Dr. Diana Bianchi – National Institute For Child Health and Human Development

[Music]

Female: Welcome to Conversations on Health Care with Mark Masselli and Margaret Flinter, a show where we speak to the top thought leaders in health innovation, health policy, care delivery and the great minds who are shaping the healthcare of the future. This week, Mark and Margaret speak with Dr. Diana Bianchi, Director of the Eunice Kennedy Shriver National Institute for Child Health and Human Development at the National Institutes of Health, dedicated to researching and promoting the advancement of maternal, infant child and adolescent health right into adulthood. Dr. Bianchi is a noted OB-GYN, pediatrician, and medical geneticist, and talks about promising research underway. Lori Robertson also checks in, The Managing Editor of FactCheck.org, looks at misstatements spoken about the health policy in the public domain, separating the fake from the facts. We end with the bright idea that's improving health and well-being in everyday lives. If you have comments, please email us at chcradio@chc1.com, or find us on Facebook or Twitter or wherever you listen to podcast. You can also hear us by asking Alexa to play the program Conversations on Health Care.

Now, stay tuned for our interview with Dr. Diana Bianchi, here on Conversations on Health Care.

Mark Masselli: We're speaking today with Dr. Diana Bianchi, Director of the Eunice Kennedy Shriver National Institute for Child Health and Human Development, part of the United States National Institute of Health. Dr. Bianchi served as the Founding Director of the Mother Infant Research Institute at the Tufts Floating Hospital for Children at Tufts Medical Center, where she also is a professor of pediatrics, obstetrics and gynecology. Dr. Bianchi has done extensive research in prenatal genomics. She earned her medical degree from Stanford, did her residency in pediatrics at Boston Children's and her Postdoc fellowship in genetics at Harvard Medical School. Dr. Bianchi, welcome to Conversations on Health Care.

Dr. Diana Bianchi: Thank you very much.

Mark Masselli: You oversee $1.5 billion budget for research, which is aimed in improving child health. It's bolstering maternal health and prenatal care all the way through adult [PH 00:02:06]. Help our listeners understand the real scope of the work at NICHD, and how your strategic plan is taking the agency's work into the future?

Dr. Diana Bianchi: Sure, first of all, the National Institutes of Health are the largest funders of biomedical research in the world and there are 27 centers. NICHD is one of those 27 institutes and we're named for President Kennedy's sister Eunice, who convinced her brother that there was a great need to develop an institute that was specifically focused on

children and on people with intellectual disabilities. About 55% of our research dollars go to child health research, 30% goes to reproductive health research, and the remainder goes to research for people with intellectual and physical disability. As part of our strategic planning process, we created a new mission statement. Our new mission statements is that NICHD leads research and training to understand human development, improve reproductive health, enhance the lives of children, adolescence and optimize abilities for all.

Margaret Flinter: Dr. Bianchi, I'd like to just dive right in and focus on the issue of maternal health, because we are seeing such alarming data on maternal mortality in this country appears to be a particularly dire issue for women of color. Share with us about this trend, and what are the interventions that are necessary to address this public health problem, and resolve what really is just a terrible example of inequity in healthcare outcomes?

Dr. Diana Bianchi: This is a public health crisis. Sadly, about 700 women in the United States each year die of complications related to childbirth. Data has shown that three out of five of these deaths are actually preventable. That's where we need to really target our work. There's significant racial and ethnic disparities in the rates of maternal mortality. For example, black women are three times more likely to experience a death around childhood than white women. Also Alaskan native women and American Indian women have about two-and-a-half times the rate of white women. About half the births in this country are covered by state Medicaid programs and that coverage right now ends at 60 days after childbirth.

Recent data have shown the complications of childbirth actually occur up to a year following the delivery of the baby. There's this gap in time when women are not going to the doctor. Problems that could be detected if they were going to the doctor, cannot be treated and that is a major problem. What NICHD is trying to do is focus research aimed at preventing or treating many of the complications of childbirth, pregnancy, and this postpartum period. These include, for example, hemorrhage, infection, hypertension that then can result in a death at stroke.

We've also invested about $80 million in something called the Human Placenta Project. We've all been connected to a placenta at one time in our lives, but it actually functions as the organ that is providing your oxygen, taking away your waste products, and giving you nutrition during your fetal life. The Human Placenta Project is aimed at detecting problems that are going on during the pregnancy, so that you can prevent complications later on. We are now recognizing that there are abnormalities that you can see as early as the first trimester, which will give us an opportunity to intervene. By studying pregnant

women, which we do actually through our Maternal Fetal Medicine Units around the country, we are able to contribute to the lifelong health of these women.

