State and Local Area Integrated Telephone Survey OMB # 0920-0406 Three-year generic clearance granted 11/30/04; expires 11/30/07

<u>Change request to add additional topics:</u> 2007 Survey of Adult Transition and Health (SATH)

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National Center for Health Statistics State and Local Area Integrated Telephone Survey (SLAITS) Generic Mechanism OMB clearance number 0920-0406, expiration 11/30/07

05/11/07

2007 Survey of Adult Transition and Health (SATH)

OVERVIEW

The State and Local Area Integrated Telephone Survey (SLAITS) mechanism is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), under OMB clearance number 0920-0406 (expires 11/30/07). This generic clearance allows NCHS to collect health and well-being data on children, families, and communities over a three year period with abbreviated clearance packages submitted for individual projects.

NCHS is applying for permission to conduct the SLAITS 2007 Survey of Adult Transition and Health (SATH). The purpose of this project is primarily to determine the feasibility of calling telephone numbers from a much earlier survey, and will also capture current health status data for subjects identified in the 2001 SLAITS National Survey of Children with Special Health Care Needs (NS-CSHCN). Considered a pilot, this project will identify target areas for improvement in future followback modules.

Although SLAITS modules typically use the National Immunization Survey's list-assisted Random-Digit-Dial (RDD) sample, the SATH will not follow this traditional protocol. Rather than use a new sample, SATH will followback households that contained a child with special health care needs between the ages of 14 and 17 years as identified in the 2001 NS-CSHCN. The subject of the initial interview is now a young adult between 19 and 23 years old who will serve as the respondent for SATH. As a second component of this pilot test, SATH respondents have the option of participating in the survey using the Internet or landline or cellular telephones.

The SATH is sponsored by the DHHS Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), which officially administers the Federal Title V maternal and child health block grant program. SLAITS data collection is conducted under contract with National Opinion Research Center at the University of Chicago (NORC).

The SATH is scheduled to be fielded from early June through early August 2007. Project funds must be spent by September 30, 2007.

The content of the 2007 interview focuses on the impact of having adequate health-related transition services and a 'Medical Home' (MH) as promulgated by the American Academy of

Pediatrics (AAP) at baseline (2001) on selected health and well-being outcome measures at time 2 (2007). Two secondary content-related research questions include:

- If a child with special health care needs receives good health-related transition services in adolescence (time 1), does this translate into good health and well-being outcomes in adulthood (time 2)?
- If a child with special health care needs receives adequate care under the "Medical Home" paradigm in adolescence (time 1), does this translate into good health and well-being outcomes in adulthood (time 2)?

No additional annualized burden hours are requested to complete this project.

A. Justification

1. Circumstances Making the Collection of Information Necessary

This pilot survey will target selected cases from the 2001 NS-CSHCN who were between 14 and 17 years of age, and identified as children with special health care needs (CSHCN, using the MCHB definition¹) which states:

"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

The determination of CSHCN status was based on having at least one of five consequence-based criteria (prescription medication use, above average service use, functional limitations, use of mental health services, and use or need for specialized therapies).

In 2002, the journal *Pediatrics* published a consensus statement approved by the boards of the three medical professional organizations² to define 'transition' for these children:

"..For many young people with special health care needs, this will mean a transfer from a child to an adult health care professional; for many others, it will involve an ongoing relationship with the same provider but with a reorientation of clinical interactions to mirror the young person's increasing maturity and emerging adulthood. Whether the transition entails a transfer of care or not, all adults with special health care needs deserve an adult focused primary care physician... physicians have an important role in facilitating transitions to adulthood and to adult health care for young people who are least likely to successfully do it on their own."

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of Children With Special Health Care Needs. *Pediatrics*. 1998;102:137-139.

² The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine.

It further describes the characteristics of a transition from a physician who treats children to one who treats adults as:

"...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."

Characteristics of health-related transition and MH services for CSHCN are listed in Table 1 below. Currently no data source exists to assess these measures other than the NS-CSHCN, and outcome data are unavailable. This descriptive dataset will represent a wide swath of young adults with special health care needs who have varying severity of conditions, activity limitations, and disabilities.

Construct	Key characteristics of this core outcome			
Medical Home	CSHCN will receive coordinated ongoing comprehensive care within a Medical Home.			
	Child had a usual source of care			
	Child had a personal doctor or nurse			
	 Child had no problems obtaining referrals when needed 			
	 Effective care coordination was received when needed 			
	The child received family-centered care			
Transition	Youths with special health care needs will receive the services necessary to make transitions to			
	adult life, including adult health care, work, and independence.			
	 Child has received guidance and support in transition to adulthood: 			
	 Doctors have talked about changing needs as child becomes an adult 			
	 Child has plan for addressing changing needs 			
	 Doctors discussed shift to adult provider 			
	• Child has received vocational or career training (this component will not be examined in			
	the 2007 survey)			

Table 1. Characteristics of health-related transition and MH services.

The lack of descriptive outcome data for MH and transition services can be explained from several perspectives. From a medical perspective, CSHCN are living longer due to advancements over time in medical care, procedures and technology, and design of durable medical equipment. In the past, a smaller percentage of these youth survived to adulthood; therefore, outcomes research as the adolescent transitioned into adulthood was not seen as critically important. The dearth of transition-related literature is in part a result of the decentralization of transition service planning, programs, and services. From a political perspective, the lack of data may reflect the delicate balance that must be maintained in the appropriation process between the finite amount of money available for data collection and emergent maternal and child health data needs that may supplant previously identified research priorities. From a methodological perspective, identifying appropriate populations can be difficult. This difficulty may be further compounded by the severity and type of special health care need(s), functional limitation, or disability the adult experiences. For example, the adult may have a cognitive or physical barrier that may require additional flexibility or alterations in

the mode of survey administration, instrument, or procedures³; or his/her special health care need(s) may require collection of data from a proxy respondent instead directly from the adult.⁴

2. Purpose and Use of the Information Collection

This pilot project will:

- test procedures to locate and interview a typically mobile, transient, notoriously difficultto-locate-and-survey, but important population subgroup,
- use various data collection modes, and if successful,
- provide outcome data at time 2 (2007) on the impact of having health-related transition services and a MH at the time of first interview (2001).

This survey will also allow us to research factors related to developmental objective 16-22 as articulated in the DHHS Healthy People 2010 initiative:

"(to) increase the proportion of children with special health care needs who have access to a medical home"⁵.

4. Efforts to Identify Duplication & Use of Similar Information

Comparable national and state estimates of CSHCN transition and MH using the MCHB CSHCN definition are available only from the 2001 SLAITS NS-CSHCN and 2005 – 2006 SLAITS NS-CSHCN (data available this summer). These surveys are about children under age 18 years so there is no source of data on young adults.

To create the instrument listed in Attachment 3 (page 65), ten major surveys conducted by numerous Federal departments were examined for suitable content, as were materials from the Cornell University Employment and Disability Institute, the Western Michigan University Transition Research Institute, and the National Resource Center for Healthy and Ready to Work Programs (NRCHRTWP, also sponsored by MCHB). At least two of these surveys provide previously unavailable nationally representative cross-sectional data, but they focused solely on disabled children with more severe functional limitations than CSHCN. While states and local areas may conduct their own surveys of programs, these data are not nationally comparable.

The SATH instrument also includes questions previously used in other large national studies (such as verbatim questions pulled from the 2001 NS-CSHCN survey instrument, as we intend to compare 2001 and 2007 interview data), or taken verbatim or modified from other large surveys (as needed). Other SATH questions were written specifically for this implementation.

³ Mitchell S, Ciemnecki A, CyBulski K, Markesich J, Mathematica Policy Research, Inc (MPR). *Removing barriers to survey participation for persons with disabilities*. Paper distributed by the Rehabilitation Research and Training Center on Disability Demographics and Statistics at Cornell University. 2006.

⁴ Ciemnecki A, Barrett K, CyBulski K, Markesich J, Sloan M, Wright D, MPR. "Can you do this interview? Methods for determining if a proxy respondent is needed". Oral presentation at the conference entitled: "The future of disability statistics: what we know and need to know", organized by the Rehabilitation Research and Training Center on Disability Demographics and Statistics at Cornell University and funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. October 5 – 6, 2006; Arlington, VA.

⁵ U.S. Department of Health and Human Services. *Healthy People 2010*. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

Instrument sections are listed below and contain questions on the following:

- Health and Functional Status
 - General health status
 - Activity limitations daily living
 - Activity limitations work
 - Activity limitations school
 - Activity limitations taking care of house or family
- Medical Home
 - Usual place for care
 - Continuous screening
 - Foregone or delayed care
 - Care coordination
 - Person-centered care
- Transition services related to health
- Community-based services
- Health Insurance Coverage
 - Current coverage and past year coverage
- Adequacy of health insurance
- Transition services related to school
- Self-determination
- Satisfaction and support
- Demographics
 - Marital status and living arrangements
 - Personal earnings and program participation

8. Efforts to Consult Outside the Agency

To develop the questionnaire, technical and content experts from CDC, MCHB, and other MCHB-funded programs worked collaboratively with expert researchers from the health policy, pediatrics, CSHCN, methodology, and measurement fields as well as representatives of a non-profit family advocacy group to identify appropriate survey content.

9. Explanation of any Payment or Gift to Respondents

We plan to offer a cash monetary incentive of \$20 to eligible respondents who participate in the SATH interview for two reasons. First, this age group is notoriously hard to contact. A monetary incentive may provide a small incentive to participate. Second, the available sample is very small and we need to use every means possible to maximize the number of completed interviews. In addition, it is likely that some respondents will choose to respond using a cellular telephone, or this could be the only contact information we have to reach the eligible respondent. Cases completed using a cellular telephone will receive an additional cash incentive of \$5 (for a maximum of \$25) to defray the direct cost of conducting the interview using their allotment of cellular minutes. Although we will contact the eligible respondent via (his/her) cellular telephone number if it is the only contact information we are given, we will strongly encourage them to complete the interview either over the web or landline telephone.

We must address cellular telephone interviewing due to the profusion of these phones among persons in the target age range. Table 2 presents recent data from the National Health Interview Survey (NHIS) for interviews completed January through June 2006. During that period, almost one-quarter of young adults reported living in a cell phone only household. If we did not include an option to contact and interview respondents on their cellular telephones, we could introduce a significant amount of bias into our estimates.

Table 2: Household telephone status among adults ages 18 to 24 years (at the time of the interview).*

Household telephone status	Percentage (18 to 24 year olds)
Landline - with cell phone	46.3%
Landline - no cell phone	18.9%
Landline - unknown cell phone status	8.1%
No landline - unknown cell phone status	1.0%
Cell phone only	22.6%
No phone service	3.0%

*<u>Data source</u>: Centers for Disease Control and Prevention, National Center for Health Statistics. National Health Interview Survey, data collected January - June 2006. Estimates are based on household interviews of a sample of the civilian noninstitutionalized population.

12. Estimates of Annualized Burden Hours

Estimated number of participants

The 2007 starting sample overview is shown in Table 3 on the next page. All 10,933 possible cases will be released for initial locating and contacting processes. The cases will then be flagged as either 'imperative' or 'standard'. The children who in 2001 were receiving all the necessary transition services (N=674) are a minority of cases but because of their importance to this study, they will receive the most intensive locating protocol (extended web-based and phone treatments, as well as expert teams of locating, interviewing, and refusal conversion staffers assigned). For distinction purposes, they are considered "imperative" cases while all others are considered "standard" cases.

The 2001 survey was not originally designed as a followback survey, and because we have no prior experience locating subjects under these circumstances, we are unsure of exactly how many subjects we will locate in 2007. Due to the lack of positively identified address information prior to first re-contact with the household, an advance letter cannot be sent. However, we will be able to send, fax, or email a 'recruitment' text to verify the survey or give eligible respondents and others more information **upon request** (eligible respondent version in Attachment 4i, page

90; the 'more general' version for persons other than the eligible respondent in Attachment 4ii, page 93).

