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Emergency Back-up and Independence Plus Audio Conference Transcript

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Rutgers Center for State Health Policy
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Emergency Back-Up and Independence Plus

Anthony: Good afternoon ladies and gentlemen and welcome to *The Emergency Back-Up and Independence Plus Conference Call.* At this time, all participants are in a listen-only mode. Following today's formal presentation, instructions will be given for the question and answer session. I would now like to turn the conference over to Susan Reinhard. Please go ahead.

Susan Reinhard: Thank you and thank you all for joining us today. We are very happy that you were able to do this, to join us for this session on emergency backup and Independence Plus. I am very pleased to direct the Community Living Exchange Collaborative at Rutgers Center for State Health Policy. This is a national technical assistance effort funded by the Centers for Medicare and Medicaid Services to provide assistance to all of the grantees of the Real Systems Change Effort. I work in collaboration with colleagues at ILRU, at the National Academy for State Health Policy and numerous consultants who we hope are able to support your needs.

This particular technical assistance effort is a result of conversations with each of you, the Independence Plus grantees, the 2003 grantees, on what you feel are some of your most important areas for assistance almost immediately as well as the CPASS grantees from 2001, 2002, and 2003 who have been interested in this topic for quite some time and we thought you would enjoy this opportunity as well.

What we have done is divided this up really into two sections. The first is with Terry Pratt who is the division director of the Division of Integrated Health Systems at CMS. She is also the policy lead for the Self-Direction Group, which includes Independence Plus and CPASS grantees. She is going to introduce a number of her colleagues that are with her in the room and they are going to talk about an overview of the requirements for emergency backup, some changes in perspective since this was all first announced in May of 2002. How quickly time flies, and some examples of what they have considered acceptable and unacceptable emergency systems. That will be about 10 or 15 minutes. I think we can pause for maybe some burning questions or two at that time if Terry would want to do that, but we want to quickly move into the states in action.

We have four states that will join us: New Hampshire, Louisiana, Florida and South Carolina. We have asked each of them to spend somewhere between five and eight minutes or so about what their specific areas of emergency backup, what exactly they are doing and some of the lessons that they have learned that they can share with you. We would like to then open it up to discussion in general. We have a facilitator, Anthony, who will help us monitor those calls so that we can have each of you have a separate time and we can manage it. I wanted you to know that this is all being recorded so that we can summarize the information and put it out on both a written format as well as a tape on the HCBS.org website for any colleagues that were not able to make the call or for any of your colleagues that you would like to share that information with.

Let me turn it over now to Terry, Terry Pratt at CMS.

Terry Pratt: Good afternoon, everyone. On behalf of those here in the room in CMS, I certainly would like to extend a heartfelt welcome to all of the grantees who joined the conference call. We are very pleased by the number of you who decided to be part of this today. I am also joined here in the room by members of our Self-Direction Task Force that we have created within the Disabled and Elderly Health Programs Group in response to the President's New Freedom Initiative.

I just wanted to explain briefly that the goal of our task force and the reason we were formed. This was a way for us to coordinate within our group a team that would be able to work together to meet the goals that were specified in the preliminary report that was done by HHS back to the President in response to the New Freedom Initiative.

With me today I have Ed Hutton who is the technical director of the Division of Integrated Health Systems. We have Nancy Thaler who is here as part of our IPA Program. Marguerite Schervish, who is a health insurance specialist. Mark Reed, also a health insurance specialist. Cathy Cope is part of our TA Coordinator and Systems Change Grant and Anita Yuskauskas, who is also a health insurance specialist. The individuals in this room represent four different components within the Disabled and Elderly Health Programs Group.

Just because of the number of people on the phone and the fact that the grants were awarded over a series of different time periods, I wanted very briefly to sort of step back in time and explain to you how we got to where we are today and particularly with regard to the subject matter. I won't say anything new in these remarks, I don't believe. But it will certainly give us a perspective from where we have come from and why we are here.

The original executive order was signed in 2001 by President Bush and as part of that executive order, he wanted us to all look for meaningful ways in which there can be opportunities for people with disabilities to live and be supported in a community. That particular directive was not just to CMS but also to a number of other departments within this executive branch.

In 2001, each one of those executive branches reported back to the President on their accomplishments and trying to achieve the goals under the New Freedom Initiative. As a direct result of that report in 2001, a by-product of that were two events that happened in 2002. The first being that Secretary Tommy Thompson reported to the president on his accomplishments under the New Freedom Initiative and at that time announced the Independence Plus Demonstration Program. At the same time or shortly thereafter, those particular model templates were sent out in the form of a state Medicaid Director letter by Dennis Smith, the Director for the Centers for Medicaid and State Operations in CMS. Those templates were the design features that we have set forth as an agency to promote self-direction in community-based programs for people with special needs.

