

CALL TO ORDER

10:00 AM

Chairman's Opening Remarks

2004-2005 National Action Plan

Secretary's Advisory Committee on Infant Mortality

The following members of the Committee are listed in order of their participation in the November meeting. The meeting was held on November 11-12, 2004 at the Washington Marriott Hotel. The meeting was held in a large conference room on the fourth floor of the hotel. The meeting was held from 10:00 AM to 5:00 PM on November 11 and 12. The meeting was held in a large conference room on the fourth floor of the hotel. The meeting was held from 10:00 AM to 5:00 PM on November 11 and 12.

Meeting Minutes of November 11-12, 2004

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The Latham Hotel
Washington, DC

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GENERAL SESSION

THURSDAY, NOVEMBER 11, 2004

CALL TO ORDER

James W. Collins, Jr., M.D., M.P.H.

Chair, Secretary's Advisory Committee on Infant Mortality

Associate Professor of Pediatrics, Northwestern University Medical School, Chicago, IL

WELCOME AND INTRODUCTIONS

Dr. Collins welcomed participants to the Secretary's Advisory Committee on Infant Mortality (SACIM) meeting. He introduced new committee member Ronald A. Finch, Ed.D. Dr. Collins then went around the table and asked the participants to introduce themselves, and also asked the observers to introduce themselves. Dr. Collins then called for and received approval of the minutes of the July 13–14, 2004 meeting. He called attention to two recent publications, which he circulated: an article written by Peter C. van Dyck, M.D., M.P.H., and his colleagues about the National Child Health Survey (*Maternal and Child Health Journal* 2004;8[3]:183–8). The other article was a report (*MMWR* 2004;53[40]:944–6) documenting an increase in HIV prevalence among Hispanics in Atlanta (Georgia).

RACIAL DISPARITIES AND SOCIAL FACTORS

Racial Disparities in Infant Mortality

James W. Collins, Jr., M.D., M.P.H., Chair, SACIM

Associate Professor of Pediatrics, Northwestern University Medical School, Chicago, IL

Dr. Collins began his presentation by noting that rates for infant mortality continue to rise despite so many current efforts. The cities with the highest infant mortality rates include Detroit, Atlanta, Newark, Cleveland, Norfolk, Baltimore, Chicago, Philadelphia, and the District of Columbia.

In 2002, African Americans had the highest infant mortality rates in the country followed by Puerto Ricans. It is interesting to note that during this year, rates for Mexican Americans were lower than those for non-Latino Whites. There is a strong correlation between infant mortality and low birth weight (LBW) infants (defined as weighing less than 2.5 kilograms [kg] at birth). LBW infants make up only 8 percent of the births but account for 66 percent of deaths. Very low birth weight (VLBW) infants (those weighing less than 1.5 kg at birth) make up only 1.5 percent of all births but account for 50 percent of all deaths.

For both African Americans and White Americans, LBW rates have remained relatively stable for the past 50 years. However, the rate for African Americans is still almost twice as high as the rate for non-Latino Whites. The rate for VLBW among African Americans has almost doubled during the past 50 years, while the VLBW rates for non-Latino Whites remained relatively stable. There is a clear association between LBW and maternal education; LBW correlates to low maternal education in both African Americans and White Americans.

Of the numerous studies on race and birth, one important study by the military on racial disparities documents that compared to Whites, LBW and VLBW rates for African Americans are higher, even when both populations receive the same standard of care. Another study examines the racial gap in perinatal outcomes for infants conceived by assisted reproductive technology (ART). This method of conception tends to self-select for an affluent and educated population. However, even in this group the rate for term LBW among African Americans is approximately 4.5 percent compared with approximately 2 percent for Whites. The racial gap in preterm LBW rates is even wider: 16 percent for African Americans compared with 6 percent for Whites. For VLBW, the rates are again markedly different: 8 percent for African Americans and 2 percent for Whites. These differences raise questions as to the causal factors responsible for this gap even among African American women who used ART to conceive. The relationship between racial disparity and infant birth weight is an epidemiologic enigma. Dr. Collins has examined how transgenerational factors, racial discrimination, and the residential environment affect LBW.

Transgenerational factors are circumstances, conditions, and environments experienced by one generation that relate to the pregnancy outcome of the next generation. For African Americans, the ultimate transgenerational process is slavery. A number of reports released in the past suggest that some of the disparities in LBW may be due to genetic factors. Dr. Collins conducted a study of the difference between infants born in the United States to U.S.-born Black women, African-born Black women, and U.S.-born White women.

Results indicate that birth weights were very similar for African-born Black women and U.S.-born White women. However, LBW rates were considerably higher for U.S.-born Black women, which led researchers to doubt a genetic etiology to the racial disparity. Socioeconomic status (SES) may play a part in this difference because African Blacks who immigrate to the United States are usually of a higher SES than African Americans born and raised in the United States. In another comparison, Black Caribbean women who immigrate to the United States and tend to be of lower SES were found to have a lower rate of LBW than U.S.-born Blacks. The study points to factors relating to life in the United States rather than to genetics.

Dr. Collins and his team designed another study of U.S.-born versus foreign-born women now living in the United States that examined the birth outcomes of their children. The team found that after one generation the daughters of the U.S.-born White women weighed more than their mothers did at birth. There were similar findings for European-born White women and U.S.-born African Americans. In both cases, the children weighed more than their mothers at birth. However, for Black women who were born in Africa or the Caribbean, their daughters weighed substantially less than their mothers at birth. The trend indicated that there was a lower birth weight only for African or Caribbean women after emigrating to the United States.

This led to developing a study on LBW women to determine if they are more disposed to having LBW infants. The study involved matching approximately 250,000 infants' birth records with their mothers' birth records in Illinois. The study found that women who weighed less than 1 kg at birth had the highest rates of LBW infants, suggesting that maternal birth weight is associated

with infant birth weight. Similar trends were seen irrespective of education level and prenatal care utilization.

Another study hypothesized that the lifetime exposure of an African American to interpersonal racial discrimination is an independent risk factor for infant VLBW. The study examined the results of a structured questionnaire for interpersonal racial discrimination answered by mothers of non-LBW infants and mothers of VLBW infants. The questionnaire looked at discrimination in five domains: work, school, seeking employment, obtaining services at a restaurant or store, and receiving medical care. The study controlled for confounders such as maternal age, education, and smoking.

Mothers with VLBW infants were more likely to say they had been exposed to racism than mothers with non-LBW infants. These findings applied to experiencing racism in one or more domains and racism in three or more domains, which suggests that racism is an independent factor for VLBW.

Another study examined the extent to which neighborhood poverty modifies the risk of infant LBW associated with advanced age among urban area African American women who reside in Chicago. The neighborhoods were classified as not impoverished and extremely impoverished (defined as high crime rates, lead in the house, high unemployment rates, annual household income of \$15,000). Among women from neighborhoods that were not impoverished, LBW rates remained relatively flat for women younger than 30 years of age. However, among all ages, women from extremely impoverished neighborhoods had rates of LBW that exceeded those for women from neighborhoods that were not impoverished. Rates for impoverished women aged 30 years or older were significantly higher.

Dr. Collins noted that pregnancy, while occurring during a limited time period, should not be considered independent of prior life experiences. His preliminary data show that early life experiences measured by maternal LBW, the lifelong accumulated experiences of interpersonal racial discrimination, and exposure to neighborhood poverty are risk factors for poor reproductive outcomes among African American women.

Biopsychosocial Contributors to Racial Disparities in Adverse Birth Outcomes

Tyan Parker Dominguez, Ph.D., M.P.H., M.S.W.

Assistant Professor, School of Social Work, University of Southern California

Dr. Dominguez spoke about how the biopsychosocial approach affects birth outcomes. There is persistent racial disparity in birth outcomes, and African Americans have the highest infant mortality and the highest rates of LBW and preterm delivery of all racial and ethnic groups in the United States. Poor birth outcomes affect the whole life of the individual and can include sequelae in childhood such as cerebral palsy, epilepsy, chronic lung disease, attention deficit hyperactivity disorder, and other ailments.

Disparities in mortality and LBW are not explained by SES, behavioral factors, or medical care. Studies are now looking at psychosocial stress as one possible factor that may affect birth outcomes. Psychosocial stress is defined as the environmental demands that tax or exceed the

adaptive capacity of an organism and results in physiological and psychological changes that may place the organism at risk for disease. The literature on stress has been accumulating for more than 40 years, especially in the fields of psychology and obstetrics. There is a relationship between increased stress levels and LBW. The literature also shows that African Americans face more serious and more numerous stressors earlier in life, encounter them more frequently, and perceive these events as more stressful than other groups do.

In a biopsychosocial model, stress affects the neuroendocrine system, the immune system, and the cardiovascular system, which in turn affect birth outcomes. Pregnant women who are under stress release more corticotropin-releasing hormone (CRH), which is known to control the placental clock. Elevated levels of CRH are related to preterm labor, preterm delivery, and fetal growth restriction.

There is a normally occurring immunosuppression when women are pregnant. However, there is additional immunosuppression when women are stressed. The combination creates a major risk for developing increased infections. Bacterial vaginosis (BV), a common infection in pregnancy, is a major risk factor for preterm delivery; and African American women have the highest prevalence of BV.

Stress is also implicated in cardiovascular disorders. Pregnancy-induced hypertension and preeclampsia, which are both major factors for preterm delivery, are common in pregnancy. The literature shows that elevated CRH levels are associated with abnormal uteroplacental blood flow. Diastolic blood pressure reactivity predicts gestational weight, and maternal anxiety is associated with the pulsatility index.

African American women tend to carry a higher stress burden, including that of racial discrimination. Racism has been linked to preterm delivery, depression, stroke, and LBW. Allostatic load is the cumulative load of exposure to threatening environmental demands, and is seen in the concept of "weathering," in which the risk of having LBW infants among African American women increases as the women age; White mothers do not display these risks.

Because other ethnic groups also are affected by racism, a study was conducted on the impact of birth outcomes in a multiethnic population. The major research questions considered were:

- Are there ethnic differences in a perceived lifetime exposure to racism events?
- Are there ethnic differences in the impact of racism on psychosocial functioning?
- Are there ethnic differences in the impact of racism on birth outcomes?

The group included 70 Latinas, 177 Whites, 25 Asians, and 51 African Americans. The women were nonsmokers, fluent in English, and no more than 18 weeks pregnant when recruited. The women were asked about specific instances of exposure to racism in childhood and adulthood. Among African American women (based on a modified version of the Nancy Krieger measure), 72 percent had experienced racism as compared with 88 percent of Asian American women, 54 percent of Latina women, and 40 percent of White women. These patterns were also seen in vicarious incidents of racism encountered as adults and as children.

The study asked how distressed (upset) these women were when they encountered racism; African Americans and Latinas were less distressed than were Asian Americans and Whites. In terms of coping responses, African Americans were more likely to keep these experiences to themselves and more likely to accept unfair treatment as a fact of life.

The study also looked at whether there were ethnic differences in the impact of racism on psychosocial functioning during pregnancy. Psychosocial functioning in response to stressful events included perceived stress, state of anxiety, and depression. According to unadjusted results, African Americans and Latinas reported higher levels of chronic stress, African Americans reported more symptoms of depression, and Latinas had marginally higher pregnancy-related anxiety than Whites did. After adjustments, however, the only ethnic difference was that Whites had less anxiety during pregnancy than Latinas and Asian/Pacific Islanders did. The study documented significant relationships between racism and psychosocial outcomes for the overall sample and within each ethnic group. Race did not modify this effect.

The study then addressed ethnic differences in the impact of racism on birth outcomes. After adjustments for a variety of confounders, Whites had significantly higher birth weights compared with African American or Asian women. A significant difference was not found in the gestational age across the different ethnic groups. It is of interest to note that for each ethnic group, racism was significantly related in bivariate correlations and in the regression analysis to birth weight only in the African American subsample. There were no significant relationships in either the correlational analysis or the regression of racism on birth outcome in any of the other ethnic groups except in the African American women. Circumstances that might account for these findings include insufficient power and the effect of having very small sample sizes for the different ethnic groups or the error generated through multiple comparisons in the regression analysis.

However, there was a trend toward significance in the interaction between the Asian and African American women; the relationship between racism and birth weight differed in these two groups. For African American women, the higher rate of exposure to racism was correlated with lower birth weights. For Asian women, more exposure to racism was correlated with higher birth weight, so this was a positive relationship. If both ethnic groups are reporting very similar levels of exposure to discrimination, why did the preliminary evidence show a significant difference in the direction of impact on pregnancy outcomes?

A theory proposed by Gilbert Gee at Michigan can address this question. He believes that there is really a threshold effect for racism. Up to a certain level of exposure, racism would be expected to affect psychosocial outcomes, emotional functioning, and emotional well being. But to affect physical health outcomes, a certain level of exposure has to be reached, and African American women may be the only group to really reach that level, at which point the racism can spill over into physical health impacts. This is a view also shared by researchers Singh and Yu, who noted that few (if any) groups have experienced the kind, degree, and duration of discrimination that U.S.-born Blacks have endured.

