AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

March 3rd to 7th, 2007

Emergency Preparedness for Special Populations: Maternal and Child Health Coming to the Table Meet the Needs of CSHCN and Pregnant Women

SUZANNE GOTTLIEB: Welcome and thank you for coming to this session. Um, I heard there were snacks out there, so I wasn't sure whether anyone would actually find their way in the room, uh, it's encouraging to see that you did. Um, I really appreciate the chance to share some of what the Massachusetts Department Of Public Health, Maternal And Child Health Programs, and, um, CSHCN programs have been doing around emergency preparedness for children with complex medical needs and their families.

And now, if I can figure out how to use the machine, I can even show you some slides. Yes, it worked. Um, we have been working based on multiple and effective collaborations between our department of public health and families who have children with complex special health needs, and then more broadly with our sister agencies, with local government, with community organizations and with individuals. It's an ongoing process, as those of you who are engaged in this emergency preparedness, I'm sure, know.

And it’s really dependent on many variables, including, at any given time, resources, personalities, um, availability, timing, commitment, everything has to align in order for this work to go forward. Before I get really going into my presentation, I would like to just ask for a show of hands, how many people, in this room, have either a personal or a family emergency plan created? Uh huh, yes. Well, you look pretty much the way most of us looked when we started this work, and we really had to get into gear in order to practice what we preached because we were out there talking to families about the importance of plans and in the first year or so, I can’t tell you how many times families actually said, yeah, do you have one?

And most of us had to say, not exactly, was the answer. But it’s, it’s encouraging to see that there are a number of people who have done that. I’d like to give you a little bit of background about why we’re doing the work. Um, and it really did come about through a, a confluence of events, the first and most obvious one being, of course, a response to the events of September 11, 2001. And hearing about the actual difficulties that families whose children have complex special health needs had encountered, hearing about their fears of what could have happened, how it could’ve been worse, and what might still happen.

And please keep in mind that we’re from Massachusetts and that it was, uh, you know, a plane from Massachusetts that was hijacked and crashed so, um, we felt pretty close to all of the action that was going on. The second, um, influence on

the work that we've been doing, some of the work that I've been doing and my staff has been doing around emergency preparedness came about, um, based on 15 years of advocacy by our state developmental disabilities community, families who had individuals in their, family members with DD had been advocating and trying to get our state legislature to really be more responsive to the kinds of supports they needed.

So, in 2002, the Massachusetts legislature enacted a law that required all human services agencies to develop, based on substantial consumer input, um, family support plans that would address the support needs of individuals with disabilities or families who had children with disabilities and make those supports much more flexible and much more family directed. So when we went out to start getting our substantial consultation, emergency preparedness really rose to the top very quickly.

Again, it was 2002 and the events of September 11th were very fresh in everyone's mind. And then the third, um, imputes was really, obviously, the federal and state mandates to, um, identify and develop strategies to address the emergency preparedness needs of special populations. We found out a number of things in our first and really ongoing rounds of communicating with all the people involved.

First what we learned about families was that very few of them, even those with the most complex children, had formal plans. Few of them knew who their first responders were, and even less, even fewer really knew what their schools were doing, what their communities were doing, or could do, around emergency preparedness. In terms of first responders, what we discovered was that many of them had no idea what the specific needs that they might be called upon to address would be among families who had kids with complex needs.

They didn't know the individual children, they weren't sure if they were gonna have the appropriate training, the appropriate equipment, or really be able to respond, effectively to a variety of different needs. And finally, we heard from communities, that they were all at different places in their plan, they also were not aware, particularly, of what individual children and families were living in their communities, and most of them were engaged in a pretty closed planning process.

It was a small group of people meeting behind closed doors. Who knows what they were talking about? But they were not, necessarily, talking about the kids and families that we were working with. Um, I wanted to share that it felt particularly relevant for me, I'm on the parent of a young adult with complex health needs who has a hearing loss. And on September 11th, he was working in a big building, doing data entry, in the back of a high floor of this building. The building was evacuated, there were announcements over the public address

system, I wasn't there, nobody who knew him was there, we were all out at, at a meeting, and he was left in this evacuated building.

So it was very traumatic, less for him, he never really quite grasped that this whole thing had happened, he just, you know, somebody came and found him and he got out. I was traumatized beyond belief by the fact that this had happened and it really clarified for me how critical it was to get cracking and do some planning. Um, I wanted to get this slide in here, I know you all know who special populations are, but I think it's an interesting graphic to see it up there on a slide, and really have a look at how diverse groups we are talking about, and how broad and deep the issues of these different groups are gonna be around emergency planning.

