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Design and Operation of the Survey of Adult Transition and Health, 2007



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Program and Collection Procedures

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Contents

Abstract	1
Introduction	1
Organization of Report	1
State and Local Area Integrated Telephone Survey	2
CSHCN and Transition Services	2
Who Are CSHCN?	2
Health Care Transition	2
Significance of Transition Services	3
Sample Design	3
Target Age Group	3
Imperative and Standard Cases	3
Proxy Interviews	4
Questionnaire	4
Development	4
Content of Detailed SATH Interview	4
Computer-assisted Telephone Interviewing	4
Internet Questionnaire	5
Pretest	6
Interviewer Training	6
CATI Training	6
Locating Training	6
Interviews via Respondent's Cellular Telephone	6
Security and Confidentiality	7
Data Collection	7
Advance Letter	7
SATH Screening, Locating, and Interviewing Processes	7
Endorsement and Internet Offer Letters	7
Toll-free Telephone Number	8
Informed Consent and Assurance of Confidentiality	8
Interview and Section Length	9
Partially Completed Interviews	9
Third Party Present During Interview	9
Monetary Incentives and Thank You Letters	9
Efforts to Maximize Response Rates	9
Interview Completion Rate	10
Quality Control	10
Interviewing	10
Interviewer Debriefing	10
Data Collection	11
Weighting and Estimation Procedures	11
Sampling Weight	11

Weighting Objective and Process	11
Estimation	12
Public-use Data File	13
Edits to Protect Confidentiality	13
Other Edits	13
Missing Data	13
Derived Variables	14
Citations	14
Further Information	14
Guidelines for Data Use	15
References	15
Appendix I. Summary of Survey Strengths, Limitations, and Appropriate Use	18
Strengths	18
Limitations	18
Appropriate Use	18
Appendix II. Locating Protocol for 2001 Respondents and 2007 Eligible Cases	19
Use of Detailed Locating Protocol	19
Locating Training	19
Identifying Cases Qualified for Locating	19
Types of Accurint® Database Searches	19
Locating Protocol	20
Locating Quality Control	21
Overall Locating Results	23
Number of Calls Placed to Locate Cases	23
Appendix III. 2007 SATH Questionnaire	24
Appendix IV. 2007 SATH Endorsement Letters	78
Appendix V. Internet Offer Letter	82
Appendix VI. Thank You Letters	83
Appendix VII. Disposition Code Frequencies and Unweighted Interview Completion Rate Calculation	85
Text Figures	
General process flow: 2007 SATH	8
Text Tables	
A. Maximum subgroup sample sizes of respondents aged 14–17 years, by transition services received: 2001 NS-CSHCN completed cases, 2007 SATH	4
B. Parts of survey screener component: 2007 SATH	5
C. Content of survey detailed interview: 2007 SATH	5
D. Length of survey interview, by section: 2007 SATH	9
E. Interview completion rates, by sample type: 2007 SATH	10
F. Summary statistics for final interview weight: 2007 SATH	12
G. Description of derived variables in public-use data file: 2007 SATH	15
Appendix Figures	
Case flow through locating searches and protocol: 2007 SATH	22
Appendix Tables	
I Survey call outcomes and number of cases qualified for locating: 2007 SATH	20
II. Accurint® return rates, by sample type: 2007 SATH	21
III. Locating and interviewing success rates for all cases, by sample type: 2007 SATH	21
IV. Locating and interviewing success rates for cases with Accurint® information, by sample type: 2007 SATH	21
V. Source of locating information, by sample type: 2007 SATH	23
VI. Unweighted distribution of final case dispositions: 2007 SATH	85

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We sincerely thank the young adult respondents and their parents or guardians who allowed us to contact them directly. Their time and effort made this project a reality.

Objectives

This report documents the survey design and operating procedures for the 2007 Survey of Adult Transition and Health (SATH). Sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, SATH was conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics as a module of the State and Local Area Integrated Telephone Survey program. A follow-back survey design was used to attempt to locate and contact 10,933 eligible cases originally identified in the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN). These data examine the transition experience of adolescents as they switched from pediatric health care providers to those that treat adults only. Eligible persons were aged 14–17 years as of 2001, had at least one special health care need, and lived in English-speaking households. In 2007, these cases involved young adults aged 19–23. State estimates cannot be obtained from SATH.

Methods

Telephone numbers sampled in 2001 were dialed to locate the 2001 NS-CSHCN respondent. This person was asked for current contact information for the eligible SATH young adult to be contacted directly. Data were collected from June 12 through August 26, 2007.

Results

Although we were unable to contact 7,409 (68%) of the 2001 parent/guardian respondents, almost all of the young adults we were able to contact participated (98%). The SATH public-use microdata file contains interview data collected in 2007 from 1,865 young adults, along with variables from the 2001 NS-CSHCN public-use file. The unweighted interview completion rate was 17.5%.

Keywords: follow-back surveys • children with special health care needs • State and Local Area Integrated Telephone Survey (SLAITS) • young adults

Design and Operation of the Survey of Adult Transition and Health, 2007

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Introduction

This report provides detailed information on a unique survey, the 2007 Survey of Adult Transition and Health (SATH), designed as a national follow-back study to the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN). Both surveys were sponsored by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration and conducted by the State and Local Area Integrated Telephone Survey (SLAITS) program of the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS). The 2001 survey produced comparable national and state prevalence estimates of children with special health care needs (CSHCN), assessed their care in community-based service systems, and provided baseline estimates to monitor progress to implement this care through six core outcomes (1). Questions in the 2001 survey were asked of the CSHCN's parent or guardian who knew the most about the child's health and health care. Detailed methodological information on the 2001 survey can be found elsewhere (2).

SATH collected current health status information directly from young adults aged 19 to 23 years who were the subject of the detailed 2001 NS-CSHCN interview (i.e., CSHCN who lived in English-speaking households when they were aged 14 to 17 in 2001). With this

follow-back design, SATH attempted to address four content and survey methods objectives:

1. Assess the impact of a medical home and receipt of health-related transition services in adolescence (time one) on selected adult health and well-being outcomes (time two).
2. Provide new national data, heretofore unavailable, linked to the 2001 survey.
3. Generate information on unique respondent locating challenges.
4. Test the feasibility of using similar locating strategies in future surveys.

These data provide a rare opportunity to examine a critical but poorly monitored experience: that of adolescents and young adults with special health care needs as they switch, or transition, from their pediatric health care providers to those that only treat adults. Cases include a range of condition severity, activity limitations, and disabilities. These data can also be used to describe their life satisfaction and plans for the future.

Organization of Report

The SLAITS program is described, followed by a definition of CSHCN and transition services. Information is provided on the sample design; survey and instrument development process; operating procedures; data collection, storage, and editing; and creation of the public-use data file (PUF). Reading [Appendix I](#) before downloading the PUF

and conducting any analyses is recommended. [Appendix I](#) summarizes survey strengths, limitations, and appropriate data use, and it explains significant survey design and data collection issues that might impact analysis and interpretability.

State and Local Area Integrated Telephone Survey

SATH data were collected by the SLAITS mechanism. SLAITS surveys, or modules, use the huge sampling frame of the CDC's National Immunization Survey (NIS) to identify eligible cases for additional data collection. Millions of telephone numbers per year are required to identify sufficient households with NIS age-eligible children. Detailed information on the NIS sample design and procedures have been published elsewhere (3–6). The 2001 NS-CSHCN sample was drawn from the NIS sampling frame, by data collection contractor Abt Associates, Inc.; the 2007 SATH was drawn from the 2001 NS-CSHCN, by data collection contractor National Opinion Research Center (NORC) at the University of Chicago. In 2007, NORC redialed telephone numbers associated with selected, completed 2001 NS-CSHCN interviews to obtain current, valid contact information for the 2001 sampled CSHCN, now a young adult. With the assistance of the original 2001 parent or guardian respondent, the young adult was then contacted directly to invite him or her to participate in the 2007 SATH.

CSHCN and Transition Services

Who Are CSHCN?

Children with special health care needs, as defined by MCHB, are those who have or are at risk of a physical, developmental, behavioral, or emotional condition and require health or related

services of a type or amount beyond that required by children generally (7). According to the 2005–2006 NS-CSHCN, 13.9% of children aged 0 to 17 had special health care needs, which translates into a cohort of approximately 10.2 million children (8). Among all households in the United States with children aged 0 to 17, an estimated 21.8% have at least one resident CSHCN (8). The prevalence estimates of CSHCN at the child and household levels increased from the 2001 to the 2005–2006 surveys.

These children are identified by the CSHCN screener as experiencing at least one of five consequences of a medical condition that has lasted or is expected to last for at least 12 months:

- Use of prescription medications.
- Above-average use of health care services for a child of the same age.
- Limits in activities that most children of the same age can do.
- Use of physical, occupational, or speech therapy.
- Having a behavioral, emotional, or developmental condition that requires treatment or counseling (9).

A reliable, valid method does not exist to fully and accurately identify children “at risk” in this definition, although a conceptual model of children at risk for special health care needs has been proposed (10).

Health Care Transition

As adolescents age and become legal adults, they usually become more independent of their siblings and parents and undergo simultaneous transitions in many areas. Examples of teenage transitions, or passages, include adolescents who move out of their parents' home to their own living space, teens who graduate and advance from high school to college, and youth who work part or full time outside of their home.

Health care transition refers specifically to the change in who directly provides and monitors the adolescent's clinical and ancillary health care—that is, the switch from pediatricians and health care providers (HCP) who treat only children and

adolescents to HCPs who treat only adults. Although this health care transition occurs for all adolescents regardless of their special health care needs status, SATH focused only on transition experiences among CSHCN. The following characteristics describe an optimal health care transition experience for CSHCN:

“(it is a) ... dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination” (11).

The conceptualization and measurement of receipt of transition services for CSHCN have evolved and improved over the past decade, with reliable national and state transition measures available only since November 2007 when the 2005–2006 NS-CSHCN data were released. Data on this topic from the 2001 NS-CSHCN are not comparable with 2005–2006 data. In the 2001 survey, transition questions were added to the instrument approximately halfway through data collection for children aged 13 to 17. In 2001, only 5.8% of CSHCN received the services necessary to make appropriate transitions to adult health care, work, and independence (12). In 2005–2006, the target age range was increased slightly to ages 12 to 17, and all transition questions were asked from the start of data collection. In 2005–2006, just over 41% of CSHCN received appropriate transition services (41.2%) (8). Although these outcomes are not directly comparable across survey years, it appears that some improvement has occurred in receipt of transition services nationally over time. At the state level in 2005–2006, the prevalence of CSHCN who received these services ranged from 24.0% in the District of Columbia to 54.4% in Missouri (13).

Although SATH data cannot be used to determine prevalence, they can be used to examine detailed characteristics of the transition experiences of young adults with special health care needs. A number of positive attitudes and practices seem to facilitate a successful transition, and some of these were assessed in SATH. For example, the Association for Retarded Citizens' (ARC) Self-Determination Scale was adapted (with permission) to assess empowerment, goal direction, and self-regulation of autonomous behaviors (14).

In contrast to health care transition, the term "health care transfer" refers to a specific event, or one piece of the complex, multiyear health care transition process (15). Generally, transition occurs in stages that are consistent with and dependent upon the child's evolving maturity level and progressive chronological age. During this process, youth should be encouraged to focus on their future, examine their values, and grow increasingly independent. Adolescents should be or become aware of their attitudes and skills (such as self-confidence, self-esteem, self-determination, and self-management) to ensure adequate problem-solving and decision-making skills.

Significance of Transition Services

Transition services have become more important over the past decades because many severely impacted children now survive their childhood health problems or complications. Many of these youth can expect to live longer due to advances in drugs, medical and surgical treatments, prevention, and improvements in primary care (16–18). In the past, severely affected children may not have survived long enough to begin the transition to adult health care. Papers on transition-related topics issued by many leading medical groups such as the Society of Adolescent Medicine (19), the American Academy of Pediatrics (18,20), and a joint consensus statement issued by the American Academy of Pediatrics, American Academy of Family

Physicians, and the American College of Physicians—American Society of Internal Medicine (11), are evidence of the importance of this topic.

Sample Design

This multimode follow-back survey used a purposive sample of cases consisting of completed 2001 NS-CSHCN interviews, a specified age range, and residence in English-speaking households as of 2001. In contrast, the 2001 survey used a complex, cross-sectional survey design with clustering and stratification and a probability sample (2). The 2007 SATH was not designed to necessarily provide representative national or state prevalence estimates, but instead was focused on generating descriptive data to facilitate comparison of outcomes between groups.

Target Age Group

SATH target subjects (N=10,933) were 14- to 17-year-old CSHCN who lived in English-speaking households as identified in the 2001 NS-CSHCN detailed interview. This group was selected because in 2007, they would be legal adults capable of giving informed consent for their own interview and health care. Information collected in 2001 for some of these cases included whether the youth had received transition services or had a medical home in adolescence. These transition questions were added to the 2001 survey more than halfway through the data collection period and were therefore not asked of respondents who had completed the survey prior to that point (n=6,476 cases). Of the initial 2001 target cases, 4,457 received the transition questions in 2001. Attempts were made to contact the youth in both groups, totaling 10,933 cases, to participate in SATH. The SATH PUF contains 1,052 completed interviews with youth who did not receive the 2001 transition questions.

Imperative and Standard Cases

For SATH, transition services were defined as the parent's reporting in 2001 that the child's health care providers discussed his or her changing health care needs, helped develop a plan to address these changing needs, and discussed the need for him or her to transition to an adult health care provider. If a CSHCN reportedly received all three of these transition services in 2001, the SATH case was defined as an "imperative" case, subject to a more extensive locating protocol to increase the number of completed interviews. Cases that did not receive all three transition services were defined as "standard" cases. Standard classification included all 2001 cases that did not receive the transition questions because the youth's 2001 interview was completed prior to this addition. The dichotomy between standard and imperative cases reflected the project's budgetary constraints. Although a broad definition of transition services can include a vocational education component, it was not included in this definition because the 2001 interview data for the vocational education question had little to no variability, and these data were not collected for the entire 2001 data collection period.

Table A examines the maximum possible subgroup sample sizes by transition service received for eligible SATH cases. Over 650 cases were identified as imperative (n=674), and the remaining 10,259 were defined as standard cases.

The difference in the assumed number of located imperative and standard cases reflects the more extensive locating protocol applied to imperative cases; the locating protocol is detailed in Appendix II. Because the 2001 NS-CSHCN survey was not originally designed to support a follow-back survey, locating cases was challenging. No current information was available to locate the 2001 NS-CSHCN respondents, and the only information initially available was the randomly generated, sampled telephone number dialed in 2001.

Table A. Maximum subgroup sample sizes of respondents aged 14–17 years, by transition services received: 2001 NS-CSHCN completed cases, 2007 SATH

Subgroup	2001 sample size
All children aged 14–17 from English-speaking households	10,933
Children aged 14–17 who received transition services questions ¹ . . .	4,457
Talked about changing needs	2,311
Planned for changing needs	1,326
Spoke about adult doctor	962
Received none of these transition services	2,054
Received some but not all transition services	1,637
Received all of these transition services—imperative cases.	674

¹Added to the survey more than halfway through the data collection period; not asked of respondents who completed the survey prior to that point.

NOTES: NS-CSHCN is National Survey of Children with Special Health Care Needs. SATH is Survey of Adult Transition and Health. Subgroup sample sizes exclude vocational education from the transition definition.

Proxy Interviews

Proxy interviews were allowed to accommodate young adults who were unable to complete the SATH interview on their own because of physical, cognitive, speech, or hearing difficulties. Interviewers asked the person who made the majority of the decisions about the young adult’s health care to verify that the sampled person was unable to participate, and then asked him or her to serve as a proxy respondent for the SATH interview. Proxy respondents were told to answer the questions from the point of view of the young adult and were read the consent statement. Proxy respondents completed 113 SATH interviews.

Questionnaire

Development

A panel of federal experts from MCHB and CDC and other health policy experts met to consider content domains for the SATH questionnaire. Topic domains were selected by their health policy relevance for the target population and include demographics, health and functional status, medical home status, transition services (when received) related to health and school, health insurance coverage, and community-based services. Additionally, questions were included that assessed levels of self-determination, satisfaction, and support.

When possible, items from existing related surveys were adapted or included to maximize comparability and minimize the need for extensive pretesting. The following surveys and measures were reviewed during questionnaire development:

- ARC Self-Determination Scale (14)
- National Health Interview Survey (22)
- Special Education Elementary Longitudinal Study (SEELS) (23)
- National Longitudinal Study of Adolescent Health (AddHealth) (24)
- Healthy and Ready to Work (HRTW) (25)
- Survey of Income and Program Participation (SIPP) (26)
- National Longitudinal Transition Study (NLTS–2) (27)
- Plan to Achieve Self-Support (PASS) (28)
- National Survey of Supplemental Security Income Children and Families (29)
- ILR School Employment and Disability Institute’s Transition Quality Indicators (30)
- National Longitudinal Survey of Youth (NLSY) (31)
- International Health Policy Survey of Adults with Health Problems (32)
- National Education Longitudinal Study (NELS) (33)
- National Survey of Children’s Health (NSCH) (34)
- National Survey of Children with Special Health Care Needs (2)

The final SATH data collection instrument is described in [Appendix III](#).

SATH screener

The SATH screener was divided into four parts to guide introductory procedures to locate and contact the 2001 NS-CSHCN respondents and 2007 eligible SATH participants; the sequential parts are described in [Table B](#). If the 2001 respondent could be located, interviewers asked if he or she knew the current location of the 2007 eligible SATH respondent. If the youth still lived with the 2001 respondent, the interviewer asked to speak to the youth directly; if not, interviewers attempted to collect updated contact information for the eligible SATH respondent (e.g., name, address, telephone number, and e-mail address).

When interviewers or locators contacted and spoke to the 2001 respondent, they obtained implicit permission to link the 2001 NS-CSHCN data to the 2007 SATH interview data, per NCHS Research Ethics Review Board requirements. If the 2001 respondent provided updated contact information for the target of the 2007 SATH interview or allowed the interviewer to talk directly to the resident youth, this was considered implicit permission to link the 2001 and 2007 survey data.

Content of Detailed SATH Interview

[Table C](#) summarizes key constructs and subdomains included in the SATH instrument, in addition to the SATH screener.

At interview completion, respondents were thanked for their participation, asked whether the interview was conducted using a cellular or mobile telephone, and provided a valid mailing address to receive their monetary remuneration.

Computer-assisted Telephone Interviewing

SATH used multiple data collection modes to address the perceived needs and preferences of its highly mobile, young target population. Data collection

Table B. Parts of survey screener component: 2007 SATH

Screener component	Outcome	Conclusion
1	2001 R no longer at dialed number	Updated contact information for 2001 R was collected from informant, if possible. If 2001 R was known to be deceased, informant was asked if he or she knew of an intermediary contact person who might know location and contact information for SATH-eligible person.
2	2001 R located	Consent and current contact information obtained to contact 2007 SATH-eligible person directly. If person still resided in the home, interviewer asked to speak to him or her directly. By giving current contact information, 2001 R implicitly consents to contacting 2007 eligible person and including selected 2001 responses on 2007 SATH PUF.
3	Current contact information for 2007 eligible case can be collected	Attempted to contact 2007 SATH-eligible person directly.
4	Current contact information for 2007 eligible case cannot be collected	If informant knew of intermediary contact person who might know location of SATH-eligible person, his or her name, address, and telephone number were collected.

NOTES: SATH is Survey of Adult Transition and Health. R is respondent. PUF is public-use file.

Table C. Content of survey detailed interview: 2007 SATH

Screener
CATI and Web introduction, informed consent
Section 1: Health and functional status
Subdomain 1: General health status
Subdomain 2: Activity limitations—daily living
Subdomain 3: Activity limitations—work
Subdomain 4: Activity limitations—school
Subdomain 5: Activity limitations—taking care of house or family
Section 2: Medical home
Subdomain 1: Usual place for care
Subdomain 2: Continuous screening
Subdomain 3: Foregone or delayed care
Subdomain 4: Care coordination
Subdomain 5: Person-centered care
Section 3: Transition services related to health
Section 4: Community-based services
Section 5: Health insurance coverage
Section 6: Transition services related to school
Section 7: Self-determination
Section 8: Satisfaction and support
Section 9: Demographics
Subdomain 1: Marital status and living arrangement
Subdomain 2: Personal earnings and program participation
CATI and Web questionnaire exit
Callback and answering machine scripts

NOTES: SATH is Survey of Adult Transition and Health. CATI is computer-assisted telephone interviewing.

for telephone cases (either household landline or cellular telephone) was conducted with a computer-assisted telephone interviewing (CATI) system. Once initial programming of the CATI system instrument was completed, it underwent rigorous testing to ensure it functioned correctly. CATI software presented individual questionnaire items on separate screens. Skip logic commands were embedded appropriately to ensure correct questions were asked based on preloaded information or previous responses. Interviewers entered responses directly into the computer in real time. The software determined whether each response was valid (e.g., within an allowable range and consistent

when checked against other data) according to pre-established parameters. This technology reduced the time required to transfer, process, and release data, and promoted high data quality and accuracy. Data were also collected over the Internet. The CATI and Internet introductions and instrument can be found in [Appendix III](#). Contrary to expectations, the landline telephone was the preferred SATH interview completion mode: 67.2% of respondents completed the interview via a landline telephone, 32.2% completed the interview via a cellular phone, and less than 1% completed the interview over the Internet.

All modes of data collection—CATI (landline and cellular telephone) and Internet—used identical instruments, questionnaire sections, question wording, and order. The CATI instrument was administered by the interviewer, whereas the Internet questionnaire was self-administered. The CATI and Internet questionnaires resided in the same production environment and accessed a single sample file, and all survey data regardless of mode were saved to a single database. System architecture did not allow interviewers and respondents to simultaneously access the CATI and Internet questionnaires for a particular case, which eliminated the potential for one mode to override the other. The screener portion was accessible only through the CATI instrument to ensure that Internet respondents were not able to access it. All screening was conducted by telephone interviewers; the Internet was used only to collect SATH questionnaire data.

Internet Questionnaire

The Internet questionnaire option provided SATH respondents a secure, user-friendly interface and integrated several Web questionnaire design principles advocated by Dillman (35). Specifically, the welcome screen was motivational, emphasized the ease of responding, and instructed respondents in how to proceed to the next page. An on-screen graphic conveyed the interview's progress to discourage respondents from exiting the survey

when only a few questions remained. Individual questionnaire items appeared on separate screens, and each item was displayed using a consistent format to enhance readability. Response and navigation buttons were appropriately spaced on the screen to reduce user error. Internet respondents were allowed to return to a previously answered question or resume their session at a later time. Finally, each screen contained an embedded link that made it easy for respondents to submit requests for technical support via e-mail.

To address security concerns, the Internet questionnaire resided on a secure server behind the network firewall. Access for Internet respondents was restricted through the use of uniquely assigned passwords provided via e-mail or, upon request, via hard-copy letter.

Pretest

A pretest was not conducted due to the condensed locating and data collection schedule.

Interviewer Training

All SATH contact attempts and interviews originated from the NORC telephone center in Chicago. Interviewer recruitment began in May 2007, 1 month prior to the scheduled data collection start date. Interviewer training was conducted in two sessions over 3 days in June 2007 with a total of 43 attendees, all of whom were certified as SATH interviewers at the end of the training. One cohort of 21 interviewers was trained during June 4–5, 2007, and a second cohort of 22 more experienced interviewers attended 1 day of training on June 6, 2007.

CATI Training

CATI training emphasized two main activities that interviewers would perform: screen to identify eligible respondents and conduct the SATH interview. All interviewers completed a 5-hour, project-specific CATI training and certification process before dialing

potential SATH respondents. These sessions emphasized and reinforced the importance of identifying the correct eligible SATH respondents. Trainers pointed out various elements in the SATH introduction used to verify that the contacted respondent was the 2001 NS-CSHCN respondent or the intended SATH respondent. Verification elements included the 2001 NS-CSHCN respondent's relationship to the SATH respondent (e.g., mother, father, or other guardian), and the SATH respondent's date of birth (if available), gender, and age. Trainers also conveyed the overall survey purpose and sponsor, a description of the target population, and the potential need to locate a portion of SATH respondents outside of the CATI screener. Interviewers were instructed not to discuss the 2001 survey or CSHCN until the correct respondent's identity was verified.

Trainers reviewed key concepts in each section of the SATH instrument, in the detail necessary to provide interviewers with a well-rounded knowledge of questionnaire content. Trainers then led mock interviews and alternated playing the role of the 2001 NS-CSHCN and 2007 SATH respondents to familiarize interviewers with the entire questionnaire and interview process. Mock interviews also included refusal aversion scenarios requiring trainees to practice skills in gaining cooperation and to demonstrate project knowledge. These skills improved their abilities and built their confidence to adeptly answer frequently asked questions to avert item-level, unit-level, and global refusals. At the end of the training sessions, they participated in review exercises structured as an interactive, engaging game that required each person to access newly acquired project and protocol knowledge. Interviewers then were administered a written evaluation that tested project knowledge. Finally, interviewers completed a final mock interview to demonstrate their ability to successfully conduct SATH screeners and interviews.

