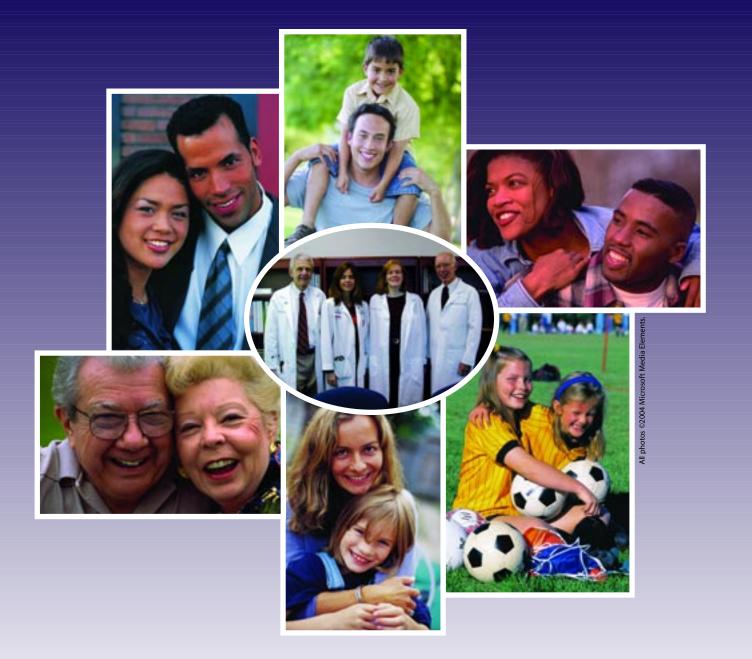
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Infant Mortality
in North Carolina
A New Perspective on a Persistent Problem

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Fit Together Launched for a Healthier NC

As medical professionals you see the evidence every day - the Centers for Disease Control and Prevention report that 27 percent of North Carolina high school students are overweight or at risk of being overweight and more than half of North Carolina adults are overweight or obese.

In April, Blue Cross and Blue Shield of North Carolina and the N.C. Health & Wellness Trust Fund Commission announced a \$4.5 million comprehensive statewide campaign to battle obesity and promote healthy lifestyles.

A study in the Journal of the American Medical Association reports that obesity can cut 20 years off the expected life span of young people. Some public health experts believe that the coming generation of adults may have a shorter life expectancy than the current generation if current trends do not change.

The Fit Together partnership is designed to help create a climate of change. The good news is that simple steps, such as regular, moderate physical activity, can improve health. That can mean something as easy as yard work, family walks or playing outdoors.

There are many innovative initiatives already underway in communities across our state. Fit Together will serve as a clearinghouse for information about obesity and "best practices" in obesity programs across North Carolina. And Fit Together will include a three-year public education campaign. We all know that obesity is becoming a health crisis; now we have to help North Carolinians create healthier habits.

As the state's largest health insurer, BCBSNC has made tackling obesity a top corporate priority. In the coming months, we will be announcing new services for our members designed to prevent and treat obesity and tools for medical professionals so you can help your patients improve their physical activity and nutritional habits.

We will be announcing more details about Fit Together soon, including a television ad campaign, an awards program and a Web site. We invite you to share information about programs in your area that could help us overcome obesity and to start the conversation with your patients today.

For more information about Fit Together or to share information about successful programs in your community, e-mail us at feedback@fittogether.org.



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North Carolina

Founded by the North Carolina Medical Society in 1849 Published by The North Carolina Institute of Medicine (ISSN 0029-2559)

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Co-Sponsors of the Journal are:

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North Carolina EDICAL JOURNAL

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Morth Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

May/June 2004, Volume 65, Number 3

Published by the North Carolina Institute of Medicine

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"Blessed with superb medical facilities and a reputation for advanced healthcare planning, our state has perennially ranked among the worst in rates of infant death among all 50 states."

Demand for Continuing Medical Education Programs on Cancer Care Among Primary Care Physicians in North Carolina

Roger T. Anderson, PhD, Kathleen Dziak, BA, Jeffery McBride, MA, MBA, Fabian Camacho, MS, Anita C. Hege, MPH, and Frank M. Torti, MD

Abstract

Background: Primary care physicians have a central role in cancer prevention and control services, yet relatively little attention has been given to their needs for continuing medical education (CME) that clarify or update screening guidelines, enhance recognition of signs or symptoms of cancer, and address ongoing health issues in patients treated for cancer (e.g., pain control, lymphedema, tertiary prevention).

Methods: A random sample of 600 primary care physicians practicing in urban and rural locations in North Carolina was selected to assess past cancer-related CME sessions, and demand for current cancer education topics.

Results: Of 539 eligible, 231 surveys were returned (43%). Approximately 37% of respondents had attended no cancer-related CME in the last two years. Highest interest for cancer CME topics was found for screening for breast and skin cancers, general update diagnostic skills, pain management and patient/family support, side effects from treatment, lymphedema management and lymphedema diagnosis, genetic susceptibility, diet and smoking cessation. Interest levels by CME topic did not vary by urban/rural practice settings.

Conclusion: There is low access but high demand for cancer-related CME topics among primary care physicians. Strategies are needed to fill this need and to assess impact.

Keywords: cancer screening, CME, primary care.

Introduction

Cancer is an increasingly common diagnosis and cause of death nationally among adults. In North Carolina, one in every two men and one in every three women will be diagnosed with cancer during his or her lifetime. The economic costs of cancer care and impact to families in North Carolina are estimated at \$2.9 billion annually. Primary care physicians occupy an important position in delivering effective and high quality care for cancer prevention and control, through screenings, referrals, patient education, and, for those treated for cancer, coordinating longer-term disease management. For cancer prevention, guidelines for early detection through routine screening have been established for breast, cervix, colon, and prostate cancers conditioned on considerations of patient age and known risk status. However, evidence exists that life-saving prevention, early detection, and control may not be carried out even when

beneficial support is overwhelming.9 Reasons for this gap are complex, but potential confusion over cancer screening detection policy from a lack of uniformity in type and interval screening specifications among the various medical professional organizations guiding primary care has been cited as important. At the same time, technology for cancer screening is advancing as genetic markers and new immunologic assays replace traditional tests, potentially adding to the complexity of obtaining and interpreting the screen for the patient. For patients with a history of cancer, the primary care physician may play a pivotal role by leading the patient's general health maintenance (in the context of a cancer history) and promoting the prevention of recurrence. Physician education in comprehensive, state-of-the-art cancer prevention and detection and health maintenance is therefore central to delivering effective cancer screening and prevention services.

Keeping abreast of new developments in cancer prevention

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and control can be a challenge for primary care physicians (PCPs). 10 Many physicians rely on formal continuing medical education (CME) courses to provide information. There are a number of formats by which physicians receive CME credit (e.g., didactic, large or small discussion groups, workshops, internet access, etc.). Each format has strengths and/or weaknesses. 11-14 There is a growing body of literature regarding which type of CME format primary care physician's prefer 15-17 and which patient care topics physicians seek most. 18 However, in the area of cancer control, no studies have been published on PCP interest or need for CME programs for primary care providers despite the fact that cancer is a leading chronic disease with formal best practice recommendations for screening 19 and vigilance. Given competing community resources for educational programs to fulfill category 1 credit requirements and the availability of funds to attend such sessions, the most effective cancer CME programs are likely to be those meeting the demand and interest of the intended physician audience.

In North Carolina, an Advisory Committee on Cancer Coordination and Control (NCACCC) has been established to develop and coordinate a comprehensive cancer control plan for the state. A centerpiece of the committee's strategy is collaboration with primary care systems and medical associations to identify resources needed to promote cancer prevention and control. To meet this objective, this study was conducted to assess demand for cancer care and treatment CME in both urban and rural areas of the state. This report: 1) describes interest levels in the four distinct aspects of cancer-related healthcare services: screening, diagnosis, treatment, and follow-up care by physician characteristic and patient groups served; and 2) examines the preferred method of accessing a cancer-related CME program.

Methods

A sampling frame was assembled of all primary care physicians listed on the North Carolina Physician Roster, and grouped according to urban and non-urban area using the North Carolina Data Center designations of metropolitan place names.

The survey was designed to collect data on screening, diagnosis, treatment, follow-up care, and preferred method for receiving CME on cancer related topics. A 66-item needs assessment survey was developed by study collaborators at the Wake Forest University School of Medicine (WFUSM). The prototype instrument was pre-tested at WFUSM among physicians in the gynecology and primary care clinics and reviewed for content. New items were generated from content review and physician feedback. Modifications to the survey were finalized and approved by the NCACCC office. The final format included content areas in the following cancer care and prevention topics: cancer prevention and risk factor reduction, screening and interpreting test results, diagnostic techniques, treatment options and prognosis, and follow-up care to surgery. A survey sample of 300 physicians was selected per urban and non-urban grouping (N=600). The sample was mailed a questionnaire with a postage-paid return mailer. Returned and completed surveys from the initial mailing were tracked and a replacement survey was sent after a two-week non-response period. After the second mailing, telephone calls were placed to the physician's office when the phone numbers were available in the listing. Arrangements were made with office staff to deliver a faxed copy of the survey.

Data analysis was performed to describe means and proportions of the survey category responses. Tests of significance were performed using two sample t-tests with pooled variance estimates, and judged to be significant at p < .05 without correction for multiple comparisons. To describe CME topics of most interest, ratios of 'very interested' (VI) to 'not at all interested' (NI), were calculated as VI/NI. This ratio served as a means of ranking CME topics in terms of strong preference (or demand) among items in the case where there may be considerable variability in interest for the topics considered. For example, a topic where 30% of respondents are 'very interested,' 40% are 'interested' and 30% are 'not interested' (30/30 = 1) has much less widespread appeal than a topic with interest ratings of 30%, 60%, and 10%, respectively (30/10=3). In the former case the number of respondents who desire the CME topic is balanced by the number who have no interest at all, whereas in the latter, the CME topic is appealing to most. Thus, a ratio larger than 1 indicates more interest than disinterest for the topic; a ratio below 1 suggests that high level interest may be specific to subgroups, such as practice type. Tests of significance were performed on the logarithms of the demand ratios, using asymptotic statistics described in Agresti.²¹ The null hypothesis in this case was that the logarithm of the demand ratio is equal to 0 (so that the demand ratio is equal to 1).

Results

Survey Return Completion Rate

Removal of invalid addresses (N=21) and non-practicing physicians (N=40) resulted in a final sample size of 539 physician names. Of these, 97 (18%) initial mailings were returned, with a replacement survey being sent after a two-week non-response period yielding 54 additional responses (10%). After the second mailing, telephone calls were placed to the physician's office when the phone numbers were available in the listing. Arrangements were made with office staff to deliver a faxed copy of the survey resulting in another 80 (15%) completed surveys for a cumulative total of 231 (43%) surveys completed and returned.

Physician Profile

The physician mean number of years in practice was 16.6 years (±12) and the provider mean age was 48.2 years (±11). As shown in Table 1, approximately 48% of physician respondents classified themselves as family medicine, 27% internal medicine, 20% gynecological, and 4.5% as other. Most respondents were male (89%), with a majority serving rural group practice settings (55%). Survey respondents estimated that more than one-third of their patients were smokers (34%) and nearly one-third (32%) had an estimated income below \$20,000 per year.

Table 1.Respondent Physician Profile: Gender, Type of Practice, Type of Specialty,
Patient Population Served, and Estimated Population Low Income/Underserved

Category	Sub-Category	N (%)
Gender	Female	(11.1)
	Male	(88.9)
Practice	Private	(21.3)
	Group	(71.0)
	Other	(07.7)
Specialty	Family Medicine	(48.4)
	Internal Medicine	(26.9)
	Gynocology	(20.2)
	Other	(04.5)
Patient Population/Service area	Urban practice	(44.6)
	Rural	(55.4)
Estimate of low-income/Underserved	Patients with income < \$20,000	(31.7)
	Patients with high school diploma	(24.3)
	Current smokers	(34.1)

A substantial proportion of physicians, nearly 37%, had not attended any cancer-related CME sessions in the past two years, and only 22% indicated attending one session (see Table 2).

CME Interest

Table 3 summarizes physicians' interest in participating in cancer-related CME topics. The highest interest in the *Screening* category was in general screening, with 58% being 'very interested.' For the *Diagnosis* and *Treatment* categories, 47% of primary care physicians surveyed were 'very interested' in a general update of diagnostic skills and 35% were 'very interested' in side

effects from treatment for follow-up care. For cancer *Prevention* topics, 53% of physicians were 'very interested' in methods to identify and address high risk.

Demand ratios

In Table 4, the item response, or 'demand,' ratios show that within the Screening CME topic category, general screening (23.12), breast (7.63), and skin (3.67) drew highest levels of interest (demand), while colonoscopy (0.47) exhibited lowest interest. In the Diagnosis and Treatment topic categories, general update diagnostic skills (8.12), pain management (4.49) and patient/family support (3.28) were reported to be of high interest, while research protocols (0.53) had the lowest interest. The highest interests in Follow-up care were side effects from cancer (3.35), side effects from treatment (2.72), long-term follow-up (1.88), lymphedema management (1.20) and lymphedema diagnosis (1.05), while lowest demand was therapist availability (0.92). For Risk factor prevention and Risk reduction topics, genetic susceptibility (4.04), diet (2.97), and smoking cessation (2.45) showed highest interest, while sun exposure (1.08) exhibited comparably lower interest.

Table 2.Continuing Medical Education:
Number of Sessions Physician
Attended in Past Two Years

Number of Sessions	Percentage
0	36.9%
1	21.7%
2	15.2%
3	12.0%
4+	14.7%

There were no statistically significant differences in CME interest and demand proportions by urban/non-urban practice location (data not shown). For medical specialty type (Table 4), family medicine practitioners had a statistically higher (p < .05)level of interest in pain management, general prevention, and long-term follow-up of patients treated for cancer. Obstetrics/ gynecology practitioners had significantly higher interest in CME topics addressing breast, cervical and ovarian cancer screening, and genetic susceptibility than either internists or family practice physicians.

As shown in Table 5, the preferred method of accessing a cancer-related CME course/program was by in-person lecture (63%), rather than a video-conference or lecture format (6%), which was not favored. In terms of sponsorship, the Area Health Education Centers (AHECs) were viewed as the most favorable mode of sponsorship (37%). Finally, 23% of physicians reported a 'very favorable' attitude toward accessing a CME session over the Internet.

Discussion

This study found a high interest for CMEs focused on selected cancer topics for primary care providers. Further, self-reported attendance at formal CME sessions targeting cancer care was not high, with more than one-third (37%) attending no sessions in the past two years.

Most interest was reported for CME information relating to screening for breast, ovarian, skin and prostate cancers, all of which are highly relevant to primary care and have guidelines for screening that are evolving through evidence-based medicine. Also of interest were sessions on identifying high risk for cancer and strategies for risk factor reduction (e.g., smoking cessation), pain management and side effects of treatment, lymphedema and long-term follow-up care. Relatively low interest was found for specific procedures such as biopsy, sigmoidoscopy, and tumor staging, which primary care providers usually do not perform.

While on-site lectures are the most preferred means of attending a CME session, nearly one-quarter of the respondents viewed Internet CME access as a favorable means of attending CME programs. Unlike CMEs targeted to hospital staff or

Table 3.CME Topic Interest and Demand Ratio: Screening, Diagnosis and Treatment, Follow-up Care, and Prevention Categories

Category	Item	% Very Interested (VI)	% Not Interested (NI)	Ratio (VI/NI)	
Screening	Breast	48.1%	6.3%	7.63	
	Ovarian	42.2%	7.8%	5.41	
	Skin	37.1%	10.1%	3.67	
	Cervical	42.1%	11.9%	3.54	
	Clinical breast exam	39.6%	16.4%	2.41	
	Disc results with patients	36.1%	15.6%	2.31	
	Prostate	37.6%	16.6%	2.26	
	Flex sigmoidscopy	31.6%	32.3%	0.97	
	Excise skin lesions	29.3%	31.8%	0.92	
	Punch biopsy	24.8%	32.5%	0.76	
	Endometrial biopsy	28.5%	40.5%	0.70	
	Colposcopy	18.4%	39.6%	0.47	
	General screening	57.8%	2.5%	23.12	
Diagnosis and Treatment	Pain Management	46.2%	10.3%	4.49	
	Patient/family support	35.8%	10.9%	3.28	
	Treatment options	35.0%	12.1%	2.89	
	Patient care and management	33.8%	12.3%	2.74	
	Relative care	30.2%	19.1%	1.58	
	Hospice care	32.1%	20.5%	1.56	
	Antibiotic fever	28.5%	23.4%	1.22	
	Emetics	26.8%	22.3%	1.20	
	Leukopenic fever	26.7%	25.3%	1.05	
	Multidisciplinary teams	18.9%	22.6%	0.83	
	Research protocols	19.2%	36.4%	0.53	
	General update diagnostic skills	47.1%	5.8%	8.12	
	Staging	20.8%	23.9%	0.87	
Follow-up Care	Side Effects from cancer	32.2%	9.6%	3.35	
	Side effects from treatment	34.5%	12.7%	2.72	
	Long-term follow-up	32.1%	17.1%	1.88	
	Lymphedema management	28.1%	24.0%	1.20	
	Lymphedema diagnosis	27.7%	28.4%	1.05	
	Therapist availability	23.1%	25.2%	0.92	
Risk Factor Prevention/ Reduction	Identify high risk	52.6%	9.9%	5.30	
	Genetic susceptibility	42.0%	10.4%	4.04	
	Diet	33.0%	11.1%	2.97	
	Smoking	35.7%	14.6%	2.45	
	Exercise	30.7%	15.6%	1.97	
	Genetic counseling	29.2%	23.1%	1.26	
	Sun exposure	23.2%	21.4%	1.08	

healthcare providers within academic clinical departments capable of attracting large numbers, primary care physicians in the community may find it more difficult to attend off-site CMEs, making video conferencing an attractive media format to adopt for category 1 credit.

While needs assessments, such as this one, are the cornerstone of sound education, studies are needed on the effectiveness and impact of various continuing education formats in terms of number reached and, ultimately, in changing cancer prevention and control practices or outcomes. The effectiveness of CME programs as

Table 4.Topic Demand Ratio[†] by Specialty: Screening, Diagnosis and Treatment, Follow-up Care, and Prevention.

Category	Item	Family Medicine	Internal Medicine	OB/ GYN	
Screening	General screening	24.0***	59.5***	47.0***	
	Skin	4.1***	11.0*	2.4	
	Breast	6.6***	8.0**	70.6***	
	Cervical	4.1***	1.4	63.6***	
	Ovarian	14.0***	1.7	69.7***	
	Prostate	5.1***	2.0	0.6	
	Flex sigmoidscopy	1.4	0.6	0.8	
	Punch biopsy	1.0	0.4*	1.4	
	Excise bio/skin	1.5	0.3**	2.0	
	Endometrial biopsy	0.9	0.1***	3.6*	
	Coloscopy	0.4**	0.1***	4.5**	
	Clinical breast exam	2.3*	1.2	9.5**	
	Discussing results with patients	2.4*	1.4	3.3*	
Diagnosis and Treatment	Update diagnostic skill	14.7***	19.0**	3.0	
	Staging	0.9	0.9	0.7	
	Multidisciplinary teams	1.1	0.5	0.9	
	Treatment options	3.3***	1.7	4.3*	
	Find protocols	0.7	0.2**	0.8	
	Pain management	8.2***	2.7	2.0	
	Leukopenic fever	2.0*	0.8	0.4	
	Antibiotic fever	1.6	1.0	0.8	
	Emetics	2.3*	0.7	0.9	
	Palliative care	2.4*	1.5	0.7	
	Patient care/management	3.5***	3.0	1.4	
	Hospice care	2.5	1.1	0.8	
	Patient/family support	4.5	2.2	4.0	
Follow up care	Side effects from cancer	1.0	0.5	0.9	
-	Side effects from treatment	3.3***	1.7	4.3	
	Lymphedema diagnosis	0.7	0.2**	0.8	
	Lymphedema management	8.2***	2.8	2.0	
	Therapist availability	2.0*	0.8	0.4	
	Long-term follow up	1.6*	1.0	0.8	
Risk Factor Prevention/ Reduction	General Cancer prevention	19.0***	8.5**	8.5**	
	Diet	8.0***	0.8	4.7*	
	Exercise	6.2***	0.5	3.0*	
	Smoking	3.2***	1.5	2.8*	
	Sun exposure	2.8**	0.4*	1.1	
	Identify high risk	8.4***	5.2***	2.9*	
	Genetic susceptibility	5.3*** 1.8		37.5***	
	Genetic counseling	1.9*	0.8	1.0	

effective instruments of change has been challenged.²²⁻²⁴ Davis and colleagues²⁵ reviewed the general research literature covering 24 separate CME-based interventions and found that benefit, in terms of provider practice or healthcare outcomes, was

dependent upon method of delivery, nature of the interaction, and enabling resources provided. Didactic CME-based interventions failed to change physician behavior, despite effects on knowledge and attitude. Studies using interactive techniques,

such as case discussion or demonstrations, were more effective, as were sequenced interventions allowing practice and feedback loops, and enabling materials (brochures, patient reminder cards, etc.) designed to facilitate implementing the recommended changes.

