

Attachment H: RCC and ADSC Chain Outreach Package

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Attachment H1-RCC Chain Outreach Package-NCHS Cover Letter with FAQs

[NCHS Letterhead]

Date

Position

Name of Organization

Address of Organization

Organization City, State, Zip Code

Dear <Position >:

The Centers for Disease Control and Prevention's National Center for Health Statistics is conducting the National Study of Long-Term Care Providers (NSLTCP). This new national study will collect information every two years about residential care communities, adult day services centers, home health agencies, hospice agencies, and nursing homes. Data obtained will be used to help inform long-term care providers, planners, researchers, and policymakers about community-based care, which is increasingly becoming an important part of the long-term care continuum in this country.

This letter is to inform you that one or more of the residential care communities in your organization may be invited to participate in NSLTCP. This study includes a nationwide survey of about 11,000 residential care communities. They will be requested to provide factual and numerical information, such as community characteristics (size, ownership, staffing, and services provided) and aggregate resident characteristics (demographics and functional status). No information about individual residents will be collected. Answering the questions will take about 30 minutes on average.

Information will be collected primarily by mail-in questionnaire and secure web-based interview. You may view the questionnaire at _____ . All information collected will be held in the strictest confidence according to section 308(d) of the Public Health Service Act (42, U.S. Code, 242m(d) and the Confidential Information Protection and Statistical Efficiency Act (Title 5 of PL 107-347). The collected information will not be published or released in any form if the individual establishment is identifiable unless the individual or establishment has consented to such release.

Participation is voluntary; however, I want to emphasize that it is important that we obtain data from all sampled residential care communities to achieve statistically accurate findings. I ask you to support and encourage the members of your organization who are contacted to complete this survey. The most reliable information comes from conducting interviews directly with providers themselves. We need their help to make this study a success. If you have any questions, please call an NSLTCP representative at (XXX) XXX-XXXX or go to the CDC website at <http://www.cdc.gov/nchs/nsltcp.htm>.

I greatly appreciate your cooperation.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics

National Survey of Long-Term Care Providers (NSLTCP)
Frequently Asked Questions

Who designed this study? What issues is it examining?

Researchers at CDC's National Center for Health Statistics (NCHS) designed the National Study of Long-Term Care Providers (NSLTCP). Over the past several years, representatives from the assisted living industry, family care homes, adult day services centers, and residential care helped to design the study questions and protocol. NSLTCP will track trends in the supply and use of residential care, the characteristics and practices of residential care communities, and the characteristics of residential care residents.

Why should our communities participate?

NCHS recognizes that residential care communities are an important part of the long-term care spectrum in the United States. NCHS recently completed the first ever nationwide study of residential care facilities (see enclosed Data Brief). NSLTCP is similar to surveys NCHS has done for other types of long-term care providers, such as nursing homes, hospice, and home health care agencies. When your communities participate you help ensure that the survey data for residential care communities are up-to-date and reflect an unbiased national sample that health care planners and policymakers can use to inform long-term care policy.

What other residential care communities are being contacted to participate in this survey?

The survey includes approximately 11,000 residential care communities operating in the United States. This is a random national sample, and we do not release the names of these communities that participate to anyone. This is to protect the privacy of individual places and the residents they serve.

Where did you get the names of the residential care communities?

Individual state licensing agencies provided the names of all licensed, certified or otherwise regulated residential care communities in their respective states.

Will the results be made public, and if so when and where?

A summary report is anticipated for December 2013. A public use dataset will also be available December 2013. These materials will be made available online at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be informed when they are available you may want to join the Long-Term Care ListServ at http://www.cdc.gov/nchs/dhcs/longterm_listserv.htm. Note also that identifying information about participants will not be contained in the public use dataset.

I approve of communities in my organization participating. Who do I notify?

Please convey to your community directors that they have your approval to participate in the NSLTCP if they are invited to do so.

Can I tell you which of our communities to contact?

The communities were selected using a scientific process to draw a statistically valid random sample. If we were to switch communities the sample would no longer be random and unbiased and the study data will not be valid.

Will information be held confidential?

