# A Case Study of Faith-Based Outreach in New York City: Lessons Learned from A Risk Reduction Initiative

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Maternal and Child Health Bureau

Rockville MD 20857

Dear Colleague:

On behalf of the Health Resources and Services Administration's, (HRSA) Maternal and Child Health Bureau (MCHB), I am pleased to share with you a new publication relating to MCHB's Sudden Infant Death Syndrome (SIDS) and Other Infant Death Program. The title of the publication is A Case Study of Faith-Based Outreach in New York City: Lessons Learned From a Risk Reduction Initiative.

This publication describes the efforts undertaken by the New York City Satellite Office of the New York State Center for SIDS to design and implement a grandparent/elder faith-based SIDS risk reduction program to address African-American infant mortality in four New York City communities. The communities that were included are located in Central Harlem, Bedford Stuyvesant-Brownsville, the South Bronx, and Southeast Queens.

The report was submitted by the Association of SIDS and Infant Mortality Programs under contract to HRSA. The primary authors are Evelyne Longchamp, M.A., R.N., Danita Hall, C.S.W., and Joan Arnold, R.N., Ph.D. In addition, the CJ Foundation for SIDS provided the financial support, in part, for the Faith Based Outreach Effort in New York City.

MCHB is distributing this publication to Federal, State and local policy makers, research institutions, public health programs/agencies, advocacy groups, and health professionals. If you would like to receive additional copies of this publication, please contact the National SIDS and Other Infant Death Resource Center at 1-866-866-7437 or by e-mail at sids@circlesolutions.com.

I hope you find this publication very useful in your efforts to reduce the risk of SIDS and other infant death.

Sincerely yours,

Peter C. van Dyck, M.D., M.P.H.
Associate Administrator for Maternal and Child Health

Enclosure

**A Case Study of Faith- Based Outreach in New York City: Lessons Learned from a SIDS Risk Reduction Initiative**

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## Introduction

In 1999, the New York City Satellite/Medical Health Research Association of New York City Inc. (MHRA) of the New York State Center for Sudden Infant Death (NYC Satellite Office) designed a grandparent/elder focused faith based SIDS risk reduction outreach strategy to address African American infant mortality disparity. This monograph is a case study that describes the research driven process that the NYC Satellite Office followed to design and implement this initiative in four African American communities. The lessons learned from this project can be instructive to others as they consider an approach in their own local settings.

## Background

The *Back to Sleep* campaign provided a critically important and new element to Sudden Infant Death Syndrome (SIDS) and Other Infant Death (OID) programs. In addition to bereavement support and education to an array of professionals and communities about the sudden and unexpected nature of death in infants, programs developed risk reduction strategies for SIDS as a primary intervention. The Association of SIDS and Infant Mortality Programs (ASIP) was instrumental in providing guidelines to programs for risk reduction education (Fernbach, English-Rider, McClain, & Shaefer, 1994; Fernbach, McClain & Shaefer, 1998).

In 1994, the NYC Satellite Office began reaching out to prenatal and infant care providers with the *Back to Sleep* message. The target audience was pregnant women, mothers of infants and any providers coming in contact with them. Efforts were expanded to include and educate trainers in institutions so the message would be incorporated into existing institutional training and continued. Women out of the mainstream of care were reached through presentations at shelters for homeless people and at a large detention center which also housed a nursery.

In 1998, a landmark series of articles were published in the *Journal of the American Medical Association* (JAMA). These articles included a report on the National Infant Sleep Position Study (Willinger, Hoffman, Wu, Hou, Kessler, Ward, Keens & Corwin), a longitudinal assessment of sleep position (Lesko, Corwin, Vezina, Hunt, Mandell, McClain, Heeren, & Mitchell), and an analysis of sleep position among inner-city infants (Brenner, Simons-Morton, Bhaskar, Mehta, Melnick, Revenis, Berendes, and Clemens). Although a direct cause and effect relationship could not be established, these studies demonstrated that as more infants were placed on their backs to sleep the SIDS rate decreased.