I know I've been at many meetings where people have been somewhat offended by this grouping, and have really, not only said it wasn't politically correct, have really felt it was just inappropriate, completely. And I, I think that the best way to explain it is that all of these groups are individuals or groups who may very well require more or a different type of support in the event of an emergency. And I, what we're coming to now in Massachusetts, after we aggregated everybody, is really splitting off individual, individual people in groups so that we can do a better job of planning.

I wanted to show you this, too. I know you're all aware of disasters, but I was so thrilled with myself that I could attach graphics to these things, that I thought I would put up a slide being a, a completely technological idiot. It was, uh, it was very exciting to be able to create this. Um, and again, it's good to see these things laid out so that we can recognize that we're talking about a variety of situations that can occur without warning. And that we have to really be aware that we need plans on the state level, on the local level and on the individual level that are going to address any or all of these things that might occur.

Um, we've learned that some plans can be made and can be generalized to fit most of these situations, but we also know that there's a need, that, to create plans that are structured to meet specific situations. For families whose children have complex special health needs, we've also really been clear that it's often necessary to customize plans and interventions that are appropriate for their unique circumstances.

And the, the point that I want to really hammer in, which, you know, you're MCH people so I probably don't have to, but, I want to do it anyway, is that the key thing in this planning process is that families really need to be at the table as the process goes forward, and that we need to be working and assisting communities to develop partnerships that include families. We've tried to identify for the various partners and stake holders the benefits of including families, and they're the usual ones that family can really help agencies and planners to

understand their unique needs, that families, very often, provide a reality check for agencies, um, that we can ask families to have a look at, to take part in the development of responses and know that these things are gonna work, that they're not something that was developed in isolation without input from the very folks who are going to be involved.

And finally, as a major benefit, we talked to agencies and organizations about being able to utilize the information and the resources that families have or the other things that they can access. So what've we done? Um, a bunch of things starting by, we saw that the Department Of Public Health, Maternal And Child Health, saw a major piece of our role as being to promote the partnership, to really impose on our state planning efforts, the MCH best practice model of family involvement.

Um, bring that to the state level and use it as a model for what was going on in the community. We became part of our special populations working group, which was led by our Center For Emergency Preparedness. And a good part of our role, the Maternal And Child Health, and the CSHCN role was really to advocate for family involvement and to represent the needs of individuals with disabilities and families who had kids with special health needs.

Because it was such a huge group of people in the special populations, uh, different groups could get lost if their advocates weren't at the table, so, we

thought that that was a good role for MCH. Um, other things that we've done, we started in 2005 going out, statewide, having regional meetings, and trying to find out from families what was their personal level of preparedness, what did they need from us, how could we be most effective and most helpful in getting them ready in the event of any kind of emergency or disaster?

Those meetings, that first round statewide, were such a tremendous learning experience for all of us. For me and my staff, all of whom are parents of kids with special health needs, and for the, our colleagues within the CSHCN program and Maternal And Child Health programs. And the thing that really, really, really jumped out for us is that effective response is local. That, at the state level we had all kinds of mandates and responsibilities, but a major one was really going to be to facilitate communication and planning at a local level and ensure that our families were represented.

Other things that we did in those first couple of years was the development of and the dissemination of resources. There, on the back table there are a couple of sample packets that we developed for families and for professionals. I only brought two because they're heavy, please feel free to take a look, if you would like to have one, just let me know and I will be glad to send one out to you to use as a template.

Um, another thing that happened was that in all of these meetings, many of the same issues and questions rose to the forefront. And rather than addressing them individually and one by one, we put together a frequently asked questions document. There are also copies of that document on the back table, it's available on our Department of Public Health website as well. Um, and we are happy to share any materials that we have created, any lessons that we've learned.

Okay, we did more things, we didn't stop. Um, this past year, what we did, based on what we've learned in our, in our previous work, with help from our Department of Public Health regional emergency planners, was to facilitate a series of community level conversations. Those conversations were so powerful, they brought together, and I'm watching the tape back there which is making me very nervous, but we did tape one of them, actually, of the community conversations that we did, and re-looking at it, I could not believe what happened when we brought to the table all these diverse stakeholders.

When the local emergency planners and the people from the schools and the elder services people in the community and state officials and families all came together and talked about who they were, what they needed, what they had done, how they could help each other, it was really an impressive occurrence. Um, so our job, we felt, was to facilitate and to continue to facilitate that

collaborative planning process and to be a repository of the information and, and then disseminate it back out so other people could, um, utilize it as well.