As cancer screening methods and technologies evolve to encompass genetic screens and refinement of risk estimation, the need among primary care providers for continued cancer control and prevention education is likely to grow. Studies are needed to develop effective CME-based interventions for cancer care.

Conclusion

Results of this survey indicate that strong interest exists for cancer CME topics among primary care providers, with more than one-third (37%) of respondents reporting no previous attendance of CME-provided cancer care educational sessions.

Acknowledgement: The authors are grateful for assistance in survey development provided by Dr. Robert L. Michlelutte, Department of Family and Community Medicine, WFUSM. **NCMJ**

Table 5.
Preferences for Continuing Medical Education Format

Format	% Very Appealing
Lecture, in person	62.5%
Lecture, teleconference	6.1%
Small group workshop	20.8%
Independent study	24.1%
Hospital sponsored	24.5%
Area Health Education Center sponsored	36.8%
Panel discussion	12.1%
Internet access	23.1%

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POLICY FORUM

Infant Mortality in North Carolina: A New Perspective on a Persistent Problem

Introduction

Gordon H. DeFriese, PhD, and Kristie K. Weisner, MA

Issue Brief:

North Carolina's Infant Mortality Problems Persist: Time for a Paradigm Shift

Julia L. DeClerque, DrPH, MPH, Janice A. Freedman, MPH, Sarah Verbiest, MSW, MPH, and Stuart Bondurant, MD

COMMENTARIES

Improving Pre-pregnancy Health Is Key to Reducing Infant Mortality

Robert G. Dillard. MD

Infant Mortality 1963 to Present: Medical Developments and Legislative Changes *William R. Purcell, MD*

North Carolina Makes Strides to Reduce SIDS, but Challenges Lie Ahead Christine O'Meara, MA, MPH

Folic Acid and Birth Defects Prevention: A Public Health Success Story Robert E. Meyer, PhD, MPH, and Anna Bess Brown, MPH

Addressing Perinatal Health Disparities: Another Place for a Paradigm Shift Vijaya K. Hogan, DrPH

Making a Difference in Infant Survival: Evidence-based Actions to Reduce Tobacco Exposure during Pregnancy and Infancy in North Carolina Cathy L. Melvin, PhD, MPH, and

Preterm Birth in North Carolina Mary Lou Moore, PhD, RN, FAAN

Sally Herndon Malek, MPH

Expanding Medicaid Income Eligibility for Family Planning: An Opportunity to Improve Reproductive Outcomes and Lower Medicaid Costs

Joe L. Holliday, MD, MPH

SPECIAL ARTICLE

There Is Life (and Death) Beyond the Infant Year: North Carolina's Recent Experience in Reducing Child Deaths Tom Vitaglione, MPH

...the largest proportion of associated with general health conditions and health factors

INTRODUCTION

Policy Forum:

Infant Mortality in North Carolina: A New Perspective on a Persistent Problem

For decades, North Carolina health professionals and public health activists have confronted stark statistics, which indicate an inability to adequately prevent infant deaths in our state, especially among racial and ethnic minorities. While comparisons of our infant death rates with those in other states no longer put us at the absolute bottom of the national distribution, we are clearly among the few states at the lower levels of accomplishment with regard to this important indicator of health and healthcare disparity.

For health professionals who have worked so hard to address these issues, the persistence of these problems has been an especially frustrating and challenging part of their careers. Yet, it is important to recognize that measurable and positive changes have occurred, slowly but surely, over the past decade or so. Important changes have been brought about through: assurance of better access to primary healthcare services for pregnant women and children, a campaign to promote consumption of folic acid during women's childbearing years and pregnancy, state and federal nutritional and dietary supplement programs, the availability of excellent neonatal care services across the state, and the Back To Sleep Campaign and other child care initiatives. For a problem as pervasive and complex as this, there is no single intervention that can stem the tide and result in dramatic results overnight.

The Editors of the *North Carolina Medical Journal* are pleased to have an opportunity to focus on these perennial public health issues. The Policy Forum in this issue is made possible through a grant from the March of Dimes of North Carolina, with whom we are pleased to have undertaken a close collaborative relationship in addressing the many issues discussed in these pages. While the March of Dimes did provide funding for the printing and distribution of this issue, the opinions expressed are those of the authors and not the March of Dimes.

We think our readers will find the initial paper in the Forum by Dr. Julia DeClerque and colleagues of great interest. Dr. DeClerque et al. argue for a change in the way we have conceptualized and approached infant mortality in North Carolina and the nation. Drawing on the work of the World Health Organization and a number of agencies and programs here in the United States, these authors call our attention to the fact that the largest proportion of infant deaths are associated with general health conditions and health factors present (and in many cases preventable) among women of childbearing ages prior to pregnancy. Hence, it is suggested and statistically demonstrated that the greatest potential impact on infant mortality rates may be realized by addressing the more general health of women in these age groups, whether or not they are pregnant.

This "paradigm shift" will not be easily explained, or accepted by policy makers who often prefer to invest in healthcare services and programs targeted to specific health conditions, with the expectation that clearly associated results will be demonstrated in the near-term. The proposal for focusing infant mortality reduction efforts with an approach that addresses the general health of women in childbearing ages (whether or not pregnancy has been established) will require a very different perspective and a very different set of programmatic investments. We hope the commentaries that follow this Issue Brief will help clarify the importance of this paradigm shift, as well as provide an update on what is arguably one of North Carolina's most persistent public health dilemmas.

Gordon H. DeFriese, PhD Editor-in-Chief and Publisher Kristie K. Weisner, MA Managing Editor

North Carolina's Infant Mortality Problems Persist: Time for a Paradigm Shift

Julia L. DeClerque, DrPH, MPH, Janice A. Freedman, MPH, Sarah Verbiest, MSW, MPH, and Stuart Bondurant, MD

Improvements over the past two decades in the medical care of women during pregnancy and of newborn infants have contributed to North Carolina's success in reducing its high infant mortality rate to an historic low. These efforts are to be applauded and they must be sustained. One of the largest remaining gaps, however, is the absence of significant initiatives that focus on improving a woman's health before she becomes pregnant. Future improvements in reducing rates of infant death or improving birth outcomes will depend upon a renewed sense of urgency to provide the best healthcare to pregnant women and their babies and a willingness to expand the current focus on improving pregnancies to improving the health and psychosocial well-being of *all* women of reproductive years.

Background

Infant mortality is the leading cause of child death, affecting close to 1,000 North Carolina babies and their families every year. While the state's rate is at an historical low (8.2 deaths/ 1,000 live births in 2002), North Carolina continues to post one of the highest rates in the nation (Table 1). Racial and ethnic disparities in infant death rates persist: African American babies have a two to three times greater rate of death than white babies (14.2/1,000 and 5.9/1,000, respectively, in 2002). Interestingly, Latino women in North Carolina, many of whom are newly arrived immigrants, have among the best birth outcomes at present. However, experience from other states suggests that the longer immigrants live in this country the more likely they are to experience infant loss. North Carolina currently has a window of opportunity to learn about and sustain the factors that lead to these healthy births. With the rapid growth of a young, Latino population, taking action now may serve to prevent a worsening of the state's infant mortality rate among this group in the future.

While death rates have declined over time, the major causes of infant death have remained fairly constant. North Carolina's babies, like those in other states, are most likely to die as a result of conditions related to prematurity and low-birth weight, congenital anomalies and Sudden Infant Death Syndrome (SIDS). Preterm birth, the leading correlate of newborn death, is increasing for all groups in North Carolina. Preterm birth affects more than 15,000 North Carolina babies annually, including one out of every eight white babies, and one out of six for African American babies (Table 1). Young African American women have worse health status (obesity, diet, exercise, exposure to disease) than young white women. Efforts to further reduce infant mortality should emphasize reduction in the glaring health disparities experienced by African Americans in North Carolina—especially children, teenagers, and women of childbearing years. More than 10,000 babies are born with low-birth weight (less than 5.5 pounds), and more than 3,000 infants are born with birth defects each year in North Carolina causing death, illness, emotional trauma and great economic burden for families and the state.

Studies show that poor birth outcomes can be caused by a myriad of problems. Women with unintended pregnancies or closely spaced pregnancies, those who are under age 18 or older than 35, smokers, and those with high stress and limited resources all have a higher risk of having premature or low-birth weight babies. 123

North Carolina's Programs to Reduce Infant Mortality

North Carolina has a long-history of services and programs aimed at reducing the state's high infant mortality rates. Over the years, the state has expanded access to prenatal care and the

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Table 1.
Leading Causes of Infant Deaths (NC, US, Selected Years)

	Total		Non-Latino White		Non-Latino African- American		Non-Latino Native American		Latino	
	NC	US	NC	US	NC	US	NC	US	NC	US
Preterm births* (% live births)	13.2	11.8	11.4	10.6	18.3	17.6	14.1	12.8	11.6	11.4
Low-birth weight births* (% live births)	8.9	7.6	7.4	6.7	13.7	13.1	10.4	7.1	6.2	6.4
Infant Mortality** (deaths per 1,000 live births)	9.0	7.0	6.7	5.8	15.7	13.9	11.8	8.9	6.2	5.7
Deaths due to birth defects** (deaths per 1,000 live births)	.1591	.1413								
Deaths due to SIDS** (deaths per 1,000 live births)	.0844	.0677								
Deaths due to prematurity/low-birth weight** (deaths per 1,000 live births)	.1787	.1112								

^{*} Data for 1999-2001. Numbers reflect percentage of live births.

array of pre- and post-natal services available to pregnant women and infants, increased the state's outreach and education efforts, and expanded family planning services to reduce unwanted pregnancies (see pages 170 and 172). In addition, the state and

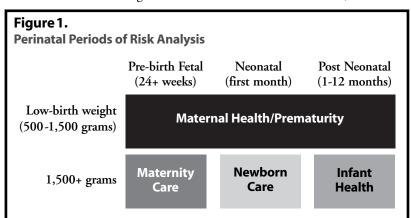
local communities have helped launch targeted infant mortality campaigns aimed at high-risk groups or communities; and have created special programs aimed at reducing some of the causes of infant deaths. These efforts have helped contribute to a 35% reduction in the state's infant mortality rate since 1988 when provisional data from the Centers for Disease Control and Prevention listed North Carolina as having the worst infant mortality rate in the country. While these efforts have been critically important in reducing the state's infant mortality rate, there is a need to analyze existing data with new eyes to better pinpoint the underlying

cause and specific patterns of risk that should be addressed, and therefore the appropriate timing of interventions that will have the most impact.

A New Way of Analyzing the Problem: Perinatal Periods of Risk (PPOR) Analysis

For more than a decade, the World Health Organization has used an analytic approach, the "Perinatal Periods of Risk Analysis" (PPOR) to analyze the cause of feto-infant mortality, and to develop appropriate interventions. In 1997, the Centers for Disease Control and Prevention (CDC), City MatCH at the University of Nebraska Medical Center, the National March of Dimes Foundation, and the Health Resources and Services Administration/Maternal and Child Health Bureau created a partnership to test this model in the United States.

PPOR helps to "map" fetal and infant deaths into four distinct periods based on when the deaths occur and the birth weight of the baby or fetus at the time of death. The three categories for the age of death are broken into fetal deaths (24 weeks or

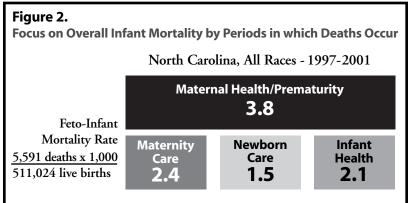


greater of gestation), neonatal deaths (within the first month after birth), and postneonatal (1-12 months of life). Birth weight is divided into two categories: low-birth weight (500-1,499 grams) or higher birth weight (1,500 + grams). Because of large reporting differences in vital records across geographic locations, fetal deaths are limited to those occurring after 24 weeks of gestation, and to those fetuses or infants weighing at least 500 grams at the time of death. This analysis creates four groups: maternal health/prematurity, maternity care, newborn care, and infant health (See Figure 1). The maternal health/prematurity category covers all low-birth weight feto-infant deaths, regardless of whether the death occurs in the fetal, neonatal, or post-neonatal time period.

Deaths linked to maternal health/prematurity result from risk factors that are present before a woman becomes pregnant, such as a history of substance abuse, tobacco use, unstable

^{**} Data for 1998-2000. Numbers reflect deaths per 1,000 live births.

Source: March of Dimes Prematurity Website. Available at: http://peristats.modimes.org/statestep1.cfm?state_id=37 (accessed June 4, 2004).



housing/family structure, effects of poverty and stress, or a recent previous delivery. These problems can be addressed by focusing on preconceptional health, unintended pregnancy, smoking, drug abuse, and specialized perinatal care.

Deaths in the maternity care period link to factors that are most prominent during pregnancy, like poor weight gain, infection and lack of prenatal care. Some of these deaths can be prevented by ensuring women have early and continuous prenatal care, referral of high-risk pregnancies and good medical management of women with diabetes, seizures, postmaturity or other medical problems. Deaths in the newborn care period are attributed to risks that occur during delivery and through the first month postpartum. Prevention of newborn deaths focuses on advanced neonatal care and treatment of congenital abnormalities. The final period, infant health, includes deaths that occur due to factors occurring after the first month of life through the end of the first year—factors such as injuries, SIDS, congenital anomalies and infections. These deaths can be addressed through SIDS risk-reduction activities, breast-feeding promotion, access to medical homes, and injury prevention. PPOR is more of an heuristic exercise to help clarify the relative risk of these different periods of time and each periods' contribution to the likelihood of perinatal death, and is a tool for examining whether programs are focused appropriately in timing and emphasis of their efforts.

With this in mind, feto-infant deaths can be "mapped" for a geographic area to identify which of the four periods are associated

with the greatest mortality risk. Each cell includes the number of fetal or infant deaths that meet the age and weight criteria. For example, a death to an infant in the 26th week of gestation that was under 1,500 grams would be counted in the maternal health/prematurity cell.

So, what does this analysis look like for North Carolina? There were 5,591 feto-infant deaths in North Carolina between 1997-2001 that met the age and weight thresholds. This yields a feto-infant mortality rate of 9.8 deaths for every 1,000 live births. More than a third of the feto-infant deaths fall into the maternal health/prematurity cell

with risks attributable primarily to maternal factors (see Figure 2).

This same analysis can be used to compare rates across different subpopulations. For example, PPOR can be used to compare a high-risk group with a reference group of women expected to have better birth outcomes. Because we know that we have a high infant mortality rate among African-Americans in North Carolina, we can use the PPOR analysis to compare feto-infant birth outcomes of African Americans with a reference group of white, non-Hispanic women, over the age of 20, with greater than a high school education. The difference between

the reference and target population risks is the excess risk that exists. This excess risk must be addressed if all members of the local community are to have equal access and opportunity to optimize their health and if there is to be further progress in reducing overall infant mortality rates.

The feto-infant mortality for African American births is extremely high; at 14.7 deaths per 1,000 live births it is more than double that of whites (6.0 per 1,000). It also shows that, for the target population, almost half of the deaths are related to maternal health/prematurity (6.5 of the 14.7 deaths per 1,000 live births). Interestingly, the feto-infant deaths attributed to maternity care and those related to infant health are not as high as those associated the maternal health/prematurity, but at 3.4 and 3.2 per 1,000, respectively, these risks must still be addressed. One surprise that the data show is the extremely low rates of excess death attributable to the newborn period (0.4 per 1000). This tells us that African American babies in North Carolina have mortality rates associated with newborn care that are comparable to those among whites. This is cause for celebration, but also a signal that our efforts to address the problem of infant-mortality in North Carolina need a new and targeted approach.

To summarize, this PPOR review tells us that the most prominent period of excess risk for mothers and babies in North Carolina, especially African Americans, is the stage where the majority of the excess risk occurs (4.4 of the 8.7 or

Figure 3. **Excess Feto-Infant Mortality for African Americans in North Carolina** 1997-2001 Target Population Reference Population Excess (excess risk for (African Americans) (white, non-Hispanic) African American babies) 6.5 2.1 1.5 1.2 1.9 1.6 3.2 2.0 14.7 total deaths per 6.0 total deaths per 8.7 total deaths per 1,000 live births 1,000 live births 1,000 live births

51%) and calls attention to the importance of factors related to the general health of women in childbearing ages. Efforts to improve this situation would direct our attention to the preconceptional period, or the health of women of childbearing ages before they become pregnant or between pregnancies.

This analysis also highlights North Carolina's current strengths and recent accomplishments in newborn care as it relates to infant mortality prevention. Intensive care nurseries and hospitals are doing an excellent job caring for sick neonates and transferring at-risk infants to appropriate facilities. The state's medical technology, expertise, and infrastructure are strong and have had demonstrable success. It is important that this system be maintained, particularly through regionalization, to ensure that tiny and sick babies are born in facilities with the personnel and resources to manage their complex care. Moderate numbers for the maternity care and infant health periods likely also reflect the impact of the many public health and community-based programs already in place that serve pregnant and parenting women.

Women's Health Status in North Carolina

So how does the health of North Carolina's women measure up? The NC Program for Women's Health Research, a collaborative program of the UNC School of Medicine, the UNC School of Public Health and the Cecil G. Sheps Center for Health Services Research, produces an annual North Carolina Women's Health Report Card. The purpose of the report card is to allow the state to chart progress and problems on a large number of women's health indicators. Grades are given based on the percentage change from previous years and/or how satisfactory the current measure of each health indicator is.

As in previous years, the 2003 Women's Health Report Card documented that the state of women's health in North Carolina has much room for improvement. Data show that 45% of all live births were the outcome of unintended pregnancies (66% for African Americans) and that almost 16% of all women received late (after the first trimester) or no prenatal care. There were three cases of HIV/AIDS per 100,000 white women and 54 cases per 100,000 African American women; 248 sexually transmitted disease cases (syphilis, gonorrhea, chlamydia) per 100,000 white women and 2,522 per 100,000 for African American women.

Women's health in North Carolina received an "F" for its high rate of binge drinking among women (4.5%), high percentage of women with diabetes (6.7%), high percentage of women who are obese (23%), and high percentage of women with high blood pressure (28.9%). Indicators for African American women are even higher than those listed here. Additionally, 23% of women in North Carolina smoke (almost 14% during pregnancy), and there were 3,883 hospitalizations per 100,000 women for substance abuse or mental health diagnoses.

Research has shown that women who begin their pregnancies either underweight or overweight, with high blood pressure or diabetes, women who drink, smoke, have mental health problems, or sexually transmitted diseases are at greater risk for poor birth outcomes. The NC Women's Health Report Card clearly documents that North Carolina's women, especially its African American women, have not achieved the health status they need (as reflected by their scores) for achieving healthy birth outcomes. This report card underscores the conclusions reached by the PPOR model. Prenatal care, neonate care and infant health are important, but ultimately the ability to achieve and sustain improved birth outcomes will coincide with improved health status and increased access to care for women before they become pregnant or between pregnancies.

Time for a Paradigm Shift

In light of consistently falling short of the standards set by most other states in the nation, as well as the racial disparity and increasing rates of premature birth seen in North Carolina, there is a clear need to expand our perspective by adding a strong and effective intervention to improve the health of all women of childbearing age, especially young women. Research to find more effective evidence-based prevention strategies should be supported while the sound knowledge we now have provides a basis for the design of reasonable and promising health programs to reduce the burdens of unhealthy lifestyles.

Prenatal care has improved pregnancy outcomes in many ways. However, it has not been shown to be effective in reducing the incidence of premature births. One possible reason for such a failure is that the causes of prematurity are predominately related to a woman's general health, social, environmental, and emotional circumstances. In order to reduce the incidence of prematurity, it is reasonable to assume that it will be necessary to address those circumstances before, as well as during, pregnancy. Thus, it is time to reshape the focus of infant mortality reduction efforts. In addition to images of pregnant women and mothers holding newborns, the faces of all women of reproductive age should be part of the picture. A *life course* approach—that acknowledges the cumulative effects of risks and stressors over decades and even generations—should be considered in this new perspective.

To shift to this paradigm a number of things must happen. First and foremost our schools, the healthcare system and community agencies need to help all women, and especially the young, to gain understanding and motivation for healthier lifestyles. There needs to be increased access to and coverage for women's wellness services in many venues. These services need to be comprehensive, widely available, personally tailored, userfriendly and rewarding, and employ a bio-psychosocial approach. Reproductive health measures need to include other health indicators such as oral health, diabetes, blood pressure, smoking status and exposure to secondhand smoke, drug use, nutritional status, domestic violence, levels of stress and coping strategies, and mental health status.

Women must be educated about the need for these services and a demand created. Services should be designed to provide such rewards for participation that recruitment occurs naturally and continuation of participation is sought. Further, providers will require training on topics related to preconceptional or interconceptional health and the need for wellness visits. A screening tool adapted for women's life cycles could be used to help a woman and her provider track her health over her life course. More research will be required and must be conducted outside of the clinical setting and no longer limited to prenatal patients in a medical context. Studies must be designed to incorporate psychosocial, environmental and biological contexts of women's situations to understand multi-level effects. They must also be designed to take place within communities and families.

North Carolina's current initiatives focusing on smoking cessation, folic acid supplementation and family planning should be expanded and instituted statewide. Improving our

delivery of these messages to targeted audiences and expanding our reach on these three factors alone will have an impact on the health of future children. In addition, the NC Department of Health and Human Services' focus on reducing health disparities is one that should be embraced widely. Within the mosaic of issues that are part of infant health, it is time that attention be paid to the pieces which represent maternal health and maternal well-being.

