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SCHAKOWSKY MAPS OUT PLAN TO IMPROVE HEALTH CARE FOR MINORITY CHILDREN

DELIVERS COMPREHENSIVE SPEECH TO DOCTORS AT ADVOCATE LUTHERAN GENERAL HOSPITAL IN PARK RIDGE

PARK RIDGE, IL - U.S. Representative Jan Schakowsky (D-IL) today delivered a comprehensive speech on health care for minority children to doctors at Advocate Lutheran General Hospital in Park Ridge.

"Minority children, their families and their caregivers are faced with two problems, not just one - the need to guarantee access to quality medical care and the need to guarantee that the care is free from bias," Schakowsky said.

She added, "According to Covering Kids, 9.8% of all children in Illinois were uninsured, although 40% of the 351,200 children were eligible for Medicaid or SCHIP but not enrolled. However, 26% of Latino children, 16% of African-American, 14% of Asian-American, and 22% of low-income children had no coverage."

During the speech, Schakowsky recommended that critical steps should be taken to improve health care for minority children. Those steps should:

- 1. protect the public programs and providers that are the bedrock of care for minority children;**
- 2. ensure that all minority children (and their families) are enrolled in coverage;**
- 3. ensure that insurance coverage needs guarantee real - not theoretical -- access to medical care;**
- 4. give children all the services they need in an effective, real world way;**
- 5. bring health care outreach and service to children, particularly to schools;**
- 6. break down language/communications barriers;**
- 7. improve cultural sensitivity and diversity;**
- 8. recognize the special needs of immigrant communities;**
- 9. increase research; and**
- 10. think comprehensively in ways beyond access to medical services.**

Below is the full text of Schakowsky's speech.

I want to thank Dr. Deshmukh for inviting me and I want to thank all of your for your work in caring for children. Pediatricians have been at the forefront of fighting not just for individual patients but for the health of our nation. As a mother, grandmother and policymaker, I want you to know how much I appreciate your commitment and your skills on both fronts.

It is good to be here with you today to discuss how we get quality health care to minority children so that we can give them a good send-off for their future lives. This has always been a critical issue but it has become increasingly so for several reasons.

First, as we look at the trendlines in children's health, many of those lines appear to be headed in the wrong direction. And second, as I'll discuss in a few moments, the problems of racial and ethnic disparities in health care are proving to be far more complicated and more difficult to eliminate than previously thought.

Minority children, their families and their caregivers are faced with two problems, not just one - the need to guarantee access to quality medical care and the need to guarantee that the care is free from bias.

I am glad to give you my thoughts on these issues but I am more eager to have a dialogue with you today and in the future. As frontline physicians and health care professionals committed to the very best care for children and their families, you have a lot to teach me and other policymakers about best solutions. We need your recommendations and your counsel so that we can do the best for our kids.

We have just come out of a period of unparalleled economic prosperity and unprecedented budget surpluses at the federal and state levels. Yet, despite that, we were unable to make much more than a dent in reducing the number of uninsured or reducing racial disparities in health care.

At the end of the economic upturn, nearly 40 million Americans - including over 8 million children - were still uninsured. Although most of those children were eligible for Medicare or the State Children's Health Insurance Program (SCHIP), we had not reached them and gotten them enrolled.

And even with money at our disposal, we didn't reduce racial and ethnic disparities. According to the Agency for Healthcare Research and Quality, minorities consistently rate all aspects of health care more negatively than whites. At each age of lifespan until age 44, African Americans, Latinos and Native Americans have higher mortality rates than whites. Despite a 16% decline in infant mortality, African American infant mortality and low-birth weight rates are still twice those of whites. In fact, the percentage of Hispanics with a regular health care provider actually dropped from 60% in 1997 to 55% in 2001 - the height of economic prosperity.

Problems of uninsurance and underinsurance are still disproportionately felt by minorities and by minority children. In 2001, 1 in 8 whites were uninsured, compared to more than 1 in 3 Hispanics, 1 in 3 Native Americans, and 1 in 5 African Americans. Only Asian Americans were close to the percentage of whites, (14% compared to 12%), but that masks great variations among subpopulations. For example, Vietnamese Americans were more likely to be uninsured than Hispanics and three times as likely to be uninsured as Chinese Americans.