The studies also revealed a correlation between lower use of the back sleeping position and the presence of the following demographic characteristics of mothers: single, African American, one or more previous children, living with a relative of the previous generation (i.e. grandparent), low-income, and less than high school education. Even when infants were initially placed to sleep on their backs, by three months of age, infant care practices reverted to the tummy sleep position. Recognizing that a substantial proportion of infants from a low-income population were placed in the tummy sleep position, efforts to promote the back sleep position in groups at high risk for tummy placement were recommended (Brenner, Simons-Morton, Bhaskar, Mehta, Melnick, Revenis, Berendes, and Clemens, 1998).

These published reports served as an impetus for the NYC Satellite Office to further expand and reshape its efforts in risk reduction. Despite the overall decline in infant deaths, the racial and geographic disparity in infant mortality rates in New York City was apparent. The need to consider different strategies and to more aggressively target African American families with risk reduction information was evident.

**Addressing the Need**

The relationship linking poverty, ethnic identity and health care has always been powerful and difficult. In New York City, poverty in the African American community has resulted in many forms of deprivation and disparity. African American families have also been subjected to issues of limited access and availability to health care and to substandard health services in certain low-income communities of New York City. The National Center for Education in Maternal and Child Health (NCEMCH) states: "Despite increasing health care expenditures and extraordinary medical breakthroughs, the U.S. health care system fails to effectively serve many of the Nation's communities. Much evidence indicates that minority race and ethnicity are associated with disparate health outcomes..." (Berglas & Lim,1998).

R.B. Hill's classic work on the strengths of black families notes that the African American family in many ways has learned to survive based on beliefs passed down over generations (Hill, 1971). The extended family is often the mainstay and family dynamics reflect the importance of elders in decision making and assuming responsibility for family functioning. It is not uncommon for the infant of an adolescent mother to be raised by the grandmother or great-grandmother as the mother resumes school or employment. In situations when the mother is absent from the home, perhaps due to incarceration or residence in a protective shelter as a consequence of domestic violence, the grandmother often is the nominal parent (Grandparents Raising Grandchildren, National Satellite Video Conference, 1999).

In many instances, the grandmother is considered the matriarch in the African American family, serving as the family leader, filtering and controlling information into the family network (Clark, 1981). Often, grandmothers actively maintain the intergenerational ties. She may be considered the keeper of family wisdom, and as such, is sought out for critical decision making. When it comes to infant care practices, the grandmother is often looked to as being the expert. Her wisdom, acquired from long-held practices of childrearing, provides a safe anchor of support, particularly for the inexperienced young mother (Hunter, 1997). When the grandmother speaks, family members often feel obliged to listen and to follow her guidance.

Further, the grandmother is frequently grounded in the home. Other members may enter and leave the family network but the grandmother often provides the continuity. She may literally and figuratively maintain the stability of the home and hold the family together (Harrison, 1993; Wilson, Tolson, Hinton, & Kiernan, 1990).

Therefore, after reviewing the research literature, demographic factors and considering possible reasons for the disparity, the NYC Satellite Office determined that focusing on African American grandparents was key in these New York communities. Given the significance of the grandparent/elder in guiding infant care practices in African American families (Hunter, 1997), the NYC Satellite Office decided to disseminate the *Back to Sleep* message to this target audience. This decision was reinforced by a report from focus groups which demonstrated that African American grandparents and other senior caregivers were receptive to SIDS risk reduction information (Flick, Vemulapalli, Stulac, & Kemp, 2001). Program staff understood that reaching grandparents directly was essential.

"Black Americans may choose one religious tradition over another – they may even invent new forms of worship – but they always remain people of faith" (Williams & Dixie, 2003). In these four communities, church services,

particularly storefront churches, were recognized as meeting places for many African American families, especially the elders. A new strategy to promote the *Back to Sleep* message would mean developing a non-traditional approach to health education with new venues for connection into community life. Since the church is often at the core of many African American families' functioning, community outreach to churches became the preferred method and setting to reach grandparents/elders.

Risk reduction education requires a change in presumably long-held infant care beliefs and practices. For that reason, a trusting relationship between those giving the message and those receiving the message was of utmost importance. Community representatives and participation were found to be essential in planning and implementing programs. Notably, such involvement also fostered an important sense of community ownership. The clergy were often gatekeepers, providing access to their congregations (Comer, 1988). Consequently, when programs collaborated with local churches to share educational information the results were more likely to be successful (Servin, 1997).