In addition to those templates, CMS is working on three other activities associated with that template. Instructions for how to complete the template in response to comments that we have

received back from you, a resource guide and technical assistance guide as well. Those components will eventually function together in a public forum for all states to have as a resource.

But what we have noticed in the interim through these TA calls is that we have had a number of states that ask questions and we are very grateful that those resources are used. What we are starting to notice are themes of questions. In response to the template, an area that received a fair amount of reaction was exactly the reason that we are here today was the emergency backup plans. In the template, the purpose for it being there is the recognition that person-centered planning is a process that involves assessment and discussion of the risks that are involved for these individuals and for safety.

Since the introduction of those templates in 2002, we have had a number of states that have pioneered them, have used them to submit program models for QA-QI review and approval and that actually has occurred.

As of May 2002, we had an individual waiver templates for state self direction programs that sets forth our requirements. As of today, we have a number of states who have actually utilized those templates, had experiences in this particular area which they plan to share with you today after Anita spends some time talking about what the federal requirements are. Anita?

Anita Yuskauskas: OK, thanks Terry. Hi everybody and welcome. It is nice to be here on this rainy afternoon in the Northeast. As many of you know, emergency planning is part of CMS's requirement for self-directed services, particularly when participants hire and supervise their own staff. Since CMS's key driver involves the state's assurance for the health and welfare of program participants, this feature of self-directed programs addresses one of the ways that states can meet this assurance.

Basically, CMS's requirement is that the state has a viable system in place for assuring emergency back up or emergency response capability in the event that those providers of services and supports that are essential to the individual's health and welfare are not available. While emergencies are defined and planned for on an individual basis, the state also must have system procedures in place. That translates into basically that we look for the states to have an immediate response or a backup for self-directed services when the absence of those services would jeopardize the participant's health and welfare.

There are two levels to the backup. One is the individual level, as I mentioned and the other one is the system level.

At the individual level, CMS looks to the state to assure that that is covered within the plan of care. So the plan of care should identify issues or situations that prevent a risk to the person's health or welfare and to plan ways to manage the risk and also to respond promptly in emergency situations. The response plan can be unique to the person and it can include informal supports as well as formal services. So that is the backup at the individual level.

Then at the system level, we look for assurances by the state that involves written assurances, a system that is immediately accessible and one that is realistically operational. Let me go back and go over those again. At the system level, we are going to look to the state to have something in writing to describe their backup, their system-wide backup system so that we can see there is evidence of that procedure in place.

The system response can be geographically specific. It can be specific to a provider or it can be part of an already existing system.

One thing that we want to stress is that the state's backup system does not have to be a newly created system and it doesn't have to be one single entity available across the entire state. We are really trying to provide a lot of flexibility in how the state responds as long as they have some kind of system in place. OK, so that is the written part.

"Immediately accessible" means that participants must have access immediately to some kind of a support in case or in the event that the individual backup system fails, or whenever a service delivery failure places the person at risk. So there has to be something that is immediately there.

The third part is operational. When I say "realistically operational" we all know that when there are new wrinkles in the system that they can often cause unexpected impediments, administrative burdens, all those kinds of situations. What we are looking for is that there are no impediments to accessing emergency backup services so that all the prior authorizations and whatever other administrative details need to be taken care of are addressed upfront within that procedure that the state lays out.

I have tried to be very succinct and brief in my comments and so I think at this point because CMS's procedure around emergency backup is brief and purposely so that states can utilize their own resources in whatever way that suits them best. I think you are going to get most of the meat of this discussion within our examples. So I am happy to turn it over to the states now. (Unclear) first?

Susan Reinhard: OK, Anita. So this is Susan. We will just hold off questions for CMS after we hear from the four states and take them as a group. Is that OK?

Anita Yuskauskas: Sounds good.

Susan Reinhard: OK. Let me ask Barbara Reed from New Hampshire to start us off. Barbara is going to speak about in-home support waiver for children with developmental disabilities. She is with the division; she is the division liaison for developmental services at the Department of Health and Human Services in New Hampshire. Thank you Barbara for joining us.

Barbara Reed: Hi, welcome. First of all, I hope all of you are a lot warmer than we are up here. It is practically snowing.

Susan Reinhard: It is cold.

Barbara Reed: New Hampshire had the first in the nation Independence Plus Waiver to use the new template that you all were talking about so I think we sort of thrashed around a bit to work with CMS to see exactly how much detail and so forth that they wanted. Our waiver is probably a bit different than what some of you are dealing with because it addresses only children up to the age of 21 with developmental disabilities who are living at home with their parents. They also are children that have a number of individual and family factors which make their care perhaps more difficult and really challenge the family's ability to stay intact. So we are limited to children and I think by the very fact that they are minors, some of the emergency support backup system is already inherent in the fact that they are living with their families and they are children.