	'Imperative cases'	'Standard cases'
Definition	2001 CSHCN completed cases	All other 2001 CSHCN
	where it was reported the child	completed cases
	received <u>all</u> transition services	
Sample size (total n)	674	10,259
Projected percentage of 2001	60%	40%
completed cases that are able		
to be located		
Projected percentage of 2001	50%	40%
cases that are able to complete		
the SATH		
Targeted <i>minimum</i> goal:	200	1,641
number of completed cases in		
2007		
Minimum expected completed	1,8	341
interviews		

Table 3.	Starting sample	sizes & characteris	tics for 2007 surve	y subgroups.
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Table 4 on the next page illustrates the projected annualized burden of the 2007 SATH, a 15 minute interview. The total sample size is 10,933 CSHCN cases; 674 of these are considered 'imperative' and received all transition services. The remaining 10,259 cases are all of the other age-eligible CSHCN cases.

We project that we will be able to locate 60% of the SATH-eligible imperative cases, and 40% of the SATH-eligible standard cases. Once located, we estimate that 50% of the imperative cases will complete the SATH interview, compared to 40% of the standard cases.

The burden listed in Table 4 is based on these percentages, resulting in completion of an estimated 200 imperative cases and 1,641 standard cases; for a grand total of 1,841 completed SATH interviews for this pilot project.

Respondents	Number of	Number of	Average burden per	Total burden hours
	respondents	responses	response (in hours)	
		per		
		respondent		
Locating process:	10,933	1	3 / 60	547
2001 respondents				
Locating process:	1,500	1	3 / 60	75
'leads' or persons other than				
the 2001 respondent who				
may have contact				
information for the SATH-				
eligible respondent				
SATH respondents	1,841	1	15 / 60	460
TOTAL PROJECTED BURDEN HOURS			1,082	

Table 4. Projected annualized burden estimate, 2007 SATH.

The burden for the total 2007 SATH is 1,082 hours. These hours are part of the total burden already approved for 2005, that is, 55,190 annualized burden hours. We are NOT requesting an increase in the number of annualized burden hours.

16. Plans for Tabulation & Publication & Project Time Schedule

The unweighted and unedited data will be examined by the contractor and NCHS for logic, consistency, and flow. Frequencies of all variables will be reviewed to ensure the data meet our expectations. The timing of sections and subsections will be reviewed. We also plan to assess the success of the locating process, in part by monitoring the number of eligible SATH respondents we are able to successfully locate and level of effort.

Initial data analyses of SLAITS surveys focus on baseline descriptive runs, and assess data quality, methods, and substantive measures. Item non-response rates will be examined to evaluate the potential sensitive nature of specific questions. A high frequency of "refused" responses or interview break-off points might indicate questionable validity for an individual question. Interviewers are debriefed periodically to identify anecdotes with the questionnaire (comprehension, expectations, skip patterns, insufficient response categories), and procedures. NCHS and NORC personnel periodically attend and/or conduct these group and individual interviewer debriefings.

After the initial data quality assessment, cross tabulations of primary categories of dependent variables with categories of independent variables examine common themes and various premises. Due to projected data limitations such as small cell sizes, it is unlikely that we will be able to perform multivariate analyses using SATH data. Table 5 on the next page lists the proposed project time schedule.

Activity	Date
Instrument content & layout finalized	March 1, 2007
Continued to more precisely define the locating procedures and scripts	March - April 2007
 Solicit & obtain appropriate project clearances NCHS Research Ethics Review Board NORC Institutional Review Board Office of Management and Budget 	April – May 2007
Data collection	Early June – Early August 2007
Assess locating procedures and data quality (observe interviews, review preliminary data, debrief interviewers)	Ongoing process throughout data collection period
Internal files delivered to NCHS	late September 2007
Data collection and delivery activities must be completed by the contractor	end of the Federal fiscal year, September 30, 2007
Data analysis	Ongoing

Due to the compressed schedule and small sample size, there is no pretest for this survey. After completing the first week of the survey, SLAITS and NORC staff will review and assess procedures, debrief interviews, observe interviews, and examine early data to determine whether any procedures need to be modified.

If there are no disclosure risks and the data are of sufficient quality, a SATH public use file (PUF) will be prepared and cleared through the NCHS Disclosure Review Board (DRB). Preparation for this would begin in October 2007. If it is determined the SATH PUF cannot be produced, a confidential data file will be prepared for use through the NCHS Research Data Center (RDC). The RDC provides restricted access to researchers (who meet certain qualifications) to confidential NCHS data in a secure environment, without jeopardizing the confidentiality of respondents. More information on the policies and procedures of the NCHS RDC can be found at: <u>http://www.cdc.gov/nchs/r&d/rdc.htm</u>.

B. Statistical Methods

1. Respondent Universe & Sampling Methods

The 2001 frame was linked to the National Immunization Survey (NIS) sampling frame. The 2007 SATH, however, employs a convenience or purposive sample and will have no link to the current NIS.

The universe from which the original 2001 sample was drawn is all US households with landline telephones. The SATH universe consists of 14 to 17 year old CSHCN cases identified in the 2001 NS-CSHCN and are now adults 19 to 23 years old. Details of the SATH sample frame are listed in Table 4 on page 9. The 2007 survey will **only** be conducted in English.

For 2001 cases completed using TTY or RELAY systems, we will leave a message with their answering system (if any) to contact NORC using a toll free number connected to a TTY machine to complete the interview.

To the best of our knowledge, the main difficulty is having an old phone number to locate someone who can provide valid contact information, and then locating the eligible young adult respondent. Due to the complexity of the locating process (described below), only very experienced personnel will be assigned to this project. Their advanced level of experience will allow them to better identify households that may need to be contacted using special procedures such as the TTY.

If a 2001 sampled telephone number connects to a household or business and the person on the phone states that he/she knows nothing about the 2001 interview or person who is now 19-23 years old, the call will be terminated and sent back to locating. If a person at the 2001 number refuses to provide any contact information for the eligible respondent, all contact will cease. Cellular telephone numbers will be dialed by hand (not auto dialed).

2. Procedures for the Collection of Information

Advance letter

An advance letter will not be sent due to projected low match rates of addresses prior to contact and the condensed time period of data collection. We also do not want to alert what may be the wrong household about an upcoming government survey.

Locating the 2001 sampled children

The 2001 procedures did not assume a followback survey; consequently, we have only the 2001 telephone number for the parent or guardian, the child's birth date or age at interview for the majority of cases, and possibly, the child's first name. We have established procedures to locate

the survey subjects under various assumptions ranging from: living at home with their parents, to the parents and survey subject have moved in the interim and do not live together.

The SATH locating protocol (Attachment 6ii, page 104) is based on procedures (and uses the same experienced staff) as the Provider Record Check (PRC) component of the NIS that locates and contacts health care providers across the country to verify parent-reported immunization data. The SLAITS contractor will use commercial databases available to government, legal, risk management, law enforcement, and commercial customers with legitimate uses to locate current contact information for the respondents.

Experienced trained locators (who are also highly trained and experienced telephone interviewers) will call the 2001 sampled telephone numbers. The computerized system will keep track of the outcome of each call. Locators will maintain detailed notes on each number dialed and its outcome. The computer also captures the date, time of day, and length of call. Refusal cases are tabulated separately with detail as to the timing and nature of the refusal. Figure 1 (next page) summarizes the locating and introductory processes.

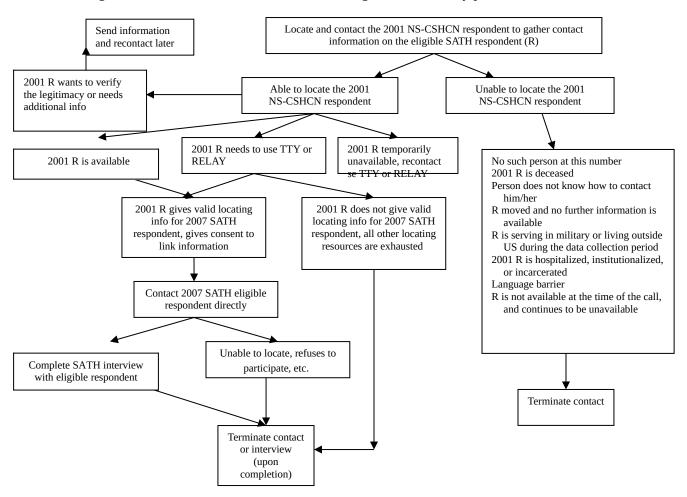


Figure 1. Flowchart of the 2007 SATH locating and introductory processes.

Data collection methods

Once the 2001 respondent is located, the locator will collect current contact information about the eligible SATH respondent. The 2001 respondent is free to give as much or as little contact information as they wish to share. This includes his/her name (first, middle, and last), nickname, or initials; phone numbers (each number will be queried if the number is cellular or residential); email (personal, business, or school); street and mailing address; residence type (private, dorm, etc.); and date of birth or age (confirmation). We are unsure of the specific nature of the contact information that will be supplied; therefore, we have taken many possible contact scenarios into account when designing the scripts and procedures. We will offer respondents the option of completing the survey over the telephone or over the Internet. CATI and web survey introduction and exit scripts, as well as proposed screening and locating text, can be found in Attachments 1 and 2 (pages 17 and 26 respectively).

Separate procedures are in place to collect information for 'leads' who may know how to locate the 2001 respondent if he/she cannot be located. We plan to ask for contact information for persons who may know how to locate the 2001 respondent and/or the 2007 eligible respondent. If the locators are successful at obtaining valid contact information, the initial contact of the eligible young adult may occur via (his/her) cellular phone(s), landline telephone(s), email address, addresses, and/or fax number(s).

Telephone

If we contact the eligible young adult by telephone, we will encourage him/her to complete the interview over the telephone immediately so we do not risk losing the case. A web-based internet application has been developed to collect data in lieu of the traditional computer-assisted telephone interviewing (CATI) program that we have used consistently for other SLAITS modules. This allows us to streamline instrument development and reduce the amount of preparation time because only one version of the survey will need to be constructed regardless of mode, instead of having to construct a CATI-version and a web version. More information on the data collection program and web data collection is available in Attachment 6iii (page 107).

Internet

Eligible SATH respondents who wish to complete the survey over the web will be mailed (or emailed) a letter that contains a link to a website which will display a screen with the information below, as well as a Personal Identification Number (PIN) and password to enter (Attachment 7i, page 114). Reminder letters for potential web participants will be sent or emailed as needed (Attachment 7ii, page 115).

3. Methods to Maximize Response Rates and Deal with Nonresponse

Thorough locating techniques by experience personnel will help us make as many positive contacts as possible. Callbacks and reminders will be conducted to the extent the ERB allows. Finally, token incentives will be provided to those who elect to participate in the interview. Traditional response rates are not appropriate for this non-probability sample. Because we have not attempted this survey design in the past, we are unsure as to how many definite matches we will be able to confirm.

Ongoing analysis will be conducted to evaluate the extent to which nonresponse and other biases are impacting the quality of the data being collected. Examination of expected demographic characteristics, interview break-offs, and other qualitative and quantitative measures will be constantly reviewed and assessed. Should changes to the survey design be warranted, proper clearances will be sought.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following person was consulted on the statistical aspects of design, data collection, and analysis:

> Stephen Blumberg, Ph.D. Senior Health Scientist, SLAITS National Center for Health Statistics Division of Health Interview Statistics sblumberg@cdc.gov 301-458-4107

Attachments

- 1. CATI and web survey introduction and exit scripts
- 2. Screening and locating text
- 3. Data collection instrument: 2007 Survey of Adult Transition and Health (SATH)
- 4. Text of SATH recruitment or verification message to be emailed, faxed, or mailed (upon request)
 - i. To the eligible young adult respondent
 - ii. To persons other than the eligible young adult respondent (more general)
- 5. SATH thank you letter (accompanies remuneration)
- 6. Backup supporting material
 - i. NORC protocol for physical and network security
 - ii. Detailed description of the locating process & database
 - iii. Detailed description of the program & process used for web data collection
 - iv. Selected persons involved in developing SATH content and procedures
- 7. Letter sent or mailed to potential web respondents
 - i. Contains the personal identification number (PIN) and password to access the instrument on the secure NORC website
 - ii. Reminds potential web respondents to complete the survey

Attachment 1

CATI and web survey introduction and exit scripts

OMB Number 0920-0406 Expiration date 11/30/07

CATI QUESTIONNAIRE INTRODUCTION

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 404-639-4604; or send an email to omb@cdc.gov.

The Public Health Service Act is Volume 42 of the US 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.

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

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 YOUTHNAME_A-YOUTH_NAME_D"]?

