

MARICOPA ASSOCIATION OF GOVERNMENTS
HUMAN SERVICES TECHNICAL COMMITTEE
MEETING MINUTES
OCTOBER 20, 2005

TECHNICAL COMMITTEE MEMBERS

ATTENDING

Carl Harris-Morgan, Town of Gilbert, Chairman	Sandra Reagan, Southwest Community Network
*Lorenzo Aguirre, City of El Mirage	Sylvia Sheffield, City of Avondale
Nichole Ayoola, City of Mesa	Judy Tapscott, City of Tempe
Judy Bowden, Mesa United Way	Wayne Tormala, City of Phoenix, Vice Chair
+Linda Snidecor for Kelly Dalton, City of Goodyear	+Patrick Tyrrell, City of Chandler
Moises Gallegos, City of Phoenix	*Neal Young, City of Phoenix
+Paige Garrett, Glendale Human Services Council	<u>OTHERS PRESENT</u>
Jayson Matthews for Kate Hanley, Tempe Community Council	Blue Crowley, Citizen
Connie James, City of Scottsdale	Teresa Franquiz, MAG
Jim Knaut for Mary Lynn Kasunic, Area Agency on Aging	DeDe Gaissthea, MAG
*Barbara Knox, DES/RSA	Janet Kirwan, SARRC
Virginia Sturgill for Margarita Leyvas, Maricopa County	Don Peyton, Phoenix Fire Dept
*John Paul Lopez, City of Tolleson	Donna Power, Easter Seals
*Joyce Lopez-Powell, VSUW	Amy St. Peter, MAG
*Dan Lundberg, City of Surprise	
Jose Mercado for Doris Marshall, City of Phoenix	+Those members present by audio/videoconferencing.
Sandra Mendez, DES/CSA	*Those members neither present nor represented by proxy.
*Kyle Moore, DES/ACYF	
Susan Neidlinger, DES/DDD	

Agenda items were considered in the order in which they appear.

1. Open Meeting for Discussion

Chairman Carl Harris-Morgan, Town of Gilbert, called the meeting to order at 1:05 p.m. and introductions ensued.

2. Call to the Audience

Ms. St. Peter, MAG, commented on behalf of Blue Crowley who wished to address the committee on two issues. The first comments regarded his concern over the number of homeless people who died over the summer due to the heat. He wished to say that more

money should be made available to provide shade at bus stops, as well as to provide more public showers. His second comment was that the light rail project is getting a lot of money, but the new downtown Human Services Campus is only getting used furniture.

3. Approval of May 19, 2005 Human Service Technical Committee Minutes

Chairman Harris-Morgan called for a motion to approve the May 19, 2005 HSTC meeting minutes. Connie James, City of Scottsdale, moved to approve the minutes. Susan Neidlinger, Department of Economic Security, seconded the motion. The minutes were approved unanimously.

The notes from the September 15, 2005 meeting were provided for the Committee's review, there were no formal minutes to approve, as there was not a quorum at the September meeting.

6. Update on MAG Regional Domestic Violence Council Activities for Domestic Violence Awareness Month

Chairman Harris-Morgan introduced Teresa Franquiz, MAG, who provided an update on current and future activities of the MAG Regional Domestic Violence (DV) Council. Ms. Franquiz stated that the DV Council started off DV Awareness Month with a press conference on September 28, 2005. The event was well covered by the media with four TV stations, one print outlet and one radio station covering the event.

She added that Employers Against Domestic Violence (EADV) held a training event for employers on October 6 at Encanto Park in Phoenix. The event was well attended with approximately 40 participants. Ms. Franquiz stated that the Health Cares About Family Violence (HCAFV) Subcommittee has recently completed two trainings for healthcare providers. One is for pediatricians and will be made available online, and the other is for nurses and will be made available in Valley nursing schools.