Another thing that we've done that's been really exciting has been to work collaboratively, as I said, with some of our sister agencies. We have developed and disseminated training for those agencies, um, that are working with families who have children with complex health needs. A really terrific example, I think, is our work with our State Department Of Mental Retardation. Our DMR contracts with a number of vendors across the state to provide family support. And this year we started training all of those family support workers around assisting families who have kids with complex needs to do emergency preparedness.

And the collaboration has been so effective that DMR has made it a performance measure for all of their family support vendors that they have to document that they are doing emergency planning with families. So that's really extended our reach, tremendously. Um, we've worked with all the other human service agencies that are mandated to do family support plans to include information about emergency preparedness in their plans, and we've done training for local government for community agencies for family groups and for other interested individuals.

Another initiative that we've been involved in that has been really exciting has been working, statewide, with all of our EMS providers. The children's

emergency medical services program at the department, um, reached out to our EMS providers to say, um, we think it would be really terrific if you got to know a lot of these families so that you would know what they needed. We weren't sure how they were gonna react because, you know, everybody always feels they have too much to do, but we got a tremendous response from our EMS providers.

Most of them gave us contact information and times and places so that we could have families contact them and begin the process of getting to know each other and building trust. What was really interesting was family reaction. As I said, we thought it would be the EMS providers who said no, no, no, we can't do this, what it's really been has, is families have had, are having trouble with the balance of what they see as a loss of personal privacy, as the possibility of being stigmatized, balancing that against, okay, someone who needs to know me knows who I am, what my children's needs are, and can respond quickly and effectively in the event of an emergency. So we're still working out the details of that.

Another piece of work that we thought was very clearly a job for Maternal and Child Health was helping some of the stakeholders involved in this process understand why some families might need special assistance. It's obvious to us, it's obvious to you guys, it wasn't so obvious to people at the community level, that a different type or level of support might be needed. So we've done work

with community groups, with local governments, with first responders to really help them get it, that when there's durable medical equipment involved, when there's technology needs, when there are social, emotional and mental health issues, when there might be cognitive challenges, that it is very likely that what works for the general population is not necessarily going to work for the families that we're talking about.

We also wanted to be concrete with these community agencies about some of the things they could do, because in our early conversations and in our early outreach efforts, people said, oh yeah, yeah, yeah, well just tell us what to do, so, we did, which was sort of fun. Um, and what we really laid out for people was, first of all, this very important principle of inviting families to join the process and making it a much more open process.

We gave them guidelines to really increase their awareness of what some of the additional issues that I talked about a minute ago might be. We gave them resources and supports to figure out how to put in place some of the accommodations that would support families whose children have special health needs. And then, as I said, we developed a lot, quite a bit, a number of resources and materials that we have been disseminating.

I mentioned that we had done training for family support vendors and other community and family groups, and I just wanted to give you a snapshot of the,

uh, type of curriculum that we developed. It's really been a three tiered approach, and it has been effective both for professionals and for families. So what we've done is really, in the first level we talk about basic preparation, which means for professionals and for families, we expose them to tools to create a personal or a family emergency plan, we've introduced the AAP Emergency Health Form, we've, um, disseminated a lot of Red Cross materials, the talk about sheltering, the talk about creating disaster kits, that really allow people to figure out some of the concrete things that they need to do.

Um, in a, in a second level, we've worked to help people understand strategies to build networks, to figure out how to share information, who needs to know what, how do you get your plans out to your schools, to your childcare providers, um, to the community. And we've framed this around the families, which has really been resonant for them, to really identify who comes if you can't, to really know, have your family, make sure your family understands what your child's needs are, make sure your neighbors understand, make sure the larger community understands.

And that, as I've said, has been very resonant for families because it's a great fear and it was one of the fears that was voiced in our very early discussions that families had wondered, had the, um, had September 11th been an even larger event, could they have gotten to their kids? Would their kids have had their

medications? Would people have understood what their special health needs were?

And then in our third tier here, what we've really tried to do, um, as I said was, um, to get out to the larger community to identify resources and to make it clear what roles individuals could play. That's where we are. Um, I started by saying that this is an ongoing process, I think it will be in place forever. Um, and again, it will be dependent on resources, but we know that there is so much work to do and we know that the fact that so many people wanted to hear about this topic here says that it's an issue for everyone.

So, it's ongoing but we wanted to just lay out the framework of what we've done and it's a small piece of the Massachusetts effort around emergency preparedness, focused entirely on children with complex special needs and their families. That's where we are. Any, any…