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Public Health Data to Address Disparities:

Meeting the Challenges

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CHRISTINA MALIN: Well, I'm somewhat dismayed to hear that I'm the star of this presentation because I feel willfully inadequate. I'm here for Dr. Karen Ramstrom who is the Policy Development Branch Chief at the California Department of Public Health and the Maternal, Child and Adolescent Health Division. She is my supervisor. And as Suzanne said, the budget acts did fall and she thought she was going to be able to come, travel was pre-authorized, everything was looking good and then when our friend, Governor Schwarzenegger threatened to lay off 20,000 state workers if a budget wasn't passed, that's when everyone freaked out and said, no travel.

So, I'm here because I work actually for the University of California San Francisco, technically I'm an employee of UCSF and I'm contracted to the California Department of Public Health. So I'm not technically a state government employee, so I'm able to travel and have a budget to do so. So, I'm really glad to be here today. My title is that I'm the Preconception Health Coordinator for the Maternal, Child and Adolescent Health Division. So my job really revolves around an initiative to ensure the health of women of childbearing age before pregnancy. And within that, certainly adolescents fall into that realm and I am trying within

this very broad job description of mine to work with the programs that are serving youth to look at health of youth in general but with an eye to the fact that most youth will end up becoming parents at some point. So, being able to ensure their health before that happens and delaying that until it's an appropriate time is certainly important.

So, I'm familiar with this group, the California Adolescent Sexual Health Work Group. I'm a member of that group, but I've only attended two meetings. I've been with the Department of Public Health for less than a year. So I'm really not super-experienced in this area but I did talk it over with Karen pretty extensively and I think I can give you a general overview of the work that we're doing. And if there are any questions that I can't answer, then Karen can certainly get back to you. I can take cards, names, what have you and she can get back to you. So we'll do our best.

So, the plan here is for me to talk about the Adolescent Sexual Health Work Group, or ASHWG as it's known, because what has come out of this collaborative are some unanticipated opportunities -- you see in the title slide -- which were essentially an opportunity for us to look at disparities data in our state in a different way. So ASHWG was formed for a particular reason, but out of that has come a data subcommittee which I'm going to tell you about. And from that, we were able to look at data about disparities in a way that we would not have if this collaborative had not come together.

So this is going to be a practical talk about how – the process that led up to our ability to have -- basically use existing data sources. The two other talks that you've heard address some really interesting issues about data collection in the field and how race, ethnicity categories are defined or how people identify or don't identify and whether self-disclosure is really a part of how all this data are collected. And this is really an example of how we work with existing data. So it's just really scratching the surface. But given our constraints, it shows what can be done with existing data sources. Do I hit enter? Okay.

So ASHWG is a standing work group of managers from the California Department of Education and the California Department of Public Health and key non-governmental organizations, community-based agencies that all work to improve or address the sexual and reproductive health of California adolescents. And you see the vision statement here, which is to create a coordinated, collaborative and integrated system among both government and non-government organizations to promote and protect the sexual and reproductive health of youth in California.

The way this collaborative came about is that in 2003, a number of states were invited to two Regional Stakeholder Meetings. Were any of you here at those stakeholder meetings? I believe they were held in Las Vegas. No? Again, this is way before my time. But I've heard the stories about these meetings and you see

the Regional Stakeholder Meetings were sponsored by NASTAD, by CDC, by AMCHP, a number of other organizations that you see up there. And the purpose was to identify ways that states could better integrate approaches for STI, HIV, and teen pregnancy prevention across agencies, interdepartmental collaboration.

And so from California -- the idea was to invite folks from Department of Ed, Department of Public Health, from STD branch, maternal and child health and also, I guess, there was a legislative component. The California team, as you see up there, where this four people, there was somebody , Nicole Vasquez who was from -- I can't remember the legislator's name now, she's no longer involved with this issue -- but there were only four people from California because at that time California was, guess what, in another budget crisis, only 35 billion at that time.