It would be interesting to conduct this study with a Native American comparison group, because this population also has a very long history in this country of social inequality and poor

treatment. Native American women have poor health across a variety of indices, although they do not have birth outcomes as poor as African American women do.

The last point is the importance of thinking about physiological mediators, and how psychosocial factors are translated into adverse physical health outcomes, a phenomenon that Nancy Krieger has referred to as physically embodying social inequality. Health psychologist Theresa Seeman has characterized this experience as racism and social inequality getting under the skin. A comprehensive biopsychosocial model of stress can help explain the big picture and provide more informed planning and more effective interventions.

In conclusion, studies documented ethnic differences in exposure to racism with accompanying differences in distress levels and coping mechanisms; studies also found that racism impacts psychosocial functions across all groups, but adverse birth outcomes were only apparent among African American women.

Discussion

- Bernard Guyer, M.D., M.P.H., asked if Dr. Dominguez could elaborate more on the fact that 40 percent of White women experienced racism. Dr. Dominguez responded that we should remember that racism is a perceived factor, but it is not clear why this number is so high.
- Renee T. Barnes, M.S., R.N., asked where the participants of the study lived, in terms of neighborhoods. Dr. Dominguez indicated there is no clear answer to that question; the two hospitals selected both accept Medicaid and therefore serve a wide variety of sociodemographic patients.
- Maxine Hayes, M.D., M.P.H., F.A.A.P., asked how to translate this information into interventions and what those interventions would look like. Dr. Dominguez replied that one approach involves treatment guidelines and reinforces a specific type of treatment for certain symptoms. This approach would be helpful because African Americans in similar life circumstances as other groups do not necessarily receive the same treatment, even when they have the same level of insurance. Also, taking an Afrocentric approach to prenatal care that empowers women about their racial identity and makes them feel positive about it, along with interventions such as sister care, singing, and body movement, have improved the birth outcomes of these women compared with African American women who remain with traditional health care. Dr. Collins added that a recently published study looked at alleviating job strain and found better birth outcomes among women who received help and were able to identify as well as cope with job stresses.
- Dr. Hayes asked if it would be important to target mothers whose own mothers had given birth to LBW babies as a means of identifying this population to stop the cycle. Dr. Collins found that to be an excellent comment because it is not a current practice yet it can produce tangible and quantifiable results.
- Dr. Finch noted that his group has been looking at practical ways to address the issue of disparity. The group has surveyed 1,500 benefit managers from different companies and

found that they are unaware of the results documenting disparities in health care. This finding needs to be addressed with employers. Dr. Finch added that the group is also evaluating the way providers address disparities in the delivery of care. Large employers are basing their renewals on performance in eliminating these disparities and are refusing to reenroll plans that do not demonstrate progress in this area. Results indicate that equal benefits do not necessarily eliminate disparities.

- Dr. Guyer asked Dr. Dominguez if a factor analysis was conducted to determine what other variables affect outcomes. For example, sets of variables such as chronic illness and pregnancy spacing that could have an effect on outcomes were not part of the study. The study shows that numerous multideterminant factors cause disparity, and the solutions are probably multiple and multideterminant as well. It would be important to attach attributable risks to some of these interactions in future studies because a number of studies being grouped did not look at the same variables in unison. Future studies should examine the contributions from all of these components in a model that examines specific populations. Dr. Collins agreed and felt it would be important to look at attributable risk rather than relative risk.
- Robyn J. Arrington, Jr., M.D., thought the presentation was excellent. He was a military medical officer in the U.S. Army for 30 years and asked if there were any significant differences in the military because of the disciplined environment (such as fitness tests) compared with the civilian population. Dr. Collins responded that the study he cited looked at birth weight but did not examine factors in the military's health care system that made things better when comparing women who are not in the military. But, he suspected that issues of fitness and obesity could play a factor in this equation.
- Kay A. Johnson, M.P.H., M.Ed., noted that her group took the *Unequal Treatment* document from the Institute of Medicine (IOM) and engaged in an exercise with several hundred maternal health leaders to determine how to monitor treatment disparities. More people at the State and local health departments need to think about monitoring performance in the context of unequal treatment. It would also help to measure the treatment against a standard of care, and to conduct more in-depth surveys about provider attitudes; perhaps that is something that should be constantly monitored. Dr. Hayes added that entities, such as accreditation bodies, need to hold institutions accountable for better performance, and this committee might suggest this model as a method for obtaining better outcomes.
- Ann Miller, Ph.D., commented that in the recent election, the electorate has spoken, and came out in big numbers to express concern about the rights of the unborn and how to ensure that they have a safe birth. She noted that the country is very divided on some of the methods that could achieve this goal. Dr. Miller asked if the Maternal and Child Health Bureau (MCHB) had developed some materials that could help congregations of faith to develop programs that would nurture African American women. She believes it is important to note that love really does make a difference for life and that prejudice does not just cause emotional damage, but it also kills children and babies. Perhaps it would be important to engage these congregations in making a difference.

- Robert E. Hannemann, M.D., asked about the relationship between preterm birth and LBW and whether LBW was attributable to preterm birth or to another factor. Dr. Dominguez responded that the studies focused on birth weight, not gestational age. Dr. Collins added that his studies were looking more at preterm birth. The study on neighborhoods showed that where a person lives has a greater impact on growth restriction than on prematurity. LBW and preterm are two separate outcomes that overlap but have independent determinants.
- Yvonne Moore, M.D., asked if studies have examined distressors of dysfunctional African American families such as mothers having multiple fathers of their children or the absence of a father role in the home. Dr. Dominguez explained that her researchers have studied social supports, marital status, and the quality of that relationship. However, these were not included as variables in the racism study that was described. In the future Dr. Dominguez wants to examine social supports and whether a stable relationship with an infant's father could, for example, modify the impact of stress and racism on an adverse outcome.
- Kevin J. Ryan, M.D., M.P.H., noted that the studies emphasized the interpersonal experience of racism. However, societal and institutional racism may also play a role. Dr. Ryan asked whether anything can be done about this. Dr. Dominguez responded that it is very difficult to operationalize institutional racism so researchers can measure it and demonstrate its impact.
- Yvonne Bronner, Sc.D., R.D., L.D., commented that if education and income are strong predictors of outcomes, would it be possible to examine increases in high school graduation rates and increases in junior college enrollment rates as clear, long-term predictors that can improve outcomes. Dr. Collins agreed that education and also not smoking are tremendously important in producing better outcomes. His study investigated income incongruity and that African Americans had lower incomes than Whites with the same level of education. So, education itself is only part of the solution. The full solution is a combination of education and income. Dr. Collins' group found that African Americans who experience negative income incongruity are at risk for poor birth outcomes.
- Michael Lu, M.D., M.P.H., Assistant Professor at UCLA's Schools of Medicine and Public Health, remarked that in terms of translating research into practice, some but not all of the answers are available. He and his colleagues have been developing a plan to close the gap and address infant mortality from both a multiple determinants model and a life course perspective. The first four points of the plan address the health care needs, such as interconception care, preconception care, improving the quality of prenatal care (e.g., implementing a number of standards of care), and the overall improvement of access to health care for African American women throughout their life. The next four points address family and community systems. Some pragmatic approaches to turn research into practice to affect birth outcomes include improving the coordination of family support services through family resource centers, home visitation, care coordination, and so forth; and restoring or increasing father or male involvement in African American families.

Dr. Lu also believes that these issues need to be addressed with ecological models. Neighborhood community factors have to be addressed—such as unemployment and

incarceration. There are also larger social policy factors that have to be addressed: tax policies, welfare policies, and child support policies all need to be examined.

The next four points of the plan address institutional and policy factors that are known to significantly impact women's reproductive health—especially closing the gap in education not just in high school and college, but from a whole life perspective that starts with early childhood programs, preschool, prekindergarten, summer schools, and after school programs.

Another area of importance is closing the income gap and reducing poverty. It will be very difficult to reduce the gap in infant mortality unless we actually start reducing the gap in all of these other domains, and particularly in terms of education, income, and the criminal justice systems.

Another point is to start addressing some of the policy issues that are proportionally affected, particularly for women of color. For example, the impact of maternity leave policies, and how the United States compares with European countries. It is also important to look at how the current child care policy impacts the overall cumulative allostatic load that women experience. Finally, it is important also to address racism, particularly institutionalized racism. There are national efforts spearheaded by CityMatCH and the Boston Public Health Commission that are beginning to provide models for how institutions can begin to address racism.

Dr. Lu also spoke about the concept of social capital, which describes the connectedness between a pregnant woman and her community. Studies have shown that the higher the social capital, the lower the mortality in the community, including infant mortality.

Dr. Lu has been working with a program headed by Loretta Jones from South Central Los Angeles that targets African American families. Through focus groups, they have developed a series of suggestions that could really increase the day-to-day support communities can offer pregnant women. There is a list of 100 things communities can do for a pregnant woman that are called “100 Intentional Acts of Kindness Toward a Pregnant Woman.” This list will soon be publicized through churches, barber shops, nail salons, and other community areas.

- Dr. Hayes reported that a request has been issued for nominations for a committee the IOM has now commissioned. The board on health science policies at the IOM has commissioned an 18-month study of premature birth and assuring healthy outcomes. The study will be sponsored by the National Institute of Child Health and Human Development (NICHD), the Centers for Disease Control and Prevention (CDC), the Environmental Protection Agency, the Health Resources and Services Administration (HRSA), NIH Office of Research on Women's Health, the March of Dimes, the American College of Obstetricians and Gynecologists, and the Society for Maternal-Fetal Medicine. She urged the committee to contact her with any suggestions for potential candidates. Dr. Hayes also suggested that it perhaps would be advantageous for SACIM to make a connection with this study group, if through no other way than to support the IOM's commission study because it is looking at

some of the same issues as SACIM is. Perhaps one of the recommendations from the committee is tying some of SACIM's work with the IOM study.

- Ms. Barnes asked Dr. Dominguez whether researchers looked at the desirability of the pregnancy (whether or not the mother wanted the pregnancy) as a possible stressor. Dr. Dominguez indicated that the main stressor in the study was racism. However, her team has examined desirability in other studies and found that African American women have higher rates of not planning to become pregnant and of not being happy about being pregnant. These responses, however, were early in the pregnancy, and as the pregnancy progressed desirability seemed to increase.
- Ms. Barnes also commented on transgenerational research and the length of time in this country related to birth outcome. She wondered whether this outcome was somehow related to the deterioration of the African American family, to the absence of males in the household, or to other factors. She asked whether the researchers considered looking at those transgenerational trends and their correlation with family structure. Dr. Collins responded that the data can limit this kind of study; he has looked at this issue only among married women. However, it would be important to examine the extended family as a whole.
- Dr. Guyer noticed a troubling trend in Dr. Collins' data—among higher income, more educated Black women, the birth outcome gap is even greater. He wondered whether the business community really has a major role to play in trying to develop plans that would address this even larger racial disparity among high income employed professionals. For example, literature shows that for most employer-funded health plans, maternity and perinatal related costs are the biggest single expenditure under those plans. If that is the case, businesses may also have a financial incentive to do something to close the gap.

DEPRESSION IN PREGNANT AND POSTPARTUM WOMEN

Kimberly Yonkers, M.D.

Associate Professor of Psychiatry, Yale University

Dr. Yonkers thanked the committee for asking her to give a presentation. Her research has traditionally focused on depression in postpartum women, but she has recently been studying perinatal depression.

There is a dearth of information on perinatal depression, which could be considered a major medical problem. Depression may also impact birth outcomes. Yale University has received support from HRSA to screen pregnant patients for depression, and also has a grant from NICHD for a field study to examine depression and its relationship to birth outcomes.

Some of the symptoms of depression include sleep disturbances, anhedonia, fatigue, loss of energy, appetite disturbances, diminished esteem, and concentration difficulties. Depression leads the causes of disability worldwide: more than anemia, falls, alcohol use, and pulmonary disease. The cost of depression in the United States is high, probably close to \$44 billion, when considering direct and indirect costs.

Depression is a common illness that frequently occurs in women. Rates of depression increase in adolescents and are higher in girls than in boys. About 21 percent of women in the United States will experience depression in their lives and it will mostly likely occur during their reproductive years. About 20 years ago, the belief was that if women had a psychiatric illness and became pregnant, the illness would be ameliorated by the hormonal changes. Data today refute this notion; pregnant women are not protected from depression.

A study published in the *British Medical Journal* (Evans et al. 2001;323[7307]:257–60) a few years ago focused on depression during pregnancy. The study was a large cohort and included the entire population of pregnant women in Bristol (England) who received a questionnaire at various times during pregnancy and then during the postpartum period. The questionnaire was considered reliable and predictable. The study documented that almost 12 percent of the women fulfilled the criteria that are consistent with a clinical syndrome such as minor or major depression. The study also found that compared with depression during pregnancy, depression decreased after the postpartum phase. Another study in Detroit found, through clinical interviews, higher rates of minor depression during the third trimester compared with the postpartum period.