Ms. Franquiz commented that the Victim Services Subcommittee is finishing a Domestic Violence Shelter Capacity White Paper, which they have been working on in partnership with ASU West. The paper will show in a statistically reliable way how many calls for DV shelter go unmet in an average month because of lack of space. The paper will be recommended for approval by the DV Council at their November 1 meeting and will be made available to the public after its final approval by the MAG Regional Council.

Ms. St. Peter added that the members of the DV Council and the MAG staff are very excited about all of these projects and are looking forward to bringing them forward to HSTC members. Chairman Harris-Morgan asked how members could access the trainings. Ms. St. Peter said that anyone could contact MAG staff for a copy.

5. Discussion of Emergency Evacuation Plans for Persons with Disabilities

Chairman Harris-Morgan introduced Don Peyton, Phoenix Fire Department, who led a discussion on local evacuation plans for persons with disabilities in the MAG region. Mr. Peyton said that he could provide members with a high-level overview of what's being done with evacuation plans in general, but that Donna Powers from Easter Seals, who

would be joining the meeting shortly, could provide more detailed information on plans as they pertain to persons with disabilities.

Mr. Peyton informed the Committee that the City of Phoenix has contracted with a private firm, Dennis Compton and Associates, to lead a task force that will revise emergency evacuation plans for the city in the event of a major disaster similar to Hurricane Katrina. The City is working with the City of Los Angeles to establish a mutual aid agreement in case of a large-scale disaster in either city. Residents of Phoenix would evacuate to LA in case of an emergency and vice versa. A large piece of this plan will entail how to deal with a large number of evacuees from southern California if something happens there. The Governor is currently revising emergency operations throughout the state and evacuation procedures are a large part of those revisions. He noted that a lot of things have been changed because of what happened in the Gulf Coast.

Mr. Peyton said that Donna Powers, Easter Seals, has been working with first responders to better integrate education about persons with disabilities into Community Emergency Response Teams (CERT) training. This has become especially important as the last group of Katrina evacuees to arrive at Phoenix area shelters were mostly elderly and disabled people. It appears that they were some of the last to be evacuated and they had injuries that needed to be addressed. Many of them ended up in hospitals. These issues are now being looked at locally in case there is some catastrophic disaster here in the Phoenix area. He suggested that in the future when the process gets started, that MAG invite all the people working on redeveloping those plans to come in and work together.

Moe Gallegos, City of Phoenix, asked if Donna Powers is in charge of the CERT teams. Mr. Peyton replied that he is actually in charge of the teams. Mr. Gallegos said that the group of CERT team members at the Coliseum serving Katrina evacuees was outstanding. He informed Committee members that the teams were complimented many times and people couldn't say enough good things about them. They obviously filled a void for everyone who needed it. He added that one significant factor in their success was that they were easily recognizable by the distinctive green vests they wore.

Jayson Matthews, City of Tempe, asked if there are any plans for the City of Phoenix to work with other cities. Mr. Peyton replied that certainly any effective plan would have to include all of the cities in the region working together. He noted that Warren Leake with Maricopa County Emergency Management has been tasked with developing emergency evacuation plans at the County level. Jan Kimmel is working on the State level for the Governor's Office. He noted that everyone will need to be part of a coordinated process. The City of Phoenix would not develop evacuation plans without working with other cities, if for no other reason because everyone will be using the same freeways in case of an evacuation.

Jim Knaut, Area Agency on Aging, echoed Mr. Gallegos's sentiment about the CERT teams and their wonderful performance in response to the emergency evacuees. He noted that his own agency has seen firsthand how challenging it can be to serve the elderly who came from New Orleans.

Donna Powers joined the meeting at this point. She said that a lot of work has already been done to pave the way to incorporate plans for disabled persons into standard evacuation procedures. She has been working with Mr. Peyton and the CERT teams for about a year. The CERT training manuals instruct trainers to include people with disabilities in their training simulations. She said this is very important because responders need to practice assisting people in wheelchairs and people with other types of physical disabilities. She stated that in her opinion, this type of planning needs to be done by one entity and shared among the various organizations, rather than each developing their own plans.