But still, it prevented people from traveling and a sort of ironic twist of fate is that because of that, California really delegated down and they sent mid-level managers to this meeting when I think the folks that were initially invited were more of the upper level administrative leaders. So those people didn't end up going. They delegated down. But that really worked in our favor, I think. And you'll see as I go on with the presentation that that allowed this committee to really get some work done in a way that may not have happened if those upper level leaders who generally tend to have less time for these kinds of projects had been the initial sort of -- the initial invitees or inaugural people for this effort. So I

think in the end that was a good thing. And we did survive that budget crisis, so hopefully we'll survive this one as well.

This slide just shows why integration and collaboration across health and education are important. And it's something that – it just underscores I think what most of us recognize that health and education disparities affect -- affect similar population. So the same adolescents who are at risk for poor academic performance are also those who are at risk for unintended pregnancy, STDs and HIV or other negative health outcomes.

So this is just a diagram that we can sort of use as a conceptual framework that underscores why it is important for us to really work across agencies. And it's something that - it's a problem in many government organizations, this issue of silos. It's a very overused metaphor but it certainly does - it certainly exists for a reason. People are very focused on their work and don't often think about what's going in other departments and how people can collaborate to really work synergistically and improve the health of the target population, for a lack of better word.

Integration also allows not only for sharing of knowledge among health and education agencies but also allows for better intervention so that young people can get consistent messages from whatever agency they're interfacing with. It bridges programmatic gaps and can improve efficiency, cost savings, better use

of resources, and other factors that also elevates the importance of issues. If you have a number of different departments that are working on something, makes it more high profile, it may be more likely to get more policy attention or better resources. So, all around, it's a good idea.

At this meeting, this regional stakeholders meeting, part of the process for that small team was to come up with a vision statement and a sort of strategic action plan for how those state programs would collaborate to reduce STDs, HIV and unintended pregnancy. So, as I said, we're in the middle of a budget crisis at that point, so those four folks soldiered on, went to the meeting, did their work, began to develop the vision statement, didn't actually meet with upper level administrative leaders until, I think, 14 months after the meeting because everyone was in a panic about what was going on. But eventually, they did meet with upper level - the administrative leaders of these departments - Department of Ed and Department of Public Health - presented the vision statement and presented the action plan. And those administrative leaders asked these four folks, this initial group, to put together a workgroup, a working group of midlevel managers from California Department of Education, from the Department of Public Health, STD and Maternal, Child, and Adolescent Health, to sort of expand this strategic action plan and develop some priorities for work. And that group was formed and morphed into the adolescent sexual health workgroup, or ASHWG, which sort of really came - took shape in 2005. So the meeting was in

2003, and then by 2005, there was this workgroup. So it's been in existence now for three and a half years.

I'm going to skip over this slide. So this is the ASHWG membership. We have - I don't think I mentioned that the administration asked that initial workgroup to put together members from Department of Ed and from Department of Public Health, but also to include key nongovernmental agencies, really, to make participation rich. And what I have discovered in my short time with the Department of Public Health is that it's a lot easier to get things done if you have private partners, because the wheels of government move very slowly. And if you can create a coalition with a public/private partnership, you're going to have a lot more success.

So, over the past three years, that membership has really grown to include participation from the NGOs that you see on the slide there. California Family Health Council is the Title X contractor for the state of California, so they manage all the Title X family planning clinics. MCH Action is the sort of advocacy arm for the MCH directors at the local health jurisdiction level. And the California Adolescent Health Collaborative is a freestanding, nonprofit organization that we - that the MCH division contracts with a lot of our - our Title V moneys go to them to provide technical assistance to the local health jurisdiction for adolescent sexual and reproductive health programs. So they've been a key player, and the data that I'm going to talk about a little bit later is posted on their Web site. So -

well, unfortunately we don't have Internet access in here, so I won't be able to show you that. But I'll give you the URL so you can look at it later. So, again, just a list of the partners.