Risks factors for perinatal depression include a history of depression, diminished partner support, unemployment, adverse life events, an unplanned pregnancy, and adolescence. Perinatal depression can affect the mother's functional status and quality of life. In addition, studies show that depression may worsen perinatal outcomes and has the potential to have deleterious and enduring effects on a child's cognitive and emotional development.

Data show that depression in and of itself can worsen perinatal outcomes. Steer and colleagues (*Journal of Clinical Epidemiology* 1992;45[10]:1093–9) looked at both LBW and small for gestational age (SGA) in a cohort of approximately 300 women, and found that compared with women who are not depressed, women who are depressed have a threefold to fourfold higher risk for adverse outcomes that include LBW, preterm delivery, and SGA.

Another study by Orr and colleagues (*American Journal of Epidemiology* 2002;156[9]:797–802) of African American women from Baltimore looked at the preterm premature rupture of membranes (PROM) in a cohort of approximately 1,400 women. Using the Center for Epidemiological Studies Depression Scale to screen for depression, the researchers found that for women who were in the top 10 percentile on the scale, the odds of having PROM were 96 percent higher.

In addition, there is a possibility that the illness itself, aside from the biology, could lead to less than optimal birth outcomes. For example, women who are depressed exhibit poor weight gain, they tend to enter prenatal care late, and they display a general self-neglect, especially if they are profoundly depressed. Also, in a depression the hypothalamic-pituitary axis is already primed so when the woman starts gestating, she is pushed forward and will not only deliver early but will deliver a small baby.

Possible reasons why depression may increase poor perinatal outcomes include the following:

- Depression is associated with cigarette smoking, drug abuse, and concurrent medication use.
- Depressive symptoms may lead to poor weight gain, late or delayed prenatal care, and self-neglect.
- Both depression and preterm delivery are associated with elevations in CRH.
- Both depression and preterm delivery are associated with elevated immune factors.

Unfortunately, depression in pregnant women is often not recognized and is therefore undertreated. Yale University researchers studied 400 women in Connecticut and found that 33 percent of the cases of depression had no prior mention of depression either in their medical charts or patient reports.

The study looked at some factors that increased the likelihood that somebody would be identified as having depression. Domestic violence was actually a predictor; the odds ratio for this particular factor was much higher than for anything else. This finding really speaks to the medical community as it tries to address domestic violence by actively screening for the slap/hit/kick question and then taking subsequent action.

Studies have examined treatment rates among individuals who were screened for depression. Smith and colleagues (*Psychiatric Service* 2004;55[4]:407–14) found that only 26 percent of women diagnosed with depression were ever identified by a health care practitioner for treatment. Practitioners for only 2 percent of the women with depression had addressed the disorder during a prenatal visit; practitioners for only 12 percent of those in the study who were suicidal had addressed the problem during a medical visit.

Yale University is also participating in the New Haven Healthy Start program. The goal of the program is to improve birth outcomes for “at-risk” families by using a universal risk assessment scale to identify at-risk women (women who used drugs, are depressed, or experience post-traumatic stress disorder [PTSD]). The coordinator may then call Yale’s MOMS hotline to do a psychiatric evaluation of women found to be at risk. The MOMS hotline is able to provide a mini-psychiatric assessment, examine barriers to care, and offer referrals as well as a strong followup. Doctors often visit the woman at the clinic if it is necessary. More information about the program can be found at <http://www.nhhealthystart.org>. Dr. Yonker’s group also created a manual that lists providers and is designed to be a resource for patients, matching them with their insurance providers and the languages they speak. This manual can be found at <http://www.Researchforher.com>.

As a baseline in the New Haven community, about 12 percent of women with depression had one health system visit. However, after 1 month in the program, data show more than one health system visit for about 24 percent of those patients. Some of the barriers to treatment are cost (transportation costs or a co-payment of \$10 or \$20), distance (location of service), waiting lists, no child care, unemployment, unstable housing, financial problems, and monolingual clients.

A model was created to determine who was more likely to follow up with a treatment referral; pregnant women were actually less likely to follow up than postpartum patients were.

Individuals who had already been introduced to the mental health treatment system did better because they were more likely to follow up with some sort of referral.

In summary, mood disorders peak during a woman's reproductive years. Women are not protected from an episode of depression during pregnancy. Also, depression during pregnancy may have a deleterious impact on birth outcomes, which may be mitigated through screening and treatment. It would help, in part, to decrease the stigma of the illness, to educate clinicians and patients about symptoms, and to educate the public about the impact of the illness.

Strategies to address the issue of depression include the need to optimize detection, referral, and treatment during pregnancy. It is also important to expand the pool of providers. New Haven has put forth an extensive effort to create and disseminate a list of providers, efforts that are really lacking in other geographic areas of the country. Also, finding mental health providers who can speak languages other than English is very difficult. This need is particularly difficult to meet for ethnic minorities who speak a language other than English or Spanish. Decreasing the stigma of a mental illness, including among clinicians, is also very important.

Discussion

- Joyce E. Roberts, C.N.M., Ph.D., asked Dr. Yonkers to elaborate on the treatment strategies for clinicians in primary care settings, given that now there is less time allotted to patients during visits. Dr. Yonkers responded that there is tension between having doctors provide quality treatment and getting patients out the door in a certain amount of time. Yale University has another project that administers integrated treatments along with prenatal care, which adds 30 minutes to the visit once a month. Doctors do not have to provide this service; nurses or social workers are capable of providing it. There is a great deal of resistance from the medical community to offer this service, but the cost is that people go untreated. The truth is that clinicians cannot be asked to add additional time to their visits they are not able to bill for. Obstetricians do not want to treat depression because they are not compensated for doing so. This scenario is similar to what happened with treating depression in primary care settings more than a decade ago. There was a lot of resistance in the psychiatric community to teaching primary care providers how to treat depression. However, primary care providers are doing a great job today treating depression.

Psychotherapy is also an option. Psychotherapy has actually been condensed and taught to nurse practitioners as well as to internists, and it can also be delivered in prenatal care settings. All of these options could be made available in offices and clinics of obstetrician/gynecologists and nurse practitioners in obstetric settings.

- Dr. Hayes mentioned that screening for depression does not always mean that depression will be clinically treated when it is identified. She asked whether bundling the services so clinicians could be reimbursed would create an uptake in treatment. Dr. Yonkers indicated the system in Connecticut is already bundled. However, there is an issue of who is an eligible provider. For example, to save money, Connecticut decided that psychologists are not eligible providers for Medicaid. So, patients may visit a social worker or a psychiatrist

for depression, but psychiatrists typically do not take Medicaid because of the limits on reimbursement and issues of liability.

- Dr. van Dyck asked what causes PTSD, the relative risk of PTSD compared with depression, and the differential diagnosis of PTSD from depression. Dr. Yonkers explained that the number one sequelae from a traumatic event is depression. The prevalence of PTSD is less than that for depression by about 7 percent, although women are at a higher risk of developing the disease. The symptoms of PTSD also differ from those of depression and include high startle, recurring nightmares, lack of sleep, and intrusive flashbacks. Pilot data from screenings in New Haven and Bridgeport found that the odds ratio of having a preterm delivery was threefold higher compared with the risk of having a LBW infant among persons diagnosed with PTSD during pregnancy. Dr. van Dyck asked if stress can occur outside of the pregnancy and whether it could be multifactorial rather than caused by one or two events. Dr. Yonkers replied that stressors can occur even before conception. For PTSD, the person needs to have at least one event. But people who have experienced traumas in the past are most susceptible to developing PTSD after a traumatic event.
- Robert E. Sapien, M.D., asked whether there is a quick tool that clinicians can use to screen pregnant women for depression. Dr. Yonkers mentioned that the Edinburgh Post Natal Depression Scale and the Patient Brief Health Questionnaire are available on the Web and are bilingual. The issue for pediatricians is to decide who their patient is; typically, their patient is not the mother. Perhaps it would be helpful for pediatricians to have links for obstetric and gynecology clinics to refer patients to.
- Susan Meikle, M.D., M.S.P.H., with the Agency for Healthcare Research and Quality, noted that an interagency working group—the Safe Motherhood Group—has funded an evidence report on perinatal depression. The following three questions will be addressed in a report currently under development: what is the incidence and prevalence of depression during pregnancy and the postpartum period; what is the accuracy of different screening tools for detecting depression during pregnancy and in the postpartum period; and whether prenatal screening for symptoms of depression with subsequent intervention leads to improved outcomes. This report will be completed in February 2005 and will be available to the public.

HEALTH CARE COVERAGE/FINANCING ISSUES

An Overview of Recent Trends in Health Coverage for Low-Income Children and Families

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Donna Cohen Ross

Director of Outreach, Center on Budget and Policy Priorities

Mr. Rousseau thanked the committee for the opportunity to meet with such a distinguished group of researchers. He presented a profile of uninsured children in the United States. He also

discussed the role of Medicaid and the State Children's Health Insurance Program (SCHIP) in covering low-income families.

More than 60 percent of all children in the United States are insured through their parents' employers and through other private sources; 27 percent of children are covered by Medicaid. Medicaid or other public programs cover about half of the low-income children in the United States. It is interesting to note that most uninsured children are U.S. citizens. Nearly three quarters of these children live in families with family incomes less than 200 percent below the poverty level. A higher proportion of Hispanic and Asian American children are uninsured compared with African American and White children. Sixty-seven percent of uninsured children come from families with one or more full-time workers.

Employer-sponsored coverage changed between 2000 and 2003: the number of children covered by their parent's jobs declined by 4.3 percentage points, while the number of adults with private coverage fell by 3.8 percentage points.

During that same time period, as employer-sponsored insurance coverage for children and adults declined, Medicaid and SCHIP coverage increased, particularly among children, as family incomes declined. The result was a net decline in the rate and number of uninsured children.

In contrast, the percentage of adults without health insurance coverage increased significantly between 2000 and 2003 as a result of a dramatic decrease in their job-base coverage and a significantly smaller increase in Medicaid coverage (compared with Medicaid coverage for children) mainly because Medicaid eligibility levels for parents and adults without children are lower. Adults thus accounted for all of the aggregate growth in the number of uninsured—nearly 5 million adults lost their workplace health insurance between 2000 and 2003.

For low-income children, the percentage of children covered by employer-sponsored insurance declined from 36.1 percent in 2000 to 30.9 percent in 2003. As families lost jobs and income, the Medicaid and SCHIP programs fulfilled their roles as providers of safety net coverage. The percentage of low-income children with health insurance coverage increased from 36.5 percent to 44 percent. The net result was that the rate of uninsured low-income children actually decreased from 21.9 percent in 2000 to 20.3 percent in 2003.

Since 2000, therefore, while the number of uninsured Americans increased from 39.6 million to 44.7 million, the number of uninsured children actually declined. Overall, the percentage of adults without health care coverage increased significantly between 2000 and 2003, primarily due to unemployment, and the number of children living in poverty increased by 1.5 million.

Medicaid provides comprehensive health coverage with no cost-sharing for more than 25 million low-income children—at a cost of nearly \$45 billion in 2003. SCHIP provides a more limited set of benefits with premiums and cost-sharing to roughly 4 million children who are not eligible for Medicaid. Total SCHIP spending for 2003 reached \$6 billion. Together, these programs provide a critical health care safety net to roughly 25 percent of the children in the United States, with coverage for more than half of all low-income children nationwide.

Medicaid pays for a comprehensive set of services for children, including physician and hospital visits, disease screening and treatment, well-child care, vision care, and dental services, with no cost-sharing for low-income children.

The program also finances two out of every five births in the United States, and pays for 50 percent of the hospital stays for premature and LBW infants. It is important to keep in mind that although children represent nearly half of all Medicaid enrollees, they account for only 19 percent of the Medicaid budget.

There are some differences between Medicaid and SCHIP. SCHIP is a block grant rather than an open-ended entitlement, and covers a smaller number of children. Also, SCHIP costs less than Medicaid (\$6 billion compared with \$45 billion, respectively) and provides limited coverage. Cost-sharing and premiums are permitted under SCHIP. The number of uninsured children eligible for SCHIP has increased significantly over the years. Since the enactment of SCHIP in 1998, enrollment has grown. However, after making steady progress in providing a safety net for these children, State budget deficits have led to a recent decline of enrollment in 11 States and in the District of Columbia for the first time in SCHIP's history.

The expansion of public programs combined with strong outreach efforts have had a dramatic impact on the increase in the number of eligible children and the reduction in the number of uninsured children during the last 8 years. The number of uninsured children who were not eligible for public programs fell from nearly 8 out of 12 million, or 62 percent in 1996, to only 3.8 out of 10 million, or 38 percent, in 2002. However, the estimated 3.4 million children who remained eligible but unenrolled in Medicaid, plus the 2.8 million who were uninsured but eligible for SCHIP, mean that in 2002, 6.2 million uninsured children remained eligible but unenrolled in U.S. public insurance programs.