**Developing a Plan**

In 1998, the infant mortality rate for the entire City of New York was 6.8 per 1,000 live births. However, on investigating the infant death rates by Health Center District of residence, racial disparity was recognizable. In the borough of Manhattan, the infant mortality rate for Central Harlem was 11.4. In the borough of Brooklyn, the infant mortality rate for Bedford was 13.9 and for Brownsville, 9.4. In the South Bronx, the infant mortality rate for Tremont was 8.1; and in Southeast Queens, the infant mortality rate for East Jamaica was 7.9. Each community affected by such disparity could be identified by its ethnic/racial composition. These communities were predominately African American.

Thus, the NYC Satellite Office identified four African American communities — Central Harlem, Bedford Stuyvesant-Brownsville, the South Bronx and Southeast Queens — as its target for the *Back to Sleep*/SIDS risk reduction initiative. The intent was to reach out to these communities through partnerships with clergy.

It was hoped the clergy, providing access to their congregations, would enable the SIDS risk reduction message to be received in these communities. The clergy, through reputation and standing in the community, would assure the SIDS risk reduction message was vital (Williams & Dixie, 2003). It was anticipated that the church would provide access to the primary target – grandparents – since the church was central to the lives of many African American families, particularly family elders.

**Identifying and Contacting Churches, Communities and Ministers**
At the start, staff obtained directories of churches in the target communities. The Program Director wrote a letter to clergy which introduced the NYC Satellite Office, described the *Back to Sleep* campaign and illustrated the disparity in infant death rates by race and neighborhoods. The letter, including *Back to Sleep* literature, offered the opportunity for free educational workshops to congregations. A total of 769 letters was sent to churches. If there was no response to the letter, follow-up telephone calls were made to churches in an effort to make appointments for SIDS risk reduction educational presentations.

As the outreach efforts unfolded, additional opportunities to promote the *Back to Sleep* message to targeted communities were identified. For example, an article entitled, "Saving Our Babies" was written for the *Love Express*, a newspaper with a circulation of 96-97,000 copies per month and disseminated through churches and other community and business organizations. A community member with knowledge of the faith community and a working relationship with numerous African-American ministers was identified. This member of the African American clergy was the outreach coordinator for a program blending faith and medicine sponsored by one of the major medical centers in the Bronx. The community member's expertise in forging alliances with churches in the Bronx facilitated access to specific churches and created a communication link with the respective ministers about the SIDS risk reduction campaign. Efforts to locate key individuals in each community followed.

Other opportunities to reach clergy included entree to the Clergy Coalition, an alliance of clergy that meets monthly and often considers health and social service concerns for agenda items. Staff also contacted the Queens Federation of Churches and the Southeast Queens Clergy. These organizations offer a forum for church leaders to meet together and discuss shared concerns or to address common issues. Organizations like these provide and maintain up-to-date mailing lists of clergy and their churches. These lists were used for the initial mailing to familiarize clergy with the *Back to Sleep* campaign and the educational programs offered by the NYC Satellite Office in each borough.

**Identifying and Training Consultants/Clergy Outreach Educators**
While only a small program within MHRA, the NYC Satellite Office fulfills a large mission. This mission is to provide outreach, education and direct bereavement support services related to sudden and unexpected infant death for the entire City of New York. Existing staff and funding could not adequately address an additional comprehensive project. The evolving initiative of a faith-based outreach to grandparents – bringing the SIDS risk reduction message to selected African American communities of the city — would require special funding in order to provide staff capacity to achieve the intended objectives. A proposal

was submitted to the C. J. Foundation for SIDS, a nationwide voluntary health organization dedicated to recognizing the special needs of the SIDS community through funding SIDS research, support services and public awareness, located at the Hackensack University Medical Center in New Jersey.

The proposal was funded enabling the NYC Satellite Office to hire consultants/clergy outreach educators to conduct the SIDS risk reduction workshops in the various churches throughout the four targeted communities. Each consultant knew the city and its neighborhoods well. They were also familiar with health and social service agencies as well as referral mechanisms.