So, these are the overarching goals of ASHWG that were developed when the group first came together. So the idea is to work together to increase awareness of ways to foster an integrative approach to HIV, STD, and teen pregnancy prevention, and to strengthen communication and collaboration among those programs that are working to prevent those teen pregnancy, STDs, and HIV. And the priorities that ASHWG group came up with initially in response to the request from administrative leaders are these: the first one is the one that's really the focus of this presentation -- improving and expanding, sharing, and use of HIV, STD, and teen birth data -- primarily, to try to improve comparability access and presentation of the data. Now, again, we're working with already collected data. But as somebody had mentioned earlier, probably due to federal funding requirements and a lot of things that I'm afraid I'm not very conversant on. Different programs collect data in different ways, and that makes it difficult to compare across programs. If you want to look at, say, teen pregnancy in a certain age group, those categories didn't always match up. The data were all there, but they were just -- the reporting conventions are different. So this priority was established to try to be able to look at these data in a more integrated fashion.

The second priority is to ensure the educators, counselors and case managers deliver effective behavioral interventions around sexual and reproductive health for youth. And so, there was a subcommittee that came up with a really nice set of core competencies for providers, which is not the focus of this talk but I can certainly let people know where to find those. It's a really nice set of -- I think they post it on the Web site. So, that's been a focus, and that's been a successful project today. From that, then would be, sort of, an adolescent sexual health 101 training for providers using those core competencies, which is something that we're starting to roll out in California now.

The Third one is to identify, develop and promote the use of culturally appropriate curricula. And California does have some pretty stringent requirements about curricula, about what curricula, sexual and reproductive health curricula need to include. So it's a bit of a challenge to find good ones and also meet those criteria. So that's been another project that ASHWG has been involved with. Improving access to services, including awareness of adolescent legal rights as it relates to sexual and reproductive health -- another priority. And then, finally, to identify funding policy recommendations and other resources to support all of this work.

So, again, ASHWG priority number one, so that's really the focus of the talk today. The primary goal or the one that we've started to work on in some depth is to generate and disseminate data reports on sexual health-related conditions, including risk behavior. So again, we want to integrate and present data that's

already being collected in a more, sort of, useable and sensible way. And then, also, within that -- once you got all that, it's easier to see what the gaps and deficiencies are, and again the collaborative being multi-disciplinarian at structure, is able to, sort of, come together and figure out best ways to strategize about how to overcome those gaps and deficiencies. And then, finding out, you know, figuring out, okay, all very well, and good to have these data together. How do we really get them out to the communities, especially at the local level, so that it can be put -- so data can be put into practice? And what kind of guidance you folks need in order to put those data into practice is another big piece.

So the first objective then is the one that I think we've had put the most energy into. And as I mentioned, the ASHWG was really formed in 2005 -- this is 2009, so it's been three years in the making and we only have just gotten these data tables that I'm going to show you up on the Web, like, last week, so that's why the up-to-date URL isn't in this presentation. But I think we can update it before it goes on the Web so that you will be able to click on this presentation and get right to the Web site that has these data tables on it.

So my point there is that, you know, even though there's this great collaborative that works really well, and it's multi-disciplinarian, focused on the same target population, people are essentially doing this as volunteers, in a way. I mean, everybody else has their scope of work they have to work on, but they come to these ASHWG meetings, they're members, perhaps, of this data subcommittee,

working on this. But it's a volunteer effort, and it takes time. You're working with government agencies, things have been done in a certain way for a long period of time. Again, it's like turning a big tanker around. It takes a really long time for things to happen. So, it has been three years in the making to get these data tables ready.

The hope then -- and so, basically, what we've done is we've standardized them with respect to adolescent age, race, ethnicity and time frame as best we could, with some exceptions. The goal is then to be able to update them annually, to have them readily accessible online, and also to link them to other Web pages, so that people can better access them. And two and three are priorities for the future. We'd like to be able to -- basically, the state level data is helpful and useful, but local data are really what are interesting to people. And there are definitely some challenges with local data, which I'll talk about in a few minutes, and I'm sure many of you are familiar with this. But we would like to try to find some better ways to collect and present data at the local level for the local health jurisdictions.

And then the other piece that people are interested in following up on is looking at behavioral data, because we're talking about just outcome data -- Chlamydia rates, gonorrhea rates, teen pregnancy rates. What about some of those other -- what about the behavioral factors that are influencing these outcomes if we want to design good programs that are going to try to address these poor outcomes,

we really need to look at what the behavioral factors are that are contributing to them. So maybe we can look at trying to collect those core data as well. So, I mean, that's a pretty big fish to fry, but that's on the docket, at least, for the future.