The waiver is small. We have 200 on it. We are going in, or we just went in last January into our second of the three years. We have only one service, if you want to call it that, available to consolidate a service, but within that we have personal care, respite, home and vehicle modifications, consultative services and care coordination. Families do have a service plan that basically is organized through one of our developmental services area agencies, of which we have 12 that represent different geographical areas of the state. They are really the employers of record and do the actual Medicaid claiming. Although the consumer-directed component is very much supported and reinforced by them in the sense that oftentimes the service plan and the agreement with the family will have a general management in perhaps the care coordination charge, but the rest is the family-directed portion of the service plan.

As you spoke of Anita, we do have a couple of levels. The first level being more on the person level that is reflected in the service agreement in that we put out somewhat of a template to sort of cue our family support care coordinators into what was required into a service agreement and there is actually a section for each one of the component services. For instance, personal care - where they have to identify a contingency for the provision of that service should the provider not be available at the last minute or something interferes with the provision of that service. We have often had many, many families run into a lot of trouble because they are getting pulled out of situations, their work and so forth, to come address an issue with their children. So we have the contingency planning section of the service agreement.

We also have within the personal care section a place to indicate where there are safety issues that particularly have to be addressed and behavioral issues and there is also a section around medication administration and requirements if someone other than the family member is going to be giving medications to that child. We also have within the service agreement, which would be intuitive anyway, is a list of emergency contacts. Individuals such as family members, physicians, and so forth that are to be contacted in case of emergency, as anyone would have.

As far as the systems level, as you all are aware New Hampshire is very big on local control and each one of our area agencies has really their own system in place that works best for their particular families. There are cases in which the actual Service Coordinator has a pager and the specific families that are on that Care Coordinator's list call that person. All of the Area Agencies have a central number that in the off-hours and in the weekend hours you can call and

be put in touch with whoever is on call. Sometimes they rotate off with Care Coordination, who is on call.

So every area agency has a different way of handling that 24/7 availability but they all have it. We had a few examples where, for instance, during the holiday season last winter a family ran out of fuel, called their Care Coordinator on a weekend and within 24 hours they were able to get oil for their tank and so forth. We have had cases in one case where a child with a dual-diagnosis and had sort of a flare-up on a weekend and was a single mother. The care coordinator was able to work through the protocol, behavioral protocol with the mother and have an emergency admission for that child to have medications adjusted and so forth.

So each one of our Area Agencies sort of models their approach to this depending on the regional demands. At this point, we haven't really had any reports that it hasn't gone satisfactorily. I think New Hampshire has had a very strong family support program for many years now. It was very consumer directed so I think folks have been very comfortable with that availability and backup plans and so forth.

As far as the cost, the cost for the backup service is typically included in the Care Coordination salary and the annual charge, if you will, in a family's budget for Care Coordination through the agency is about $3,000. So that is where we are in New Hampshire.

Susan Reinhard: Judy, I wonder if you could mention; I had heard that you had an agreement with a medical school that sounded interesting. People on a work-study? Is that still available?

Judy Moore: I am not aware of that.

Susan Reinhard: OK. Well let me move on and everyone will be able to ask questions in a few minutes. We have in Louisiana Judy Moore, the program manager for the Louisiana Department of Hospitals and with her is a colleagues, Jean Molanson. Am I saying that correctly, Jean?

Jean Molanson: That is close enough.

Susan Reinhard: Close enough, OK. They will be talking about the New Opportunities Waiver.

Judy Moore: OK. Let me just describe our plan to you first of all. Due to the annual hurricane seasons and flooding issues as well as other emergency concerns addressed by our state related to the industry and the weather, we believe that our emergency planning should be on two different levels. One would be an emergency response level related to weather, hurricanes, and those kinds of things. The other would be related to other types of emergencies such as worker unable to come to work, hospitalizations, etc.

So in the first issue, in terms of emergency response, we developed four levels in order to address this issue. Level one would be the individual that would require total assistance and

would be on life-sustaining equipment. We attached this process to our state emergency response system and we do have special needs shelters that were developed by our state so that we could attend to these types of individuals who had life-sustaining equipment in a hurricane or such as that.

The level two would be individuals requiring total assistance to respond to an emergency, but they do not require life-sustaining equipment. Level three would be an individual who would respond independently to an emergency but would require transportation to complete the process. Level four would be the individual who could respond independently, has supports to meet all their needs including transportation.

The next level would be those that are the general area would be the backup plan for just general issues. That would be a process for knowing what to do and whom to call in case of an emergency and we of course are doing that in the process of the annual planning. The case manager or broker, assistance broker and the participant drill down as far as possible to identify the backup needs and to secure contact information that may mean the difference between life and death. The comprehensive plan of care is developed on an annual basis and of course updated as needed. It is during these times that the manager, the case manager and the participant and their chosen circle of supports discuss these most important issues. The more clearly the emergency plan is defined, the better this affords a defense in times of trouble.