Women who are healthy are a vital component of North Carolina's future, whether they are pregnant or not. It's time to make the investment, to assure the health of women, and to have a long-term, positive impact on the health of newborns. **NCMJ**

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Programs and Policies to Address the Problem of Infant Mortality: A Long History

Reducing infant mortality has been on North Carolina's agenda for several decades, albeit with varying levels of intensity and funding. Concerted efforts to prevent infant death began in 1972 when Governor Robert Scott created the Maternal and Infant Health Task Force to determine why North Carolina had such high infant mortality rates. Subsequent groups, including a statewide Perinatal Council (late 1970s to late 1980s) and Governor James Martin's Governor's Commission on the Reduction of Infant Mortality (1989-1995), addressed the same issue and championed legislation and policies, mobilized local coalitions and funded community-based organizations to address this problem. The NC General Assembly also played a leadership role in the fight to reduce North Carolina's infant mortality rate. Between 1990-1994, Senator Russell Walker and Representative David Diamont introduced a four-year infant mortality reduction campaign that helped create or expand many of the existing programs aimed at reducing infant mortality. Subsequently, the NC General Assembly has continued to support legislation and/or funding to address this issue.

Private foundations and organizations such as: the March of Dimes, the Kate B. Reynolds Charitable Trust, The Duke Endowment, and the North Carolina Healthy Start Foundation have also played pivotal roles in helping raise awareness about infant mortality and in supporting programs and research. At the local level, partnerships have developed between the business community, the faith community, local organizations, and coalitions to address the specific needs in the community, to strengthen networks and referrals that serve a common public and to fill gaps in services.

Over the years, efforts to reduce North Carolina's high infant mortality rate have focused on family planning and adolescent pregnancy prevention; improving the quality, comprehensiveness and accessibility of prenatal care; interventions that target particular populations or areas of the state; and interventions targeting specific risk factors or causes of infant

deaths. These statewide and local efforts have lead to a 35% reduction in the state's infant mortality rates since 1988 when the state trailed the rest of the nation. However, recent budget cuts could jeopardize the progress that has been made.

Family Planning and Adolescent Pregnancy Prevention Programs

Pregnancies that are planned by women who are physically, emotionally, socially, and financially ready are more likely to produce healthy babies. Unfortunately, almost half of all pregnancies in North Carolina and in the nation are unintended —often with serious consequences for the babies, women, families, communities, and the state. Family planning services are offered across the state through local health departments and physicians in private practice.

In 1999, the NC General Assembly mandated that insurers provide contraceptive coverage in their private health insurance plans. Women who are on Medicaid also have access to family planning services, and others can access services through local public health departments or community agencies. Nonetheless, there are many women who still lack access to family planning services. The NC General Assembly authorized the NC Department of Health and Human Services to seek a Medicaid waiver to extend family planning services to women and men (ages 19-55) with incomes below 185% of the federal poverty guidelines (See Holliday article, pages 170-172). If implemented, this initiative will provide North Carolina's families with improved access to the services they need to lengthen the intervals between pregnancies (birth spacing), to reduce the likelihood of unintended pregnancies and subsequent abortions, and ultimately to improve the outcomes of subsequent pregnancies once they occur.

In addition, state funding over the years has supported specific programs to reduce adolescent pregnancies, including

A Very Brief Historical Sketch of Perinatal Care in North Carolina PERINATAL PLAN DEVELOPMENT Mission: To reduce infant mortality and morbidity in NC by developing a statewide voluntary, cooperative, multilevel regionalized system for 1974 1912 1913 inpatient and outpatient perinatal healthcare, emphasizing medical, psychosocial, and financial aspects of patients needs. The goals are 1) Develop (6) Perinatal regions, each will have an active regional committee composed of multi-disciplines. 1975 Implementation plan developed (see below box at right) 2) Describe and designate hospitals into one of three types. Phase I: Pilot project involving Duke, UNC, health departments, and hospitals in 3) Recruit the participation of health departments to provide routine southeastern part of state screening of pregnant women and infants. Some will establish Phase II: Funding to develop statewide Level III Perinatal Intensive Care Services in centers providing care to multi-county area. Appoint a Perinatal Statewide Education Committee. Phase III: Development of statewide educational program and funding of Perinatal 5) Manual "Regionalized Perinatal Health Care Program" published. Outreach Education Coordinators in (6) perinatal regions. STATEWIDE PERINATAL COUNCIL Phases implemented gradually over period of years. Discuss and address issues related to perinatal care. Special interest group and committees formed to: 1974 Bill initiating funding for regionalized system is passed and statewide Council appointed. Study preterm labor - "White Paper" on preterm labor developed. 1973 Task Force report to NC General Assembly recommending regionalization of perinatal services. ■ Develop "Guidelines for Perinatal Care" ■ Develop a Statewide Perinatal Professional Educational Plan 1972 Governor Scott created Maternal and Infant Health Task Force to determine why North Carolina had such ■ Appoint a Perinatal Statewide Education Committee a high infant mortality rate and to recommend ways to reduce infant mortality.

the competitive Adolescent Pregnancy Prevention Program, Targeted Adolescent Pregnancy Prevention Program, the Adolescent Parenting Program and the Adolescent Pregnancy Prevention Coalition of North Carolina. (The state's adolescent pregnancy prevention programs are now under one combined program using TANF funds for teen pregnancy prevention.) Through these concerted efforts, teen pregnancy rates have declined in North Carolina to their lowest since the mid-1980s, thereby reducing the number of high-risk pregnancies, impacting overall infant mortality, and giving more teens a better chance to succeed in life. Funding for these projects, with demonstrated results, has come under attack in recent years due to the state's financial situation.

Improving the Quality, Comprehensiveness, and Accessibility of Prenatal Care

North Carolina ranks sixth in the nation for its excellent track record in ensuring that pregnant women get early and continuous prenatal care.² Statewide programs include the Baby Love Program (Medicaid for Pregnant Women), which provides prenatal care and care coordination to pregnant women who are at or below 185% of the Federal Poverty Level (FPL); high-risk maternity clinics, a regionalized Perinatal Referral System; the Perinatal Outreach Education and Training program; prevention and treatment programs for sexually transmitted diseases and HIV/AIDS; residential Perinatal Substance Abuse Treatment Programs; Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); the NC Family Health Resource Line (1-800-FOR-BABY / 1-800-367-2229)—a statewide, toll-free, bilingual information and referral line; and the bilingual First Step Campaign coordinated by the North Carolina Healthy Start Foundation, which distributes free educational materials statewide. These services provide information to pregnant women and help link them with available resources, provide prenatal care in an appropriate setting, address known risk factors, and offer educational opportunities and resources to healthcare providers. Recent budget cuts have threatened some of these critical mainstays of prenatal care and infant mortality prevention (for example, the 2004 NC General

Assembly considered proposals to cut the number of pregnant women eligible for Medicaid by reducing the income eligibility criteria). These cuts threaten the state's previous progress in improving the health of pregnant women and babies.

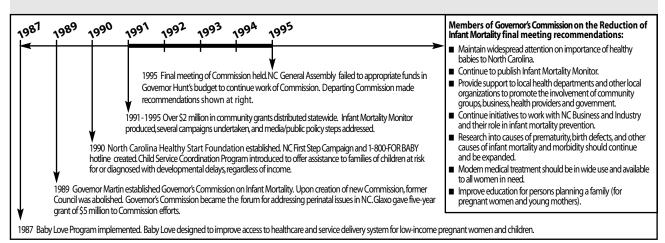
Targeted Interventions Based on Population and Geography

Infant mortality rates vary in North Carolina based on geography, race, and income. A number of unique initiatives in the state address special populations at high risk. The statefunded Healthy Beginnings Program (formerly the Minority Infant Mortality Reduction Program) provides 15 multi-year grants to local organizations that address unique issues in their communities, and the Targeted Infant Mortality Reduction Projects provide funding to eight local health departments to address factors in their community related to reducing infant death. In addition, the federal Maternal and Child Health Branch, US Department of Health and Human Services funds the NC Healthy Start Baby Love Plus and the UNC Pembroke Healthy Start Corps projects, which are used to coordinate four regional consortia in 17 counties (Triad, Eastern, Southeastern and Northeastern regions). These consortia provide outreach and other services to pregnant and postpartum women such as peer support, transportation, and enhanced case management.

Other programs initiated in the past addressed inequities between prenatal services available in rural and urban regions of the state. Both the Nurse-Midwifery Project and the Rural Obstetrical Care Incentive Program increased rural women's access to quality prenatal care by bringing medical providers to underserved areas; however, these programs were eliminated in prior years' budget cuts.

Targeted Interventions Based on Risk Factors and Causes of Infant Death

North Carolina strategically addresses certain causes of infant death, including SIDS, prevention of birth defects, and risks associated with low-birth weight. For example, the North Carolina Back To Sleep Campaign is a public-private partnership aimed at reducing Sudden Infant Death Syndrome (SIDS),



the third leading cause of infant death. This statewide, public education campaign, coordinated by the North Carolina Healthy Start Foundation and the state's SIDS Program, helps to promote behaviors before, during, and after pregnancy that reduce the risk of SIDS. As a result, SIDS deaths have decreased 36% in North Carolina since 1995. A new state law, effective December 1, 2003, should help further reduce SIDS deaths in childcare facilities. The law mandates that: babies under the age of 12 months who are cared for in licensed childcare facilities be placed to sleep on their backs, facilities have written safe sleep policies, and all childcare providers receive state approved training.

The prevention of birth defects, the second leading cause of infant death, is addressed in several ways. Pregnant women receive Maternal Serum Alpha-Fetaprotein screening to detect birth defects in utero and genetic counseling services are offered to families before and during pregnancy to assess their genetic risks and/or to receive counseling about a detected condition. The NC Birth Defects Monitoring Program records detailed information about all infants born with birth defects. Not only does this provide critical information for health monitoring and research, the program has a mechanism to refer affected children to Child Service Coordinators as needed. Utilizing a primary prevention strategy, the interagency NC Folic Acid Council works to decrease North Carolina's high rate of neural tube defects through: a statewide public education campaign to encourage women to take a daily multivitamin with folic acid, professional education, a statewide college campus outreach project, and focused initiatives in the western and eastern parts of the state. The Fetal Alcohol Syndrome Coalition addresses prenatal alcohol consumption, the leading cause of mental retardation. Perinatal Substance Abuse Treatment Programs provide gender-specific, in-patient treatment for pregnant women or women with young children. Since the mid-1990s the NC Family Health Resource Line has served as a bed locator service for healthcare providers who need referrals for their pregnant patients or patients with young children.

Smoking during pregnancy is the single most preventable cause of low-birth weight, yet North Carolina women smoke at a rate that is greater than the national average (13.2% versus 12.0% in 2001). The statewide Women and Tobacco

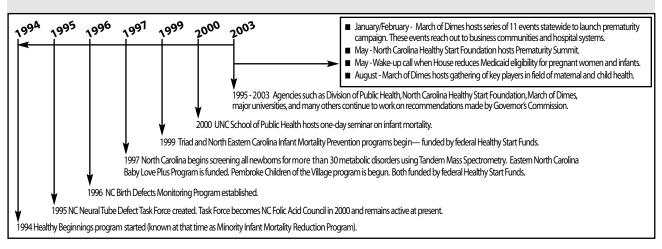
Coalition for Health has evolved over the years and now plays an important role in promoting smoking cessation for women of reproductive years. North Carolina's "Guide for Counseling Women Who Smoke" has been a national model for health-care providers since 1996. Trainings have been institutionalized and are now available for public and private providers through *QuitNow NC* and the state's Perinatal Outreach and Education Trainers.

The state also has 12 Level-Three Neonatal Intensive Care Nurseries, which are equipped to care for North Carolina's sickest babies. The Neonatal Transport Program, annual cross-hospital provider conferences, and Neonatal Outreach Educators and Trainers are some of the ways the state addresses prematurity and other birth related problems once they have happened.

In addition, North Carolina leads the nation in newborn screening services that are offered to all babies born in the state. It was the first state to use tandem mass spectrometry—an innovation in newborn screening. North Carolina screens for every disorder including hearing (with the exception of biotinidase³) allowing for early detection and treatment of a variety of lethal and potentially debilitating conditions.

Even within the programs described above, and using current proven best practice strategies, there is room for improvement. More pregnant women need to get early prenatal care and to be screened and treated for infections. All pregnant women should be taught the signs and symptoms of preterm labor. More healthcare providers need to be trained, reimbursed and willing to talk with their pregnant patients about alcohol, tobacco and other drugs, and to provide counseling and follow-up services. All new parents should be advised to place their children to sleep on their backs. Additional mental health services are needed and public awareness must be raised about North Carolina's "Safe Surrender" law, which allows a new mother, unable or unwilling to care for her baby, to surrender a young infant (up to seven days old) to a responsible adult and not face criminal charges.

There is no doubt that focusing on pregnancy and neonatal care has improved North Carolina's birth outcomes. Current services and programs are vital to maintaining the hard-earned progress that has been made on behalf of the women and infants of this state.



North Carolina is Moving in the Right Direction

North Carolina continues to post improving infant mortality rates. The rates have fallen to 8.2 per 1,000 live births in 2002. While we continue to rank near the bottom in national comparison, we are slowly moving in the right direction.

The number of babies lost to SIDS continues to decline and the number of babies born with birth defects, particularly those of the brain and spine, continues to decline.

Adolescent pregnancy is at an all time low for North Carolina. Many more women are receiving early and adequate prenatal care.

In Our Favor

- Major medical centers, universities, and pharmaceutical companies are doing cutting edge research on the topic of prematurity and maternal and infant health. These not only benefit the larger population, but they have the potential to make the latest medical treatment options available to North Carolina's women and infants. They also hold a wealth of information about their study populations.
- 2. There is strong leadership in the arena of smoking cessation—particularly for youth and pregnant women. This includes having Smoke Free Families leadership in North Carolina, the QuitNow NC campaign supported by NC Prevention Partners and many others, the Women and Tobacco Cessation for Health (WATCH) committee, and award-winning products such as the *Guide for Counseling Women Who Smoke*—a self-help guide for healthcare providers who want handbooks to help pregnant women quit and to reduce second hand smoke exposure. The state has access to national quit lines with one available specifically for pregnant women—and plans to start such a line just for

- women in North Carolina. The National American College of Obstetricians and Gynocologists (ACOG) organization has supported a strong partnership with North Carolina and is bringing important resources and connections to the table. A number of groups have supported innovative smoking cessation grants across the state. The NC DHHS Division of Public Health has a position dedicated to this issue and the perinatal outreach educators and trainers consider smoking cessation a cornerstone issue.
- **3.** Non-profits such as the March of Dimes and North Carolina Healthy Start Foundation are strong and collaborative players in North Carolina. Through grassroots outreach and excellent education products, these and other agencies build on their strengths to make an impact.
- **4.** The state has a very strong Folic Acid Campaign and a very strong Back To Sleep Campaign.
- 5. The Division of Public Health's Women's and Children's Health Section is well respected and organized—it manages a host of excellent programs and services.
- **6.** The state receives significant funding from the Federal Healthy Start Intiative (Health Resources and Services Administration/Maternal and Child Health Bureau).
- 7. The State Center for Health Statistics has a number of key data collection tools, including the NC Birth Defects Monitoring Program (recently funded by the Centers for Disease Control and Prevention as a Center of Excellence), Pregnancy Risk Assessment Monitoring System (PRAMS), and Behavioral Risk Factor Surveillence System (BRFSS). The Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill is an active partner in data organization and evaluation.
- **8.** Healthcare professions in neonatology and maternal/fetal medicine have begun to meet jointly on issues of relevance to both groups.

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Improving Pre-pregnancy Health Is Key to Reducing Infant Mortality

Robert G. Dillard, MD

We could have asked our grandmothers. They would have told us what has otherwise taken at least 30 years, countless studies, and millions of dollars to discover. In order to have a healthy baby, a woman must be healthy, not only during pregnancy, but perhaps more importantly, before she conceives.

Efforts to Reduce Infant Mortality Since 1970

North Carolina's high rate of infant mortality compared with other state and national rates has been a source of puzzlement and embarrassment for years. Blessed with superb medical facilities and a reputation for advanced healthcare planning, our state has perennially ranked among the worst in rates of infant death among all 50 states. In hopes of improving the state's position, state leaders in the mid-1970s began developing a system to provide universal access to high-risk prenatal care and neonatal intensive care. It seemed logical that exposing women with pregnancy complications to the best care available would result in improved pregnancy outcomes.

Fifteen years later, few states had a more remarkably successful regional perinatal system than North Carolina's. During those 15 years, North Carolina's infant mortality rate dropped by a dramatic 36%. The other 49 states had similar rates of improvement. Most did so without strong regional programs like North Carolina's. Virtually all of the nation's improvement in infant mortality, including North Carolina's, had come as a result of improvements in birth-weight-specific deaths among premature infants. In 1988, only Georgia had a higher rate of

infant mortality than North Carolina's.³

In 1988, a task force appointed by the NC Secretary of Health and Human Resources reported that the state's excessive rate of infant mortality resulted from an excessive number of premature births. It made a number of

recommendations to address the problem, including recommendations to improve prenatal services, but recognized that prematurity and infant mortality reduction required "social and economic interventions" as well as healthcare approaches.⁴

In the first half of the 1990s, the NC Governor's Commission on the Reduction of Infant Mortality was charged with the task of implementing programs to address the problem of premature birth. It disbursed funds from a variety of sources to enhance prenatal services and to focus on social and emotional issues among poor pregnant women during their pregnancy. Acknowledging the dramatic disparity between white and minority populations, the Commission targeted initiatives to minority women.

Prenatal Care Is Not Enough

By the mid-1990s, prenatal care had not been shown to reduce rates of premature birth, especially among poor and minority women.⁵ As attractive and relatively inexpensive as prenatal care is, a medical model directed at a six-to-eight month interval in a woman's life can not erase the influence of years of social, economic, and emotional distress and hardship.

Premature birth is strongly associated with poverty, stress, racism, substance abuse, short inter-birth intervals, previous premature delivery, certain types of work activities, and inadequate nutrition. Lower genital tract infections are strongly associated with premature delivery. However, treatment of such infections does not reduce preterm births. ⁶ It seems increasingly likely that

"As attractive and relatively inexpensive as prenatal care is, a medical model directed at a six-to-eight month interval in a woman's life can not erase the influence of years of social, economic, and emotional distress and hardship."

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such infections are a manifestation of stress in pregnancy.⁷

It is time to disabuse ourselves of the notion that prenatal care is the key to reducing infant mortality by reducing premature deliveries. It is time now to focus on the health of women of childbearing age before they become pregnant. Such a task will be far more difficult than establishing a regional perinatal network or ensuring access to prenatal care. It will entail enhancing education for minority populations to break the vicious cycle of poverty and the stress that comes from it. Communities must own up to the pervasive and devastating effects of racism and then begin to eliminate racism in our culture. We must address the serious consequences of smoking and illegal substance abuse. Women, especially poor women, must have the right to become pregnant when they want to be

"It is time now to focus on the health of women of childbearing, age before they become pregnant."

pregnant and not to become pregnant when they don't want to be. In a time of job shortages in North Carolina, it will be difficult to ensure that pregnant women can avoid jobs that make it less likely that they will deliver a premature baby. However, the short- and long-term economic and social consequences of not doing so overwhelm the modest expenses of temporary reassignment. The overwhelming nutritional problems that lead to poor pregnancy outcomes have their roots in childhood. We must do a better job teaching our children to eat well, and more importantly, we must provide them with better food choices.

New Approach to Providing Health Services to Women of Childbearing Age.

In addition to community-based initiatives, we need to develop a new approach to providing health services to women of childbearing age. Such an approach would begin in early adolescence and continue until menopause. The system would combine elements of standard medical care, public health, and social services. It would start with a comprehensive, age-linked, annual assessment. The assessment tool would address traditional medical topics, but also focus on social, economic, and environmental issues. Analysis of such a broad individual assessment would facilitate appropriate referral to clinical, public health, and other community resources.

Each community would identify its available resources and link them to applicable sections of the assessment. Such a linked catalog of services would facilitate timely and appropriate referrals. Community care workers, familiar with available resources, would be assigned to women whose assessments indicated the

presence of high-risk factors in order to ensure that such women had ready access to the best available resources.

Implementing such a system, including identification of funding sources, development of culturally-sensitive and specific tools, creation of the best methods for gaining access to women who would benefit from the system, and evaluation of the impact of the system will require considerable effort on the part of community leaders. However, if the system were successful in addressing and correcting the serious health, economic, social, and environmental factors that lead to premature birth and other poor pregnancy outcomes, infant mortality rates would drop. North Carolina could then deserve the reputation it has as a forward-looking southern state. **NCMJ**

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Infant Mortality: 1963 to Present Medical Developments and Legislative Changes

William R. Purcell, MD

n August 8, 1963 a premature infant boy, Patrick Bouvier Kennedy, was transferred from Otis Airforce Base near Hyannis Port to Boston Children's Hospital. He died the next day at age 39 hours from respiratory distress syndrome.