Yes, youth comes to phone	1 [GO TO NEW_RESP_SC]
No, youth unavailable	2 [GO TO REACH_SC]

REACH_SC When would be a good time to call back to reach [FILL YOUTHNAME_A-YOUTH_NAME_D"]?

___:___

(1) AM
 (2) PM
 (3) NOON
 (4) MIDNIGHT
 (7) DON'T KNOW
 (9) REFUSED

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, and their health status and health care as they get older. In 2001, we spoke to someone in your household about health care. The Centers for Disease Control and Prevention would now like to discuss changes that may have occurred to your health or healthcare in the past few years.

CONTINUE	1 [GO TO SL_INTRO]
PROXY NEEDED	2 [GO TO PDIFF]

PDIFF What difficulty do you have that prevents you from participating for yourself?

Hearing difficulty	1	[GO TO WEB
	-	OPTION; IF
		WEB DECLINED, GO
		TO RELAY, RELAY
		DECLINED, GO TO
		PROXY_INT]
Speech difficulty	2	[GO TO WEB OPTION]
Cognitive barrier	3	[GO TO PROXY_SCR]
Physical barrier	4	[GO TO WEB OPTION]
DK	77	[GO TO WEB OPTION]
REFUSED	99	[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?

CONTINUE NOW USING RELAY1	[GO TO RELAYNOW]
SCHEDULE CALLBACK WITH RELAY2	[GO TO RELAYCBK]
DON'T KNOW77	[GO TO RELAYNOW]
REFUSED99	[GO TO RELAYNOW]

- RELAYNOW I have to call into the TTY machine to continue this interview. I will call you back in less than five minutes at [FILL SAMPLED PHONE XXX-XXX]. Please stay by your TTY machine for the next five minutes. Thank you, and good bye.
- RELAYCBK. When would be a good time to call back to reach you using RELAY?

___:___

RELAYCBK_2 (1) AM (2) PM (3) NOON (4) MIDNIGHT (7) DON'T KNOW (9) REFUSED

PROXY_SCR

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

YES, CURRENTLY ON PHONE1	[START PROXY INTERVIEW]
NO, NOT AVAILABLE2	[GO TO REACH_PROX]

PROXY_INT I understand that you are the person who makes the majority of the decisions about the [FILL NAME?]. 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:]

Yes, hearing difficulty.....1 [CONTINUE]

Yes, speech difficulty	2 [CONTINUE]
Yes, cognitive barrier	3 [CONTINUE]
Yes, physical barrier	4[CONTINUE]
No, youth is able to do the interview	5 [TERMINATE & CONTACT YOUTH R]

Because [FILL he/she] cannot be interviewed and you are knowledgeable about [FILL: his/her] healthcare, 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 it is your choice to participate in this research. You may choose not to answer any question you don't wish to answer or stop at any time. This study is authorized by the U.S. Public Health Service Act. By law, we will take all possible steps to protect your privacy and are required to use your answers only for statistical research. I can give you more information on this and other federal laws if you want. The survey will take about 15 minutes. In appreciation, you will receive \$20. (IF CALLING KNOWN CELL PHONE NUMBER: You will also receive an additional \$5 to defer your costs for doing the interview on your cell phone.) 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.

CONTINUE, RECORDING ACCEPTABLE1	[GO TO CONF_DOB_X]
CONTINUE, DO NOT RECORD2	[DISABLE RECODRDING
	& GO TO CONF_DOB_X]
PROXY NEEDED	2 [GO TO PDIFF]

HELP SCREEN (SL_INTRO): The Public Health Service Act is Volume 42 of the US 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.

CONF DOB_x

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?

YES.....1 [GO TO F2Q11]

NO......2 [GO TO NEWDOB_X]

NEWDOB_X 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)

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

CATI QUESTIONNAIRE EXIT

ALL PATHS LEAD TO THIS EXIT PATH WHEN CONFDOB_X=1 or NEWDOB_X IS WITHIN RANGE

CLOSE

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

YES1	[GO TO AC_NAME
	INTRO]
NO2	[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 CELL_PAY]

CELL_PAY

Did we conduct this survey on your cell phone?

YES1	[GO TO CELL_SCRIPT]
NO2	[GO TO AC_REFUSED]

CELL_SCRIPT

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

AC_Refused	[BLANK]
	Address correct and confirmed01 GO TO AC2
	Refused to give/confirm address
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 Transition and Health, please call the study's toll-free number, xxx-xxx. 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. Thanks again.

2007 SATH WEB QUESTIONNAIRE INTRODUCTION

OMB Number 0920-0406 Expiration date 11/30/07

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 404-639-4604; or send an email to omb@cdc.gov.

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

[STANDARD PIN and password entry screen FORTHCOMING]

The Centers for Disease Control and Prevention (CDC) is doing a nationwide survey 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. The CDC would like to examine changes that may have occurred in your health or healthcare in the past few years by getting information directly from you.

It is your choice to participate in this research. You may choose not to answer any question you don't wish to answer--simply leave it blank. You may also stop the survey at any time without penalty, or continue it at a later time. <u>INSERT BREAK OFF INSTRUCTIONS</u> (currently being developed by NORC). You will be able to restart the survey where you left off.

This study is authorized by the U.S. Public Health Service Act. This and other strict laws require us to protect your privacy and use your answers only for statistical research. You can see these laws by clicking <u>here⁶</u>.

This survey will take about 15 minutes. In appreciation, you will receive \$20. If you have any questions about this study, please call the study's toll-free number, xxx-xxxx.

The survey contains questions about your health, health status, and health care as you get older. <u>INSERT</u> <u>WEB QUEX NAVIGATION INSTRUCTIONS</u> (currently being developed by NORC).

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

YES1	[GO TO F2Q11]
NO2	[GO TO NEWDOB_X]

NEWDOB_X

⁶ If this link is selected, another screen will appear with the following text: "The Public Health Service Act is Volume 42 of the US 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".

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)

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

WEB QUESTIONNAIRE EXIT

ALL PATHS LEAD TO THIS EXIT PATH WHEN CONFDOB_X=1 or NEWDOB_X IS WITHIN RANGE

Those are all the questions. Thank you for participating in the 2007 Survey of Adult Transition and Health. 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 this survey, please call the study's toll-free number, xxx-xxx. 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. Thanks again!

Attachment 2:

Screening and locating text

OMB Number 0920-0406 Expiration date 11/30/07

2007 SATH SCREENER

SCREENER PART 1: LOCATE 2001 CSHCN RESPONDENT

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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?

YES, I AM \ge 18 YO	1 [GO TO INTRO_1A]
THIS IS A BUSINESS	2 [GO TO PH_CONF]
NEW PERSON COMES TO PHONE	3 [<u>GO TO INTRO 1</u>]
LANGUAGE BARRIER	
(ANY LANGUAGE OTHER THAN ENGLISH)	4 [GO TO
	TERM_BRIEF]
NO PERSON AT HOME WHO IS OVER 17	5 [<u>GO TO S2_B]</u>
OUT OF SCOPE	6 [GO TO
THANK_YOU_OOS]	
HHM ENDED CALL	7 [GO TO UNIVERSAL
EXIT-T1]	
ANSWERING MACHINE	
MSG_PENDING SCREEN	-
R WILL CALL 800 LINE/VERIFY WEBSITE	9 [GO TO
M1_NAME_WEB_ADD]	
R ASKS FOR LETTER-MAILED	10 [GO TO UNIVERSAL
	EXIT-M1_NAME]
R ASKS FOR LETTER-EMAILED	11 [GO TO UNIVERSAL
	EXIT M1_EMAIL]
SUPERVISOR REVIEW	12 [GO TO CALL NOTES
BOX]	
(RAISE YOUR HAND TO GET PERMISSION BEFORE	E USING THIS CODE)
REFUSED	99 [GO TO
TERM_BRIEF]	

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?

YES1	GO TO [BLANK] SCRIPT SHOWN BELOW
NO2	GO TO PH CONF

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

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

YES1	[GO TO PH_TIME]
NO2	[GO TO NEWPHONE]
NUMBER HAS CHANGED/	
NUMBER FORWARDED3	[GO TO NEWPHONE]
REFUSED4	[GO TO TERM_TY]

NEWPHONE	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 "XXX-XXX-XXXX)?
 - (1) LESS THAN FOUR YEARS [GO TO TERM_TY]
 - (2) MORE THAN FOUR YEARS [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 Transition and Health, please call the study's toll-free number, XXX-XXX.)
- INTRO_1A In (INTDATE-YYYY), we conducted a nationwide telephone study on children's health with an adult at this phone number about a child who was between the ages of 14-17 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. This study is authorized by the U.S. Public Health Service Act. It and other federal laws require us to protect your information and keep it private.

Is [he/she] available?

HUNG UP DURING INTRO	1 [GO TO UNIVERSAL EXIT-T1]
YES, CURRENTLY SPEAKING WITH HIM/HER	2 [GO TO INTRO_2001R]
YES, 2001 R COMES TO THE PHONE	3 [GO TO INTRO_2001R]
YES, 2001 R IS AVAILABLE BUT NEEDS THE IWER	

TO CALL BACK SO R CAN SWITCH TO TTY	4 [GO TO RELAYNOW]	
THIS PERSON NEEDS THE INTERVIEWER TO		
CALL BACK LATER AND CONDUCT THE INTERVIE	EW	
USING TTY	5 [GO TO RELAYNOW]	
LANGUAGE BARRIER		
(ANY LANGUAGE OTHER THAN ENGLISH)	7 [GO TO TERM_BRIEF]	
NO SUCH PERSON AT THIS NUMBER	8 [GO TO PHONE_01INFO]	
NO, THE PERSON YOU NEED TO SPEAK WITH IS		
NOT AVAILABLE	9 [GO TO REACH_CB]	
NO, 2001 R HAS MOVED	10 [GO TO 2001R_CONT]	
NO, 2001 RESPONDENT IS HOSPITALIZED,		
INSTITUTIONALIZED OR INCARCERATED	11 [GO TO TERM_TY]	
NO, 2001 RESPONDENT IS DECEASED	12 [GO TO F1Q]	
NO, 2001 RESPONDENT IS SERVING IN THE MILITA	ARY	
OR LIVING OUTSIDE USA	13 [GO TO TERM_TY]	
NO, THE PERSON DOES NOT KNOW HOW TO CONT	ГАСТ	
THE 2001 R	14 [GO TO REACH_5]	
PERSON WANTS TO VERIFY THE LEGITIMACY OF		
THE SURVEY OR NEEDS ADDITIONAL		
INFORMATION	15 [GO TO UE- 1_NAME_WEB]	
R KNOWS 2 OR MORE POSSIBLE 2001 RESPONDEN	TS	
WHO LIVE OR USED TO LIVE AT THIS NUMBER16 [GO TO DOB_PROBE]		
SPACE		
IF VOLUNTEERED: YOUTH IS SERVING IN THE MI	LITARY,	
INCARCERATED OR LIVING OUTSIDE USA	17[GO TO WEB_OFFER]	
IF VOLUNTEERED: YOUTH DOES NOT HAVE ANY	CONTACT INFO	
(HOMELESS, ETC.)	18 [GO TO REACH_5]	
IF VOLUNTEERED: YOUTH IS DECEASED	19 [GO TO F1Q_Y]	
DON'T KNOW	77 [GO TO REACH_5]	
REFUSED	99 [GO TO TERMINATE AFTER RC ATTEMPT]	

- RELAYNOW I have to call into the TTY machine to continue this interview. I will call you back in less than five minutes at [FILL SAMPLED PHONE XXX-XXX]. Please stay by your TTY machine for the next five minutes. Thank you, and good bye.
- RELAYCBK. When would be a good time to call back to reach you using RELAY?

(1) AM (2) PM (3) NOON (4) MIDNIGHT (7) DON'T KNOW (9) REFUSED

PHONE_

01INFO	Do you know the person that had this phone number in 2001?
--------	--

YES1	GO TO 2001R_CONT
NO2	GO TO PH_CONF

REACH_5 Do you know who else I can contact who might know this [FILL AGE_CALC] yearold's / [FILL AGE_CALC] year-old's [RELATION] contact information?

YES	1[GO TO
	LEAD_REACH_01
	IF 2001 R LEAD;
	LEAD_REACH_Y
	IF YOUTH LEAD]
NO	2 [GO TO PH_CONF]
DON'T KNOW	77 [GO TO PH_CONF]
REFUSED	99 [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 that is currently 19 to 23 years old?