So briefly stated, that is our existing plan. We have two parts to our plan. A little history on how we have developed that is that in the process of the development of our new opportunities waiver, we also developed a new comprehensive plan of care. Prior to this, we relied totally on direct service provider agencies to independently meet the needs of those folks who had emergencies. They more or less came to the rescue of participants in emergency situations. They still do for the majority of our folks.

However, if we are indeed to embrace the philosophy of self-determination, we had to agree with participants that along with freedom comes responsibilities. Participants told us that they wanted more freedom in the area of managing their own staff, including hiring their own staff and making other decisions. Therefore, it was incumbent upon the Bureau to develop a process whereby those freedoms could become a reality and at the same time we could maintain those assurances that we are mandated to comply with.

So the Bureau, through contract and rule making, added an additional level of support for participants in the development of these backup systems using our case management agencies. They are in each region of our state and who are responsible for support planning and quality assurance. These are independent agencies who coordinate the process for the annual planning and the serve as service brokers for the participants. They really play a pivotal role in the development of this plan and are key in overseeing that this individualized plan is executed when an emergency occurs. In fact, they also have beepers and they are on call 24/7.

I have had some of these individuals tell me that they keep a list of the people they work with and in the event of an emergency they have that information right at hand so that they can begin to implement their emergency plan immediately.

Some of the challenges with this implementation were the New Opportunities Waiver was approved in April of, April 24th, as a matter of fact, of 2003. We immediately began to process and transitioning all our participants from our existing MRDD Waiver to the New Opportunities Waiver. We began that in June of 2003 and we completed that process in December of 2003. We transitioned over 4,000 people who currently receive New Opportunity Waiver services.

So we have only been fully operational since January '04 with this particular process. We have trained the case managers. We have worked with some of our advocacy groups such as a group, Families Helping Families, who are helping us to train families and participants about this process. So there is always a challenge in change. However, I have to say in spite of the difficulty of this change, we have had some pretty positive feedback from our case managers who see a value in this process and also see the freedom it brings to our participants. We have also had some positive responses from participants as well. So we believe that we have seen some success and we hope as we develop this further and people get accustomed to it, it will work very nicely.

As to the estimated cost, the cost associated with using this process and these levels of support are minimal at the present time because we are utilizing the existing framework to accomplish this process. As I said, we already had the contracts in place with our independent case management agencies, so we have asked them to take on this additional work. We have also asked them to document the additional time that is required in this new waiver. Our current case management caseload size is a maximum of 35 participants per case manager. We would like to see if the timelines differ and the roles change within the self-determination process. If the data indicates that this needs more time, then we will need to address it in the contract process when new contracts are established. There would be some possible options for changes, which may include caseload size, roles, responsibilities, rates, etc. So we are looking forward to collecting data on this.

The adequacy of the system, as I stated earlier, it appears to be working well. As we have more experience, we will be able to grade this process more accurately. Currently our quality assurance process is designed to identify areas of concerns, trends and patterns, which we will watch very closely. In terms of anticipated changes, we were most pleased to have been awarded the CMS Independence Plus Grant in October of 2003. So our next goal is to create an additional level of support for individualized backup systems for our participants. This tertiary level would provide additional assurances that individuals receiving waiver services are safe. As they achieve increased control over their lives and resources, our plan is to first of all explore what other states are doing and then develop a specific plan to Louisiana's needs. So that is our story.

Susan Reinhard: Well, we hope, Judy, that this call will help you learn from the other states who are presenting and will continue to provide you information. Jean, did you want to add anything?

Jean Molanson: No, I think she summed it up quite nicely.

Susan Reinhard: Pretty organized.

Jean Molanson: Oh yeah.

Susan Reinhard: Thank you. We are going to turn to Florida to Beth Kidder and Carol Schultz with the Agency for Healthcare Administration in Florida. They are going to talk about the 1115 Independence Plus Demonstration there. Beth?

Carol Schultz: OK, this is Carol Schultz and actually I was going to go over the emergency backup plan.

Susan Reinhard: Sorry Carol.

Carol Schultz: That is no problem. Florida's emergency plan was a challenge because or Consumer-Directed Care Plus Program includes a diverse population from three home and community-based service waivers. The Adult Disabled Adult Waiver, Developmental Services Waiver and the Traumatic Brain and Spinal Cord Injury Waiver. We had to develop a viable system for all three groups. The system has to provide emergency response in the event the consumer's own required two critical backup plans failed. Though we were requiring the participants to have an emergency backup plan, it was important to us that the plan supported consumer choice and the principles of self-determination.

So the consumers selected the provider of their choice for both their purchasing plan and the emergency backup plan. When I talk about the purchasing plan, this is the individual care plan that lists all the goods and services, including costs that the individual's monthly budget is based on.