According to Covering Kids, 9.8% of all children in Illinois were uninsured, although 40% of the 351,200 children were eligible for Medicaid or SCHIP but not enrolled. 26% of Latino children, 16% of African-American, 14% of Asian-American, and 22% of low-income children had no coverage.

Today, we are in the middle of an economic downturn. Lay-offs combined with higher premiums that make employer-based coverage unaffordable for companies and workers have added to the number of uninsured children and parents. (89% of uninsured children live in a household headed by a worker). Two million people lost health

insurance last year. Recent figures estimate that over 45 million were uninsured in the first half of this year.

And the problems are likely to get worse before they get better. Health economists predict double-digit medical inflation for years to come. More and more businesses are planning to shift more and more premium costs to workers or cut dependent coverage. Minority workers disproportionately work in jobs where these changes will be felt the most. Minority small businesspeople are at the mercy of a dysfunctional individual insurance market that charges the highest rates and limits benefits. Their families, then, are most at risk.

At the time that we most need new public investments in health care, the federal surplus has been eliminated and we are back into deficit spending, largely because of last summer's tax cuts. And states like Illinois are cutting funding at the same time that eligibility and costs are on the rise.

The expected increase in uninsurance will have real consequences.

Although the myth still persists that uninsured children and adults receive the medical care that they need, you and I know that is not true. Uninsured children are seven times more likely not to get needed medical care than insured kids (21% to 3%), seven times more likely not to get a prescription filled (14% to 2%), and seven times more likely to be kept away from sports because of parental fears of possible injuries (20% to 3%). Uninsured children are four times less likely to see a dentist (27% to 7%) and three times less likely to see a doctor (34% to 11%).

Uninsured children are far more likely to miss school, suffer from untreated ear infections and asthma, go without vision care, be obese and so on.

And, while we may take some comfort in knowing that the percentages of uninsured children and uninsured minority children are lower than the percentages for adults, the consequences of being uninsured are more serious. According to the National Institute of Child Health and Human Development, (part of the National Institutes of Health), the best way to improve health outcomes and reduce racial/ethnic disparities is by providing good care before birth and during the first decade of life. Because they are uninsured, millions of children, especially minority children, are being denied the chance to have a healthy start and maximize their chances for a healthy, productive future. And, without good care at the start of life, they may never be able to catch up.

While coverage is essential, it is not enough. The sad fact is that insured minorities - whether they are in managed care plans, PPOs, or fee-for-service, public or private plans - routinely report more problems in accessing health care, particularly in getting access to specialists.

The recent report by the Institute of Medicine, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," confirms what many had known before: that the causes for racial health disparities are too deep and complicated to be solved just by providing a health insurance card to the uninsured.

The report concludes that, even taking into account factors such as insurance status, income, age, and health status, people of color often receive a lower quality of basic clinical services and fewer referrals to specialists.

As the introduction to the report states, ".in examining the roots of these disparities, the committee is struck by the fact that the resources are complex and multifactoral. Included among the factors are clinical uncertainty, stereotypical behavior, and

subconscious bias that may extend all the way to prejudice."□□

It is not surprising that medical care confronts some of the same discriminatory behaviors that plague the rest of society.□ What is most welcome is that members of the medical community - like the American Academy of Pediatrics - are so focused on solutions to end that discrimination.

None of us has the magic solution to improving health care for minority children.□ I want to lay out some of my own ideas about steps we need take.□ Before doing so, I want to assure you of two things.□ First, that many of my colleagues in Washington are as committed to solving this problem as you are - we will do whatever we can to stand with you in fighting for the needs of our children.□

Second, we recognize that this is not a "one size fits all" question.□ Minorities are heterogeneous groups, with different problems and different needs.□ Aggregating subpopulations and different populations under one label masks those very real differences.□ What may work for Native Americans may not be what is necessary for African Americans or Filipinos.□ We are committed to finding solutions that work for every child and every situation.

However, for the sake of this morning's discussion, here are some basic thoughts on what we need to do.

We need to protect the public programs and providers that are the bedrock of care for minority children.

Minority children disproportionately depend on Medicaid.□ They are nearly 40% of the population under 18, but they are represent□ almost 60% of the children on Medicaid.□ As Medicaid enrollment and costs escalate, states are cutting back and some in the federal government are even talking about privatization.□

In the Medicare drug bill that just passed the House in June, there was a little noticed provision to establish a National Bipartisan Commission on the Future of Medicaid and to look at increased utilization of "competitive, private enterprise models" and increased cost-sharing.□ Cost-cutting proposals might have less of an effect on children than persons with disabilities and seniors in Medicaid, (children are 51% of enrollment but 15% of expenditures because most children are relatively cheap to cover), but proposed changes could seriously affect minority children with disabilities and cost-sharing increases would bar access to care for low-income minority children.