___:__

(1) AM
 (2) PM
 (3) NOON
 (4) MIDNIGHT
 (7) DON'T KNOW
 (9) REFUSED

FILL CONTACT NAME AT APPOINTMENT SCREEN IF R WILL PROVIDE IT.

F1Q I'm sorry to hear that (FILL SEX-HE/SHE) passed away. Please accept my condolences.

ON-SCREEN HELP HERE FOR TRANSITION

[GO TO YOUTH_CONT]

F1Q_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) DK (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-MMMDDYYYY]. Do you know who this might be?

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

YES1	[GO TO 2001R_CONT]
DON"T KNOW77	[GO TO REACH_CB]

OMB Number 0920-0406 Expiration date 11/30/07

PATH TO COLLECT POSSIBLE 2001 RESPONDENT'S CONTACT INFORMATION

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2001R_CONT Could you please tell me the name of this [FILL CURRENT AGE] child's [FILL RELATION]?

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

YES	1 [GO TO 2001R_NAME_A]
NO	2 [GO TO 2001R_NAME_D]
DON'T KNOW	3 [GO TO 2001R_NAME_D]
REFUSED	4 [GO TO 2001R_NAME_D]

2001R_NAME_A What is the [FILL RELATION]'s first name?

FIRST_____

2001R_NAME_B What is the [FILL RELATION]'s middle name?

MIDDLE

2001R_NAME_C What is the [FILL RELATION]'s last name?

LAST_____

2001R_NAME_D Does the [FILL RELATION] have a nickname, initials or another name that they may prefer? NICKNAME/OTHER NAME__

2001R_PH Could you please tell me (FILL 2001 R_NAME_A OR FILL 2001 R_NAME_D if given)'s (FILL BLANK OR second...ninth) phone number?

YES	1 [RECORD phone number(s) IN
	2001R_PH_X]
NO	2 [GO TO 2001
	$R_EM_X]$
DON'T KNOW	77 [GO TO 2001
	R_EM_X]
REFUSED	99 [GO TO 2001
	R_EM_X]

2001R_ PH_X

2001 R PHONE NUMBER COLLECTION SCREEN	
XXX-XXX-XXXX	[GO TO 2001 R_PH_CONF]

2001R_PH_ CONF

CONF	Is that a cellular telephone number?	
	YES	1 [GO TO 2001R_CONFHH]
	NO	2 [GO TO 2001R_CONFHH]
	DON'T KNOW	77 [GO TO 2001R_CONFHH]
	REFUSED	99 [GO TO 2001R_CONFHH]
2001R_ CONFHH	Is that number a private residence?	
	YES	[GO TO 2001R_PH_LOOP]
	NO	[GO TO 2001R_PH_LOOP]
	DON'T KNOW	[GO TO 2001R_PH_LOOP]
	REFUSED	[GO TO 2001R_PH_LOOP]
2001R_PH_ LOOP Does (FILL 2001 R_NAME_A OR FILL 2001 R_NAME_D if given) have anoth phone number where (he/she) can be reached?		D if given) have another
	YES	[GO TO NEXT 2001 R_PH]

2001R	NO DON'T KNOW REFUSED	[GO TO 2001R_EM_X]
_EM_X	Could you please tell me (FILL 2001 R_NAME_A OR FII given)'s (FILL BLANK OR secondninth) electronic ma	
		1 [RECORD E-MAIL ADDRESS ELEMENTS IN 2001R_MAIL_1 TO 2001R_EMAIL_9]
	NO	2 [GO TO 2001R_AD_X]
	DON'T KNOW	77 [GO TO 2001R_AD_X]
	REFUSED	99 [GO TO 2001R_AD_X]
2001R_ EMAIL_1 through 2001R_ EMAIL_9	EMAIL ADDRESS COLLECTION SCREEN	
	@	
2001R_EM_ CONF	Is this email address for personal, business or school use?	
	PERSONAL	1 [GO TO 2001R_EM_LOOP]
	BUSINESS	2 [GO TO
	SCHOOL USE	2001R_EM_LOOP] 3 [GO TO 2001R_EM_LOOP]
	DON'T KNOW	77 [GO TO 2001R EM LOOP]
	REFUSED	
2001R_EM_ LOOP	Does (FILL 2001 R_NAME_A OR FILL 2001 R_NAME_ address where (he/she) can be reached?	_D if given) have another email
	YES	[GO TO NEXT 2001R_EM_X]
	NO	[GO TO 2001R_AD_X]
	DON'T KNOW	[GO TO 2001R_AD_X]

OMB 83-C State and Local Area Integrated Telephone Survey (SLAITS) package: 0920-0406			
	REFUSED	[GO TO 2001R_AD_X]	
2001R_AD _X	Could you please tell (FILL 2001 R_NAME_A OR FILL 20 [FILL BLANK OR secondninth] street address or address 2001RPH_9 not equal null then FILL in case we cannot read	ses [IF 2001RPH_1 through	
	YES	1 [GO TO 2001R_AD_ST_X]	
	NO DON'T KNOW REFUSED	2 [CONF_INTRO_01R]77 [CONF_INTRO_01R]	
2001R_AD_ ST_X	What is the street address?		
2001R _AD_ APT_X	What is the apartment number?		
2001R _AD_ CITY_X	APT # What is the city and state? CITY		
2001R _AD_ STATE_X	State Dropdown Menu		
2001R _AD_ ZIP_X	What is the zip code? ZIP [GO TO 2001RCONYHH	[]	
2001R CONYHH	Is that address a private residence?		
	YES	[GO TO 2001R_AD_LOOP]	
	NO	[GO TO 2001R_INST]	
	DON'T KNOW	[GO TO CONF_INTRO_01R]	
	REFUSED	[GO TO CONF_INTRO_01R]	
2001R_ INST	Can you describe the type of residence?		
	UNVERSITY/COLLEGE HOUSING (DORM)1	[GO TO 2001R_AD_LOOP]	

	MILITARY BASE2	[GO TO 2001R_AD_LOOP]
	PRISON	[GO TO 2001R_AD_LOOP]
	OTHER INSTITUTION4	[GO TO 2001R_AD_LOOP]
	DON'T KNOW77	[GO TO 2001R_AD_LOOP]
	REFUSED99	[GO TO 2001R_AD_LOOP]
2001R_AD_ LOOP	Does (FILL 2001 R_NAME_A OR FILL 2001 R_NAME_D if given) have another address where (he/she) can receive mail?	
	YES	[GO TO NEXT 2001R_AD_X]
	NO	[GO TO CONF_INTRO_01R]
	DON'T KNOW	[GO TO CONF_INTRO_01R]
	REFUSED	[GO TO CONF_INTRO_01R]
CONE INTRO		
CONF_INTRO_ 01R	I would like to confirm that I have the correct information for the person that we'll be contacting.	
	[<u>INTERVIEWER</u> : CONFIRM ALL NAMES AND SPEL] RESPONDENT. IF LAST NAMES ARE THE SAME, M THE SAME SPELLING.]	
CONF_NAME_ 01R	-	
UIK	The name I have for this person is [FILL NAME OF FROM 2001RNAME_A-2001R_NAME_D]. Is this correct?	
	YES1 2001R_FUTCONT	[GO TO
	NO2	[GO TO 2001R_CONT AND CORRECT]

2001R FUTCONT

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

YES	1 [GO TO FUTCONTNAME]
NO	2 [GO TO PH_CONF]
DON'T KNOW	77 [GO TO PH_CONF]
REFUSED	99 [GO TO PH_CONF]

FUTCONT NAME

What is your name?

NAME_____

[GO TO PH_CONF]

SCREENER PART 2:

OBTAIN CONTACT INFORMATION FOR SATH-ELIGIBLE RESPONDENT FROM THE 2001 CSHCN RESPONDENT

DETERMINE IF PROXY RESPONDENT IS NEEDED TO COMPLETE THE 2007 SATH

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 3 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 404-639-4604; or send an email to omb@cdc.gov.

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INTRO_ 2001R

(NOTE: Text in parentheses will appear if speaking with 2001 R. If 2001 R 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 2001interview.) The Centers for Disease Control and Prevention would like to add to the information (you) provided in 2001 by speaking to (this/your) child about [FILL SEX-his/her] current heath 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 phone, or complete the survey on the Internet. This study is authorized by the U.S. Public Health Service Act. It and other federal laws require us to protect your information and keep it private. (I'd like to continue unless you have any questions.)

INTERVIEWER INSTRUCTION: IF NO QUESTIONS, ASK THE FOLLOWING:

Can you tell me how to get in touch with this [FILL AGE_CALC]-year old?

OR USED TO LIVE AT THIS NUMBER	4 [GO TO DOB_PROBE_Y]
YES, YOUTH IS AVAILABLE BUT NEEDS THE IWER	R
TO CALL BACK SO R CAN SWITCH TO TTY	5 [GO TO RELAYNOW]
YES, YOUTH IS AVAILABLE BUT NEEDS	
CURRENT RESPONDENT TO INTERPRET	6 [GO TO NEW_RESP]
NO SUCH PERSON AT THIS NUMBER	7 [GO TO REACH_5]
NO, THE PERSON YOU NEED TO SPEAK WITH IS	
NOT AVAILABLE	8 [GO TO REACH_SC_AGE]
NO, YOUTH HAS MOVED	9 [GO TO YOUTH_CONT]
NO, THE PERSON DOES NOT KNOW HOW TO CONT	TACT
THE YOUTH	11 [GO TO REACH_5]
NO, YOUTH IS HOSPITALIZED,	
INSTITUTIONALIZED OR INCARCERATED	12 [GO TO PROXY_SCR]
NO, YOUTH IS INCAPABLE	13 [GO TO DIFF_Q]
NO, YOUTH IS SERVING IN THE MILITARY OR	
LIVING OUTSIDE USA	13 [GO TO WEB_OFFER]
NO, YOUTH IS DECEASED	14 [GO TO F1Q_Y]
PERSON WANTS TO VERIFY THE LEGITIMACY OF	
THE SURVEY OR NEEDS ADDITIONAL	
INFORMATION	15 [GO TO UE- 1_NAME_WEB]
DON'T KNOW	77 [GO TO REACH_5]
PEELISED	99 ΙΟΟ ΤΟ ΤΕΡΜΙΝΑΤΕ

DOB_

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

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

YES1	[GO TO INTRO_2001R
	"Can you tell me how to get
	in touch with?"]

	Don't Know	7 [GO TO REACH_5]
REACH_SC_	AGE When would be a good time to call back to reach the [FII	L AGE]-year-old?
	:	
	(1) AM (2) PM (3) NOON (4) MIDNIGHT	
	(7) DON'T KNOW (9) REFUSED	
DIFF_Q	What difficulty does [FILL HE/SHE] have that prevents participating?	[FILL him/her] from
	I	WEB DECLINED, GO TO RELAY, RELAY DECLINED GO TO PROXY_SCR]
	Cognitive barrier	
	Physical barrier	
	DK	
	REFUSED	9 [GO TO PROXY_SCR]
WEB_OFFE	R We have a web-based survey available. [FILL: Would yo the survey using the web?	u like to /Can they] complete
	YES	1 [GO TO WEB OPTION]
	NO	2 [GO TO PROXY_SCR]
PROXY_SCF	, ,	
FROX1_5C	Is the person who makes the majority of the decisions about health care available?	out the [FILL AGE]-year old's
	YES, CURRENTLY ON PHONE	1 [START PROXY_INT]
	YES, YOUTH MAKES OWN DECISIONS	2 [GO TO WEB_OFFER]
	NO, NOT AVAILABLE	3 [GO TO REACH_PROX]
REACH_ PROX	Can you tell me how I could contact the person who mak about the [FILL AGE]-year old's health care?	es the majority of the decisions

	YES	1 [GO TO PROX_NAME_A]
	NO	2 [GO TO PH_CONF]
	DON'T KNOW	77 [GO TO PH_CONF]
	REFUSED	99 [GO TO PH_CONF]
PROX_NAME	FIRST	
PROX_NAME_	_B What is their middle name? MIDDLE	
PROX_NAME_	_C What is their last name? LAST	
PROX_NUM	Could you please tell me this person's telephone number?	
	YES	1 [RECORD phone number(s) IN PROX_PH_X]
	NO	2 [GO TO PH_CONF]
	DON'T KNOW	77 [GO TO PH_CONF]
	REFUSED	99 [GO TO PH_CONF]
PROX_PH_X	PROXY PHONE NUMBER COLLECTION SCREEN XXX-XXX-XXXX [G0	D TO PROXY_PH_CONF]
PROX_PH_ CONF	Is that a cellular telephone?	
	YES	1 [GO TO PROX_CONFHH]
	NO	2 [GO TO PROX_CONFHH]
	DON'T KNOW	77 [GO TO PROX_CONFHH]
	REFUSED	99 [GO TO PROX_CONFHH]
PROX_ CONFHH	Is that number a private residence?	