Florida developed a hierarchy of emergency backup and while it did add additional layers of protection, it allows the consumer to select the plan that best fits their needs. The plan assures the consumer's health and safety in an emergency by a hierarchy of backup protection. There are four levels and they vary by degree of emergency needs. The four levels are, level one is the consumer's own two emergency backup for critical services on their purchasing plan. Level two is the informal network of family and friends. Level three is enrolled Medicaid provider network. Level four is extreme emergency. Generally, a consumer will access these levels in order starting with level one, but in the case of an extreme emergency of course, they may go directly to level four. I will give a brief overview for each one of these levels.

The Consumer Purchasing Plan Emergency Backup. The CDC Plus Program requires our consumers to include two backup providers for each critical service in their emergency backup plan on their purchasing plan. We have a separate page provided on the form to describe the service, the estimated hours and the cost. Emergency backup providers on the plan can be CDC Plus employees, employees of an enrolled Medicaid provider, such as a home health agency or nurse registry or informal caregivers such as family members, friends or neighbors. The cost for this is included in the monthly budget expenditure or as a part of their savings plans.

Level two is the informal network and if the consumer's own backup providers can't provide backup as planned, the consumer can reach out to their network of family, friends and neighbors to provide interim support. This network is probably providing some level of personal care already and in the event of an emergency may provide emotional support as well.

Level three is the enrolled Medicaid provider network. If levels one and two can't be accessed and the informal network fails for the consumer, they can go to level three. This level involves accessing enrolled Medicaid providers such as home health agencies, nurse registries or other home and community-based service providers. Again, due to the diverse level of our population, a backup plan has to be developed for each of our groups for elders, consumers with developmental disabilities, adults with physical disabilities and consumers with brain and spinal cord injuries.

For our adult consumers, the Florida Department of Elder Affairs will work with contracted lead agencies across the state. Each lead agency has a 24-hour on call telephone number and they can either send someone or provide services for our elders.

Consumers with developmental disabilities can work with the Developmental Disabilities District Program offices who will provide Medicaid emergency service workers for the DD population. The cost of both of these levels is set aside on their monthly savings and their purchase plan.

The Adult Services Program will provide emergency backup for their consumers with Medicaid enrolled provider agencies within the disabled adult provider network. Again, the consumer will set aside funds in their purchasing plan savings to cover these costs.

The Brain and Spinal Cord Injury Program will contract with emergency backup services with an enrolled Medicaid home health agency. They will provide service workers for the consumer.

In all of these plans, the consumer's Consultant will help the consumer with paperwork, locating the agency and figuring the cost. In most cases, the consultant remains the consumer's first contact in an emergency and they also carry a pager 24 hours of the day.

Beyond these emergency backup plans, we have level four, the extreme emergency backup. In this case, Adult and Child Protective Services can be called in if there is a situation where possible abuse, neglect or exploitation is suspected. There is also the Division of Emergency Management, which can be called in in the event of natural or manmade disasters. They coordinate disaster relief throughout the Florida County Emergency Management Agencies.

The last is of course 9-1-1 and all CDC Plus consumers are advised to call the emergency telephone number in the event of a crisis where health or safety is in immediate jeopardy.

The history or development of our plan came about through several discussions with our program partners in our workgroup meetings. Each program area investigated the best options for their consumers and we also had discussions with CMS who were very helpful by the way in clarifying what we were looking for in our plans.

Challenges with implementation were training the consultants from the consumers to the new policy. CDC Plus went into effect January 2004 so we are still working with this expansion. We have a great deal of things that we need to look at on our purchasing form which is one of the problems that we had in our implementation and it may be that the form itself is too complex and we may need to revisit this.

Because the expanded program has only been in effect since January 2004, frankly the adequacy of our system and anticipated changes can't really be determined at this time. As far as the cost goes, they are part of the consumer's monthly budget and the average amount right now is unknown. We don't have that information right now.

So this is new ground for Florida and we will have to chart the problems along the way and make changes as they come to light, but we at this time have one person who will shortly be implementing her emergency backup plan by hiring backup workers to provide for her critical needs because her regular workers are going on vacation.

Susan Reinhard: You have your first consumer to have your study with.

Carol Schultz: Exactly.

Susan Reinhard: Carol, did you want to add anything?

Beth Kidder: No, we had agreed that for now we will be happy to take any questions when we are done.

Susan Reinhard: All right. Great. I want to congratulate you all for staying on time and letting South Carolina have some time. Roy Smith and Daryle Doyle will talk about the 1915(c) Independence Plus Waiver they have there.

Roy Smith: OK. I think that a lot of the things that we have to say have been covered so I will try to hit the things that may be a little bit unique to us.

Our Independence Plus waiver covers people who are elderly or physically disabled. We started it regionally in the state. We are now in one of our 13 offices in the state and we want to go statewide, but part of our development of this program as well as ensuring the backup system is to start locally and then go statewide as we become more assured that we are doing what we are supposed to. We have only about 25-30 people in the program right now. The age range is from the early 40's to 99 is our oldest person in our consumer-directed waiver.

