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WE ARE MAKING A DIFFERENCE: LEADERSHIP, INNOVATION AND INVESTMENT IN MATERNAL AND CHILD HEALTH

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Digital Storytelling: Addressing Barriers to Care for Depression

EMILY FEINBERG: I'm actually really thrilled to be able to share some of the work and the digital stories that I'll be presenting today in this workshop. Oh, can you hear me? There, okay. No. You can't--get closer to it. Can you hear me now? Okay. Is that--can you hear me if I'm here? No. Can you--how's that? Better? Okay. So let me give you an overview of what we will be covering today in the workshop. And I'm gonna talk a little bit about what digital stories are, the context that we develop, the stories that I'll be presenting today, the rationale for the stories in terms of addressing disparities in care. Talk a little bit about their use for specific activities and particularly the work that we done--we have done--has focused more on education and community dialogue and use for specific populations. I'll be showing five different stories throughout the session. And depending on how much time we have for discussion--we want for discussion and then we'll deal more with the nuts and bolts of creating the stories. I had--you have a bunch of handouts. You have the slides and the other handouts really talk a lot more about the nuts and bolts of story development. For those of you that

think you might be interested in thinking about how to integrate this into the practice of your organizations.

I also want to acknowledge my collaborator in the Cindy Engler who couldn't be here today. Uh, she work with Boston Public Health Commission and we worked together around development of stories both in project that she's worked on, PSAP, and also in the projects that I've been working on and we'll talk more about that as we go through. (Inaudible)

So to give a little bit of background on the digital storytelling, this was an approach that developed at the Center for Digital Storytelling in Berkeley. And the idea is that it really recognizes the power of narratives to convey women's stories and the importance of women's voice in stories. It--the idea of storytelling is not new. I mean, it's a--the long tradition, particularly in cultures that have strong oral traditions. But what's new here is the idea of using these stories to promote community change and advocacy and also with the advent of new technologies, the ability to do and create these stories using both free and easily accessible technologies. So these can--the stories can be produced on laptops with free and available software.

And I thought the best way to start out the presentation was actually to show you a story so you have some context of what we'll be talking about. So this is the first story that we'll be presenting and this was developed as part of a training

workshop. There's a number of ways that stories can be developed and the--one of the models is a sort of train the trainer workshop. And this was developed as part of a train the trainer workshop. And Melissa, who created this story, just to let you know, has given us permission to show this. And I started with this story because I think it covers a number of the themes that we'll deal with in greater depth and those are stigma related to mental health issues in immigrant communities, the role of cultural beliefs and traditions, and issues related to treatment and medications. So I'm challenged by the technology but I think I got it down, so let's--let's see if this works. (Inaudible)

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: (Inaudible) Okay, so how come I couldn't do that? Okay, so I want to take a step back now. And now that you have a little bit of sense of what it is that we--what digital stories are and give you some sense of the context that we develop these stories. And the first was in the context of a project that I have been working off for the past five years that's actually been funded by one of MCHB's Healthy Tomorrows for Children grants called Project Eastmark. And the goal of this project was to use the electronic medical record to screen mothers for depression and to refer them to treatment. The other project that this--that stories were developed in the context of was the Preconception Screening and Assessment Project or PSAP which screened women of reproductive age for a series of behavioral risks and a new project that we are sort of--just in its early

stages called Project Solve which is working with community-based organizations, mainly redstarts, healthy families and early intervention to increase their capacity to address the mental health issues of women in the programs.

So a little bit more about the projects. Project Eastmark came about sort of with the basic premise that maternal depressive symptoms were under-identified in low-income, culturally diverse women and that pediatric primary care really represented an alternative venue which--to identify and manage maternal depressive symptoms. We worked at primarily three community health centers to investigate the potential to integrate routine maternal depressive screening into well-child visits and also to see sites that had electronic records. What was the potential to use the electronic record to integrate care across disciplines in the community health centers? And the sort of rationale for this approach was the idea that treating mothers is really very good for children. Well, treating mothers is good for mothers but to try to convince pediatrics providers, we felt like we needed the link in the relationship between maternal depressive symptoms and child outcomes. As a five-year demonstration project and--thank our funding sources--these are the three primary sites that we worked with. These are all health centers in the Boston area.

And I said, our key barrier was to identify mothers with maternal depressive symptoms, to facilitate a pediatric-based intervention. I'm happy to talk about that

later but I'm not going to go into depth here and really think about integrating depression care across disciplines.