There was little we could do in 1963 to care for premature and low-birth weight babies. In many hospitals small prematures were kept warm, given oxygen and subcutaneous fluids and sometimes placed on "rocking" beds. Some even suggested that if kept cool they would better tolerate low-blood oxygen levels. As expected, many of the low-birth weight infants who survived were more likely to be "small for gestational age" than "premature."

High Infant Mortality Rates Led to Legislative Changes

In 1963, 31.1 out of every 1,000 babies born alive in North Carolina died before they reached their first birthday. The infant mortality rate for white infants was 22 and 50.6. There were premature nurseries but no real neonatal intensive care units. There were no ventilators designed for premature infants and there was no simple way to measure newborn blood gases. Vascular access through the umbilical cord was used mainly for exchange transfusions. The role of continuous positive airway pressure and surfactant were not generally understood. This was five years before Dr. J. F. Lucey published his article in *Pediatrics* regarding the use of "blue lights" for the treatment of neonatal hyperbilirubinemia. ¹ Neonatal hypoglycemia was rarely considered.

Historically, North Carolina has always had one of the highest infant mortality rates in the country. In the early 1970s, the NC General Assembly and the Governors' Office tried to address this problem by establishing a regional perinatal care system and providing funds for maternity clinics, family planning and delivery services. Later, in the

mid-1980s, the General Assembly expanded Medicaid to increase coverage for pregnant women and infants. Reimbursement rates for delivery services and prenatal care were increased as well.

In the fall of 1989, the Centers for Disease Control and Prevention (CDC) reported that North Carolina had the worst infant mortality rate of any state in the nation (1988 provisional data). Governor Martin created the Governor's Commission on Infant Mortality and changed Medicaid policies to cover all pregnant teens, regardless of parental income, in an effort to encourage them to seek prenatal care. In 1990, the NC General Assembly implemented a four-year plan to reduce infant mortality by expanding access to prenatal care, primarily through the reduction of financial barriers to that care. This involved expanding Medicaid to cover women and infants with incomes up to 185% of the federal poverty guidelines and again increasing reimbursement for prenatal care and delivery. The Rural Obstetric Care Incentive program was expanded to help offset malpractice insurance premiums for providers who were willing to provide maternity care in medically underserved areas. Funding was provided for teams of nurse midwives to provide obstetrical services in these areas and a nurse midwifery program was created at East Carolina University.

Infant malnutrition became a rarity after the onset in 1974 of the federal Supplemental Nutrition Program for Women Infants, and Children (WIC) Program. The WIC Program provides vouchers to low-income pregnant and post-partum women to purchase food for themselves, their infants and their children up to age five. The Legislature also created a birth

defects registry and helped the March of Dimes fund a folic acid awareness program.

Although most infant deaths occur in the perinatal period, measures were taken to reduce the death rate and injury to older infants. Legislation was adopted requiring infant car seats for all infants and back to sleep programs

"Historically, North Carolina has always had one of the highest infant mortality rates in the country."

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for infants in childcare centers. Severe penalties were adopted for operating unlicensed childcare centers or for giving medications to children in childcare centers without parental permission. During this time North Carolina developed one of the best childhood immunization programs in America.

Medical Developments in Obstetrics and Neonatology

Since 1963 there has been a revolution in obstetrics and neonatology with technology leading the way. The use of ultrasound and fetal monitors are now routine procedures and amniocentesis has become a common tool in pregnancy management. The use of Rh (D) immune globulin has made exchange transfusions a rarity. The devastating effects of alcohol usage, smoking, and inadequate folic acid are generally understood.

A real revolution has occurred in the care of premature and sick newborns. A fantastic transport system now brings the medical centers' neonatal intensive care nursery into the local hospital. Pediatricians across the state are trained in the resuscitation and stabilization of sick newborns while awaiting transport teams. Blood gases can be measured percutaneously or with only a few drops of blood. The impact of assisted ventilation, continuous positive airway pressure, surfactant, hand washing, sepsis, hypoglycemia, and phototherapy on the survival of sick newborns is well recognized. Touch and loving care have been shown to increase the chances for survival so now we even encourage parents to touch and hold their ill newborns. This is a far cry from the days when parents weren't even allowed in the nurseries! The recognition of the importance of breast milk in nutrition and resistance to infections have also had a major impact on infant survival and well being.

We Have Reduced Infant Mortality Rates, but Challenges Remain

In 1963 there were 107,322 live births in North Carolina and there were 3,342 infant deaths (31.1 deaths per 1,000 live

births). In 2002 there were 117,307 live births with 957 infant deaths for an infant mortality rate of 8.2, the lowest ever recorded in North Carolina. Clearly, the advances in medical knowledge and expertise, coupled with policy changes that made it easier to access prenatal care have helped to improve the state's infant mortality rate. However, we cannot rest on these accomplishments. North Carolina still has a higher than average infant mortality rate. Nationally, there were seven infant deaths per 1,000 live births in 2002. Further, while North Carolina's infant mortality rate has improved for all races, the infant mortality rate is still more than two times higher for minorities (14.2 per 1,000 live births) than whites (7.0 per 1,000 live births).

Patrick Kennedy brought the difficulties faced by premature infants to the world's attention and made all of us in healthcare aware of the inadequacy of our knowledge, our technology, and our ability to provide the help that was needed. Surely some of the credit for the revolutionary advances in obstetrics and neonatology must be given to that tiny baby boy born to Jacqueline Kennedy at Otis Airforce Base in 1963.

Despite the advances in care and treatment, many questions remain only partially answered. What causes prematurity? What causes birth defects? What causes SIDS? What causes racial disparity? We do know that healthy lifestyles help prevent prematurity. We know that adequate folic acid prevents neural tube defects. We do know that placing infants on their backs to sleep reduces the incidence of sudden infant death syndrome. We know that lifetimes of poverty, stress, and subclinical infections may contribute to racial disparity in birth outcomes.

All of these partially answered questions and many more must remain on the front burner of our state and national government and on the front burner of all involved in providing healthcare to pregnant women and their infants. We must continue to find ways to improve North Carolina's unacceptable levels of infant mortality, and especially, racial disparities.

Acknowledgement: Kevin Ryan, MD, MPH, Division of Public Health, NC Department of Health and Human Services and Pam Silberman, JD, DrPH, NC Institute of Medicine, for advice and information. **NCM**

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North Carolina Makes Strides to Reduce SIDS, but Challenges Lie Ahead

Christine O'Meara, MA, MPH

Sudden Infant Death Syndrome (SIDS) is the third leading cause of infant mortality in North Carolina. Five-year trends show that approximately 100 babies under the age of one year continue to die suddenly and unexpectedly in North Carolina each year.

The SIDS landscape is one in which North Carolina's rate has consistently exceeded the national rate. In 1988 the NC SIDS rate was 1.87 per 1,000 live births compared to the US rate of 1.4 per 1,000 live births. In the intervening thirteen years, SIDS rates have dramatically decreased. The state's lowest SIDS rate ever, 0.7 per 1,000 live births, was reported for 2002. From 1995 to 2002 the NC SIDS rate has fallen 36%.

While this decline in SIDS is certainly good news, it tells only half of the story and should be viewed with cautious optimism. As with infant mortality, the SIDS rates reflect an unacceptable disparity among populations. African American infants are dying from SIDS at twice the rate of white infants. From 1998-2002 NC African Americans accounted for 41% of SIDS deaths, a rate of 1.35 per 1,000 live births, compared to the white rate of .66 per 1,000 births or 58% of SIDS cases. American Indians accounted for 1% of SIDS deaths, a rate of .83 per 1,000 live births, during this same timeframe.

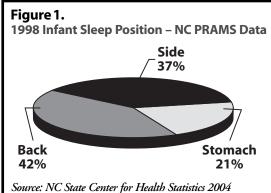
Public education and awareness campaigns have contributed to reductions in SIDS rates. The reversal in the infant sleep positioning message from the prone to the supine or to the side by the American Academy of Pediatrics (AAP) in 1992 and the 1994 National Back To Sleep Campaign's reinforcement of this message resulted in a greater proportion of infants positioned on their back or side for sleeping and a corresponding 50% drop in SIDS deaths nationally. The AAP revised its

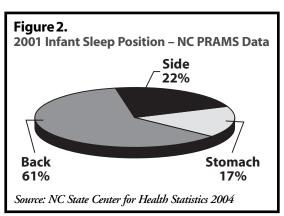
infant sleep position recommendation for healthy infants from stomach to back only in 2000. Closer to home, the statewide NC Back To Sleep Campaign, also launched in 1994, is credited with contributing to the more than 30% reduction in SIDS we

have today.

NC Pregnancy Risk Assessment Monitoring System (PRAMS) data collected by the State Center for Health Statistics documents a significant shift in infant sleep position by North Carolina parents and primary caregivers since 1998.³

Both Figures 1 and 2 demonstrate that the back sleep position is the most commonly used position for sleeping infants, followed by the side. A comparison of sleep position changes from 1998 to 2001 shows a marked increase of 19% for infants placed on their backs to sleep with corresponding decreases in the side (15%) and, to a lesser degree, the stomach (4%) sleep positions. The NC Back To Sleep Campaign goal, in keeping with the national goal, is to reduce the

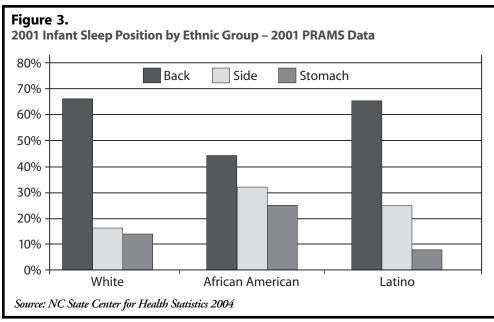




prone sleep position for infants to not more than 10%.

According to PRAMS data, two-thirds of whites and Latinos place their infants on their backs for sleeping, a practice that is much less common among African Americans (43%). African Americans are much more likely to favor the stomach sleep position for infants (24%) compared to whites (14%) or Latinos (8%). The side sleeping position for infants is also preferred more often among African Americans (32%) and

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Latinos (25%) and occurs less frequently among whites (18%). Cultural practices, the influence of a grandmother in the household, medical conditions, parent's preference, modeling and parent education by medical professionals such as newborn nursery staff, and experience with a previous infant contribute to infant sleep position practices. Concerns about choking, plagiocephaly (flat heads), or a bald spot are oftentimes barriers to placing babies supine for sleeping.

Epidemiological and PRAMS data are critical elements for the NC Back To Sleep Campaign's social marketing strategies and are used to identify audience and sleep position messaging. Statewide data depicting the distribution of SIDS deaths are used to target media markets at the county level. These data point to a continued need to inform North Carolinians about SIDS risk reduction and to particularly engage the African American community in infant safe sleep strategies. State efforts are challenged to keep up with the demand for culturally

competent Spanish language SIDS education and outreach for Latinos.

SIDS is a Leading Cause of Deaths in NC Childcare

National research suggesting that a disproportionately high number (20%) of SIDS deaths occurred in childcare sounded an alarm that prompted the targeting of childcare providers for SIDS risk reduction education and training. Researchers found that, while more infants were positioned for sleep on their backs in childcare, those succumbing to SIDS

infants spend there.

The state has almost 16,000 infants in licensed childcare, according to the NC Division of Child Development (DCD). Figure 4 illustrates that two-thirds of all deaths from 1997 to 2002 in NC childcare were attributed to SIDS. During this sixyear period, there were 34 SIDS deaths and 16 deaths due to other causes.

in childcare were more likely

to have been placed on their

stomachs for sleeping. Of the smaller subset of babies

(N=99) for whom informa-

tion about the length of time in childcare was avail-

able, one-third had died during their first week in

childcare and one-half of

these occurred on the first day.⁴ Unaccustomed prone

sleepers may be at a higher

risk when positioned prone. Approximately 7% of North

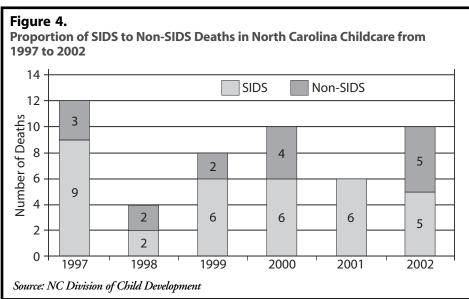
Carolina's SIDS deaths occur in childcare settings, a

figure one might expect to observe given Census data

and the amount of time

SIDS Risks Present in NC Childcare

Observational and survey data collected in 2002 prior to the implementation of the Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) initial training, and prior to SIDS risk-reduction legislation in 2003, showed that SIDS risk factors were present in a sample of 217 regulated childcare centers and homes in North Carolina. Sleep position varied and included side, stomach, back, and sitting. Babies



slept in a variety of places such as cribs, bassinets, playpens, bouncy-seats, car seats, and, in the case of one childcare home, on a sofa. The immediate sleep environment contained toys, stuffed animals, and excess bedding. Although rare, there was evidence of cigarette smoke in one family childcare home. Very few facilities had a written safe sleep policy in place. Though some caregivers had attended SIDS workshops, childcare providers identified SIDS training and policy development as needed and most expressed a desire to have educational print materials for parents.

Media is a Catalyst to Combat SIDS

A cascade of recent events has impacted how North Carolina's babies are sleeping at home and in childcare. SIDS has been in the media spotlight frequently in the past year, not only as a news feature but also in the halls of the NC General Assembly. Consequently, we are witnessing a ripple-effect of safe sleep policies being implemented in a variety of childcare settings and adopted in private homes.

Beginning February 16, 2003, the Raleigh New & Observer published a three-day investigative series entitled Case Closed: Deaths in Day Care⁵ that focused attention on SIDS, the unauthorized administration of medication in childcare and the operation of unlicensed, illegal childcare in the state. A strongly worded editorial on February 19, described the shortcomings in North Carolina's regulation of day care center's as not only unacceptable, but despicable! This editorial demanded that the Governor and legislative leaders toughen childcare oversight and regulation and outlined several strategies to address health and safety concerns in the state's more than 9,000 licensed childcare facilities. To tackle SIDS, the News & Observer called for a state law requiring that infants in day care not be put to sleep on their stomachs. Representative Martha Alexander, a stalwart child advocate, was quick to act, and by late February House Bill 152, the precursor to the NC SIDS Law, had been

The NC SIDS Law

December 1, 2003 is an historic moment in the state's battle against SIDS. North Carolina joined the ranks of a handful of states legally mandating that licensed childcare providers position babies 12 months of a age or younger on their backs for sleeping, having written policies in this regard, and obtaining training for childcare workers. House Bill 152 expanded General Statue 110-91 pertaining to mandatory childcare standards and was ratified as GS 110-91-15. The NC Prevent SIDS law includes a waiver provision based on medical need, for infants six months of age or younger. The law also allows a parent or legal guardian to waive the back to sleep requirement for infants older than six months. This allowance represents a political compromise and is not a best practice in accordance with recommendations of the AAP and the National Resource Center for Health and Safety in Child Care. Nonetheless, other elements of the law do reinforce standards designed to lower SIDS

risks in childcare, including the mandate to develop a written safe sleep policy and to discuss it with parents prior to the child's enrollment. The type of required SIDS-related training was unspecified in the law.

NC Childcare Licensing Rules

The next step was to codify the more broadly written law into specific licensing rules for childcare providers. Developing guidelines for everyday practice is the responsibility of the NC Child Care Commission (CCC). The Commission is comprised of legislative appointees and includes childcare providers, community leaders, a pediatrician and Division of Child Development (DCD) staff. The Commission's rules committee, faced with the task of weaving legal requirements into childcare licensing rules, included a subset of Commission members, child advocates, legal counsel, DCD staff members and this author. Rule changes affecting behaviors and environmental factors associated with SIDS risks were proposed, reviewed by the Commission, tweaked, and then posted for public comment for two months from December 2003 to February 13, 2004. Revisions to the proposed rules incorporated feedback from the public review process and were then subjected to legal review by the Rules Review Commission in March and entered into the Code by the Office of Administrative Hearing in April. The resulting licensing rules went into effect May 1, 2004.

Of significance, the rules pertaining to safety and sanitation include prohibitions on tobacco use around children in family childcare homes and vehicles when transporting children, where none had existed heretofore. Secondhand smoke more than doubles the chances of SIDS, exacerbates asthma, is an allergen, and triggers respiratory infections. Tobacco products are a leading cause of childhood poisoning.

The revised licensing rules addressing infant/toddler sleep safety and SIDS apply to childcare providers licensed to care for infants 12 months of age or younger and are summarized as follows:

- An infant 12 months of age or younger is to be positioned on the back for sleeping unless a waiver states otherwise. A physician waiver exempting back to sleep for infants six months of age or younger is required. Childcare providers may choose to implement a parent waiver for infants older than six months.
 - Note: The Alternative Sleep Position Waiver—Physician Recommendation form, developed by the DCD, must be completed by the child's primary care physician in the event a medical condition necessitates it. The waiver states the medical reason for a sleep position other than the back and the recommended alternative sleep position must be identified.
- 2. A notice indicating that a waiver is in effect and stating the recommended sleep position must be posted near the child's crib. The signed waiver is to be kept in the child's file.
- 3. A written safe sleep policy or poster must be prominently posted and this information communicated to parents before a child is enrolled. The policy must be discussed with

parents of currently enrolled infants within 30 days of the rules' effective date.

- 4. The crib, bassinet or playpen will have a firm padded surface.
- 5. Baby's head or face shall not be covered.
- 6. Tobacco products can not be used at any time children are in care; and smoking or use of tobacco products is not allowed indoors when children are in care, or in a vehicle when children are transported.
- 7. The room temperature where babies sleep cannot exceed 75°F
- Sleeping babies must be visually checked and the frequency
 of checking and observations documented. This record
 must be kept on file for one month following the reported
 month.
- Awake infants shall have a daily opportunity to play while on their stomachs.
- The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) training is the designated training.
- 11. Owners/operators/directors, lead infant teachers, substitutes and volunteers counted in the child-to-staff ratio must obtain ITS-SIDS training. Providers must renew their ITS-SIDS certification every three years. New hires shall receive ITS-SIDS training within four months of hire or within four months of the rules becoming effective, whichever comes later.

ITS-SIDS Training Project

The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) Project is a train-the-trainer initiative developed as part of the NC Back To Sleep Campaign, a program of the North Carolina Healthy Start Foundation. It adheres to the AAP recommendations, national child health and safety gold standards and best practices aimed at reducing SIDS. ITS-SIDS was initially funded for two years by the NC Division of Child Development on July 1, 2002—almost one and a half years before the NC SIDS law went into effect. Given the sequence of events and training needs, the Division expanded funding for Phase Three from December 1, 2003 through June 30, 2005.

Project goals are to: (l) introduce a safe sleep standard in NC childcare, (2) develop a cadre of certified ITS-SIDS trainers and (3) provide contact hour credits for childcare providers. The objective is to train 180 certified ITS-SIDS trainers who would, in turn, train 14,500 childcare providers over the course of the three years. ITS-SIDS trainers are made up of Child Care Resource and Referral staff, Smart Start Partnership staff, Child Care Health Consultants, Cooperative Extension Service Agents, Migrant Head Start staff, childcare directors and private trainers.

With changes in the legal and licensing requirements the demand for ITS-SIDS training across the state has skyrocketed. A total of 208 ITS-SIDS trainers have been certified. As of May 28, 2004, over 17,950 childcare providers have received ITS-SIDS training and 982 trainings have been scheduled or completed. While not all North Carolina counties have a resident ITS-SIDS trainer, all 100 counties do have training coverage. A

fourth train-the-trainer series is planned for fall 2004 to address trainer attrition and to provide updated information.

How Will the NC Licensing Laws Affect Healthcare Providers?

There are several areas where physicians, perinatal health-care providers and parent educators are impacted by the sleep safety and SIDS risk-reduction childcare requirements. First, physicians may be approached by parents to complete the *Alternative Sleep Position Waiver—Physician Recommendation* form. This waiver exempts a child 12 months of age or younger from being placed on his or her back to sleep based on a medical condition and specifies the recommended sleep position for that child. The baby's doctor is also asked to indicate the time frame for which the waiver applies. The onus of responsibility for the baby's sleep safety in childcare is shared by both the caregiver and the baby's primary care physician.

Parent-physicians desiring to waive the back sleep position for their child and attempting to sign the medical waiver themselves, muddy the legal waters and place the caregiver in an awkward situation. This scenario has already occurred in North Carolina and in other states. In Illinois, for example, providers are instructed to tell the parent-physician that they must choose. Either they assume the role of parent or that of doctor, but not both.

Particularly striking is the juxtaposition between what parents observe in the hospital or are taught by newborn nursery staff and what is played out in the childcare arena. Tension around the issues of infant sleep position, swaddling, use of sleep positioning devices such as blanket rolls or wedges and co-sleeping twins is a dynamic situation already occurring downstream from the hospital setting and now surfacing in childcare settings.

Not all of North Carolina's hospital nurseries practice the back to sleep standard of care for healthy babies. Some, but not all, of the state's Neonatal Intensive Care Units (NICU) have guidelines for transitioning infants from their stomach or side sleep position to their back; this should be as routine as the testing done for car seat safety among preemies. Similarly, educating about infant sleep safety and transitioning to the back sleep position should be incorporated into routine hospital practices as part of preparing all infants for discharge.