All certified interviewers had dialing experience before they contacted any eligible SATH respondents (e.g., all interviewers were staffed on other

telephone surveys before attempting SATH data collection). This ensured that all SATH interviewers had prior telephone survey experience and were comfortable with the data collection software, instrument, and interviewing process in general.

Locating Training

Approximately 2 weeks after telephone interviewing began, all interviewers received a separate, 4-hour project-specific locating training to prepare them to use information to locate respondents; this training is detailed in [Appendix II](#). CATI and locating trainings were held separately to allow interviewers to become comfortable with the screener and instrument. As interviewers gained experience working through the SATH screener and interview, they developed an understanding of the importance of the locating activities and had uninterrupted time to improve their strategies and locating skills. SATH interviewers were also trained as locators because they could potentially encounter situations where locating activities immediately led to the opportunity to conduct a SATH interview. Locating activities started with the 2001 telephone number.

Interviews via Respondent's Cellular Telephone

Given the proliferation of cellular telephones, particularly within the age range of the targeted respondents, SATH interviewers were prepared to administer the survey via cellular telephone to maximize convenience. During the training, interviewers were informed that a cellular telephone number provided by the 2001 NS-CSHCN respondent to reach the target young adult in the eligible SATH case would be dialed manually, to ensure compliance with the restrictions of the Telephone Consumer Protection Act of 1991. Once SATH respondents confirmed the call was taking place on a cellular telephone, interviewers were instructed to mention that an additional \$5 would be provided

for the respondent's cellular air time and applicable long-distance charges. Except to manually dial cellular telephone numbers, these interviews followed identical data collection protocols implemented for landline telephones.

Security and Confidentiality

All staff assigned to SATH signed the NCHS Nondisclosure Affidavit, which committed them to perform project work in accordance with the authority and restrictions of Section 308(d) of the Public Health Service Act. The affidavit acknowledged the employees' understanding of the consequences of unauthorized disclosure under Section 513 of the Confidentiality Information Protection and Statistical Efficiency Act of 2002 (CIPSEA) and the Privacy Act of 1974, 5 U.S.C. Section 552a(i)(1). All employees and contractors, permanent or intermittent, were also required to watch a video produced by NCHS on "Confidentiality Requirements for NCHS Contractors" prior to being given access to data protected under these authorities.

Data Collection

Modular recruitment, consent, and data collection procedures are highlighted in this section.

Advance Letter

Advance letters were not sent because case telephone numbers were not recently address-matched to a current, valid street address in 2007.

SATH Screening, Locating, and Interviewing Processes

The [text Figure](#) depicts the general process flow and modular nature of the SATH locating and interviewing tasks.

Initial contact attempt

SATH data collection began June 12, 2007, and ended August 26, 2007. Telephone numbers from 2001 were

loaded in the CATI system, and interviewers dialed through the sample to determine whether the 2001 telephone number still reached the 2001 NS-CSHCN respondent. This was an efficient and effective way to determine whether respondents could be easily located and contacted at the last known telephone number or if more extensive locating efforts would be needed.

Only English-speaking households from 2001 were contacted for SATH due to cost constraints. When interviewers contacted households where no household member spoke English, the case was sent to locating.

Contacting 2001 respondent

The 2001 respondent's relationship to the 2007 eligible SATH respondent was preloaded into the CATI system and questionnaire so that interviewers could specifically ask to speak with the young adult's mother, father, grandparent, or other guardian who responded in 2001. If the 2001 respondent indicated the youth still lived in the home, the interviewer asked to speak to him or her directly. If the youth no longer resided with the 2001 respondent, interviewers collected updated contact information (e.g., name, address, telephone number, and e-mail address).

Identifying and contacting 2007 respondent

If available, the SATH CATI instrument contained three preloaded pieces of information to assist interviewers and the 2001 respondent to identify the correct 2007 eligible SATH case: the 2007 eligible respondent's gender, age at the time of the 2001 NS-CSHCN interview, and date of birth. The CATI system calculated the young adult's current age based on the amount of time that had passed since the 2001 NS-CSHCN interview and the young adult's date of birth. Data were collected for the 2001 survey from October 2000 to April 2002 (2).

If the 2001 respondent indicated that two or more persons with identical gender and age resided in the household, the interviewer provided the date of birth for the intended SATH respondent

to identify the correct young adult. If the date of birth did not uniquely identify the SATH respondent, the interviewer informed the 2001 respondent that someone would recontact them with additional information that might indicate which young adult was eligible for SATH. The case was then referred to project staff who accessed a file provided by NCHS to help differentiate same-aged persons. This file contained information from the 2001 NS-CSHCN—such as the specific special health care needs of children in the household—that could be used to identify which young adult was eligible for SATH. Project staff accessed this file for 16 cases during data collection and identified the intended respondent in 10 cases. In the remaining six cases, no information uniquely identified the intended SATH respondent.

To further verify that the correct young adult had been identified, the potential SATH respondent was asked to confirm his or her date of birth. The recorded date of birth was confirmed for 1,757 cases. For the remaining 159 cases, the data of birth either was incorrect or unavailable. These respondents were given an opportunity to provide the correct date of birth before they began the interview.

Endorsement and Internet Offer Letters

During SATH data collection, 57 respondents requested an endorsement letter ([Appendix IV](#)) that provided supplemental information about the SATH survey, such as the purpose, an assurance of confidentiality, and points-of-contact regarding respondent rights. The endorsement letter was available in two versions: one for gatekeepers, parents, or informants verified the survey's legitimacy, described the study in general terms, and asked the recipients for their cooperation. The second version, directed to 2007 respondents, specifically stated that someone in their household had participated in an earlier survey on their behalf, and that CDC wished to interview them. The letter mentioned the interview would take

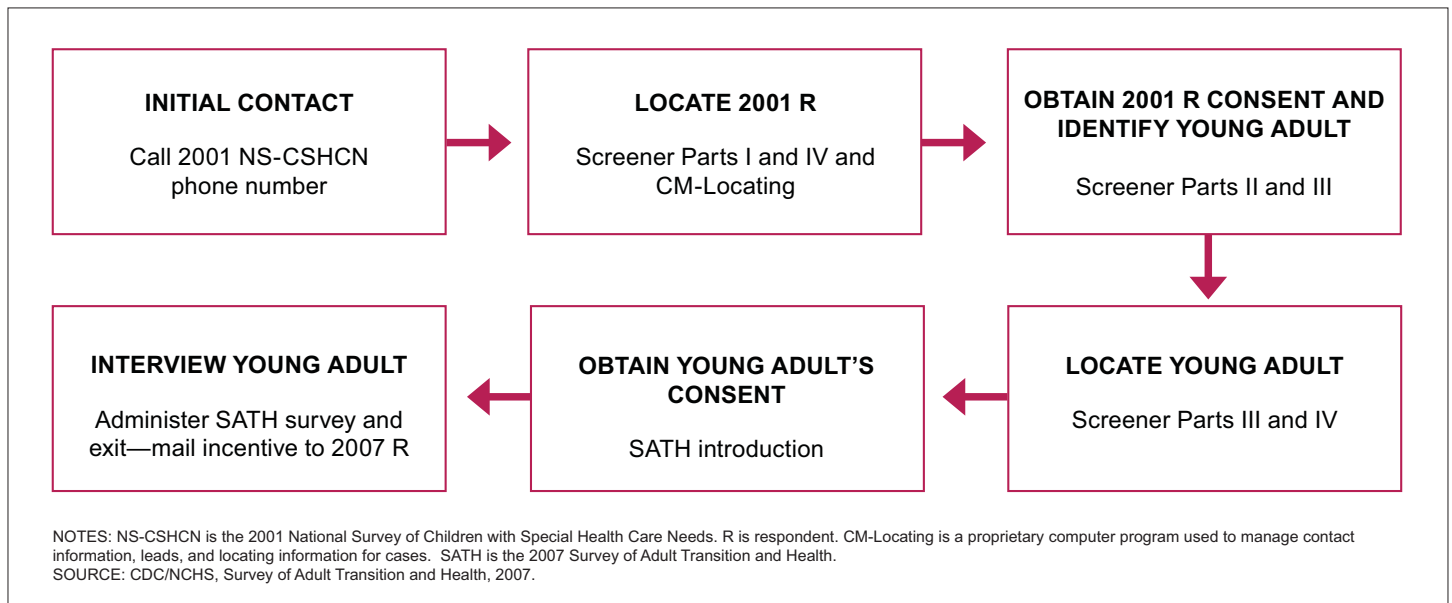


Figure. General process flow: 2007 SATH

about 15 minutes, and the respondent would receive a \$20 token of appreciation.

The Internet offer letter (Appendix V) was sent upon request if the young adult sent an e-mail using an address link on the SLAITS SATH-specific website during data collection, or if he or she expressed a desire to complete the interview by Internet when called by an interviewer. This letter provided the Internet questionnaire website address and a unique password to access the questionnaire. Internet offer letters were sent to 73 respondents. The letters reminded respondents that they would receive a \$20 token of appreciation and provided the project’s toll-free telephone number to answer questions or complete the survey over the telephone.

Toll-free Telephone Number

A toll-free telephone number attended by NORC was provided in SATH answering machine messages, exit scripts, and the Internet survey introduction, and by SATH interviewers at the respondents’ request. Respondents could call this number to gather additional information about the project or complete the interview if the 2001 respondent previously provided consent in the SATH screener. Respondents associated with 155 eligible SATH cases

placed 289 calls to the toll-free number during the production period. Of the 155 eligible cases, 121 respondents completed the SATH interview.

Informed Consent and Assurance of Confidentiality

Participation in surveys conducted by NCHS is voluntary, and information collected on individuals is confidential. For SATH, assurance of confidentiality was provided to potential respondents as part of the informed consent procedures. In the CATI system, interviewers acknowledged that they read the following script to potential respondents:

“Before we continue, I’d like you to know that this research is authorized by the U.S. Public Health Service Act so your answers will be kept strictly private. Your participation is voluntary. You may choose not to answer any question you don’t want to answer or stop at any time without penalty.”

If a respondent requested a description of the authorizing legislation, the interviewer read the following:

“The Public Health Service Act is Volume 42 of the U.S. Code, Section 242k. The collection of information in this survey is authorized by

Section 306 of this act. The confidentiality of your responses is assured by Section 308d of this act.”

Section 308d of the Public Health Service Act (42 U.S.C. 242m) states:

No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under section ... 306 ... may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Secretary) to its use for such other purpose and in the case of information obtained in the course of health statistical or epidemiological activities under section ... 306, such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented (as determined under regulations of the Secretary) to its publication or release in other form.

Strict procedures were followed to prevent disclosure of confidential data in survey operations and data dissemination.

The 2001 respondent's willingness to help locate the eligible SATH case was considered consent to proceed. If the potential respondent could be located using updated contact information, or if he or she still lived in the home, the following consent script was read upon speaking directly to the eligible SATH respondent:

“Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any question you do not wish to answer, or stop at any time without penalty. Your answers will be used for statistical purposes, and will be linked to your parent or guardian from several years ago. We are required by the Public Health Service Act to keep your answers strictly private. I can give you more information on this and other federal laws if you wish. They state that your answers will be used only for statistical research. The survey will take about 15 minutes. In appreciation, you will receive \$20. (IF CALLING KNOWN CELLULAR TELEPHONE NUMBER: You will also receive an additional \$5 to defer your costs for doing the interview on your cellular telephone). In order to review my work, my supervisor may record and listen as I ask the questions. I'd like to continue now unless you have any questions.”

A specific description of federal laws that protect respondent confidentiality was available to interviewers if respondents requested additional information.

Interview and Section Length

The SATH questionnaire was approximately 14 minutes in total length. Dynamic time stamps were embedded throughout the questionnaire to measure section and total interview administration time. [Table D](#) provides the average administration times in minutes for both areas.

Table D. Length of survey interview, by section: 2007 SATH

Section	Mean length in minutes (SD)
Overall interview length	14.36 (3.10)
Section 1: Health and functional status	2.83 (0.81)
Section 2: Medical home	4.4 (1.71)
Section 3: Transition services related to health	1.07 (0.39)
Section 4: Community-based services	0.58 (0.41)
Section 5: Health insurance coverage	1.33 (0.36)
Section 6: Transition services related to school	0.74 (0.28)
Section 7: Self-determination	0.96 (0.27)
Section 8: Satisfaction and support.	0.88 (0.23)
Section 9: Demographics	1.66 (0.46)

NOTES: SATH is Survey of Adult Transition and Health. SD is standard deviation. Cases were excluded from the timing analysis on a section-by-section basis for three reasons: the overall interview time was less than zero; a section began and ended on separate calls, resulting in invalid timings; or an interviewer returned to a previous questionnaire item to check or correct an answer, resetting the dynamic section timestamp and creating invalid timing for a section.

Partially Completed Interviews

Almost all SATH respondents who began the interview completed it. A partially completed interview was defined as a case in which a respondent completed question F7Q01 in Section 6 (transition services related to school). Only 6 of the 1,865 cases included in the final PUF had a partially completed interview.

Third Party Present During Interview

SATH interviewers assured 2001 respondents that information from the 2001 NS-CSHCN would not be communicated to the young adults. Likewise, interviewers assured the 2007 respondents that their information would not be communicated to their parents or guardians. Even with these assurances, telephone surveys present a challenge in that a household member could listen to the interview by picking up another landline telephone extension in the home. During the interviewer debriefing session, interviewers indicated that on at least two occasions they suspected that a parent listened to at least a portion of the SATH interview. Consequently, a third-party protocol was established. If an interviewer suspected a third party was listening to the interview, the interviewer asked the SATH respondent if someone else was on the line. If the respondent indicated no, or if the parent left the call at that point, the interview

continued. If the parent insisted on remaining on the line and the SATH respondent expressed comfort with this, the interview continued and the interviewer completed a case form indicating that a third party had been on the line during the interview. After this protocol was instituted, one case was subsequently flagged as having a third party present during the SATH interview.

Monetary Incentives and Thank You Letters

SATH respondents who completed the interview and provided a valid address at the interview's conclusion received a cash incentive of \$20 accompanied by a thank-you letter ([Appendix VI](#)). If the respondent completed the interview via cellular telephone, an additional \$5 in cash was included. The \$5 cellular telephone reimbursement amount was calculated using an average of per-minute charges associated with national cellular telephone plans at the time of the interview.

Efforts to Maximize Response Rates

Numerous approaches were used to maximize response rates, including:

- Using established tested survey questions as much as possible during SATH development stages to minimize possible points of refusal or ambiguity.

- Using monetary incentives and cellular telephone reimbursement.
- Establishing a toll-free number to allow respondents to participate immediately, ask questions about the survey, obtain additional survey-related information, or verify survey legitimacy.
- Referring cases to locating staff to follow up on leads provided by Accurint® (a locating vendor that maintains a proprietary data-linking system to public records).
- Managing the sample with flexible calling schedules and close monitoring of SATH interviews and sample dynamics, particularly during production slowdown.
- Contacting leads to maximize chances of locating the intended SATH respondents.
- Using specially trained refusal converters to target SATH refusals based on case history.

Interview Completion Rate

Final case disposition classifications are shown in [Appendix VII. Table E](#) provides the number of completed interviews and interview completion rate by sample type. Overall, 1,916 interviews were completed, of which 1,865 are included in the public-use file. The preferred interview completion mode was the landline telephone: 1,288 respondents completed the interview via landline telephone (67.2%), 616 completed via cellular telephone (32.2%), and 12 completed via the Internet (less than 1%).

The SATH interview completion rate was 17.5% using American Association for Public Opinion Research (AAPOR) standards (21), calculated as

the total number of sufficient partial and fully complete interviews divided by the total eligible sample. The rate is primarily driven by the inability to contact original households and is not due to a high refusal rate. Of the original 2001 parents or guardians, we were unable to contact 7,409 (68%). Of the young adults we were able to contact, almost all of them cooperated; the AAPOR cooperation rate was just over 98% (N = 1,916).

Quality Control

Project staff continually monitored SATH interviewers, locators, and data consistency. In addition, an interviewer debriefing session was held 1 week after data collection began to solicit comments and concerns from interviewers.

Interviewing

Telephone center supervisors were available to interviewing staff at all times to resolve any questions or concerns about a case. Supervisors regularly observed the data collection process to monitor interviewers informally. In addition, supervisory staff used remote telephone and computer-monitoring technology to evaluate whether interviewers performed according to project specifications. This formal monitoring was conducted to ensure that interviewers read introductory materials properly, adhered to screening and locating procedures, followed questionnaire item wording and sequence, answered respondent questions properly, and probed any vague responses properly. Computer

monitoring also allowed supervisors to ascertain whether interviewers entered answers accurately into the CATI system.

Supervisory staff monitored 10% of all SATH interviewing calls. To avoid bias, the CATI monitoring system automatically selected which interviewers to monitor. The highest priority for selection was assigned to newly trained interviewers, those with the fewest monitoring sessions, or those with the weakest performance reviews. Experienced interviewers were prioritized based upon the length of time since their last monitoring session and recent monitoring scores. Each interviewer was typically monitored at least once a week; however, some interviewers were monitored more often. In addition, telephone interviews were recorded with permission from the respondents. These recordings were valuable tools for providing interviewers feedback on performance.

Cases completed via the Internet questionnaire were not monitored, given the self-administered nature of the mode. A case could not be simultaneously accessed via Internet and CATI, which eliminated concerns that one data collection mode might overwrite another.

Interviewer Debriefing

After 1 week of data collection, an interviewer debriefing session was conducted with three SATH interviewers to solicit interviewer feedback on the screening and interviewing process. Overall, interviewers were very enthusiastic about the study. They reported that the CATI instrument

Table E. Interview completion rates, by sample type: 2007 SATH

	Imperative cases	Standard cases ¹	Overall
Sample size (n)	674	10,259	10,933
Targeted number of completed interviews	1,845
Interview completion rate	21.1%	17.3%	17.5%

... Category not applicable.

¹Transition service questions were added to the survey more than halfway through the data collection period and were not asked of respondents who completed the survey prior to that point. Cases without 2001 transition information were classified as standard cases.

NOTE: SATH is Survey of Adult Transition and Health.

functioned properly, 2007 respondents were eager to participate in the survey, and respondents did not have difficulty understanding the survey questions.

During the debriefing, interviewers raised two concerns and asked for additional job aids to address two separate issues. First, interviewers commented that some parents refused to place the 2007 respondent on the telephone, stating concerns over what type of information from the 2001 NS-CSHCN would be divulged to the young adult. An additional frequently asked question and answer was drafted to address this concern:

Question: “How do I know that you will not divulge information from the 2001 survey to my son or daughter?”

Answer: “We appreciate your participation in the 2001 survey. Federal laws prohibit us from revealing your answers to anyone, including your son or daughter. If you have questions about your rights as a study participant, you may call 1–800–223–8118, toll-free, and leave a message asking to speak to the Chairperson of the Ethics Review Board.”

Interviewers revealed that on at least two occasions, a parent remained on the line to listen to the young adult’s interview. Because it was desirable to conduct the telephone interview in a setting as private and confidential as possible, the following protocol was distributed to interviewers to help them handle instances when they suspected that a third party was on the call:

Situation: If a parent (or other household member) stays on the line during the interview with the 2007 respondent:

Response: “Is someone on another telephone?”

If the R says “Yes,” say “According to our confidentiality standards, it would be ideal for us to conduct this interview with only you (i.e., the 2007 respondent) on the telephone line. Is that an option?” If [the] parent hangs up, continue the interview. If the parent insists

on staying on the line, continue the interview and complete a form to indicate the parent’s presence on the call.

If the R says, “No” (and it is clear that the parent is still on the telephone), say, “That’s ideal. According to our confidentiality standards, it’s important that we conduct this interview with just you on the telephone line.” Continue with the interview and complete a form to indicate the parent’s presence on the call.

In a number of cases, the parent continued to stay on the telephone line during the interview because he or she was trying to assist the interviewer. For example, youth who experienced moderate or severe functional limitations may have had difficulty communicating their answers over the telephone in a way the interviewer could understand. During quality control monitoring, this situation occurred a few times and it was noted (at least for these cases) that the parent or guardian did not in any way attempt to influence or change the answer of the youth.

These responses to interviewers’ concerns were distributed to all interviewers after the debriefing session. Supervisors reviewed the new question and answer as well as the protocol for handling a third party with all interviewers to ensure that they were aware of and understood the new information.

Data Collection

The CATI and Internet systems were programmed to ensure complete and accurate data collection using automated data checking techniques such as response-value range checks and consistency edits during the interview process. These features enabled interviewers to obtain needed clarifications while still on the telephone with the respondent. If an Internet respondent failed to answer a question, the Internet program alerted the respondent that a question was not answered and prompted them to enter a response. Throughout data collection, project staff reviewed interview data for

consistency between fields, appropriate response-value ranges, skip logic patterns, and missing information.

Weighting and Estimation Procedures

Sampling Weight

The 2007 SATH sampling weight for each case was derived from the original 2001 NS-CSHCN sampling weights. The SATH weight was then adjusted for non-response to the SATH interview with demographic information from the 2001 NS-CSHCN. However, a detailed analysis of SATH non-response bias has not been completed. Young adults from households that did not move between 2001 and 2007 are likely overrepresented in the data set, and these young adults may differ in important ways from young adults who live in households that did move between 2001 and 2007. Because of the sample design, response rate, and the possibility of nonresponse bias, analysts may wish to consider the SATH sample as a convenience or purposive sample rather than a random sample. Data from a purposive sample should not be used to test hypotheses about the target population.

Weighting Objective and Process

The SATH target population was CSHCN in the United States aged 14–17 in 2001 who lived in English-speaking households, with a completed NS-CSHCN interview (n=10,933). The SATH weighting process was designed so that the 1,865 completed SATH cases on the PUF should represent this target population when an adjusted version of the 2001 weight is applied. Of the 1,916 completed cases, 1,865 are included on the SATH PUF.

The SATH weighting plan was developed independently within each of three weighting domains:

Domain 1—The CSHCN received all transition services as of the 2001 interview.

Domain 2—The CSHCN did not receive transition services, but had a medical home in 2001.

Domain 3—The CSHCN did not receive transition services or care in a medical home in 2001.

These weighting domains were developed because separate inference was desired in each domain. It was also desired to divide Domain 1 into “medical home” versus “not medical home,” but too few interviews were completed in Domain 1 to make this division possible. Within each domain, the SATH weighting procedure was conducted as follows:

- Adjust the 2001 NS-CSHCN interview weight for nonresponse to the SATH interview.
- Truncate the extreme nonresponse-adjusted weights.
- Adjust, or “rake,” these weights so that their sum agrees with marginal control totals from the NS-CSHCN.
- Truncate the extreme raked weights.
- Repeat raking and truncation steps until no extreme weights remain and end on a raking step.

Step 1: Adjust for nonresponse to SATH interview

The 2001 NS-CSHCN interview weights for SATH respondents in each domain were adjusted to account for nonresponse to the SATH interview. Within each domain, nonresponse adjustment cells were formed and weights for nonrespondents within each cell were redistributed among the respondents within the cell. The nonresponse adjustment cells were formed using data collected during the 2001 NS-CSHCN interview from 11 variables in the child, household, and interview files. For each variable, a logistic regression equation modeled that variable’s relation to SATH response propensity. Variables found to be

significant at the 0.05 level were then placed in a logistic regression model with stepwise selection. Variables chosen in the stepwise selection were used to form nonresponse adjustment cells. These cells were then collapsed until each contained a minimum number of SATH respondents per cell, with the variables least significantly related to response propensity collapsed first. Variables chosen by the stepwise model process are listed by domain:

- Domain 1—Presence of a medical home and poverty status (2,36).
- Domain 2—Poverty status, total persons, and race and ethnicity.
- Domain 3—Poverty status, total adults, race and ethnicity, and elevated services need.

In Domain 1, the number of adults in the household was significantly related to SATH response propensity, but due to the small number of SATH respondents with only one adult in the 2001 household, the number of adults could not be used to form nonresponse adjustment cells in Domain 1.

Step 2: Truncate extreme nonresponse-adjusted weights

The nonresponse-adjusted weights were then truncated, or trimmed, within each domain to reduce the mean square error of estimates. If the weight was greater than the median plus six times the interquartile range of the weights in the domain, the weight was set equal to six times the interquartile range. This cutoff point was chosen after the impact of various cutoff points on design effects and mean square errors were examined.