Yes. NSLTCP is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in the strictest confidence according to law [Section 308 (d) of the Public Health Service Act (42 United States Code 242m (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Information collected in this survey may be used only for statistical purposes. Any government staff, contractor, or agent who willfully discloses confidential information may be subject to a jail term or a \$250,000 fine.

Who supports this study?

This survey is supported by American Seniors Housing Association (ASHA), Assisted Living Federation of America (ALFA), LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA). The enclosed letter of support provides this specific information.

Attachment H1-RCC Chain Outreach Package-Place holder for NSRCF Resident Data Brief

[screenshot]

Entire report found at:

<http://www.cdc.gov/nchs/data/databriefs/db91.pdf>

Other safeguards for your privacy

- Items that could be used, either directly or indirectly, to identify health care providers or their patients are removed from public-use data files. Names, addresses, dates of birth, dates of service, and location of the health care establishment are never released to the public.
- NCHS withholds statistical totals if they represent a location so small that the numbers might identify someone.
- Information security procedures, including use of coded passwords and physical security of computers, prevent unauthorized access to the data.
- The restriction on who sees personal information extends from the highest levels of our government (we can deny the President and any member of Congress access to confidential information as well as Immigration, Justice, and IRS officials) to the kinds of inquiries we are all increasingly worried about (market research firms, insurance companies, employers). Your survey responses are also protected from the Freedom of Information Act as well as court subpoenas.
- All published summaries are presented in such a way that no respondent can be identified.

We believe that our procedures for safeguarding information and our record of protecting the privacy of respondents are reasons why so many providers readily participate and provide reliable, high quality information. As a result, ample representative and accurate statistical information on health care utilization is made available every year to the American public, health care providers, the U.S. government, and the research community.

For further information

NCHS data are released in printed reports, CD-ROMs, and on the NCHS website,

<http://www.cdc.gov/nchs/>

For more information about how NCHS protects the information you provide, see:

<http://www.cdc.gov/nchs/about/policy/confidentiality.htm>

or contact:

Information Dissemination Staff
3311 Toledo Road, Room 5412
Hyattsville, MD 20782

For specific questions about how NCHS protects the information you provide, contact:

Confidentiality Officer
Eve Powell-Griner, Ph.D.
3311 Toledo Road, Room 7116
Hyattsville, MD 20782

Telephone: (888) 642-4159
E-mail: EPowell-Griner@cdc.gov

CS217034
137967 (10/2010)

How the National Health Care Surveys Keep Your Information

Strictly Confidential

National Ambulatory Medical Care Survey
National Hospital Ambulatory Medical Care Survey
National Survey of Ambulatory Surgery
National Hospital Discharge Survey
National Survey of Residential Care Facilities
National Nursing Home Survey
National Hospital Care Survey



Centers for Disease
Control and Prevention
National Center for
Health Statistics

Protecting the public's privacy...no idle pledge

There is safety in numbers,
especially our numbers!

The law . . .

Information collected in the National Health Care Survey (NHCS) is used for research and statistical purposes. No information that could identify a person or establishment can be released to anyone—including the President, Congress, or any court—without the consent of the provider.

The affidavit . . .

Anyone working for the National Center for Health Statistics (NCHS) must sign an affidavit—a legal document making them subject to the Privacy Act, the Public Health Service Act, and other laws.

The penalties . . .

Unauthorized disclosure of confidential statistical information is considered a class E felony that is punishable by imprisonment for up to 5 years, a fine of \$250,000, or both.

The record . . .

Since its first survey in 1957, NCHS has not released any confidential information to anyone not entitled to have it.

NCHS is well known for the high quality statistical information it provides. Maintaining that level of quality is not possible unless those who provide us with this information can be guaranteed confidentiality.

The confidentiality of records is of primary concern to NCHS. This principle is firmly grounded in federal laws, including the Privacy Act, the Public Health Service Act, the E-Government Act of 2002, and Title 18 of the United States Code. NCHS staff must sign a pledge to obey these laws and associated regulations to prevent disclosure of information, and they must follow strict procedures concerning data access, physical protection of records, avoidance of disclosure, and maintenance of confidentiality.