We also have, as Louisiana described and I am sure Florida has the same thing in the South, we have a system in place that is largely designed for hurricanes, tornadoes and other natural disasters which covers a plan to identify people to see what their needs are. For predictable disasters such as hurricanes, our plan would be to contact the people in advance to determine, to work out a plan for movement if necessary or to ensure they are safe in their location if they don't need moving and to also contact them as quickly thereafter the emergency has passed as

we possibly can. We also as part of our assessment, we determine what kinds of emergency disaster needs a person has and that is built into the plan of care that is developed for them.

As far as the ongoing individual issues, we do have, as the other states have described, individual backup plans. These plans are based upon the individual's needs and largely involve informal supports, family members, friends, neighbors rather than agencies as the first line of contact. All of the people in our program are hiring individuals. Right now, none of them has elected to receive agency-delivered services. So we also would designate for them as part of our assessment, what types of risk levels that they have because of their physical or other needs. So for example, someone who needed assistance in getting out of bed in the morning would receive one level of designation. Someone who needed less intense of a less immediate care would receive another designation. That way we are able to target our energies towards and identify the ones who are most at risk. We can try to address those individually.

The Care Advisors who work with the people in our program all have cell phones and are available to work with them. We have something maybe a little bit less formal than Florida's but very similar to the level one, level two and level three. Our level four, we do have Adult Protective Services, but level four is basically 9-1-1. If someone has immediate needs that cannot be met in any other way, we would call 9-1-1 for emergency assistance on that. If there is no informal supports available, if the family members who will constitute the backup plan or the other friends or neighbors who constitute are unavailable, each of our offices has a list of agencies who provide services and provide agency-directed services. We don't have any experience with that at this point. I am happy to say that we have not had anybody who has hit past the first two levels of the backup plan. Pretty much what has been in place individually has worked for them fairly well.

We also have several other things from the system level, but I want to talk about one that is a little bit different than maybe what we have heard from the other states and that is what we call our Care Cost System. I am going to describe that for two or three minutes. That system basically is something we have developed to monitor the delivery of services across all of our waiver programs. It involves an electronic system where people providing the in-home services will make a call to a toll-free number when they arrive at the home. They will make another call when they leave the home and those two calls together will define the time that they are providing services. It will also bill for them but that is not what we are here to talk about today. As defining that, our Care Advisors work with the consumers in the program as to what their needs are, how many hours of services they are receiving and so forth. They access real-time reports off the web, which are able to demonstrate how much of that service delivery has been met. If there is an expectation of service delivery and there is no report, that the person has received it, then the Care Advisor would contact the consumer to determine if there was any issue at hand.

I don't know how it is in other states, but a lot of, particularly with family members providing the first level of support, some of the consumers are fairly unwilling to complain if they are not getting services unless they are in a real crisis situation. So this lets us take them a little bit, put them a little bit to one side and be able to monitor the service delivery without having to rely on their, informing upon their family members or complaining about family members and so forth.

We also use the system to monitor the delivery of all other services so along with the ones that are the most critical such as the hands-on assistance with ADLs, we would monitor such things as daycare participation and home-delivered meals or whatever other services are chosen by the participant in the program. This allows us from a systemic approach to see what services are being delivered to ensure that those are consistent with the plan of care and the participant's budget amount and to be able to go in and monitor that.

The care advisor, at a minimum, will make monthly contact with the participants here. The reality is so far; experience so far is that it is far, far more than monthly. In making those contacts, the care advisor would access the web-based reports and then be able to talk to the participant about service delivery and any issues that are happening.

I guess also I would like to add, and we can certainly leave time for questions, I would like to add that this kind of a dynamic on a consumer-directed waiver is to how you ensure people's ability to make their own choices and guarantee that they are always provided services. We have a lot of self-screening for this program. We have another waiver, a 1915(c) waiver, which is not self-directed which many people have chosen, and a subset of those people have chosen this waiver. Part of that, I think, involves being willing to make these kinds of decisions and become very actively involved and to assess the risk and be able to work with it.

So we start with the philosophy that we want to work with them to individualize the plan as much as possible. Then we need another layer behind it, which we provide, by Care Call and the agencies and the other things we have described to meet the assurances that we need to make for their safety. So I will leave it at that.

Susan Reinhard: Thank you, Roy. I think that last point is something that Judy was pointing out as well, the freedoms and the responsibilities and it is very important to have that discussion and create a system around it.

Before I turn it over to questions from the participants, let me just ask anyone from CMS if you want to respond to any of this and any of the state folks if you want to ask each other questions?

Judy Moore: I have a question for South Carolina.

Susan Reinhard: OK.