YES	[GO TO PROX_PH_LOOP]
NO	[GO TO PROX_PH_LOOP]
DON'T KNOW	[GO TO PROX_PH_LOOP]
REFUSED	[GO TO PROX_PH_LOOP]

PROX_PH_

LOOP

Does (FILL 2001 R_NAME_A OR FILL 2001 R_NAME_D if given) have another phone number where (he/she) can be reached?

YES	[GO TO NEXT PROX_PH_X]
NO	[GO TO PH_CONF]
DON'T KNOW	[GO TO PH_CONF]
REFUSED	[GO TO PH_CONF]

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SCREENER PART 3:

COLLECT ELIGIBLE ADULT (2007 RESPONDENT) IDENTIFIERS & LOCATING INFORMATION

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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 young adult?	
	INTERVIEWER INSTRUCTION: IF R NOT COMFORNAME, ACCEPT INITIALS.	RTABLE PROVIDING
	YES	1 [GO TO YOUTH_NAME_A]
	NO	2 [GO TO YOUTH_NAME_D]
	DON'T KNOW	3 [GO TO YOUTH_NAME_D]
	REFUSED	4 [GO TO YOUTH_NAME_D]
YOUTH_NAME_A	A What is the young adult's first name?	
	FIRST	
YOUTH_NAME_H	3 What is the young adult's middle name?	
	MIDDLE	
YOUTH_NAME_O	2 What is the young adult's last name?	
	LAST	
YOUTH_NAME_I	D Does the young adult have a nickname, initials or an prefer? NICKNAME/OTHER NAME	

YOUTH_PH	Could you please tell me (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given)'s (FILL BLANK or secondninth) phone number?		
	YES	1 [RECORD phone number(s) IN YPH_1 TO YPH_9]	
	NO	2 [GO TO YOUTH_EM_X]	
	DON'T KNOW	77 [GO TO YOUTH_EM_X]	
	REFUSED	99 [GO TO YOUTH_EM_X]	
YPH_X	YOUTH PHONE NUMBER COLLECTION SCREEN XXX-XXX-XXXX [C	GO TO YOUTH_PH_CONF]	
	<u>ADD PROBE</u> : IS THERE A GOOD TIME TO CALL [FIL IF YES, SELECT APPOINTMENT SCREEN	L YOUTH_NAME_A]?	
YOUTH_PH_ CONF			
	YES	1 [GO TO YCONFHH]	
	NO	2 [GO TO YCONFHH]	
	DON'T KNOW	77 [GO TO YCONFHH]	
	REFUSED	99 [GO TO YCONFHH]	
YCONFHH	Is that number a private residence?		
	YES	[GO TO YOUTH_PH_LOOP]	
	NO	[GO TO YOUTH_PH_LOOP]	
	DON'T KNOW	[GO TO YOUTH_PH_LOOP]	
	REFUSED	[GO TO YOUTH_PH_LOOP]	
YOUTH_PH_ LOOP Does (FILL YOUTH_NAME_A OR FILL YOUTH_NAME_D if given) have as phone number where (he/she) can be reached?		E_D if given) have another	
	YES	[GO TO NEXT YOUTH_PH]	

NO	[GO TO YOUTH_EM_X]
DON'T KNOW	[GO TO YOUTH_EM_X]
REFUSED	[GO TO YOUTH_EM_X]

YOUTH_EM

_X

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

YES	1 [RECORD E-MAIL ADDRESS ELEMENTS IN
	YEMAIL_1 TO YEMAIL_9]
NO	2 [GO TO YOUTH_AD_X]
DON'T KNOW	77 [GO TO YOUTH_AD_X]
REFUSED	99 [GO TO YOUTH_AD_X]

YEMAIL_X

EMAIL ADDRESS COLLECTION SCREEN

_____@_____

YOUTH_EM_ Is this an email address for personal, business or school use?

CONF

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

YOUTH_EM_ LOOP

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

YES	[GO TO NEXT
	YOUTH_EM_X]

NO	[GO TO YOUTH_AD_X]
DON'T KNOW	[GO TO YOUTH_AD_X]
REFUSED	[GO TO YOUTH_AD_X]

YOUTH_

YCONYHH

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 phone"]?

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

YOUTH_AD_ ST_X	What is the young adult's street address or mailing address?
YOUTH_AD	
APT_X	What is the young adult's apartment number? APT #
YOUTH_AD_	
CITY_X	What is the young adult's city and state? CITY
YOUTH AD	
STATE_X	State Dropdown Menu
YOUTH_AD_	What is the young adult's zip code?
ZIP_X	ZIP [GO TO YCONYHH]

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

YES1	[GO TO YOUTH_AD_LOOP]
NO2	[GO TO YOUTH_INST]
DON'T KNOW77	[GO TO YOUTH_AD_LOOP]
REFUSED	[GO TO YOUTH_AD_LOOP]

YOUTH_

INST

Can you describe the type of residence?

UNVERSITY/COLLEGE HOUSING (DORM)1	[GO TO YOUTH_AD_LOOP]
MILITARY BASE2	[GO TO YOUTH_AD_LOOP]
PRISON	[GO TO YOUTH_AD_LOOP]
OTHER INSTITUTION4	[GO TO YOUTH_AD_LOOP]
DON'T KNOW77	[GO TO YOUTH_AD_LOOP]
REFUSED99	[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?

YES	[GO TO NEXT YOUTH_AD_X]
NO	[GO TO CONF_INTRO]
DON'T KNOW	[GO TO CONF_INTRO]
REFUSED	[GO TO CONF_INTRO]

CONF_INTRO

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

[INTERVIEWER: CONFIRM ALL NAMES AND SPELLINGS WITH THE RESPONDENT. IF LAST NAMES ARE THE SAME, MAKE SURE THEY HAVE THE SAME SPELLING]

CONF_NAME

1 E.S	[GO IO CONFDOD_A
NO2	[GO TO
	YOUTH_NAME_A -

YOUTH_NAME_D TO MAKE CORRECTION]

CONF

DOB_X	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 no	t available, confirm age)	
	Is this correct	?	
	YES	1	GO TO Y_FUTCONT
	NO	2	GO TO NEWDOB_1
NEW DOB_1		prrect month, day and year of birth of [FILL ` H_NAME_D if given]?	YOUTH_NAME_A OR
	/	/ (mm/dd/yyyy)	
Y_ FUTCONT		t you again if we have problems contacting [TH_NAME_D if given)?	FILL YOUTH_NAME_A
	YES		1 [GO TO
			2001R_NAMECONF_A]
	NO		2 [GO TO TERMINATE]
	DON'T KI	10W	77 [GO TO TERMINATE]
	REFUSED		99 [GO TO TERMINATE]
2001R_ NAMECONF_4	Ą	What is your name?	
2001R		NAME	
PHONECONF_	A	And what is the best phone number to reach	ı you?
		PHONE NUMBER COLLECTION SCREE XXX-XXX-XXXX	EN

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SCREENER PART 4:

COLLECT IDENTIFIERS AND LOCATING INFORMATION FOR 2001 OR 2007 RESPONDENT LEADS

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

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 3 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 404-639-4604; or send an email to omb@cdc.gov.

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LEAD_REACH_Y

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

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

YES	1 [GO TO LEAD_NAME_A]
NO	2 [GO TO LEAD_NAME_D]
DON'T KNOW	3 [GO TO LEAD_NAME_D]
REFUSED	4 [GO TO LEAD_NAME_D]

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

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

MIDDLE____

LEAD_NAME	L_C	What is the [FILL RELATION]'s last name?	
		LAST	
LEAD_NAME	_	Does the [FILL RELATION] have a nickname, ini may prefer? NICKNAME/OTHER NAME	J
LEAD_PH		ou please tell me (FILL LEAD _NAME_A OR FIL (FILL BLANK OR secondninth) phone number	
	YES		number(s) IN
	NO		LEAD_PH_X] 2 [GO TO LEAD _EM_X]
	DON	Г KNOW	
	REFUS	SED	
LEAD_ PH_X		R PHONE NUMBER COLLECTION SCREEN XX-XXXX [0	GO TO LEAD _PH_CONF]
LEAD_PH_ CONF	Is that a	cellular telephone number?	
	YES		1 [GO TO LEAD _CONFHH]
	NO		2 [GO TO LEAD _CONFHH]
	DON'T	KNOW	77 [GO TO LEAD _CONFHH]
	REFUSI	ED	99 [GO TO LEAD _CONFHH]
LEAD_ CONFHH	Is that n	umber a private residence?	
	YES		[GO TO LEAD _PH_LOOP]
	NO		[GO TO LEAD _PH_LOOP]

Siale and Local Area Integrated Telephone Survey (SLAITS) package: 0920-0406				
	DON'T KNOW	[GO TO LEAD _PH_LOOP]		
	REFUSED	[GO TO LEAD _PH_LOOP]		
LEAD_PH_ LOOP	Does (FILL LEAD _NAME_A OR FILL LEAD _NAME_I phone number where (he/she) can be reached?	D if given) have another		
	YES	[GO TO NEXT LEAD _PH]		
	NO	[GO TO LEAD _EM_X]		
	DON'T KNOW	[GO TO LEAD _EM_X]		
	REFUSED			
		[
LEAD _EM_X	Could you please tell me (FILL LEAD R_NAME_A OR FI given)'s (FILL BLANK OR secondninth) electronic mail			
	YES	1 [RECORD E-MAIL ADDRESS ELEMENTS IN LEAD_MAIL_1 TO LEAD_EMAIL_9]		
	NO	2 [GO TO LEAD_AD_X]		
	DON'T KNOW	77 [GO TO LEAD_AD_X]		
	REFUSED	99 [GO TO LEAD AD X]		
LEAD_ EMAIL_1 through LEAD_ EMAIL_9	EMAIL ADDRESS COLLECTION SCREEN			
	@			
	@	·		
LEAD_EM_ CONF	Is this email address for personal, business or school use?			
COM	PERSONAL	1 [GO TO		
	DICINECC	LEAD_EM_LOOP]		
	BUSINESS	2 [GO TO LEAD_EM_LOOP]		
	SCHOOL USE	3 [GO TO		
	DON'T KNOW	LEAD_EM_LOOP] 77 [GO TO LEAD_EM_LOOP]		

LEAD_EM_ LOOP

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

YES	[GO TO NEXT LEAD_EM_X]
NO	[GO TO LEAD_AD_X]
DON'T KNOW	[GO TO LEAD_AD_X]
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 secondninth] street address or addresses [IF LEADPH_1 through LEADRPH_9 not equal null then FILL in case we cannot reach them by phone]?
	YES 1 [GO TO LEAD_AD_ST_X]
	NO 2 [CONF_INTRO_LEAD]
	DON'T KNOW 77 [CONF_INTRO_LEAD]
	REFUSED
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]
LEAD	

	YES	[GO TO LEAD_AD_LOOP]
	NO	[GO TO LEAD_INST]
	DON'T KNOW	[GO TO CONF_INTRO_LEAD]
	REFUSED	[GO TO CONF_INTRO_LEAD]
LEAD_ INST	Can you describe the type of residence?	
	UNVERSITY/COLLEGE HOUSING (DORM)1	[GO TO LEAD_AD_LOOP]
	MILITARY BASE2	[GO TO LEAD_AD_LOOP]
	PRISON	[GO TO LEAD_AD_LOOP]
	OTHER INSTITUTION4	[GO TO LEAD_AD_LOOP]
	DON'T KNOW77	[GO TO LEAD_AD_LOOP]
	REFUSED99	[GO TO LEAD_AD_LOOP]
LEAD_AD_ LOOP	Does (FILL LEAD R_NAME_A OR FILL LEAD R_NAME address where (he/she) can receive mail?	E_D if given) have another
	YES	[GO TO NEXT LEAD_AD_X]
	NO	[GO TO CONF_INTRO_LEAD]
	DON'T KNOW	[GO TO CONF_INTRO_LEAD]
	REFUSED	[GO TO CONF_INTRO_LEAD]
CONF_INTRC	LEAD I would like to confirm that I have the correct information	for the person that we'll be

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

[<u>INTERVIEWER</u>: 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?			
	YES1	[GO TO		
	LEAD_FUTCONT]			
	NO2	[GO TO LEAD_CONT		
		AND CORRECT]		
LEAD_FUTCO				
	May we contact you again if we have problems contacting the	-		
	YES	1 [GO TO		
		FUTCONT_LEAD_NAME		
]		
	NO	2 [GO TO PH_CONF]		
	DON'T KNOW	77 [GO TO PH_CONF]		
	REFUSED	99 [GO TO PH_CONF]		
FUTCONT_				
LEAD_NAME	5			
	NAME			
	[GO TO PH_CONF]			

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

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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 [RELATION]?