Step 3: Adjust (rake) weights to control totals

Next, the truncated weights from step 2 were adjusted, or raked, so that the sum of the weights agreed with

marginal age, sex, and race and ethnicity control totals for each domain. The weights for 51 dropped cases were redistributed by age, sex, and race and ethnicity. The control totals were formed by summing the 2001 NS-CSHCN interview weights for eligible SATH children by age, sex, and race and ethnicity categories.

Step 4: Truncate extreme raked weights

Consistent with step 2, the raked weights were then truncated in each domain to the median plus six times the interquartile range of the weights in the domain.

Step 5: Repeat raking and truncation until no extreme weights remain, and end on raking step

Truncation and raking steps were then repeated iteratively within each domain until no extreme weights existed. After three rounds, the weights were adjusted a final time to produce the final SATH interview weight. [Table F](#) provides summary statistics for the final SATH PUF person-level weight (WEIGHT_SATH).

Estimation

Although the SATH PUF contains one interview weight for each sampled young adult, analysts may wish to consider the SATH sample as a convenience sample rather than a random or complex sample because of the sample design, response rate, and the possibility of nonresponse bias. Analysts should review the sample sizes with which they work: Compared with other SLAITS modules, the SATH sample size is very small, and the SATH data file should not be used to calculate national prevalence estimates. It can be

Table F. Summary statistics for final interview weight: 2007 SATH

	Unweighted sample size	Minimum weight	Maximum weight	Mean weight	Sum of weights
United States.	1,865	18.87	9,784.54	1,290.68	2,407,111.00

NOTE: SATH is Survey of Adult Transition and Health.

used to calculate weighted percentages, proportions, and more to use in hypothesis generation, but these figures should not be labeled as nationally representative prevalence estimates.

Public-use Data File

A SATH PUF in SAS format is available for free download anytime with programs to read the file and attach permanent formats. It contains one record for each partially or fully completed SATH interview, and selected data collected from the 2001 NS-CSHCN interview are attached to each case record in the PUF. The 2001 data strengthens the analytic use of the SATH data set, provides comparison data to track outcomes over time (albeit from different respondents), and provides benchmarks to classify certain subgroups for comparative analysis.

The SATH PUF contains 1,052 completed interviews with youth who did not receive the 2001 transition questions.

Edits to Protect Confidentiality

NCHS takes extraordinary measures to ensure the identity of survey respondents, and subjects cannot be disclosed. No NCHS publicly released microdata files may contain any information that would directly or indirectly lead to the disclosure of any respondent's or subject's identity. The risk of inadvertent disclosure of confidential information about individual respondents is higher with a publicly released data set that has detailed geography variables, a detailed and extensive set of survey observations, or a sizeable proportion of the total population of interest. Common techniques to reduce the risk of inadvertent disclosure include coarsening a data set by suppressing survey variables, collapsing multiple variables into one, collapsing response categories for other variables, and introducing noise in the data.

Some of these measures were applied to the SATH data file and

selected variables to reduce the risk of inadvertent disclosure:

- SATH PUF does not include the 2001 and 2007 interview dates.
- The 2001 NS-CSHCN variables on the 2007 SATH PUF were taken directly from the 2001 NS-CSHCN PUF.
- Top- and bottom-coding are techniques routinely applied to variables to mitigate a disclosure risk for extreme values. In SATH PUF, three variables were top-coded.

The variable F3Q21 was recoded as F3Q21R ("In the past 12 months, the number of preventive care visits"), F3Q22 was recoded as F3Q22R ("In the past 12 months, the number of preventive dental visits"), and F10Q21 was recoded as F10Q21R ("The next question is about your total income in the past 12 months, including income from all sources such as wages, salaries, Social Security, help from relatives, and so forth. Can you tell me that amount before taxes?"). Values for the variable F3Q21R were top-coded at 20 or more preventive care visits; for F3Q22R, at eight or more preventive dental visits; and for F10Q21R, at more than \$50,000.

Analysts who wish to work with unsuppressed data files may apply to the NCHS Research Data Center (RDC) at NCHS headquarters in Hyattsville, Maryland. Data files housed in the RDC may also be accessed remotely. Information on fees and procedures is available from <http://www.cdc.gov/rdc>.

Other Edits

Very little editing of SATH interview data was necessary. The CATI and Internet instruments did not allow values to be entered that were not response options to the questions. Post-interview data editing was required only when interviewers typed an incorrect code for "don't know" or "refused" responses to the income question (F10Q21) or did not code the open-ended question (F2Q30A) correctly.

Question F2Q30 asked respondents what they were doing most of the time during the past 12 months, with the following response options:

- 1 = WORKING AT A JOB OR BUSINESS
- 2 = LOOKING FOR WORK
- 3 = TAKING CARE OF HOUSE OR FAMILY
- 4 = GOING TO SCHOOL
- 5 = SOMETHING ELSE

If "something else" was chosen, at the next question (F2Q30A) the respondent was asked for a description, which the interviewer recorded verbatim. A review of responses to F2Q30A found that often the recorded verbatim response should have been coded into one of the existing choices at F2Q30. Moreover, many of the recorded verbatim responses were similar in nature. Therefore, a new variable, F2Q30RR, was created and set equal to F2Q30 if F2Q30 was valid, or set equal to the appropriate F2Q30 code if the F2Q30A verbatim response could be coded into an existing F2Q30 response option. Several new codes were added to F2Q30RR to accommodate the most common verbatim responses:

- 6 = REHABILITATION
- 7 = DAY PROGRAM
- 8 = VOLUNTEERING/MISSIONARY WORK
- 9 = RECREATION

Missing Data

Although data users often ignore all missing values, SAS provides a mechanism for analysts who wish to distinguish between different kinds of missing data. The following missing value codes are used in SATH PUF:

(.L) *Legitimate skip*: The variable is missing due to valid questionnaire paths based on a previous answer to a root question.

(.M) *Missing in error*: The variable is missing due to interviewer or system error. In cases of interviewer error, the interviewer may have

deleted the data by accident or not recorded an answer for the question. In cases of system error, the data may not have been collected or saved properly after it was entered by the interviewer in the CATI system.

(P) Partially completed interview: The variable is missing because the respondent hung up after he or she answered question F7Q01 before completing the full interview.

Derived Variables

Derived variables are created to facilitate analysis or address confidentiality concerns. Derived variables from the 2001 NS-CSHCN PUF or 2007 SATH data included in the 2007 SATH PUF are listed in [Table G](#). The 2001 NS-CSHCN Design and Operations report (2) contains additional information on 2001 derived or flag variables included in the 2007 SATH PUF. For example, the SATH PUF contains two geographic variables from the 2001 PUF (STATE and MSASTATR).

Several derived variables were created specifically for SATH PUF (variables MET1, MET2, MET3, MET5, and MET6) using 2001 data, to assess the care of CSHCN in community-based service systems (1) [i.e., did the care of the CSHCN received meet conditions to achieve five of the MCHB core outcomes in 2001 (numbers 1, 2, 3, 5, and 6)]. Many of these derived core outcome variables used data from various 2001 variables for the derivation. The five derived core outcome variables are:

- MET1: Families of CSHCN were partners in decision-making and satisfied with the services they received (met conditions for MCHB core outcome 1).
- MET2: CSHCN received coordinated, ongoing comprehensive care within a medical home (met conditions for MCHB core outcome 2).
- MET3: Families of CSHCN had adequate private or public insurance to pay for the services they needed (met conditions of MCHB core

outcome 3).

- MET5: Community-based service systems were organized so that families of CSHCN could use them easily (met conditions for MCHB core outcome 5).
- MET6: Youth and adolescents with special health care needs received the services necessary to make transitions to adult life, including adult health care, work, and independence (met conditions of MCHB core outcome 6).

A derived variable called REGION gives geographic detail about SATH cases in four census regions (Northeast, Midwest, South, and West) based on their 2001 state data. To create the REGION variable, the original sampling strata (78 Immunization Action Plan (IAP) areas, later reduced to 55 IAP) were collapsed into 18 strata by systematically combining three to six areas into each stratum. At no point were areas in one census region collapsed with areas in another census region, so it is possible to calculate regional estimates. One derived variable was created exclusively from SATH data: The variable PROXY was created to examine the actual respondent(s) during the course of the SATH interview (proxy respondents were allowed to respond for the young adult if he or she was severely impacted by disability).

Citations

Any published material derived from SATH data should acknowledge CDC, NCHS, and SLAITS as the original source. The suggested citation, “Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, Survey of Adult Transition and Health, 2007,” should appear at the bottom of all tables. A disclaimer should also be included crediting any analyses, interpretations, or conclusions reached to the author(s) (i.e., recipient of the data file). NCHS and SLAITS are responsible only for the initial data.

Using the acronyms SATH and SLAITS in titles, keywords, and

abstracts of journal articles and publications facilitates retrieval in bibliographic searches.

Further Information

Data users can obtain the latest information about the State and Local Area Integrated Telephone Survey mechanism by periodically visiting the NCHS SLAITS website at <http://www.cdc.gov/nchs/slaits.htm>. This site features free, downloadable PUFs and documentation for SLAITS modules; important information about any modifications or updates to data and documentation; and current contact information. After reviewing appropriate documentation, questions may be e-mailed to slaits@cdc.gov.

Researchers may also wish to join the SLAITS electronic mail listserv. To subscribe or unsubscribe, visit http://www.cdc.gov/nchs/slaits/slaits_listserv.htm and follow the directions listed. The listserv has approximately 1,000 global subscribers who use SLAITS data or are interested in the SLAITS mechanism. Subscribers periodically receive e-mail with news about SLAITS surveys, new releases of data or documentation, publications, or related conferences. Listserv membership is not shared.

For more information on NCHS, its publications, or data files, contact:

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Table G. Description of derived variables in public-use data file: 2007 SATH

Variable name	Description
REGION	Census regions (Northeast, Midwest, South, West), 2001
MSASTATR	Metropolitan Statistical Area status with 500,000-person threshold, 2001
TOTADULT	Total number of adults in household, 2001
TOTKIDSR	Total number of children in household aged 0 to 17 years, 2001, recoded
TOTKIDSMR	Total number of male children in household aged 0 to 17 , 2001, recoded
TOTKIDSMR	Total number of female children in household aged 0 to 17 , 2001, recoded
NM_SPR	Total number of children in household with special health care need, 2001, recoded
NM_NSPR	Total number of children in household without special health care need, 2001, recoded
NM_SPMR	Total number of male children in household with special health care need, 2001, recoded
NM_SPFR	Total number of female children in household with special health care need, 2001, recoded
NM_NSPMR	Total number of male children in household without special health care need, 2001, recoded
NM_NSPFR	Total number of female children in household without special health care need, 2001, recoded
AGE2001	CSHCN's age in years, 2001
HISPANIC	CSHCN of Hispanic or Latino origin, 2001
RACER	Race of target CSHCN, 2001
RACE_HI	Race of target CSHCN, Hawaii, 2001
RACEASIA	Race of target CSHCN with Asian specification, 2001
RACENAAN	Race of target CSHCN with American Indian or Alaska Native specification, 2001
RELATION	Respondent's relationship to child, 2001, recoded
MOTHER_EDUCR	Education level of child's mother, 2001
UNINS_YR	Past 12 months, CSHCN ever not insured, 2001
MS_UNINS	Past 12 months, number of months without insurance coverage, 2001
YS_UNINS	Number of years without insurance coverage, 2001
POVLEVEL	Poverty level of household based on HHS 2001 guidelines
MET1	Did CSHCN meet conditions of 2001 MCHB Core Outcome 1?
MET2	Did CSHCN meet conditions of 2001 MCHB Core Outcome 2?
MET3	Did CSHCN meet conditions of 2001 MCHB Core Outcome 3?
MET5	Did CSHCN meet conditions of 2001 MCHB Core Outcome 5?
MET6	Did CSHCN meet conditions of 2001 MCHB Core Outcome 6?
UNINS	In 2001, was CSHCN not insured using NCHS definition?
PROXY	Actual respondent(s) during course of SATH interview, 2007

NOTES: SATH is Survey of Adult Transition and Health. CSHCN is child or children with special health care needs. MCHB is Maternal and Child Health Bureau of the Health Resources and Services Administration. NCHS is National Center for Health Statistics.

Guidelines for Data Use

In the interest of mutual benefit, NCHS requests that recipients of data files cooperate in certain actions related to their use.

Data users who wish to publish a technical description of the data should make a reasonable effort to ensure that the description is not inconsistent with that published by NCHS.

The Public Health Service Act (Section 308d) provides that data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. *Any effort to determine the identity of any reported case is prohibited by this law.* NCHS goes to great lengths to assure that the identity of data subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to

identification, are omitted from the data files. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information. Therefore, users must:

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References

1. McPherson M, Weissman G, Strickland BB, et al. Implementing community-based systems of services for children and youths with special health care needs: How well are we doing? *Pediatrics* 113:1538-44. 2004.
2. Blumberg SJ, Olson L, Frankel M, et al. Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *National Center for Health Statistics. Vital Health Stat* 1(41). 2003.
3. Zell ER, Ezzati-Rice TM, Battaglia MP, Wright RA. National Immunization Survey: The methodology of a vaccination surveillance system. *Public Health Rep* 115:65-77. 2000.
4. Smith PJ, Battaglia MP, Huggins VJ, et al. Overview of the sampling design and statistical methods used in the National Immunization Survey. *Am J Prev Med* 20:S17-24. 2001.

5. National Immunization Survey. Data user's guide and Data documentation, codebook and frequencies [online, by survey year]. Available from: http://www.cdc.gov/nis/data_files.htm.
6. Smith PJ, Hoaglin DC, Battaglia MP, et al. Statistical methodology of the National Immunization Survey, 1994–2002. National Center for Health Statistics. *Vital Health Stat* 2(138). 2005. Available from: http://www.cdc.gov/nchs/data/series/sr_02/sr02_138.pdf. Accessed June 4, 2008.
7. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics* 102:137–40. 1998.
8. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs, Chartbook 2005–2006. Rockville, MD. 2007.
9. Bethell CD, Read D, Stein RE, et al. Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambul Pediatr* 2:38–48. 2002.
10. Newacheck PW, Rising JP, Kim SE. Children at risk for special health care needs. *Pediatrics* 118:334–42. 2006.
11. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians–American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 110:1304–6. 2002.
12. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: Results from the National Survey of Children with Special Health Care Needs. *Pediatrics* 115:1562–8. 2005.
13. Maternal and Child Health Bureau, Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health. MCHB core outcome #6, National Survey of Children with Special Health Care Needs, 2005–2006. 2007. Available from <http://cshcndata.org/Viewdocument.aspx?item=161>. Accessed February 4, 2009.
14. U.S. Office of Special Education Programs (OSEP). Facts from OSEP's National Longitudinal Studies: The self-determination of youth with disabilities. Menlo Park, CA: SRI International. 2005. Available from: www.nlts2.org/fact_sheets/nlts2_fact_sheet_2005_06-2.pdf. Accessed February 4, 2009.
15. Callahan ST, Winitzer RF, Keenan P. Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Curr Opin Pediatr* 13:310–6. 2001.
16. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. *Prog Transplant* 16:291–302. 2006.
17. Reiss J. Promising practices in health care transition. Proceedings of the state of the science conference on building the capacity of service delivery systems for children and youth with disabilities and special health care needs. March 18–19, 2004; Washington, DC. Sponsored by the Consortium for Children and Youth with Disabilities and Special Health Care Needs. 2004.
18. American Academy of Pediatrics, Committee on Children with Disabilities and Committee on Adolescence. Transition of care provided for adolescents with special health care needs. *Pediatrics* 98:1203–6. 1996.
19. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *J Adolesc Health* 14:570–6. 1993.
20. American Academy of Pediatrics, Committee on Adolescence policy statement. Achieving quality health services for adolescents. *Pediatrics* 121:1263–70. 2008.
21. American Association for Public Opinion Research. Standard definitions: Final dispositions of case codes and outcome rates for surveys. 5th edition. Lenexa, KS: AAPOR, 2008.
22. National Center for Health Statistics. National Health Interview Survey (NHIS) [online]. Hyattsville, MD. 2009. Available from: www.cdc.gov/nchs/nhis.htm. Accessed October 28, 2009.
23. U.S. Department of Education, U.S. Office of Special Education Programs. Special Education Elementary Longitudinal Study [online]. Washington, DC. 2007. Available from: <http://www.seels.net/grindex.html>. Accessed October 28, 2009.
24. National Institutes of Health, National Institute of Child Health and Human Development. National Longitudinal Study of Adolescent Health (AddHealth) [online]. Bethesda, MD: Eunice Kennedy Shriver National Institute of Child Health and Human Development with cooperative funding from 17 other federal agencies. 2008. Available from: <http://www.cpc.unc.edu/projects/addhealth>. Accessed October 29, 2009.
25. Maine State Title V CSHCN Program (HRTW Center headquarters). Healthy and Ready to Work National Resource Center [online]. Augusta, ME. Available from: <http://www.hrtw.org>. Accessed October 29, 2009.
26. U.S. Department of Commerce, U.S. Census Bureau. Survey of Income and Program Participation [online]. Washington, DC. 2006. Available from: www.census.gov/sipp. Accessed October 29, 2009.
27. U.S. Department of Education, National Center for Special Education Research. National Longitudinal Transition Study–2 [online]. Washington, DC. Available from: <http://www.nlts2.org>. Accessed October 28, 2009.
28. U.S. Social Security Administration, Office of Program Development and Research. Plan to achieve self-support [online]. Baltimore, MD. 2009. Available from: <http://www.ssa.gov/disabilityresearch/wi/pass.htm>. Accessed October 29, 2009.
29. U.S. Social Security Administration, Office of Policy. National Survey of Supplemental Security Income Children and Families [online]. Baltimore, MD. 2002. Available from: <http://www.ssa.gov/policy/docs/ssb/v66n2/v66n2p7.html>. Accessed October 29, 2009.
30. Cornell University, School of Industrial and Labor Relations, Employment and Disability Institute. Transition Quality Indicators [online]. Ithaca, NY. Available from: <http://www.ilr.cornell.edu/EDI/p-transqual.cfm> and <http://www.transqual.org>. Accessed October 29, 2009.
31. U.S. Department of Labor, Bureau of Labor Statistics. National Longitudinal Survey of Youth [online]. Washington, DC. Available from: <http://www.bls.gov/nls>. Accessed October 29, 2009.

32. The Commonwealth Fund. International Health Policy Survey of Adults With Health Problems [online]. New York, NY. 2002. Available from: <http://www.commonwealthfund.org/Content/Surveys/2002/2002-International-Health-Policy-Survey-of-Adults-with-Health-Problems.aspx>. Accessed October 29, 2009.
33. U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics. National Education Longitudinal Survey [online]. Washington, DC. Available from: <http://nces.ed.gov/surveys/NELS88/>. Accessed October 28, 2009.
34. U.S. Centers for Disease Control and Prevention, National Center for Health Statistics. National Survey of Children's Health [online]. Hyattsville, MD. 2009. Available from: <http://www.cdc.gov/nchs/slait/nsch.htm>. Accessed October 29, 2009.
35. Dillman, DA. Mail and Internet surveys: The tailored design method. New York, NY: John Wiley & Sons, Inc. 2000.
36. U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. Poverty guidelines, research, and measurement [online]. 2009. Washington, DC. Available from: <http://aspe.hhs.gov/POVERTY>. Accessed October 29, 2009.

Appendix I. Summary of Survey Strengths, Limitations, and Appropriate Use

Certain features of the 2007 Survey of Adult Transition and Health (SATH) sample design and data set should be considered prior to analysis. The features discussed below are detailed throughout the report but summarized here for easy reference.

Strengths

- **Largest survey conducted to date with this subgroup.** To our knowledge, this file contains the largest publicly available national sample to study the transition period of children with special health care needs (CSHCN). The topics covered in this survey are relevant to policy and yield a rich source of information on a rare population.
- **Identical variables assessed at 2 points in time, 6 years apart.** Because of the follow-back design feature, longitudinal data are available.
- **Single data file.** The 2001 and 2007 variables are included in a single public-use data file (PUF) for ease of use.
- **Self-reported data from young adults.** In 2001, the survey respondent was the parent or guardian who was most knowledgeable about the health and health care of the sampled CSHCN. In 2007, data were collected directly from the subject of the 2001 interview.
- **Cooperation and refusal rates.** Although this survey has a relatively low response rate—17.5% using standards of the American Association of Public Opinion Research (AAPOR) (21)—this rate is primarily driven by the inability to contact the original respondents in responding households and is not due to a high refusal rate.

Approximately 7,409 (68%) of the original 2001 parent or guardian respondents could not be contacted. When we were able to contact the 2001 respondent and obtained current contact information for the young adult, many eligible subjects chose to participate. Of the young adults we were able to contact, almost all of them cooperated; the AAPOR cooperation rate was just over 98%.

Limitations

- **Sample design.** A total of 10,933 cases eligible for follow-up were identified in the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN). The 2001 survey was a cross-sectional random-digit-dial (RDD) telephone survey, and was not originally designed as a longitudinal survey. Very limited, 6-year-old contact information was available to locate these households in 2007. Telephone numbers sampled in 2001 were dialed first to locate the 2001 original respondent. If this person could be located, current contact information was requested for the eligible SATH young adult so that he or she could be interviewed personally. If the telephone number was not useful, the case was researched using commercial means to try to find the original respondent. Many of these attempts were not fruitful.
- **Interview completion rate.** Completed interviews were obtained from 1,916 young adults, of which 1,865 cases are included in the SATH PUF. The unweighted SATH interview completion rate was 17.5%.

- **Nonresponse bias.** Sampling weights for the 2007 SATH data set were derived from the original 2001 NS-CSHCN sampling weights. SATH weights were then adjusted for nonresponse to the SATH interview with demographic information from the 2001 NS-CSHCN. To date, an extensive analysis of SATH nonresponse bias has not been completed. Young adults from households that did not move from 2001 through 2007 are likely overrepresented in the data set and may differ in important ways from young adults who live in households that moved during that period.

Appropriate Use

Because of the sample design, response rate, and the possibility of nonresponse bias, the SATH sample may be considered as a purposive sample rather than a random sample. Data from a purposive sample should not be used to conclusively test hypotheses. However, these data are worthwhile for:

- Hypothesis generation, or developing ideas to be substantiated in data analyses with other, more robust data sets (e.g., those drawn from random samples).
- Exploratory analysis of relationships between variables, recognizing that results may only be narrowly extrapolated and cannot be generalized to the national population of young adults with special health care needs.

Analysts should include a disclaimer in their work that credits any analyses, interpretations, or conclusions reached to the author(s) (i.e., recipient of the data file) and not to the National Center for Health Statistics, which is responsible only for the initial data.

Appendix II. Locating Protocol for 2001 Respondents and 2007 Eligible Cases

Use of Detailed Locating Protocol

One objective of the 2007 Survey of Adult Transition and Health (SATH) was to evaluate a methodology to locate eligible random-digit-dial (RDD) sample cases based solely on a telephone number in the absence of other information. For the 2007 SATH, case locating began with a residential telephone number that was last dialed 6 or 7 years earlier for the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN). In addition to the elapsed time since the 2001 interview, locating activities were also essential due to the high anticipated mobility of the young target population. SATH locating activities identified cases that qualified for locating; required cross-training for SATH interviewers as locators; generated leads with results of computer database searches; and dialed leads in an attempt to identify the 2001 household and respondent and gain current contact information for the 2007 SATH case. A lead could be any piece of information such as a name, address, or updated telephone number.

Identifying cases subject to targeted locating

The entire SATH sample was dialed initially within the computer-assisted telephone interviewing (CATI) system to determine whether the telephone number was still a working number, and if so, whether it connected to the household that completed the 2001 NS-CSHCN interview. Because respondent name and address information were collected in 2001, there was no advantage to submitting the 2001 telephone numbers to a commercial prescreening process (such as Targus or Marketing System Group's GENESYS) to attempt to match the telephone number to a valid address. If the telephone number connected to the 2001 NS-CSHCN respondent or someone who could provide updated

contact information for the 2001 respondent, the case remained in the CATI system. If the telephone number did not connect to the 2001 respondent or to someone who knew his or her whereabouts, the case was transferred to the CM-Locating system, a proprietary computer software program used to manage information generated during the locating process. These cases were subject to additional locating efforts.

Locating Training

SATH interviewers were cross-trained as locators to maximize efficiency and increase the yield of completed interviews, because they could segue immediately into the consent process and interview if the respondent were located. To gather case-specific information to complete these tasks, a commercial computer database and a proprietary program were used to generate and manage leads. Accurint®, a widely used locate-and-research database tool available to government, law enforcement, and commercial customers, was used by the National Opinion Research Center in this project. Through numerous hands-on activities and exercises, trainees learned methods to pinpoint the intended respondent using these data as well as techniques to perform Internet-based searches if the leads were unproductive. Trainees also learned to use a proprietary software package called CM-Locating to support respondent locating activities by tracking and documenting locating progress. In this system, supervisors and locators entered updated contact information for located cases, tracked leads, and assigned case disposition codes as "final unlocatables." Finally, trainees learned to navigate between CM-Locating and the data collection software (Fusion CATI) in the event they located a respondent who was immediately available to complete the interview.