Parents are being taught in the hospital to swaddle infants for comfort and for security, but are they being informed about the signs of overheating, a SIDS risk factor? Are they instructed about when to discontinue swaddling? When parents insist that their four-week, six-week, or three-month old infant be swaddled in childcare, providers are in a quandary. Is swaddling helpful or harmful at these ages? The likelihood of overheating increases for a swaddled child. Furthermore, is the childcare provider using correct swaddling techniques that will prevent the blanket from covering the baby's head?

Bed sharing or co-sleeping with a parent or with a sibling poses dangers to infants by increasing the likelihood of SIDS, overlay (parent or sibling rolling onto infant), suffocation, overheating, entrapment, and injury due to falls from a bed without railings. The pros and cons of co-sleeping are extremely controversial.⁶ Breast feeding advocates promote bed sharing while professionals involved in SIDS risk-reduction education and sleep safety discourage it.

Data suggest that twins are at a greater risk for SIDS due to several factors: being born with a lower birth weight, a shorter gestation, and more complications during pregnancy. The cobedding of twins in hospitals, at home, and in childcare settings remains a complex issue. Hospital practices for twin sleeping arrangements influences the infant sleep practices that parents adopt at home. In North Carolina childcare, crib sharing among infants—even twins—is a violation of childcare licensing rules, yet parents have sought and have obtained a physician's waiver to allow this practice. In one case the physician stated there was no medical reason for co-sleeping the twins, but that the parent had requested it. Again, the safety of the infants, the reasoning of this decision, and the legality of this action are called into question.

SIDS Risk Reduction in Childcare Reaches Parents

One favorable consequence of the safe sleep standards now required in NC childcare is that caregivers are informing parents about the steps they are taking to reduce SIDS risks. This has a spillover effect and extends the arm of SIDS awareness from the childcare setting into the infant's own home. Indeed, many of the ITS-SIDS trainers are being asked by childcare providers to present at parent orientations or to conduct workshops with parents. Providers can share free educational materials with parents that are developed and distributed by the North Carolina Healthy Start Foundation.

Childcare providers are also taking the safe sleep and SIDS risk reduction message home. Many professional childcare workers are themselves parents or grandparents. Evaluations from their ITS-SIDS training show they plan to adopt the recommendations in their personal lives and to share the information with others.

Growing National Efforts to Address SIDS

The American Academy of Pediatrics has recently reconvened their task force on Infant Sleep Position and SIDS to reassess SIDS-related research and to address issues such as hospital nursery guidelines, waivers in childcare, swaddling and co-sleeping. A position statement updating their 2000 recommendations is expected in autumn 2004. Hospital nurseries and Neonatal Intensive Care Units (NICUs) nationwide are re-examining their sleep position guidelines in light of the earlier standards set forth by the AAP. And, the AAP together with the National Resource Center for Health and Safety in Child Care and other

national SIDS organizations has initiated a nationwide "Back To Sleep Campaign" for childcare facilities and has incorporated elements of North Carolina's ITS-SIDS training curricula. The AAP is partnering with the National Conference of State Legislators to promote safe sleep/back to sleep and SIDS risk reduction legislation in states across the county.

North Carolina is Leading the Way in SIDS Risk Reduction

North Carolina is an active leader in SIDS risk reduction in childcare. The state has adequate SIDS-related legislation, carefully revised licensing rules, a robust ITS-SIDS training program and an active Back To Sleep public education and awareness media campaign in motion. Networking occurs on a national level and statewide provider and parent education is fostered through the solid cadre of ITS-SIDS trainers. However, challenges and gaps remain, particularly in the areas of developing and sustaining more in-depth and interactive parent and grandparent SIDS risk-reduction interventions. There is a pressing need to competently address targeted SIDS risks for African Americans and among our growing Latino population and to make culturally and linguistically appropriate outreach available to Latino childcare providers and families. And there remains a need for hospital nurseries and NICUs across the state to convey and model a clear and consistent safe sleep/back to sleep message to parents.

Limitations on workplace tobacco use in childcare settings and growing awareness among childcare providers and parents via the ITS-SIDS training that smoking triples the SIDS risk (babies' secondhand smoke exposure doubles it) may stimulate an increased demand for smoking cessation services. Healthcare providers can play a significant role in reinforcing information about the link between SIDS and smoking. Counseling women not to smoke or to avoid secondhand smoke during pregnancy is an essential first step to combating SIDS. The relationship between pre-term/low-birth weight births and SIDS needs to be more clearly understood. This information should then be conveyed to women and families.

While we have a steady compass and a roadmap to help plot our fight against SIDS, only time will tell the extent to which recent policy changes will impact the tragedy of SIDS in child-care and possibly in family homes. It is clear that too many North Carolinians have experienced heartbreak because of SIDS and that we must adequately support community-based efforts to promote infant/toddler sleep safety and SIDS risk reduction in culturally and linguistically appropriate ways for families, other caregivers, and for healthcare professionals. More can and should be done to inform parents and caregivers that lowering SIDS risks begins before the baby is born as well as afterward.

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Folic Acid and Birth Defects Prevention: A Public Health Success Story

Robert E. Meyer, PhD, MPH, and Anna Bess Brown, MPH

ot very many years ago, prevention of birth defects was rarely given serious considers: rarely given serious consideration as an important public health strategy for reducing infant mortality and improving birth outcomes. Some common misconceptions about birth defects—that they are rare events which account for relatively few infant deaths, and that they are essentially unpreventable probably contributed to the fact that birth defects were largely overlooked as a focus of most infant mortality reduction efforts. Yet, contrary to the perception of many people, birth defects (or congenital malformations, as they are sometimes described) are not that rare. Approximately 3% of all infants are born with serious birth defects. In North Carolina, that translates to about 3,000-3,500 babies affected each year—a number that is 50% greater than the number of babies who are born with very lowbirth weight. Birth defects are listed as the underlying cause of death in about one in every five infant deaths in North Carolina, and approximately 30% of all infants who die in the

first year of life have one or more birth defects diagnosed. Moreover, many types of birth defects are largely or entirely preventable. Some examples include fetal alcohol syndrome, retinoic acid

"Birth defects are listed as the underlying cause of death in about one in every five infant deaths in North Carolina..."

embryopathy, congenital rubella syndrome, and folic acid preventable birth defects such as anencephaly and spina bifida. While it is true that the etiology of the majority of birth defects is currently unknown, the same is also true for most preterm births, yet the latter still has been a chief focus of infant mortality reduction efforts for decades.

Beginning in the early 1990s, a series of landmark events began to set the stage for a significant change in the perception of birth defects as an issue deserving of public health attention. The first of these was the completion of the randomized controlled trial conducted by the Medical Research Council in the United Kingdom which, building upon previous observational studies, demonstrated that preconceptional intake of the B-vitamin folic acid could prevent up to 70% of spina bifida and anencephaly, the two most common types of neural tube defects (NTDs). In September 1992, the US Public Health Service published the recommendation that "All women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other neural tube defects." In 1996 the Food and Drug Administration promulgated a rule requiring all enriched grain products to be fortified with folic acid, effective January, 1998. Subsequently, the national Institute of Medicine reaffirmed the US Public Health Service recommendation and added that women of childbearing years should take 0.4 mg of synthetic folic acid daily.

In North Carolina during this time, a concerted effort took

root to reduce the prevalence of neural tube defects by promoting awareness and consumption of folic acid among women of childbearing age. In 1994, the NC Neural Tube Defect Task Force, later renamed the NC Folic Acid Council, was created. North Carolina was among the first states in the United States to establish such a council, and the group has achieved national recognition for the leadership role it has taken to promote the benefits and consumption of folic acid. Recognizing the need for better surveillance data to help design, target, and evaluate folic acid interventions, the Council worked with the NC General Assembly to establish the NC Birth Defects

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Monitoring Program (BDMP) in 1995. The purpose of the BDMP is to collect, analyze, and disseminate critical information needed for the prevention and treatment of birth defects in North Carolina.

Data from the BDMP indicated that the neural tube defect rate in North Carolina was approximately twice the national rate, and that the rate in the western part of the state was nearly three times that of the United States. Thus, the initial focus of the state's folic acid awareness efforts concentrated in the western region, in partnership with the Fullerton Genetics Center and other key healthcare providers in the region. The results of these efforts were impressive. Between 1995 and 2002, the prevalence of NTDs in the western region has decreased by about 75% or approximately twice the decline seen compared to the state as a whole which, concurrently, had also reaped significant benefits from an array of local, state, and national folic acid initiatives. These initiatives include the fortification program and numerous public awareness campaigns both within and outside the state. The success of these efforts are evident by recent data from the BDMP. Statewide in the year 2002 alone, there were an estimated 80-90 fewer pregnancies affected by NTDs compared to the number that would have been expected had the rates remained the same as in 1995 (prior to folic acid interventions). More than one-half of these pregnancies probably would have ended in medical termination or fetal/infant death, while the remaining infants would have been born with significant disability and other serious health problems.

The BDMP provides the foundation for the Folic Acid Campaign. The program's surveillance data inform the Campaign regarding populations of greatest need, help the Campaign evaluate its effectiveness, and aid in strategic planning. It is also useful to combine these data with information from the Pregnancy Risk Assessment Monitoring System (PRAMS) and the Behavioral Risk Factor Surveillance System (BRFSS) in order to track trends in folic acid knowledge and consumption. With longstanding support from the March of Dimes, the NC Folic Acid Campaign conducts community and healthcare provider education, vitamin distribution, and media campaigns in its efforts to educate North Carolinians about preventing neural tube defects by taking folic acid daily.

The Campaign has succeeded in raising awareness about the benefits of folic acid. Data from NC PRAMS show that in 2001, 86% of women who gave birth that year had heard or read about folic acid (up from 74% in 1998); however, the fact that still only 27% of women reported taking it every day before becoming pregnant indicates that much work remains

to be done before all folic acid preventable birth defects are eliminated. The major challenge now lies in reaching those sociodemographic populations in which the prevalence of NTDs has not declined substantially, and in which multivitamin use remains low. For example, a recent analysis by the BDMP found that the prevalence of spina bifida had decreased very little among women who were less than 25 years of age, who had less than a high school education, and who were on Medicaid compared to their counterparts who were older, better educated, and not receiving Medicaid.³ Efforts to refocus the Campaign on these populations are already underway.

There is still much work to be done by the Folic Acid Campaign and by healthcare providers. Of the women who know that folic acid prevents birth defects, but do not take vitamins, 89% say they would take vitamins containing folic acid if their healthcare providers recommended they do so.⁴ This is a tremendous opportunity for healthcare providers to create public health change by causing a change in the behavior of patients. Every woman who is capable of becoming pregnant should be encouraged by her physician to take 0.4 mg (400 mcg) of folic acid in the form of a multivitamin every day, in addition to eating a well-balanced, healthy diet. Because the development of the neural tube occurs within the first few weeks of pregnancy (often before a woman even knows she is pregnant), it is essential to stress that folic acid must be taken *every day before pregnancy* and continued through at least the first trimester.

In their article elsewhere in this issue of the Journal, DeClerque et al. highlight the need for infant mortality prevention efforts to place a greater emphasis on improving the health of women before they become pregnant. Those who have been involved with birth defects prevention have long recognized the fact that the preconceptional period is the only viable window for effective primary prevention, because most major structural congenital malformations occur very early in pregnancy. Although we do not yet fully understand the mechanisms leading to early preterm birth and we do not know when the optimal window for prevention is, it is only reasonable to assume that, in general, the healthier a women is before pregnancy, the better her chances are of having a full-term, healthy infant. In their paper DeClerque and colleagues call for a "paradigm shift" toward focusing on improving preconceptional health—and more generally women's health—as a strategy for combating infant mortality. That recommendation, which has the potential for reducing infant morbidity and mortality related to both birth defects and low-birth weight, is a welcome one indeed. **NCM**J

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Addressing Perinatal Health Disparities: Another Place for a Paradigm Shift

Vijaya K. Hogan, DrPH

There are persistent racial and ethnic disparities in infant mortality in the state of North Carolina that are preventable and unjust by all standards of social justice. The five-year infant mortality rate (1998-2002) for African American infants was 15.4 compared to 6.3 for white infants—a greater than two-fold excess mortality risk for African American infants. ¹

Prematurity/low-birth weight is the leading contributor to neonatal mortality in the United States,² and the leading cause of overall infant mortality in many states including North Carolina.³ Preterm birth has been the leading cause of death for black infants for more than a decade and is the greatest contributor to the excess mortality experienced by black compared to white infants in this state.

One of the *Healthy People 2010*[†] goals is to eliminate health disparities. Among this goal's objectives is to address the racial

and ethnic disparities in all aspects of perinatal health, including prematurity. The *Healthy People 2010* objective is to reduce the rate of preterm births to 7.6 by 2010. Yet, the preterm birth rate continues to increase, both among multiple and singleton deliveries. There has been little progress over

time in reducing the rates of preterm births and similarly little sustained progress in reducing the disparity. If we are to begin to make progress toward the 2010 objective, it is critical to step back and assess why we have not made more aggressive progress in eliminating the excess risk of infant mortality and preterm birth experienced by African American infants.

Barriers to Reducing Perinatal Health Disparities

One problem lies in the fact that little progress has been made in understanding the etiology of preterm birth. Another problem is the failure to define effective mechanisms to address known risk factors. These problems affect women of all ethnicities, but most acutely, African American women. The third problem—which uniquely affects women of color—rests in a failure to correctly conceptualize the causes of health disparities, and approach their elimination in a logical and scientific way. While discussion and action are needed to address all three of these problems, this paper attempts to focus attention on the latter in order to spur discussion and action toward the needed paradigm shift in disparity elimination.

The existence of a national objective to eliminate health disparities as specified in the *Healthy People 2010* goal effectively charges all of public health and medicine with a responsibility to actively work toward the elimination of these disparities. Receipt of federal funding, such as Title V,

often requires that states include strategies for monitoring and addressing health disparities, and states may often additionally require local accountability and plans to address disparities. There is no doubt that the existence of the *Healthy People 2010* objective has elevated the issue of health disparities and their elimination to a higher level of national and state priority. But despite this, there does not appear to be a systematic process for understanding and addressing health disparities.

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"Preterm birth has been the leading cause of death for black infants for more than a decade..."

Healthy People 2010 is a set of national health objectives for the first decade of 2000. Healthy People 2010 builds on initiatives pursued over the past two decades. The 1979 Surgeon General's Report, Healthy People, and Healthy People 2000: National Health Promotion and Disease Prevention Objectives both established national health objectives and served as the basis for the development of state and community plans.

Indicators of the Existing Paradigm's Failure to Reduce Disparities

First, the current approach assumes that everyone in medicine and public health is scientifically prepared to conduct planning and research around health disparities. Second, there is a predominant notion that to address the disparity, one simply needs to target "evidence-based" interventions specifically to African American (or other vulnerable) populations. Neither of these assumptions is necessarily correct.

Not everyone is scientifically prepared to conduct planning and research around health disparities. It would be hard to imagine someone addressing diabetes without having some training it the subject area, yet most in public health and medicine do not have any preparation for addressing health disparities. The curricula of schools of medicine, nursing, or public health do not routinely require study of health disparities.

One of the fundamental components of a prevention approach to any disease is to know its contributing factors and then act to reduce the effects of these factors. Yet, most people either do not know what factors contribute to health disparities or do not act on them. Factors cited in literature as affecting disparities overall include: healthcare, behavior, culture/acculturation, social factors, psychosocial factors, environmental factors, racism, stress, genetic factors, economic factors, socioeconomic position, neighborhood factors, national, state or local policies, historic and life course exposures, weathering, and other intergenerational factors as contributors. ⁸⁻¹¹ Currently.

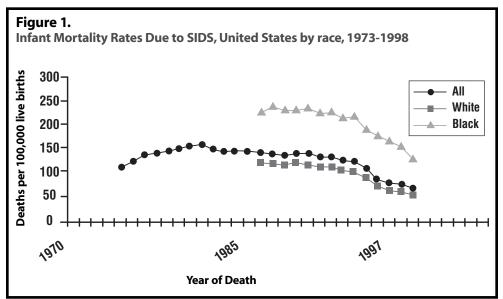
there is little empirical data to define the relative contribution of each of these factors to any specific disparity, but for perinatal outcomes, individual studies have shown a persistence of a disparity when behavioral, healthcare, and, in some cases, socio-economic status factors are considered.¹² Genetic factors are unlikely to be a major contributor to health disparities. 13 In fact, in the summer of 2000, the director of acting National Institutes of Health stated before the US Senate Subcommittee on Public Health that:

Government, but the private sector as well...."14

Additionally, a highly touted national Institute of Medicine (IOM) report reviewing evidence on healthcare inequities recognized that:

"...racial and ethnic disparities in health status largely reflect differences in social, socioeconomic, behavioral risk factors and environmental living conditions. Healthcare is therefore necessary, but insufficient, in and of itself to redress racial and ethnic disparities in health status. A broad and intensive strategy to address social-economic inequality, concentrated poverty, inequitable and segregated housing and education... individual risk behaviors as well as disparate access to medical care is needed to seriously address racial and ethnic disparities in health status" 15

Yet, recent trends in research and intervention focus on healthcare factors, genetic research, and downstream clinical factors. The language used, and the implicit approaches to disparity elimination, reflect a certain naiveté (or maybe denial) about what it takes to truly eliminate disparities. For example, it is not unusual to hear public health and medical professionals interchange the use of the terms "health disparity" and "healthcare disparity." They are two distinct phenomena, with disparities in healthcare being only one contributing factor to overall health status disparities. Understanding the distinction is not unimportant as it is reflected in subsequent actions to eliminate health disparities. While healthcare factors are estimated to cause 10-30% of the morbidity disparities, ¹⁶ we spend 90% of



"The causes of health disparities are multiple. They include poverty, level of education, inadequate access to medical care, lack of health insurance, societal discrimination and lack of complete knowledge of the causes, treatment and prevention of serious diseases affecting different populations. The causes (of health disparities) are not genetic, except in rare diseases like sickle cell... The elimination of health disparities will require a cross-cutting effort, involving not only various components of the Federal

our resources on this one contributor. Some of this spending should be reallocated to address the social determinants of health and to the pertinent research issues that will generate new knowledge to fuel progress toward eliminating disparities.

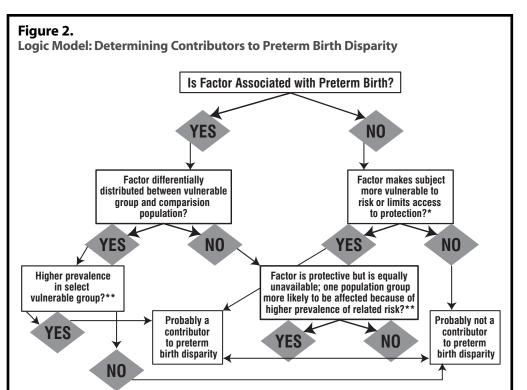
Another limitation of the current paradigm for disparity elimination is a sole reliance on targeting evidence-based interventions for the disease as a strategy to reduce disparities. Targeting evidence-based interventions as a disparity elimination strategy assumes that reducing specific risk factors for the disease in vulnerable populations is all that is needed to reduce the disparity. Factors that cause the disease are not necessarily the same as those that cause the disparity. Efforts to reduce the disparity may require interventions above and beyond those that reduce the disease. Take for example the decline is Sudden Infant Death Syndrome (SIDS) rates (Figure 1).

The significant declines over the past several years are widely attributed to the impact of one "evidencebased intervention" (i.e., the Back To Sleep campaign). However, these declines occurred among all population groups, including African Americans; yet the magnitude of the disparity between African American and white populations remained unchanged. This indicates that something more than the standard evidence-based interventions targeted to

vulnerable populations may be necessary. Additional attention needs to be paid to the factors that make some populations more vulnerable to specific health threats. That is, strategies to reduce/eliminate disparities must target the risk factors for the disease as well as risk factors for the disparity. It will take more than business as usual to really get at the causes of the disparity.

Logic Model: Determining Contributors to Preterm Birth Disparity

If we want to address the disparity as well as see continued declines in all groups in troublesome perinatal outcomes, we have to take a more strategic, logical, and scientific approach. First, we have to improve the knowledge base within public health, medicine, and society as a whole with respect to what causes, and how we could eliminate, health inequities. Second, we need to focus research more strategically toward the issues that will bring more bang for the buck—that is, to support and conduct research that sheds light on how we can more effectively address social determinants of health, as these factors are acknowledged to be the strongest contributors to the disparities in health status. Third, we need to take a more logical approach with the use of existing knowledge to define strategies, and in defining what the priority research issues should be.



- * The factor may be an "upstream" contributor that has not been directly associated with preterm birth, but has been associated with increased prevalence of other more proximal risk factors for preterm birth. One example might be "racism."
- ** Caution is advised in ruling out factors by this criterion. Even if prevalence of a single risk factor is lower, the prevalence of co-existing risks (with which this factor may interact) may be higher and interactive effects may contribure to disparity. For a hypothetical example, smoking prevalence may be lower among African Americans, but a higher percentage of African American smokers may have other co-occurring risks, increasing the risk of disease outcome.