Medicaid faces various challenges in covering low-income children. Nearly 60 percent of children who are in fair or poor health nationally are covered by Medicaid, while private health insurance covers less than 30 percent of the children who are not in good health. It is also important to note that a higher proportion of the low-income children in Medicaid have physical or cognitive impairments than do low-income children with private insurance coverage. Yet, Medicaid is able to cover the sicker population at a lower per capita cost than does private insurance, largely because of lower payment rates under Medicaid.

Nonetheless, Medicaid coverage compares favorably with private insurance on several basic access measures. Medicaid provides low-income children with a level of access to care that is comparable to and even exceeds the level of access available to low-income children with private coverage. Low-income uninsured children, on the other hand, have markedly worse access to care than those with Medicaid or private coverage.

SCHIP's budget has decreased over the years, although spending continues to grow annually. Unspent SCHIP allotment funds that expire are no longer available to States. In 2004, \$1.6 billion in unspent Federal SCHIP funds in nine States will be reverted to the U.S. Treasury while other States will have projected shortfalls by 2007.

Additionally, the White House has indicated its desire to see unspent SCHIP funds, which total around \$1 billion, used to fund a new outreach effort. This goal is laudable, but without the resources to actually pay for coverage, States will be hard pressed to finance their share of the costs associated with the increased enrollment that outreach initiatives produce. Indeed, recent reductions in outreach have occurred not because States lack funds for outreach, but rather because they do not have the resources to provide the coverage. States have actually reduced outreach as a way to control enrollment growth.

Many States have reported that Medicaid eligibility was protected last year by the Jobs and Growth Tax Reconciliation Act of 2003. This Act increased the percentage of costs that would be financed by the Federal Government. This fiscal relief from the Federal Government helped States avert or at least postpone Medicaid cuts they were considering. In addition, as a condition of receiving the fiscal relief, States were prohibited from reducing their Medicaid eligibility rolls between September 2, 2003, and June 30, 2004. Because of serious State budgetary problems, it is likely that without the additional funding and protection from that legislation, there would have been Medicaid eligibility cuts similar to those seen before the enactment of the legislation, and more may be seen in the coming year.

Maintaining coverage and stemming the increase in the number of uninsured will continue to be a challenge in the next few years. The employer-sponsored insurance market is expected to continue to erode, with fewer employers offering health insurance or offering insurance at higher premiums than low-income workers can afford.

In addition, medical spending and health care costs continue to rise. Private insurance premiums have risen by more than 59 percent since 2000, with the most recent annual increase of 11.2 percent. Finally, public resources are becoming increasingly constrained by Federal deficits, and a State budget crisis is looming. Public programs appear less well positioned to absorb any future declines in employer-sponsored coverage.

Ms. Ross spoke about trends in eligibility, enrollment, and renewal in Medicaid and SCHIP. Her organization conducted a survey that was released in October 2004, and she shared the findings throughout her presentation.

SCHIP was a very effective strategy to buffer the erosion of private health care coverage in the past few years as families lost employer-based coverage and were unable to cover their children. Three strategies that boosted enrollment in Medicaid and SCHIP included expanded eligibility requirements, simplified enrollment and renewal procedures (e.g., less paperwork required), and increased outreach.

Previous surveys found that States have made steady progress in enrolling children and parents since 1990. However, there are some signals that these trends may be reversed by new policies in the system. On the surface, income eligibility remained stable. But if one looks beneath the surface, nearly 23 States made it harder for eligible children and families to secure and retain coverage by implementing financial barriers (premiums), freezing enrollment, or reinstating procedural barriers. Most of the changes happened only in SCHIP because Medicaid is protected from some changes by law. A series of adverse effects on enrollment began to emerge.

Today, 33 States require premiums or enrollment fees for SCHIP. Some States require premiums priced at 200 percent of the Federal poverty line. Eight States have created enrollment freezes that bar eligible children from participating, which has caused serious financial hardships for low-income families. The freezes in SCHIP also affect children in Medicaid because when children lose their eligibility at a certain age, they are usually transferred to SCHIP. If the program is frozen, these children will become uninsured.

In 1999, Ohio did many things that made it easier for children to enroll in SCHIP, including expanding coverage, adopting a new (less cumbersome) family application form, and reducing verification requirements. These efforts resulted in increased enrollment. In 2003, the opposite happened in Washington State when verification requirements were increased, a 12-month eligibility was eliminated, and a 6-month renewal was instituted. These factors led to a marked decrease in enrollment. Unfortunately, an increased number of States have retracted simplifications of the procedures, which could possibly lead to a decrease in SCHIP enrollment.

Some States have experienced improvements in the past year. Illinois has expanded eligibility, increased parental coverage, reduced income verification requirements, and adopted presumptive eligibility for children. In terms of outreach, Illinois has expanded its community-based enrollment program. Enrollment has increased by 104,000 children and 73,000 parents since January of 2003.

There are two options for simplifying the procedures that might be of some interest in the future. One is the elimination of the asset test. In the Medicaid program, States can look at family income as well as assets to determine eligibility, although two decades ago States were given the option of eliminating assets from their Medicaid eligibility criteria for very young children and pregnant women. However, this option was never universally adopted by States, although it is considered a very important strategy. A cluster of States still include assets in their eligibility criteria for Medicaid.

Another underutilized strategy also considered effective is presumptive eligibility, which is an option that could be applied to children. If the information the family provides indicates that the pregnant woman or the child appears to be eligible for Medicaid, that person can be enrolled immediately and can receive care right away. There is a specific time period for completing the process while receiving the needed care. A 1991 Government Accountability Office study found that States that had dropped the asset test and had at the same time adopted presumptive eligibility also experienced the most rapid growth in enrollment of pregnant women.

Most, but not all, States use income eligibility criteria for pregnant women that are above the minimum of 133 percent of the Federal poverty line. Medicaid parental income eligibility criteria vary among the States. In half of the States, a parent from a family of three who works full time at minimum wage (earning \$893 a month) earns too much to qualify for Medicaid. In 14 States, that same parent who earns income at only half the poverty line earns too much to qualify for their State's Medicaid program. Coverage for parents is important. Research shows that when a parent is enrolled in the Medicaid program it is more likely that the eligible child will be also enrolled and will receive preventive and primary health care.

The emphasis has been on simplifying enrollment for children, and there is now a growing interest in doing the same for parents, but not nearly as much has been done for parents as for children. For example, only about 22 States have eliminated the asset test for parents compared with 45 States that have eliminated the asset test for children.

When coverage or policies are not the same for parents and their children, it is very hard to coordinate coverage for the whole family. Alabama developed a very good model when the asset test was eliminated for the parents, one simplified and uniform application for coverage that included every family member was created. Children no longer had to go through one door and the parents through another, resulting in very uncoordinated care.

In conclusion, barriers to safety net coverage are reappearing at a time when there is a need for public programs to be more accessible. Most of these obstacles are visible only in SCHIP because Medicaid is largely prohibited from imposing restrictive barriers. There is a need for ongoing State and Federal funding to support current caseloads and to expand future enrollment in SCHIP.

The Role of Medicaid in Reducing Infant Mortality

Kay A. Johnson, M.P.H., M.Ed.

Research Assistant Professor of Pediatrics, Dartmouth-Hitchcock Medical Center

Ms. Johnson presented a synthesis of the role of Medicaid in reducing infant mortality in the United States. Medicaid underwent several expansions in the 1980s. Congress focused on four strategies for Medicaid maternity reforms: eligibility, streamlined enrollment, enhanced benefits/content of care, and increased reimbursement for obstetric services. By 1994, Medicaid was the health insurance provider for more than 1.4 million infants, 68 percent of whom were from families that had a head of the household who was working.

Medicaid has special eligibility and enrollment rules for pregnant women. One of the most important provisions is presumptive eligibility, which expedites enrollment by presuming eligibility based on a simple income test. The second set of rules includes continued coverage once a woman has been granted eligibility; she is eligible for services throughout her pregnancy and 60 days after giving birth, even if her income changes slightly.

The 2001 Kaiser Women's Health Survey targeted low-income women covered by Medicaid, aged 18–64 years whose incomes were up to 200 percent of the poverty line. Seventeen percent of the women were African American, 12 percent were Latino, and 6 percent were Caucasian.

Adams and colleagues (2004) examined characteristics of women before and after welfare reform. Only 58 percent of women received some sort of public aid after welfare reform compared with 74 percent before the reforms took effect. The women no longer receiving assistance presumably became employed. Medical risks stayed relatively the same (64 percent before the reforms had no medical risks compared with 60 percent after the reforms). There were significant changes, however, in the form of insurance coverage. The percentage of women with private insurance increased from 15 to 22 percent after the reforms while the number of

women insured by Medicaid dropped from 53 to 29 percent. At the same time, the percentage of uninsured women rose from 32 to 49 percent. So about one-third to about one-half of the women who were covered by Medicaid became uninsured after welfare reform.

Family planning waivers exist in 22 States. These waivers follow different strategies. One strategy provides Medicaid coverage during the pregnancy and includes the delivery charges; after 60 days, family planning is covered for 18 or 24 months. Some States provide 18 to 24 months of family planning for any woman who had been in a Medicaid program. In California, any low-income man or woman who does not otherwise have insurance is eligible for Medicaid coverage for family planning. These approaches represent a significant expansion of services. As a result, approximately 1.4 million people in California, and an additional 500,000 people in other States, received family planning services.

Federal law requires that States have a mechanism for automatic enrollment of newborns whose mothers participate in Medicaid. In other words, if Medicaid financed the birth, the State should automatically enroll the newborn after birth. However, some States do not have the functional mechanisms to do this effectively. Also, continuous coverage is guaranteed for infants only through their first year.

The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program is a set of service requirements for Medicaid providers that deserves support. Services that States have extended to infants and children, whether or not the children were covered under a State plan for adults, include

- Case management for care coordination
- Home visits
- Prescriptions following newborn screening
- Maternal-infant therapy in cases of abuse
- High-risk newborn followup
- Physical therapy

The EPSDT services for infants can vary considerably from State to State. Data from seven States show that the average period of eligibility is very high in Tennessee compared with Florida, Illinois, Louisiana, Massachusetts, Pennsylvania, and North Carolina. However, the screening ratio in Tennessee was not as high as in other States. Also, Tennessee enrolled Medicaid infants in managed care to ensure appropriate care, in contrast to the moderate period of eligibility in Louisiana. Louisiana has a large screening ratio and a low managed care, but only a small proportion of the babies were actually referred for treatment out of those services.

The EPSDT mandates services that private insurance plans are less likely to cover, such as preventive care. EPSDT criteria require coverage for any service that will prevent, ameliorate, or cure a condition.

Under EPSDT, Medicaid providers can be hospitals, health centers, managed care organizations, and a full range of health professionals determined, however, on a State-by-State basis.

Medicaid may reimburse on a fee-for-service or on a capitated basis. Medicaid typically pays below commercial rates, even when fees have increased.

The Urban Institute examined trends in obstetric fees, and found an overall 7.5 percent increase in fees between 1993 and 1998. These increases did not keep pace with inflation in real dollar terms, and variations ranged from \$1,500 in Alaska to \$296 in New Jersey. A study that used National Maternal and Infant Health Survey data found that a 10 percent increase in fees resulted in a 1 percent increase in early prenatal care.

There have been numerous debates about the impact of Medicaid fee increases on access to maternity care and two arguments have emerged. One analysis argues that if obstetricians are paid more (or more fairly), they will be more likely to participate in the Medicaid program. The other analysis contends that although some providers say they do not participate because of inadequate reimbursement, they actually do not want patients who are minorities and who are also poor, low-income, and disorganized.

Another factor that has affected the entire health care system is managed care. Data from case studies in eight city/county areas across the country conducted between 1997 and 1998 show that when managed care was introduced, the entire health care system had to be restructured. Families, State agencies, and providers all found the enrollment process challenging and cumbersome. However, everyone blamed someone else, and no one wanted to assume responsibility for the process.

An Urban Institute study found mixed evidence about the effects of mandatory managed care enrollment on the timing, initiation, and adequacy of prenatal care. The study also found lower C-section rates, with considerable variation among States and counties; there was no impact on LBW.

Managed care organizations around the country and the Center for Health Care Strategies are currently developing quality improvement projects that focus on the business process, provider incentives, quality improvement, outreach, and content of care. The intent is to identify and generate best practices; their results have not yet been published.

To improve pregnancy outcomes, there must be reductions in financial barriers that inhibit access to prenatal care for low-income women. This solution would also reduce spending for high-risk newborn care. States with multifaceted strategies to improve Medicaid and access to maternity care were more successful in enrolling pregnant women early, providing a continuity of care, and improving the outcome of pregnancy, particularly among women with the highest risks.

However, a Massachusetts study showed that Medicaid expansions for pregnant women did not improve birth outcomes. Other studies also suggest that barriers to care continue to limit the potential impact of Medicaid prenatal expansion efforts:

- Women who became eligible only after a confirmed pregnancy test experienced delays in enrollment and in linkage to their providers.
- All areas did not ensure access to appropriate and quality care.