She noted that evacuation procedures are different for people with different types of disabilities. For example, she thought that she was personally prepared until the electricity went out and she realized that her speakerphone no longer worked. She realized then that she would be unable to physically pick up the phone in an emergency because she is a quadriplegic. The most important thing will be to educate the disability community on things that are pertinent to their own disabilities. Blind people face particular challenges. One trick she has known blind individuals to use is to have a whistle and a pair of shoes under the bed. That way they can whistle for help and won't step on anything sharp. For those with chemical and environmental illnesses, sheltering is incredibly important. They can be made much more ill by trucks responding to a scene. Those with epilepsy can be put into a seizure because of the lights of responding vehicles. She noted how difficult it is for responding units to incorporate all these specific needs into their response plans. At Easter Seals, they advocate for personal responsibility so that the disability community can prepare themselves as much as they can.

Ms. Powers offered to take questions. Mr. Gallegos asked whether having an accessible list of disabled individuals in the community would be helpful to first responders. She responded that in an emergency, the identification of people with disabilities becomes important, but often people don't want to be identified before it becomes absolutely necessary. There is an assumption on the part of many people, including those with disabilities, that when people call 911, the operation will be able to access a great deal of information about the person calling and their home. This is one reason why there needs to be more education in the community about what really happens.

Jose Mercado, City of Phoenix, asked about the outcome of an evacuation drill recently held in Casa Grande. Ms. Powers said that lot of things were learned that day. For example, the need to have handicapped accessible transportation is very important. They found in the course of the drill that there was no way for people to get to the hospital unless they had their own transportation. She reiterated that she thinks people with disabilities need to be given a more active role. There was also a lot learned at the beginning of the wildfire season when there was another drill in Oracle, Arizona. It was found that responders were prepared to evacuate homes and take care of livestock, but when it came to getting people in wheelchairs out of the danger zones, there was little done.

Judy Bowden, Mesa United Way, said that she is aware of a group of parents who have children with special needs who are promoting the use of an In Case of Emergency (ICE) card. This card could be kept in a visible location in the home to be available for first responders so that they know about the individual/s inside with special needs. It could also be made available from outside the home, like an emblem in the window, for example. Ms. Powers said that there was a similar system when she was living in Madison, Wisconsin as a child. There was a red sticker on her bedroom window so that firemen would know of her disability. However, in larger, more urban areas, people are scared to put a mark in their window because it could identify them to anyone as being vulnerable. Instead, she is familiar with a recommendation for disabled persons to store an ICE phone number into their cell phones. The number can be labeled "In Case of Emergency" and the corresponding number can go to someone who can be contacted for information. This would be helpful in case the person involved in the emergency can't talk.

Mr. Gallegos said that over the summer when it was extremely hot, his department discussed how utility companies keep a register of people who are vulnerable in their homes. In a similar way, if providers knew who was vulnerable, then they could organize well checks in these types of cases. Mr. Matthews suggested that this could be done through water companies, as well as utility companies, by utilizing their databases. In Tempe, when the City tried to get information on vulnerable populations, they went through the utility companies. Ms. Powers suggested that the Department of Motor Vehicles may also have this type of information.

Susan Neidlinger, Department of Economic Security, said that her Division has looked at this issue too and has worked closely with the Red Cross in the past. It is very difficult to evacuate those with developmental disabilities as well. DES is required to have an emergency evacuation plan for this population.

Ms. Powers said that keeping a "vial of life" is often encouraged within the disability community. This can be a piece of paper kept in a clearly visible location, such as on the refrigerator so that first responder will likely notice it. It should include information on the person's disability, their doctor's contact information, a list of medications and allergies. If responders do a "swoop and scoop", then there is a piece of paper available they can take with them. She suggested that it is better to keep the vial of life in the freezer in case there is a fire. She also keeps her health insurance card there along with her vital information. She keeps a piece of paper on the front of the refrigeration that says the vial of life is in freezer. Her own vial of life explains where her manual wheelchair is kept.