Judy Moore: This is Judy from Louisiana. Is the Care Call system a voice recognition kind of thing for your workers or...?

Female: No, it is not. It is just a dial-up system and each worker has a unique identifying number which identifies them as the worker plus it also ties back to the client's home.

Judy Moore: Thank you.

Male: It has caller ID?

Roy Smith: Yes it does.

Susan Reinhard: You know, Roy we might want to just to even have that on a different call. I know you demonstrated this at the CMS conference in March and I saw it when I was there in South Carolina, but it might be something we should do a call just on that. There are a lot of benefits to what you are doing.

Roy Smith: We'd be glad to do that.

Susan Reinhard: Thank you. All right, let me open it up to all questions then. Anthony? Anthony, are you there?

Anthony: Yes I am. Thank you.

Susan Reinhard: Thanks.

Anthony: Ladies and gentlemen, at this time we will begin our question and answer session. If you have a question, please press the "*" followed by the "1" on your pushbutton phone. If you would like to decline from the polling process, please press the "*" followed by the "2". You will hear a three-tone prompt acknowledging your selection. Your questions will be polled in the order they are received. If you are using speaker equipment, you will need to lift the handset before pressing the numbers.

Our first question is from the line of Andrea Childs in Phoenix, Arizona. Please go ahead.

Andrea Childs: Hi, I have a question for the gentleman from South Carolina. You talked about the first level, or one of the levels anyway as the individual backup plan with friends, neighbors and family. Then you indicated that if then no one is available at that level, the consumer calls somebody and a list is given to them?

Roy Smith: Yes, the Care Advisor would just, our description of we would more traditionally call a case manager, but want to emphasize that it is less direct than a case manager. The Care Advisor is available by cell phone. If there is a need for services, he or she could provide a list of the agency providers in that area as well as the list of individuals who would be available to provide services through our Attendant Program.

Andrea Childs: So that person carries that phone 24 hours a day?

Roy Smith: That is something they don't do right now. Unlike some of the other states, 24/7 is not something that we have in place. They do have the phone, but I would not guaranteed availability on it.

Andrea Childs: OK. I know in Arizona if you have an emergency, they never happen at 8-5. Those happen after hours. We can handle those that happen 8-5, so I was just wondering how you do indeed serve your customers after everybody has gone home for the day. So if they have

an emergency after seven o'clock at night, they call this person and they give them a list? Is it telephone numbers or something?

Roy Smith: No, the Care Advisor would try to work with the consumer to find services.

Andrea Childs: OK, so they don't give a list or names or numbers. They assist the consumer in finding a person.

Roy Smith: That is correct. Now all of this is somewhat theoretical because we have not had a whole lot of cases to work on now. We are also doing an independent evaluation of our program just to address these kinds of issues and see if we are meeting them satisfactorily.

Andrea Childs: OK. Thank you.

Susan Reinhard: And thank you, Andrea.

Anthony: And our next question is from the line of Kay Green in Jefferson, Missouri. Please go ahead with your question.

Kay Green: Yes, hi. We are wondering with the Call Care system, how do document services, what; is that a requirement? Do you also have to document what was done each day?

Female: The tasks are not identified in the call they make. They are not identified in the call they make at present.

Roy Smith: That is done by case notes.

Kay Green: Case notes?

Roy Smith: And also for consumer direction, the Care Advisor would go over, as I am sure is the case in other states would go over the care advisor and the consumer would go over what it is that is needed and expected and what the needs are.

Susan Reinhard: Kay, would you be interested in hearing more about this on another call?

Kay Green: Yes I would.

Susan Reinhard: OK. We will arrange it.

Roy Smith: I think that would be good. I don't want to take all the time on our system here.

Susan Reinhard: I can see that there is a lot of interest so we will do that.

Roy Smith: OK.

Anthony: Thank you and our next question is from the line of Erin Barrett in Barry, Massachusetts. Please go ahead with your question.

Erin Barrett: Hi. This is Erin.

Susan Reinhard: Hi Erin.

Erin Barrett: I have a question about the Florida waiver. Can you explain a little bit more how the process, the method is for setting aside funds? Is it on a monthly basis and how is that done?

Carol Schultz: You are talking about the monthly budget for the consumer?

Erin Barrett: All I know is that I made note that funds are set aside to the individual budget for the emergency backup fund. I was wondering if emergency backup isn't happening on a routine basis, how money or if money is taken out on a monthly basis. Just the process for doing that.

Carol Schultz: It is part of their care plans. When they set up with their Consultant and we, we call our case managers "Consultants" after they have been trained to the CDC Plus Program. The consultant sits down with the consumer and they determine what the two emergency backup systems will be and if it is with a home health service, then they get the cost for the estimated hours that they believe they will need and the amount that it is going to be and that is part of their monthly budget.

Susan Reinhard: Carol, just to kind of extend Erin's question, I think Erin that this is what you are getting to; how do they get, how can they anticipate that? Is it a best guess scenario?