The PSAP project, its goal was to develop a screening tool for women of reproductive age for multiple behavioral risks. And it was designed to be used in primary care. The goal was really brief and primary care. And the sort of secondary goal was to link screening to assessment, education, and intervention. So the idea was universal screening so that even for women who's--didn't have any identified behavioral risks, there was an educational component about it. The PSAP project was implemented primarily with the lead agency, The Boston Public Health Commission and the Massachusetts Department of Health--Department of Public Health and two community health centers. Funding was through MCHP. And since then its expanded some to additional health centers and expanded its somewhat its implementation model. And one of the challenges in--both challenge and premise--for PSAP project was Y-screen and primary care. And the underlying premise here is that primary care is really kind of somehow a safety net and pivotal point of care for women. It's where women have long-term relationships and that it can be integrated into a wide range of health-related activities not specifically related to pregnancy-related care, which is often where depressive screening for women is focused.

There's an opportunity to think about mental health care across the women's lifespan and opportunity for early intervention. The PSAP project spent a long

time in terms of tool development and they developed kind of a continual feedback loop of--they convened a screening working group that had experts in the areas of substance use, domestic violence, depression, and (inaudible)--those three areas. And there was also a project advisory committee that included community members, most from the health centers, from the Boston Healthy Start Coalition and consumers in the community. And the feedback loop worked with the sort of screening working group that's sort of, we say, experts looking at--reviewing particular tools, really honing down the tools that--to put on the screening tool. It then went to the project advisory committee for sort of further refinement, acceptability to populations where it'd be implemented. And then was further sort of refined and tested with focus group of consumers. This was a quite diverse group that the two health centers represented. One health center was primarily Latino women, mainly Puerto Rican and Dominican. Second health center had both Thai, Vietnamese, Brazilian, Hispanic, White women. So pretty broad diversity. Um, there was also meetings with the health care providers at the particular site and surveys of--with the providers in terms of acceptability of the tool. And I'm gonna talk a little bit as we get further in about some of the disconnect between the goals of PSAP which was screening in primary care, in terms of women's expectations and providers' expectations.

Project Solve which is sort of the newest area that we're thinking about digital story implementation. As I mentioned is really--the goal is to support and increase the capacity of community-based organizations to address maternal

emotional well-being, It shares some of the premises with Project Eastmark in terms of looking at child-focus settings as a potential venue to intervene with women around mental health issues, those areas being less stigmatized and where women who often don't access traditional mental health services are already receiving services.

So when we think of use for digital stories, there's really we can kind of think of it in three categories. Education, which is the primary focus of our work, community and community dialogue. But there are examples where digital stories have been used in a much broader sense for fundraising, for advocacy, and for policy change. And I'll give you a few examples that I was really impressed with in terms of the way digital stories have been used. There was one project in California that was a collaboration with--whatever California's specific name is for their department of social services. And they sponsored a yearly workshop for youth in foster care where--where youth would apply to the workshop. It would have a particular theme. Like it might be permanency or transitions. And the--a group of-- a large group. I think about a hundred youth would come to the training workshop, would develop stories. These stories would then be integrated in the--into the training curriculum for social workers who were working with foster youth. There's also been examples where digital stories have been used to address issues around domestic violence, again from the West Coast, from California. And some places where people have used digital stories to really showcase their work to funders and other community agencies. So for example, in Boston, one

group developed a digital story around the issues of mortgage, home foreclosures, and mortgages to really talk about the work and demonstrate the work they were doing to other agencies in the community. So it give you a little bit of a sense of sort of the range of ways that digital stories can be used. Um, so this again is some of the examples.

Um, I'm going to talk specifically about some of the work that I have been doing for the last few years which is using digital stories to address barriers to care in Southeast Asian communities. Two of the health centers that we've been working with served large Southeast Asian communities. One Cambodian, one Vietnamese. And it became very clear from our early work around screening mothers for depressive symptoms that the tools were not working as well in those communities. And it was a combination of issues, some related to stigma, some related to what we refer to as mental health literacy, which is really no--really not a sort of understanding of what are mental health issues, how do they look, what do you do about them, what's the role of different providers in care. There was also issues around the cultural context of emotional health. I've worked closely with community members in terms of thinking about translations and how do we explain what we're doing and in both languages, there's not exactly a word for what we think of as depression. So there are--there's a very medicalized term and then there's sort of a more symptomatic term. So really understanding how do you think about the cultural context of emotional health within both the linguistic and cultural experiences of the Cambodian and Vietnamese

communities. And both communities share a legacy of trauma, Cambodian community perhaps more so than the Vietnamese community that we were working with. But that, that legacy was--you'll see in these stories that we'll show, definitely and undercurrent and the question the community members felt was how to bring that forward, acknowledge that as a shared experience and then move forward from that.