Mark Masselli: Well, you sort of pulling the thread on that. You're continuing also in the area of maternal health is sort of focus in on medications that women are prescribed during pregnancy. That's not an area that is well researched. The NICHD is maybe instructed or working with Congress as a mandated task force over the past couple of years to look at the issue. I'm wondering if you could shine a light on the goals of the task force and its current status.

Dr. Diana Bianchi: We actually were directed as part of the 21st Century Cures Act, which was a very large piece of legislation that was signed into law at the very end of 2016. One of its provision was to create this task force to analyze research specific to pregnant women and lactating women. Because on average, about 90% of pregnant women take at least one medication during their pregnancy, and most women take between three and five during their pregnancy. There's this old school general assumption that it's much safer not to take anything. This may actually harm the mother and her fetus. NICHD convened a group of experts from obstetrics, from nursing, from pharmacology to create a series of recommendations. The most important one was to include and integrate pregnant and breastfeeding women in the overall clinical research agenda, and then provide training opportunities to expand the workforce of clinicians and investigators, so that pregnant women are protected through research, instead of from research.

Margaret Flinter: Well, I'd like to go to another kind of specific issue within your domain and this research on reproductive health including fertility and infertility, maybe also conditions that aren't so often talked about, but we know are widespread, such as endometriosis. How do you approach this as the institute in this area?

Dr. Diana Bianchi: We specifically put reproductive health in our mission statement, because really our research involves everything related to reproduction from the formation of the reproductive organs through some of the medical complications that ultimately result in infertility. We've decided to highlight endometriosis that affects one in 10 women. It results from endometrial tissue, which is the tissue that normally lines the womb, but this tissue is growing in places outside of the womb. It could be in the abdomen, it could be in the lungs, and it does cycle and bleed in those locations, which results in severe pelvic pain. On average, affected women spend that 18 days per year in bed. It also leads to infertility.

At NICHD, we have a specific branch that is devoted to gynecologic health and disease, and they are funding research that is examining the causes of endometriosis. We're also funding research that's trying

to prospectively identify biomarkers that could identify women who really do have endometriosis. Currently, there's no diagnostic test. NICHD-funded research has recently led to the development of a new medication that treats the pain associated with endometriosis. Also, right here on our Bethesda campus where we have the NIH Clinical Center, we've just started a new program in pediatric and adolescent gynecology. The focus of that program is to treat girls and young women who are suffering from a variety of menstrual disorders.

Mark Masselli: We're speaking today with Dr. Diana Bianchi, Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health. You're also a renowned medical geneticist with a special expertise on reproductive genetics and your research is focused on non-invasive genetic testing and how it can help identify illnesses in children, even facilitating prenatal diagnosis and treatment. Then, I'm wondering if you could just talk a little bit about how it might focusing on preventing illnesses improving the long-term health of children who are at risk?

Dr. Diana Bianchi: I think along with the Human Genome Research Institute, we have co-funded a recent large project, and it's called the Newborn Sequencing in Genomic Medicine and Public Health Program. This study has explored the implications and the opportunities associated with the use of DNA sequencing information in the newborn period. When I was at Tufts, for example, in the newborn ICU, there we would have babies that -- they weren't necessarily premature, but they were not thriving, and we didn't know what was wrong with them. What the insight study had shown is that you can use whole genome sequencing or whole exome sequencing to diagnose what is exactly wrong with the sick newborns, and 52% of the case study, they actually came up with the diagnosis. It also had very significant implications for families.

One of the center's was comparing the current standard of care, which is newborns get a little stick in their heel, and there's a little sample of blood that is taken, and the blood is analyzed through various proteins. What the investigators, in that part of the insight project wanted to see was whether sequencing would perform better than traditional heel-stick biochemical analysis, and it did not perform better. There were significant number of diagnoses missed by DNA sequencing that were picked up with the biochemical testing.