Sandy Reagan, Southwest Community Network, noted that the Arizona 211 system was also designed for disaster preparedness. She asked if there is a component for disabled persons on the 211 website. Ms. Powers said that she has made several presentations around the state on planning for people with disabilities and all the groups she spoken to are advocating for that. She added that if any cities or towns are going to have CERT drills, they should call the Statewide Independent Living Council to get people with various disabilities to participate. The number for SILC is 602.262.2900. Tony Dirienzi is the executive director of that agency. He can also be reached at silctonyd@qwest.net.

Ms. Neidlinger said that another challenging population to evacuate are those with co-occurring physical and developmental disabilities. Ms. Powers agreed and said that they should also be included in practice drills. Wayne Tormala, City of Phoenix, asked if part of the recommended evacuation plans includes attempting to broaden the network of helpers; for example, bringing in block watch groups. Mr. Peyton said that at this point, every suggestion is being considered. Everyone in every community will need to get involved and training will be useful for everyone, not just first responders. He suggested that everyone has a mandate to get to know as much about their communities as possible. Ms. Powers suggested that Homeowners Associations are a great place to spread the word by using their newsletters. Mr. Peyton suggested that if there is a CERT program nearby, everyone should try to go through the training, which is about 21 hours. This may be a better alternative than placing the responsibility upon the planners. He echoed Ms. Powers' opinion that one key is going to be transportation. Mr. Peyton said the collaborative effort in this room is encouraging. A decentralized grassroots response may be the most effective, in combination with a governmental response.

4. Discussion of Current Research on Autism

Chairman Harris-Morgan introduced Janet Kirwan, Southwest Autism Research & Resource Center (SARRC), who provided information on current research on autism and the status of the T-Gen project.

Janet Kirwan explained her position as the Family Services Director at SAARC and said that she is also the parent of 17-year-old son with autism. Her son benefited from receiving early services and is now a senior in high school. He is the head of a big tidal wave of lots of people who have been diagnosed with autism. There were one in 500 people diagnosed with autism in 1999. Now the figure is one in 166. It is now the most common disorder of childhood. What is disturbing is that we have few treatments and no cure. This group is going to be aging into the population and there will be major challenges to the education system. They will likely overpower the long-term care system in Arizona. She stressed the need to look for some resources to better help this group of individuals.

Ms. Kirwan also has an 18-year-old daughter who wants to marry and have children someday. However, she is worried because there are often multiple cases of autism in families. Because it is more common in boys than girls, this is an indicator that autism is genetic. There is currently a lot of research going on around the world to try and discover the cause of autism. There is a need to find the genetic basis for the disorder, but if one is not found, then environmental factors will be looked at. Researchers are looking at multiplex parents and investing their genes and the genes of unaffected siblings. If they the non-autistic children have an unaffected genetic pattern, then researchers will be looking for prenatal and/or early period of development factors.

SAARC is currently involved in a project with Autism Genetic Resource Exchanged (AGRE) to conduct genetic research on blood samples. The samples are being kept at a repository at Rutgers University to make immortalized cell lines. This will involve a

practice like cloning the DNA in the samples so researchers can always access those cell lines. This will keep families from repeatedly having to donate blood samples.

There are also other clinical tests conducted at SAARC. For example, they are seeking to find out why some autistic children are very “stemmy.” (Engage in self-stimulating activities). They engage in self-stimulation activities all the time and cannot stop. Others are obsessive and rigid and cannot tolerate change. Others are sensory involved and want to bang on things. SAARC has done a project with T-Gen where they took 100 boys under 10 years old with autism and 100 boys without autism who were unrelated. Researchers looked at all of their genetic profiles. T-Gen researchers were very excited to be able to identify a good percentage of autistic children’s genetic material from their peers. The success rate was not 100 percent, though. They are going to duplicate the project to develop a test at birth in order to identify autistic children much earlier. This will alert parents of the need for medications, treatments, and interventions that can prevent the expression of the disorder.