So we wanted to develop these stories to promote community dialogue. Um, both among community members themselves and really to work with the healthcare providers in those communities so that they had a better understanding of the experiences that the women and the families that they care for from the health end, how they understood their sort of emotional well-being. These--particularly the Cambodian community where literacy issues were a major issue--the sense of oral tradition was strong and it was felt that this approach was really a good fit for community dialogue.

So just to give you a little bit of background on the two communities, the Vietnamese community that we worked with is in Dorchester, Massachusetts which is a kind of one of the subsegments of Boston. It's probably the largest community within the Boston--Boston divisions. There have been two waves of immigration, their first one being in 1975 to '77 when these were really more well-educated professionals and military staff that came directly after the war. And in the next wave of immigration was mainly boat people who had spent a significant

time in the silent camps. The early Vietnamese members who came to Boston had refugee status and the reason that I mentioned that is that it was really important because it offered them certain benefits in terms of health access and access to certain public programs. Since the '90s, the relocation program has ended. New Vietnamese immigrants who are coming to the country no longer have refugee status. The other issue is the issue of north-south tensions which persist in communities today and it plays out in really difficult ways. Boston has had--I think has not had the same degree of tensions as other areas (inaudible) from the West Coast but--and Boston has the first Vietnamese community center in the country. It's not because it's the largest community but I think there've been struggles and difficulties about uniting Vietnamese communities around some sort of common goal in order to move forward from that past experience.

In the community in Dorchester, men worked mainly as floor sanders or do stone work, and almost all of the women who are employed work in nail salons.

The Cambodian community which is centered in Lowell, Massachusetts is the second largest Cambodian community in the US. It's about 18% of Lowell's population, so it's really quite significant. It's a young population, so it's about a third of the school age population. Major immigration happened in the 1980s and there's something I--how did the Cambodian community end up in Lowell? Well, there was a benefactor, an An Wang, who (inaudible) numbers of cultural sort of big performing arts center in the city was named for him for a while. And he had

weighing computers and developed a whole series of assembly plans that were located around the Lowell community, and hired lots of Cambodian immigrants. And that became sort of a magnet where more and more people moved and relocated to the areas. And so that was the--sort of the start of the main place where the Cambodian community was employed. Since then, his company has gone. The computer assembly plans are gone. And so this sort of access to reasonable, paying, steady jobs is much less. And most of the immigrants who came had survived the Pol Pot regime and the legacy of trauma is just enormous. I don't know how familiar people are with that, but it's quite intense.

So when--before we started to think about the stories, we did a series of interviews with mother to learn about their views about the acceptability of discussing maternal depressive symptoms during well-child visits. And we did 47 interviews and about a half of them were with Southeast Asian women. And it was kind of from these interviews that we became aware of the kinds of issues that would be important to address through the stories. So these are two quotes from the interviews and what kind of came out was that the symptoms of maternal depression were similar. The sense of sadness, wanting to be alone, this sense of deadness, dullness, but that the causes and understandings of causes and treatment for depression care were very much rooted in people's cultural traditions. So some have to do with sort of relationships between physical symptoms and body symptoms. But then we felt it was important to have woman

of similar cultural backgrounds address sort of how they felt about their depression and what they did about it.

So I'm going to show two stories from two Cambodian women. These stories are somewhat different in terms of how they were developed. These were developed sort of on much more one on one relationship because in this case, the issue of stigma was huge and people were really reluctant to come forward and develop a story that could be used in their community. So Rina's story--she works as a liaison with the police department and she was okay about having her story used both in forms like this but also within her community. The second story that I'll be showing--the woman was fine about the story being on the web, fine about coming to big meetings but did not want it used in her community. And I think it's the sense of being identified within your community and so that's sort of one thing to think about is if you think about some integrating these--this approach within your work is how do you work with people individually so that the stories that you develop and produce, you can then use in the forms that make sense? And the other is the process of actually doing stories. And these are really intense stories. And doing them required a very close working relationship between both facilitator and--we also had someone help us with the technical aspects of the story. Because the stories just brought out lots of issues that sort of--people hadn't—they were really difficult to deal with.

So I'm going to show both, both stories in a row, and then talk a little bit about some of the commonalities and some of the themes and ways that we will be using these stories. And now I'm going to see if (inaudible).