Sorry about the busy slide. Karen has a penchant for busy slides. But this, at least, will be -- at least you'll have this level of detail and information when you download this off the Web if you want to. But just to process for this data integration subcommittee of ASHWG that was formed, we made sure to include an epidemiologist representative from each of the offices, from MCH, from the office of AIDS and from STD, plus a steering committee liaison. So within ASHWG, there's the membership group, which is fairly large, and then you saw that list of people, all those different entities. And then there's a steering committee of about five people, and there's a member of each of the subcommittees on that steering committee. So it really serves as kind of a hub for management of this whole process.

So, having that epidemiologist representation from those departments has made a huge difference in being able to get access to these data, and that's really key. And then, as I said, the plan is to -- what we've done is standardized, to the best of our ability, the demographic categories used in these routine surveillance activities. So we've tried to -- the age groups were -- they were collected in different categories. Maybe it was 15 to 19 in some areas, 15 to 17 in others, 10

to 20 in others. So we've been able to work with the epidemiologist's help, with the data in those different programs, to put them all on the same categories across -- [inaudible] genders we're collecting. And then, also, race, ethnic categories and timeframes, because some HIV data were collected over a five-year periods, whereas the teen pregnancy data, for example, were collected annually. So, we've been able to standardized that pretty well.

And it's -- that'll be on the Web site. Well, they are on the Web site now. And then, it's important also to periodically reaffirm support of the leadership groups. The leadership group then are basically the bosses of those folks on the steering committee, the administrative leaders -- the Department of Public Health, the Department of Education. So ASHWG steering committee members meet with the leadership group periodically, every year, every six months, to just check in, establish that this is, you know, still a priority. And to date, we've had really good support because leaders recognize that we're only as good as the data that we have. We need good data to drive good intervention. So this is something that they've been supportive of. And as I mentioned, our next steps would be to integrate local and behavioral data.

So some of the challenges that we've come up with -- as I mentioned, we've done this to the best of our ability. You're probably familiar with the fact that there are different reporting conventions. For example, for birth rates, it's per thousands, where as for Chlamydia, gonorrhea, STDs, it's generally per hundred

thousands. That's how the rates are calculated. So it's -- we talked about, well, what do we want to do about this? To truly have a standardized data set, you would need to adjust those rates. You have to have them all per hundred thousand or all per thousand. And I'm not familiar with how these conventions came about, but to change them would be difficult. Not only would it be a big project, but it would also -- you'd risk, sort of, confusing people because people are accustomed to seeing rates per thousand when it's births, and rate per thousand when it's STDs. So, that's not something that we've done. It's just something out there. It's kind of like a barrier to this being 100 percent standardized. What we have done is collected them all in one place and standardized the categories as best we can, and you'll see that when I show you some examples.

As I mentioned, it's also -- state-level data are good, but it's also really helpful for folks in the local health jurisdictions to have local data. We have 61 local health jurisdictions in California, and they're very diverse, ranging from Los Angeles, which has a bigger population than many states in this country, to, say, Amador County or Inyo County, where there are maybe two births a year, so very rural county. So there are issues, then, with numbers and confidentiality concerns. And being able to -- sometimes HIV data are -- at the local health level, we wouldn't be able to show annual data because maybe there's only one Latino person in that county, or a couple of Latino people in that county, so -- with HIV. So it would be very -- the confidentiality issues are quite apparent. So, we talked

about how would you do that at a local level. Maybe -- I think the thing that people are focusing on now is maybe you would start with some of the larger counties and do that first, and then maybe come up with some kinds of standards to ensure confidentiality with data collection and data presentation with smaller counties, but those are challenges to -- for the future.

In the Bay Area, in the San Francisco Bay Area, there are nine counties. They're of sizeable counties, some are bigger than others. But in some of these areas, there are still small numbers. So those people from maternal child health data have come together and pulled their data over the nine counties, so that they're better able to look at trends and outcomes on a, sort of, group level. And that's worked well for them, but that may not work well for all counties. You have to think about similar demographics, similar socio-economic status between those counties. There are a lot of issues that might come up.