Before being given access to the CM-Locating system and information returned by Accurint®, SATH staff received explicit guidelines on the use and limitations of locating information for project-authorized use. The guidelines clearly stipulated criteria authorized as search elements (e.g., telephone number and address) and those that were not (e.g., credit history, criminal history, and searches for noneligible SATH individuals). Locators were informed that their efforts were subject to periodic and random reviews to ensure resources were being used responsibly, and that any violations would be subject to immediate action including (but not limited to) termination, legal action, or referral to federal or state regulatory agencies.

Identifying Cases Qualified for Locating

The entire sample was dialed during approximately 2 weeks prior to transfer of any cases to locating to ensure that a sufficient number of dials had been placed to each number. Table I shows seven call outcomes that qualified a case for locating, and the number of cases that qualified under each outcome.

An additional 1,915 cases with two or more noncontact outcomes during CATI dialing were transferred to locating during the final 2 weeks of the field period. These cases were added to the system in an attempt to verify telephone numbers or locate new numbers using information returned from Accurint®. The numbers also continued to be dialed in the CATI system, in case interviewers were able to contact someone and locate the 2001 respondent.

Types of Accurint® Database Searches

Two types of searches were performed in the Accurint® database: an

Table I. Survey call outcomes and number of cases qualified for locating: 2007 SATH

Call outcome	Number of cases qualifying
Business or government line only	300
Disconnected, number changed, or respondent no longer at this number	2,811
Fast busy, fax or modem, or technical problems on two successive attempts.	550
Household did not speak English.	0
Per the respondent if he or she could be located (or the person answering the phone if not), household did not have a child with the given birth date or age range	390
Maximum hang-ups during introduction or refusals ¹	226
Supervisor review or other case review determined that case required locating	100
Total number of cases that qualified for locating.	4,377

¹If a case reached the maximum number of hang-ups during the introduction or the maximum number of refusals, and interviewers had not been able to determine if the telephone number reached the 2001 household, the case was sent to locating to determine whether the Accurint® information noted if that number still belonged to the 2001 respondent. If the telephone number had changed hands since 2001, locators attempted to find a new telephone number for the 2001 respondent. If the telephone number had not changed hands since 2001, the case was finalized as a refusal.

NOTE: SATH is Survey of Adult Transition and Health.

initial “custom batch reverse search” for all cases, followed by a “standard batch search” for only those cases identified as needing additional locating information. The searches differed in the recency and type of information yielded.

Initial custom batch reverse search

SATH presented unique locating challenges because the only piece of information initially available was the 2001 NS-CSHCN, RDD-generated telephone number. The Accurint® database was used for a custom batch reverse search to yield names and addresses of persons ever associated with the sampled telephone numbers. Of the 10,933 cases submitted, reverse search results were produced for 6,123 cases (56%). On average, the custom batch reverse search returned 1.8 leads per case, with a range of 1 to 12 leads per case (defined as any piece of information such as a name, address, or updated telephone number). This file of reverse search results was used to start the Accurint® current or standard batch search for cases identified in CATI that still needed to be located.

Current batch search

Names and addresses obtained from the custom batch reverse search were used to run a standard batch search for only those cases that needed to be located. This search provided current

telephone numbers or address information associated with an individual. Of the 4,377 cases that needed to be located, 1,289 cases (29.4%) received current batch search results. On average, the current batch search returned 2.6 leads for each case, with a range of 1 to 28 leads per case. Results from the current batch search were loaded into the CM-Locating system and assigned to locators. No current information was returned for 1,104 cases (25.2%). For these cases, the names and addresses obtained from the custom reverse batch search were loaded into CM-Locating as a starting point to generate leads via Internet searches. On average, these cases had 1.9 leads per case, with a range of 1 to 8 leads per case. No “ever” or “current” Accurint® information was available for the remaining 1,984 cases (45.3%), which were finalized as “final unlocatable.” Table II illustrates Accurint® return rates by sample type. An overview of case flow through the locating searches and protocol is presented graphically in appendix Figure.

Locating Protocol

Supervisors assigned cases to be located to two-person teams who worked complementary schedules (e.g., different shifts), which allowed locators to work together efficiently to place the requisite number of call attempts to each lead, begin or complete an interview once the respondent was located, or

finalize the case as unlocatable. Although team members worked different shifts, they communicated case details such as stopping points, the value of certain leads, and contact information to each other via case notes.

Locators focused their efforts on cases deemed more attainable. Additional resources were allocated to imperative cases. Many Internet search pages directed locators to the Intelius website (<http://www.intelius.com>), which searches public records and returns locating information for a fee. Locating activities were limited to free Internet searches due to budgetary constraints, and to limit duplicative information since Intelius searches were not likely to return different information than an Accurint® search since both search public records.

Locators dialed through the potential current telephone numbers provided by Accurint® to attempt to reach the 2001 NS-CSHCN respondent. If this resulted in no contact after three dialing attempts completed at three different times (e.g., weekday, weeknight, and weekend), or if all Accurint® leads failed to produce a result, locators performed one Internet search using each name and address provided by Accurint®. This basic Internet search was run at <http://www.theultimates.com>, a website that simultaneously searched six different search engines including <http://www.infospace.com>, <http://www.dogpile.com>, <http://www.whitepages.com>, <http://www.yahoo.com>, <http://www.whowhere.com>, and <http://www.switchboard.com>. If this search produced more than 10 leads or the same results as Accurint®, it was considered “failed.” If it yielded 10 leads or less, the locator dialed through each lead in at least three attempts at different dates and times (e.g., weekday, weeknight, and weekend). If these leads failed for a standard case, the case disposition was finalized.

The same protocol was applied to imperative cases. If all locating steps failed, imperative cases were assigned to one of four advanced locators for additional searches. Advanced locators used <http://www.zabasearch.com>, a

Table II. Accurint® return rates, by sample type: 2007 SATH

Number of cases identified for locating, by type	Standard n = 4,101	Imperative n = 276	Total n = 4,377
Current batch search	29.1% (n = 1,195)	35.1% (n = 94)	29.4% (n = 1,289)
Custom batch reverse search	25.1% (n = 1,029)	27.2% (n = 75)	25.2% (n = 1,104)
No Accurint® data (final unlocatable).	45.8% (n = 1,877)	38.8% (n = 107)	45.3% (n = 1,984)

NOTES: SATH is Survey of Adult Transition and Health. Accurint® return categories are mutually exclusive.

website that browses various public records, and <http://www.superpages.com> for additional advanced white pages searches. This included a search that returned variations on the searched name rather than exact matches, and reverse searches of telephone numbers to obtain the names of persons to whom the numbers are currently listed.

When dialing leads, locators used the following introduction if a person answered the telephone:

“Hello. My name is _____, and I’m calling from the National Opinion Research Center at the University of Chicago. In 2001, we may have conducted a survey with an adult in this household about the health care of a child who was approximately <AGE> years old. The child would now be about <AGE PLUS 6>. If possible, I’d like to speak with that child’s <RELATION> now. Is <he/she> available?”

After this introduction, locators followed a script that guided them through four different scenarios:

- If the 2001 respondent was confirmed and available, the locator immediately attempted to complete the screener with the 2001 respondent to identify the location of the 2007 SATH respondent (or if the 2007 SATH respondent was immediately available, to complete the interview with him or her).
- If the locator confirmed the 2001 or 2007 respondent resided in the household but was currently unavailable, appointments were scheduled to call the respondent.
- If the 2001 respondent did not reside in the household but the person answering the telephone

knew him/her, locators probed to obtain new address and telephone information.

- If the person who answered the telephone refused to provide contact information, the locator left the project’s toll-free number and asked that it be given to the respondent. If the person who answered the telephone did not know the current contact information, the locator finalized the case as unlocatable.

Locating Quality Control

Locating supervisors worked closely with locating teams to monitor progress, offer assistance, and respond to questions or concerns. On a daily basis, supervisors reviewed case notes to offer direction for cases that proved particularly difficult.

Locating source success rates

Locators attempted to find respondents during the final 7 weeks of the 11-week field period. Of the 4,377 cases identified for locating, 1,984 received no Accurint® results and were deemed unlocatable before cases were assigned to locating teams. Locators worked the remaining 2,393 cases for which Accurint® information was available. Relying solely on Accurint® returns and free Internet searches, they located respondents for 208 cases (8.7% of the 2,393 workable cases). [Table III](#) shows success rates by sample type among all cases identified for locating (n = 4,377).

[Table IV](#) shows success rates by sample type when the analysis is limited to cases with information returned from the Accurint® searches (n = 2,393).

[Table V](#) provides the total number of cases located by sample type, and

Table III. Locating and interviewing success rates for all cases, by sample type: 2007 SATH

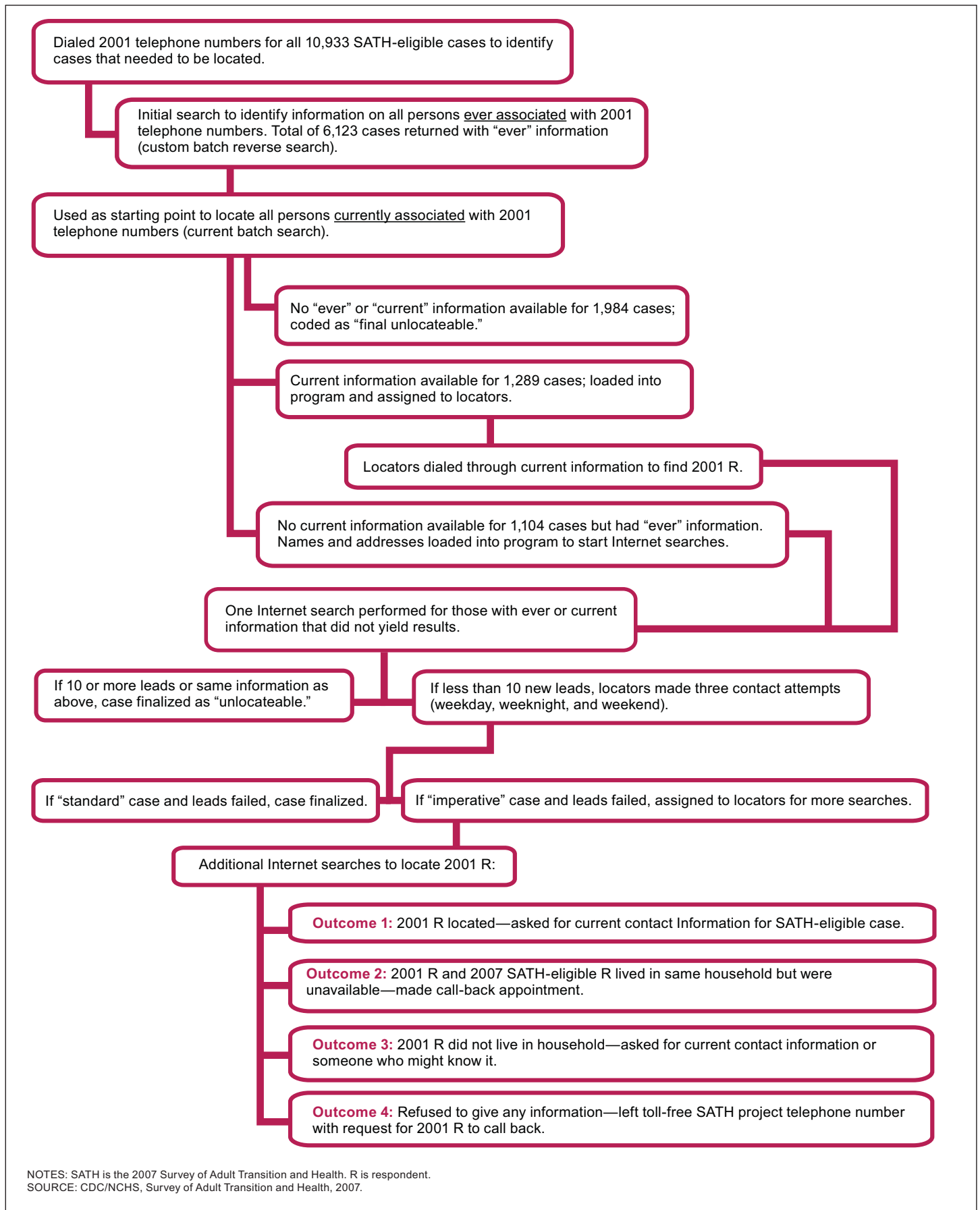
	Standard	Imperative	Total
Number of cases identified for locating	4,101	276	4,377
Number of cases located	179	29	208
Number of cases in which interview was completed	105	12	117
Percentage of cases located	4.4%	10.5%	4.8%
Percentage of located cases in which interview was completed	58.7%	41.4%	56.3%
Percentage of cases identified for locating in which interview was completed	2.6%	4.3%	2.7%

NOTE: SATH is Survey of Adult Transition and Health.

Table IV. Locating and interviewing success rates for cases with Accurint® information, by sample type: 2007 SATH

	Standard	Imperative	Total
Locating cases with Accurint® information	2,224	169	2,393
Number of cases located	179	29	208
Number of cases in which interview was completed	105	12	117
Percentage of cases located.	8.0%	17.2%	8.7%
Percentage of located cases in which interview was completed	58.7%	41.4%	56.3%
Percentage of cases with Accurint® information in which interview was completed	4.7%	7.1%	4.9%

NOTE: SATH is Survey of Adult Transition and Health.



NOTES: SATH is the 2007 Survey of Adult Transition and Health. R is respondent.
 SOURCE: CDC/NCHS, Survey of Adult Transition and Health, 2007.

Figure. Case flow through locating searches and protocol: 2007 SATH

Table V. Source of locating information, by sample type: 2007 SATH

	Standard	Imperative	Total
Total cases located (n)	179 (86.1%)	29 (13.9%)	208 (100%)
From Accurint®	117 (65.4%)	16 (55.5%)	133 (63.9%)
From Internet sources	15 (8.4%)	8 (27.6%)	23 (11.1%)
From other sources ¹	20 (11.2%)	2 (6.9%)	22 (10.6%)
Unable to determine.	27 (15.1%)	3 (10.3%)	30 (14.4%)

¹Includes cases located using unidentified Internet sources as well as information provided by contact persons that led to the respondent.

NOTE: SATH is Survey of Adult Transition and Health.

whether the case was ultimately located based on Accurint® information or Internet searches. In some instances, the ultimate source of locating information could not be determined based on a review of case notes.

Overall Locating Results

The preceding section described locating efforts that occurred within the CM-Locating system but outside of the SATH CATI screener. Although the CATI screener and CM-Locating efforts were managed in separate systems, both techniques supported SATH interview completion.

The final SATH case dispositions in [Appendix VII](#) provide a hierarchical summary of whether interviewers and locators were able to locate the 2001 and 2007 respondents and complete the SATH interview. Overall, interviewers located 3,524 NS-CSHCN respondents from 2001 (or 32.2% of the SATH sample). The vast majority were located with the SATH CATI screener (n = 3,316, or 94% of the located cases—that is, the case never qualified for locating within CM-Locating because the respondent either resided in a household still associated with the 2001 telephone number, or valid contact information was provided to locate the 2001 respondent). Only 208 respondents were found through more extensive efforts that hinged on Accurint® or Internet search information.

Number of Calls Placed to Locate Cases

The CATI system tracked the number of calls placed to locate the 2001 respondent, begin the SATH survey with the 2007 respondent, and

complete the SATH interview. However, these data underreport the actual total number of calls placed, because calls made to locate the respondent with Accurint® or Internet searches are not included.

On average, interviewers placed one less call to locate standard cases (mean = 6.4 calls, median = 4.0 calls, SD = 5.98) than imperative cases (mean = 7.5 calls, median = 5.0 calls, SD = 8.42). When the 2001 respondent was located, both standard and imperative cases required approximately four additional calls to begin the 2007 SATH interview (standard cases: mean = 3.8 calls, median = 2.0 calls, SD = 5.2; imperative cases: mean = 4.1 calls, median = 2.0 calls, SD = 6.1). Once contact was made with the 2007 eligible cases, the vast majority of standard and imperative SATH case respondents completed the interview on the same call (standard cases: mean = 0.1 calls, median = 0.0 calls, SD = 0.7; imperative cases: mean = 0.1 calls, median = 0.0 calls, SD = 0.8).

Appendix III. 2007 SATH Questionnaire

The following public burden estimate statement was available as a CATI screen:

According to the Paperwork Reduction Act (PRA) of 1995, no persons are required to respond to a collection of information unless such collection displays a valid OMB control number. The valid OMB control number for this information collection is 0920–0406. The time required to complete this information collection is estimated to average 15 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have any comments about the accuracy of the time estimate(s) or suggestions for improving this form please write to: CDC Reports Clearance Officer, 1600 Clifton Road, MS-D74, Atlanta, GA 30333; call 404–639–4794; or send an e-mail to omb@cdc.gov.

Data collection conducted under contract to the CDC by the National Opinion Research Center (NORC) at the University of Chicago.

Form approved
OMB No. 0920–0406
Exp. Date 11/30/07

2007 Survey of Adult Transition and Health (SATH) Questionnaire

Screener Part 1: LOCATE AND SCREEN 2001 NS-CSHCN RESPONDENT	26
Screener Part 2: OBTAIN CONSENT FROM 2001 NS-CSHCN R AND DETERMINE PROXY R	32
Screener Part 3: COLLECT YOUTH (2007 R) IDENTIFIERS AND LOCATING INFORMATION	35
Screener Part 4: COLLECT IDENTIFIERS AND LOCATING INFORMATION FOR 2001 OR 2007 R LEADS	39
CATI QUESTIONNAIRE INTRODUCTION	46
WEB QUESTIONNAIRE INTRODUCTION	48
Section 1: HEALTH AND FUNCTIONAL STATUS	49
Subdomain 1. General health status	49
Subdomain 2. Activity limitations—Daily living	50
Subdomain 3. Activity limitations—Work	51
Subdomain 4. Activity limitations—School	53
Subdomain 5. Activity limitations—Taking care of house or family	55
Section 2: MEDICAL HOME	56
Subdomain 1. Usual place for care	56
Subdomain 2. Continuous screening	57
Subdomain 3. Foregone or delayed care	58
Subdomain 4. Care coordination	59
Subdomain 5. Person-centered care	60
Section 3: TRANSITION SERVICES RELATED TO HEALTH	62
Section 4: COMMUNITY-BASED SERVICES	63
Section 5: HEALTH INSURANCE COVERAGE	64
Subdomain 1. Current coverage and past-year coverage	64
Subdomain 2. Adequacy of health insurance	65
Section 6: TRANSITION SERVICES RELATED TO SCHOOL	66
Section 7: SELF-DETERMINATION	67
Section 8: SATISFACTION AND SUPPORT	68
Section 9: DEMOGRAPHICS	69
Subdomain 1. Marital status and living arrangements	69
Subdomain 2. Personal earnings and program participation	70

CATI QUESTIONNAIRE EXIT.....	71
WEB QUESTIONNAIRE EXIT.....	72
CALLBACK SCRIPTS AND ANSWERING MACHINE SCRIPTS.....	73
ANSWERING MACHINE SCRIPTS	77

Screener Part 1: LOCATE AND SCREEN 2001 NS-CSHCN RESPONDENT

INTRO_1 Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. May I please speak to someone who is 18 years of age or older?

(1) YES, I AM ? 18 YO [GO TO INTRO_1A]
(2) THIS IS A BUSINESS [GO TO PH_CONF]
(3) LANGUAGE BARRIER (ANY LANGUAGE OTHER THAN ENGLISH)[GO TO TERM_BRIEF]
(4) NO PERSON AT HOME WHO IS OVER 17 [GO TO S2_B]
(5) ANSWERING MACHINE[GO TO MSG_PENDING SCREENED]
(6) R WILL CALL 800 LINE/VERIFY WEBSITE [GO TO UE-M1_NAME_WEB]
(7) R ASKS FOR LETTER—MAILED [GO TO UE-M1_NAME_WEB]
(8) R ASKS FOR LETTE—E-MAILED [GO TO UE-M1_NAME_WEB]
(9) SUPERVISOR REVIEW[GO TO CALL NOTES BOX]
(RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE)

SALZ_BUS We are interviewing only private residences. Thank you very much.
[TERMINATE INTERVIEW]

S2_B Does anyone live in your household who is over 17 years old?

(1) YES [GO TO [BLANK] SCRIPT SHOWN BELOW]
(2) NO [GO TO PH_CONF]

[BLANK] Thank you, we'll try back another time.

PH_CONF Before I go, I'd like to confirm the telephone number I have dialed. Is this area code [FILL TELEPHONE]?

(1) YES [GO TO PH_TIME]
(2) NO, MISDIAL [GO TO TERM_TY]
(3) NO, NUMBER HAS CHANGED/NUMBER FORWARDED [GO TO NEWTELEPHONE]
(99) REFUSED [GO TO TERM_TY]

NEWTELEPHONE_1 Can you tell me what number I have reached?

Nnn-nnn-nnnn [GO TO PH_TIME]

PH_TIME How many years have you had this telephone number (FILL 1-866-900-9601)?

(1) LESS THAN FOUR YEARS [GO TO SALZ_BUS IF INTRO_APPT01R
OR
INTO_APPT_PNDG_SCRD=2 ELSE GO TO TERM_TY]
(2) MORE THAN FOUR YEARS [GO TO SALZ_BUS IF INTRO_APPT01R
OR
INTO_APPT_PNDG_SCRD=2 ELSE GO TO TERM_TY]

TERM_TY Those are all the questions I have. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions. (If you would like more information about the Survey of Adult Health and Transition, please call the study's toll-free number, 1-866-900-9601.)

INTRO_1A In (INTDATE-YYYY), we conducted a nationwide telephone study on children's health with an adult at this telephone number about a child who was between the ages of 14–18 years of age at the time. This child would now be approximately [FILL AGE] years old. The Centers for Disease Control and Prevention is now interested in speaking to this [FILL AGE]-year-old's [FILL RELATION] again.

Is [he/she] available?

- (1) YES, CURRENTLY SPEAKING WITH HIM/HER [GO TO INTRO_2001R]
- (2) YES, R2001 COMES TO THE TELEPHONE [GO TO INTRO_2001R]
- (3) YES, R2001 IS AVAILABLE BUT NEEDS THE IWER
TO CALL BACK SO R CAN SWITCH TO TTY[GO TO RELAYNOW_ R2001]
- (4) THIS PERSON NEEDS THE INTERVIEWER TO CALL BACK LATER AND
CONDUCT THE INTERVIEW USING TTY [GO TO RELAYCBK_ R2001]
- (5) LANGUAGE BARRIER (ANY LANGUAGE OTHER THAN ENGLISH)[GO TO TERM_BRIEF]
- (6) NO SUCH PERSON AT THIS NUMBER [GO TO TELEPHONE_01 INFO]
- (7) NO, THE PERSON YOU NEED TO SPEAK WITH IS NOT AVAILABLE. [GO TO CB1]
- (8) NO, R2001 HAS MOVED [GO TO R2001_CONT]
- (9) NO, 2001 RESPONDENT IS HOSPITALIZED, INSTITUTIONALIZED OR
INCARCERATED [GO TO TERM_TY]
- (10) NO, 2001 RESPONDENT IS DECEASED [GO TO F1Q]
- (11) NO, 2001 RESPONDENT IS SERVING IN THE MILITARY OR LIVING
OUTSIDE USA[GO TO TERM_TY]
- (12) NO, THE PERSON DOES NOT KNOW HOW TO CONTACT THE R2001 [GO TO REACH_5]
- (13) PERSON WANTS TO VERIFY THE LEGITIMACY OF THE SURVEY OR
NEEDS ADDITIONAL INFORMATION [GO TO M1_NAME_WEB (UE)]
- (14) R KNOWS 2 OR MORE POSSIBLE 2001 RESPONDENTS WHO LIVE OR
USED TO LIVE AT THIS NUMBER [GO TO DOB_PROBE]
- (15) IF VOLUNTEERED: YOUTH IS SERVING IN THE MILITARY OR LIVING
OUTSIDE USA [GO TO WEB_OFFER]
- (16) IF VOLUNTEERED: YOUTH IS HOSPITALIZED, INSTITUTIONALIZED OR
INCARCERATED[GO TO TERM_TY]
- (17) IF VOLUNTEERED: YOUTH DOES NOT HAVE ANY CONTACT INFO
(HOMELESS, ETC.) [GO TO REACH_5]
- (18) IF VOLUNTEERED: YOUTH IS DECEASED [GO TO F1Q_Y_M]
- (77) DON'T KNOW [GO TO REACH_5]

RELAYNOW_R2001

I have to call into the RELAY service to continue this interview. I will call you back in less than 5 minutes at [FILL SAMPLED TELEPHONE 1-866-900-9601]. Please stay by your RELAY machine for the next 5 minutes. Thank you, and good bye.