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

YES1	[GO TO
------	--------

LEAD_NAME_A_01]

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Stat

State and Local A	Area Integ	grated Tel	ephone Survey (SLAITS) package: 0920-0406	
	NO)		2 [GO TO LEAD_NAME_D_01]
	DO	N'T KN	OW	3 [GO TO LEAD_NAME_D_01]
	RE	FUSED		4 [GO TO LEAD_NAME_D_01]
LEAD_NAME_	_A_01	What is	the [FILL RELATION]'s first name?	
LEAD_NAME_	_B_01		the [FILL RELATION]'s middle name?	
LEAD_NAME_	_C_01		the [FILL RELATION]'s last name?	
		Does the may pre	e [FILL RELATION] have a nickname, init fer? NICKNAME/OTHER NAME	ials or another name that they
LEAD_PH_01		-	e tell me (FILL LEAD _NAME_A_01OR B BLANK OR secondninth) phone number	
				number(s) IN LEAD_PH_X_01]
			V	_EM_X_01] 99 [GO TO LEAD
LEAD_ PH_X_01		R PHON (XX-XX	E NUMBER COLLECTION SCREEN XX [GO TO	_EM_X_01] LEAD _PH_CONF_01]
LEADR_PH_ CONF_01	Is that a	a cellular	telephone number?	

NO	2 [GO TO LEAD _CONFHH_01]
DON'T KNOW	77 [GO TO LEAD _CONFHH_01]
REFUSED	99 [GO TO LEAD _CONFHH_01]

LEAD_ CONFHH_01 Is that number a private residence?

YES	[GO TO LEAD _PH_LOOP_01]
NO	[GO TO LEAD _PH_LOOP_01]
DON'T KNOW	[GO TO LEAD _PH_LOOP_01]
REFUSED	[GO TO LEAD _PH_LOOP_01]

LEAD_PH_

LOOP_01 Does (FILL LEAD R_NAME_A_01 OR FILL LEAD R_NAME_D_01 if given) have another phone number where (he/she) can be reached?

YES	[GO TO NEXT LEAD R_PH_01]
NO	[GO TO LEAD _EM_X_01]
DON'T KNOW	[GO TO LEAD _EM_X_01]
REFUSED	[GO TO LEAD _EM_X_01]

LEAD

_EM_X_01 Could you please tell me (FILL LEAD_NAME_A_01 OR FILL LEAD_NAME_D_01 if given)'s (FILL BLANK OR second...ninth) electronic mail or e-mail addresses?

YES	1 [RECORD E-MAIL ADDRESS ELEMENTS IN LEAD_MAIL_1_01 TO LEAD_EMAIL_9_01
NO	2 [GO TO LEAD_AD_X_01]
DON'T KNOW	77 [GO TO LEAD_AD_X_01]

LEAD EMAIL_1_01 through LEAD_ EMAIL_9_01 EMAIL ADDRESS COLLECTION SCREEN *@* . Is this email address for personal, business or school use? LEAD_EM_ CONF PERSONAL..... 1 [GO TO LEAD_EM_LOOP_01] LEAD EM_LOOP_01] LEAD_EM_LOOP_01] LEAD_EM_LOOP_01] LEAD EM LOOP 01] LEAD EM LOOP_01 Does (FILL LEAD _NAME_A OR FILL LEAD _NAME_D if given) have another email address where (he/she) can be reached? LEAD_EM_X_01] DON'T KNOW...... [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...ninth] street address or addresses [IF LEADPH 1 through LEADRPH 9 not equal null then FILL in case we cannot reach them by phone]? YES..... 1 [GO TO LEAD_AD_ST_X_01] NO..... 2 [CONF_INTRO_LEAD_01

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	DON'T KNOW	77	
	REFUSED	[CONF_INTRO_LEAD_01] 99	
		[CONF_INTRO_LEAD_01]	
LEAD_AD_ ST_X_01	What is the street address?		
LEAD _AD_ APT_X_01	What is the apartment number? APT #		
LEAD _AD_ CITY_X_01	What is the city and state? CITY		
LEAD _AD_ STATE_X _01	State Dropdown Menu		
LEAD _AD_ ZIP_X_01	What is the zip code? ZIP [GO TO LEADCONYHH	[]	
LEAD CONYHH_01	Is that address a private residence?		
	YES	[GO TO LEAD_AD_LOOP_01]	
	NO	[GO TO LEAD_INST_01]	
	DON'T KNOW	[GO TO CONF_INTRO_LEAD_01]	
	REFUSED	[GO TO CONF_INTRO_LEAD_01]	
LEAD_ INST_01	Can you describe the type of residence?		
	UNVERSITY/COLLEGE HOUSING (DORM)1	[GO TO LEAD_AD_LOOP_01]	
	MILITARY BASE2	[GO TO LEAD_AD_LOOP_01]	
	PRISON3	[GO TO LEAD_AD_LOOP_01]	
	OTHER INSTITUTION4	[GO TO LEAD_AD_LOOP_01]	

DON'T KNOW77	[GO TO LEAD_AD_LOOP_01]
REFUSED99	[GO TO LEAD_AD_LOOP_01]

LEAD_AD_

LOOP_01 Does (FILL LEAD R_NAME_A OR FILL LEAD R_NAME_D if given) have another address where (he/she) can receive mail?

YES	[GO TO NEXT LEAD_AD_X_01]
NO	[GO TO CONF_INTRO_LEAD_01]
DON'T KNOW	[GO TO CONF_INTRO_LEAD_01]
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?

YES1	[GO TO
LEAD_FUTCONT_01	L
NO2	[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 LEAD interview?

YES	1	[GO TO
	FL _0	JTCONT_LEAD_NAME 1]
NO	2	[GO TO PH_CONF]
DON'T KNOW	77	[GO TO PH_CONF]

FUTCONT_LEAD_NAME_01 What is your name? NAME

[GO TO PH_CONF]

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, XXX-XXX-XXX. 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. Thanks again.

UNIVERSAL EXIT (UE)

NO_CONTACT		
_	CONTINUE1	GO TO INTRO_1
	ANSWERING MACHINE2	GO TO MSG (OR SASERVIF NO MESSAGE LEFT)
	OTHER TECHNOLOGICAL CIRCUMSTANCES3	GO TO CALL NOTES
	ВО	Х
	DISCONNECTED/NUMBER NOT ASSIGNED/4	GO TO CALL NOTES
	BO	Х
	CALL CAN'T BE COMPLETED	
	FAX/MODEM/DATA LINE5	TERMINATE
	PRIVACY MANAGER/NO INCOMING CALLS/	
	CALL IS BLOCKED OR NOT ACCEPTED7 EXIT-P1	GO TO UNIVERSAL
	FAST BUSY8	TERMINATE
	NUMBER CHANGED9	TERMINATE
	ENGAGED/BUSY/ALL CIRCUITS ARE BUSY10	TERMINATE
	NO REPLY/RING NO ANSWER11	TERMINATE
	SUPERVISOR REVIEW12	GO TO CALL NOTES
	ВО	Х
	RESPONDENT CALLED INTO 800 LINE13	GO TO INTRO_1
M1 NAME		

M1_NAME_

WEB	Do you have access t	o the internet?	
	Yes EXIT		GO TO UNIVERSAL
	No	2	GO TO UNIVERSAL EXIT- M1_NAME

M1_NAME_

WEB_ADD I would like to offer you the project's web address. It provides a lot of additional project information.

FILL WEB ADDRESS

M1_EMAIL In order to email a letter to you, I will need to collect your email address. The letter will contain a toll-free number that you may call to complete the interview at your convenience.

	Continue1 EXIT-M2	GO TO UNIVERSAL
	Refused to give information2 EXIT-M3	GO TO UNIVERSAL
M2	You will be receiving the letter in the next week [FILL or two toll-free number that you may call at any time to complete the	
M3	Thank you very much on behalf of the Centers for Disease Co	ntrol and Prevention.
M1_NAME	In order to send you a letter, I will need to collect your name a letter will contain a toll-free number that you may call to comp convenience. (Read if necessary: If you feel uncomfortable gives send the letter to "Resident".)	plete the interview at your
	Continue1 EXIT-M2	GO TO UNIVERSAL
	Refused to give information2 EXIT-M3	GO TO UNIVERSAL
M2	You will be receiving the letter in the next week or two. It will that you may call at any time to complete the interview. Than the Centers for Disease Control and Prevention.	
M3	Thank you very much on behalf of the Centers for Disease Co	ntrol and Prevention.
T1	Did the respondent agree to a call back or say something to inc participate? (Or do you need to code this case as a callback?)	licate he/she was too busy to
	Yes1 EXIT-CB1	GO TO UNIVERSAL
	No2 EXIT-T2	GO TO UNIVERSAL
	R requested letter-emailed5	GO TO UNIVERSAL EXIT-M1_EMAIL
	R requested letter-mailed5	GO TO UNIVERSAL EXIT-M1_NAME
	R will call 800 Line/Verify website6	GO TO UNIVERSAL EXIT-VERIFY_INFO
	Take Me Off Your List8	GO TO CALL NOTES BOX
	Out of Scope9	GO TO CALL NOTES BOX
	R not over 17/R does not live in HH10 BO	GO TO CALL NOTES

Return to INTRO	11 GO TO INTRO IF T1
A	APPEARS DIRECTLY
A	AFTER INTRO

T2	Did the respondent say anything other than hello before he/she hung up?		
	Yes 1 EXIT-T3	GO TO UNIVERSAL	
	No2	TERMINATE	
T3	Did a respondent convey that there were no eligible children b	efore hanging up?	
	Yes, No one under 25 lives in HH No, did not say EXIT-T4		
Τ4	Did the respondent say this number was for a nationally recognished health, or government institution, or a home business that is not		
	Yes-Business1	TERMINATE	
	Yes-Dorm/Prison/Hostel2	TERMINATE	
	No3 EXIT-T5	GO TO UNIVERSAL	
Т5	Did the respondent say something to indicate that he/she refus they just hang up?)	ed to participate? (Or did	
	Yes1 EXIT-R1	GO TO UNIVERSAL	
	No2 EXIT-T6	GO TO UNIVERSAL	
Т6	CODE AS GENERAL CALL BACK OR SUPERVISOR REV	VIEW	
	GENERAL CALL BACK1 BOX &TERMINATE	GO TO CALL NOTES	
	SUPERVISOR REVIEW2	GO TO CALL NOTES BOX & TERMINATE	

CB1	Is there	
	A specific time to call back1	GO TO APPT SCREEN
	A range of time to call back2	GO TO APPT SCREEN
	Someone else gave a time to call back	GO TO APPT SCREEN
	No specific time to call back,	
	said they were too busy4 T	ERMINATE
VERIFY_		
INFO	REFER TO FAQ/JOB AID TO ANSWER RESPONDENT Q	UESTIONS
	Terminate the Interview (Hang up)1 BOX	GO TO CALL NOTES
	Continue Interview2	GO TO INTRO_1
R1	Was respondent male or female?	
	Male1	
	Female2	
	Could not be determined3	
R2	What was the reason for refusing? (Multiple responses possibl	e)
	Too busy/Doing something else right now1	
	Interview will take too long2	
	Not interested3	
	No solicitation wanted/Don't need anything/	
	Don't want to buy anything4	
	Requested not to be called back5	
	Concerned about confidentiality6	
	Won't give information over the phone7	
	Negative about government8	
	Negative about surveys9	
	On National Do Not Call List10	
	No reason given11	
	None of the above12	
R3	What questions did the respondent ask? (multiple response pos	ssible)
	The study purpose	1
	NORC	2
	Who is sponsoring the	
	study (NCHS, DHHS, CDC, NIP)	3

Source of name and address on letter	4
Questioned legitimacy of study	5
The use of the data	6
The confidentiality of the data	7
Access to study results	8
How did you get my phone number?	9
Where are you calling from?	10
No questions	11
None of the above	12

R4 Did the respondent threaten legal or governmental action or use hostile words or a hostile tone? These are refusals that are so strong that we don't want to call them back.