- Provider payments were inadequate in many States, and the regulations that required adequate reimbursement were repealed.
- The content of prenatal care generally did not conform to the recommendations (whether publicly or privately financed).
- In managed care, few States continued to emphasize psychosocial interventions, effective care coordination, presumptive eligibility, and other approaches that had demonstrated positive results.

Another important question that needs to be asked is whether the literature supports the conclusion that expanding Medicaid for prenatal/maternity care coverage has had a positive impact? Studies suggest that barriers to care continue to limit the impact of Medicaid. Women who become eligible only after a confirmed pregnancy experience delays in seeing a provider. Not all States and localities can ensure access to qualified providers, particularly for high-risk women, and inadequate payments to providers further limit access.

Despite many weaknesses in the program, the strength of Medicaid is that it provides a framework for financing and improving care and outcomes for poor and underinsured women and infants.

Discussion

- Dr. Hayes asked how to take this knowledge to a level of visibility that would attract the attention of policymakers, many of whom may be new. Ms. Johnson agreed that this could be a good opportunity to educate policymakers. She is writing a book on the history (20 years) of maternal and child health policy. This book was, in part, a result of briefing papers prepared for former President George Bush that included presumptive eligibility, so involving policymakers is very important. Mary Lou de Leon Siantz, Ph.D., R.N., F.A.A.N., agreed, and emphasized that it would also be important to target new staff members who often have access to the policymakers.
- Jennifer M. Cernoch, Ph.D., mentioned that States define medical necessity according to their needs. She asked whether Ms. Johnson had reviewed how all of the States define medical necessity and how the definition impacts health care delivery. Ms. Johnson responded that Harriet Fox and Peggy McManus have done a good deal of work on how States implement these provisions for children with special needs. However, good studies have not been carried out for infants and high-risk newborns and are sorely needed. Mr. Rousseau added that they are working with Cindy Mann at Georgetown and Andy Schneider, a Medicaid policy expert, to examine the definition of medical necessity and its impact on health care.
- Fredric D. Frigoletto, Jr., M.D., noted that one conclusion points toward an improvement in infant mortality and asked whether there is a need to be more specific and separate infant mortality from neonatal mortality rates, because they are quite different. He also indicated that increases in Medicaid costs are not always pejorative. It could also be due to the increased cost of pharmaceuticals and the use of technology. Ms. Johnson responded that the

separation of infant from neonatal mortality rates could be achieved differently. Studies have focused on LBW, but data sets exist that could enable researchers to conduct these studies in other areas.

- Dr. Hannemann asked what panel members thought the direction would be for these programs. A few years ago, the direction was to fund Medicaid with block grants, which caused a great deal of turmoil in the States. However, reimbursement issues are surfacing and there are fewer physicians in the program. Ms. Ross noted that a proposal for a block grant is anticipated soon. States recognize that the tradeoffs are mixed; some want more flexibility to fit the programs to their resources and the block grants appear to be a good option. But in the context of the ability to respond to increased needs, block grants can be seen differently. The Center on Budget and Policy Priorities is working on this issue.
- Dr. Hannemann questioned whether there is clarity in the relationship between reimbursement, the number of providers, and type of service. Ms. Ross responded that the issue of cost shifting should be brought to the surface; otherwise, there will be a tendency to make this program smaller. Part of the education program is to show that Medicaid and SCHIP work and bring additional resources to the State's health care system. Ms. Johnson added that States, rather than the Federal Government, set provider reimbursement rates.
- Dr. Ryan asked Ms. Johnson about the future of family planning waivers, perhaps the best strategy for addressing infant mortality. Ms. Johnson responded that waivers were rescinded at one point during this administration but later reinstated. This administration has approved all of the waivers so there is no reason to believe that they will not continue to be approved. However, if the program is block granted, then each State will make those decisions.

SUCCESSFUL PERINATAL OUTREACH STRATEGIES IN FRESNO COUNTY

Rebecca Carabez, Ph.D., R.N.

Director, Maternal, Child and Adolescent Health, Fresno County Department of Community Health

Dr. Carabez thanked Dr. Collins and Dr. van Dyck for the invitation. Fresno is a large county in the middle of California that is mostly agricultural, with the exception of metropolitan Fresno. Almost \$3 billion in fruits and vegetables originate from Fresno. The population of the county is diverse, about 44 percent Hispanic and 40 percent White, with a small African American population. Approximately one in three children live in poverty and 1 in 10 pregnant women are teenagers. The rate of LBW for African Americans is almost 2 1/2 times higher in Fresno than in the rest of California. The county is also known as "the other California" because it has a very diverse population and large disparities.

With no ethnic neighborhoods, Fresno has a mixed population; poverty and low-income housing are common. Therefore, outreach efforts in the county include neighborhoods and door-to-door canvassing, as well as at laundromats, in migrant camps, through block parties, and at health fairs and zoos.

Fresno's Healthy Start Program, called Babies First, provides care coordination (including perinatal education), linkages, transportation, interpretation, nutrition, breastfeeding education, child injury prevention, perinatal depression awareness, parenting education, and other services. Social workers provide transportation to medical appointments, use cell phones to schedule appointments or find a provider, and serve as translators. Because all materials for the program were branded with this name and logo, Babies First became a well-known name throughout Fresno. There were multimedia outreach efforts in Spanish, English, and Hmong. Publicity also included TV public service announcements, billboards, posters, brochures, bus advertising, and presentations in movie theaters and malls. Also, small cards were left in bathrooms of laundromats. In addition, radio interviews highlighting Babies First will be used throughout the next year to keep the message in the media.

The program also focuses on perinatal depression through an awareness campaign, as a way for mothers to be aware that if something is not right, the cause could be depression or issues related to mental health. There are also mental health clinicians in Babies First who provide home visits, so clients do not necessarily have to travel to a center to apply for eligibility, and can be referred directly to mental health providers by a clinician. Clinicians also often drive clients to their prenatal appointments and are able to treat the client in private rooms while waiting to be seen, which can often take a long time.

Many barriers were found, including transportation (because Fresno is a large and rural area), language, poverty, and lack of child care. Domestic violence and substance abuse issues are common. It was also important to find culturally appropriate images and to use correct language and meaning in the advertising and print materials. A marketing company has helped Babies First to communicate better by using focus groups. Focus groups revealed that people do not want to know about the effects of drugs, in general; they want to know how specific drugs will affect them. Similarly, they wanted to understand what is a LBW baby. This led to the creation of program materials showing images of LBW babies and information on specific substances—methamphetamines, alcohol, and smoking.

Babies First has a 24-hour hotline where clients can leave messages. The hotline is available in English, Spanish, and Hmong and the telephone number is advertised on TV and in other media. The hotline includes a menu of choices that accommodate questions and provide referrals. The menu includes domestic violence, emergency shelter, pregnancy services, finding a doctor, applying for accessing medical exams and immunizations, breastfeeding information, drug and alcohol support services, family planning, and WIC.

Outreach is a big part of the Babies First program. Outreach workers sweep through Babies First project areas: first through the English-speaking areas, then the Spanish-speaking areas, and finally the Hmong areas. The strategy is one of saturation, because the outreach workers return to the same areas, ensuring that they always maintain a presence. Outreach workers will also use cell phones to make appointments for clients, transport the client if necessary, and help with translation. The goal is to create an environment where clients will have access to whatever care and services they need.

The outreach happens first, then people are put on a list for care coordination, a determination is made as to whether or not they are high risk (e.g., teenager or a substance-abusing mom), and then they are enrolled in a nurse family partnership program. There is also a separate component for care coordination that includes linkages to pregnancy-related services, transportation, translation services, perinatal and nutrition education, and antepartum, postpartum, well woman, and infant care.

There is also breastfeeding outreach and assistance by First Five, the Children and Families Commission. These are all of the areas they have been charged to address. Healthy Maternal, Child, and Adolescent Care also addresses child injury prevention including car safety, awareness of perinatal depression, substance abuse, tobacco education, and domestic violence.

The program also includes a complete domestic violence education and prevention component. Many clients report domestic violence in concert with substance abuse issues.

Babies First reached more than 100,000 people through street outreach, health fairs, neighborhood block parties, the Moms & Kids Hotline, and media advertising. Infant mortality rates have dropped from 11 percent in 1996 to 4 percent in 2001.

Discussion

- Dr. Hayes wanted information about changes in the infant mortality rate for African Americans, especially for the 1997–2001 period. Dr. Carabez responded that these data are available, and although there was a small decrease, the rate is still high.
- Dr. Ryan noted that the data did not include out-of-county births to residents and asked how these data would affect infant mortality. Dr. Carabez responded that there is a Children's Hospital located 5 miles north of Fresno, and because there are few rural hospitals in Fresno, some women from Fresno will have their babies in Madera County. Dr. Sapien added that women out of the county will have their deliveries in Madera, but tertiary care is available in Fresno.
- Dr. Collins mentioned a surge in infant mortality in 1992 in the county, and asked Dr. Carabez what had caused this increase. She explained that there is only speculation, that this surge occurred very close to when crack cocaine use peaked in the area, but there is no clear explanation.
- Dr. Frigoletto asked whether any demographic characteristics indicate a difference between Hispanics and African Americans, because these two groups are of a similar economic status. Dr. Carabez talked about recent arrivals, such as the Hmong community that arrived in the 1990s. New arrivals in the Hmong community include about 2,000 people, most of them younger than 25 years of age. In Hmong culture, it is common to see young mothers (sometimes 12 years old) who are married and starting a family. For this reason, researchers are examining the age of the mother, family constitutions, and support, and are currently dissecting the data.

- Dr. Cernoch asked whether there is an explanation for the peak in 1992 and again in 2000 (rate by ethnicity) in infant mortality among African Americans. Dr. Carabez suggested that it was the year Children's Hospital shifted and access was different at that time, and it was probably related to access.
- Ms. Barnes added that fear of the U.S. Immigration and Naturalization Service and other Government programs is a barrier. In her area of Tidewater, Virginia, one of the key factors for the success of an outreach program was using outreach workers from the same neighborhoods, which increased trust in the workers and produced good results. She asked whether Dr. Carabez had attempted to match the outreach workers with the population. Dr. Carabez responded that they do that and it is essential for the workers to know the area, people, and language. Ms. Barnes added that it is not only the language but also the idioms that make a big difference with the targeted population. Dr. Carabez agreed and noted that in Fresno, there are more than 100 different languages spoken.
- Dr. Ryan wanted information about general patterns for causes of infant mortality. Dr. Carabez indicated that they are part of an eight-county group that will use the Perinatal Periods of Risk approach to answer these questions.
- Ms. Ryan noted that the program did well in matching translators to ethnic groups, and she asked whether they had examined cultural/racial differences in various health care needs. Dr. Carabez answered that a recent focus group on breastfeeding found that the most influential person for making this happen was the male head of a Hmong clan; once he was convinced that breastfeeding would be good for the community, other Hmong women participated in focus groups and he appeared in radio programs supporting breastfeeding.
- Dr. Frigoletto asked Dr. Collins whether his presentation earlier today suggested that the common denominator for the rate of decline is medical intervention. Dr. Collins agreed. Dr. Frigoletto credited neonatologists, the Neonatal Intensive Care Units, and the obstetrical input for contributing to the rate of decline.
- Dr. Hayes suggested that it is important to think about financing other determinants of health outside of the technical and medical components that could also be useful in solving the problem. In the current environment as we assess content of care for pregnancy, one needs to examine those interventions that currently are not billable—and determine whether they make a difference in outcome. She added that it is important to consider financing successful strategies that have been identified through Healthy Start in the '80s. These strategies may have more to do with the nonmedical component.
- Dr. Ryan agreed with comments from Dr. Frigoletto and Dr. Hayes about major determinants of birth outcomes that are not related to the medical component. However, he noted that the quality of medical care provided to different ethnic and racial groups is not equal, although it is not a well-explored subject, but there certainly is evidence to support this disparity with respect to access. There is room for improvement in this area. Dr. Hayes agreed that it is important to substantially improve the quality of care for populations of color.

FRIDAY, NOVEMBER 12, 2004

HRSA Overview and Update

Stephen Smith

Senior Advisor, HRSA

Mr. Smith's presentation focused on current HRSA activities and priorities. HRSA's mission is to provide national leadership, program resources, and services needed to improve access to culturally competent, quality health care. HRSA's work is primarily with uninsured, underserved, and special needs populations.

HRSA's seven strategic goals are to:

- Improve Access to Health Care
- Improve Health Outcomes
- Improve the Quality of Health Care
- Eliminate Health Disparities
- Improve the Public Health and Health Care Systems
- Improve the Ability of the Health Care System To Respond to Public Health Emergencies
- Achieve Excellence in Management

HRSA has 80 different programs funded by the Congress. The Agency's budget is \$7 billion for all programs. HRSA sponsors 3,650 community health centers around the country serving 13.2 million people. The Agency also provides \$1.7 billion in grants to these centers. The Ryan White CARE Act was created to serve 530,000 low-income people with HIV/AIDS. It provides patients with medical care, medications, and social services. HRSA has given over \$2 billion in grants to 600 organizations through this program. HRSA is working to eliminate the waiting list for patients to receive the necessary AIDS drugs and has moved funds to eliminate these waiting lists in 10 States so far. HRSA also works in international AIDS relief in 15 countries, mostly sub-Saharan Africa, the Caribbean, and Vietnam.