One logic model for determining if a factor is a potential cause for perinatal disparities is proposed in Figure 2. To begin with, we have to determine if a factor is a contributor to the disparity in preterm birth, and if so, include this on the list of factors that need to be addressed (Figure 2). This model is most useful for including additional factors that may not be otherwise considered. To be defined as a contributing factor to the disparity, the variable in question should be a risk factor for preterm birth or affect the distribution of a known risk factor. It should also be more prevalent in the vulnerable group. For example; maternal infection (e.g. bacterial vaginosis) is associated with preterm birth (YES), is differentially distributed between African Americans and whites (YES), and with higher prevalence among African Americans (YES). Therefore, it is very likely a contributor to the disparity. In contrast, smoking is associated with preterm birth (YES), is differentially distributed between these two groups (YES), but the prevalence is higher among whites (NO); therefore, it is probably not a major contributor to the disparity. This does not mean, however, that smoking cessation should not be included in an intervention strategy. Since smoking is a risk factor for preterm birth and other serious diseases, it should be included. Genetic factors are another example. These may be associated with preterm birth, but are not shown to be differentially distributed, and therefore are not likely to be a contributor to the diparity.

Logic Model: Planning Strategies to Eliminate Preterm Birth Disparities

Once a set of factors is determined to be associated with the preterm birth disparity, the factors can then be prioritized to determine where to place resources more effectively. Figure 3 offers a model that can be used to determine intervention priorities. In the model, if prenatal healthcare factors contribute little to the disparity (LOW), but the feasibility of improving the quantity or quality of care was high (HIGH), then one needs to reassess the amount of resources placed on this factor and consider reallocation to a degree proportionate to the relative impact. Maternal infection is considered a strong contributor to preterm birth disparity, with estimates of up to 30% of disparity attributed to this cause (HIGH). The feasibility of mediating this risk is minimal at this time because of the conflicting nature of results from existing treatment trials (LOW). This does not, however, suggest that one should do nothing. In fact, since it is a strong contributor, even more action is needed to develop the evidence base for effective intervention strategies.

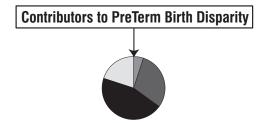
A risk factor that is a strong contributor should have higher priority compared to one that is a lesser contributor. If a risk factor is a strong contributor and is relatively easy to change, this should be included in a disparity elimination strategy. If it is not easy to change (e.g., racism), then instead of passing over it, we need to focus attention on increasing the feasibility of change and support the research needed to develop an "evidence base"

for successfully mediating these risks. Conversely, if a factor is a small contributor, whether easy or difficult to change, we need to reassess our efforts and the resources spent on these factors. An example might be genetic factors, which are not likely to be strong contributors to the disparity, have a low feasibility of change, thus resources (research and other) would be better placed toward addressing stronger contributors.

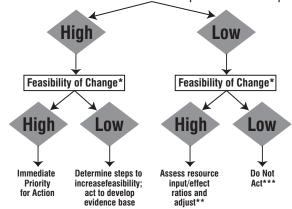
Conclusion

Health disparities have not been approached with the same scientific rigor that we use for addressing other health conditions. Before defining strategies to eliminate health disparities, professionals should be required to study or understand the underlying contributors. Assumptions and personal biases about causality also need to be critically examined. The probability of success in eliminating disparities will be affected by the depth

Figure 3.Logic Model: Planning Strategies to Eliminate Preterm Birth Disparities



What is the relative % contribution to preterm birth disparity?



- * Feasibility of change: evidence base for best practices to address the factor exists; prevailing economic, political, and institutional climate will be supportive with reasonable effort
- ** If proportion of resources put toward addressing this factor exceeds its percent contribution to disparities, consider reallocation of resources toward factors with greater importance
- *** Spending resources on these factors may be wasteful, counterproductive, and inefficient in efforts to eliminate disparity

of healthcare professionals' knowledge of the causes of health disparity. The responsibility for eliminating health inequities lies with all of society. Thus, it is important for all to have a strong conceptual understanding of: why it is important for the health of all that disparities be addressed, what contributors affect health inequities, how much certain risk factors contribute, and how they exert their effects. This understanding can increase the probability that efforts to eliminate health disparities are realistic and holistic, have a strong conceptual basis, are reasonably keyed to the true causes, and thus have greater probability of successfully reducing inequities. It is important to avoid spending considerable resources on a strategy or intervention that addresses a minor contributor at the expense of large ones, all the while promising to eliminate overall health inequities. In the current political climate, the price of failure to make progress could significantly reduce future prioritization of funding to address health inequities. **NCM**J

North Carolina Efforts to Address Perinatal Health Disparities

Belinda Pettiford, MPH

The NC Office of Minority Health and Health Disparities (OMHHD), within the Department of Health and Human Services (DHHS), released its health disparities' report in January 2003. In this report, the state received a "D" in perinatal health disparities, specifically infant mortality. As part of the follow-up to this report, the DHHS has made eliminating health disparities a higher priority.

In its ongoing efforts to address perinatal health disparities, the Women's and Children's Health Section (WCHS) of the NC Division of Public Health, DHHS, has implemented several programs within the last 5-10 years.

The state's Minority Infant Mortality Reduction Program, Healthy Beginnings, is a collaborative effort between WCHS and OMHHD. This program provides \$50,000 yearly to 13 community-based organizations, faith entities, health departments, and health centers. These organizations provide outreach to bring people into care, education for parents, and support services to primarily African American women, infants, and families within certain geographic areas (one project focuses on American Indian families).

North Carolina's federally funded Healthy Start Program, Baby Love Plus, is also designed to address perinatal health disparities. This program has covered 14 counties with a primary focus on improving birth outcomes in African American and American Indian communities. Services include community consortia development, case management from prenatal to two years post-partum for mother and child, health education, outreach, and perinatal depression screening.

All of these efforts emphasize strong community, family, faith, and health provider relationships, along with a key focus on community leadership development. Due to funding cuts with both programs and other budgetary limitations, WCHS continues to look for resources to expand these efforts as part of the overall DHHS's disparity plan.

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Making a Difference in Infant Survival:

Evidence-based Actions to Reduce Tobacco Exposure During Pregnancy and Infancy in North Carolina

Cathy L. Melvin, PhD, MPH, and Sally Herndon Malek, MPH

Health and Economic Consequences in North Carolina

Three of the top four causes of infant death in North Carolina are directly associated with either maternal smoking during pregnancy and/or infant exposure to tobacco smoke after birth.¹ Rates of preterm birth/low-birth weight, respiratory

distress syndrome and Sudden Infant Death Syndrome (SIDS) could all improve dramatically if pregnant women and their partners did not smoke during and after pregnancy, and if infants were always in smokefree environments, especially in their homes, child care locations, public places and automobiles.

In 2002, 15,440 women, or 13.2% of all women giving birth in North Carolina smoked while pregnant. A 2002 report on the association of maternal smoking during pregnancy with infant mortality in North Carolina showed that mothers who

smoked had nearly twice the risk of an infant death or low-weight birth as mothers who did not smoke. For SIDS, the risk associated with maternal smoking was more than five times as high. Low-birth weight rates (per 1,000 live births) for smokers were 12.6 compared to 6.4 for non-smokers and 'small for gestation age' rates for smokers were 10.0 compared to 4.0 for non-smokers. When data by cause of death were examined, 50% of the infants who died of SIDS had mothers who smoked during pregnancy. 1

If no pregnant women smoked during pregnancy, the overall infant mortality rate for the state would drop an estimated 10 to 20%. Furthermore, the mortality rates would improve most

in underserved and disadvantaged communities where women are more likely to smoke while pregnant.

Secondhand smoke is a known human lung carcinogen, and there is increasing evidence of its threat to both the short- and long-term health of pregnant women and infants.² Regardless of whether mothers smoked while pregnant, infants living in households or being cared for outside the home where they are

exposed to secondhand smoke (SHS) may be at greater risk for SIDS.^{3,4} These infants are also at greater risk than infants without this exposure for respiratory and growth-related problems.^{3,4} In 2001, 11.7% of new mothers in North Carolina reported that their infants were often in the same room with someone who was smoking.⁵

Not only does prenatal exposure and/or exposure to SHS endanger the lives of infants, they also result in higher public expenditures for the care of mothers and infants participating in the Medicaid program in North

Carolina. Costs during the first year of life for infants of women who smoked while pregnant were \$4,353 compared to \$3,769 for infants of non-smoking women.¹ Overall this difference amounts to nearly \$6.5 million in excess Medicaid costs during one year for the infants of mothers who smoked.¹

"If no pregnant women smoked during pregnancy, the overall infant mortality rate for the state would drop an estimated 10 to 20%."

What Works to Reduce the Impact of Smoking on Infant Death?

A number of strategies have been proven to help pregnant and parenting smokers quit smoking and to increase the number of smoke-free environments for families. *The Guide to*

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Community Preventive Health Services presents recommendations for use by communities and healthcare systems on population-based interventions to promote health and to prevent disease, injury, disability, and premature death. Three strategic areas for intervention in tobacco use and prevention were identified through systematic reviews of the literature: reducing exposure to environmental tobacco smoke; reducing tobacco use initiation by children, adolescents, and young adults; and increasing tobacco cessation. (See www.thecommunityguide.org for a complete listing of proven strategies to prevent and reduce tobacco use.)

Brief clinician counseling with pregnancy-specific self-help materials for pregnant smokers has been found to increase cessation rates by 30 to 70%. Depending on the underlying prevalence of smoking in a particular group, this improvement could double or even triple cessation rates and save \$3 for every \$1 invested in treatment. Similar counseling interventions along with appropriate pharmacotherapies for non-pregnant smokers have also been shown to significantly increase their chances of quitting smoking.

Telephone support, when combined with other efforts such as educational approaches or medical therapies, is effective in helping smokers to quit when implemented in both clinical and community settings. These help, or quit, lines are a valuable resource for clinicians who may need to refer their patients to external sources of counseling and support during their quit attempts.

Mass media education campaigns when combined with other interventions have also proven to be effective in preventing and reducing tobacco use.⁶ Advertisements aimed at promoting cessation coupled with other interventions such as provider cessation services using the "5A's" and full service, proactive quitlines are strongly recommended strategies.⁶

Increasing the numbers and types of smoke-free environments for pregnant women and children can reduce their exposure to SHS and its consequences. Policies and legislation aimed at creating smoke-free environments in worksites and public places have been found to increase cessation rates among smokers and to reduce SHS exposure for smokers and non-smokers alike. ⁶

Strategies that increase the price of cigarettes and other tobacco products also have an impact on initiation of smoking and smoking cessation. Pregnant women seem to be especially sensitive to changes in price; for every 10% increase in the price of cigarettes, maternal smoking falls by 5%. ¹¹ Increasing excise taxes on tobacco products in many states has prompted a significant number of smokers to quit smoking altogether. ¹¹ Since many pregnant women are already motivated to quit smoking for their baby's health, the increase in price provides one more incentive to help them quit smoking.

Is North Carolina Using These Strategies?

North Carolina is making substantial progress in some, but not all, of these areas. To help clinicians who care for pregnant women gain the skills, confidence, and materials they need to help pregnant women quit smoking, the state has pursued a number of strategies. The Maternal and Child Health (MCH) Program within the NC Department of Health and Human Services (DHHS) has established a performance standard for treating tobacco use among pregnant clients. MCH programs must identify pregnant smokers and treat them using the Public Health Service "5A's" approach to cessation counseling. Award winning training materials for providers have been developed and training sessions have been held across the state. The Health and Wellness Trust Fund Commission has provided funding to increase tobacco cessation services for pregnant teens. Backup support and consultation is also available for clinicians working with pregnant smokers. Each year, programs compile data to assess their progress and identify areas for improvement in their approach to treating pregnant smokers.

The Women and Tobacco Coalition for Health (WATCH) has been working through a grant from the American College of Obstetricians and Gynecologists to conduct a number of activities designed to increase smoking cessation rates in North Carolina. This group is currently conducting a survey of clinicians providing prenatal care in North Carolina to understand how clinicians currently treat tobacco use among pregnant women they serve and to identify training and other needs that clinicians may have. Information gathered in this survey will help organizations involved in the coalition to develop new programs, materials, and approaches to help clinicians.

As part of an effort to reduce SIDS risk, the NC Child Care Commission recently approved changes to North Carolina's childcare licensing rules to address tobacco use and SHS exposure in child care facilities, including family child care homes. Recognizing that the risk for SIDS is more than doubled when babies breathe SHS and that tobacco products are a leading cause of childhood poisoning, the Commission expanded the prohibition on smoking in family child care homes so that the operator(s) cannot use tobacco products at any time children are in care; and that smoking or use of tobacco products is not allowed indoors when children are in care or in a vehicle when children are transported. Changes in policy and regulations such as these dramatically reduce the exposure of infants and young children to SHS and the risks associated with it.

North Carolina's local school boards are increasingly promoting 100% tobacco free school policies to eliminate secondhand smoke exposure and provide positive role modeling at school and school events. Thirty-six of North Carolina's 117 school districts have 100% tobacco-free schools policies; this is up from six school districts in 1999.

Significant progress has been made in North Carolina's private sector to protect workers from exposure to SHS, however this progress is considerably greater in the white collar sector. Disparities exist in blue collar and service industry sectors where many low-income women work. State law is a barrier to local government protections for secondhand exposure. The 1993 law entitled "Smoking in Public Places" (GS 143-597), states legislative intent "...to address the needs and concerns of both smokers and nonsmokers in public places by providing for designated smoking and non-smoking areas." This law requires state-controlled buildings to set aside 20% of space for smoking and preempts local governments from passing stricter rules. 12

Are There Other Things North Carolina Can Do?

The state can expand efforts to train all clinicians in evidencebased interventions for pregnant and parenting smokers and take steps to assure adequate reimbursement for these interventions, especially through the Medicaid program and the state employee's health insurance plan(s). One of the barriers clinicians frequently cite as a reason for not providing cessation services is the lack of reimbursement for such services. An investment in the reimbursement of cessation services for pregnant smokers brings short-term cost savings for healthcare systems and the state, and has been shown to increase the likelihood that clinicians will offer these services.

Currently two quitlines are available to North Carolina residents. The American Legacy Foundation Great Start Quitline for pregnant smokers can be reached at 1-866-66-START. The National Cancer Institute Quitline for all smokers/tobacco users at 1-888-44-UQUIT is currently available during weekday hours. Plans are in place to have this line become a full-service, proactive quitline in January 2005. These quitlines bring evidence-based cessation help directly to smokers. They are also an important referral resource to clinicians as they work with pregnant and parenting smokers. Marketing these quitlines in North Carolina will enhance their utilization and result in more successful quit attempts. Mass media campaigns designed to promote quitting and the use of local and national resources such as these quitlines among pregnant women and the members of their households are strongly recommended by the Community Preventive Services Task Force, but currently not funded in North Carolina.

An increase in the state excise tax on cigarettes would also increase the likelihood that pregnant and parenting smokers would quit smoking. North Carolina's tobacco tax is currently five cents per pack, the third lowest in the nation. With an increase to 75 cents, North Carolina's tax would be close to the

national average (currently 72.9 cents). And, a 75-cent increase in the cost of a pack of cigarettes would result in a 17.5% decrease in the number of pregnant women in North Carolina who smoke.

Adoption of a 100% tobacco-free school policy by North Carolina school boards would eliminate smoking at school and school events by students, staff, and visitors so that students, faculty and staff are protected from secondhand smoke and nonsmoking is promoted as a social norm. Blue collar and service industry sector worksites should be smokefree in order to provide worker protection from secondhand smoke, a known, preventable health hazard. If private sector worker protections are not adequate, the law prohibiting local rulemaking to protect people from secondhand smoke in public places and workplaces should be reconsidered in light of new evidence of the serious risks of secondhand smoke exposure for pregnant women and other vulnerable populations, and the effectiveness of nonsmoking policies in protecting pregnant women and infants from harm.

Summary

North Carolina faces major challenges in dealing with smoking and its consequences during pregnancy and infancy. Evidence-based strategies exist to help pregnant and parenting smokers to quit, to discourage young people from becoming smokers and to reduce exposure of infants to SHS. North Carolina is making progress in implementing these strategies, but more infant lives could be saved each year if the state adopted a more comprehensive approach to addressing tobacco use by improving cessation services for pregnant and parenting smokers, reimbursing clinicians for providing cessation services, increasing state excise taxes on tobacco products, establishing statewide help or quitline services and adopting tobacco-free school policies. These proven strategies can make a difference. **NCMJ**

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Preterm Birth in North Carolina

Mary Lou Moore, PhD, RN, FAAN

Decreasing infant mortality is closely linked to decreasing preterm births. Unfortunately, the rate of preterm births in North Carolina and in the United States, after declining in the 1980s, has been rising again for the past several years. The goal of this commentary is to examine North Carolina data related to both preterm births per se and to those factors that have been associated with preterm birth.

At times, low-birth weight (LBW) rates will be used in this paper when preterm data are not available. While both rates follow similar patterns, readers should recognize that LBW refers to the birth of infants weighing less than 2,500 grams (5 pounds, 8 ounces), while preterm births are those before 37 weeks gestation. Some of the data reported here (smoking and intimate partner violence, for example) are based on self-report

by women who are pregnant or delivering; such self-reporting may result in underestimation of the true rate of the outcome or exposure reported.

Preterm births may be medically indicated because of the health of the mother or fetus, may follow preterm premature rupture

of the fetal membranes, or may be the result of spontaneous onset of labor. The antecedents of preterm birth are multifactoral and vary from one birth to another. Thus, the reasons for increasing rates of preterm birth are not clear. Two factors have been identified in both national and North Carolina data as potentially contributory: increasing maternal age and an increasing number of multiple gestation births. 1,2

Maternal Age and Multiple Births

More women are delaying childbearing until their mid-thirties and into their forties than in previous generations. In North Carolina in 1998, 10.5% of all births were to women over the age of 35. By comparison, only 3.6% of births in 1978 and 5.8% of births in 1988 were to North Carolina women ages 35

or greater. The birth rate (births per 1,000 women in a population) for women ages 35 to 39 was more than twice as great in 1998 (32.7%) than in 1978 (13.8%). Although both rates were somewhat lower than comparable rates for the United States (34.7% and 19.0%), the trend is the same. During this same period, LBW rates for mothers in this age group increased from 8.8% to 10.2%. in North Carolina. 1

Multiple births increased from 2.0 % of live births in 1980 to 2.8% in 1997, a 40% relative increase. Women over the age of 35 naturally have higher rates of multiple births. In North Carolina the 1999-2001 rate was 43.3 for women ages 30-39 and 51.5 for women ages 40 and over, compared to 17.6 for women under age 20.2 In addition, the increased use of in vitro fertilization with the implantation of two or more embryos

appears to be a contributory factor. The rate of preterm birth in multiple gestation pregnancies in North Carolina for 1999-2001 was 61.2, slightly higher than the rate of 59.2 for the United

"...births to teen mothers have dropped each year in both the United States and in North Carolina."

States.³ The increase in multiple births between 1980 and 1997 appears to account for 70% of the increase in the LBW rate in NC during these years.²

At the other end of the childbearing age continuum, births to teen mothers have dropped each year in both the United States and in North Carolina. In the ten years from 1992-2001, pregnancy rates for North Carolina teens ages 10-14 decreased from, 3.3 per 1,000 to 1.7 per 1,000, a decrease of 48.5%. For adolescents ages 15-19 rates decreased from 30.7% to 16.4%, a decrease of 46.6%. These decreases surpass the national rate of decrease of 26% since 1991. Nevertheless, rates continue to be higher than in many developed nations. In a review of 14,718 births, teens under 15-years of age were almost 50% more likely to have a preterm infant than adult women. Teens ages 16 and 17 were not found to be at increased risk in this study.

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Cigarette Smoking

Cigarette smoking and preterm labor, addressed in another paper in this issue,²⁶ has been linked to preterm and low-birth weight births for more than half a century. In a five-year study of low-income women receiving care in a public clinic in Forsyth County, North Carolina, cigarette smoking had a far greater effect on both low-birth weight and preterm births in African American women than in white women, even though fewer African American women smoked. In this study, 21.2% of African American women reported smoking cigarettes. African American women who smoked more than one-half pack of cigarettes a day had a preterm birth rate of 20.4% compared with a rate of 9.2% for non-smokers (p=.003 after adjusting for age and other risk factors).⁸

Physical and Emotional Stress

Stress has been associated with preterm birth in a number of studies. Accumulation of trauma over one's lifetime (allostatic load), 10 job related stress, 11,12 and racism are examples of stresses experienced by many pregnant women in North Carolina. Through a complex physiologic pathway, stress raises levels of corticotropin-releasing hormone (CRH) leading to the production of Adrenocorticotropic hormone (ACTH) and glucocorticoids with subsequent preterm labor. Stress has also been associated with decreased immune competence, increasing the likelihood of infections which, in turn, are associated with preterm labor.

Intimate partner violence, a particular form of stress, was first identified as a correlate of preterm birth in 1989¹³ and has since been confirmed in a number of studies. In a study using data from the population-based NC Pregnancy Risk Assessment Monitoring System (PRAMS) for 1997 though 2000, 14 the prevalence of physical violence during the 12-month period prior to pregnancy was 6.9% and 5.5% during pregnancy. These rates decreased from 8.4% and 8.1% for the two periods in 1997 to 6.5% and 5.2% in 2000. Rates of preterm birth were 10.1% for women experiencing violence and 9.6% for those who did not report violence. Rates of LBW were 10.1% for women reporting violence and 7.6% for those who did not. Women experiencing violence were more likely to begin prenatal care after the first trimester; to smoke before, during, and after pregnancy; to report high levels of stress in the 12 months before birth; and to experience postpartum depression.