RELAYCBK_R2001

When would be a good time to call back to reach you using RELAY?

CREATE AN APPOINTMENT

TELEPHONE_01INFO

Do you know the person that had this telephone number in 2001?

- (1) YES [GO TO R2001_CONT]
- (2) NO [GO TO PH_CONF]

REACH_5

Do you know who else I can contact who might know this [FILL AGE_CALC] year-old's / [FILL AGE_CALC] year-old's [RELATION] contact information?

- (1) YES [GO TO LEAD_REACH_01
IF R2001 LEAD; LEAD_REACH_Y IF YOUTH LEAD]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

REACH_CB

When would be a good time to call back to reach (an adult) at this telephone number who would know of anyone who lives or used to live at this telephone number and is currently 19 to 23 years old?

- (1) SET APPOINTMENT [USE APPT ICON]
- (77) DON'T KNOW [CALL NOTES BOX]
- (99) REFUSED [CALL NOTES BOX]

FILL CONTACT NAME AT APPOINTMENT SCREEN IF PROVIDED.

FIQ

I'm sorry to hear that (FILL SEX—HE/SHE) passed away. Please accept my condolences.

- (1) CONTACT SATH R OUTSIDE OF THIS HOUSEHOLD [GO TO YOUTH_CONT]
- (2) SATH R AVAILABLE [GO TO NEW_RESP_SC]

FIQ_Y

I'm sorry to hear that (FILL SEX-HE/SHE) passed away. I was calling about a study we are conducting for the Centers for Disease Control and Prevention but I will not need to continue. When did (FILL SEX-HE/SHE) pass away?

MMDDYYYY

- (77) DON'T KNOW
- (99) REF [GO TO TERM_DTH]

TERM_DTH

Thank you, and please accept my condolences. Goodbye.

DOB_PROBE

The person with whom I would like to speak would be the [FILL RELATION] of a [FILL MALE/FEMALE] child born on [FILL DOB-MMDDYYYYY]. Do you know who this might be?

TRAINING POINT: FAQ ABOUT HOW WE HAVE DOB AND WHY WE NEED TO CONFIRM IT.

- (1) YES [GO TO R2001_CONT]
- (77) DON'T KNOW [GO TO REACH_CB]

PATH TO COLLECT POSSIBLE R2001's CONTACT INFORMATION

R2001_CONT

Could you please tell me the name of this [FILL CURRENT AGE] child's [FILL RELATION]?

IWER INSTRUCTION: IF R NOT COMFORTABLE PROVIDING NAME, ACCEPT INITIALS.

- (1) YES [GO TO R2001_NAME_A]
- (2) NO [GO TO R2001_NAME_D]
- (77) DON'T KNOW [GO TO R2001_NAME_D]
- (99) REFUSED [GO TO R2001_NAME_D]

R2001_NAME_A

What is the [FILL RELATION]'s first name?

FIRST _____

R2001_NAME_B

What is the [FILL RELATION]'s middle name?

MIDDLE _____

R2001_NAME_C

What is the [FILL RELATION]'s last name?

LAST _____

R2001_NAME_D

Does the [FILL RELATION] have a nickname, initials or another name that they may prefer?

- (1) YES [GO TO R2001_NAME_E]
- (2) NO [GO TO R2001_PH_X]
- (77) DON'T KNOW [GO TO R2001_PH_X]
- (99) REFUSED [GO TO R2001_PH_X]

R2001_NAME_E

What is the nickname or initials ?

NICKNAME/OTHER NAME _____

R2001_PH

Could you please tell me (FILL R2001_NAME_A OR FILL R2001_NAME_D if given)'s (FILL BLANK OR second. . .fifth) telephone number?

- (1) YES [RECORD telephone number(s) IN R2001_PH_X]
- (2) NO [GO TO R2001_EM_X]
- (77) DON'T KNOW [GO TO R2001_EM_X]
- (99) REFUSED [GO TO R2001_EM_X]

R2001_PH_X

R2001 TELEPHONE NUMBER COLLECTION SCREEN

nnn-nnn-nnnn [GO TO R2001_PH_CONF]

R2001_PH_CONF_1

Is that a cellular telephone number?

- (1) YES [GO TO R2001_CONFHH]
- (2) NO [GO TO R2001_CONFHH]
- (77) DON'T KNOW [GO TO R2001_CONFHH]
- (99) REFUSED [GO TO R2001_CONFHH]

R2001_CONFHH_1

Is that number a private residence?

- (1) YES [GO TO R2001_PH_LOOP]
- (2) NO [GO TO R2001_PH_LOOP]
- (77) DON'T KNOW [GO TO R2001_PH_LOOP]
- (99) REFUSED [GO TO R2001_PH_LOOP]

R2001_PH_LOOP

Does (FILL R2001_NAME_A OR FILL R2001_NAME_D if given) have another telephone number where (he/she) can be reached?

- (1) YES [GO TO NEXT R2001_PH]
- (2) NO [GO TO R2001_EM_X]
- (77) DON'T KNOW [GO TO R2001_EM_X]
- (99) REFUSED [GO TO R2001_EM_X]

R2001_EM_X

Could you please tell me (FILL R2001_NAME_A OR FILL R2001_NAME_D if given)'s (FILL BLANK OR second. . .fifth) electronic mail or e-mail addresses?

- (1) YES[RECORD E-MAIL ADDRESS ELEMENTS IN R2001_MAIL_1 TO R2001_EMAIL_9]
- (2) NO [GO TO R2001_AD_X]
- (77) DON'T KNOW [GO TO R2001_AD_X]
- (99) REFUSED [GO TO R2001_AD_X]

R2001_EMAIL_X

E-MAIL ADDRESS COLLECTION SCREEN

_____@
 _____, _____

R2001_EM_CONF

Is this e-mail address for personal, business or school use?

- (1) PERSONAL [GO TO R2001_EM_LOOP]
- (2) BUSINESS [GO TO R2001_EM_LOOP]
- (3) SCHOOL USE [GO TO R2001_EM_LOOP]
- (77) DON'T KNOW [GO TO R2001_EM_LOOP]
- (99) REFUSED [GO TO R2001_EM_LOOP]

R2001_EM_LOOP

Does (FILL R2001_NAME_A OR FILL R2001_NAME_D if given) have another e-mail address where (he/she) can be reached?

- (19) YES [GO TO NEXT R2001_EM_X]
- (19) NO [GO TO R2001_AD_X]
- (19) DON'T KNOW [GO TO R2001_AD_X]
- (19) REFUSED [GO TO R2001_AD_X]

R2001_AD_X

Could you please tell (FILL R2001_NAME_A OR FILL R2001_NAME_D if given)'s [FILL BLANK OR second. . .fifth] street address or addresses [IF R2001PH_1 through R2001PH_9 not equal null then FILL in case we cannot reach them by telephone]?

- (1) YES [GO TO R2001_AD_ST_X]
- (2) NO [GO TO CONF_INTRO_01R]
- (77) DON'T KNOW [GO TO CONF_INTRO_01R]
- (99) REFUSED [GO TO CONF_INTRO_01R]

R2001_AD_ST_X

What is the street address?

R2001_AD_APT_X

What is the apartment number?
 APT # _____

R2001_AD_CITY_X

What is the city and state?
 CITY _____

R2001_AD_STATE_X

State Dropdown Menu

R2001_AD_ZIP_X

What is the zip code?

ZIP _____ [GO TO R2001CONYHH]

R2001CONYHH_X

Is that address a private residence?

- (1) YES [GO TO R2001_AD_LOOP]
- (2) NO [GO TO R2001_INST]
- (77) DON'T KNOW [GO TO CONF_INTRO_01R]
- (99) REFUSED [GO TO CONF_INTRO_01R]

R2001_INST_X

Can you describe the type of residence?

- (1) UNIVERSITY/COLLEGE HOUSING (DORM) [GO TO R2001_AD_LOOP]
- (2) MILITARY BASE [GO TO R2001_AD_LOOP]
- (3) PRISON [GO TO R2001_AD_LOOP]
- (4) OTHER INSTITUTION [GO TO R2001_AD_LOOP]
- (77) DON'T KNOW [GO TO R2001_AD_LOOP]
- (99) REFUSED [GO TO R2001_AD_LOOP]

R2001_AD_LOOP

Does (FILL R2001_NAME_A OR FILL R2001_NAME_D if given) have another address where (he/she) can receive mail?

- (1) YES [GO TO NEXT R2001_AD_X]
- (2) NO [GO TO CONF_INTRO_01R]
- (77) DON'T KNOW [GO TO CONF_INTRO_01R]
- (99) REFUSED [GO TO CONF_INTRO_01R]

CONF_INTRO_01R

I would like to confirm that I have the correct information for the person that we'll be contacting.

CONF_NAME_01R

The name I have for this person is [FILL NAME OF FROM R2001NAME_A- R2001_NAME_D].

Is this correct?

- (1) YES [GO TO R2001_FUTCONT]
- (2) NO [GO TO R2001_CONT AND EDIT]

R2001_FUTCONT

May we contact you again if we have problems contacting this person who may have completed the 2001 interview?

- (1) YES [GO TO FUTCONT_NAME]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

FUTCONT_NAME

What is your name?

NAME _____

FUTCONT_PHCONF

TELEPHONE NUMBER COLLECTION SCREEN

nnn-nnn-nnnn [GO TO PH_CONF]

Screener Part 2: OBTAIN CONSENT FROM 2001 NS-CSHCN R AND DETERMINE PROXY R

INTRO_2001R

(NOTE: Text in parentheses will appear if speaking with R2001. If R2001 is deceased, text in parentheses will be omitted.)

In [INTDATE-YYYY] we conducted a nationwide children’s health care telephone study with (you) about a [FILL AGE] ____ ____ year-old child in your household. (Thank you for participating in the 2001 interview.) The Centers for Disease Control and Prevention would like to enhance the information (you) provided in 2001 by speaking to (this/your) child about his or her current health care. This child would now be [FILL AGE_CALC= 'INTDATE MINUS DOB' PLUS 'CURRENTINTDATE-INTDATE' = 'CURRENT AGE IN 2007']. In appreciation, we’d like to offer [FILL SEX—him/her] \$20. [FILL SEX—He/She] can be interviewed by telephone, or complete the survey on the Internet. (I’d like to continue unless you have any questions.)

IWER INSTRUCTION: IF NO QUESTIONS, ASK THE FOLLOWING:

Can you tell me how to find this [FILL AGE_CALC]-year-old?

- (1) YES, YOUTH COMES TO TELEPHONE [GO TO NEW_RESP_SC]
- (2) YES, OUTSIDE OF HH/MOVED [GO TO YOUTH_CONT]
- (3) YES, TWO OR MORE PEOPLE THAT AGE LIVE OR USED TO LIVE AT THIS NUMBER [GO TO DOB_PROBE_Y]
- (4) YES, YOUTH AVAILABLE-CALL BACK NEEDED FOR RELAY SWITCH [GO TO RELAY]
- (5) YES, YOUTH IS AVAILABLE BUT NEEDS CURRENT RESPONDENT TO INTERPRET [GO TO NEW_RESP_SC]
- (6) NO SUCH PERSON AT THIS NUMBER [GO TO REACH_5]
- (7) NO, THE PERSON YOU NEED TO SPEAK WITH IS NOT AVAILABLE. [GO TO YOUTH_CONT]
- (8) NO, THE PERSON DOES NOT KNOW HOW TO CONTACT THE YOUTH [GO TO REACH_5]
- (9) NO, YOUTH IS HOSPITALIZED, INSTITUTIONALIZED OR INCARCERATED [GO TO TERM_TY]
- (10) NO, YOUTH IS INCAPABLE [GO TO DIFF_Q]
- (11) NO, YOUTH IS SERVING IN THE MILITARY OR LIVING OUTSIDE USA [GO TO WEB_OFFER]
- (12) NO, YOUTH IS DECEASED [GO TO F1Q_Y_M]
- (13) PERSON NEEDS ADDITIONAL INFORMATION [GO TO-M1_NAME_WEB (UE)]
- (77) DON’T KNOW [GO TO REACH_5]

DOB_PROBE_Y

The person I would like to speak with was born on [FILL DOB-MMDDYYYY]. Do you know who this might be?

TRAINING POINT: FAQ ABOUT HOW WE HAVE DOB AND WHY WE NEED TO CONFIRM IT

- (1) YES [GO TO INTRO_R2001 at “Can you tell me how to find...?”]
- (77) DON’T KNOW [GO TO REACH_5]

DIFF_Q

What difficulty does [FILL HE/SHE] have that prevents [FILL him/her] from participating?

- (1) Hearing difficulty [IF WEB_OFFER=2, GO TO RELAY THEN IF RELAY=3 GO TO PROXY]
- (2) Speech difficulty [GO TO WEB_OFFER]
- (3) Cognitive barrier [GO TO PROXY_SCR]
- (4) Physical barrier [GO TO WEB_OFFER]
- (77) DON’T KNOW [GO TO WEB_OFFER]
- (99) REFUSED [GO TO PROXY_SCR]

WEB_OFFER

We have a Web-based survey available. [FILL: Would you like to /Can they] complete the survey using the Web?

[If entry from PDIFF, then fill with “Would you like to ...” If entry from DIFF_Q, then fill with “Can they ...”]

- (1) YES [GO TO WEB LETTER]
- (2) NO [GO TO PROXY_SCR]

WEB_LETTER

We can e-mail or mail a letter to you with directions on completing the survey via the Web. Which would you prefer?

- (1) E-MAIL WEB LETTER [GO TO WEB_LETTER_EMAIL]
- (2) MAIL WEB LETTER [GO TO WEB_LETTER_MAIL]

WEB_LETTER_EMAIL

What is your e-mail address? _____ @ _____ , _____

- (1) Continue [GO TO WEB_LETTER_EXIT]
- (99) Refused to give information [GO TO TERM_TY]

WEB_LETTER_MAIL

What is your mailing address?

ADDRESS COLLECTION GRID

WEB_LETTER_EXIT

You will be receiving the letter in the next week or two. It will contain information about our Web survey. It also contains a toll-free number that you may call at any time with any questions you may have. When you call, please refer to the identification number printed on your letter.

[GO TO TERMINATE]

PROXY_SCR Is the person who makes the majority of the decisions about the [FILL AGE]-year-old's health care available?

- (1) YES, CURRENTLY ON TELEPHONE [START PROXY_INT]
- (2) YES, YOUTH MAKES OWN DECISOIONS [GO TO WEB_OFFER]
- (3) NO, NOT AVAILABLE [GO TO REACH_PROX]

REACH_PROX

Can you tell me how I could contact the person who makes the majority of the decisions about the [FILL AGE]-year-old's health care?

- (1) YES [GO TO PROX_NAME_A]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

PROX_NAME_A

What is first name of this person who makes these decisions?

FIRST _____

PROX_NAME_B

What is their middle name?

MIDDLE _____

PROX_NAME_C

What is their last name?

LAST _____

PROX_NAME_D

Does this person have a nickname, initials or another name that they may prefer?

- (1) YES [GO TO PROX_NAME_E]
- (2) NO [GO TO PROX_PH_X1]
- (77) DON'T KNOW [GO TO PROX_PH_X1]
- (99) REFUSED [GO TO PROX_PH_X1]

PROX_NAME_E

What is the name or initials?

NICKNAME/OTHER NAME _____

PROX_NUM1 Could you please tell me this person's telephone number?

- (1) YES[GO TO PROX_PH_1X]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

PROX_PH_1X PROXY TELEPHONE NUMBER COLLECTION SCREEN

NNN-NNN-NNNN[GO TO PROX_PH_CONF_X; GO TO PH_CONF WHEN LAST # ENTERED]

PROX_PH_CONF_X

Is that a cellular telephone?

- (1) YES [GO TO PROX_CONFHH]
- (2) NO [GO TO PROX_CONFHH]
- (77) DON'T KNOW [GO TO PROX_CONFHH]
- (99) REFUSED [GO TO PROX_CONFHH]

PROX_CONFHH_X

Is that number a private residence?

- (1) YES [GO TO PROX_PH_LOOP]
- (2) NO [GO TO PROX_PH_LOOP]
- (77) DON'T KNOW [GO TO PROX_PH_LOOP]
- (99) REFUSED [GO TO PROX_PH_LOOP]

PROX_PH_LOOP

Does (FILL PROX_NAME_A OR FILL PROX_NAME_D if given) have another telephone number where (he/she) can be reached?

- (1) YES[GO TO NEXT PROX_PH_X]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

Screener Part 3: COLLECT YOUTH (2007 R) IDENTIFIERS AND LOCATING INFORMATION

YOUTH_CONT

I'd like to collect a few pieces of information in order to contact this [FILL AGE]- year-old. Could you please tell me the name of the youth?

IWER INSTRUCTION: IF R NOT COMFORTABLE PROVIDING NAME, ACCEPT INITIALS.

- (1) YES[GO TO YOUTH_NAME_A]
- (2) NO[GO TO YOUTH_NAME_D]
- (77) DON'T KNOW[GO TO YOUTH_NAME_D]
- (99) REFUSED[GO TO YOUTH_NAME_D]

YOUTH_NAME_A

What is the youth's first name?

FIRST _____

YOUTH_NAME_B

What is the youth's middle name?

MIDDLE _____

YOUTH_NAME_C

What is the youth's last name?

LAST _____

YOUTH_NAME_D

Does the youth have a nickname, initials or another name that they may prefer?

- (1) YES[GO TO YOUTH_NAME_E]
- (2) NO [GO TO YOUTH_PH1]
- (77) DON'T KNOW[GO TO YOUTH_ PH1]
- (99) REFUSED[GO TO YOUTH_ PH1]

YOUTH_NAME_E

What is the name or initial?

NICKNAME/OTHER NAME[GO TO YOUTH_ PH1]

YOUTH_PH

Could you please tell me (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given)'s (FILL BLANK or second. . .fifth) telephone number?

- (1) YES [RECORD telephone number(s) IN YPH_X]
- (2) NO [GO TO YOUTH_EM_X]
- (77) DON'T KNOW [GO TO YOUTH_EM_X]
- (99) REFUSED [GO TO YOUTH_EM_X]

YPH_X

YOUTH TELEPHONE NUMBER COLLECTION SCREEN

nnn-nnn-nnnn [GO TO YOUTH_PH_CONF]

IWER INSTRUCTION:

WHEN IS THE BEST TIME TO CALL [FILL YOUTH_NAME_A]?

IF YES, SELECT APPOINTMENT SCREEN

YOUTH_PH_CONF

Is the telephone number that you've just given me a cellular telephone?

- (1) YES [GO TO YCONFHH]
- (2) NO [GO TO YCONFHH]

- (77) DON'T KNOW [GO TO YCONFHH]
- (99) REFUSED [GO TO YCONFHH]

YCONFHH Is that number a private residence?

- (1) YES [GO TO YOUTH_PH_LOOP]
- (2) NO [GO TO YOUTH_PH_LOOP]
- (77) DON'T KNOW [GO TO YOUTH_PH_LOOP]
- (99) REFUSED [GO TO YOUTH_PH_LOOP]

YOUTH_PH_LOOP

Does (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given) have another telephone number where (he/she) can be reached?

- (1) YES [GO TO NEXT YOUTH_PH]
- (2) NO [GO TO YOUTH_EM_X]
- (77) DON'T KNOW [GO TO YOUTH_EM_X]
- (99) REFUSED [GO TO YOUTH_EM_X]

YOUTH_EM_X

Could you please tell me (FILL SEX→HIS/HER) (FILL BLANK OR second. .fifth) electronic mail or e-mail addresses?

- (1) YES [RECORD E-MAIL ADDRESS ELEMENTS IN YEMAIL_X]
- (2) NO [GO TO YOUTH_AD_X]
- (77) DON'T KNOW [GO TO YOUTH_AD_X]
- (99) REFUSED [GO TO YOUTH_AD_X]

YEMAIL_X E-MAIL ADDRESS COLLECTION SCREEN

_____ @ _____, _____

YOUTH_EM_CONF_X

Is this an e-mail address for personal, business or school use?

- (1) PERSONAL [GO TO YOUTH_EM_LOOP]
- (2) BUSINESS [GO TO YOUTH_EM_LOOP]
- (3) SCHOOL USE [GO TO YOUTH_EM_LOOP]
- (77) DON'T KNOW [GO TO YOUTH_EM_LOOP]
- (99) REFUSED [GO TO YOUTH_EM_LOOP]

YOUTH_EM_LOOP

Does (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given) have another e-mail address where (he/she) can be reached?

- (1) YES [GO TO NEXT YOUTH_EM_X]
- (2) NO [GO TO YOUTH_AD_X]
- (77) DON'T KNOW [GO TO YOUTH_AD_X]
- (99) REFUSED [GO TO YOUTH_AD_X]

YOUTH_AD_X

Could you please tell me (HIS/HER) street address or mailing address [IF YPH_X not equal null then FILL "in case we cannot reach them by telephone"]?

- (1) YES [GO TO YOUTH_AD_ST_X]
- (2) NO [GO TO CONF_INTRO]
- (77) DON'T KNOW [GO TO CONF_INTRO]
- (99) REFUSED [GO TO CONF_INTRO]

YOUTH_AD_ST_X

What is the youth's street address or mailing address?

YOUTH_ADAPT_X

What is the youth's apartment number?

APT # _____

YOUTH_AD_CITY_X

What is the youth's city and state?

CITY _____

YOUTH_AD_STATE_X

State Dropdown Menu

YOUTH_AD_ZIP_X

What is the youth's zip code?

ZIP _____ [GO TO YCONYHH]

YCONYHH_X

Is the youth's address you just gave me a private residence?

- (1) YES[GO TO YOUTH_AD_LOOP]
- (2) NO [GO TO YOUTH_INST]
- (77) DON'T KNOW[GO TO YOUTH_AD_LOOP]
- (99) REFUSED[GO TO YOUTH_AD_LOOP]

YOUTH_INST_X

Can you describe the type of residence?

- (1) UNIVERSITY/COLLEGE HOUSING (DORM)[GO TO YOUTH_AD_LOOP]
- (2) MILITARY BASE[GO TO YOUTH_AD_LOOP]
- (3) PRISON[GO TO YOUTH_AD_LOOP]
- (4) OTHER INSTITUTION[GO TO YOUTH_AD_LOOP]
- (77) DON'T KNOW[GO TO YOUTH_AD_LOOP]
- (99) REFUSED[GO TO YOUTH_AD_LOOP]

YOUTH_AD_LOOP

Does (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given) have another street or mailing address where (he/she) can be reached?

- (1) YES[GO TO NEXT YOUTH_AD_X]
- (2) NO [GO TO CONF_INTRO]
- (77) DON'T KNOW [GO TO CONF_INTRO]
- (99) REFUSED [GO TO CONF_INTRO]

CONF_INTRO I would like to confirm that I have the correct information for the youth that we'll be contacting.

[IWER INSTRUCTION: CONFIRM ALL NAMES AND SPELLINGS WITH THE RESPONDENT.]

CONF_NAME The name I have for the youth is [FILL YOUTH_NAME_A- YOUTH_NAME_D].

Is this correct?

- (1) YES[GO TO CONFDOB_X]
- (2) NO[GO TO YOUTH_NAME_A- YOUTH_NAME_D TO EDIT]

CONFDOB The [FILL birth date/age] I have for [FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given] is [FILL: BIRTH DATE FROM DOB/ AGE].

(If DOB is not available, confirm age)

Is this correct?

- (1) YES [GO TO Y_FUTCONT]
- (2) NO [GO TO SCR_DOB]

SCR_DOB What is the correct month, day and year of birth of [FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given]?

_____ / _____ / _____ (mm/dd/yyyy)

Y_FUTCONT May we contact you again if we have problems contacting [FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given]?

- (1) YES [GO TO R2001_NAMECONF_A]
- (2) NO [GO TO TERMINATE]
- (77) DON'T KNOW [GO TO TERMINATE]
- (99) REFUSED [GO TO TERMINATE]

R2001_ NAMECONF_A

What is your name?

NAME _____

R2001_ TELEPHONECONF_A

And what is the best telephone number to reach you?

TELEPHONE NUMBER COLLECTION SCREEN

- (1) Nnn-nnn-nnnn [GO TO PH_CONF]
- (2) Another Telephone Number
[R2001_TELEPHONECONF_XX]

IWER INSTRUCTION:

WHEN IS THE BEST TIME TO CALL [FILL YOUTH_NAME_A]?