Even without federal action, Medicaid is at risk.□ According to the National Association of State Budget Officers, 47 states (including Illinois) took steps or proposed steps to reduce expenditures in 2002 and 2003 by cutting payments, eliminating benefits, increasing cost-sharing, reducing eligibility, or limiting access to prescription drugs. SCHIP is also in jeopardy. This is 5th anniversary of SCHIP, which covers 4 million children who would otherwise be uninsured.□ SCHIP was designed as a one time, 10-year program, with federal funds being phased out over time.□ Federal funding dropped \$1 billion this year and is scheduled to remain at that level for the next 2 years, then decrease again.□ According to the Office of Management and Budget, planned cuts will cost 900,000 children their health care over the next three years.□ We need to stop those cuts.

Finally, we need to fight to make sure that Medicaid and SCHIP payments to providers

are fair and reasonable. An American Academy of Pediatrics study released this month found the major reason why primary care pediatricians don't accept Medicaid patients is low reimbursement. At the federal level, we are working to pass bills like H.R. 854, the Medicaid Safety Net Hospital Act, to increase DSH payments and H.R. 3414, the State Budget Relief Act, to increase the federal share of Medicaid.

These bills are designed to provide the funds needed to make sure that payments are adequate. We cannot expect quality care if hospitals don't have the resources and we cannot expect pediatricians and other professionals to care for our children if doing so costs them money.

All minority children (and their families) must be enrolled in coverage.

I am vice-chair of the House Universal Health Care Task Force, and I believe that our nation needs to join the rest of the world in guaranteeing health care to its residents. That's a necessary fight but a tough one, so in the meantime we need to do everything possible to take advantage of existing opportunities.

Nearly 150,000 children in Illinois are eligible but not enrolled in Medicaid or SCHIP. All of us need to work together to get them enrolled by increasing outreach and helping with the application process, taking the message to clinics and hospitals, schools, worksites, unemployment offices, child care centers, supermarkets - anywhere that parents of eligible but uninsured children are likely to be.

We also need to maximize federal dollars. Unless we are able to change the current law, Illinois will have to turn back \$10 million in unspent SCHIP dollars. It is a crime that we were given federal money and couldn't figure out how to use it. Similarly, we should be increasing eligibility standards in Medicaid and SCHIP. We get \$1 in federal funds for every \$1 we spend in state Medicaid funds - so cutting state funds by a dollar actually costs us a total of \$2. On the other hand, spending a dollar gets us two dollars. Even with the tight fiscal budget, we should demand funding for children's health and talk about raising eligibility levels - after all, there is no greater investment we can make. Finally, we can make changes that will increase coverage - such as eliminating the requirement that children need to be uninsured for 3 months before they are eligible and presumptive eligibility for Medicaid and SCHIP.

Insurance coverage needs to guarantee real - not theoretical -- access to medical care.

Affordability is an enormous issue in minority communities, which are disproportionately low-income. Coverage becomes theoretical if it imposes cost-sharing requirements that families cannot meet. Copayments that seem reasonable to policymakers - even \$1 or \$2 - can be impossible to meet for families with several children or a special need's child who needs multiple doctor's visits and prescriptions.

A 2001 Commonwealth Fund survey found that 1 in 4 patients don't follow their doctor's advice, and the biggest reason cited was cost: by 24% of whites but 41% of Hispanics, 30% of blacks, and 27% of Asian Americans. Higher cost-sharing requirements - planned by Medicaid, SCHIP, employers and private insurers - will make an already

serious problem even worse.

Managed care also presents barriers by limiting patient-physician interaction, continuity of care and access to specialists. The expectation that managed care patients will know and utilize their rights is particularly difficult for immigrant families.

We need to give children all the services they need in an effective, real world way.

In addition to providing minority children with preventive, early intervention and basic health care services, we need to make sure that we address all the health care needs they face.

I am particularly concerned about mental health services, which are still stigmatized generally and in some minority populations in particular. According to the U.S. Surgeon General's report, 78% of African American and 86% of Hispanic children don't get access to needed mental health services (compared to 69% of whites).

