

Attachment 1: SPDS letters

a. Advance Letter & FAQ

Dear Parent or Guardian,

Thank you for your help!

[TEXT FILL: “Earlier this year”/”Last year”/etc.], your household participated in the National Survey of Children with Special Health Care Needs over the telephone. Based on the answers you provided during this survey, your household is eligible for an important survey on children with learning and developmental conditions. Information about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children with these conditions in your state and throughout the United States.

In the next few weeks, the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC), will call your household and ask to talk to the same parent or guardian who completed the telephone survey [TEXT FILL: “earlier this year”/”last year”/etc.]. This voluntary survey will take about a half hour to complete.

In appreciation for your continued time and effort, we will send you \$20 once the survey is complete.

We hope you will share this important information about your child by phone when an interviewer calls to ask you to take part in the study. If you do, you can choose not to answer any questions you do not wish to answer. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you may have and ways to get more information about the survey.

To learn more about the study or to take part right away, call 1-XXX-XXX-XXXX, toll-free. You can also visit the study’s website for additional study information – www.cdc.gov/nchs/slait.htm.

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

Sincerely,

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

If you prefer to use TTY



Call the AT&T Relay Service at 1-800-855-2880 and request that X-XXX-XXXX be called. The call is toll-free.

Survey of Pathways to Diagnosis and Services Frequently Asked Questions

What is the purpose of this study?

The purpose of this study is to better understand the processes by which learning and developmental conditions in children are diagnosed and treated. This study also aims to describe the types of services that children with these conditions use, and to identify any problems they have in getting the care they need. People have very different experiences with their children's health and health care. In order to improve children's health and well-being overall, it is important that we learn about diagnosis and treatment, and about any problems that children have in getting care that they need. This study is authorized by Section 306 of the Public Health Service Act and funded by the National Institute of Mental Health.

Why do I qualify for this study?

Your household participated in a telephone survey about the health and health care of children with special health care needs. Based on the answers provided in this survey, a child in your household *has or has once been diagnosed with* autism, Autism Spectrum Disorder, a developmental delay, or intellectual disability. If we are contacting your household in error, we would greatly appreciate talking to a parent or guardian so we can confirm that your household should not be a part of this study.

How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your information and the child's information will never be associated with any results.

If you would like more information about the confidentiality of the research or the federal laws that ensure the protection of your information, including the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act, these are described in detail at: www.cdc.gov/nchs/about/policy/confiden.htm. If you want to know more about your rights as a study participant you may call 1-800-223-8118, toll-free. This is the number for the Research Ethics Review Board at NCHS. You will be asked to leave a message and say you are calling about Protocol XXXX-XX.

How will this information be used?

Maternal and child health agencies in your state will use this information to improve diagnosis and treatment of children with learning and developmental conditions. The federal government will also use this information to learn about the types of support services that states need for these children.

You may visit <http://www.cdc.gov/nchs/slaits.htm> to find general information about the study.

Is there a toll-free number to learn more?

To learn more about the study or to take part right away, call **1-877-259-4326**, toll-free. The National Center for Health Statistics has hired NORC at the University of Chicago to conduct the survey. You can call NORC's toll-free number to take part in the study right away, learn more about the study, and hear what you will be asked.

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b. Telephone Refusal Conversion Letter

Dear Parent or Guardian,

The National Center for Health Statistics needs your help!

Recently, your family was called on the telephone and asked to take part in an important survey about children who have or have once been diagnosed with learning and developmental conditions. We have not been able to complete the interview yet. We hope you will reconsider our request. Information about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children in your state and throughout the United States.

In appreciation for your time and effort, we have enclosed \$5. As promised, we will send you an additional \$20 once the survey is complete.

We hope you will share this important information with us by phone when an interviewer calls to ask you to take part in the study. If you would like to participate right away or find out more about the survey, please call the toll-free telephone number 1-XXX-XXX-XXXX. You can also find additional information about the survey at our website – [**http://www.cdc.gov/nchs/slaits.htm**](http://www.cdc.gov/nchs/slaits.htm).

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

Sincerely,

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

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c. Thank You Letter (telephone interview only)

Dear Parent or Guardian,

Thank you for taking part in the **Survey of Pathways to Diagnosis and Services** over the phone recently. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with learning and developmental conditions in your state and throughout the United States.

In appreciation for your time and effort spent answering our questions, we have enclosed \$20.

If you would like more information about the Survey of Pathways to Diagnosis and Services, you can visit the study's web site at www.cdc.gov/nchs/slait.htm or call the toll-free telephone number for the study at 1-XXX-XXX-XXXX.

Thank you again for your help with this important research.

Sincerely,

<s>

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

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d. Mail Cover Letter & Instructions

Dear Parent or Guardian,

Thank you for taking part in the **Survey of Pathways to Diagnosis and Services**. The information that you gave about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children with learning and developmental conditions throughout the United States.