UNKNOWN SPEAKER: (Inaudible)

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: It's just background. Does anybody have any questions that I could answer at this point? That was kind of intense.

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: Um, let me go through a little more and then if we don't get to that point then, yes. Um, so in terms of these two stories there were two common themes and which, we think our--they really strike you but in terms of for provider understanding in working with Cambodian families, one is the intergenerational transmission of the impact of trauma. And this is particularly an issue because many of the younger women in particular either were very young or might not have experienced the actual trauma. But they're definitely living with parents and sort of elders who have experienced the legacy of trauma. And for many of the women, they have talked about that sort of parenting as a reminder of the loss that they had as children so that as they become parents themselves,

the issue of where was--what was it like for me as a child and where was my mother during this time kind of has reawakened. And the issue of parenting in the absence of parenting models is something that I think for service providers who are working in these communities is really important to sort of put this in the context of the community as a whole.

We switch gears a little bit and think about disparities related to access to care. And when we think of disparities related to access to care, we often focus mostly on sort of the provider side, sort of what are the services that are there and whether or not people can actually access them. But I think part of what I've learned from this process is that we kind of have to think about disparities in access to care is a kind of a two-way street in the sense that some of the disparities come about because while the services may be there, there's a reluctance of women's part to access them, related to stigma and this issue of mental health literacy. And in the two--in the stories that I'm going to show in this portion of the presentation, one of the women very eloquently talks about how important it was for her to understand what did mean to get mental health services. What did the psychiatrist do? What did the counselor do? What was the role of your primary care provider? And so part of what we see is the role of these is stories (inaudible) education around what mental services are, how you access them, what feels good and bad about them, the choice that you have in the process of receiving mental health services. There's definitely, we learned in the interviews and some came out of these stories was that there's a real fear

that women feel like that if they agree I'm going to do something, that mean they're going to be forced to do things that they don't want. And that particularly related to medication issues.

Talking of disparities, there are disparities that arise from women's reluctance or apprehension to actually access the services that may be available. There's also provider perceptions about patient preferences. A reluctance to talk to women about mental issues and their emotional well-being. That certain assumptions that providers may have about the way women present themselves--and one of the stories talks quite a bit about that. There's also issues related to language and cultural issues, finding a person that a woman feels comfortable with. And then also issues related to monetary issues of actual insurance and ability to pay for services.

So from the PSAP project, they learned a lot about the this idea about the disconnect between provider and consumer perceptions and thought about digital stories as the way for providers to hear what women thought. So providers felt they screened for depression, and that may be I look at the woman and if she seems sad, then I know whether or not she's depressed. There is also certain providers feeling that this was not the role of the primary care provider, that women did want their primary care providers to be asking them about their own emotional health, that it was not culturally appropriate. This was a particular issue for one health center that--this is not the health centers that I was working at but

one of the health centers for PSAP project that had large numbers--not large--but sizeable numbers of Asian women. They thought that the Southeast Asian woman would be insulted if someone asked them these questions. And that there was also an issue around the education component. Whose role is it to provide sort of basic education around behavioral risk? The consumer side--consumer side were not being asked these questions, even when you think you're asking me, that they wanted their PCP to do the screening. They wanted someone they knew and had a connection with. They wanted--they felt all women in all cultures should be screened for depression and also for substance abuse and alcohol use. And then everybody should receive some education even if you had no risk factors present.

So it was kind of this disconnect that--(inaudible) how do you deal with this? Well, coming in saying, this is what women said, that helps. Quotes help, but we felt that stories, actual stories would be far more powerful in creating provider change. So the take home message from the interviews and focus groups with providers and consumers was that women felt their voices were not being heard and how to put forth women as the experts in their own experience and how women could really be educators to the healthcare community about the kinds of services that they wanted and they felt they needed.

So I'm going to just switch discs and the next two--this story is the story of Maria who's a Latino woman from Guatemala and she had experienced some of us

might call the more the traditional barriers in terms of accessing services, in terms of getting diagnosed in primary care and getting treatment. And it's her discussion you'll hear in part of the story--it's a longer story than the others that I've shown--talks about this idea of mental health literacy about needing to understand what providers' roles are, and how that would make feel much more comfortable in terms of accessing services. So let me (inaudible)

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: So I wanted to (inaudible). Um, Maria was able to--since this story completed was able to reconnect not with the same psychologist but with another provider and is doing okay. So it's--and the other part of the story that some people wonder about the first picture with her dressed in--people chose their own pictures of the way they wanted to present themselves and this was a picture that she brought to the workshop and wanted as part of the story.