Infection

Two groups of infections have been associated with preterm birth, infections of the genitourinary tract and periodontal infections. Genitourinary infections have been recognized as important correlates of preterm birth for a number of years. Identification and treatment of these infections necessitates access to and utilization of prenatal care.

Less attention has been given to periodontal disease. In a case control study of 124 pregnant and postpartum mothers, controlling for other risk factors, women with periodontal disease

were found to be 7.9 times more likely to have preterm LBW births.¹⁵ In a randomized study of 351 women in Chile, women treated for periodontal disease prior to 28 weeks gestation had a preterm rate of 1.84% compared to 10.11% for untreated women.¹⁶ In North Carolina the availability of periodontal care for low-income women must be examined and, if it is not adequate, this issue must be addressed in plans to reduce preterm births.

Preventive Interventions

Two studies conducted entirely or partially in North Carolina suggest potential preventive interventions. A randomized multisite study of natural progesterone (17 alpha-hydroxyprogesterone caproate: 17P) injected intramuscularly beginning at 16 to 20 weeks gestation until 36 weeks included women from two North Carolina sites. All of the women in the study had experienced one or more previous preterm births. There was a statistically significant difference in births less than 37 weeks (36.3% vs. 54.9%; p=.0001) and less than 32 weeks (11.4% vs. 19.6%; p=.018) with the lower rates in women receiving 17P. There was also a significant difference in infant mortality rates: 2.6% for the 17P group and 5.9% for the placebo group (p=.05), as well as a decreased incidence in morbidity, including necrotizing enterocolitis and intraventricular hemorrhage (p=.05).¹⁷ A study of 17P in Brazil using vaginal progesterone in a population with additional risk factors for preterm birth, also found a statistically significant reduction in preterm births. 18 The American College of Obstetricians and Gynecologists Committee on Obstetrical Practice has stated that "further studies are needed to evaluate the use of progesterone" in women with conditions other than a previous documented history of preterm birth "because unresolved issues remain, such as optimal route of drug delivery and long-term safety of the drug."19

In a five-year randomized study of nurse telephone intervention in low-income women receiving care in a public clinic in Forsyth County, North Carolina was highly effective in 759 African American women aged 19 and over with a 34% reduction in LBW births and a 44% reduction in preterm births. There was no difference in younger African American women or in white women.²⁰ Telephone intervention led to a cessation in smoking in 25%, of participants and reduction in an additional 21%. ²¹ Specific interventions included two or more phone calls per week with assessment, behavioral suggestions as appropriate (e.g. smoking cessation, need to contact healthcare providers at the clinic), education about preterm labor, and emotional support. When study data were examined by risk for preterm labor using a modification of the risk factors of Papiernik²² and Creasy,²³ the greatest impact was on women identified at low risk. Previous studies by others have shown that only 50% of women who will have preterm births can be identified in a risk screening; the other 50% will have no identifiable risk factors and will be considered at low risk, but should nevertheless not be ignored in prevention efforts.²⁴

A Changing Paradigm for Prematurity Prevention

The data reviewed here suggest several directions that may lead to the reduction of preterm births. As stated in the lead paper in this issue of the Journal, ²⁵ the prepregnancy period is an ideal time for intervention. Unfortunately, all women do not have access to preventive healthcare during this time, and nearly half of all pregnancies are unplanned. Whenever possible, prior to pregnancy, we should:

- Educate women and their partners about the increased risk of preterm birth when pregnancy is delayed beyond age 35;
- Encourage abstinence from smoking at each health encounter and provide specific assistance for smoking cessation;
- Screen women for intimate partner violence at each health encounter and have a protocol for appropriate referral;
- Be aware of the possibility of periodontal disease and refer women for dental care;
- Encourage the use of contraception to reduce the number of unwanted pregnancies.

- During pregnancy, we can:
- Support efforts to assure accessibility to prenatal care for all pregnant women;
- Continue assessment and intervention for identifiable stressors, smoking, intimate partner violence, and infection, including periodontal infection;
- Consider strategies such as nurse telephone intervention or other forms of frequent contact for pregnant women, particularly those with limited incomes and education.

Conclusion

Just as many pieces of fabric form a patchwork quilt, many factors contribute to preterm birth in North Carolina. Approaches to prevention of preterm birth must be multifaceted, should begin early in a woman's life, and must continue though the prenatal period, creating an environment in which every woman achieves the best possible pregnancy outcome. **NCMJ**

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Expanding Medicaid Income Eligibility for Family Planning: An Opportunity to Improve Reproductive Outcomes and Lower Medicaid Costs

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The State of North Carolina is requesting federal approval from the Centers for Medicare and Medicaid Services (CMS) to extend eligibility for family planning services to all women and men from 19 to 55 years of age with incomes at or below 185% of the federal poverty level. Unlike the Medicaid expansions for pregnancy-related care, which are specifically provided for in the federal statute, a family planning expansion must be approved by CMS as a Medicaid Family Planning 1115 Demonstration. To be approved, the proposal must be budget neutral—the added Medicaid family planning costs must be offset by at least a similar decrease in maternity and infant healthcare costs. As with maternity care, services may be offered by both public and private providers.

Current Medicaid regulations provide coverage to pregnant women and to infants (younger than a year) at or below 185% poverty. However, these women are eligible for Medicaid benefits only during the period following the confirmation of their pregnancy through 60 days postpartum. After 60 days postpartum, women who no longer meet the state's more stringent financial criteria for participation in the Medicaid program lose eligibility for all benefits, including family planning. It has been estimated that more than two-thirds of the approximately 45,000 women eligible for Medicaid each year due to pregnancy lose their Medicaid coverage after 60 days postpartum, leaving them without family planning or preventive health services coverage.

Among all North Carolina women of childbearing age, there are estimates that more than 318,000 women aged 20-44 are in need of publicly supported contraceptive services and do not have Medicaid coverage for these reproductive health services. Although the 170 publicly supported family planning clinics in North Carolina serve 125,500 women aged 20-44, this represents only 39% of all women in need. Publicly supported contraceptive services are provided to 179,340 low-income women of all ages each year in North Carolina, and these women avert over 41,000 pregnancies each year.²

Unintended Pregnancies

A key goal of the Medicaid Family Planning 1115 Demonstration is to reduce the rate of unintended pregnancies within a state's low-income female population. Unintended pregnancies are those that are unwanted or occur before a woman intended to become pregnant (i.e., mistimed). More than half of all pregnancies in the United States and North Carolina are unintended.³ In North Carolina, an estimated 45% of the more than 115,000 live births each year were unintended at the time of conception.⁴ In addition, there are approximately 27,000 induced abortions each year in North Carolina, and presumably the vast majority of those result from unintended pregnancies. Women ages 20 and older account for over 85% of all unintended pregnancies.⁵ More than three out of every five (61%) pregnancies to low-income women (income less than the federal poverty level) are unintended, compared to 41% of pregnancies for higher-income women (income more than double the federal poverty level). They also are less likely to use effective contraceptive methods and to use contraception consistently. Women whose prenatal care is paid for by Medicaid are significantly more likely than other women to report an unintended pregnancy resulting in a live birth.8 The national *Healthy People 2000* goal was to reduce unintended pregnancies to 30% of all pregnancies, while the Healthy People 2010 goal is to increase intended pregnancies to 70%.

Reproductive Outcomes

Unintended pregnancy is associated with delayed entry into prenatal care as well as low-birth weight, poor maternal nutrition, smoking, and use of alcohol and other drugs. ^{10,11,12} Additionally, the opportunities and benefits of preconceptional healthcare are lost. As reported in the Running the Numbers column in this Journal (page 177), ⁴ North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS) data from

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1997-2000 showed a strong association between an unintended pregnancy and low-socioeconomic status, never taking a multivitamin (folic acid) before pregnancy, late entry into prenatal care, smoking during pregnancy, postpartum depression, and not breastfeeding. ^{13,14}

The overall premise for the Medicaid Family Planning 1115 Demonstration supports the concept that providing Medicaid coverage for family planning services increases the likelihood that low-income women will use these services and thus be less likely to have unintended pregnancies. In turn, fewer pregnant women and subsequent infants and children will need Medicaid coverage. Also, fewer of these pregnant women, infants, and children will have complicated medical conditions, because women with unintended pregnancies are at a higher risk for preterm delivery and other complications. Moreover, improving the spacing of births among the low-income, postpartum population will result in reductions in the overall number of births that will be supported by Medicaid funding. 15 The provision of this benefit might also be expected to reduce the number of low-birth weight and premature deliveries and infant deaths attributable to closely spaced pregnancies among those families whose poverty limits their access to health services. This, in turn, impacts the costs that are incurred for the lifetime care of infants who are born with a disability due to their premature and/or very low-birth weight. Additionally, expanding coverage for family planning and related preventive services offers a major health benefit to low-income populations.

Proposed Family Planning Services

The proposed family planning demonstration will cover family planning clinical services currently covered by Medicaid as well as some limited sexually transmitted disease (STD) treatment for STDs identified during the initial family planning visit. Additional covered clinical services could be added in the future if funds were available and budget neutrality could be maintained. Services recommended for coverage are the following:

- Family planning initial or annual examinations (including appropriate physical exams)
- Family planning counseling and supply visits
- All FDA-approved and Medicaid covered methods of birth control (including removal of implants/inserts)
- Tubal ligations and vasectomies and necessary post-procedure follow-up (upon receipt of proper federal sterilization consent form per current Medicaid regulations)
- Laboratory tests that are in conjunction with the family planning visit, including STD screening tests, pregnancy tests, and Pap tests
- Antibiotics for STDs detected during a family planning initial or annual visit
- HIV testing including pre- and post-test counseling visits
- Referral to a primary care physician or clinic, when needed

Abortion services will not be covered under this program nor will infertility services and related procedures. Unfortunately, except for treatment of some STDs, treatment will not be covered for medical conditions/problems discovered during screenings (e.g., urinary tract infections, diabetes, or hypertension) or caused by or following a family planning procedure (i.e., medical complications from family planning procedures). Treatment for AIDS and cancer will not be covered.

Projected Cost Savings

The purpose of family planning demonstration waivers such as the one North Carolina has requested from CMS is to prove that approaches that expand family planning services to lowincome adults will ultimately reduce Medicaid costs for maternity and infant care. Other states (including South Carolina and Arkansas) have already demonstrated that significantly expanding family planning services to low-income populations results in savings greater than the government expenditures needed to provide the family planning services. This is true because the annual cost of family planning services per participant is approximately \$350 while the average cost of prenatal, delivery, and infant healthcare is almost \$9,000. In addition to savings for maternity and infant healthcare costs, reducing the number of unintended pregnancies will result in savings in future government expenditures for social services, public assistance, and other healthcare costs.

The match for Medicaid family planning services is an especially favorable one for the state—\$1.00 in state match for every \$9.00 in federal Medicaid expenditures. The favorable Medicaid match will allow existing state family planning funds, when used as the state match, to expand family planning services nine-fold. No additional state funding will be required to fund the Medicaid Family Planning 1115 Demonstration. Thus, even with the State's current budget shortfall, the importance of implementing this waiver—with support and involvement of both the public and private sectors—cannot be overstated.

Evaluation of Efforts by Other States

The first national evaluation of the Medicaid Family Planning 1115 Demonstrations funded by the CMS has just been completed. There are currently 18 Medicaid Family Planning 1115 Demonstrations located throughout the United States. Some have operated longer than others. The South Carolina demonstration, which began in 1993, was first, Rhode Island followed in 1994, and demonstrations in Virginia, Mississippi, and Illinois are the most recent to be approved. This evaluation concluded that all of the state programs evaluated were budget neutral. Savings from averted births exceeded the cost of expanded family planning coverage when the proposed model budget neutrality formula was applied.

Timeline

Preparations to expand Medicaid income eligibility for family planning services in North Carolina are well underway. The proposal has been approved by the NC General Assembly. Once CMS approval is obtained, implementation can begin within three to four months. Within the NC Department of Health and Human Services, the Division of Medical Assistance, with support from the Division of Public Health, will be responsible for the Medicaid Family Planning 1115 Demonstration. Postpartum women, especially those at high risk for poor pregnancy outcomes, will be given priority for enrollment. Approximately 4,000 women and men will be

provided family planning services during the first full year. This annual number will increase each year, with 20,000 people being served by the fifth year.

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There Is Life (and Death) Beyond the Infant Year: North Carolina's Recent Experience in Reducing Child Deaths

Tom Vitaglione, MPH

The 1990s witnessed a significant reduction in infant mortality in North Carolina, and this success has continued into the new millennium. For several years this success was guided by the NC Governor's Council on the Reduction of Infant Mortality, established in response to the dreadful news that the state had experienced the worst infant mortality rate in the nation in 1988.

Traditionally, the infant mortality rate has been considered a key indicator of the overall status of children within a society. Thus, it deservedly receives significant attention in public policymaking and in the media. Interestingly, the death rate of children after their first birthday receives less attention, perhaps because there are fewer of them (in 2001, for example, there were 1,005 infant deaths in NC and 524 deaths in children ages 1-17), or perhaps because the loss of an infant engenders a greater sense of tragedy. Nevertheless, an important measure of a society is the protection it affords its most vulnerable citizens, and especially its children of all ages.

This brief article is thus focused on North Carolina's experience in reducing death rates in children ages 1-17 in the period 1991-2001, a period in which the infant mortality rate declined by 22%. What progress did North Carolina make with regard to older children, and how did this progress occur?

Introduction

The road to progress in reducing deaths in older children began much the same way it began for infants: with bad news.

In 1991, a series of child abuse homicides in North Carolina received wide publicity. Data reviews indicated that this was an all too common phenomenon. Further reflection revealed concerns about all child deaths in the state. A few years earlier, North Carolina had achieved the distinction of having the worst infant death rate in the nation. It was now becoming apparent that, while the state's ranking in overall child deaths was not that bad, preventable child deaths were a tragically large problem.

As a response, the NC General Assembly held hearings on child abuse homicide, and interest grew in having an ongoing

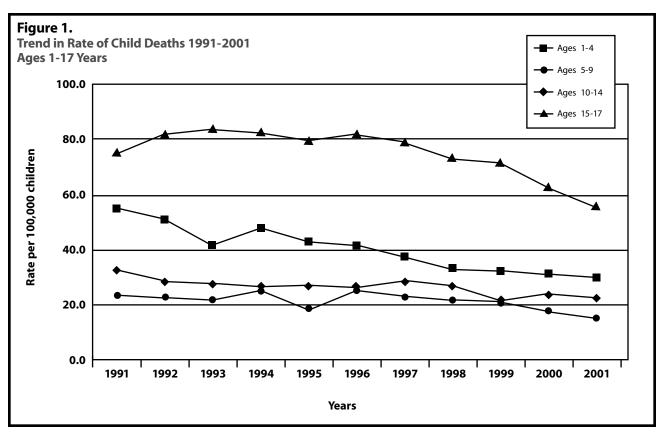
study of its cause and possible prevention. The interest then expanded to cover all child deaths, culminating in a watershed legislative decision to adopt an initiative known informally as the "child fatality prevention system."

The Child Fatality Prevention System

Three critically important components of the child fatality prevention system were established:

- Local Child Fatality Prevention Teams, with multi-agency membership established by statute, were directed to review all child deaths in each county. (A prior Executive Order had established similar teams to focus exclusively on deaths suspected to have resulted from abuse or neglect. Under the new legislation, counties were given the option of combining these teams or operating them separately.) Teams make recommendations to change local procedures, policies and ordinances aimed at preventing future deaths. Recommendations with statewide ramifications can be referred to the other components of the prevention system described below.
- A State Child Fatality Review Team, with statutory multiagency membership and chaired by the Chief Medical Examiner, was directed to assist in the review of unexplained, unexpected child deaths, with particular focus on those suspected to be the result of abuse or neglect. Once again, the purpose of the reviews is to develop recommendations that could prevent future child deaths. The State Team is specifically required to report its findings and its recommendations to the Child Fatality Task Force described below.
- The NC Child Fatality Task Force is the lynchpin of the entire system. It is a 37-member legislative study commission, including legislators and multi-agency membership, with the overall charge to study the incidence and causes of child deaths, as well as to make recommendations for changes in legislation, rules and policies that would prevent deaths and promote the safety and well-being of children. It is responsible for assuring that multidisciplinary reviews of child deaths

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are taking place, and is also responsible for assuring that, as noted above, local and state recommendations to reduce child deaths are studied and transmitted to state agencies and the NC General Assembly.

A Decade of Activity

All three components of the child fatality prevention system have been very active since inception. Though virtually the entire system is volunteer-based, the objective of saving children's lives and promoting their well-being stimulates a high degree of participation.

It is not possible to document all of the many accomplishments of local teams in changing local procedures, policies and ordinances. Changes in medical referral systems and emergency responses, heightened collaboration among child-caring agencies, street signs and traffic signals at hazardous intersections, and swimming pool safety ordinances are just some of the highlights that have made a difference in protecting children. In addition, many problems noted locally were referred to the State Review Team and the Child Fatality Task Force for review and action.

Because it operates in a more public venue and focuses on fewer, but more far-reaching issues, the activities and legislative accomplishments of the Task Force are more easily recounted. Since even these accomplishments would create a very lengthy list, below is a non-exhaustive list of highlights:

- Child passenger safety laws were strengthened twice.
- A Graduated Drivers License System was adopted.

- Smoke detectors are now required in all rental property.
- The sale of fireworks to youth under age 17 is now prohibited.
- "Zero tolerance" for alcohol in drivers less than 21 was adopted.
- Comprehensive kindergarten health screening is now required statewide.
- Numerous measures were adopted to reduce infant mortality, including expansion of Medicaid services for pregnant women and infants, a birth defects monitoring system, a folic acid awareness campaign, "safe sleep" practices in child care facilities, and overall awareness efforts under the auspices of the Healthy Start Foundation.
- Bicycle helmets for riders less than 16 are now required.
- The Infant Homicide Prevention Act, providing a "safe haven" for abandoned infants, was adopted.
- The penalty for illegally selling firearms to a minor was changed from a misdemeanor to a felony. In addition, safe storage of firearms is now required in homes where children reside.
- NC General Statutes, Chapter 7A was re-written to strengthen the protective services system.
- State funds for additional child protective services workers were appropriated at least twice.
- Protective services "hot lines' were established in each county.
- Additional funds were appropriated for the medical evaluation of children suspected to have been abused.

The Outcomes

All of the above, as well as all of the local efforts, were intended to reduce child deaths in North Carolina. As the child fatality prevention system reached its tenth birthday in 2001, some remarkably good news was reported in this regard.

Figure 1 depicts the steady decline in the child death rate for each age group since 1991.

Table 1 compares the percentage decline in death rates in the period 1991-2001 for each age group, including infants. The percentage decline in each of the older age groups

exceeded that for infants, producing a remarkable overall decline of 28% for all groups birth through age 17 combined.

Table 2 depicts another startling outcome. For each and every major category of death, there was a substantial decline in the death rate in the period 1991-2001. (Beyond the infant year, injuries in their various forms are by far the leading causes of death.)

Discussion

The data depicted in the figure and tables taken together, are a firm indication that the remarkably good news about the decline in North Carolina's child death rate is not the result of happenstance. The overall decline has been steady and significant, the declines were enjoyed by all age groups, and the declines occurred in all cause of death categories.

It would not be scientifically accurate to conclude that the implementation of the child fatality prevention system in 1991 is solely responsible for the ten-year decline in child death rates. However, considering all the state and local activity generated by this system, it must surely be highly correlated with the positive outcomes.

North Carolina's success in reducing death rates for both infants and older children offers some interesting comparisons.

First, enhanced attention to both areas (with concomitant attraction of resources) was the result of media coverage. For infant deaths, it was the coverage of the state's last place national showing; for older children, it was coverage of a series of child abuse homicides. The state's infant and child death rates had not been previously ignored by public health officials, and proposals to reduce those rates had frequently been made. It took media coverage, however, to create a political environment that would entertain these proposals.

Second, the establishment of public commissions—the Governor's Council on the Reduction of Infant Mortality and

Table 1. Death Rates By Age

Age	Death	Rate*	% Change
	1991	2001	
Infant	10.9	8.5	- 22%
1-4	54.0	30.1	- 44%
5-9	22.8	15.0	- 34%
10-14	32.8	21.7	- 34%
15-17	74.9	57.6	- 23%
Overall	107.0	76.4	- 28%

* For infants, the death rate is the number of deaths per 1,000 live births. For all other groups, the death rate is the number of deaths per 100,000 children.

the Child Fatality Task Force—was critical to the success of prevention efforts. Though these commissions have had neither administrative authority nor funding for services, they have exerted influence on the development and coordination of services. Perhaps most importantly, they have enhanced awareness of the critical issues, and have not been tethered by the administrative bureaucracy in advocating for solutions. (Note: The Governor's Council was dissolved in 1995, and its functions were undertaken by the Task Force.)

Third, the causes of death for infants and older children are quite dissimilar.