Unblemished record for maintaining privacy during data collection and processing

NCHS collaborates with other organizations, for example, the U.S. Census Bureau and private research companies, to collect and process data for NHCS. These groups have an impeccable record of protecting the privacy of survey respondents.

HIPAA Privacy Rule on health information and survey participation

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permits you to make disclosures of protected health information without patient authorization for public health purposes and for research that has been approved by an institutional review board (IRB) with a waiver of patient authorization. The NHCS meets both of these

criteria. As part of the IRB approval process, reviews were conducted of the surveys' procedures for handling protected health information, and practices were determined to be appropriate for safeguarding respondent confidentiality. Additionally, disclosures may be made under a data-use agreement with NCHS for some surveys that do not collect directly identifiable data.

Copies of IRB approval letters and other related materials, such as data-use agreements, are available upon request for each component survey of the NHCS. There are several things that you must do to assure compliance with the Privacy Rule when participating in the survey. First, the privacy notice that you generally provide to your patients must indicate that patient information may be disclosed for either research or public health purposes. Second, you may need to keep a record of the disclosure that shows that some data from the patient's medical record were disclosed to CDC for NHCS (we will provide forms to assist you in record keeping). If you do not transmit health information electronically (such as claims data), you are not subject to the Privacy Rule or the requirements described above.

For additional information on the HIPAA Privacy Rule, see:

<http://www.hhs.gov/ocr/hipaa>



In 2012, CDC's National Center for Health Statistics (NCHS) will be launching the National Study of Long-Term Care Providers (NSLTCP), a first ever national study of the major providers of long-term care. This data collection effort will include a representative sample of residential care and assisted living communities across the country.



National data collection will start in September 2012 and end in January 2013. The following organizations encourage your participation:

- American Seniors Housing Association (ASHA)
- Assisted Living Federation of America (ALFA)
- LeadingAge
- National Center for Assisted Living/American Health Care Association (NCAL/AHCA)



Residential care directors will be asked to provide information about their communities through a mail, Web or telephone survey and will take about an hour to complete. The survey includes questions about residential care services, staffing, and practices, and resident demographics, physical and cognitive functioning, and payment sources. This information will help policy makers, health care planners, and residential care/assisted living providers better understand, plan for, and serve the future long-term care needs of the aging population.



While data from this survey will be made publicly available, all data will be kept confidential and will be aggregated, so that the names of the communities, staff, residents and respondents will not be identifiable

Attachment H2-ADSC Chain Outreach Package-Cover letter with FAQs

[NCHS Letterhead]

Date

Position

Name of Organization

Address of Organization

Organization City, State, Zip Code

Dear <Position >:

The Centers for Disease Control and Prevention's National Center for Health Statistics is conducting the National Study of Long-Term Care Providers (NSLTCP). This new national study will collect information every two years about adult day services centers, residential care communities, home health agencies, hospice agencies, and nursing homes. Data obtained will be used to help inform long-term care providers, planners, researchers, and policymakers about community-based care, which is increasingly becoming an important part of the long-term care continuum in this country.

This letter is to inform you that adult day services centers in your organization are being invited to participate in NSLTCP. This study includes a nationwide survey of about 5,000 adult day services centers. They will be requested to provide factual and numerical information, such as center characteristics (size, ownership, staffing, and services provided) and aggregate participant characteristics (demographics and functional status). No information about individual participants will be collected. Answering the questions will take 30 minutes on average.

Information will be collected primarily by mail-in questionnaire and secure web-based interview. You may view the questionnaire at _____ . All information collected will be held in the strictest confidence according to section 308(d) of the Public Health Service Act (42, U.S. Code, 242m(d) and the Confidential Information Protection and Statistical Efficiency Act (Title 5 of PL 107-347). The collected information will not be published or released in any form if the individual establishment is identifiable unless the individual or establishment has consented to such release.

Participation is voluntary; however, I want to emphasize that it is important that we obtain data from all adult day services centers to achieve statistically accurate findings. I ask you to permit, and encourage, the members of your organization who are contacted to complete this survey. The most reliable information comes from conducting interviews directly with providers themselves. We need their help to make this study a success. If you have any questions, please call an NSLTCP representative at (XXX) XXX-XXXX or go to the CDC website at <http://www.cdc.gov/nchs/nsltcp.htm>.