HRSA's Maternal and Child Health Bureau (MCHB) programs focus on reducing infant mortality, immunizing infants, and preventing adolescent pregnancies. Through these programs, HRSA provides services to 27 million pregnant women, infants, and children in the United States, with a total funding of over \$1 billion.

HRSA has about 40 Health Professions Education and Training programs that are directed toward academic institutions and help train physicians, nurses, and other health care providers. These programs help boost the number of minorities who enter the health professions and place health care professionals in underserved areas. HRSA's Rural Health Care programs help to improve access and build the availability of services in rural areas. Technical assistance to small rural hospitals is also provided through this program. HRSA also has a Bureau that focuses on health care systems and includes programs that match organ donors to recipients, aid in health

care facility construction, support hospital preparedness, and provide vaccine injury compensation.

HRSA has been working on some new initiatives. These include health care expansion services that help to build infrastructures for clinics and health care services to improve communities' access to care. This is a 5-year effort to increase the numbers of centers across the country from 3,200 to 4,400 (1,200 new centers). This will increase the number of people served from 10 million to 16 million.

HRSA also has a program that trains ready responders for 4 weeks out of the year for disaster preparedness. These responders include professionals in many areas such as psychiatrists, physicians, dentists, and nurses. During the year, they are placed in hard-to-serve areas around the country. They have been recently deployed to Florida due to hurricane-related issues.

The Agency also has a Stop Bullying Campaign, which focuses on children ages 9 to 14 years who experience bullying inside or outside the school environment. This program was launched with Dr. Carmona and also the former Ms. America. The Agency has created a Web site with educational materials for children, adolescents, parents, educators, and other community leaders to help deal with the issues of bullying.

In addition, HRSA has taken the lead in providing services across the U.S./Mexico border, which is 2,000 miles long and serves 11 million people. This area has some of the worst health statistics in the country. Through an international U.S./Mexico commission, HRSA has created a binational health week that supports 200 events throughout the border in 14 cities both in the United States and Mexico. Events have included health fairs, research policy forums, public walks, immunizations, outreach efforts, etc. These programs are very important because communicable diseases travel easily across this very porous border.

Discussion

- Dr. Guyer asked how this committee and HRSA's programs communicate, namely how committee discussions are translated into HRSA programs. Mr. Smith responded that the programs are molded by informed research and evidence-based practice. Also, the health disparities collaborative helps move the latest evidence in treatment into practice. In a new pilot for a perinatal collaborative, various bureaus are working together to help technical experts identify the best methodologies to be tested in the community health centers, with eventual spread to the Community Health Center program. HRSA has less direct influence on hospital settings, but makes the best possible use of information that the committee puts forward.
- Dr. Hayes wanted to know more about HRSA's strategic planning on infant mortality contextual issues, and how HRSA works with the Centers for Disease Control and Prevention (CDC) to improve the environments and contextual issues that pregnant women face and to implement some committee recommendations. Mr. Smith responded that he was not aware of many examples of working with CDC in this area. HRSA has worked with CDC in other areas such as, for example, the flu vaccine issue and hospital preparedness program. Dr. van

Dyck added that a relatively new CDC interface will examine infant mortality, contextual, and neighborhood issues in four States. CDC also is conducting a sister initiative in other States as well. These two initiatives are interrelated but not overlapping. HRSA and CDC also work together on the Interagency Low Birth Weight Committee and have jointly participated in the Closing the Gap initiative. Mr. Smith mentioned that HRSA is very open to working with CDC and open to recommendations from the committee on areas where the two organizations could have a close partnership.

MCHB UPDATE

Peter van Dyck, M.D., M.P.H.

Associate Administrator for Maternal and Child Health, HRSA

Dr. van Dyck spoke about newborn screening. Each year, 4 million U.S. infants are screened to detect conditions that threaten their lives and long-term health. Because screening is a program mandated by State laws and administered by the States, programs vary from State to State. The Federal role is facilitative and collaborative with States. In the summer of 2004, the Secretary established an Advisory Committee staffed by MCHB personnel; the SACIM representative is Dr. Collins.

Newborn screening is not just screening for three conditions (PKU, galactosemia, and hypothyroidism), the way it used to be. Technology has grown rapidly and States screen from 3 to more than 40 conditions. However, because States screen for different conditions, some children are not screened for treatable conditions.

In 2002, only 5 percent of States screened for more than 20 conditions. Data from September 2004 indicate that more than 27 percent of U.S. births are covered by States that screen for more than 20 conditions, which is a significant improvement. Once New York and California begin to screen for more than 20 conditions, well over 50 percent (perhaps up to 70 percent) of all U.S. births will be screened for more than 30 conditions.

To address these disparities, MCHB is developing a set of national guidelines for screening newborns. Screening should go beyond providing only results. It should include followup and access to diagnosis and treatment, lifelong health management, and evaluations of quality assurance and cost effectiveness.

To help ease inequities among States and to facilitate the regionalization of newborn screening, MCHB has commissioned a report from the American College of Medical Genetics to recommend specific conditions that all States should include. The criteria for including a test in the uniform State screening panel include: (1) diseases/conditions that are identifiable in the first 48 hours of life, that have a known basic natural history, and that are treatable; and (2) tests with documented reliability, appropriate sensitivity, and specificity. MCHB's goal for the guidelines and policies is to provide expert assistance, such as decisionmaking tools for evaluating new tests as they appear in the medical literature; minimum uniform standards (including standardized testing nomenclature) and related policies and procedures; appropriate health outcomes for evaluation protocols; treatment protocols that include rare disorders; and a national

program to evaluate quality assurance, oversight controls, and centralized data collection and analysis with effective and appropriate privacy and confidentiality protections.

Dr. van Dyck then summarized underlying principles for these guidelines. Universal newborn screening is an essential public health responsibility that is critical to improving health outcomes of affected children. To ensure the best interests of affected newborns, policies and services should integrate a continuum of care that includes families, health professionals, and the public. The medical home and public and private components of the screening program should be in close communication to ensure an identifiable source of care for all affected infants. Evaluations and recommendations for what conditions to screen for should be predicated on scientific evidence and expert opinions. Public awareness, professional training, and family education are important program responsibilities. Dr. van Dyck concluded by referring participants to the National Newborn Screening and Genetics Resource Center's Web site (<http://genes-r-us.uthscsa.edu>) for more information.

Discussion

- Noting that the Federal Government does not have the authority to enact mandatory procedures for the States to adhere to, Dr. Hayes asked if Dr. van Dyck envisions Federal legislation that would provide financial support to States for more uniform screening throughout the country. Dr. van Dyck responded that he hopes the goal of establishing a common panel will be reached within 5 years. State participation would have to be voluntary. In 2004, HRSA received \$2 million earmarked for establishing some of the recommendations for newborn screening. The money went to seven regional centers across the United States in the form of grants to set up referral centers, facilitate the flow of tests, identify experts to treat medical conditions, and create educational campaigns. Each State points to one of these regional centers. Another \$2 million request is in HRSA's 2005 budget. There is a great deal of bipartisan support for and recognition of this important issue.
- The additional costs of a mass spectrometry machine for multiple tests are not very high. Tests may increase from approximately \$50 to \$100, but most of the expenses are covered by private insurance carriers or by Medicaid. Currently, MCHB is calculating the States' liability for followup and for testing for more conditions. Followup would be an additional albeit modest burden. The costs of treatment without screening are high; many of these infants come into the emergency room with unknown conditions and diseases in a crisis state that run up treatment costs. Early intervention costs considerably less, so comprehensive screening will actually save money. MCHB is currently conducting cost-benefit analyses on this topic.
- Dr. Ryan asked if identifying best diagnostic and followup practices would help States. He also asked Dr. van Dyck to discuss cystic fibrosis screening. Dr. van Dyck remarked that there has been some discussion of cystic fibrosis, but no determination has been made about whether to add it to the panel's agenda. About 9 or 10 States currently screen for this condition and expanding the screening may be a practical decision. MCHB is taking a careful look at that possibility. Dr. Collins reminded everyone that there is no cure for cystic fibrosis. However, it may take years for families to receive an accurate diagnosis, and they

may have another child before this happens. So, there is a family planning impact and an economic impact from the resources a family needs to seek a diagnosis. Dr. Collins added that some rare diseases might not significantly impact infant mortality, but they do impact the system as a whole in terms of costs and burdens on individuals and families.

PERFORMANCE MANAGEMENT IN TITLE V

Stephen E. Saunders, M.D., M.P.H.

Associate Director, Office of Family Health, Illinois Department of Human Services

Dr. Saunders noted that Illinois has 12.4 million people, approximately two-thirds of the population lives near Chicago, and the rest of the State is largely rural. Illinois has an extensive local health department system throughout the State. Of the 180,000 annual live births in the State, 44 percent are covered by Medicaid. Illinois is trying to build on MCHB's performance model, as well as integrate various funding streams. Dr. Saunders indicated he would focus on the following title V performance measures: immunizations, first trimester enrollment for services, initiation of breastfeeding, VLBW, and infant mortality.

There are two statewide maternal and child health care programs in Illinois that provide services to low-income pregnant women and infants: the WIC program and the Family Case Management (FCM). The State also has a sophisticated management data information system (MIS) called Cornerstone. This paperless system provides information on a daily basis about women who enroll in Medicaid, enhances the provision of services, measures performance, and tracks outcomes.

WIC and FCM programs serve about 40 percent of all the live births in Illinois and about 85 percent of all Medicaid births in the State. These programs identify and locate women in need of services, assess their needs, and create an individualized care program for each person. WIC and FCM have lower VLBW rates compared with women who are not in either program, and the goal is to enroll all eligible women into one of these programs. Overall, women who participate in WIC and/or FCM have significantly lower health care expenditures compared with nonparticipants.

Approximately 6 years ago, WIC, FCM, and numerous other programs served the same populations separately and independently with little or no coordination. The Illinois Department of Human Services decided to integrate WIC and FCM into a statewide model and set a target date. Using maps to monitor full, partial, and no integration of services across the State, the Department laid out clear goals and strategies, provided technical assistance to regional staff and mentors to local staff, and monitored and reported the progress of local agencies on a quarterly basis.

The MIS also provided a series of progress reports for the State's immunization initiative. The strategy was to improve statewide immunization rates by focusing on children aged 2 years enrolled in WIC. An immunization report was created to rank performances and was distributed on a quarterly basis to all WIC grantees; grantees who ranked at the top would have fewer site visits. This performance-based approach facilitated a positive competitive spirit, and the State

went from a 70 percent immunization rate in September 2001 to almost 90 percent in June 2004 in the WIC population.

Reports that ranked performance contributed to statewide improvements in service delivery by enabling the Department to target technical assistance to poor performers. However, to balance numerous reports with the need to preserve efficient and effective data analysis, the Department integrated a composite of the indicators to be measured into an overall ranking report (there were about 12 indicators). In addition to the ongoing mentoring of local staff by regional personnel, the general ranking report is sent to all agencies on a quarterly basis. This process has helped to sustain improvements in VLBW, infant mortality, and overall infant health outcomes and expenditures. The VLBW rates for women receiving Medicaid who were enrolled in the WIC/MCH programs were 1.5–1.75 percent, compared with 3-4 percent for Medicaid recipients outside of Illinois' system. The overall VLBW rate for Medicaid recipients in Illinois is decreasing, which points to the benefits of including low-income, high-risk women in programs that provide comprehensive and integrated medical and social services (e.g., WIC, public health nurses, nutritionists, etc.).

Researchers recently analyzed selection and prematurity biases in the Illinois programs and specifically controlled for medical, demographic, and socioeconomic confounding factors. The findings were presented at CDC's Tenth Annual Maternal and Child Health Epidemiology Conference on December 8–10, 2004, in Atlanta, Georgia.

Since 1991, Illinois has seen a significant decrease in infant mortality rates: from 10.5 per 1,000 births in 1991 to approximately 7 per 1,000 births in 2002. In 1980, Illinois ranked 47th when compared with other States. In 2002, the State ranked 30th, with comparable infant mortality rates to other States of a similar size, such as Florida, Michigan, Ohio, and Pennsylvania.

Dr. Saunders pointed out that most grantees want to do a good job but may not know how to judge their performance. He noted that performance measures and monitoring, periodic informative feedback, onsite technical assistance and mentoring, and rewards and incentives can advance an environment of healthy competition that results in positive change by shifting the focus from process to outcomes (such as immunizing more children and treating more women early during their pregnancies). Other positive strategies include MIS programming, ongoing data quality assurance strategies, and bringing Federal initiatives into statewide programs.