An example was also given of Monterey County, which is a fairly sizeable county, I think almost 500,000, yeah, population, 500,000. But in 2005, there were only three African-American gonorrhea cases and two male, African-American -- three African-American cases among males and two among females. So those are fairly small numbers, and just -- there's not a high African-American population in Monterey County. And if you presented those by race/ethnicity in a year's time period, you would have some issues.

The other thing - when we talk about behavioral data sources, there's a lot of rich data, but the sources are very fragmented and to be able to kind of coalesce those and work with those is another challenge that we're talking about now that we've gotten this first step taken care of. There is, in California, the Healthy Kids Survey, which has a sexual health module with some good sexual health behavior questions in it but it's optional. Not everybody does it. And then in the Youth Risk Behavior Survey is also - has not been done routinely in California, although I think that's changing. It's just been recently restored to a statewide sample. So, again, we don't - that's something we can work with, we hope, in the future, but there will be some issues with coordination.

This slide is just here to show that the California Department of Public Health has a strategic plan and within that strategic plan, one of the priorities is to reduce disparities, and also there's a sub-priority - I don't know if you can read that - about improving the quality and availability of data to inform public health decision making. So this is a coup for this kind of project. When you have buy-in from the top administrators in the department, it makes it a lot easier to push these kinds of things through.

So this is what the table looks like. Again, I wish I had access to the Internet to be able to show you, but - so what we're talking about is, really, it's a document. It's an Excel document. It's a spreadsheet with all of the - I don't know if you can even read that - but it's Chlamydia rates for adolescent females by age group,

California 2000 to 2006, is the top thing. So you're able to go to the Web site and find all of these tables in one place - Chlamydia, gonorrhea, unintended pregnancy, HIV/AIDS, and then sort of subtopics within that all in one place. And along with the tables, there are also some graphs.

So, I mean, I've done research project. I remember when I was in graduate school, I would do research projects, and you had to go all over the place to find these data. You wouldn't get them all in - you couldn't just click on one Web site and find all the sexual health and reproductive health data pertinent to the adolescent population. So, this is what we've tried to remedy. Again, it's not a huge - big wonderful project, it's not linked data. We're not talking about integrated data surveillance or anything like that. But within what we have and the limited amount of time and money that we have to work with, this is one way to make these data a little bit more accessible to people.

So - and the focus of this talk is not these data per se but more the process. So I'm not going to talk about these data or these charts beyond the fact to show you that, as I'd said earlier, the title of this talk was unanticipated opportunities, so as we began to pool these data together and to have them all in one place, we saw, "Okay, we have some disparities that we knew about, but they're across the board." They affect the same populations with respect to HIV/AIDS, with respect to sexually transmitted infections, and with respect to unintended pregnancy. So

that was something that kind of hit us over the head as we worked with this project.

Any questions as I'm going through this? Okay. Yeah.

UNKNOWN SPEAKER: In terms of data that could be contributed by the Department of Education, do you know - was a decision made early on about whether [inaudible] things like school drop-out rates or academic performance [inaudible] since we're all interested in the weights-

CHRISTINA MALIN: Right.

UNKNOWN SPEAKER: -how do you integrate that as well?

CHRISTINA MALIN: Yeah. What was that? Oh, yeah, I'm sorry. The question was about the contribution of data sources from the California Department of Education such as school drop-out rate and whether we had considered getting those data, integrating them into this project.

And, as I said, this is really a preliminary step. We started with these outcome data because they were the easiest to get to for us. We have talked about looking at those kinds of data. So when we talk about behavioral data, not just sexual risk-taking behavior but also other behavioral data that sort of relate to

resiliency and education drop-out, as you said. So that is something that we do want to have happen. As I mentioned, the surveys, the Healthy Kids Survey, which is - and the YRBS survey, which I believe the Department of Education has purvey over, we - there's an ad hoc group that's hopefully going to come together to write a letter on behalf of ASHWG to try to get those sources of data and also to suggest that the sexual health module, which as I said is optional, that some of those questions could be moved into the core component of Healthy Kids. So that's a project that - but as I said, it does take time for these things to happen.