I greatly appreciate your cooperation.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics

National Survey of Long-Term Care Providers (NSLTCP)
Frequently Asked Questions

Who designed this study? What issues is it examining?

Researchers at CDC's National Center for Health Statistics (NCHS) designed the National Study of Long-Term Care Providers (NSLTCP). Representatives from the adult day services sector helped to design the study questions and protocol. NSLTCP will track trends in the U.S. adult day services programs, including center supply and use, characteristics and practices of centers, and characteristics of center participants.

Why should our facilities participate?

NCHS recognizes that adult day services programs are an important component of long-term care in the United States. NSLTCP will be similar to surveys NCHS has done for other types of long-term care providers, such as assisted living communities, nursing homes, and home health care agencies. When you allow your centers to participate you help ensure that the survey data for adult day services centers are up-to-date and reflect an unbiased national sample that health care planners and policymakers can use to inform long-term care policy.

What other adult day services centers are being contacted to participate in this survey?

The survey includes approximately 5,000 adult day services centers operating in the United States. We do not release the names of these centers that participate to anyone. This is to protect the privacy of individual places and the participants they serve.

Where did you get the names of the adult day services centers?

A nonprofit association of adult day services centers compiled a list of all adult day services centers in the U.S. under contract to NCHS.

Will the results be made public, and if so when and where?

A summary report is anticipated for December 2013. A public use dataset will also be available December 2013. These materials will be made available online at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be informed when they are available, you may want to join the Long-Term Care Listserv at http://www.cdc.gov/nchs/dhcs/longterm_listserv.htm. Note also that identifying information about participants will not be contained in the public use dataset.

I approve of centers in my organization participating. Who do I notify?

Please convey to your center directors that they have your approval to participate in NSLTCP if they are invited to do so.

Will information be held confidential?

Yes. NSLTCP is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in the strictest confidence according to law [Section 308 (d) of the Public Health Service Act (42 United States Code 242m (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Information collected in this survey may be used only for statistical purposes. Any government staff, contractor, or agent who willfully discloses confidential information may be subject to a jail term or a \$250,000 fine.

Who supports this study?

This survey is supported by the National Adult Day Services Association (NADSA). The enclosed letter of support provides this specific information.

ADULT DAY SERVICES (ADS) CENTERS BROCHURE (4-page foldout)

National Study of Long-Term Care Providers National Health Care Surveys



Cover page NSLTCP artwork to be developed

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



Centers for Disease Control and Prevention

National Center for Health Statistics

Introduction

The National Study of Long-Term Care Providers (NSLTCP) is a new national data collection effort to gather ongoing information about the characteristics of adult day services centers and other long-term care providers. Also included are residential care/assisted living communities, nursing homes, home health agencies and hospice agencies. The Centers for Disease Control and Prevention's National Center for Health Statistics sponsors NSLTCP. This brochure describes the adult day services component of this ground-breaking study.

Importance

In 2010, there were an estimated 4,600 adult day services centers in the United States that served about 260,000 older persons and younger adults with disabilities on any given day.¹ Adult day services centers are an important and growing segment of the long-term care provider industry, serving community-based individuals, and their family caregivers, who need supportive services to enable them to continue to reside at home. This study, to be conducted every two years, will provide an up-to-date snapshot of the characteristics of these centers and the participants who rely on their services. The information collected will provide reliable national and **state-level estimates** of key policy-relevant characteristics and practices of adult day services centers. These data will help characterize how these centers meet the needs of elders and adults with disabilities and help shape future long-term care policies.

Survey and content

Data collection is estimated to begin Fall 2012. All 5,000 adult day services centers throughout the United States are included in NSLTCP. RTI International is collecting the data for the National Center for Health Statistics. Directors are contacted by mail to complete the survey. No information about individual adult day services center participants will be collected. Information will be collected on these and other topics:

About adult day services centers-

- Basic characteristics- ownership, average daily attendance, years in operation
- Services provided- social work, case management, therapeutic, transportation
- Staffing- types and numbers of employees and staff under contractual arrangement
- Practices-Depression screening, use of Electronic Health Records, chronic disease management, person-centered care

¹ 2010 MetLife, Inc., Ohio State University College of Social Work, National Adult Day Services Association (NADSA) National Study of Adult Day Services.

