.7	2.8	0.064
Hispanic	14.1	1.8	0.128
Earnings of parent or guardian in previous month (mean)	$1,185.31	46.28	0.039
Household receipt of food stamps last month	29.8	1.4	0.047
Health insurance coverage	89.1	0.8	0.009

In their examination of unmet health care needs and medical out-of-pocket expenses of SSI children, DeCesaro and Hemmeter (2009) discuss the NSCF data presented in Table B-3.

Table B-3. Sample Sizes, Percentages, Standard Errors, and Coefficients of Variance for Selected Variables for Children Ages 0 to 17 Who Received an SSI Payment in the Month before the Interview

Variable	*N*	Percent	Standard error	Coefficient of variation
Living arrangement				
Two parents	863	27.8	0.7	0.025
Single parent	1,885	60.5	0.7	0.012
Other arrangement	407	11.7	0.4	0.034
Health status				
Poor	291	8.7	0.3	0.034
Fair	949	30.0	0.6	0.020
Good	1,079	33.0	0.5	0.015
Very good	482	16.4	0.5	0.030
Excellent	354	12.0	0.3	0.025
Type of Disability				
Physical	1,093	38.5	0.5	0.013
Mental disability – Behavioral	1,412	39.9	0.5	0.013
Mental retardation	192	5.8	0.3	0.052
Other	325	11.2	0.4	0.036
Missing or no disability	133	4.6	0.3	0.065

Hemmeter, Kauff, and Wittenburg (2009) presented the data in Table B-4 in their article looking at the experiences of child SSI recipients before and after their redetermination for adult benefits.

Table B-4. Percentages, Standard Errors, and Coefficients of Variance for Selected Variables for SSI Recipients Age 17 to 18

Variable	Percent	Standard error	Coefficient of variation
Employment			
Ever employed age 16-17	40.7	1.3	0.032
Ever earned over $2,000 at age 16 or 17	11.2	0.8	0.071
Training			
Ever received vocational training	35.8	1.1	0.031
Education			
In school (6th-12th grade)	58.6	1.4	0.024
Graduated high school	11.0	0.6	0.550
Dropped out of school	30.4	1.4	0.460
Special education	81.5	0.8	0.010

Note: *N* = 730.

Appendix C. Power Analyses for Using National Survey of CSHCN for Comparison Group

This appendix presents the ESS and power analysis for using the National Survey of CSHCN to identify a comparison group of children who are potentially eligible for SSI.

First, we used SUDAAN to calculate several proportions using the National Survey of CSHCN data: (1) percentage on Medicaid, (2) percentage on SSI by poverty level, (3) percentage with a disability, and (4) percentage with a mental impairment. We found DEFFs to mostly range from 3.5 to 3.9. The weights in the National Survey of CSHCN are highly variable, which contributes to the high DEFFs. The design included a list-assisted random-digit dialing approach and sampled only one child per household so there was no clustering. The National Survey of CSHCN was designed to produce state estimates and had a target of 750 completed interviews in each state. The DEFFs for percentage on SSI by state are on the whole much smaller but vary from 0.1 to 7.5, with many less than 1 and an average equal to 2.0.[11]

Table C-1 provides the expected number of completes and a precision analysis, using the assumption that the sample design will be the same as that used for the prior National Survey of CSHCN. A longitudinal aspect is also provided. The counts shown in the table may be considered lower bounds, because only those with a severe condition (as opposed to slight or moderate) were included in the analysis. The total Wave 1 potentially eligible sample among ages 0-17 from CSHCN is 3,259 (not on SSI, report severe disability, greater than 3 times the poverty level), which is effectively, 1,018 completes with an MOE = 0.031. With an assumed attrition rate of 0.75, the expected number of completes for Wave 2 would be 2,444, corresponding to an ESS of 764 and an MOE = 0.036. For potentially eligible who are 14-17 years of age, or have a mental impairment, the resulting effective number of completes for Wave 1 would be 320 and 600, respectively. The MOE for 14- to 17-year-olds and children with mental impairments is estimated to be 0.058 and 0.40, respectively, for Wave 1.

Table C-2 provides a power analysis (80%) on the difference between Waves 1 and 2 for an attribute proportion equal to 0.50 and a Type I error of 0.05. A difference of 0.067 could be detected on a Wave 1 attribute proportion equal to 0.5 between Wave 1 and Wave 2 estimates, with 80% power, assuming the unit correlation between Wave 1 and Wave 2 is equal to zero. Among 14- through 17-year-olds, the MDD is 0.122, and among those with mental impairment, the MDD is 0.085. The MDDs are shown when the unit correlation between Wave 1 and 2 responses is equal to 0.5 and 0.8. The MDDs decrease to 0.04, 0.073, and 0.051 for total potentially eligible, 14- through 17-year-olds and those with mental impairment, respectively.

When comparing SSI recipients to those potentially eligible for SSI, Table 6-12 can be used for guidance. For example, if an attribute's estimated proportion is 0.25 for SSI recipients, and if there is an ESS of at least 1,000 SSI recipients and 1,000 potentially eligible, then a difference of five percentage points can be detected. However, if there are 300 effective completes, as is the case for 14-through 17-year-olds in the potentially eligible group, then about a 10 percentage point difference can be detected from an estimated proportion of 0.25 for SSI recipients.

[11] One potential drawback of using the National Survey of CSHCN is that the sample sizes are large due to the state-level focus. One might try to "undo" the oversampling in the NIS in a way to reduce the sample size (and costs) while attaining similar precision (see Krenzke, Rust and Mohadjer 1999 for a discussion of undoing the oversampling from an existing sample).

Table C-1. National Survey of CSHCN Expected Number of Completes and Precision Analysis Results

	Wave 1				Wave 2			
Subgroups	Expected number of completes	Average DEFF for proportions	Effective number of completes	MOE $p = 0.50$	Attrition rate	Expected number of completes	Effective number of completes	MOE $p = 0.50$
SSI potentially eligible	3,259	3.20	1,018	0.031	0.75	2,444	764	0.036
Ages 14-17	900	3.00	300	0.058	0.75	675	225	0.067
Mental impairment	1,921	3.10	620	0.040	0.75	1,441	465	0.046
Lost benefits	716	3.00	239	0.065	0.75	537	179	0.075
Denied benefits	1,919	3.00	640	0.040	0.75	1,439	480	0.046

Table C-2. National Survey of CSHCN Power Analysis Results

	Wave 1 vs. Wave 2			Wave 1 vs. Wave 2			
Subgroups	MDD for p1-p2 (p1 = 0.50), $\rho = 0$	MDD for p1-p2 (p1 = 0.50), $\rho = 0.5$	MDD for p1-p2 (p1 = 0.50), $\rho = 0.8$	Power to detect MDD = 0.05, $\rho = 0$	Power to detect MDD = 0.10, $\rho = 0$	Power to detect MDD = 0.05, $\rho = 0.5$	Power to detect MDD = 0.05, $\rho = 0.8$
SSI potentially eligible	0.067	0.052	0.04	0.55	0.99	0.77	0.95
Ages 14-17	0.122	0.096	0.073	0.20	0.63	0.30	0.48
Mental impairment	0.085	0.067	0.051	0.37	0.91	0.55	0.79
Lost benefits	0.137	0.108	0.082	0.17	0.53	0.25	0.40
Denied benefits	0.084	0.066	0.050	0.38	0.92	0.57	0.80