Then there was another part to this very interesting study that looked at healthy newborns and did having information on the baby's DNA sequence freaked out the parents. It turned out that it didn't. 88% of the newborns carried at least one mutation, which is what you would expect. The families felt that it was helpful information to do genetic counseling and to help them with future pregnancy planning. Even

more recent research has suggested that if you combine artificial intelligence with the DNA sequencing information, you can greatly speed up the rate in which you diagnose rare disorders. It took about two weeks to make a diagnosis. Now, the diagnosis can be made in a day or so, and that has tremendous implications for the care of that child as well as cost. So much of genetics in my practice lifetime has been focused on making a diagnosis. We're seeing such a shift now in rare genetic disorders, in which specific treatment is becoming available and that is so exciting.

Margaret Flinter: Dr. Bianchi, an other area of focus was adolescent health. What drove you to update your mission statement with that specific focus and any direction that focus is going at this point in time?

Dr. Diana Bianchi: I'm a pediatrician, as well as a parent. We all know that it's a critical time period in which there's so much change undergoing in the body as well as the brain and we're analyzing where we invest money. We realize that adolescence was a major gap area, and so we created a Trans-NIH Pediatric Research Consortium. What things we found was that every institute had this gap in adolescence in the transition to adulthood, especially important for teenagers with chronic disease, and especially those with intellectual disabilities. At NICHD, we're focusing, one is on learning to drive, which is a real rite of passage for most teenagers. One of our investigators had parents cars equipped with special cameras, and filmed teenagers for the first few months.

[Informal Talk]

Dr. Diana Bianchi: They found not surprisingly that those first three months the teenagers were eight times more likely to get into a serious accident. There needs to be a much more gradual transition into complete independence while driving.

Another area of research for adolescence is on prevention of HIV. We funded a study, in which teenagers who are at risk for HIV infection were given a single pill of Truvada. This is part of Pre-Exposure Prophylaxis for HIV or PrEP. The NICHD studies showed that the drug was effective at reducing HIV with no evidence of harmful side effects. They were particularly looking at effects on bones and kidneys. The results provided important evidence to the FDA, which ultimately led to the drugs approval. One of the things that I started was to invite the voice of the participant. We invite someone who has lived with the condition and has been treated by something that has come out of NICHD research, so we can see the benefits.

Recently, we had a young man named, Maurice, who talked about his experiences and what the benefit of taking the single pill was. We also had a recent woman who shared her experiences with endometriosis and the long painful journey associated with that.

Mark Masselli: Your Institute is doing so many things and certainly there's no more important public health crisis than the opioid crisis today. It's your agency that's focusing in how this crisis is affecting women and newborn children. I read a story the other day, in West Virginia where they were setting up a daycare center for newborns who are affected by the opioid crisis. I'm wondering again, if you could tell our listeners what efforts are underway.

Dr. Diana Bianchi: Yeah. First of all, we're very grateful to Congress that authorized additional money in this budget year as part of a large program called Helping to End Addiction Long-term or the HEAL initiative. Because the rates of newborns exposed to opioids via their mother has quadrupled, we started a series of clinical studies to determine exactly what's going on across the country. We were really surprised that there is no standard of care. The problem with these babies is that they are very irritable, they don't sleep well, they're difficult to console, and they have later developmental and educational problems. we felt that it was very important to try to establish some sort of national standard. For example, some nurseries are treating with morphine, some nurseries are treating methadone, other nurseries are doing something called eat, sleep and console, where the babies get no drug treatment at all. It's very important to know the best way to treat these babies. You would think that no drug treatment would maybe be preferable, but we don't know what happens to these babies when they leave the nursery and they go into these fragile families.

An important part of the HEAL program is what we're calling ACT NOW, Advancing Clinical Trials with Neonatal Opioid Withdrawal Syndrome. These will be performed in nurseries around the country where there's a high prevalence, you mentioned West Virginia. One of the things we want to find out is, if not treating these babies is safe, nobody has really studied that in a prospective randomized.

Margaret Flinter: We've been speaking today with Dr. Diana Bianchi, Director of the Eunice Kennedy Shriver National Institute for Child Health and Human Development at the National Institute of Health. You can learn more about their work by going to nichd.nih.gov, or follow her on Twitter at nichd_nih. Dr. Bianchi, we thank you so much for your groundbreaking work, your leadership over many decades in advancing research in the health of children, adolescence, and all people, and for joining us on Conversations on Health Care today.

Dr. Diana Bianchi: Thank you so much for having me. It's been great.

[**Music**]

Mark Masselli: At Conversations on Health Care, we want our audience to be truly in the know when it comes to the facts about health care reform and

policy. Lori Robertson is an award winning journalist and Managing Editor of FactCheck.org, a nonpartisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in US politics. Lori, what have you got for us this week?