So, anyway, so teen birth rates is higher among Hispanics. I'm just skipping through these so you can see. But basically this is what we - what's quite apparent was that there are overlapping priority populations. You see higher rates of teen pregnancy in Hispanic, African American teens, higher STD rates among African American, Latinos, and also the same for HIV. So, not anything that we didn't really know, but it certainly makes it easier to work on a coordinated project if everybody has the same focus within these different departments.

As I said, disparities were not an original priority goal for ASHWG, but the focus on data integration did bring these to light. So it's forced ASHWG now to think about how they're going to address these disparities. And at the reconvene meeting in Tampa, which was - everyone who went to that initial stakeholder

meeting came back together in Tampa to look at their priorities - the priorities that were identified, we decided to stick with those, but we've decided also to add another workgroup or priority workgroup to address these issues of disparities. Okay, now we have some of these data, we need more to be able to understand the best way to develop interventions, but let's put together a working group that's going to try to turn these data into practice. So that's a new priority for ASHWG. And we can make good use of what we have, but we look into the future, we really would benefit from having more behavioral survey data, not available for all school districts but at least we can start with some local health jurisdictions to develop some kinds of programs that could be pilot tested and might have relevance to other health jurisdictions as well.

The upper management support was really critical. Again, I think the fact that we had - we were able to get upper management support but that they were midlevel managers involved from the very beginning that were able to come back, hit the ground running, do the work, and then get buy-in from leadership really pushed the process along, I think, in California. My understanding is that ASHWG has really made quite a bit of progress despite our poor showing at that meeting in 2003 because of the budget crisis. We've moved along pretty well because of the fact that we had these midlevel folks that were involved from the very beginning. And having the epidemiologists support is really key, really key. And I know how difficult it can be to get data without having that buy-in from upper level Epi on your committees.

This slide really just relates to our interest in being able to collect more behavioral data or data about protective factors, both internal and external, to create a more nuance picture of what's actually going on with these young people. And this slide is also just another one about integration and collaboration across health and education. These indirect contributing factors that you see in green in the middle, those root causes that were - that we know drive so many of these disparities are, really, we find these to be in common among youth who both have - who are at disparate risk for poor - for drop out and other poor educational outcomes and also for poor health outcomes. So what's the remedy here? What - this is a big issue and how do we address it.

This is not really the focus of the talk, but the reason that I'm showing you this is that - it's not enough just to come up with these data and to see, "Okay, we have these disparities and, yes, we know that some of these behavioral data or these root causes have something to do with it," but what are we going to do about it? And that's why this committee has come together just in the last month or so that we decide to develop this committee to look at disparity. So we'll have to keep you posted on what ends up happening with that group.

But I think that even - I think the interest among this group is really to look at adopting a youth development focus in our work, to look at those protective factors, to look at those broader root causes, not just unavailability of condoms or

sex ed in the schools, but looking at what kinds of opportunities youth have or don't have in their communities, and trying to incorporate that into the sorts of interventions that we design especially at the local level.

These are just some preliminary ideas that people in this new workgroup to address disparities have come up with as possible strategies for ways to decrease racial disparities among - in sexual health outcomes among youth at the individual organization and policy level.

So, Karen wanted me to leave you with this thought, which is that you've heard about what we were able to do with existing data sources. Again, it's not integrated data surveillance. We're not able to change data categories. We're not able to link data, but we're working with what we have. And it's helpful to people to have all these data in one place. We'd really like to be able to add behavioral data and more data, say, from the Department of Education or other sources. We think that we can leverage this partnership, this ASHWG partnership to be able to access more data sources and to be able to include those in an integrated dataset.

But do we have to wait until that happens? What action can we take now? And her focus is really that we know that youth in our country need - I mean we know what drives disparities and we know what youth need, and we should still think about integrating a youth development focus into our work even if we don't

necessarily have data to support that. We definitely want those data, especially from a policy perspective, it's important, but we don't have to sit back and wait, especially in terms of providing technical assistance to the local level about ways to work with youth on healthy behavior change that really makes - really comes from a place of addressing those system-wide factors. So, that was her sort of parting note to all of you.

And I think that's the end of the presentation. And I apologize again for not being an expert on this. I'm happy to try to answer any questions that you might have.