Discussion

- Dr. Hayes noted that the data in the quarterly reports are current but infant mortality data from around the country are not. There is a lag, and the current infant mortality rate at any given time is unknown; the data need to be current. Dr. Saunders agreed that the data are old. It is interesting to note that data from the west and south sides of Chicago show that a big contribution to infant mortality in this population of women is preterm birth. Women who have had one preterm birth are more likely to have a future preterm birth. The problem is that these women frequently get lost in the system so when they become pregnant again, they have another preterm birth. The Closing the Gap project will focus on longer followup after a preterm birth or a medical complication.

- Dr. Moore was interested in the low rates for prenatal care in the first trimester. Based on her experience, these rates reflect whether or not a pregnancy is desired (“wantedness”). A woman who wants the child will usually come in early for prenatal care. Dr. Moore asked if there ever is any attempt to partner with crisis pregnancy services. Dr. Saunders responded that Pregnancy Risk Assessment Monitoring System data show that the rate for unintended/mistimed pregnancies for women receiving Medicaid is about 65 percent. So, it is a big problem, and these women may not obtain care as early as they should.
- Dr. Frigoletto remarked that this presentation is a clear example of the importance of information technology and quality assurance. Dr. Saunders agreed that the results could not happen without the information systems in place; there needs to be real-time data. The data are tied to reimbursements—to be reimbursed for WIC expenditures, grantees must submit the necessary data.
- Dr. Ryan added that in North Carolina, some of the more serious problems occur when systems are inadequate and do not provide up-to-date information. It is very difficult to hold people accountable if an agency is using 2-year-old data. He asked if Dr. Saunders’ group had considered converting FCM to fee-for-service, whether the FCM program was interested in the content of the interaction between the family care coordinator and the client, and whether the care coordinator or the system decides the content of that encounter. Dr. Saunders responded that some guidelines exist that coordinators need to follow with their clients. The care plan is in the information system that was mentioned (MIS). The role of the nursing staff is to review and assess the care plan in the context of the needs of the client, and to determine whether they match. FCM is based on a Medicaid administrative claim (50 percent), so there is no advantage to make a change. In addition, the administrative claim restricts providers to health departments rather than being open to all parties. Local agencies can also claim their costs for MCH services.
- Dr. Guyer found it interesting that Illinois did not have an immunization campaign, which is often unsuccessful, but used a systems approach. He asked what data grantees receive through the report and what grantees do with the information. Dr. Saunders responded that the data are broken down by individual clinics. Grantees have found it helpful to access the system to obtain a report on children who are not current in their immunizations.
- Dr. Guyer then asked what differentiates the people at the bottom of the list and what they are doing differently. Dr. Saunders answered that this is hard to determine. It is more a question of systems at the clinic level. For example, if the clinic offers immunization shots when women come for WIC services, they have a higher participation rate than if the patients have to come back the next day. Some agencies will use a negative incentive by giving clients only 1 month of WIC coupons at a time instead of a 3-month supply, which brings clients into the clinic more frequently and creates more opportunities for treatments. So, it is a question of process and incentives on a clinic-by-clinic basis.

- Dr. Hayes highlighted that the State did not have an immunization campaign but still obtained good results. Perhaps money allocated for campaigns could be used to build better MIS infrastructures that will be more effective in the future.
- Dr. Collins asked how much effort is involved in optimizing the system so one gets timely vital records and whether this is in the foreseeable future. Dr. Saunders responded that the Department of Public Health administers vital records but many issues appear to be related to resources, such as staff capacity and the time it takes to obtain records on relevant events that occur across State lines.
- Dr. Ryan added that in typical rural counties, year-specific infant mortality is not useful because the numbers are small. However, proxies such as LBW can be obtained much quicker.

GEOGRAPHICAL DIFFERENCES: NEIGHBORHOOD STUDIES

Patricia O'Campo, Ph.D.

Professor, University of Toronto

Dr. O'Campo described a project funded by MCHB, "Advances in Statistical Analysis Applied to Health Disparities." The object of this study is to form a university/health department partnership to examine racial disparities using multilevel analyses. This is a collaboration of eight sites in Maryland, Michigan, North Carolina, and Pennsylvania.

Dr. O'Campo presented a quick review of multilevel modeling. At the individual level, studies may examine demographics, health behaviors, socioeconomic status, and other factors that determine health status. At the multilevel model (hierarchical or contextual), researchers can study other factors such as neighborhoods, workplaces, health care settings, etc. These factors are contextual but are also directly or indirectly related to health outcomes. Together, these factors constitute a multilevel model.

The idea of including communities and neighborhoods as variables in public health studies is not new. However, recent methodological and statistical advances have created the adoption of contextual models in public health, particularly linking multilevel methods to interventions and policies. Every year, an increasing number of multilevel models focusing on neighborhoods are presented in the literature, and this trend is expected to continue.

This study focused on a policy-relevant, multilevel, analytical model to understand contextual aspects of health disparities among mothers and children. Other separate goals were to: (1) disseminate findings to a wide audience of researchers and practitioners, and (2) identify and address State health department training needs to increase their capacity to undertake similar policy-relevant research. In October 2002, an initial meeting was held to put in place a foundation for the preliminary work. The team received Institutional Review Board clearance for all of the study sites, which was easy in some States and more difficult in others. At this initial meeting, members also discussed the unit of analysis and decided to use Census tracts to obtain the appropriate data. One of the first activities of the team was to create the Neighborhood Deprivation Index (NDI). A higher score in this index represents more

deprivation and lower income. Subsequently, the research focused on creating a multilevel model for the first outcome, Disparities in Preterm Birth.

Dr. O'Campo summarized key points and limitations of four studies focusing on multilevel modeling and preterm birth. Three studies with small sample sizes had limited abilities to examine outcomes such as very preterm birth. One study on income (Pickett et al. *Annals of Epidemiology* 2002;12[6]:410–8) found different models for African American and White women; another (Ahern et al. *Journal of Epidemiology and Community Health* 2003;57[8]:606–11) examined how context indirectly influences preterm birth and outcomes, and the third (Kaufman et al. *Annals of Epidemiology* 2003;13[5]:377–84) examined how income and other socioeconomic characteristics reduce the risk of preterm birth. A large study in Canada (Luo et al. *Epidemiology* 2004;15[6]:679–86) demonstrated class disparities between the highest and lowest income quintiles of preterm birth data. Generally, these studies lack geographic diversity; they examine a narrow set of neighborhood characteristics and lack a solid theoretical link between the choices of neighborhood traits and outcomes; and there is no consensus on how to model neighborhood characteristics. In addition to using a mix of methods, the literature is split on whether to use individual variables at the contextual level or condense them into an index. Similarly, a recent summary of 32 MCH multilevel studies of residential neighborhoods found that most studies identified a theory that informed their work; few provided a rationale for their choice and operationalization of neighborhood variables; and most are mixed for the use of indices versus single variables as neighborhood characteristics. Consequently, results are equivocal for many outcomes despite a handful of studies for each outcome.

From a methodological standpoint, the goal of the study was to assess the association of area level effect on preterm outcomes using 2000 Census data. The following seven socioeconomic domains of theoretical and empirical interest were identified: poverty, housing, employment, occupation, worker class, education, and racial heterogeneity. Also, 13 theoretically relevant Census variables crudely associated with preterm birth were identified. The large correlations between the Census variables prevented the study from producing separate indices for specific domains. Through the NDI, the data showed that, in general, Michigan was the most deprived area followed by Baltimore, Maryland, and Philadelphia, Pennsylvania. The least deprived area was Montgomery County, Maryland.

The whole data sample was divided into quartiles, and the researchers examined how the quartiles were related to preterm birth. The expectation was that the most deprived quartiles would have higher rates of preterm births, which was generally correct. The data were also stratified by race (White non-Hispanic and Black non-Hispanic). There was a similar pattern for Black non-Hispanics, with some exceptions. These data were very helpful in informing the next research questions, as follows:

- What is the relationship between neighborhood deprivation and preterm birth by maternal race?
- Does the relationship between neighborhood deprivation and preterm birth remain after controlling for selected individual level characteristics?
- Does the relationship vary by geographic setting?

It is important to note that the Census data and the data for the number of births were for slightly different years because of the availability of data at each site as well as questions attributable to data quality. The team was confident that these small differences would not significantly affect results and the decision was made to proceed. The individual level data (preterm births, maternal age, and maternal education) came from birth records. Neighborhood level data from the 2000 Census focused on the NDI.

When these data were graphed, the results consistently showed that there was a higher preterm birth rate for African Americans than for Whites in all cities. There was a difference in the distribution of maternal age and education across sites. In Montgomery County, for example, there were fewer births to younger women when compared with Michigan or Baltimore. In all areas, as deprivation increased so did the risk for preterm birth. This pattern was similar after adjustments for age and education. In conclusion, the study found that

- As neighborhood deprivation increases, the risk of preterm birth increases for both White and Black non-Hispanic women, but the effect is modest.
- The effect of neighborhood deprivation on the risk of preterm birth appears greater for White non-Hispanic compared with Black non-Hispanic women. However, the hypothesis was that race is a proxy for other differences.
- Despite the observed variation by geographic area, the overall effect of neighborhood deprivation was similar across sites.
- Stratification by “high” and “low” levels of neighborhood deprivation did not explain differential effects by race. However, these analyses were conducted on an exploratory basis.

Dr. O’Campo indicated that a quadratic model did not work well. The next steps for her group include further investigations of stratification issues (perhaps using different cutoffs or analyses), joint race and class disparities, other policy-relevant analyses (such as examining teenagers and other neighborhood factors that might be of interest), resilience within poor neighborhoods, and modeling other outcomes such as small for gestational age and birth weight. Finally, Dr. O’Campo emphasized the need to consider training issues to increase the capability of every State to conduct these types of analyses.

Discussion

- Dr. Guyer asked if the mean in the index represents all Census tracts in that area. Dr. O’Campo responded that this would be the case, and zero is the mean for all data pooled together. Dr. Guyer asked for an estimate of how many Census tracts are represented in the sites. Dr. O’Campo noted that it would be in the hundreds. For example, Baltimore has about 200 Census tracts.
- Dr. Collins asked whether the difference in data between African Americans and Whites was due to the length of time a person was living in a deprived neighborhood. He wondered whether there was some measure of length of exposure to a deprived community for each of these races and how this exposure might affect preterm birth. Dr. O’Campo responded that this was a good point. It is difficult to know how long people have been exposed to a

deprived neighborhood. It also is difficult to obtain this information from Census data even when migration is included because the data do not identify what kinds of neighborhoods the people came from and how deprived those neighborhoods were.

- Dr. Hayes asked if the team had given any thought as to how the data could be used to develop policy implications, especially for intervention and action. Dr. O'Campo responded that poverty and deprivation clearly matter. Analyses in the immediate future will help determine whether teenagers show the same pattern as adults. The data examined thus far will probably not help address specific policy issues. Dr. O'Campo reiterated that her State partners recently had indicated that splitting the NDI into separate domains would provide more policy-relevant information about housing, employment, occupation, worker class, education, racial heterogeneity, etc.
- Dr. Ryan asked how the NDI was created (with weights applied), and how social support and networks might affect the analysis. Dr. O'Campo answered that in developing the NDI they took all 13 variables and did factor analyses that weighted the index. Based on preliminary discussions, the research group considered ways to proxy data to capture social interactions and social cohesion, perhaps by examining the number of community groups in each neighborhood.
- Dr. Hannemann asked whether income alone in neighborhoods was a strong enough predictor of risk. Dr. O'Campo responded that the study depended on vital and Census data that are collected only every 10 years and have limited information about neighborhoods, each woman's family, where she receives care, etc. However, in theory, data that have rich contextual as well as individual information could provide answers to precise questions. She added that if it was possible to link vital records to other data (such as WIC data), the results could get much closer to program- and policy-relevant comments, especially if restrictions and barriers at the system level (such as confidentiality issues) could be addressed.
- Dr. Guyer asked what was learned about the magnitude of effect and how did it compare with the individual level analysis. Dr. O'Campo noted that a population-attributable risk analysis would be needed to answer that question, and her group had not conducted one. In the future, her team plans to examine cross-level interactions such as how context may modify the ways in which individual characteristics are associated with outcomes, as in the relationship between early prenatal care initiation and LBW. Dr. Bronner asked whether their data would allow these analyses. Dr. O'Campo indicated that they would, and added that her team will be working closely with their State partners to determine which analyses are more relevant to policy.

COMMITTEE BUSINESS/SETTING THE AGENDA FOR THE FUTURE

After commenting on and raising questions about the expert presentations, the committee addressed a set of proposed recommendations for research on LBW.

- Dr. Hannemann noted that SACIM's concern about LBW originated 3 or 4 years ago when LBW and infant morbidity rates were rising, and this committee chose to focus on how to ameliorate the situation. The original report was sent to Secretary Thompson in June 2002. The major recommendation in that report, which was accepted, was the formation of an interagency workgroup to examine the research and make recommendations to the Secretary for an HHS research agenda on preterm birth and LBW. The workgroup would evaluate the findings and share their recommendations with SACIM.