Yes1 BOX	GO TO CALL NOTES
No2 BOX	GO TO CALL NOTES

P1 [BLANK]

IF A PRIVACY MANAGER ASKS YOU TO STATE YOUR NAME, SAY "On behalf of the Centers for Disease Control and Prevention." IF A PRIVACY MANAGER ASKS YOU TO ENTER THE NUMBER YOU ARE CALLING FROM, ENTER THE NIS TOLL-FREE NUMBER (866-999-3340).

Continue Interview1	GO TO INTRO_1
Answering Machine2	GO TO MSG_Y
Ring no answer3	GO TO SASERV
Refused/ Number is invalid4	GO TO SASERV
Take Me Off Your List5	TERMINATE

Attachment 3:

2007 Survey of Adult Transition and Health (SATH) Instrument

OMB Number 0920-0406 Expiration date 11/30/07

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 404-639-4604; or send an email to omb@cdc.gov.

The Public Health Service Act is Volume 42 of the US 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.

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

State and Local Area Integrated Telephone Survey (SLAITS) Survey of Adult Transition and Health (SATH) Spring & Summer 2007

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SECTION 2: 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?

YES
 NO
 DON'T KNOW
 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?			
	 Working at a job or Looking for work Taking care of hous Going to school Something else DON'T KNOW REFUSED 		[SKIP TC [SKIP TC [SKIP TC [SKIP TC [SKIP TC [SKIP TC) F2Q31]) F2Q31]) F2Q31]) 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 (7) DON'T KNOW (9) REFUSED		7]	
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 (2) Sometimes (3) Usually (4) Always (7) DON'T KNOW (9) REFUSED 		1]	
F2Q33	Does your health affect your ability to work a great deal, some, or very little?			
	 (1) A great deal (2) Some, or (3) Very little? (7) DON'T KNOW (9) REFUSED 			
F2Q34	Because of your health, did you need any services, accommodations, or other to help you do your job better?			accommodations, or other assistance
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q35 [SKIP TO NE2 [SKIP TO NE2 [SKIP TO NE2	XT SUBDO XT SUBDO	DMAIN]

	5 1		
F2Q35	Did your job(s) or business(es) provide any services, accommodations, or other assistance to help you do your best there?		
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q36] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN]	
F2Q36	Did you ask or apply for any services, accommodations, or other assistance from your j or business?		
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [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 h	ave a job or business in the next 12 months?	
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED		
F2Q39	Does your health affect	t 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 (7) DON'T KNOW (9) REFUSED	[SKIP TO Q47] [SKIP TO Q47] [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(2) Sometimes(3) Usually(4) Always	[SKIP TO Q44]		
	(7) DON'T KNOW (9) REFUSED	[SKIP TO Q44] [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, or (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 (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q45] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN]		
F2Q45	Did the school(s) you attended provide any services, accommodations, or other assistant to help you do your best there?			
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q46] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN]		

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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, or
 (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 3: 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?	
	(03) THERE IS MORE THAN ONE PLA (77) DON'T KNOW	SKIP TO Q03] ACE SKIP TO Q03] SKIP TO Q03]
F3Q02		out your health, what kind of place do you go to ency room, hospital outpatient department,
	 (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 M (77) DON'T KNOW (99) REFUSED 	1OST OFTEN
F3Q03	Is there a place that you USUALLY go whe physical examination or check-up?	hen you need routine preventive care, such as a
	(03) THERE IS MORE THAN ONE PLA (77) DON'T KNOW	SKIP TO Q05] ACE SKIP TO Q05] SKIP TO Q05]
F3Q04		what kind of place do you go to most often? Is it an outpatient department, clinic, or some other
	 (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 M (77) DON'T KNOW (99) REFUSED 	1OST OFTEN

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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 check-ups and dental cleanings?

TIMES (777) DON'T KNOW (999) REFUSED

IF F3Q21 \geq 1 OR F3Q22 \geq 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?
 - YES
 NO
 DON'T KNOW
 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 F3Q22 = 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

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- 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?
 - Never
 Sometimes
 Usually
 Always
 DON'T KNOW
 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 4: 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 (7) DON'T KNOW (9) REFUSED	[SKIP TO Q03] [SKIP TO Q03] [SKIP TO Q03]
F4Q02	Was a plan for addressing these changing needs developed with your doctors or other health care providers?	
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q04] [SKIP TO Q04] [SKIP TO Q04] [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 adults?	s or other health care providers treat only children, teenagers, or
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q07] [SKIP TO Q07] [SKIP TO Q07]
F4Q05	Have they talked with you about eventually seeing doctors or other health care provid who treat adults?	
	(1) YES (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q07]

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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 5: 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 6: 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		about your health insurance or health care plans. Does your health 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 (2) NO (7) DON'T KNOW (9) REFUSED	[SKIP TO Q21B] [SKIP TO NEXT SUBDOMAIN] [SKIP TO NEXT SUBDOMAIN] [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 7. 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 8. 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 9. 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 10. DEMOGRAPHICS

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

Subdomain 1. Marital status and living arrangements

- 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 (77777) 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 one 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

Attachment 4i:

Text of SATH recruitment or verification message to be emailed, faxed, or mailed to the eligible adult respondent

(upon request)

OMB 83-C State and Local Area Integrated Telephone Survey (SLAITS) package: 0920-0406

Flesch Kincaid Reading Level is 8.3

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

You have requested information describing an important study by the Centers for Disease Control and Prevention (CDC). This survey is about the health of young adults, and their 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 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-XXX-XXX) 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 take part online 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 decide to take part. Your participation is completely voluntary. It will take you about 15 minutes to answer the questions.

This study is authorized by the U.S. Public Health Service Act. It and other federal laws require us to protect your information and keep it private. The information you report will only be used for 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,

Edd Sill

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.



If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-855-2880 and request that 1-866-999-3340 be called.

(side 2) 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 get understand how your health and health care have changed since you were a teen.

How will you protect my privacy?

We are bound by strict laws 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 1-866-999-3340.

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 phone number. Say that you are calling about Protocol #XXXX-XX. 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 phone number of a doctor or clinic near you.

Attachment 4ii:

Text of a more general SATH recruitment or verification message to be emailed, faxed, or mailed to persons other than the eligible young adult respondent

(upon request)

SATH General Endorsement Letter

(Flesch Kincaid Reading Level is 8.0)

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 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) protect 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/slaits/sath.htm.

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

Sincerely,

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



If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-855-2880 and request that 1-888-990-9986 be called.

(side 2)

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. Results from this survey may help improve the health of adults in your area and the nation, now and in the years ahead.

How will you protect privacy?

We are bound by law to maintain strict confidentiality standards. 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 1-866-999-3340.

If you would like to learn more about the legal rights of survey respondents, 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 phone number. Say that you are calling about Protocol #XXXX-XX. 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 phone number of a doctor or clinic near you.

Attachment 5

SATH thank you letter

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health

Centers for Disease Control and Prevention

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

Dear Respondent:

Service

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 \$XX (20/25).

If you have any questions, you can call the study staff toll-free at 1-800-XXX-XXXX, or you can visit the study's web site at <u>http://www.cdc.gov/nchs/about/major/slaits/sath.htm</u>.

Thank you again for your help.

Sincerely, El al fiel

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

Attachment 6

Additional backup material

- i. NORC protocol for physical and network security
- ii. Detailed description of the locating process & database
- iii. Description of the program & process used for web data collection
- iv. Selected persons involved in developing SATH content and procedures

Attachment 6i.

NORC protocol for physical and network security

NORC at the UNIVERSITY OF CHICAGO

Innovative solutions in research and technology

Physical Security/Facilities

NORC enforces a variety of physical security measures across all facilities, and ensure that access to all confidential data are restricted to only those employees that posses both the need and proper authorization to review such information. A keycard, key access, or human monitoring system (often times a combination of one or more may be used) restricts access to every facility.

- All server rooms, wiring closets, and network ports on the Wide Area Network (WAN) (with the
 exception of dial-up users) are located behind locked doors within the boundaries of a secure
 area inside the facility with restricted access to designated persons.
- All data collection and processing sites are located in restricted areas that are readily protected by either security systems, including video cameras and the aforementioned keycard systems or human monitors.
- Project-specific servers protect data and data access, which is only granted to members of project teams by Information Technology (IT) staff. The IT staff also maintains locked and secured filing and data storage facilities, and each of the project-specific, password-protected portal sites.
- Individually identifiable data on hard copy documents is captured electronically, separated from the questionnaire, and disposed of in accordance with project-specific instructions. When physical copies must be retained or are not in use, they are stored in locked file cabinets that are accessible only to authorized project staff.

Network Data Security

Internal network storage is provided for each project to mitigate the potential of data loss due to accidents, computer equipment malfunction, failure, or human error; and to administer access rights.

- Production file servers are equipped with fault tolerant disk arrays and redundant power supplies to minimize the risk of losing valuable project data. These data are protected by surge suppression and Uninterruptible Power Supplies (UPS).
- All operating system vendors are routinely monitored by a designated IT infrastructure resource monitor for security patches with all updates applied as necessary. Data transfers to removable media for purposes of client delivery or archival is performed by the IT department to control data formatting and provide assurance that the media is readable by the client. This also gives the IT

department the opportunity to scan the deliverables for viruses while maintaining detailed shipping manifests and receipts of all deliveries.

- All authorized network users are issued a user-id and password which must be used to sign into each of the project applications and data areas located on the network. Employees are required to change their server passwords on a regular basis.
- The installation of any software package on a computer is controlled, and requires successful completion of a through software review and approval process.
- Remote access into the network is performed through NORC's firewall using a Virtual Private Network (VPN). A firewall and a packet filtering router have been set to protect each NORC Internet Access Point, and a designated NORC IT infrastructure resource is employed to monitor the Local Area Network (LAN) and WAN for signs of intrusion and other security violations. Hostbased applications such as FTP and web servers are run only on servers inside the data center, and are separate from servers designated to store and collect client data.
- Connectivity between all sites is protected by dedicated data circuits. Any data that are placed on any public networks is encrypted. There is also a dedicated IT resource to maintain a software package that proactively searches for security holes and recommends fixes in a timely manner.
- NORC routinely engages third-parties to conduct network security audits, which includes comprehensive attempts at network penetration from undisclosed sources and a review of policies and procedures.

Application Security

All applications that manage case, response, and corporate financial data protect against unauthorized access and restrict authorized access to the minimum necessary level.

<u>User Rights</u>

Once logged into the application system, each user-id is assigned a 'rights mask' that allows the user access only to limited views of data.

Case-Level Security

Unique case identifiers are used to create a partition between response data, and data that could be used to identify an individual.

Encryption Key Management

All applications used in any environment outside of the WAN are required to use digital certificates that encrypt data using Secure Sockets Layer (SSL) technology (where applicable).

Electronic Data Transfer External to NORC

Should a project obligation require that data be electronically transmitted to or from the secure private network, encryption technology will be used.

Access Control / Authentication

All attempts to access data are logged by the hosting server for review.

Employee Exit

Human Resources (HR) and IT coordinate so that user accounts are deactivated upon employee exit. An exit interview checklist of security-related steps is utilized by both HR and IT.

Backup Procedures

All data that currently reside on the network is backed up on tape on a nightly basis. These tapes are stored in a secure, off-site location. Any information housed on these tapes is retrievable from the storage facility within 12 hours. All backups made for the purpose of disaster recovery have a retention period of one year. At the conclusion of a project, an archive is immediately created in strict accordance with contractual requirements. All archived project materials are stored off-site and easily accessible to staff.