To prepare the consultants for their outreach educator roles, the NYC Satellite Office designed and conducted two intense training sessions which included practice presentations (Arnold & Fernbach, 2000; Arnold & Ramsey, 1981). The consultants were:

- trained in understanding the complexities of SIDS, latest research and risk reduction strategies.
- briefed in an adult learning format about how to recognize group dynamics, handling conflict, and recognizing and accepting differing cultural interpretations about SIDS and child rearing practices.
- prepared to "get the message out" and to learn how to abbreviate the risk reduction message for a short presentation as well as lengthen their presentation for a discussion.
- equipped with a variety of presentation styles, for example, at the pulpit, in the vestibule of the church, at a community fair or at a workshop.
- given culturally appropriate *Back to Sleep* materials created by NICHD for the African American SIDS risk reduction campaign ( a brochure, *Babies Sleep Safest on Their Backs: Reduce the Risk of SIDS,* and a one-minute video, *SIDS: A Video on Helping to Reduce the Risk*).

Regardless of the venue, the consultants were ready to deal with misinformation and misconceptions about SIDS and infant care practices. Their informational messages were to be clear, direct, supportive and respectful. The consultants were matched to the communities of concern so that cultural identity was maximized and the cultural identification with the community was underscored. In addition, these consultants were available on evenings and weekends when most of the sessions were requested or convened.

**Describing the Educational Format**

Small group sessions were held at churches in each of the four identified communities. Depending on the particular church and the minister's ability to schedule, some sessions followed religious services while others were scheduled

as evening events. Several ministers invited the consultants to be part of a church health fair.

During the warmer months of May through October, many churches conduct open-air street fairs to provide health information and screening for church members and their neighbors. In these instances, it was helpful to display a banner advertising the *Back to Sleep* campaign to attract participants. Fliers were distributed and the public service announcement (*SIDS: A Video on Helping to Reduce the Risk*) was shown on a portable VCR.

Culturally appropriate *Back to Sleep* materials were distributed at each session. Requests for Spanish information were also common *(Necesito dormir boca arriba: Reduzca el riesgo del síndrome de muerte súbita del bebé, a brochure by NICHD and a one-minute video, Síndrome de Muerte Infantil Súbita: Un Video Sobre Como Ayudar a Prevenir La Muerte de Cuna* ).

The *Back to Sleep* public service announcement (PSA) was a valuable addition to the outreach educational program. It is a straightforward presentation in a brief and direct format. This video provides a convincing message that was viewed as authoritative. One of the outreach educators also shared her experience as a SIDS parent. Her personal message about losing a child gave powerful validation to the risk reduction message.

Dispelling myths about sleep position and encouraging the discussion of conflicting points of view becomes an important teaching method when conveying the SIDS Risk Reduction message to congregations. Principles of adult learning guided the interactions assuring that previous knowledge of the participants was acknowledged and validated before introducing new material (Freire, 1970; Knowles, 1970, 1980; Brookfield, 1991). In addition, methods such as role playing and learning exercises using questions/answers were applied to reinforce learning. To encourage ownership of the new information, participants were asked to share this information with others in their families and neighborhoods.

**Evaluating the Process and Effectiveness of Promoting the Message**

Approximately 40 events took place each year with an average attendance of 60 people at each event. Following the activities, the NYC Satellite Office's senior consultant interviewed the clergy outreach educators using a standardized Clergy Outreach Evaluation. The evaluation information offered a way to learn about the effectiveness of delivering the SIDS risk reduction message to congregations.

Six questions were asked:

1. How were you received by the congregation?
2. Was the congregation responsive by giving you non-verbal approval or asking questions?
3. Were there any indications from the congregation that this message will be shared with family and friends?
4. What obstacles did you face in planning and delivering the outreach?
5. What would you do differently to make the outreach more effective?
6. How can congregations be more effectively engaged?

Evaluations revealed that the responses to the educational programs were overwhelmingly positive. Each clergy outreach educator was well received by the respective congregations. Regardless of the venue – during or after the religious service or at a church health fair – the outreach educator was welcomed and the message of risk reduction was received with thoughtful attention.

Most importantly, congregations accepted the SIDS Risk Reduction message as new and valuable information. Sessions were characterized by dynamic interchange with many questions, verbal approval and non-verbal signs of attention and comprehension.

Often, the elder members of the church congregations would declare that they raised their own children by putting them on their "stomachs to sleep". They questioned why a change in practice was necessary since their children had survived and not succumbed to SIDS. Such discussions reinforced the staff's perception that grandmothers are key to education about infant care practices in many families.