Minority children are also far more likely to contract Sexually Transmitted Diseases (STDs). Congenital syphilis is 30 times higher among African American infants and 9 times higher among Hispanics than whites; gonorrhea is 23 times higher among African-American adolescents than whites. Minority teen girls have a high rate of HIV infections - half of all new HIV infections are under 25 and contracted mostly through sexual activity.

That means we can't rely on abstinence only education - which ignores the behavior reality of teens.

That also means that we have to make sure that teens have access to confidential counseling and services. A recent survey of teenaged Planned Parenthood clients in Wisconsin found 59% would postpone testing for STDs and 47% would stop using clinics altogether if their parents were notified of their use of contraceptives.

We need to bring health care outreach and service to children, particularly to schools.

School administrators and teachers know that good health and learning go hand in hand. Insured children are less likely to miss school or activities and are more attentive in school.

Schools are one of the best ways to reach children, through school mailings, enrollment, school lunch programs, assemblies, teacher-parent conferences, and counselors.

We need to give schools all the resources they need to provide outreach and health care services. Dr. Deshmukh's work at Maine East High School next door is a prime example. She studied the school and found that there are 36 languages spoken with 52 cultures represented. Nearly half of the students were not born in the U.S. and three-quarters of their parents were born abroad. 17% of the students don't have a doctor and 17% are uninsured. Over half of the students would use a school health center and now, in a partnership with Lutheran General, they will have one.

I look forward to seeing the study that shows improvements in health outcomes as a result.

Language/communications barriers need to be broken down.[] []

Clearly, language is a challenge in communities like ours where so many different languages are spoken.[] Translation is a major problem - only 48% of non-English speakers who said they needed an interpreter during a health care visit actually got them, according to a Commonwealth Fund study.[] We need to support efforts, particularly in public programs like Medicaid, to demand adequate translation services. And we need to provide the funding to do that.[] My colleagues and I are working on proposals in this area to provide additional funding so that assuring translation services doesn't require cuts elsewhere in Medicaid.

But translation is not the only issue with communications.

Although this lecture focuses on children, younger children are often dependent on their parents or grandparents or other adults to get them into the system and then ensure that they get follow up treatment.[] In other words, in order to make sure that the children get care, we need to make sure that their adult family members understand doctors' orders and are comfortable asking questions.

Unfortunately, many patients don't understand their doctors' instructions and don't ask questions.[] While non-English speakers have the most difficulty, they are not the only ones who have trouble.[] 23% of African Americans, 27% of Asians and 33% of Hispanics (and even 16% of whites) have problems communicating with their doctor and say that they had questions they didn't ask, didn't fully understand the doctor or that their doctor didn't listen to what they were saying.[] Asian Americans were least likely to feel that their doctors understand their background and involve them in decisionmaking.

One way to deal with this problem is to locate services within the community.[] I am working with Abha Pandya and Asian Human Services to fund the first, culturally sensitive Asian community health center.[] []

Another way is, again, through cross-cultural education.

Finally, we need to make sure that health plans give doctors and other health care professionals the time to spend with their patients to encourage communications and build a trusting relationship.

Improve cultural sensitivity and diversity.[] []

The Institute of Medicine study "Unequal Treatment," as well as Kaiser Family Foundation focus groups and other studies, show that the majority of physicians believe that treatment disparities based on racial or ethnic background rarely (55%) or never (14%) happen.[] They also prove that racial stereotypes do exist in health care (like the rest of society) and affect quality of care.[] [] []

Examples of unconscious stereotyping by doctors and health care administrators are common in focus groups:[] comments like Asians won't complain or discuss symptoms, Native Americans don't show emotions, Hispanics and African Americans won't eat healthy diets and won't comply with treatment orders.[] []

Nearly half of the general public, on the other hand, believes that discrimination exists.[] African Americans, Hispanics and other minorities report less involvement in medical decisions, partnership with physicians, lower levels of trust in physicians, and lower levels of satisfaction with care.

Even when socioeconomic factors are removed, discrimination persists. In an Agency for Healthcare Research and Quality study in which white and black patient actors presented with the same symptoms, same insurance coverage and same professions, black women were only 40% as likely and blacks overall 60% as likely to get cardiac catheterization as whites.