About participants- aggregate level distributions

- Demographics
- Physical functioning
- Cognitive functioning
- Alzheimer's disease and other dementias
- Participant transitions

Goals and intended uses of the data

The National Study of Long-Term Care Providers is designed to provide national data and state-level data where feasible, about the characteristics of adult day services centers and other long-term care providers, the services they offer, general information on staffing, demographics and health of the clientele they serve, and payment for these services. These data can then be used by providers, consumers, policymakers, and researchers to:

- estimate the U.S. national supply of adult day services centers and other types of paid regulated long-term care providers;
- estimate key policy-relevant characteristics and practices of these long-term care providers;
- estimate the national use of these providers;
- estimate key policy-relevant characteristics of these providers nationally; and
- within the above goals, produce state-level estimates for as many states as feasible with the National Center for Health Statistics' confidentiality and reliability standards;
- enable comparisons within and between different types of long-term care providers at a similar point in time as well as monitoring trends over time.

Confidentiality

The Centers for Disease Control and Prevention's National Center for Health Statistics is required by law to maintain the confidentiality of data it collects. All data that directors provide will be kept in strict confidence and will be used only for statistical purposes. All information, publications, and data files will be released in such a way that no individual provider, staff, or participant can be identified. Participants receive assurance of this confidentiality under the Public Health Services Act. Any National Center for Health Statistics staff, contractor, or agent who willfully discloses confidential information may be subject to a jail term or a \$250,000 fine.

Data dissemination

The adult day services centers and assisted living/residential care survey data will be available in public-use files from the NSLTCP website: <http://www.cdc.gov/nchs/nsltcp.htm> by late 2013. A long-term care overview report is also planned for release in late 2013 and will be on the NSLTCP website.

NSLTCP supporters

- National Adult Day Services Association (NADSA)



- American Health Care Association
- American Seniors Housing Association
- Assisted Living Federation of America
- Center for Excellence in Assisted Living (CEAL)
- LeadingAge
- National Association of Home Care and Hospice
- National Center for Assisted Living
- National Home and Palliative Care Organization

To learn more about NSLTCP call

301-458-4747, or visit the NSLTCP website:

<http://www.cdc.gov/nchs/nsltcp.htm>

Other safeguards for your privacy

- Items that could be used, either directly or indirectly, to identify health care providers or their patients are removed from public-use data files. Names, addresses, dates of birth, dates of service, and location of the health care establishment are never released to the public.
- NCHS withholds statistical totals if they represent a location so small that the numbers might identify someone.
- Information security procedures, including use of coded passwords and physical security of computers, prevent unauthorized access to the data.
- The restriction on who sees personal information extends from the highest levels of our government (we can deny the President and any member of Congress access to confidential information as well as Immigration, Justice, and IRS officials) to the kinds of inquiries we are all increasingly worried about (market research firms, insurance companies, employers). Your survey responses are also protected from the Freedom of Information Act as well as court subpoenas.
- All published summaries are presented in such a way that no respondent can be identified.

We believe that our procedures for safeguarding information and our record of protecting the privacy of respondents are reasons why so many providers readily participate and provide reliable, high quality information. As a result, ample representative and accurate statistical information on health care utilization is made available every year to the American public, health care providers, the U.S. government, and the research community.

For further information

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or contact:

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Hyattsville, MD 20782

Telephone: (888) 642-4159
E-mail: EPowell-Griner@cdc.gov

CS217034
137967 (10/2010)

How the National Health Care Surveys Keep Your Information

Strictly Confidential

National Ambulatory Medical Care Survey
National Hospital Ambulatory Medical Care Survey
National Survey of Ambulatory Surgery
National Hospital Discharge Survey
National Survey of Residential Care Facilities
National Nursing Home Survey
National Hospital Care Survey



Centers for Disease
Control and Prevention
National Center for
Health Statistics

Protecting the public's privacy...no idle pledge

**There is safety in numbers,
especially our numbers!**

The law . . .