The primary concern raised about placing babies on their backs to sleep was about the infant's vomiting and possibly choking while in the back sleeping position. Once these questions were addressed, members of the congregations indicated they would share information about SIDS risk reduction with other family members, babysitters and neighbors. Some indicated a desire to share the information with anyone they knew who was pregnant or thinking about becoming pregnant. Brochures about the *Back to Sleep* message were readily received.

**Disseminating the Message: Challenges and Opportunities**

Staff confronted several key challenges in their efforts to provide outreach for this initiative. A primary barrier was the difficulty in reaching clergy to gain approval for the educational program. In the targeted communities, clergy are often not employed full time at their churches. Many hold other full time jobs and are available only immediately before the actual service for which they are busy

preparing. Some churches do not have staff to answer the telephone and may not have an answering machine to take messages.

In larger churches that do employ full time staff, the demands on the clergy are great. There are multiple faith-based initiatives inundating clergy with requests to address a range of health and social problems. Clergy in high-risk communities, in particular, are repeatedly approached for ways to access these hard to reach populations. Often, the Church secretary or office manager screens calls and tries to dismiss requests when ministers are overwhelmed with demands for their time or for opportunities to interface with their congregations.

One minister suggested the best way to contact clergy is to attend the service and present oneself in face-to-face interaction after the service. Overall, once the consultant spoke with the clergy and confirmed the educational program, the response from the congregation was consistently positive.

Planning accurately for the educational session was another challenge to this initiative. The number of people expected for a given educational session or health fair was not known until the actual event. While time was allocated at a religious service to present the risk reduction message it was often limited and provided no opportunity for follow-up questions.

Information sharing without accompanying dialogue cannot guarantee that the risk reduction message was accurately received or understood. In these instances, the outreach educator would wait until the service was over and make herself available to those members of the congregation that wanted to ask questions and discuss the issue individually. Usually if 60 people attended a service, about 15-20 people would seek out the educator after the service. All participants at the service would willingly accept the *Back to Sleep* brochure.

**Lessons Learned**

The NYC Satellite Office found that continued efforts to educate high-risk populations about the *Back to Sleep* message through clergy outreach is an important and effective strategy. Once clergy and their congregations can be reached, the message is well received.

Based on evaluations and experience with the initiative, staff and consultants/ clergy outreach educators suggested additional strategies for making the outreach efforts more effective. For example, obtaining and utilizing e-mail addresses may increase the success of communication with clergy. Locating gatekeepers with direct access to clergy is another significant step in gaining the attention of clergy, given their work and religious schedules and the number of demands made upon them to gain access to their congregations.

A more in-depth workshop format may encourage greater community engagement and multiply the risk reduction message to existing groups in the churches. People meeting for a common or shared interest may be more effective audiences. Further, a workshop that could be offered at community-based conferences was recommended.

Creating a Sudden Infant Death/*Back to Sleep* banner to display at health fairs is helpful. A colorful banner attracts participants to the *Back to Sleep* table and gives the message greater recognition. Literature that is colorful, eye-catching and translated into several languages is also recommended to attract a broad audience to the *Back to Sleep* message.

Methods for engaging the congregations more effectively were considered. Staff found that spring and summer were more ideal times to plan presentations since groups tend to gather more frequently for events during these seasons.

Since members of the congregation responded positively to pamphlets, personalized handouts may increase the feeling of ownership and connection with a particular congregation. Focusing on different teaching strategies to increase dialogue can also be considered i.e. question/answer format, written questions. These teaching materials could be distributed with pens or pencils that advertise the *Back to Sleep* message and serve as take home gifts for the participants.

A two-part presentation was recommended as a vehicle for effectively providing information that is both didactic and interactive. Returning the week following the initial session could serve to reinforce the risk reduction message, enable participants time to share the information with family and friends and report on their discussions. This follow-up could become an evaluation measure to determine if the risk reduction message is accepted, understood and communicated to others. If the participants return the following week with information about their discussions, special prizes or incentives could be given away.

**Summary**

SIDS risk reduction efforts have had an impact on decreasing the infant mortality rate nationally and at the community level. However, racial disparity remains a factor, particularly for African Americans. Efforts to reach the African American population in four New York City communities at high risk for infant mortality were undertaken by the NYC Satellite Office.