IF YES, SELECT APPOINTMENT ICON.

Screener Part 4: COLLECT IDENTIFIERS AND LOCATING INFORMATION FOR 2001 OR 2007 R LEADS

PATH TO COLLECT INFORMATION FOR LEAD THAT KNOWS HOW TO CONTACT 2007 RESPONDENT (I.E., YOUTH)

LEAD_REACH_Y

Could you please tell me the name of the person that may know how to contact the [FILL AGE]-year-old?

IWER INSTRUCTION: IF R NOT COMFORTABLE PROVIDING NAME, ACCEPT INITIALS.

- (1) YES [GO TO LEAD_NAME_A]
- (2) NO [GO TO LEAD_NAME_D]
- (77) DON'T KNOW [GO TO LEAD_NAME_D]
- (99) REFUSED [GO TO LEAD_NAME_D]

LEAD_NAME_A

What is the first name?

FIRST _____

LEAD_NAME_B

What is the middle name?

MIDDLE _____

LEAD_NAME_C

What is the last name?

LAST _____

LEAD_NAME_D

Does the [FILL RELATION] have a nickname, initials or another name that they may prefer?

- (1) YES [GO TO LEAD_NAME_E]
- (2) NO [GO TO LEAD_PH_X]
- (77) DON'T KNOW [GO TO LEAD_PH_X]
- (99) REFUSED [GO TO LEAD_PH_X]

LEAD_NAME_E

What is the name or initials?

NICKNAME/OTHER NAME _____

LEAD_PH_X

Could you please tell me (FILL LEAD_NAME_A OR FILL LEAD_NAME_D if given/else "this person")'s (FILL BLANK OR second. . .fifth) telephone number?

- (1) YES [RECORD telephone number(s) IN LEAD_PH_X]
- (2) NO [GO TO LEAD_EM_X]
- (77) DON'T KNOW [GO TO LEAD_EM_X]
- (99) REFUSED [GO TO LEAD_EM_X]

LEAD_PH_11_X

LEAD R TELEPHONE NUMBER COLLECTION SCREEN

nnn-nnn-nnnn [GO TO LEAD_PH_CONF]

IWER INSTRUCTION: WHEN IS THE BEST TIME TO CALL?

IF YES, SELECT APPOINTMENT SCREEN

LEAD_PH_CONF_X

Is that a cellular telephone number?

- (1) YES[GO TO LEAD _CONFHH]
- (2) NO[GO TO LEAD _CONFHH]
- (77) DON'T KNOW[GO TO LEAD _CONFHH]
- (99) REFUSED[GO TO LEAD _CONFHH]

LEAD_CONFHH_X

Is that number a private residence?

- (1) YES [GO TO LEAD _PH_LOOP]
- (2) NO [GO TO LEAD _PH_LOOP]
- (77) DON'T KNOW [GO TO LEAD _PH_LOOP]
- (99) REFUSED [GO TO LEAD _PH_LOOP]

LEAD_PH_LOOP_X

Does (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given) have another telephone number where (he/she) can be reached?

- (1) YES [GO TO NEXT LEAD _PH]
- (2) NO [GO TO LEAD _EM_X]
- (77) DON'T KNOW [GO TO LEAD _EM_X]
- (99) REFUSED [GO TO LEAD _EM_X]

LEAD_EM_X Could you please tell me (FILL LEAD R_NAME_A OR FILL LEAD R_NAME_D if given)'s (FILL BLANK OR second. . .fifth) electronic mail or e-mail addresses?

- (1) YES [RECORD E-MAIL ADDRESS ELEMENTS IN LEAD_MAIL_X]
- (2) NO [GO TO LEAD_AD_X]
- (77) DON'T KNOW [GO TO LEAD_AD_X]
- (99) REFUSED [GO TO LEAD_AD_X]

LEAD_EMAIL_X

E-MAIL ADDRESS COLLECTION SCREEN

_____ @ _____, _____

LEAD_EM_CONF_X

Is this e-mail address for personal, business or school use?

- (1) PERSONAL [GO TO LEAD_EM_LOOP]
- (2) BUSINESS [GO TO LEAD_EM_LOOP]
- (3) SCHOOL USE [GO TO LEAD_EM_LOOP]
- (77) DON'T KNOW [GO TO LEAD_EM_LOOP]
- (99) REFUSED [GO TO LEAD_EM_LOOP]

LEAD_EM_LOOP_X

Does (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given) have another e-mail address where (he/she) can be reached?

- (1) YES [GO TO NEXT LEAD_EM_X]
- (2) NO [GO TO LEAD_AD_X]
- (77) DON'T KNOW [GO TO LEAD_AD_X]
- (99) REFUSED [GO TO LEAD_AD_X]

LEAD_AD_X Could you please tell (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given)'s [FILL BLANK OR second. . .fifth] street address or addresses [IF LEADPH_1 through LEADRPH_9 not equal null then FILL] in case we cannot reach them by telephone?

- (1) YES [GO TO LEAD_AD_ST_X]
- (2) NO [CONF_INTRO_LEAD]
- (77) DON'T KNOW [CONF_INTRO_LEAD]
- (99) REFUSED [CONF_INTRO_LEAD]

LEAD_AD_ST_X

What is the street address?

LEAD_AD_APT_X

What is the apartment number?

APT # _____

LEAD_AD_CITY_X

What is the city and state?

CITY _____

LEAD_AD_STATE_X

State Dropdown Menu

LEAD_AD_ZIP_X

What is the zip code?

ZIP _____ [GO TO LEADCONYHH_X]

LEAD_CONYHH_X

Is that address a private residence?

- (1) YES [GO TO LEAD_AD_LOOP]
- (2) NO [GO TO LEAD_INST]
- (77) DON'T KNOW [GO TO CONF_INTRO_LEAD]
- (99) REFUSED [GO TO CONF_INTRO_LEAD]

LEAD_INST_X

Can you describe the type of residence?

- (1) UNIVERSITY/COLLEGE HOUSING (DORM) [GO TO LEAD_AD_LOOP]
- (2) MILITARY BASE [GO TO LEAD_AD_LOOP]
- (3) PRISON [GO TO LEAD_AD_LOOP]
- (4) OTHER INSTITUTION [GO TO LEAD_AD_LOOP]
- (77) DON'T KNOW [GO TO LEAD_AD_LOOP]
- (99) REFUSED [GO TO LEAD_AD_LOOP]

LEAD_AD_LOOP

Does (FILL LEAD R_NAME_A OR FILL LEAD R_NAME_D if given) have another address where (he/she) can receive mail?

- (1) YES [GO TO NEXT LEAD_AD_X]
- (2) NO [GO TO CONF_INTRO_LEAD]
- (77) DON'T KNOW [GO TO CONF_INTRO_LEAD]
- (99) REFUSED [GO TO CONF_INTRO_LEAD]

CONF_INTRO_LEAD

I would like to confirm that I have the correct information for the person that we'll be contacting.

[INTERVIEWER: CONFIRM ALL NAMES AND SPELLINGS WITH THE RESPONDENT.]

CONF_NAME_LEAD

The name I have for this person is [FILL NAME OF FROM LEADNAME_A- LEAD_NAME_D].

Is this correct?

- (1) YES [GO TO LEAD_FUTCONT]
- (2) NO [GO TO LEAD_CONT AND EDIT]

LEAD_FUTCONT

May we contact you again if we have problems contacting this person who may have completed the interview?

- (1) YES [GO TO FUTCONT_LEAD_NAME]
- (2) NO [GO TO PH_CONF]
- (77) DON'T KNOW [GO TO PH_CONF]
- (99) REFUSED [GO TO PH_CONF]

FUTCONT_LEAD_NAME

What is your name?

NAME _____
[GO TO PH_CONF]

PATH TO COLLECT INFORMATION FOR LEAD THAT KNOWS HOW TO CONTACT 2001 RESPONDENT

LEAD_REACH_01

Could you please tell me the name of the person that may know how to contact the [FILL AGE]-year-old's [FILL RELATION]?

IWER INSTRUCTION: IF R NOT COMFORTABLE PROVIDING NAME, ACCEPT INITIALS.

- (1) YES [GO TO LEAD_NAME_A_01]
- (2) NO [GO TO LEAD_NAME_D_01]
- (77) DON'T KNOW [GO TO LEAD_NAME_D_01]
- (99) REFUSED [GO TO LEAD_NAME_D_01]

LEAD_NAME_A_01

What is the first name?

FIRST _____

LEAD_NAME_B_01

What is the middle name?

MIDDLE _____

LEAD_NAME_C_01

What is the last name?

LAST _____

LEAD_NAME_D_01

Is there a nickname, initials or another name that they may prefer?

NICKNAME/OTHER NAME _____

LEAD_PH_01

Could you please tell me (FILL LEAD _NAME_A_01 OR FILL LEAD _NAME_D_01 if given)'s (FILL BLANK OR second. . .fifth) telephone number?

- (1) YES [RECORD telephone number(s) IN LEAD_PH_X_01]
- (2) NO [GO TO LEAD _EM_X_01]
- (77) DON'T KNOW [GO TO LEAD _EM_X_01]
- (99) REFUSED [GO TO LEAD _EM_X_01]

LEAD_PH_X_01

LEAD R TELEPHONE NUMBER COLLECTION SCREEN

nnn-nnn-nnnn [GO TO LEAD _PH_CONF_01]

IWER INSTRUCTION: WHEN IS THE BEST TIME TO CALL [FILL YOUTH_NAME_A_01]?

IF YES, CREATE AN APPOINTMENT.

LEADR_PH_CONF_01_X

Is that a cellular telephone number?

- (1) YES[GO TO LEAD _CONFHH_01]
- (2) NO[GO TO LEAD _CONFHH_01]
- (77) DON'T KNOW[GO TO LEAD _CONFHH_01]
- (99) REFUSED[GO TO LEAD _CONFHH_01]

LEADCONFHH_01_X

Is that number a private residence?

- (1) YES [GO TO LEAD _PH_LOOP_01]
- (2) NO [GO TO LEAD _PH_LOOP_01]
- (77) DON'T KNOW [GO TO LEAD _PH_LOOP_01]
- (99) REFUSED [GO TO LEAD _PH_LOOP_01]

LEAD_PH_LOOP_01_X

Does (FILL LEAD R_NAME_A_01 OR FILL LEAD R_NAME_D_01 if given) have another telephone number where (he/she) can be reached?

- (1) YES[GO TO NEXT LEAD R_PH_01_X]
- (2) NO [GO TO LEAD _EM_X_01]
- (77) DON'T KNOW [GO TO LEAD _EM_X_01]
- (99) REFUSED [GO TO LEAD _EM_X_01]

LEAD_EM_01_X

Could you please tell (FILL LEAD_NAME_A_01 OR FILL LEAD_NAME_D_01 if given)'s (FILL BLANK OR second. . .fifth) electronic mail or e-mail addresses?

- (1) YES [RECORD E-MAIL ADDRESS ELEMENTS IN LEAD_MAIL_01_X_01]
- (2) NO [GO TO LEAD_AD_X_01]
- (77) DON'T KNOW [GO TO LEAD_AD_X_01]
- (99) REFUSED [GO TO LEAD_AD_X_01]

LEAD_EMAIL_01_X

E-MAIL ADDRESS COLLECTION SCREEN

_____ @ _____, _____

LEAD_EM_CONF_X

Is this e-mail address for personal, business or school use?

- (1) PERSONAL [GO TO LEAD_EM_LOOP_01]
- (2) BUSINESS [GO TO LEAD_EM_LOOP_01]
- (3) SCHOOL USE [GO TO LEAD_EM_LOOP_01]
- (77) DON'T KNOW [GO TO LEAD_EM_LOOP_01]
- (99) REFUSED [GO TO LEAD_EM_LOOP_01]

LEAD_EM_LOOP_01

Does (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given) have another e-mail address where (he/she) can be reached?

- (1) YES [GO TO NEXT LEAD_EM_X_01]
- (2) NO [GO TO LEAD_AD_X_01]
- (77) DON'T KNOW [GO TO LEAD_AD_X_01]
- (99) REFUSED [GO TO LEAD_AD_X_01]

LEAD_AD_X_01

Could you please tell (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given)'s [FILL BLANK OR second. . .fifth] street address or addresses [IF LEAD PH_X entered then FILL "in case we cannot reach them by telephone"]?

- (1) YES [GO TO EAD_AD_ST_X_01]
- (2) NO [CONF_INTRO_LEAD_01]

- (77) DON'T KNOW [CONF_INTRO_LEAD_01]
- (99) REFUSED [CONF_INTRO_LEAD_01]

LEAD_AD_ST_01_X

What is the street address?

LEAD_AD_APT_01_X

What is the apartment number?

APT # _____

LEAD_AD_CITY_01_X

What is the city and state?

CITY _____

LEAD_AD_STATE_01_X

State Dropdown Menu

LEAD_AD_ZIP_01_X

What is the zip code?

ZIP _____ [GO TO LEADCONYHH_01_X]

LEAD_CONYHH_01_X

Is that address a private residence?

- (1) YES [GO TO LEAD_AD_LOOP_01]
- (2) NO [GO TO LEAD_INST_01]
- (77) DON'T KNOW [GO TO [CONF_INTRO_LEAD_01]
- (99) REFUSED [GO TO CONF_INTRO_LEAD_01]

LEAD_INST_01_X

Can you describe the type of residence?

- (1) UNIVERSITY/COLLEGE HOUSING (DORM) [GO TO LEAD_AD_LOOP_01]
- (2) MILITARY BASE [GO TO LEAD_AD_LOOP_01]
- (3) PRISON [GO TO LEAD_AD_LOOP_01]
- (4) OTHER INSTITUTION [GO TO LEAD_AD_LOOP_01]
- (77) DON'T KNOW [GO TO LEAD_AD_LOOP_01]
- (99) REFUSED [GO TO LEAD_AD_LOOP_01]

LEAD_AD_LOOP_01_X

Does (FILL LEAD R_NAME_A OR FILL LEAD R_NAME_D if given) have another address where (he/she) can receive mail?

- (1) YES [GO TO NEXT LEAD_AD_X_01]
- (2) NO [GO TO CONF_INTRO_LEAD_01]
- (77) DON'T KNOW [GO TO CONF_INTRO_LEAD_01]
- (99) REFUSED [GO TO CONF_INTRO_LEAD_01]

CONF_INTRO_LEAD_01

I would like to confirm that I have the correct information for the person that we'll be contacting.

[INTERVIEWER: CONFIRM ALL NAMES AND SPELLINGS WITH THE RESPONDENT.]

CONF_NAME_LEAD_01

The name I have for this person is [FILL NAME OF FROM LEADNAME_A_01- LEAD_NAME_D_01]. Is this correct?

- (1) YES [GO TO LEAD_FUTCONT_01]

(2) NO [GO TO LEADNAME_A_01 to D_01 AND CORRECT]

LEAD_FUTCONT_01

May we contact you again if we have problems contacting this person who may have completed the 2001 interview?

(1) YES [GO TO FUTCONT_LEAD_NAME_01]

(2) NO [GO TO PH_CONF]

(77) DON'T KNOW [GO TO PH_CONF]

(99) REFUSED [GO TO PH_CONF]

FUTCONT_LEAD_NAME_01

What is your name?

NAME _____ [GO TO PH_CONF]

FUTCONT_LEAD_NUM_01

And what is the best telephone number to reach you?

TELEPHONE NUMBER COLLECTION SCREEN

Nnn-xxx-xxxx

TERM_BRIEF Thank you for your time (on behalf of the Centers for Disease Control).

TERMINATE Those are all the questions I have. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions. If you would like more information about the Survey of Adult Transition and Health, please call the study's toll-free number, 1-866-900-9601. If you have questions about your rights as a study participant, you may call 1-800-223-8118, toll-free, and leave a message asking to speak to the Chairperson of the Research Ethics Review Board.

CATI QUESTIONNAIRE INTRODUCTION

- NEW_RESP Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention.
- [If youth name available, "May I please speak to [FILL YOUTH NAME_A-YOUTH_NAME_D]?"
- (1) Yes, youth comes to telephone [GO TO NEW_RESP_SC]
(2) No, youth unavailable [GO TO REACH_SC]
- REACH_SC When would be a good time to call back to reach [FILL YOUTHNAME_A-YOUTH_NAME_D]?
- CREATE AN APPOINTMENT
- NEW_RESP_SC
- Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We are doing a nationwide survey about the health of young people in your age group, their health status and health care, and transition into adulthood. In [FILL INTDATE], we spoke to someone in your household about health care. We would now like to ask you about changes that may have occurred in your health in the past few years.
- (1) CONTINUE [GO TO SL_INTRO]
(2) PROXY NEEDED [GO TO PDIFF]
- PDIFF What difficulty do you have that prevents you from participating for yourself?
- (1) Hearing difficulty [GO TO PROXY_SCR/WEB_OFFER]
(2) Speech difficulty [GO TO PROXY_SCR/WEB_OFFER]
(3) Cognitive barrier [GO TO PROXY_SCR]
(4) Physical barrier [GO TO PROXY_SCR/WEB_OFFER]
(77) DON'T KNOW [GO TO PROXY_SCR/WEB_OFFER]
(99) REFUSED [GO TO PROXY_SCR]
- RELAY Thank you for this information. I can continue the RELAY interview in a few minutes, or schedule a time to call you back. Which would be better for you?
- (1) CONTINUE NOW USING RELAY [GO TO RELAYNOW]
(2) SCHEDULE CALLBACK WITH RELAY [GO TO RELAYCBK]
(77) DON'T KNOW [GO TO RELAYNOW]
- RELAYNOW I have to call into the RELAY machine to continue this interview. I will call you back in less than 5 minutes at [FILL SAMPLED TELEPHONE 1-866-900-9601]. Please stay by your RELAY machine for the next 5 minutes. Thank you, and good bye.
- RELAYCBK. When would be a good time to call back to reach you using RELAY?
- SELECT APPOINTMENT ICON
- PROXY_SCR Is the person who makes the majority of the decisions about the [FILL AGE]-year-old's health care available?
- (1) YES, CURRENTLY ON TELEPHONE [START PROXY INTERVIEW]
(2) YES, YOUTH MAKES OWN DECISION [GO TO PROXY_INT]
(3) NO, NOT AVAILABLE [GO TO REACH_PROX]
- PROXY_INT I understand that you are the person who makes the majority of the decisions about the [FILL NAME OR DOB/AGE]. The CDC is interested in either talking with (FILL him/her) for about 15 minutes, or having him/her complete the survey on the Internet. We understand that he/she is unable to do this. Is this correct? [PROBE TO DETERMINE IF CASE IS ELIGIBLE FOR PROXY COMPLETION AND CODE REASON:]
- (1) Yes, hearing difficulty [CONTINUE]
(2) Yes, speech difficulty [CONTINUE]
(3) Yes, cognitive barrier [CONTINUE]
(4) Yes, physical barrier [CONTINUE]
(5) No, youth is able to do the interview and is currently available .. [TERMINATE AND CONTACT YOUTH R]
(6) No, youth is able to do the interview in separate household [GO TO YOUTH_CONT]

Because [FILL he/she] cannot be interviewed and you are knowledgeable about [FILL: his/her] health care, the CDC would like to interview you in [FILL: his/her] place. Please keep in mind that these questions are written to be asked of [FILL: NAME] directly, so please answer the questions as if they were being asked of [FILL: him/her].

SL_INTRO

Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any question you do not wish to answer, or stop at any time without penalty. Your answers will be used for statistical purposes, and will be linked to your parent or guardian from several years ago. We are required by the Public Health Service Act to keep your answers strictly private. I can give you more information on this and other federal laws if you wish. They state that your answers will be used only for statistical research. The survey will take about 15 minutes. In appreciation, you will receive \$20. (IF CALLING KNOWN CELLULAR TELEPHONE NUMBER: You will also receive an additional \$5 to defer your costs for doing the interview on your cellular telephone.) I'd like to continue unless you have any questions. [SKIP IF PDIFF=1:] In order to review my work, my supervisor may record and listen as I ask the questions. I'd like to continue now unless you have any questions.

- (1) CONTINUE, RECORDING ACCEPTABLE [GO TO CONF_DOB_Y]
- (2) CONTINUE, DO NOT RECORD [DISABLE RECORDING AND GO TO ONF_DOB_Y]
- (3) PROXY NEEDED [GO TO PDIFF]

HELP SCREEN (SL_INTRO IF NEEDED):

The Public Health Service Act is Volume 42 of the U.S. Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. The confidentiality of your responses is assured by Section 308d of this Act and by the Confidential Information Protection and Statistical Efficiency Act.

CONFDOB_Y

Before we begin, I'd like to confirm your date of birth. The birth date I have for you is [FILL: BIRTH DATE FROM 2001 DOB].

Is this correct?

- (1) YES [GO TO F2Q11]
- (2) NO [GO TO NEWDOB]

NEWDOB_MDY

What is the correct month, day and year of birth?

_____ / _____ / _____ (mm/dd/yyyy)

GO TO SECTION 2: HEALTH AND FUNCTIONAL STATUS (F2Q11).

WEB QUESTIONNAIRE INTRODUCTION

The Centers for Disease Control and Prevention (CDC) is doing a nationwide survey about the health of young adults, their health status and health care, and transition into adulthood. In 2001, we spoke to someone in your household about health care. We would now like to ask you about changes that may have occurred in your health in the past few years.

Taking part in this survey is voluntary. It will take about 15 minutes. In appreciation, you will receive \$20. You may choose not to answer any question you don't wish to answer—simply select the “Refused” option. You may also choose to stop the survey at any time, or stop now and continue it at a later time. You will be able to restart the survey where you left off.

We are required by the Public Health Service Act to keep your answers strictly private. Your answers will be used only for statistical purposes and will be linked to those of your parent or guardian from several years ago. By law, we will take all possible steps to protect your privacy and are required to use your answers only for statistical research. You can view a description of these laws by clicking here.

If you have any questions about this study, please call the study's toll-free number, 866-900-9601, or send an e-mail to 6414@norc.org.

HOW TO NAVIGATE THIS WEB SURVEY: You will use the computer mouse to select your answer to most questions. For some questions you might need to type in your answer. You must choose an answer in order to proceed to the next question.

Click the “Next” button to continue to the next question. To return to a question already answered, click the “Previous” button. You may choose not to answer any questions you don't wish to answer. Simply select the Refused option. You may also stop the survey at any time without penalty, or continue it at a later time.

If you would like to stop the survey and continue at a later time, simply click on the “Stop” button.

To begin the survey, click on the “Next” button shown below.

CONFDOB_WEB

1. Please confirm your date of birth. The birth date we have for you is [FILL: BIRTH DATE FROM 2001 DOB].
Is this correct?

(1) YES [GO TO F2Q11]

(2) NO[GO TO NEWDOB_X]

NEWDOB_WEB_MDY What is the correct month, day and year of birth?

_____ / _____ / _____ (mm/dd/yyyy)

GO TO SECTION 2: HEALTH AND FUNCTIONAL STATUS (F2Q11).

SECTION 1: HEALTH AND FUNCTIONAL STATUS

Subdomain 1. General health status

- F2Q11 In general, how would you describe your health? Would you say your health is excellent, very good, good, fair, or poor?
- (1) Excellent
 - (2) Very good
 - (3) Good
 - (4) Fair
 - (5) Poor
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q12 About 6 years ago, your parent or guardian told us about your health. Compared with 6 years ago, would you say your health now is better, worse, or about the same?
- (1) Better
 - (2) Worse
 - (3) About the same
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q13 Do you consider yourself to have any kind of disability?
- (1) Yes
 - (2) No
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q14 A person with special health care needs is someone who needs special health care services because of a medical, mental health, or other health condition. People with special health care needs might need medicine, therapy, or specialty care on a regular basis—stuff other people don't typically need or only need once in a while. Do you consider yourself to have a special health care need?
- (1) Yes
 - (2) No
 - (7) DON'T KNOW
 - (9) REFUSED

Subdomain 2. Activity limitations—Daily living

- F2Q21 Because of a physical, mental, or emotional problem, do you need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside your home?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q22 Because of a physical, mental, or emotional problem, do you need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q23 Does a physical, mental, or emotional problem interfere with your ability to participate in social, religious, or recreation activities like sports, clubs, parties, or church?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED

Subdomain 3. Activity limitations—Work

- F2Q30 What were you doing most of the past 12 months: Working at a job or business, looking for work, taking care of your house or family, going to school, or something else?
- (1) Working at a job or business [SKIP TO F2Q32]
 - (2) Looking for work [SKIP TO F2Q31]
 - (3) Taking care of house or family [SKIP TO F2Q31]
 - (4) Going to school [SKIP TO F2Q31]
 - (5) Something else
 - (7) DON'T KNOW [SKIP TO F2Q31]
 - (9) REFUSED [SKIP TO F2Q31]
- F2Q30A What were you doing most of the past 12 months?
- TEXT FIELD:
-
- F2Q31 Did you have a job or business at any time in the past 12 months?
- (1) YES
 - (2) NO [SKIP TO Q37]
 - (7) DON'T KNOW [SKIP TO Q37]
 - (9) REFUSED [SKIP TO Q37]
- F2Q32 In the past 12 months, how often has your health affected your ability to work at a job or business? Would you say:
- (1) Never [SKIP TO Q34]
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW [SKIP TO Q34]
 - (9) REFUSED [SKIP TO Q34]
- F2Q33 Does your health affect your ability to work a great deal, some, or very little?
- (1) A great deal
 - (2) Some
 - (3) Very little
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q34 Because of your health, did you need any services, accommodations, or other assistance to help you do your job better?
- (1) YES [SKIP TO Q35]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F2Q35 Did your job(s) or business(es) provide any services, accommodations, or other assistance to help you do your best there?
- (1) YES [SKIP TO Q36]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F2Q36 Did you ask or apply for any services, accommodations, or other assistance from your job or business?
- (1) YES [SKIP TO NEXT SUBDOMAIN]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F2Q37 Did you want to have a job or business at any time in the past 12 months?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F2Q38 Do you have plans to have a job or business in the next 12 months?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F2Q39 Does your health affect your ability to have a job or business?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

Subdomain 4. Activity limitations—School

IF F2Q30 = 4 (MAIN ACTIVITY IS SCHOOL), SKIP TO F2Q42.