Cross-cultural education and training - of current and future health care professionals - is essential to help deal with this problem.

So, too, is providing more racial/ethnic diversity in the workforce and initiatives to counter the drop in minority medical school applications following decisions that prohibit consideration of race or ethnicity in admissions. Greater minority representation in the workforce helps directly and indirectly, by helping to erase subconscious biases that exist.

Strategies include programs to interest minority elementary and secondary school students in health care and sciences, flexible hours and selection processes for medical school, support and mentoring, working with minority residents to recruit other minorities, and programs involving Historically Black Colleges and Universities, Hispanic Serving Institutions, and tribal colleges.

Recognizing the special needs of immigrant communities.

More than one of every three children eligible for Medicaid but not enrolled lives in an immigrant family. Nearly two in five - 39% -- non-citizen children are uninsured. In addition to language and cultural sensitivity issues, immigrant children and their families have special needs. Those include: fear of authorities, confusion about programs and eligibility, lack of culturally and linguistically appropriate outreach, fear of being a public charge, the federal 5-year waiting period for Medicaid or SCHIP eligibility, mixed immigration status without the same family.

In Illinois, we enjoy the cultural richness and diversity that immigrants bring and we recognize that. When the 1996 immigration law cut off federal health care money, Illinois used its own state funds for immigrant health.

We need to make sure those funds keep flowing, that enrollment barriers (such as requirements of Social Security numbers for parents and income verification), and that outreach workers and professionals either come from the community itself or are trained adequately.

We need to build on existing coalitions of medical professionals, school administrators, immigration rights advocates and policymakers to improve outreach and enrollment policies.

More research is needed.

First, we need to continue the research efforts that have begun. There have been a number of really important research studies on racial and ethnic disparities, many of which raise more questions. Why is it that Hispanics, with higher levels of poverty, have lower levels of infant mortality than African Americans? Why do immigrants have better pregnancy outcomes than women in the first generation of families born in the U.S.? Are infection rates more of a factor in low-birth weights than social or economic

circumstances? Is it true that immigrants are less likely to get specialty referrals in managed care because they come from countries where patient involvement is not expected? These are all questions from current research articles - hypotheses and questions raised but not answered.

Second, we need more disaggregated research, looking at subpopulations and health status variations within those subpopulations (including information on minority children with disabilities).

Third, we need to make sure that clinical studies include minorities and minority children.

Finally, we need to use research to create the evidence-based guidelines necessary to promote consistency and equity of care and allow us to track improvements in health outcomes for minority children.

We need to think comprehensively.

Finally, we need to consider that minority children's health is affected in ways beyond access to medical services.

3 million children are abused or neglected and 1,000 die each year as a result. Twenty percent of women report violence during pregnancy. Domestic violence affects everyone, but particularly minority families. Infant deaths due to abuse are 3.4 times higher for African Americans and 3.5 times higher in Native Americans than whites. Although no exact statistics are available, up to 540,000 African American children and 145,000 Latino children are homeless. 30%-50% of school-age homeless children don't attend school. They are two to three times more likely to suffer from developmental delays, asthma, anemia, upper respiratory tract infections, and trauma-related injuries. Minority children are more likely to suffer from environmentally-related health problems, including toxic pollution.

So, ending domestic violence and homelessness as well as stopping environmental pollution are part of the solution.

Ending Remarks

I have just laid out an ambitious agenda that will demand new resources - expanding Medicaid and SCHIP, moving to universal coverage, increasing payments to providers, improving education and outreach, translation services, adding more school-based clinics, more indepth research, and addressing problems from housing to environmental cleanup.

Many of us in Congress are discussing how to accomplish those goals through legislation, appropriations, regulatory reform, and coordination with providers, states and consumers.

The IOM report, "Unequal Treatment," was the subject of Congressional hearings, including in the Government Reform Committee on which I serve. It is the focus of joint meetings between the Black, Hispanic, Asian American, Native American, and Progressive Caucuses.

There are some who will say that we cannot afford to act because doing so costs too much - that we must trim our sails because of budget constraints and the need to be

fiscally conservative.

I am not one of those people. We are still a prosperous and great country but we are the only industrialized country that refuses to guarantee health care to our children.

I believe that a country that ignores its children, jeopardizes its future.

You know that better than anyone. That is why I look forward to working with you to make sure that minority children - and all children - receive the medical care they need and deserve.