Data Retrieval

Only a limited number of IT personnel are authorized to request the retrieval of these data tapes from the off-site location, and must follow an identification and authorization procedure.

Virus Protection

All systems are protected from computer viruses by extremely robust security features and procedures. The technique of limiting user access to internal network data storage is designed specifically to minimize the possible impact of a virus that may breach virus protection software and procedures. Several actions are taken on a daily basis to prevent a virus from breaching the system.

- Virus scans are completed routinely through the use of commercially available and automatically updated software.
- Employee workstations are configured to automatically check all files that are used, including those coming from diskettes and email attachments, to ensure that they are not introducing viruses to the system.
- Incoming email attachments are automatically screened on the email server for viruses, Trojan Horses, worms, and related malignant software.

Paper Records Storage and Security

Business records are kept to meet operating, historical, research, audit, and legal requirements. Records are only destroyed at the appropriate time.

Temporary Storage

Secured, general storage is referred to as the 'cold storage area'. Any materials without respondent identifiers may be stored in cold storage to be easily accessible to project personnel. This space also serves as a staging area to access and inventory materials for permanent archiving. Paper files pertaining to project management are separated from production data and stored permanently at this location.

There are two locked "cages" available. Access is restricted to the records manager or librarian. All sensitive contracts, grants, personnel, and financial records are kept in one of these secure double locked areas.

Materials are stored in acid free cartons and are labeled with the project name and number, project supervisor name and telephone number, and projected destruction date. A list of contents for each box sent for storage must be provided, and materials will not be disposed of without contacting the appropriate personnel. Before storing hard copy survey materials, cartons are inventoried and contents are recorded. Requests for stored items are made to the records manager.

Long-Term Storage

Project directors may request that materials be stored on a more permanent basis at a remote storage area, and fulfills contractual obligations of records storage when limited access to records is required. We currently have a contract with O'Hare Record Retention Company (ORRC) in Cicero, Illinois. This facility has a sophisticated sprinkler system and a NORC-approved disaster plan in place. General access to the facility is limited to the records manager and NORC librarian. Should a site visit be required by either NORC personnel or our clients, we must provide the records manager at least 24 hours notice and submit a list of the planned visitors. ORRC requires that visitors provide proper identification and be accompanied by either the records manager or librarian. Space at the facility for the examination of materials is available for a reasonable fee.

All materials are inventoried and receive unique bar codes as identifiers before being delivered to ORRC, and a copy of the inventory is kept on the shared drive. Production materials may be sent directly to ORRC.

Attachment 6ii.

2007 SATH: Detailed description of the locating process & database

Description of the database used in the locating process

Accurint is owned by LexisNexis (LN) which provides comprehensive and authoritative legal, public record, news, and business information and tailored applications, will be used to conduct the locating effort. LN does not collect personal financial, credit, or medical information.

The Accurint database is a widely used 'locate-and-research' tool and allow users to locate persons; track down telephone numbers with access to over 50,000,000 non-directory assistance records (including cellular telephone numbers); link over 132 million individuals to businesses and business contact information based on probable current and historical employment information; and includes a search tool to help find individuals when only old or fragmented data are available. This database is used by NORC to track participants in large nationally-representative longitudinal surveys such as the National Longitudinal Survey of Youth (NLSY) sponsored by the Bureau of Labor Statistics (BLS). Locators will enter the 2001 telephone number into the online Accurint system and obtain some level of information.

Description of the batch locating process

NORC will use Accurint for batch locating. For the SATH, NORC will have very limited information to start with. Using a batch submission, NORC will request a list of current household members as well as household members from 2001. This information from Accurint will be pre-loaded into the locating or Case Management System (CMS) as 'leads' (these systems are integrated). If a lead for each case does not turn into either a 2001 and/or 2007 contact, the case will re-enter the locating system. Incorrect contacts determined during CATI screening will also reenter the locating system. During this locating process NORC will use an unscripted approach to initially contact the household to locate the 2001 respondent. It would be impossible to write appropriate scripts that will address every possible scenario the locators will face when 'cold calling' the 2001 telephone numbers. When the eligible cases are located, interviewers will use a traditional scripted approach to recruit the case and give informed consent information.

The CMS has the ability to email or mail project information to respondents by case disposition codes. Eligible cases can be easily and efficiently flagged if they request information. Within the locating procedure, all 'finalized' cases go to the locating supervisors who assign disposition codes.

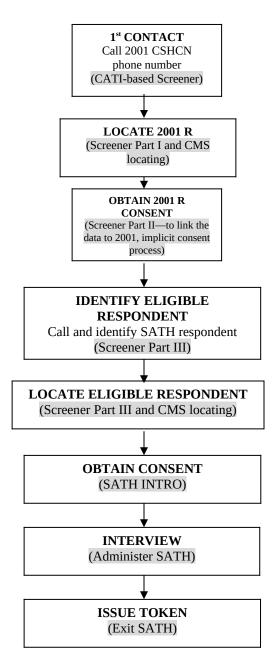
Once all telephone options to locate the case are exhausted, further searches will occur using the internet. These 'web treatments' will include the use of commonly available search engines such as Java Search and Google. These resources will only be used when needed, and certain components will be entered only by supervisors.

The children who in 2001 were receiving all the necessary transition services are a minority of cases but because of their importance to this study, they will receive more intensive locating protocol. They are considered "imperative" cases while all others are considered "standard" cases. Standard cases that cannot be located will be re-released to the locating staff for continued attempts to locate until the end of data collection. All locators are highly trained interviewers and are able to seamlessly segue into the 2007 interview if the proper person is located, is immediately available, and gives consent. Incorporated into the scripts and procedures is a recognition of the passage of time as well as the portability of telephone numbers in the interim period.

Training will clearly stipulate what criteria are authorized for search. Locators will also be thoroughly trained in what they are and are not allowed to tell people who may not be the intended household or respondent but answer their calls.

Only previously successful, professional, and very experienced locators and interviewers will be assigned to this project. Although we will encourage all respondents to respond via a landline phone or website, we will attempt to conduct the interview using a cellular phone if this is the <u>only</u> option.

The figure below summarizes the general process flow for the 2007 SATH. The shaded words in the boxes refer to either the position within the locating or interviewing process, or the relevant instrument scripts or sections.



Attachment 6iii.

2007 SATH: Description of the program & process used for web data collection

A web-based internet application has been developed to collect data in lieu of the traditional computerassisted telephone interviewing (CATI) program that we have used consistently for other modules. It allows us to streamline instrument development and reduce the amount of preparation time because only one version of the survey will need to be constructed regardless of mode, instead of having to construct a CATI-version and a web version.

Specifically, NORC will extend the functionality of the CATI data collection program that is currently used to collect NIS/SLAITS data. This program has an option that allows it to capture data entry over the web. A web server will securely deliver content to the respondent. All questionnaire data (CATI and web) can be collected into one integrated data store for analysis.

For respondents who choose to complete the interview over the telephone, the identical web-based program will be used to collect the data; however, the interviewer will read the question over the telephone to the respondent and enter the response. The computer program guides the interviewer (or respondent) through the questionnaire (question by question and page by page), automatically routing the interviewer (or respondent) to appropriate questions based on answers to previous questions. The CATI program determines if a selected response is within an acceptable range, checks entry for consistency against other data collected during the interview, and saves the responses into a survey data file. On-line help menus are also available. This data collection technology reduces the time required for transferring, processing, and releasing data.

Should a phone or web interview terminate before completion, the system allows the interviewer or respondent to resume at the break-off point at another time. Because of multiple administration modes, the instrument was simplified as much as possible to minimize confusion (very few skip patterns, et cetera).

For interviews conducted using a telephone this system documents all call attempts and the outcome of each, their time and duration, and schedules future calls. Further, it documents if and when a message should be left on the household's answering machine or voice mail. The system assigns calls to interviewers and dials the numbers, although cellular phone numbers will be hand-dialed.

We will format the questions and screens by incorporating the most up-to-date research⁷ (i.e., the screen text may not appear exactly as listed below).

The screen in the secure data collection environment will display the following text:

The Centers for Disease Control and Prevention (CDC) is doing a nationwide survey 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. The CDC would like to examine changes that may have occurred in your health or healthcare in the past few years by getting information directly from you.

It is your choice to participate in this research. You may choose not to answer any question you don't wish to answer--simply leave it blank. You may also

⁷ Dillman, Don A. *Mail and internet surveys: The Tailored Design Method, Second Edition (includes a 2007 update with new internet, visual, and mixed-mode guide).* Hoboken, New Jersey: John Wiley & Sons; 2007.

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.

This study is authorized by the U.S. Public Health Service Act. This and other strict laws require us to protect your privacy and use your answers only for statistical research. You can see these laws by clicking <u>here</u>⁸.

The survey will take about 15 minutes. In appreciation, you will receive \$20. If you have any questions about this study, please call the study's toll-free number, xxx-xxxx.

The survey contains questions about your health, health status, and health care as you get older.

Instructions will explain the navigation process, and for persons who chose to complete the survey in stages, i.e., exit the program and return to complete the survey at a more convenient time. To confirm this is the correct respondent, he/she must confirm his/her date of birth. The instrument will then display question F2Q11 (i.e., the start of section 2, health and functional status).

When the respondent completes the web survey, the screen will display the following text:

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

Please enter your name and mailing address:

NAME	
STREET	
CITY	
STATE	
ZIP	

We'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 this survey, please call the study's tollfree number, xxx-xxx. 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. Again, thank you!

⁸ This link will lead to a screen that will display the following information:

Federal laws guarantee that your answers will be used only for statistical research. The Public Health Service Act is Volume 42 of the US 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.

Attachment 6iv.

Selected persons involved in developing SATH content and procedures

LISTED ALPHABETICALLY BY LAST NAME

Stephen Blumberg, Ph.D. Senior Scientist Centers for Disease Control and Prevention Hyattsville, MD <u>sblumberg@cdc.gov</u>

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Paul Newacheck, Dr.P.H. Professor of Health Policy Institute for Health Policy Studies University of California, San Francisco San Francisco, CA pauln@itsa.ucsf.edu

Kathleen S. O'Connor, M.P.H. (CDC team leader) Survey Statistician Centers for Disease Control and Prevention Hyattsville, MD koconnor1@cdc.gov OMB 83-C State and Local Area Integrated Telephone Survey (SLAITS) package: 0920-0406

Bonnie Strickland, Ph.D. Acting Director, Division of Services for Children with Special Health Care Needs Health Resources and Services Administration Rockville, MD <u>bstrickland@hrsa.gov</u>

Peter van Dyck, MD, MPH Associate Administrator Health Resources and Services Administration Rockville, MD <u>pvandyck@hrsa.gov</u>

Attachment 7

Letters sent or emailed to potential web respondents

- i. Contains the personal identification number (PIN) and password to access the instrument on the secure NORC website
- ii. Reminds potential web respondents to complete the survey

[LETTERHEAD] 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 wellbeing, health and healthcare needs of people in your age group.

We are asking you to take part in this important survey by using our website and using the Personal Identification Number (PIN) and password provided below. In appreciation of your time and effort, we will send you \$20.

The web survey will take approximately 15 minutes to complete. Please visit this secure website to access the survey: <u>https://cdc.gov/exampleofwebsurveyforsath</u>.

PIN: [MAILMERGE]

Password: [MAILMERGE]

If you have any trouble with the web survey or if you would rather do a phone survey, please call us toll-free at 1-866-900-9601.

The person we want to interview 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 phone number. Say that you are calling about Protocol #xxxx-xx.

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

Sincerely,

Ed Sill

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

LETTERHEAD

Dear [MAILMERGE],

We contacted you earlier about the **Survey of Adult Transition and Health (SATH)** sponsored by the Centers for Disease Control and Prevention.

We are asking you again to take part in this important survey using our website and the Personal Identification Number (PIN) and password provided for you below. To thank you for your time and effort, we will send you \$20.

The web survey will take about 15 minutes to complete. Please visit this secure website to see the survey: <u>https://cdc.gov/exampleofwebsurveyforsath</u>. For security purposes, use this Personal Identification Number (PIN) and password to access the web survey:

PIN: [MAILMERGE] Password: [MAILMERGE]

If you have any trouble with the survey, or if you prefer to complete the interview by telephone, please call us at 1-866-900-9601.

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

Sincerely,

Edflil

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