- F2Q41 In the past 12 months, did you attend any type of school?
- (1) YES
 - (2) NO [SKIP TO Q47]
 - (7) DON'T KNOW [SKIP TO Q47]
 - (9) REFUSED [SKIP TO Q47]
- F2Q42 In the past 12 months, how often has your health affected your ability to attend school? Would you say:
- (1) Never [SKIP TO Q44]
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW [SKIP TO Q44]
 - (9) REFUSED [SKIP TO Q44]
- F2Q43 Does your health affect your ability to attend school a great deal, some, or very little?
- (1) A great deal
 - (2) Some
 - (3) Very little
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q44 Because of your health, did you need any services, accommodations, or other assistance to help you attend school or do your best there?
- (1) YES [SKIP TO Q45]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F2Q45 Did the school(s) you attended provide any services, accommodations, or other assistance to help you do your best there?
- (1) YES [SKIP TO Q46]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F2Q46 Did you ask or apply for any services, accommodations, or other assistance from your school?
- (1) YES [SKIP TO NEXT SUBDOMAIN]
 - (2) NO [SKIP TO NEXT SUBDOMAIN]
 - (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
 - (9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F2Q47 Did you want to attend any type of school in the past 12 months?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F2Q48 Do you have plans to enroll in any type of school in the next 12 months?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED

F2Q49 Does your health affect your ability to attend school or complete coursework?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

Subdomain 5. Activity limitations—Taking care of house or family

IF F2Q30 = 3 (MAIN ACTIVITY IS TAKING CARE OF HOUSE OR FAMILY), ASK F2Q52. IF F2Q30 = (1,2,4,5,7,9), SKIP TO NEXT SUBDOMAIN.

F2Q52 In the past 12 months, how often has your health affected your ability to take care of your house or family?
 Would you say:

- (1) Never [SKIP TO Q54]
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW [SKIP TO Q54]
- (9) REFUSED [SKIP TO Q54]

F2Q53 Does your health affect your ability to take care of your house or family a great deal, some, or very little?

- (1) A great deal
- (2) Some
- (3) Very little
- (7) DON'T KNOW
- (9) REFUSED

F2Q54 Because of your health, did you need any services, accommodations, or other assistance to help you take care of your house or family?

- (1) YES [SKIP TO Q55]
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F2Q55 Did you receive any services, accommodations, or other assistance to help you take care of your house or family?

- (1) YES [SKIP TO Q56]
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F2Q56 Did you ask or apply for any services, accommodations, or other assistance to help you take care of your house or family?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

SECTION 2: MEDICAL HOME

Subdomain 1. Usual place for care

- F3Q01 Is there a place that you USUALLY go when you are sick or you need advice about your health?
- (01) YES
 - (02) THERE IS NO PLACE [SKIP TO Q03]
 - (03) THERE IS MORE THAN ONE PLACE
 - (77) DON'T KNOW [SKIP TO Q03]
 - (99) REFUSED [SKIP TO Q03]
- F3Q02 When you are sick or you need advice about your health, what kind of place do you go to most often? Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?
- (01) Doctor's office
 - (02) Hospital emergency room
 - (03) Hospital outpatient department
 - (04) Clinic or health center
 - (08) Some other place
 - (09) DOES NOT GO TO ONE PLACE MOST OFTEN
 - (77) DON'T KNOW
 - (99) REFUSED
- F3Q03 Is there a place that you USUALLY go when you need routine preventive care, such as a physical examination or checkup?
- (01) YES
 - (02) THERE IS NO PLACE [SKIP TO Q05]
 - (03) THERE IS MORE THAN ONE PLACE
 - (77) DON'T KNOW [SKIP TO Q05]
 - (99) REFUSED [SKIP TO Q05]
- F3Q04 When you need routine preventive care, what kind of place do you go to most often? Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?
- (01) Doctor's office
 - (02) Hospital emergency room
 - (03) Hospital outpatient department
 - (04) Clinic or health center
 - (08) Some other place
 - (09) DOES NOT GO TO ONE PLACE MOST OFTEN
 - (77) DON'T KNOW
 - (99) REFUSED
- F3Q05 A personal doctor or nurse is a health professional who knows you well and is familiar with your health history. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as your personal doctor or nurse?
- (01) Yes, one person
 - (02) Yes, more than one person
 - (03) No
 - (77) DON'T KNOW
 - (99) Refused

Subdomain 2. Continuous screening

F3Q21 During the past 12 months, how many times have you seen a doctor, nurse, or other health care provider for preventive medical care such as a physical exam or checkup?

_____ _____ _____ TIMES

(777) DON'T KNOW

(999) REFUSED

F3Q22 During the past 12 months, how many times did you see a dentist for preventive dental care, such as checkups and dental cleanings?

_____ _____ _____ TIMES

(777) DON'T KNOW

(999) REFUSED

IF F3Q21 ≥ 1 OR F3Q22 ≥ 1 THEN SKIP TO F3Q31. ELSE IF F3Q21 = (000,777,999) AND F3Q22 = (000,777,999) THEN ASK F3Q23.

F3Q23 During the past 12 months, did you see a doctor, nurse, or other health care provider for any kind of medical care?

(1) YES

(2) NO

(7) DON'T KNOW

(9) REFUSED

Subdomain 3. Foregone or delayed care

F3Q31 People often delay or do not get needed health care. Examples of needed health care include medical care as well as other types of care such as dental care, mental health services, and special types of therapies. In the past 12 months, have you delayed or gone without needed health care?

- (1) YES
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F3Q32_INT There are many reasons people delay or do not get needed health care. Did you delay or did not get health care for yourself for any of the following reasons?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F3Q32A You couldn't get through to the health care provider's office on the telephone.

F3Q32B You couldn't get an appointment soon enough.

F3Q32C The clinic or doctor's office was not open when you could get there.

F3Q32D Transportation was a problem.

F3Q32E You didn't have enough money to pay the health care provider.

F3Q32F The type of care you needed was not available in your area.

F3Q32G The health care provider did not have the skills you needed.

F3Q32H The type of care was not covered by your health plan.

F3Q32I You could not get approval from your health plan or doctor.

F3Q32J Once you get there, you have to wait too long to see the health care provider.

F3Q32K You have language, communication, or cultural problems with the health care provider.

F3Q32L Going to appointments conflicts with other responsibilities at home, school, or at work.

Subdomain 4. Care coordination

- F3Q40 Does anyone help you arrange or coordinate your care among the different doctors or services that you use?
(1) YES
(2) NO
(7) DON'T KNOW
(9) REFUSED
- F3Q41 During the past 12 months, have you felt that you could have used extra help arranging or coordinating your care among the different doctors or services?
(1) YES
(2) NO
(7) DON'T KNOW
(9) REFUSED
- F3Q42 During the past 12 months, did you need a referral to see any doctors or receive any services?
(1) YES
(2) NO [SKIP TO NEXT SUBDOMAIN]
(7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
(9) REFUSED [SKIP TO NEXT SUBDOMAIN]
- F3Q43 Was getting referrals a big problem, a small problem, or not a problem?
(1) Big problem
(2) Small problem
(3) Not a problem
(7) DON'T KNOW
(9) REFUSED

Subdomain 5. Person-centered care

IF F3Q23 = 2 (NO DOCTOR VISITS IN PAST YEAR), SKIP TO NEXT SUBDOMAIN.

- F3Q51 During the past 12 months, how often did your doctors and other health care providers spend enough time with you? Would you say never, sometimes, usually, or always?
- (1) Never
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW
 - (9) REFUSED
- F3Q52 During the past 12 months, how often did your doctors and other health care providers listen carefully to you? Would you say never, sometimes, usually, or always?
- (1) Never
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW
 - (9) REFUSED
- F3Q53 How often are your doctors and other health care providers sensitive to your values and customs? Would you say never, sometimes, usually, or always?
- (1) Never
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW
 - (9) REFUSED
- F3Q54 Information about your health or health care can include things such as the causes of any health problems, how to care for yourself now, and what changes to expect in the future. In the past 12 months, how often did you get the specific information you needed from your doctors and other health care providers? Would you say never, sometimes, usually, or always?
- (1) Never
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW
 - (9) REFUSED
- F3Q55 During the past 12 months, how often did your doctors or other health care providers help you feel like a partner in your care? Would you say never, sometimes, usually, or always?
- (1) Never
 - (2) Sometimes
 - (3) Usually
 - (4) Always
 - (7) DON'T KNOW
 - (9) REFUSED

F3Q56

During the past 12 months, how often did your doctors or other health care providers encourage you to take responsibility for your health care needs, such as taking medication, understanding your health, or following medical advice? Would you say never, sometimes, usually, or always?

- (1) Never
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW
- (9) REFUSED

F3Q57

During the past 12 months, how often did your doctors or other health care providers talk directly to you and encourage you to ask questions? Would you say never, sometimes, usually, or always?

- (1) Never
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW
- (9) REFUSED

Section 3: TRANSITION SERVICES RELATED TO HEALTH

- F4Q01 Have your doctors or other health care providers talked with you about how your health care needs might change as you got older?
- (1) YES
 - (2) NO [SKIP TO Q03]
 - (7) DON'T KNOW [SKIP TO Q03]
 - (9) REFUSED [SKIP TO Q03]
- F4Q02 Was a plan for addressing these changing needs developed with your doctors or other health care providers?
- (1) YES [SKIP TO Q04]
 - (2) NO [SKIP TO Q04]
 - (7) DON'T KNOW [SKIP TO Q04]
 - (9) REFUSED [SKIP TO Q04]
- F4Q03 Would a discussion about your health care needs have been helpful to you?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F4Q04 Do any of your doctors or other health care providers treat only children, teenagers, or young adults?
- (1) YES
 - (2) NO [SKIP TO Q07]
 - (7) DON'T KNOW [SKIP TO Q07]
 - (9) REFUSED [SKIP TO Q07]
- F4Q05 Have they talked with you about eventually seeing doctors or other health care providers who treat adults?
- (1) YES [SKIP TO Q07]
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F4Q06 Would a discussion about doctors who treat adults have been helpful to you?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F4Q07 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?
- (1) YES [SKIP TO Q09]
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F4Q08 Would a discussion about health insurance have been helpful to you?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F4Q09 Have your doctors or other health care providers helped you connect with other youth or adult mentors who could provide you with social, emotional, or career support?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED

Section 4: COMMUNITY-BASED SERVICES

F5Q01 Most of the previous questions have been about medical services provided by your doctors. There are other types of services people may need or use because of their health. These services may be educational, vocational, or rehabilitation services, or community programs such as housing services, social services, or recreational services.

Thinking about your health needs and the health-related services that you need, have you had any difficulties trying to use any services during the past 12 months?

- (1) YES
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F5Q02 There are many reasons why people may have difficulty trying to use these services. Did you have difficulty trying to use these services for any of the following reasons?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F5Q02_A You could not get the information you needed.

F5Q02_B There was too much paperwork required.

F5Q02_C You didn't have enough money to pay for the services.

F5Q02_D Transportation was a problem.

F5Q02_E There were long waiting lists.

F5Q02_F There were problems in communication between service providers.

F5Q02_G You had language, communication, or cultural problems with the service providers.

F5Q02_H You could not find service providers who had the skills you needed.

F5Q02_I The types of services you needed were not available in your area.

F5Q02_J The types of services you needed were available but you were not eligible.

F5Q02_K The types of services you needed were available but you had used up all eligible benefits.

F5Q02_L You didn't have the time to figure it all out.

Section 5: HEALTH INSURANCE COVERAGE

Subdomain 1. Current coverage and past-year coverage

F6Q01_INT The next questions are about health insurance.

F6Q01 Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

- (1) YES [SKIP TO Q02]
- (2) NO [SKIP TO Q04]
- (7) DON'T KNOW [SKIP TO Q02]
- (9) REFUSED [SKIP TO Q02]

F6Q02 Are you insured by Medicaid, the State Children's Health Insurance Program (S-CHIP), or any other insurance program for people with low income or disabilities?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

IF Q01 IN (7, 9) AND Q02 IN (2, 7, 9) [SKIP TO Q04]
ELSE [SKIP TO Q03]

F6Q03 During the past 12 months, was there any time when you were not covered by ANY health insurance?

- (1) YES [SKIP TO NEXT SUBDOMAIN]
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F6Q04 During the past 12 months, have you had health care coverage?

- (1) YES [SKIP TO NEXT SUBDOMAIN]
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

Subdomain 2. Adequacy of health insurance

F6Q20 The next questions are about your health insurance or health care plans. Does your health insurance offer benefits or cover services that meet your needs? Would you say:

- (1) Never
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW
- (9) REFUSED

F6Q22 Does your health insurance allow you to see the health care providers you need? Would you say:

- (1) Never
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW
- (9) REFUSED

F6Q21A Not including health insurance premiums or costs that are covered by insurance, do you pay any money for your health care? Include out-of-pocket payments for all types of health-related needs such as co-payments, dental or vision care, medications, and any kind of therapy.

- (1) YES[SKIP TO Q21B]
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F6Q21B How often are these costs reasonable? Would you say:

- (1) Never
- (2) Sometimes
- (3) Usually
- (4) Always
- (7) DON'T KNOW
- (9) REFUSED

Section 6: TRANSITION SERVICES RELATED TO SCHOOL

F7_INTRO Next, I would like to ask you some questions about your education.

F7Q01 During the past 6 years, did you receive any vocational or career training to help you prepare for a job?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F7Q02 What is the highest grade or year of school you have completed?

- (01) 8th GRADE OR LESS
- (02) 9th–12th GRADE NO DIPLOMA
- (03) HIGH SCHOOL GRADUATE OR GED COMPLETED
- (04) COMPLETED A VOCATIONAL, TRADE, OR BUSINESS SCHOOL PROGRAM
- (05) SOME COLLEGE CREDIT BUT NO DEGREE
- (06) ASSOCIATE DEGREE (AA, AS)
- (07) BACHELOR'S DEGREE (BA, BS, AB)
- (08) MASTER'S DEGREE (MA, MS, MSW, MBA)
- (09) DOCTORATE (PhD, EdD) or PROFESSIONAL DEGREE (MD, DDS, DVM, JD)
- (77) DON'T KNOW
- (99) REFUSED

F7Q03 Did you ever meet with adults at school or somewhere else to set goals for what you would do after high school and make a plan for how to achieve them? Sometimes this is called a transition plan.

- (1) YES
- (2) NO [SKIP TO NEXT SUBDOMAIN]
- (7) DON'T KNOW [SKIP TO NEXT SUBDOMAIN]
- (9) REFUSED [SKIP TO NEXT SUBDOMAIN]

F7Q04 Did you participate in the development of that plan?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

Section 7: SELF-DETERMINATION

Note: These items are adapted from the The Arc's Self-Determination Scale.

F8_INTRO The next questions are statements about activities that you may do. For each statement, please indicate how often you do each activity: never, rarely, sometimes, usually, or always.

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always
- (7) DON'T KNOW
- (9) REFUSED

F8Q01_A I keep my appointments and meetings.

F8Q01_B I choose how to spend my personal money.

F8Q01_C I plan weekend activities that I like to do.

F8Q02 How often is the following statement true for you? "I am able to make choices that are important to me." Would you say that is never true, rarely true, sometimes true, usually true, or always true?

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always
- (7) DON'T KNOW
- (9) REFUSED

F8Q03 How often is the following statement true for you? "I am able to make friends in new situations." Would you say that is never true, rarely true, sometimes true, usually true, or always true?

- (1) Never
- (2) Rarely
- (3) Sometimes
- (4) Usually
- (5) Always
- (7) DON'T KNOW
- (9) REFUSED

Section 8: SATISFACTION AND SUPPORT

- F9Q01 In general, how satisfied are you with your life? Would you say very satisfied, satisfied, dissatisfied, or very dissatisfied?
- (1) Very satisfied
 - (2) Satisfied
 - (3) Dissatisfied
 - (4) Very dissatisfied
 - (7) DON'T KNOW
 - (9) REFUSED
- F9Q02 How often do you get the social and emotional support you need from your family or friends? Would you say never, rarely, sometimes, usually, or always?
- (1) Never
 - (2) Rarely
 - (3) Sometimes
 - (4) Usually
 - (5) Always
 - (7) DON'T KNOW
 - (9) REFUSED
- F9Q03 If the option was available, would you like to connect with other youth or adult mentors who could provide you with social, emotional, or career support?
- (1) YES
 - (2) NO
 - (7) DON'T KNOW
 - (9) REFUSED
- F9Q04 Now, thinking about your health needs and all the medical and health-related services you receive, how satisfied or dissatisfied are you with those services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?
- (1) Very satisfied
 - (2) Somewhat satisfied
 - (3) Somewhat dissatisfied
 - (4) Very dissatisfied
 - (7) DON'T KNOW
 - (9) REFUSED

Section 9: DEMOGRAPHICS

Subdomain 1. Marital status and living arrangements

F10_INTRO Now I have a few more general questions about you and your household.

F10Q11 Are you currently married, separated, divorced, widowed, or never married?

- (1) Married
- (2) Separated
- (3) Divorced
- (4) Widowed
- (5) Never married
- (7) DON'T KNOW
- (9) REFUSED

F10Q12 Are you currently living with a spouse or partner?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F10Q13 Are you currently living with your parent(s)?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

IF F10Q12 = 1 OR F10Q13 = 1, SKIP TO F10Q15.

F10Q14 Do you live alone?

- (1) YES
- (2) NO
- (7) DON'T KNOW
- (9) REFUSED

F10Q15 Are you happy with your current living arrangement, or would you like to change where you live or who you live with?

- (1) HAPPY WITH CURRENT ARRANGEMENT
- (2) WOULD LIKE TO CHANGE
- (7) DON'T KNOW
- (9) REFUSED

Subdomain 2. Personal earnings and program participation

- F10Q21 The next question is about your total income in the past 12 months, including income from all sources such as wages, salaries, Social Security, help from relatives and so forth. Can you tell me that amount before taxes?
- ___ ___ ___ ___ ___ Dollars
(777777) DON'T KNOW
(999999) REFUSED
- F10Q22 Compared to other people your age, do you think you have more ability, about the same ability, or less ability to pay for the things you need?
- (1) More ability
(2) About the same ability
(3) Less ability
(7) DON'T KNOW
(9) REFUSED
- F10Q23 At any time during the past 12 months, even for 1 month, did you receive any cash assistance from a state or county welfare program, such as [state TANF name] or General Assistance?
- (1) YES
(2) NO
(7) DON'T KNOW
(9) REFUSED
- F10Q24 During the past 12 months, did you receive Food Stamps?
- (1) YES
(2) NO
(7) DON'T KNOW
(9) REFUSED
- F10Q25 During the past 12 months, did you receive Supplemental Security Income (also called SSI)?
- (1) YES
(2) NO
(7) DON'T KNOW
(9) REFUSED

CATI QUESTIONNAIRE EXIT

ALL PATHS LEAD TO THIS EXIT PATH WHEN
CONFDOB_X or NEWDOB_X NOT EQUAL NULL

CLOSE

Those are all the questions I have. Thank you for participating in the 2007 Survey of Adult Transition and Health (SATH). In appreciation of your time, we would like to send you 20 dollars.

- (1) YES[GO TO AC_NAME INTRO]
- (2) NO [GO TO AC_REFUSED]

AC_NAME INTRO

Can you please give me your name and mailing address?

AC_NAME _____
 AC_STREET _____
 AC_CITY _____
 AC_STATE _____
 AC_ZIP _____

[GO TO CELLULAR_PAY]

CELLULAR_PAY

Did we conduct this survey on your cellular telephone?

- (1) YES[GO TO CELLULAR_SCRIPT]
- (2) NO [GO TO AC_REFUSED]

CELLULAR_SCRIPT

You will also receive an additional \$5 to defer your costs for doing the interview on your cellular telephone. [GO TO AC_REFUSED]

AC_REFUSED [BLANK]

- (1) Address correct and confirmed [GO TO AC2]
- (99) Refused to give/confirm address [GO TO AC2]

AC2 Those are all the questions I have. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions. If you would like more information about the Survey of Adult Health and Transition, please call the study's toll-free number, 1-866-900-9601. If you have questions about your rights as a study participant, you may call 1-800-223-8118, toll-free, and leave a message asking to speak to the Chairperson of the Ethics Review Board.

WEB QUESTIONNAIRE EXIT

ALL PATHS LEAD TO THIS EXIT PATH WHEN
CONFDOB_X or NEWDOB_X NOT EQUAL NULL

Those are all the questions. Thank you for participating in the 2007 Survey of Adult Transition and Health (SATH). In appreciation of your time, we would like to send you 20 dollars.

Please enter your name and mailing address:

AC_NAME_____

AC_STREET_____

AC_CITY_____

AC_STATE_____

AC_ZIP_____

AC2 I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions. If you would like more information about the 2007 Survey of Adult Transition and Health (SATH), please call the study's toll-free number, 1-866-900-9601. If you have questions about your rights as a study participant, you may call 1-800-223-8118, toll-free, and leave a message asking to speak to the Chairperson of the Ethics Review Board.

CALLBACK SCRIPTS AND ANSWERING MACHINE SCRIPTS

INTRO_LEAD_Y

(Variation of INTRO_1 should appear 1st when calling lead HH)

DESCRIPTION: CALLING LEAD HH TO GATHER SATH R's CONTACT INFORMATION/SPEAK WITH SATH R

In (INTDATE-YYYY), we conducted a nationwide telephone study on children's health about a child who was between the ages of 14–18 years of age at the time. This survey was conducted with the child's [FILL RELATION] who recently gave us your telephone number in order to contact their [FILL son/daughter]. This child would now be approximately [FILL AGE] years old and the Centers for Disease Control and Prevention is now interested in speaking to [FILL HIM/HER].

Can you tell me how to find this [FILL AGE]-year-old?

- (1) YES, WILL GIVE SATH R CONTACT INFORMATION [GO TO YOUTH_CONT]
- (2) YES, SATH R IS ON/COMES TO THE TELEPHONE [GO TO NEW_RESP_SC]
- (3) R2001 COMES TO THE TELEPHONE [GO TO INTRO_R2001]
- (4) CONFIRM BUSINESS [GO TO SALZ]
- (5) R WILL CALL 800 LINE/VERIFY WEBSITE [GO TO M1_NAME_WEB_ADD]
- (6) ANSWERING MACHINE [GO TO MSG_REACH]
- (7) R ASKS FOR LETTER—MAILED [GO TO UNIVERSAL_EXIT- M1_NAME]
- (8) R ASKS FOR LETTER—E-MAILED [GO TO UNIVERSAL_EXIT- M1_EMAIL]
- (9) SUPERVISOR REVIEW [GO TO CALL NOTES BOX] (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE)
- (99) REFUSED [GO TO TERM_BRIEF]

INTRO_LEAD_01R

(Variation of INTRO_1 should appear 1st when calling lead HH)

DESCRIPTION: CALLING LEAD HH TO GATHER R2001's CONTACT INFORMATION/SPEAK WITH R2001

In (INTDATE-YYYY), we conducted a nationwide telephone study on children's health about a child who was between the ages of 14–18 years of age at the time. The Centers for Disease Control and Prevention is now interested in speaking to the [FILL RELATION] of this child who would now be a [FILL AGE]-year-old adult. A person from the household that participated in the 2001 interview gave us your telephone number so that we may contact the parent who completed the 2001 survey.

Can you tell me how to find this [FILL AGE]-year-old's [FILL RELATION]?