In order to reach these communities with *Back to Sleep* information, two population characteristics were identified. First, grandmothers have a significant role and authority in many African American families and do influence infant care

practices. Second, the church is an important force in the life of many African American families and can be a community resource for communication, particularly with family elders. Reaching out to grandparents through their churches is the premise on which this faith-based initiative was developed.

The following findings of this New York City case study will assist other programs and initiatives attempting to reach out to populations at risk using a faith-based approach:

- Working in collaborative partnerships with community-based organizations and community leaders is necessary for reaching out to vulnerable populations in a city as large and diverse as New York City. Identifying these community-based organizations, developing a trusting relationship, becoming a valued and dependable resource requires a great investment of time and personal effort.

- Faith-based outreach is a complex initiative. Access both to clergy and congregations is the primary challenge for this community-based program to successfully deliver the SIDS risk reduction message. Strategies to increase communication with clergy are necessary. Working with contacts or gatekeepers that are known and trusted by the clergy is key to a successful faith-based initiative. It is critical to identify those individuals that have direct and ongoing access to the clergy as well as to identify community-based clergy-run organizations and gain entrée through these existing coalitions.

- Health information and health alerts must be delivered in a personal manner in order to reach the intended population. The SIDS/OID program staff must become known within the faith community. Likewise, the program staff must be helpful to clergy and expedite their requests for information or assistance. Once known and trusted a mutual process of assisting each other begins. A reciprocal relationship develops. As initial efforts prove successful, the program staff can offer more in-depth educational offerings i.e. individual workshops and workshop series for congregations, special events, papers at clergy conferences, etc. Finally, every effort should be made to make outreach efforts as personalized as possible. For example, offering handouts with the church logo or name of the church and minister, using the color and design akin to church documents, or including a message from the minister.

- The ongoing nature of this clergy outreach project is crucial to infant mortality risk reduction in the targeted communities such as New York City as a whole. Therefore, incorporating clergy outreach as an ongoing part of service delivery is essential. Continuous efforts to forge personal

relationships with clergy and clergy coalitions strengthen these outreach efforts.

- SIDS/OID program staff should consider writing for religious publications. These health-focused articles become important alerts to the congregation and gain credibility when endorsed by the minister. The clergy are powerful leaders and role models in the community. Their sanction validates health initiatives in the faith community.

- Providing concrete assistance as needed also facilitates trust and communicates a willingness to be helpful. Responses should be culturally and linguistically appropriate and respectful of cultural values and mores.

- Faith-based initiatives can be replicated with local modifications for different cultures and for different religious groups.

- The SIDS risk reduction campaign can be expanded to include risk reduction information for all causes of infant mortality. Health promotion messages related to preconception guidance for healthy pregnancy and improved pregnancy outcomes can be easily incorporated. This faith-based initiative demonstrates the importance of moving beyond a health care systems approach to care to a community-based approach to care – one which values and blends with the significant life forces of the community.

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NB: Of note are changes in the New York City SIDS mortality rate by mother's ethnicity, described as Black non-Hispanic.

| | 1991 | 2000 |
|---|---|---|
| Total SIDS Deaths | 62 | 26 |
| SIDS Mortality Rate* | 1.5 | 0.7 |

*Rates per 1,000 live births (NYC Department of Health & Mental Hygiene, Office of Vital Statistics, Summary of 2000 Vital Statistics).

In December 2002, Dr. Thomas R. Frieden, Commissioner of the New York City Department of Health and Mental Hygiene, announced the New York City infant mortality rate dropped to a new low of 6.1 infant deaths per 1,000 live births. This decline represented a decrease of 9 per cent when compared to the 2000 infant mortality rate of 6.7. Although this is the lowest infant mortality rate in the city's history and lower than the national rate for 2000, Dr. Frieden noted that unacceptably high racial and geographic disparities persist in some communities.

For example, children born to black non-Hispanic mothers have an infant mortality rate of 10.0, more than twice the rate of those born to white non-Hispanic mothers. At 13.1, Central Harlem in Manhattan has the highest infant mortality rate in 2001 and Bedford in Brooklyn at 10.0 was the only other neighborhood in the city with a double-digit infant mortality rate (NYC Department of Health & Mental Hygiene Press Release, December 13, 2002).

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