Ms. Kirwan said there are devastating figures regarding the failure to provide early interventions. Double blinded placebo studies show that with intensive behavioral intervention before four years, 40 percent can make quite significant gains. Her son benefited from this type of early intervention. The AZ Long Term Care screening tool for children over three years old is the current medical model, so children who test positive before three do not meet with one of the necessary criteria to get services. Additionally, the current model tends to screen out the higher functioning autistic children who are more likely to benefit from intervention. She said that she would like to see Arizona follow the lead of other states like California and Minnesota, where there is an effort to not screen any child under six out of any intervention programs. She often gets calls from parents whose kids have been eliminated from the possibility of receiving treatment because of the screening tool. Habilitators can be hired on a private basis, but they are so costly that only the wealthiest families can afford this option.

It costs approximately \$30,000-\$40,000 per year to support someone in a group home. Because autistic individuals are not more likely to die earlier than any other person, they will likely live long lives. This could be very, very expensive over a lifetime if someone is put into a home at an early age. She expressed the need to get better supports for these families and to find research dollars. There are 11,300 students between three to 21 years old listed on the Individualize Education Plan (IEP) as autistic, according to the Arizona Department of Education, but there are hardly any teachers trained to teach these children.

Ms. Kirwan passed around some information about the programs available to autistic children and their families at SAARC. Ms. Neidlinger asked about the research being done regarding mercury and its involvement with autism. Ms. Kirwan said that a lot of research has been done about mercury, which was formerly used as a preservative in many vaccines. It has been removed from all vaccinations since 1999. California has seen a drop of about 300 cases since that time out of the whole state. There was also a study in Denmark, but the incidence of autism was the same in both the control and test groups.

Nothing conclusive has been found yet on mercury's involvement. She said that she is worried because parents of kids with no cure are vulnerable to every potential fake cure. Chelation, for example, is a chemical that binds to the metals in the body, like zinc, copper, magnesium and aluminum, which you need in trace amounts. Some are saying that it is a viable treatment for autism and it was at one time recommended by the Department of Health for lead poisoning. However, it can potentially cause death and she's not seen a child cured by using this. She added that a significant number of people are not vaccinating their kids now, especially if they already have an autistic child, because they are afraid the vaccines could have been responsible for causing the autism. Failing to vaccinate can also be dangerous.

Patrick Tyrell, City of Chandler, asked about the numbers provided earlier stating that one in 166 children is now diagnosed with autism. He asked if those numbers also include Aspergers. She replied that this figure only takes into account the DSM IV criteria for autism. Asperger's is different, as these children don't have the language delay common with children with autism. She added that there have recently been lots of adults who were diagnosed with other things like bi-polar disorder, for example, but who have found out they were autistic. She said we're all autistic; it's just a matter of degree. Everyone has slight stemming behaviors, but they are present to a greater degree in autistic kids.

7. Review and Comment on First Drafts of Regional Human Services Plan Chapters

Chairman Harris-Morgan introduced Amy St. Peter, MAG, who began discussion on the chapters for review, including Disabilities, Aging Services, and Funding & Capacity. Ms. St. Peter stated that chapters to be included in the Plan were drafted based on the feedback gathered at the community hearings and focus groups held over the summer, as well as additional research.

Chairman Harris-Morgan clarified that the whole document will come back at the end of the process in January with the introduction, conclusion, and table of contents. He stated that at this time members are just looking at the rough drafts of the mid-section of the plan.