- (1) YES, WILL GIVE R2001's CONTACT INFORMATION [GO TO R2001_CONT]
- (2) YES, R2001 IS ON/COMES TO THE TELEPHONE [GO TO INTRO_R2001]
- (3) CONFIRM BUSINESS [GO TO SALZ]
- (4) 2001 LEAD WILL CALL 800 LINE/
VERIFY WEBSITE [GO TO M1_NAME_WEB_ADD]
- (5) ANSWERING MACHINE [GO TO MSG_REACH]
- (6) 2001 LEAD ASKS FOR LETTER—MAILED [GO TO UNIVERSAL_EXIT- M1_NAME]
- (7) 2001 LEAD ASKS FOR LETTER—E-MAILED [GO TO UNIVERSAL_EXIT- M1_EMAIL]
- (8) SUPERVISOR REVIEW [GO TO CALL NOTES BOX] (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE)
- (9) NEW PERSON COMES TO TELEPHONE [GO TO INTRO_1 then INTRO_LEAD_01R]
- (99) REFUSED [GO TO TERM_BRIEF]

INTRO_APPT_PNDG_SCRD

DESCRIPTION: APPT MADE WITH 2001 HOUSEHOLD MEMBER (HHM) BUT R2001 OR 2007 R HAS NOT BEEN IDENTIFIED (REACH_CB)

IF NAME GIVEN: Hello. May I please speak to [FILL NAME]?

IF NAME NOT GIVEN INTRO BEGINS HERE:

Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We recently spoke with [FILL "you" if name given/"someone in your household" if name not given] about an important survey on the health care of young adults. I'm calling to complete the interview now.

- (1) CONTINUE WITH INTERVIEW[GO TO S2_C]
- (2) CONFIRM BUSINESS[GO TO SALZ_BUS_Y]
- (3) LANGUAGE BARRIER
(ANY LANGUAGE OTHER THAN ENGLISH)[GO TO TERM_BRIEF]
- (4) NO PERSON AT HOME WHO IS OVER 17 [GO TO S2_B]
- (5) ANSWERING MACHINE[GO TO MSG_PENDING SCREENED]
- (6) R WILL CALL 800 LINE/VERIFY WEBSITE [GO TO UE-M1_NAME_WEB]
- (7) R ASKS FOR LETTER—MAILED [GO TO UE-M1_NAME_WEB]
- (8) R ASKS FOR LETTER—E-MAILED [GO TO UE-M1_NAME_WEB]
- (9) SUPERVISOR REVIEW[GO TO CALL NOTES BOX]
(RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) ...[GO TO TERM_BRIEF]

INTRO_APPT_SCRND_Y

DESCRIPTION: APPT TO RESUME A BREAK-OFF WITH 2007 R OR PROXY

[FILL NAME] IS BASED ON YOUTH_NAME_A OR PROX_NAME_A

IF NAME GIVEN: Hello. May I please speak to [FILL NAME]?

Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We started an interview with [FILL "you" (if name given)/"a [FILL AGE]-year-old in your household" or "a proxy for a [FILL AGE]-year-old" (if name not given)] about the health care of young adults. I'm calling back now to finish the interview. Are you the [FILL AGE]-year-old/ proxy for a [FILL AGE]-year-old that we started the interview with?

- (1) CONTINUE WITH INTERVIEW[GO TO S2_C]
- (2) CONFIRM BUSINESS[GO TO SALZ_BUS_Y]
- (3) LANGUAGE BARRIER
(ANY LANGUAGE OTHER THAN ENGLISH)[GO TO TERM_BRIEF]
- (4) NO PERSON AT HOME WHO IS OVER 17 [GO TO S2_B]
- (5) ANSWERING MACHINE[GO TO MSG_PENDING SCREENED]
- (6) R WILL CALL 800 LINE/VERIFY WEBSITE [GO TO UE-M1_NAME_WEB]
- (7) R ASKS FOR LETTER—MAILED [GO TO UE-M1_NAME_WEB]
- (8) R ASKS FOR LETTER—E-MAILED [GO TO UE-M1_NAME_WEB]
- (9) SUPERVISOR REVIEW[GO TO CALL NOTES BOX]
(RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) ...[GO TO TERM_BRIEF]

TRAINING POINT: CONFIRM THAT YOU ARE SPEAKING WITH THE SAME PERSON WHO STARTED THE INTERVIEW.

INTRO_APPT_01R

DESCRIPTION: APPT TO RESUME A BREAK-OFF WITH R2001

[FILL NAME] IS BASED ON R2001_NAME_A

IF NAME GIVEN: Hello. May I please speak to [FILL NAME]?

IF NAME NOT GIVEN INTRO BEGINS HERE:

Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We started an interview with you or someone in your household about the health care of young adults. I'm calling back now to finish the interview.

[If name not given "May I please speak with the person we spoke with [FILL APPT SET DATE]?"

- (1) CONTINUE WITH INTERVIEW[GO TO S2_C]
- (2) CONFIRM BUSINESS[GO TO SALZ_BUS_Y]
- (3) LANGUAGE BARRIER (ANY LANGUAGE OTHER THAN ENGLISH)[GO TO TERM_BRIEF]
- (4) NO PERSON AT HOME WHO IS OVER 17 [GO TO S2_B]
- (5) ANSWERING MACHINE[GO TO MSG_PENDING SCREENED]

- (6) R WILL CALL 800 LINE/VERIFY WEBSITE [GO TO UE-M1_NAME_WEB]
- (7) R ASKS FOR LETTER—MAILED [GO TO UE-M1_NAME_WEB]
- (8) R ASKS FOR LETTER—E-MAILED [GO TO UE-M1_NAME_WEB]
- (9) SUPERVISOR REVIEW[GO TO CALL NOTES BOX]
 (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE)

TRAINING POINT: CONFIRM THAT YOU ARE SPEAKING WITH THE SAME PERSON WHO STARTED THE INTERVIEW.

Intro_1_HUDI_PENDGSCRND

DESCRIPTION: INTRO FOR 2001 HHM THAT HUNG UP DURING INTRO (HUDI)

Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We're conducting a nationwide study about the health care of young adults.

- (1) CONTINUE WITH INTERVIEW[GO TO S1]
- (2) CONFIRM BUSINESS [GO TO PH_CONF]
- (3) ANSWERING MACHINE [GO TO GO TO MSG_PNDNG_SCRND]

Intro_1_HUDI_Y

DESCRIPTION: INTRO FOR YOUTH HOUSHOLDS THAT HUNG UP DURING INTRO (HUDI)

Hello, my name is _____. I'm calling on behalf of the Centers for Disease Control and Prevention. We're conducting a nationwide study about the health care of young adults.

- (1) CONTINUE WITH INTERVIEW[GO TO S1]
- (2) ANSWERING MACHINE [GO TO MSG_PNDNG_SCRND]

S1 Am I speaking to someone who lives in this household who is over 17 years old?

- (1) YES, I AM THAT PERSON [GO TO BREAK OFF POINT (INTRO)]
- (2) NO [GO TO S1_SCRIPT]
- (3) THIS IS A BUSINESS [GO TO SALZ]
- (4) NEW PERSON COMES TO TELEPHONE [GO BACK TO INTRO_APPT_PNDG_SCRD]
- (5) DOES NOT LIVE IN HOUSEHOLD[GO TO TERM_BRIEF]
- (7) NO PERSON AT HOME WHO IS OVER 17 [GO TO S2_B]
- (9) REFUSED[GO TO TERM_BRIEF]

S1_SCRIPT Is there someone who lives in this household who is over 17 that I may speak with?

- (1) YES, NEW PERSON COMES TO TELEPHONE [GO TO INTRO_APPT_PNDG_SCRD]
- (2) NO [GO TO S2B]

SALZ_BUS_Y Hello. May I please speak to [FILL NAME]?

- (1) YES, YOUTH COMES TO TELEPHONE [GO TO INTRO_APPT_SCRND_Y]
- (2) NO, YOUTH NOT AVAILABLE [GO TO SALZ_BUS_Y_APPT]

SALZ_BUS_Y_APPT

What would be a good time for us to call (him/her) back?

CREATE AN APPOINTMENT

[GO TO TERM_BRIEF WITHOUT TEXT IN PARENTHESES]

TERM_BRIEF Thank you for your time (on behalf of the Centers for Disease Control).

S2_B Does anyone live in your household who is over 17 years old?

- (1) Yes [GO TO [BLANK] script shown below]
- (2) No [GO TO PH_CONF]

[BLANK] Thank you, we'll try back another time.

S2_C Just to confirm, am I speaking with the [FILL RELATION] of the [FILL AGE]/ [FILL AGE]-year-old that we spoke with on [FILL APPT SET DATE]?

- (1) Yes [GO TO REMIND 1]
- (2) No[GO TO CB1 TO SET AN APPOINTMENT]

REMIND1 I want to remind you that we will be asking questions about [you/ IF PROXY, THEN “the [FILL AGE] year-old”] for the rest of this interview.

[CONTINUE WITH INTERVIEW AT POINT OF BREAKOFF]

ANSWERING MACHINE SCRIPTS

MSG_PENDING_SCREENED

(PLEASE READ SLOWLY AND CLEARLY.)

Hello. The Centers for Disease Control and Prevention is conducting a survey about the health care of young adults. Would you please call us, toll-free, at 1-866-900-9601 to determine survey eligibility? For most people, the survey will be very brief and we would be glad to answer any questions you have. The toll-free number again is 1-866-900-9601. Thank you.

MSG_REACH

DESCRIPTION: AM [ANSWERING MACHINE] MESSAGE FOR RESPONDENT THAT MAY KNOW 2001 OR 2007'S CONTACT INFORMATION (NO PRIOR APPOINTMENT MADE)

(PLEASE READ SLOWLY AND CLEARLY.)

Hello. The Centers for Disease Control and Prevention is conducting a survey about the health care of young adults. Would you please call us, toll-free, at (FILL "1-866-900-9601" FOR REGULAR INTERVIEWS, ELSE FILL "1-866-900-9601" FOR RELAY INTERVIEWS)? We are available days, evenings, and weekends. This will be very brief and we would be glad to answer any questions you have. The toll-free number again is (FILL "1-866-900-9601" FOR REGULAR INTERVIEWS, ELSE FILL "1-866-900-9601" FOR RELAY INTERVIEWS). Thank you.

Answering machine message for appointments:

MSG_Y_APPT

(PLEASE READ SLOWLY AND CLEARLY.)

Hello. I am calling on behalf of the Centers for Disease Control and Prevention regarding a nationwide study about the health care of young adults. When we spoke previously about this important study, you requested that we call you back at this time. I'm sorry that we've missed you. We'll try to contact you again soon but please feel free to return our call anytime at 1-866-900-9601. Also, if you have any questions, that number again is 1-866-900-9601. Thank you.

MSG_APPT_REACH

DESCRIPTION: MESSAGE FOR RESPONDENT THAT KNOWS 2001 OR 2007 RESPONDENT'S CONTACT INFORMATION (PRIOR APPOINTMENT SET)

(PLEASE READ SLOWLY AND CLEARLY.)

Hello. I am calling on behalf of the Centers for Disease Control and Prevention regarding a nationwide study about the health care of young adults. When we spoke previously about this important study, you requested that we call you back at this time. I'm sorry that we've missed you. We'll try to contact you again soon but please feel free to return our call anytime at (FILL "1-866-900-9601" FOR REGULAR INTERVIEWS ELSE FILL "1-866-900-9601" FOR RELAY INTERVIEWS).

Appendix IV. 2007 SATH Endorsement Letters

General Endorsement Letter



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

The U.S. Department of Health and Human Services and the Centers for Disease Control and Prevention are conducting the Survey of Adult Transition and Health (SATH) and we need your help to make it a success. This study focuses on the quality of health care—a topic of interest for millions of households across the country. We are particularly interested in:

- The well-being of young adults and the quality of their health insurance coverage
- The type of health care and services available for people moving into adulthood
- The impact of young adult health and health care on their families

Local, state, and federal officials depend on the results of this study to measure well-being and the status of healthcare as members of our population move into adulthood. This study will provide information about young adults and their families which will help to guide policy makers, advocates, and researchers. Although participation is completely voluntary and there is no penalty for not answering a question, we hope you will agree to help us. Answers to this study may help shape programs in the years ahead.

This study is authorized by the U.S. Public Health Service Act. It (and other federal laws) protects your information; we will take all possible steps to protect your privacy. The information you report will only be used for statistical research.

You can call the study's toll-free telephone number (1-866-900-9601) if you want to take part in the study now, or to learn more about the study's background and what you will be asked. You can also visit this web site if you'd like to participate immediately or learn more: <http://www.cdc.gov/nchs/about/major/slait/sath.htm>.

Thank you very much for your help with this important research.

Sincerely,

(SIGNATURE)

Edward J. Sondik, Ph.D.



If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-855-2881 and request that 1-866-900-9601 be called.

Director, National Center for Health Statistics
Centers for Disease Control and Prevention

Survey of Adult Transition and Health

Frequently Asked Questions

Why is this study being conducted?

The Centers for Disease Control and Prevention is committed to improving people's health, health care and well-being. State and federal health authorities are depending on the results of the Survey of Adult Transition and Health to help them understand how best to meet health care needs as people move into adulthood.

How will this information be used?

Agencies in your state will use this information to improve programs and services for children and their families. The federal government will also use this information to learn about the types of support services that states need to support young adult health, healthcare and well-being.

You may visit <http://www.cdc.gov/nchs/about/major/slats/sath.htm> to find more information about the study.

How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your private information will never be associated with any results.

If you would like more information about confidentiality, the federal laws that protect your information are described in detail at www.cdc.gov/nchs/about/policy/confiden.htm.

How do I know this is a legitimate survey?

The CDC is conducting this survey with the National Opinion Research Center at the University of Chicago (NORC) as its authorized contractor. You may call NORC to verify that this is a legitimate survey. The toll-free number is 1-866-900-9601.

If you would like to learn more about your rights as a respondent, please call the Chairperson of the Research Ethics Review Board at the National Center for Health Statistics, toll-free, at 1-800-223-8118. Please leave a brief message with your name and telephone number. Say that you are calling about Protocol #2007-27. Your call will be returned as soon as possible.

What if I have questions about health, health care, and health care facilities?

You may call the CDC Information Contact Center toll-free at 1-800-CDC-INFO (1-800-232-4636) for more information, or to get the telephone number of a doctor or clinic near you.

Endorsement Letter for 2007 SATH Respondent



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

You have requested information on an important study run by the Centers for Disease Control and Prevention (CDC). This nationwide survey is about the health of young adults, and their health status and health care as they get older. In 2001, we spoke to someone in your household about health care. We would now like to look at changes that may have occurred in your health or healthcare over the past few years by getting information directly from you.

We know little about changes that might occur in health and health care as a person ages from an adolescent to an adult. We need to learn more about people in this age range and you can help.

You can call the study's toll-free telephone number (1-866-900-9601) if you want to take part in the study now, or to learn more about the study's background and what you will be asked. You can also visit this web site if you'd like to participate immediately or learn more: <http://www.cdc.gov/nchs/about/major/slaits/sath.htm>.

We need your help to make this study a success, and hope you will agree to participate. It is your choice to participate. It will take about 15 minutes to answer the questions.

This study is authorized by the U.S. Public Health Service Act. It (and other federal laws) protects your information; we will take all possible steps to protect your privacy. The information you report will only be used for statistical research.

Your answers may help improve the health of adults in your area and the nation, now and in the years ahead. Thank you for your assistance.

Sincerely,

(SIGNATURE)

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

P.S. In appreciation for your time and effort, we will send you \$20 in cash when you complete the interview.



If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-855-2881 and request that 1-866-900-9601 be called.

Survey of Adult Transition and Health

Frequently Asked Questions

How will this survey benefit others?

We need to learn more about changes that might occur in health and health care as a person ages from an adolescent to an adult. Your answers may help improve the health of adults in your area and the nation, now and in the years ahead.

Does this study apply to me?

We are interested in talking to some young adults between the ages of 19 and 23. We need your information to understand how your health and health care have changed since you were a teen.

How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your private information will never be associated with any results.

If you would like more information about confidentiality, the federal laws that protect your information are described in detail at www.cdc.gov/nchs/about/policy/confiden.htm.

How do I know this is a legitimate survey?

The CDC is conducting this survey with the National Opinion Research Center at the University of Chicago (NORC) as its authorized contractor. You may call NORC to verify that this is a legitimate survey. The toll-free number is 1-866-900-9601.

If you would like to learn more about your rights as a respondent, please call the Chairperson of the Research Ethics Review Board at the National Center for Health Statistics, toll-free, at 1-800-223-8118. Please leave a brief message with your name and telephone number. Say that you are calling about Protocol #2007-27. Your call will be returned as soon as possible.

What if I have questions about health, health care, and health care facilities?

You may call the CDC Information Contact Center toll-free at 1-800-CDC-INFO (1-800-232-4636) for more information, or to get the telephone number of a doctor or clinic near you.

Appendix V. Internet Offer Letter



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

Dear [MAILMERGE],

The Centers for Disease Control and Prevention are conducting the **Survey of Adult Transition and Health (SATH)**. This important survey is intended to monitor the well-being, health and healthcare needs of people in your age group.

We are asking you to participate in this important survey by accessing our website and using the password provided for you below. In appreciation of your time and effort spent completing the survey, we will send you \$20.

Web:

The web survey will take approximately 20 minutes to complete. Please visit this secure website to access the survey:
<http://www.cdc.gov/nchs/about/major/slaits/sath.htm>.

For security purposes, use the password below to access the web survey:

Password: [MAILMERGE]

If you have any trouble accessing the survey or have any other questions, please call us at 1-866-900-9601.

Telephone:

If you prefer to complete the interview over the telephone, please call us at 1-866-900-9601.

Our intended subject for this survey was born in [FILL MONTH and YEAR from 2001 CSHCN DOB]. If you are not this person, please contact us at 1-866-900-9601.

All information collected for this survey is confidential and protected by the Public Health Service Act [Secs. 306 & 2012 (a)(7)]. If you would like to learn more about your rights as a respondent, please call the office of the Research Ethics Review Board at the National Center for Health Statistics, toll-free, at 1-800-223-8118. Please leave a brief message with your name and telephone number. Say that you are calling about Protocol #2007-27.

Thank you very much for your help with this important research.

Sincerely,

(SIGNATURE)

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

Appendix VI. Thank You Letters

Sent to cases completed via landline telephone



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

Dear Respondent:

Thank you for participating in the Survey of Adult Transition and Health. The information you provided about your health and health care will be used to develop adult health programs across the country. In appreciation for the time and effort you spent answering our questions, we are enclosing \$20.

If you have any questions, you can call the study staff toll-free at 1-866-900-9601, or you can visit the study's web site at <http://www.cdc.gov/nchs/about/major/slaits/sath.htm>.

Thank you again for your help.

Sincerely,

(SIGNATURE)

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

Sent to cases completed via cellular telephone



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

Dear Respondent:

Thank you for participating in the Survey of Adult Transition and Health. The information you provided about your health and health care will be used to develop adult health programs across the country. In appreciation for the time and effort you spent answering our questions, we are enclosing \$25.

If you have any questions, you can call the study staff toll-free at 1-866-900-9601, or you can visit the study's web site at <http://www.cdc.gov/nchs/about/major/slaits/sath.htm>.

Thank you again for your help.

Sincerely,

(SIGNATURE)

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

Appendix VII. Disposition Code Frequencies and Unweighted Interview Completion Rate Calculation

Table VI. Unweighted distribution of final case dispositions: 2007 SATH

Disposition category	Code or formula	Frequency or rate
Did not contact 2001 respondent	NP	7,409
Contacted 2001 respondent (or proxy if 2001 respondent is deceased), did not contact young adult	NY	1,578
Contacted young adult, interview incomplete	NI	30
Partial interview complete	PC	6
Full interview complete	FC	1,910
Total sample		10,933
Interview completion rate	(PC + FC)/TOTAL	17.5%

NOTE: SATH is Survey of Adult Transition and Health.

Vital and Health Statistics Series Descriptions

ACTIVE SERIES

- Series 1. **Programs and Collection Procedures**—This type of report describes the data collection programs of the National Center for Health Statistics. Series 1 includes descriptions of the methods used to collect and process the data, definitions, and other material necessary for understanding the data.
- Series 2. **Data Evaluation and Methods Research**—This type of report concerns statistical methods and includes analytical techniques, objective evaluations of reliability of collected data, and contributions to statistical theory. Also included are experimental tests of new survey methods, comparisons of U.S. methodologies with those of other countries, and as of 2009, studies of cognition and survey measurement, and final reports of major committees concerning vital and health statistics measurement and methods.
- Series 3. **Analytical and Epidemiological Studies**—This type of report presents analytical or interpretive studies based on vital and health statistics. As of 2009, Series 3 also includes studies based on surveys that are not part of continuing data systems of the National Center for Health Statistics and international vital and health statistics reports.
- Series 10. **Data From the National Health Interview Survey**—This type of report contains statistics on illness; unintentional injuries; disability; use of hospital, medical, and other health services; and a wide range of special current health topics covering many aspects of health behaviors, health status, and health care utilization. Series 10 is based on data collected in this continuing national household interview survey.
- Series 11. **Data From the National Health Examination Survey, the National Health and Nutrition Examination Surveys, and the Hispanic Health and Nutrition Examination Survey**—In this type of report, data from direct examination, testing, and measurement on representative samples of the civilian noninstitutionalized population provide the basis for (1) medically defined total prevalence of specific diseases or conditions in the United States and the distributions of the population with respect to physical, physiological, and psychological characteristics, and (2) analyses of trends and relationships among various measurements and between survey periods.
- Series 13. **Data From the National Health Care Survey**—This type of report contains statistics on health resources and the public's use of health care resources including ambulatory, hospital, and long-term care services based on data collected directly from health care providers and provider records.
- Series 20. **Data on Mortality**—This type of report contains statistics on mortality that are not included in regular, annual, or monthly reports. Special analyses by cause of death, age, other demographic variables, and geographic and trend analyses are included.
- Series 21. **Data on Natality, Marriage, and Divorce**—This type of report contains statistics on natality, marriage, and divorce that are not included in regular, annual, or monthly reports. Special analyses by health and demographic variables and geographic and trend analyses are included.
- Series 23. **Data From the National Survey of Family Growth**—These reports contain statistics on factors that affect birth rates, including contraception and infertility; factors affecting the formation and dissolution of families, including cohabitation, marriage, divorce, and remarriage; and behavior related to the risk of HIV and other sexually transmitted diseases. These statistics are based on national surveys of women and men of childbearing age.

DISCONTINUED SERIES

- Series 4. **Documents and Committee Reports**—These are final reports of major committees concerned with vital and health statistics and documents. The last Series 4 report was published in 2002. As of 2009, this type of report is included in Series 2 or another appropriate series, depending on the report topic.
- Series 5. **International Vital and Health Statistics Reports**—This type of report compares U.S. vital and health statistics with those of other countries or presents other international data of relevance to the health statistics system of the United States. The last Series 5 report was published in 2003. As of 2009, this type of report is included in Series 3 or another series, depending on the report topic.
- Series 6. **Cognition and Survey Measurement**—This type of report uses methods of cognitive science to design, evaluate, and test survey instruments. The last Series 6 report was published in 1999. As of 2009, this type of report is included in Series 2.
- Series 12. **Data From the Institutionalized Population Surveys**—The last Series 12 report was published in 1974. Reports from these surveys are included in Series 13.
- Series 14. **Data on Health Resources: Manpower and Facilities**—The last Series 14 report was published in 1989. Reports on health resources are included in Series 13.
- Series 15. **Data From Special Surveys**—This type of report contains statistics on health and health-related topics collected in special surveys that are not part of the continuing data systems of the National Center for Health Statistics. The last Series 15 report was published in 2002. As of 2009, reports based on these surveys are included in Series 3.
- Series 16. **Compilations of Advance Data From Vital and Health Statistics**—The last Series 16 report was published in 1996. All reports are available online, and so compilations of Advance Data reports are no longer needed.
- Series 22. **Data From the National Mortality and Natality Surveys**—The last Series 22 report was published in 1973. Reports from these sample surveys, based on vital records, are published in Series 20 or 21.
- Series 24. **Compilations of Data on Natality, Mortality, Marriage, and Divorce**—The last Series 24 report was published in 1996. All reports are available online, and so compilations of reports are no longer needed.

For answers to questions about this report or for a list of reports published in these series, contact:

Information Dissemination Staff
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 5412
Hyattsville, MD 20782
1-800-232-4636
E-mail: cdcinfo@cdc.gov
Internet: <http://www.cdc.gov/nchs>

**U.S. DEPARTMENT OF
HEALTH & HUMAN SERVICES**

Centers for Disease Control and Prevention
National Center for Health Statistics
3311 Toledo Road
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