Almost all infant deaths are attributable to birth defects, sudden infant death syndrome, and perinatal conditions related to low-birth weight and prematurity. Indeed, the underlying causes of many infant deaths are still not well understood. On the other hand, most deaths in older children are due to injuries, both intentional and unintentional. The specific causes of these deaths are well-understood.

Table 2.

Death Rates By Cause		
	Percentage Change from 1991 - 2001	
Cause of Death	Children (1-17)	
Birth Defects	- 25.6%	
Perinatal Conditions	- 29.6%	
SIDS	N/A	
Illness	- 39.4%	
Motor Vehicle	- 13.8%	
Bicycle	- 61.3%	
Fire	- 80.2%	
Drowning	- 40.3%	
Other Injuries	- 52.0%	
Homicide	- 51.0%	
Suicide	- 17.9%	

Fourth, because of the differences in causes, the interventions-educational, medical and political-are also quite different. For infant deaths, interventions focus on education during the preconceptional, prenatal, and postpartum periods; access to prenatal care; and newborn intensive care. Interventions are

"Beyond age one, injuries in their various forms are by far the leading causes of death."

fairly costly, and political support is usually a function of awareness and the availability of public funds. For deaths in older children, interventions focus on injury prevention, which is largely a function of education to guide and/or change behaviors. These interventions are often at low or no public cost. However, legislation is often sought to reinforce educational/behavioral messages (e.g., the safe storage of guns, or requirements for bicycle helmets and smoke alarms). These proposals usually engender much political debate, for they are often viewed as an infringement on individual rights or on the rights of the family to make decisions on behalf of children.

An Invitation to Physicians

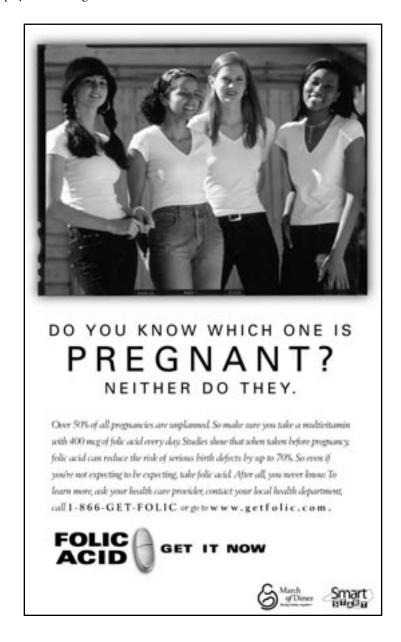
As noted above, most of the deaths in children beyond the infant year are not related directly to the provision of hands-on medical care. This does not mean, however, that physicians do not have a large role to play in reducing such deaths. Health

education and behavior-risk counseling are the critical interventions needed at the child/family level, and advocacy is often needed at the state and community level to enhance child safety.

At both levels, physicians can use their expertise and their positions of respect to raise awareness of issues and to effect remedies that will enhance the health and safety of children and youth. Physicians are encouraged to become involved with the efforts of the local child fatality prevention team in their respective counties. (Information can be obtained from the local health department.)

While North Carolina's progress in reducing infant and child death rates has been remarkable, there is much more progress to be made. Physicians are invited to increase their participation in these efforts. **NCMJ**

Acknowledgement: The author would like to thank Fatma Simsek and her collegues in the State Center for Health Staticstics for their assistance in compiling the data for this article.



Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services www.schs.state.nc.us/SCHS

Unintended Pregnancies in North Carolina

More than half of all pregnancies in North Carolina and the United States are unintended. Unintended pregnancies are those that are unwanted (now or at any time in the future) or occur before a woman wanted to become pregnant. In North Carolina, an estimated 45% of the more than 115,000 live births each year were unintended at the time of conception. In addition, there are approximately 27,000 induced abortions each year in North Carolina, and presumably the vast majority of those result from unintended pregnancies.

Among live births, women with unintended pregnancies are less likely to seek early prenatal care, more likely to smoke during pregnancy, less likely to breastfeed, and more likely to have a low-weight birth. Women with unintended pregnancies are likely to also have other risk factors (such as low-socioeconomic status), but the evidence suggests that a well-timed pregnancy in itself leads to better health behaviors and improved infant health.

The North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS) is a mail and telephone survey of a random sample of North Carolina women who have recently had a live birth. It is supported by the Centers for Disease Control and Prevention (CDC) and is currently conducted in more than 30 states. In North Carolina, approximately 1,800 women are interviewed each year. Pregnancy intendedness is captured from the PRAMS survey question that asks mothers to indicate how they felt about becoming pregnant just prior to conception. Those who answered that they wanted to be pregnant "sooner" or "then" were categorized as intended; those who answered "later" or "not then or at any time in the future" were categorized as unintended.

Forty-five percent of 1997-2000 PRAMS survey respondents indicated that their pregnancy was unintended, with 34% saying that they wanted to be pregnant later and another 11% saying that they did not want to be pregnant then or at any time in the future. The following categories of women had a particularly high percentage of live births that were unintended: age less than 20 years (76%), less than a high school education (61%), household income below \$14,000 (66%), and unmarried (73%). Having a live birth that was unintended was strongly associated with never taking a multivitamin (folic acid) before pregnancy, late entry into prenatal care, smoking during pregnancy, domestic violence, postpartum depression, and not breastfeeding.

A planned pregnancy gives women the opportunity to prepare for a healthy pregnancy. Healthy behaviors before and during pregnancy reduce the risk of a low-weight birth. Though the risk of unintended pregnancy is higher among younger women, more than 75% of all unintended pregnancies are to women ages 20 and older. Therefore, efforts to reduce unintended pregnancies must include all age groups. Access to appropriate contraceptive services is certainly very important. Many family planning programs also provide a broad range of preventive health services such as patient education and counseling; breast and pelvic examinations; cervical cancer, STD, and HIV screenings; pregnancy diagnosis and counseling; and referral to appropriate medical and social services. This emphasis on preconceptional health means that women who do choose to become pregnant are better prepared physically and mentally. Federal funds from the Title X program and Medicaid support family planning services for low-income individuals. These publicly-funded services are available on a voluntary and confidential basis.

The full report from which these results were taken was published by the State Center for Health Statistics in November 2002 (SCHS Studies No. 136) and can be accessed at http://www.schs.state.nc.us/SCHS/pubs/title.cfm?year=2002

1 Buescher PA. Healthier mothers and children through women's preventive health services. NC Med J 1990;51:262-264.

Contributed by Paul A. Buscher, PhD State Center for Health Statistics, North Carolina Division of Public Health



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Letters to the Editor

Latino Health in North Carolina

To The Editor:

In your May/June 2003 issue, you focused on Latino health in North Carolina—a subject in need of attention. The issue did not mention domestic violence and I wanted to share some information with you and your readers about this serious problem. The following paragraph is an excerpt from a client's story (with names changed). It paints a picture of the issues battered Latinas face.

"I remember once when I was three or four months pregnant with my second child, he beat me. I was crying and begging him not to hit me, but he kept on and his mom and step-dad did nothing. After he beat me, he left the house like he always does. When I asked his mom to call the ambulance she said she was not going to get her son, José, in trouble. His mother threatened to call immigration and said she would keep my son, José, Jr., because I would be taken back to Mexico."

Numerous organizations, such as the American Medical Association, the American Nurses Association and the Joint Commission for the Accreditation Organizations, endorse addressing domestic violence through the healthcare system. Domestic violence has serious physical and mental health consequences and healthcare visits may be among the few opportunities for isolated victims to receive the support they need. However, in accessing the healthcare system, battered Latinas face multiple barriers in North Carolina. In general, the Latino population faces greater challenge accessing

the healthcare system due to language barriers, cultural differences, immigration status and a lack of awareness of services. For Latinas who are victims of domestic violence, these barriers are increased by the isolation that is endemic to being a domestic violence victim. To further complicate mat-

ters, other common tactics by abusers such as threats of deportation, use of children and economic abuse hinder the ability of battered Latinas to access services.

Language barriers first and foremost result in deterring a victim



from obtaining necessary assistance. Although linguistically accessible healthcare services should be provided by recipients of federal funding pursuant to Title VI of the Civil Rights Act of 1964, few such services exist. Several of our clients have feared getting medical help on their own because they are monolingual and were used to relying on the abuser for interpretation. One battered Latina client told us "[h]e was the only person who helped me in situations where I needed to communicate, and in this situation I could not rely on him." Even if the battered

Latina is actually able to get to a healthcare provider, if the batterer acts as the interpreter, the information given health workers may be skewed.

Since not all Latinas in North Carolina are US Citizens, immigration status is also a barrier for many battered Latinas. Some immigrants are not eligible for Medicaid or Medicare except in life threatening emergencies, thereby limiting their access to healthcare. Domestic violence victims may choose to avoid receiving healthcare because they do not know how they can pay for such services and fear reprisals from the abuser. Furthermore, it is not uncommon that abusers will threaten an undocumented victim that a phone call to 911 for emergency services will result in her deportation and removal of children from her custody. Finally, cultural differences create an additional barrier for battered Latinas to access relevant services, although defining cultural differences can be a tricky enterprise. We know that cultural differences operate on both ends of the system. Healthcare providers may lack culturally competent staff. From the perspective of battered Latinas, they may be surprised to learn that they may be eligible for services. Many of our clients, for example, are unaware that they can receive mental health

> counseling as victims of domestic violence. One client informed us that in her home country, there were no services available for "women who are abused by their husbands." Many women, therefore, do not attempt to obtain assistance due to a lack of familiarity with the system

especially since it may be quite distinct from the system in their home country.

Taken all together, the power and control dynamics inherent in a domestic violence situation further aggravate the cultural

"Language barriers first and foremost result in deterring a victim from obtaining necessary assistance."

isolation created by language barriers, cultural differences, and immigration status. These dynamics create special difficulty for battered Latinas in accessing medical assistance.

Special Laws Applicable to Battered Latinas Who Are Immigrants

There are certain laws that offer battered immigrant Latinas some assistance from the extreme isolation created by their situation. The Violence Against Women Act (VAWA) can help certain battered immigrants obtain lawful immigration status and employment authorization—both crucial to a victim's ability to survive independently. If an undocumented immigrant is married to a Legal Permanent Resident or to a US Citizen, she may have remedies under VAWA. Normally, the undocumented immigrant would get immigration status through the traditional family-based immigration process, where the spouse with legal status would control the application process. In domestic violence situations, the abusive spouse often exploits the familybased immigration process by refusing to apply for lawful status in order to exert further control. VAWA was passed to remedy the traditional family-based immigration process so that the victim herself could apply for legal immigration status by filing a Self-Petition.

The VAWA Self-Petition process not only allows victims to obtain lawful immigration status, but it also may make some battered immigrants eligible for important federally-funded benefits, such as Medicaid.² Battered immigrants can qualify for federally-funded benefits it they have filed a VAWA Self-Petition and can show a substantial connection between the abuse and the need for the benefit. The victim is required to show: (1) a prima facie determination or an approval of a VAWA Self-Petition or a Family-Based Petition; (2) battery or extreme mental cruelty; (3) a substantial connection between the abuse and the need for the benefit; and (4) that she no longer resides in the same household as the abuser. Children of VAWA Self-Petitioners will also be eligible. Many of our clients have been able to show a substantial connection between the need for medical attention or mental health counseling and the effects of the abuse.3 Unfortunately, not all VAWA Self-Petitioners will automatically be eligible for Medicaid since they are still subject to the complicated restrictions facing non-US Citizens who apply for federally-funded benefits. This exception, however, at least places VAWA Self-Petitioners on the same footing with Lawful Permanent Residents in terms of accessing federally-funded benefits.

Moreover, there are certain federally-funded benefits that are available to all battered Latinas regardless of immigration status, since many battered Latinas are otherwise ineligible to file a VAWA Self-Petition. Some federally-funded benefits that are especially relevant to the health and safety of victims are: emergency Medicaid, crisis counseling and intervention programs, public health assistance for immunizations, treatment of symptoms of communicable diseases, violence and abuse prevention, medical and public health services and mental health, disability or substance abuse assistance necessary to protect life

or safety.⁵ Finally, battered Latinas, regardless of immigration status, have the right to access important criminal and civil court remedies necessary to protect their health and safety.

Suggestions for Healthcare Providers

Healthcare providers can take steps to increase battered Latinas' access to the healthcare system and to identify and assist victims. Common recommendations for increasing access for the Latino population generally are to offer bicultural and bilingual services and to conduct community education and outreach about available services. To serve battered Latinas as well, providers should be trained about the issues that are particular to battered Latinas, including the extreme isolation aggravated by their domestic violence situation and legal options for battered immigrants. Having some understanding of these issues is significant because it will shape how healthcare practitioners understand and choose to pursue treatment.

Healthcare providers should also have an adequate referral system in place for when they encounter a battered Latina who needs assistance. A good starting point is to establish contact with the local domestic violence program. Many programs are increasingly facing populations of battered Latinas and are learning about the special intricacies in assisting this population. Several of the programs within the state have also made a special effort to hire someone on their staff who is bilingual and/or bicultural; however, only a minority of the programs has bilingual staff. In addition, it is important to connect with the other local community-based organizations that serve Latinos. Many of them, particularly in communities where the domestic violence program does not have bilingual staff, serve as a de facto domestic violence program for Latinas.

Finally, a couple of statewide coalitions have worked on issues facing battered immigrants. These coalitions bring together individuals from a variety of backgrounds, including law, social work, public policy, law enforcement, and academics, in order to facilitate cooperation and the exchange of knowledge about the barriers faced by battered Latinas. Project Esperanza focused on issues relating to battered Latinas across the state. For more information, please contact the Coalition for Family Peace in Siler City, North Carolina: (919) 742-7320. There is also a larger statewide coalition called the NC Network on Behalf of Battered Immigrant Women, which addresses issues facing battered refugee and immigrant women generally. To subscribe to their list serve, please e-mail NCNetworkforBIWsubscribe@yahoogroups.com.

These coalitions would welcome the participation of healthcare practitioners who could bring to the table their unique perspective on this very important issue.

Acknowlegement: Thanks to Jan Capps and Mara Deutsch for help with this letter.

Jennifer Lee, JD Staff Attorney Farmworker Unit Legal Aid of North Carolina Raleigh, NC

REFERENCES

- 1 Violence Against Women Act of 1994, Pub. L. No. 103-322, 108 Stat. 1902, subsequently amended, Victims of Trafficking and Violence Prevention Act of 2000, 114 Stat. 1464, Pub. L. No. 106-386 (2000). There is also a more limited immigration remedy for victims of crime (U Visa) that could aid domestic violence victims who are otherwise ineligible for VAWA.
- 2 8 U.S.C. § 1641(c). This same provision applies to other federally-funded benefits such as Work First, Food Stamps, Public Housing and Section 8 Assistance.
- 3 Despite federal law, our battered Latina clients were being told by the local divisions of the Department of Health and Human Services that they were ineligible for Medicaid and other federally-funded benefits. Only with persistent advocacy on a case-by-case basis were we able to get our clients access to Medicaid and other benefits. In 2003, the Department of Health and Human Services modified their manuals to reflect federal law with more specific guidance to their workers. See "Citizen/Alien Requirements: Battered Alien (Violence Against Women Act)," Family & Children's Medicaid Manual, MA-3330, Section VI; "Immigrant Access to Benefits," DMA Administrative Letter, No. 19-03 (April 1, 2003). Similar
- clarification was made in the Manuals for Work First and Food Stamps.
- 4 All Lawful Permanent Residents who entered after August 22, 1996, for example, are subject to a five-year bar for Medicaid benefits. There is no exception from this requirement for battered immigrants. Other such restrictions were enacted by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105, and the Immigration Reform and Immigration Responsibility Act of 1996, Pub. L. No. 104-208, 110 Stat. 3009.
- 5 8 U.S.C. § 1611; 66 Fed. Reg. 3613 (January 16, 2001), A.G. Order No. 2353-2001, Final Specification of Community Programs Necessary for Protection of Life and Safety Under Welfare Reform Legislation. Federally-funded community health centers which provide primary and preventative healthcare serve all people regardless of immigration status or ability to pay. Mental health centers do not have restrictions on who can receive services based on immigration status; however, individual centers may have funding restrictions that are linked to immigration status.

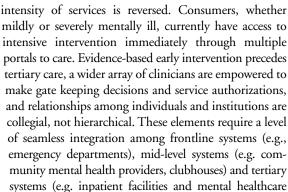
Mental Health Reform

To The Editor:

In several of the analyses of the State Mental Health Reform Plan published in the September/October 2003 issue of the *North Carolina Medical Journal*, veteran observers of the reform effort raised concerns about the capability of the state mental health workforce to

meet the challenge. Basic elements in the Plan—conservation of resources for the most severely mentally ill, increased accountability of clinicians and communities for mental health policy, consumer involvement, transfer of service delivery to the private sector and provision of evidence-based best practices for the targeted populations—pose challenges to the clinicians in the workforce as it is currently configured. The limitation of the most expensive forms of public mental healthcare to all but the most severely ill citizens will exclude some consumers from public sector facilities where they are currently being served, requiring that they seek care in different settings. Care of the uninsured and indigent citizens who do not meet target criteria is still undetermined.

Furthermore, by downsizing public mental hospitals and shifting public funding to community-based services for severely mentally ill citizens, the Plan inherently calls for a compensatory array of primary mental health services that are characterized by easy access, quick, comprehensive response, and that use an arsenal of interventions to restore normal function and divert hospitalization or incarceration. A shift to more primary mental health services means that the traditional equation of incremental



hospitals). If a commitment is made to truly change mental healthcare, this necessary configuration must be addressed honestly rather than "patching" the current system in a way that preserves existing interests. As the Plan and the Journal analysis noted, meeting the reforms in the Plan is beyond the composition and configuration of the current state workforce.

In that same issue of the Journal, Schwartz and Morrissey called for bold training and recruitment and retention initiatives to intensify clinicians' skills, while Bacon and Stallings proposed increased use of advanced practice psychiatric nurses, in particular, the psychiatric nurse practitioner (PMH-NP). We would like to focus on this one role, not as a solution to the challenges of reform, but as an exemplar of the way in which existing clinicians within the mental health system could be prepared to bring the innovative elements that were in the Plan closer to reality.

The PMH-NP, a relatively new face on the mental healthcare team in North Carolina, has proven to be a cost-effective, quality-enhancing addition to mental healthcare in other states. Currently, there are almost 3,000 registered nurses working in mental health in North Carolina—more than 300 have a master's or doctoral degree. Most of these clinicians were prepared as

PMH Clinical Nurse Specialists with advanced practice preparation in psychotherapies and primary mental healthcare, but without prescriptive authority in North Carolina. As the state mental health hospitals are downsized and consolidated, some of these experienced nurses could help meet the mental health workforce needs if they were prepared as PMN-NPs to provide the right care at all levels of acuity in these ways:

- As independent practitioners, PMH-NPs could widen the portals of immediate mental healthcare through the provision of individual, family and group psychotherapeutic interventions for less-severely mentally ill adults and children in the community and, in collaboration with a physician, prescribe and maintain psychotropic medication, thus helping to prevent progression of disorders.
- As community-based providers of care for severely mentally ill adults and children in conjunction with local managing entities (LMEs), PMH-NPs could coordinate multiple care systems and construct support systems for families and community groups who will be the primary caregivers of these citizens, and in collaboration with a physician, provide medication prescription and ongoing maintenance and education.
- As institutionally-based providers of care to severely mentally ill citizens in crisis, the PMH-NP could collaborate with physicians to manage complex physical and mental health conditions and psychiatric crises that require readjustment of psychotropic medications and alterations in care treatment plans required to maintain them once they have returned to their communities.
- As institutionally-based providers of care to medically-ill citizens, the PMH-NP, in a consult and liaison role, could collaborate with physicians to correctly identify mental health issues when appropriate, secure early intervention when appropriate and assist in correct placement in communitybased treatment facilities.

Nationally, and in North Carolina, existing advanced practice nurse educational programs prepare PMH-NPs to be costeffective, multi-skilled providers. These programs already have mechanisms such as online courses, executive formats and AHEC liaisons through which many nurses who already have psychiatric experience could be supported to return to school. Through partnerships with existing facilities, faculty can work with LMEs to place these students in preceptored experiences that will prepare them to meet the newly-evolving service roles. With additional preparation enriching their years of experience in the provision of mental healthcare, these PMH-NPs could provide cost-effective, high quality care to North Carolinians based on best-practice evidence. The model that is already in progress for nursing could be adapted by other disciplines, thus creating an exemplar of interdisciplinary care to meet the challenge of mental healthcare reform in North Carolina.

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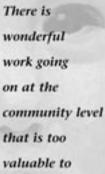
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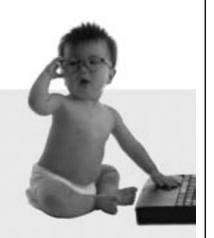








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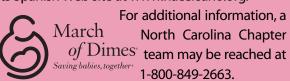
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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the NC Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The NC Institute of Medicine assumed the role of publisher of the North Carolina Medical Journal in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the North Carolina Medical Journal as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the Journal will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.



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North Carolina Medical Journal: Call for Papers

Herbert G. Garrison, MD, MPH Scientific Editor, North Carolina Medical Journal

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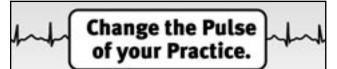
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