Ms. St. Peter commented that after the chapters were drafted, they were sent to local experts who added their insights. She thanked Ms. Neidlinger, who provided assistance with the chapter on disabilities. The Aging Services chapter was sent to Connie James, Jim Knaut, Doris Marshall, Sylvia Sheffield and Carol Kratz, who are all members of the Aging Services Work Group. The chapter on Funding and Capacity was sent to Chairman Harris-Morgan, Vice Chairman Wayne Tormala, Moe Gallegos, and Neal Young. She noted that there has been more discussion on the Funding and Capacity chapter because it is new this year. The idea to include a chapter on funding sources came from the Strategic Planning Advance in April 2005. Members at that time said that they would like to see more discussion in the Plan about what Arizona is receiving in federal funds as compared to other similar states/counties/cities. The purpose would not be to take funding away for other areas where it is also needed, but to grow the entire "pot" of funding available for human services. She said that staff has had some good feedback already and they are hoping for more feedback today.

Mr. Gallegos said that he can understand the thoughts behind showing the comparisons in funding allocations. However, one of the issues he sees with the chapter is that we can show the disparities in the allocations, but there is no discussion of what we can do about it. If we're not advocating to take funding away from others, but the total pot is not growing, then the implication is that this is just the way it is. He suggested looking at the need for some national recognition that something needs to be done. The first step is recognizing that funding is an issue, but then there needs to be a push to do something about it. A place to begin would be to talk about where to go afterwards, but the chapter as it is does paint a picture of what's happening.

Mr. Knaut agreed that the frustration is in seeing the statistics. The chapter does a good job at painting the pictures, but where do we go from here? He recognized that it is hard to convince intergovernmental affairs liaisons that human services issues are priorities. It is made even more difficult because there is very conservative leadership on the federal level. He said that he would like to see narrative on how to explore getting more funding for these activities. There are great recommendations on how to work together, but little on how to bring in more money.

Ms. Reagan said that if you don't have a plan and roadmap, it is difficult to know how to spend the dollars that you're going to receive. She agreed that it is important to work toward the goal of finding enough money to take care of the needs we've identified, but we also need to have a plan ready to go for when the money does come in.

Ms. St. Peter noted that Gloria Hurtado, Human Services Division Manager for the City of Phoenix, will be presenting at the next HSCC meeting to discuss CDBG funding and the need to at least keep it level. Mr. Knaut said that he is glad to hear that because she'll do a great job of advocating in these areas. Mr. Gallegos said that it is hard to get political leaders to focus on this. This is first year he's heard the Phoenix city council say that it's important to get federal officials to focus on these social service issues.

Mr. Tormala added that it is also important to note that funds are used differently in different areas. For example, San Antonio uses their dollars differently and is likely getting a much bigger return with greater outcomes. Ms. Ayoola agreed and said that the way funds are used in Mesa is very different from other local cities and will likely be changing again in the future. She said that the last three points discussed would be very beneficial to her in working with officials in Mesa to advocate for human services. Mr. Matthews said that this could potentially be a great lobbying tool locally and at the federal level. Social service providers have to fight for general revenue every year, and in smaller communities they really have to justify the need for those services.

Mr. Harris-Morgan recommended taking out the section on HOME funds and adding mentions of Emergency Food Shelter Program, a caveat about general funds, and a section on utility funds.

Ms. Reagan asked about the timeline with working on the SSBG recommendations this year. Ms. St. Peter said that they anticipate that the HSTC will be asked to review

the work group recommendations in January, and the MAG Regional Council will approve them in February. The intent is to include the SSBG recommendations in the plan. The SSBG work group will be called together in late November or early December.

Ms. St. Peter asked if there were any comments on the Aging Services or Disabilities chapters for members to email those in to staff by the close of business tomorrow. The chapters will go through an internal process at MAG, so there is a need to start moving through that process now. The Funding and Capacity chapter will be revised and brought before the Committee again in November, with an additional chapter on Developmental Disabilities.

8. Announcements

Chairman Carl Harris-Morgan asked if there were any volunteers from the committee who were willing to serve on the SSBG ad hoc work group this year. Jayson Matthews, City of Tempe, and Susan Neidlinger, DES, volunteered.

9. Adjourn

The next meeting of the Human Services Technical Committee is scheduled for Thursday, November 17, 2005 from 1:00 p.m. - 3:00 pm at the MAG building, 7th floor RPTA, rooms A and B.