Information collected in the National Health Care Survey (NHCS) is used for research and statistical purposes. No information that could identify a person or establishment can be released to anyone—including the President, Congress, or any court—without the consent of the provider.

The affidavit . . .

Anyone working for the National Center for Health Statistics (NCHS) must sign an affidavit—a legal document making them subject to the Privacy Act, the Public Health Service Act, and other laws.

The penalties . . .

Unauthorized disclosure of confidential statistical information is considered a class E felony that is punishable by imprisonment for up to 5 years, a fine of \$250,000, or both.

The record . . .

Since its first survey in 1957, NCHS has not released any confidential information to anyone not entitled to have it.

NCHS is well known for the high quality statistical information it provides. Maintaining that level of quality is not possible unless those who provide us with this information can be guaranteed confidentiality.

The confidentiality of records is of primary concern to NCHS. This principle is firmly grounded in federal laws, including the Privacy Act, the Public Health Service Act, the E-Government Act of 2002, and Title 18 of the United States Code. NCHS staff must sign a pledge to obey these laws and associated regulations to prevent disclosure of information, and they must follow strict procedures concerning data access, physical protection of records, avoidance of disclosure, and maintenance of confidentiality.

Unblemished record for maintaining privacy during data collection and processing

NCHS collaborates with other organizations, for example, the U.S. Census Bureau and private research companies, to collect and process data for NHCS. These groups have an impeccable record of protecting the privacy of survey respondents.

HIPAA Privacy Rule on health information and survey participation

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permits you to make disclosures of protected health information without patient authorization for public health purposes and for research that has been approved by an institutional review board (IRB) with a waiver of patient authorization. The NHCS meets both of these

criteria. As part of the IRB approval process, reviews were conducted of the surveys' procedures for handling protected health information, and practices were determined to be appropriate for safeguarding respondent confidentiality. Additionally, disclosures may be made under a data-use agreement with NCHS for some surveys that do not collect directly identifiable data.

Copies of IRB approval letters and other related materials, such as data-use agreements, are available upon request for each component survey of the NHCS. There are several things that you must do to assure compliance with the Privacy Rule when participating in the survey. First, the privacy notice that you generally provide to your patients must indicate that patient information may be disclosed for either research or public health purposes. Second, you may need to keep a record of the disclosure that shows that some data from the patient's medical record were disclosed to CDC for NHCS (we will provide forms to assist you in record keeping). If you do not transmit health information electronically (such as claims data), you are not subject to the Privacy Rule or the requirements described above.

For additional information on the HIPAA Privacy Rule, see:

<http://www.hhs.gov/ocr/hipaa>

Attachment H2-ADSC Chain Outreach Package-Letter of Support

The National Study of Long-Term Care Providers (NSLTCP) is the first ever federal study of adult day services (ADS) centers. For the first time, the NSLTCP will allow us to compare our services, participants, and funding to other providers such as home health care and assisted living communities. The information is critical as we continue to develop adult day services in this current economic environment. **The National Adult Day Services Association encourages and appreciates your participation in this important, national research effort.**

NSLTCP is designed to provide national information—and where possible state information—about ADS centers and their participants. ADS center directors will be asked to provide information about their centers through a mail, Web, or telephone survey. The survey includes questions about services, staffing, and practices; participants' physical and cognitive functioning; and sources of payment for participants' care. This information will help policymakers, health care planners, and ADS providers better understand, plan for, and serve the future long-term care needs of older persons and younger adults with disabilities. **All individual data will be kept confidential and the data will be aggregated, so that the names of ADS centers, staff, participants and respondents will not be identifiable.**

The study is being conducted by the National Center for Health Statistics (NCHS), an agency of the Centers for Disease Control and Prevention (CDC). National data collection will start in September 2012. All ADS centers will be invited to participate in the national survey. If you have any questions or concerns, please feel free to contact me at (877) 745-1440.

Teresa Johnson



Managing Director