In appreciation for your time and effort spent answering our questions, we have enclosed [MONEY AMOUNT].

The parent or guardian who completed the telephone survey was asked to complete a paper questionnaire about your child's behaviors. This questionnaire is enclosed along with a stamped, addressed envelope so you can easily return the questionnaire to us in the mail. Participation is voluntary. As in the telephone survey, all data will be kept confidential. Please see the back of this letter for instructions on completing the questionnaire.

As promised, we will send you an additional \$10 once we receive the completed questionnaire.

If you would like more information about this survey, you can visit the study's web site at www.cdc.gov/nchs/slait.htm or call the toll-free telephone number for the study at 1-XXX-XXX-XXXX.

Thank you again for your help with this important research.

Sincerely,

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

Survey of Pathways to Diagnosis and Services Paper Questionnaire Instructions

1. Please fill out the questionnaire with a pen of any color (no pencil please).
2. Please answer each question by circling *your answer or checking the box*.
3. It would help us if you answered all items as best you can even if you are not absolutely certain of the answer. However, you may choose not to answer any question you do not wish to answer. There is no penalty if you leave a question blank.
4. When you have finished the questionnaire, put it in the enclosed envelope and drop the envelope in the mail. The envelope is already addressed and stamped, so you do not have to worry about adding postage.

*If you have misplaced or lost the envelope, you may
put the questionnaire in any envelope, add postage,
and mail it to:*

[INSERT ADDRESS]

Frequently Asked Questions

How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your information and the child's information will never be associated with any results.

If you would like more information about the confidentiality of the research or the federal laws that ensure the protection of your information, including the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act, these are described in detail at:

www.cdc.gov/nchs/about/policy/confiden.htm. If you want to know more about your rights as a study participant you may call 1-800-223-8118, toll-free. This is the number for the Research Ethics Review Board at NCHS. You will be asked to leave a message and say you are calling about Protocol XXXX-XX.

How will this information be used?

In combination with the information you provided during the telephone interview, maternal and child health agencies in your state will use the information you provide in this questionnaire to better understand and improve diagnosis and treatment of children with learning and developmental conditions. The federal government will also use this information to learn about the types of support services that states need for these children. You may visit <http://www.cdc.gov/nchs/slait.htm> to find general information about the study.

Is there a toll-free number if I have any questions?

To learn more about the study or if you have questions about the instructions or the questionnaire, call 1-877-XXX-XXXX, toll-free. This toll-free number will connect you with a survey representative at NORC at the University of Chicago. The National Center for Health Statistics has hired NORC to conduct the survey.

Thank you for your participation!

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e. Mail Refusal Conversion Letter

Dear Parent or Guardian,

The National Center for Health Statistics needs your help!

Recently, your family completed an important survey about children with learning and developmental conditions over the phone. A couple of weeks ago, we sent you a paper questionnaire as the second portion of this survey, but we have not yet received the completed survey in the mail. We hope you will reconsider our request. Information about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children in your state and throughout the United States.

In appreciation for your continued time and effort, we have enclosed \$5 cash. As promised, we will send you another \$5 after returning the completed paper questionnaire. Enclosed is another copy of the paper questionnaire, along with a stamped, addressed envelope so you may easily return the questionnaire to us.

We hope that you will share this important information with us by returning the enclosed mail survey. If you have questions or would like to find out more about the survey, please call the toll-free telephone number 1-XXX-XXX-XXXX. You can also find additional information about the survey at our website – <http://www.cdc.gov/nchs/slaits.htm>.

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

Sincerely,

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

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f. Thank You Letter (post mail conversion letter)

Dear Parent or Guardian,

Thank you for returning the paper questionnaire for the **Survey of Pathways to Diagnosis and Services**. The information that you gave about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children with learning and developmental conditions in your state and throughout the United States.

In appreciation for your time and effort spent answering our questions, we have enclosed \$5.

If you would like more information about the Survey of Pathways to Diagnosis and Services, you can visit the study's web site at www.cdc.gov/nchs/slait.htm or call the toll-free telephone number for the study at 1-XXX-XXX-XXXX.

Thank you again for your help with this important research.

Sincerely,

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

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g. Thank You Letter (no mail conversion letter needed)

Dear Parent or Guardian,

Thank you for returning the paper questionnaire for the **Survey of Pathways to Diagnosis and Services**. The information that you gave about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children with learning and developmental conditions in your state and throughout the United States.

In appreciation for your time and effort spent answering our questions, we have enclosed \$10.

If you would like more information about the Survey of Pathways to Diagnosis and Services, you can visit the study's web site at www.cdc.gov/nchs/slait.htm or call the toll-free telephone number for the study at 1-XXX-XXX-XXXX.

Thank you again for your help with this important research.

Sincerely,

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