Lori Robertson: The Census Bureau in September released its report on health insurance coverage in the United States in 2018, finding that the rate and number of the uninsured increased from 2017 to 2018. The first time it has found a yearly increase since the Affordable Care Act was enacted in 2010. In 2018, 8.5% of people were uninsured for the entire year, that's up from 7.9% in 2017, and it's an increase of about 1.9 million people. Most Americans with insurance get their coverage from private health insurance companies. 67.3% of people have private coverage, with most getting that coverage through their employment. Those with Medicaid coverage dropped 0.7 percentage points from 2017 to 2018 to 17.9% of the population. Medicare coverage went up by 0.4 percentage points, covering 17.8% of the population. The percentage of children without insurance went up by 0.6 percentage points.

The Census Bureau uses data from the Current Population Survey and the American Community Survey making this measurement dependent on a large amount of responses. The Census Bureau also released information on income and poverty, finding that the median household income in 2018, $63,179, wasn't statistically different from 2017. That comes after increases in the median household income for the three years prior. The official poverty rate went down, however, by 0.5 percentage points. The rate was 11.8% in 2018.

That's my fact check for this week. I'm Lori Robertson, Managing Editor of FactCheck.org.

Margaret Flinter: FactCheck.org is committed to factual accuracy from the country's major political players and is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact that you'd like checked, email us at chcradio.com. We'll have FactCheck.org's Lori Robertson, check it out for you here on Conversations on Health Care.

[Music]

Margaret Flinter: Each week conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. Tens of millions of people around the world have conditions that make it impossible for them to speak on their own, requiring them to adopt a computerized voice box for communicating. Perhaps the most well known of these folks is the physicist, Stephen Hawking.

Stephen Hawking: I would have thought it was fairly obvious what I meant.

Margaret Flinter: The problem is that sound of Hawking, speaking through his voice box

is the same voice sound say that a 10-year-old girl with a neurological disorder might be forced to use as well. Because they're just haven't been many voice options on the market.

Female: In the US alone, there are 2.5 million Americans who are unable to speak, and many of them use computerized devices to communicate.

Margaret Flinter: At a recent TED Talk, speech researcher and innovator, Dr. Rupal Patel, showed a program she has launched that can change that reality, Vocal ID.

Dr. Rupal Patel: I thought there had to be a way to reverse engineer a voice from whatever little was leftover, so we decided to do exactly that. We set out to create custom crafted voices that captured the unique vocal identities.

Margaret Flinter: Creating a voice bank of donor voices that will allow voices to be individualized for each unique patient, seeking to communicate through an electronic voice box.

Dr. Rupal Patel: Why don't we take the source from the person we want the voice to sound like and borrow the filter from someone about the same age and size, because they can articulate speech, and then mix them. Because when we mix them, we can get a voice as clear as our surrogate talker, and is as similar in identity to our target talker.

Margaret Flinter: Volunteers like this little girl will read a series of simple phrases over a several hour period.

Female: Things happen in pairs. I love to sleep. The sky is blue without clouds.

Margaret Flinter: Then those phrases are matched with the voice footprint of the patient being provided for.

Female: This voice is only for me. I can't wait to use my new voice with my friends.

Margaret Flinter: Such speech synthesis will give that person the dignity of a speaking voice that is as closely matched to their own identity as possible. Dr. Patel, who's a professor of computer engineering at Northeastern University, has launched the website VocalID.com.

Dr. Rupal Patel: I imagine a whole world of surrogate donors from all walks of life, different sizes, different ages, coming together to give people voices that are as colorful as their personalities.

Margaret Flinter: With the bank of voice donors now building around the world, the Human Voicebank initiative, matching vocal donors with millions of people who seek to authentically communicate with friends and family in a voice that most closely matches what would be their own. Now, that's a bright idea.

Dr. Diana Bianchi – National Institute For Child Health and Human Development

[**Music**]

Mark Masselli: You've been listening to Conversations on Health Care, I'm Mark Masselli.

Margaret Flinter: I'm Margaret Flinter.

Mark Masselli: Peace and health.

Margaret Flinter: Conversations on Health Care is recorded at WESU at Wesleyan University, streaming live at chcradio.com, iTunes, or wherever you listen to podcasts. If you have comments, please e-mail us at chcradio@chc1.com, or find us on Facebook or Twitter. We love hearing from you. This show is brought to you by the Community Health Center.