Working jointly with the interagency workgroup, SACIM prioritized these recommendations. To assist preparation of the report to be submitted to the Secretary, Dr. Hannemann asked participants to review the current list of research priorities for any important issues that might be missing, and then to readopt the list. He urged that the report be submitted to the current Secretary before he leaves office. Dr. Hannemann also emphasized the importance of releasing this information as soon as possible for publication, for example, as an article in the *New England Journal of Medicine* or another similar publication.

- Dr. Frigoletto raised concerns about the recommendation under "Preterm Birth: Research Topics" that reads: "Speed the initiation of studies of 17-alpha-hydroxyprogesterone for possible reduction in risk of preterm labor for women with twin or triplet pregnancy or cervical shortening." CDC and the March of Dimes had sponsored a 1-day conference in Atlanta to review the progesterone issues and its possible impact on reducing preterm births. It became evident during that conference that perspectives on the recent research are not as one-sided as the above recommendation suggests; significant questions have yet to be answered. Dr. Frigoletto suggested revising the wording from "speed" to "energetically continue studies of 17-alpha-hydroxyprogesterone for possible reduction in risk of preterm labor for women including those with twin or triplet pregnancy or cervical shortening." This modification would include all women and not only those with twins or triplets, and could be combined with the other bulleted text, which reads "Work with the FDA and industry to hasten the process of getting 17-alpha-hydroxyprogesterone to market and using it in practice for women with a prior preterm delivery."
- Dr. Frigoletto also mentioned that he had suggested including more specific text than what now reads: "Assess and improve measures/surveillance methods for monitoring trends in preterm delivery risk." As he recalled, the committee suggested including more specific language on information management and information technology. He added that the current text does not actually reflect the recommendation of the committee. He called for more robust language, such as: "A robust information management and information technology system is needed to assist in obtaining data both for surveillance and analysis." The committee made the point that clinical records are grossly inadequate. Ms. Ryan added that Dr. Frigoletto's original comments are reflected on page 61 of the previous minutes, where

he called for “more accurate methods of collecting clinical data, namely the use of electronic standardized medical obstetrical records.”

- Dr. Hayes indicated the need to pass these recommendations on to the new IOM committee on premature births and assuring healthy outcomes. Items on this list should inform other committees that are discussing the same topics; it is important for those committees to have this information. Dr. Hayes also asked if the committee plans to meet with the HHS Secretary to discuss some of these issues. Dr. Collins noted that the main method of communication with the Secretary is through published or written documents. Dr. van Dyck added that if the report is significant, as the LBW report was that was published a few years ago, a small delegation of the committee is tasked to deliver the report to the Secretary. These opportunities arise when the committee has important information to deliver.
- Dr. Hannemann asked about the next steps to prepare these recommendations as a polished report to be sent to the Secretary. Dr. van Dyck responded that this priority-setting document would go back to the interagency task force. It would then be combined with the larger inventory that lists all of the research being conducted. The interagency committee would integrate both documents and submit the new version to the Secretary. Dr. Hannemann asked how long this would take. Dr. van Dyck projected a February 2005 date, and suggested that it would be appropriate for SACIM to send a letter supporting the work and describing the history. Dr. Hannemann asked if this document would be available for publication elsewhere, and Dr. van Dyck replied that after it is presented to and accepted by the Department, the information may be shared outside of the Agency.
- Dr. Miller made a motion to endorse this document and some amendments were raised and discussed. The committee voted unanimously to approve the motion. Dr. Hannemann suggested that he and Dr. Frigoletto would rewrite the amendments for the document, and Dr. Collins expressed his approval.

Noting that the next committee meeting will be held on March 1–2, 2005, Dr. Collins asked committee members to identify ideas for future meetings and agenda items.

- Dr. Guyer suggested the need for a specific agenda on improving the timeliness of infant mortality data. Perhaps the structure of the meeting could be a conversation on that topic between an expert panel and the committee in place of presentations. The goal would be to develop the foundation for a set of recommendations that would improve the quality and availability of infant mortality data.
- Stating the desire to have medical records that are completely electronic, Ms. Ryan suggested that, in the meantime, hospitals could collect additional data on preterm or LBW births as part of their surveillance efforts, which could help as an interim method until all systems are fully integrated. The data also facilitate the development of action plans and are therefore important to hospitals in their own right.
- Noting that many very young fetuses are delivered and maintained in a way that contributes to the neonatal death rate, Dr. Roberts stressed the need to examine how health care decisions

made at the cusp of viability (a very vulnerable period) influence care and decisionmaking during delivery. In 1994, the American College of Obstetricians and Gynecologists reported hospital rates for caring for infants at various gestational ages and related morbidity and mortality outcomes. Dr. Roberts proposed revisiting the data to consider ethical issues and how hospitals handle early births and involve parents in the decisions. She felt that without specific hospital policies, pediatric departments often are not aware of the need for discussions with parents once preterm labor occurs, and parental preferences may not be factored into many decisions hospitals make.

- Dr. Guyer suggested adding other aspects of data collection to the committee's agenda, including the reporting of perinatal mortality rates (late fetal deaths and first-week neonatal deaths). Scandinavian countries already report these data. There are classification and decisionmaking issues related to the way the data are grouped and recorded. Dr. Ryan indicated that he too is interested in perinatal mortality rates, but primarily as a classification or policy issue not a data issue; the focus on infant mortality has perhaps overshadowed other analyses. Noting the benefits of discussing the pros and cons of this issue, Dr. Ryan added that it would be interesting to compare State-specific infant mortality rates and State-specific perinatal rates and look for any classification biases. Dr. Hayes agreed and suggested the committee also consider who would be responsible for implementing this policy at the State level. It would also be helpful to include MCH epidemiology program colleagues and representatives from CDC and listen to their insights on policy implementation.
- Dr. Sapien proposed summarizing work of maternal and child death review teams to inform further discussions. Dr. Guyer added to Dr. Sapien's suggestion and asked whether the Fetal and Infant Mortality Review evaluation has been completed. This topic would provide the committee with a sense of other sources of information that go beyond vital statistics and help clarify trends. Ann M. Koontz, Dr.P.H., C.N.M., responded that the December 2004 issue of the *Maternal and Child Health Journal* is devoted to articles addressing the national evaluation of the Fetal and Infant Mortality Review program.
- Dr. van Dyck reiterated that SACIM's goals are to generate ideas, enhanced by speaker presentations; identify a key set of issues that need to be studied in more depth and that would benefit from additional HHS efforts; and then make practical recommendations to the Secretary that can be implemented.
- Dr. Ryan expressed interest in the impact of unintended and unwanted pregnancies on infant mortality and strategies to reduce these trends. Dr. Collins agreed and indicated that more than 50 percent of all pregnancies are unintended. Noting that a number of States have examined access to emergency contraception policies, Dr. Hayes proposed asking representatives from some of those States to share their experiences in this area with the committee.
- Dr. Moore indicated that crisis pregnancy centers in many communities are moving toward a medical model in which they employ physicians as medical directors and test for sexually transmitted diseases and pregnancy. They also use ultrasound as a diagnostic test to help

women make informed decisions. There is an opportunity to work cooperatively with these centers to enhance prenatal care in women who decide to carry their pregnancies.

- Dr. Cernoch suggested that it would be important to examine the reimbursement issue with Medicaid (and commercial payers), including Medicaid's impact on State systems as the primary payer of many of these services. Dr. Hannemann mentioned that this issue has been raised before and suggested expanding the discussion to include access to medical care for the majority of patients who are at risk for LBW infants.
- Dr. Finch added that in the commercial market, benefits include health care plan benefits as well as prenatal care and disability for pregnancy. Ms. Ryan noted that if commercial plans rely on a base rate from Centers for Medicare and Medicaid Services (CMS), any changes in those CMS weights affect reimbursements all the way down the line. Usually, Maternal Child Diagnosis Related Groupings are hit the hardest when it comes to reductions.
- Citing possible reductions in funding for prenatal care services for women, Dr. Roberts added that eligibility and copays make it more difficult for people who need these services to obtain them. Dr. Roberts then emphasized the need for strategies to ensure that these individuals access the services they require. She asked what is known about how funding problems are addressed so MCH services are not uniquely eroded by increased competition for fewer dollars.
- Dr. Cernoch remarked that because many of the decisions about Medicaid are made at the State level, the amount of the reimbursement and the services that are covered are important considerations. Examining the whole public health care system, including the financing component, is important. Because CMS is under the Secretary, the committee might have leverage in this area.
- Dr. Roberts reported that an editorial in yesterday's paper on health care proposed that one State should take the lead in developing innovative programs that would include universal coverage. One area that should be included in this model is maternal and child health.
- Dr. Collins suggested having the committee embrace the issue of racial disparities. Timely vital record data, surveillance, and financing are important and affect disparities. Beyond that, he asked the committee to consider what issue they want to influence the most.
- Dr. Hayes reminded the committee that disparities begin at birth. When people began scrutinizing strategies for eliminating disparities, disease-specific solutions were considered without understanding that closing the gap does not begin at adulthood. She thanked participants for putting together the agenda for the current meeting.
- As a possible format change for committee meetings, Dr. Sapien proposed having a brainstorming session with a group of experts who could serve as resources or references as the committee begins to discuss specific issues. The goal would be to produce one recommendation by the end of each meeting. In this way, at the end of the year, the committee would have at least four recommendations to deliver to the Secretary. Dr.

Hannemann indicated that the committee has done this in the past with LBW. State-of-the-art experts would present their current thinking on a topic and the committee would have the chance to contend some of the ideas and then come to a consensus. He also recommended that it probably would be more productive to have the committee business discussion at the end of the first day of committee meetings. Dr. Collins agreed that this type of format would work and mentioned the need for more time for discussion.

- Dr. Guyer asked what the ground rules were for products and whether the committee could commission a paper on a certain issue or question. He remarked that IOM committees are created to explore a specific issue and their result includes products such as publications or hearings. The ground rules for the products of IOM committees are established at the beginning of the meeting. Dr. Guyer supported the recommendation to have a product result from each committee meeting.
- Dr. van Dyck responded that it would be possible to commission a paper. He reminded the committee that although there is no set budget, some resources within reason are available to the committee. For example, it is possible to sponsor and bring in speakers or experts, to have monthly conference calls, or to convene and travel as subcommittees to discuss a certain issue. However, the resources need to follow the generation of specific issues or ideas that the committee would like to develop.
- Dr. Ryan added that if the committee decides to structure the discussion around one or two issues, it would be helpful to inform the expert presenters that one of the goals is to produce a recommendation at the end of the meeting so they would be prepared to offer a recommendation to the committee.
- Dr. Moore suggested adding a dinner/evening discussion to the committee format. Dr. van Dyck responded that, because SACIM meetings are open to the public and recorded, evening meetings would have to be held informally and not as part of a formal meeting agenda.
- Dr. Miller asked if the committee would consider nonaccidental injuries to infants. Too many infants are being harmed by the people who are supposed to take care of them. Dr. Sapien indicated that the committee could also include domestic violence with this issue.
- Dr. Guyer asked if the committee ever had agenda-setting subcommittees in the past, which he thought would help plan the program for future meetings. Dr. van Dyck responded that previously there had been the following three subcommittees: LBW, early discharge, and Healthy Start. Previous meetings have included updates on these topics for the whole committee, with presentations by one or two experts, and then members would divide into subcommittee work for the remainder of the time. And at the end of the second day, each subcommittee reported its accomplishments. The subcommittees also traveled or had regular conference work. Each committee also produced a series of written products.
- Dr. Guyer asked how long the present members would be together as a committee. Dr. van Dyck responded that members have varying terms, with the longest lasting 4 years. Dr.

Koontz added that about half of the committee would rotate off in September 2007 and the other half in 2008.

- Dr. Roberts referred to several sources of information about cost-effective solutions for maternal and child health services. The presentation on the Canadian system, the analysis on Healthy Start, and the presentation on Illinois that emphasized quality improvement are good examples. It would be useful to pool all the information together in the context of best practices for reducing infant mortality. Dr. Bronner expressed interest in working on a subcommittee that addressed these issues.
- Dr. Finch agreed that there would be a continued push for controlling costs. In the private sector, evidence-based care is being examined very closely. Perhaps it would be in the committee's interest to examine a model of evidence-based care because it captures the attention of many decisionmakers at the moment.
- Ms. Barnes indicated that many women are being seen for the first time in the second or third trimester because many obstetricians/gynecologists are closing the obstetrics portion of their practices. The loss of these practitioners diminishes provider availability for Medicaid patients and impacts infant mortality.
- Dr. Guyer suggested three topics that have emerged from the discussion as the basis for the subcommittee efforts: (1) improved perinatal data systems, (2) financing pregnancy and infant care, and (3) closing disparities. Dr. Guyer proposed developing an agenda and a product related to each of these topics.
- Dr. Collins thanked all members of the committee for their hard work and enthusiasm and added that he looked forward to the next meeting in early March 2005.

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