So in thinking about this story, we hope that it will be--we can use it to support clinicians to address women's behavioral health concerns and to present women's perspectives on their care and experience. And to me, the part that's really important is when she talks about her relationship with the psychologist, it's not that the person had to be exactly of the same ethnicity or language. It turned out that her psychologist was a Brazilian woman. They didn't share the same language or the same ethnic background, but that commonalities of, as she said,

of being a immigrant, of being a mother, that--as she, said, that was really key to her. So I think in terms of understanding what parts of women's experiences need to be validated in their relationship in terms of receiving mental health service is one to really think about. And I thought it was also interesting the part she talked with the psychiatrist of the person the traditional model, you talk and talk and the person listens to you and reflects back in this very distant way just seems so foreign to her and almost uncaring that again said understanding what people's roles were and what she might expect from that, I think would be very helpful in terms of people who have no experience with mental health services in their histories.

And this is the last story that I'm going to show. This is a story which is--I really like because it talks about the importance of pediatric providers. (Inaudible) in the beginning but I have an academic position at Boston University School of Public Health and teach and do research there but I'm also a nurse practitioner at one of the community health centers on pediatric person. So this story talks about the importance of pediatric providers in addressing family and particularly mothers' health concerns. And I have not used this story with pediatric providers but I'm really looking forward to it because I think it really talks about one of the strengths of that relationship, a feeling that pediatric providers may know a woman's family and what kind of leverage that has in terms of ability to connect families with services. And it also talks about the whole issue of formal depressive symptom screening and the assumptions that providers made about

Rosa because she came from a strong family and this sense of having lots of support and people around her. (Inaudible)

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: I'm sorry. I'm not getting this right. Just (inaudible).

UNKNOWN SPEAKER: (Inaudible)

EMILY FEINBERG: I'm going to skip the part about the elements of digital storytelling--what makes an effective story . It's really well laid out in some of the handouts so that we can talk more about some of the questions that you have. I'm going to go through this and we can go back if there's--but in terms of how did we develop this stories and how did we work with community members. So there really--well, kind of two ways. But I'm calling the individual format which where-- Rina's story and the new family stories. And those were one on one relationships. There was a woman in the local community who worked with our project who had done lots of community outreach and it was through her connections with women in the community that she approached specific women that she knew and asked if they would be interested. And this was key because for one, she was trusted, and she was able to explain the context on why it was important. But there were man women who she spoke with who did not want to. They were not willing to share their stories. And the whole--from the position of the project it was hard to

think about developing a story that would just be for the individual's use in terms of resources and budgetary considerations. So there was a little bit of a tension between identifying women who were willing to tell their stories and making commitment that their story could be used in some public way. Although, there were ranges about how that could happen. And people who developed the stories had very different levels of literacy in terms of being able to write their own stories or record their own stories. And these stories--women were probably more educated than some stories that we've done later were--we've actually done two additional stories in the Vietnamese community where the members had basically no literacy--no writing skills. So the process of brainstorming and story development was really a kind of a dialogue between the person and facilitator who had--was a community member and share a common language. And what happened in some of the stories is kind of (inaudible) process of telling the story than of a facilitator writing the story down going back and saying is this the story you want? Is this your story? A couple of give and takes of that. And then all of the women did their own voice recording. Some were actually in the process of trying to do voice overs in Khmer for the Cambodian stories which will be-- (inaudible) cable news, cable TV show, where we'll show the story and there'll be a discussion around maternal depression and--. The individuals all identified their own pictures from their family pictures as well as saying I want a picture like this and then working together to go to the web to see this is what you want your picture to be like.

The time commitment was a big issue for people. It--we outlined about the amount of time which was usually three or four, couple hour sessions. We did provide stipends to community members because we felt that it was an investment of their time and that I think was important, that it also meant that we were serious that we took their time seriously. And I talked about the issues of releases. So we talked a lot about the range of the way the information could be used and asked people to sign releases for specific information which would be on the web, in the form where they didn't know people, in a form with providers in their community. And there are some--well, some of the new family story and another story that I didn't show, we--even if the person had given permission to use it in their community, the question is is that appropriate? Because there's this story and another story which was about a Vietnamese woman's relationship with her mother-in-law, which is a very--a very serious relationship in that community. And it was very troubled and she said the story she wanted to tell but really didn't feel it was appropriate in the community to put this story out that really was disparaging to this woman. So there's also this dynamic about kind of taking a step back and if you're going to be showing this story, what are you promoting within the community? So that's another kind of tensions.