Carol Schultz: Yes, actually it is. They have to just make certain assumptions on how long they will need it and how quickly they can get back with their regular worker. So yes, it would be.

Susan Reinhard: If they don't spend it they can roll it over?

Carol Schultz: Right.

Erin Barrett: So it is going into some separate kind of savings account for emergencies?

Carol Schultz: Our consumers can save for different items every month. Their savings can roll over from one month to the next.

Susan Reinhard: That is part of your 1115 Waiver?

Carol Schultz: Right.

Erin Barrett: Great, thank you.

Anthony: Our next question is from the line of Beth McArthur in Hartford, Connecticut. Please go ahead with your question.

Beth McArthur: Yes, we were just interested in receiving any copies of the risk screening tools that you use in conjunction with your individual plan process and any copies of the templates or forms that you use for individual planning that shows how you incorporate the backup plans into the planning process.

Susan Reinhard: Are you looking for a specific state or in general you are looking for those kinds of...

Beth McArthur: I think there were two states at least that referenced that they incorporate the emergency backup plans with their individual plan or their plan of care.

Susan Reinhard: Yes. I think you all did, didn't you? Do any of the states want to address that if you are able to share information?

Female: I can certainly send the purchasing plan to her if she would like. I can do it on email.

Susan Reinhard: All right. How about if you give it to us and we will send it to everyone?

Female: OK, I can do that. I can send it to who has been emailing us?

Susan Reinhard: That is correct.

Female: OK, we'll do.

Susan Reinhard: Thank you.

Female: New Hampshire, we can send you our template for the service agreement through email.

Female: Louisiana, we can send you our plan of care or support.

Susan Reinhard: Great. We can also post all of these on the HCBS.org website.

Male: South Carolina can go ahead and do the same.

Susan Reinhard: Thank you. How does that sound, Beth? OK? I think she is off. Anthony?

Anthony: Yes, there are no further audio questions at this time. Susan, you may continue.

Susan Reinhard: Great. Well, let me just turn to CMS to Terry, to Anita; Ed, is there anything you would like to add?

Terry Pratt: From CMS, I will go out on a limb here and just based on what we were hearing from the state presentations, there were some commonalities here that I think might be worth

noting to those grantees who are in the process of developing their next steps and looking to address emergency backup.

Some of the commonalities that we heard were relative to geographic regions. Where do you live and what is the natural disaster most likely to occur in your area? You may be in an area where you have few or none, but in the Southeast, and I did grow up there, the incident for hurricanes and tornadoes are pretty prevalent and everybody who lives in the South pretty much knows what you need to do.

Another trend or key step we seem to be hearing is this continuum of contingency backup, not even labeling it "emergency" but that in the event of a person's plan of care, that there is a contingency for the plan that is written on how those services would be provided absent the provider of choice not being available.

While I think we still get to the same end product, which is emergency backup, it takes on sort of a different connotation in that gradations of backup and decision making were used by these states. At least two if not three states said they used a four-tier system with ultimately in some instances the backup being 9-1-1 in the case of a true, critical emergency plan.

I think the other trend that we heard here was the utilization of existing resources and being able to tap into protective services. So those were just three of the things that I personally heard that the states were using in the development of their backup plans for the provisions of services that met and satisfied our requirements.

I go on to point out that none of those particular requirements were anything that we, as Anita said, expressly wrote down; that what we had was a framework in which we felt it was necessary for states to develop a plan that would satisfy us. What you heard on the phone by states today were things that they came up with that in turn satisfied the framework that we have set out in our template and in our subsequent conversations. I will invite others from the table to add additional comments.

Susan Reinhard: Thank you for that summary, Terry.

Terry Pratt: I was listening.

Susan Reinhard: Are there others? Other comments here?

Female: CMS appears to be done.

Susan Reinhard: And is there any; I don't know if we really addressed unacceptable, examples of unacceptable emergency systems. Certainly the states who presented were selected because they do have acceptable systems, but is there anything you wanted to add about that? Are you seeing things that are unacceptable coming across your desk?

Nancy Thaler: This is Nancy Thaler. From a quality perspective, the only thing I would suggest thinking about is what is put in place to monitor whether or not emergencies are responded to promptly.

Susan Reinhard: All right. So it is not just having it, but it is how you are monitoring how it is working.

Nancy Thaler: Yes.

Susan Reinhard: OK.

Nancy Thaler: The other general comment that seemed to be coming in response to the question is using 9-1-1 as the sole backup system doesn't go far enough. We would want to see more and today we have heard demonstrative examples of state systems that get to that place, but 9-1-1 can certainly be embodied in the continuum of backups, but not utilized solely as the backup system.

Susan Reinhard: Great. Well thank you all. Thank you to all the participants, all the speakers, all of those who asked questions. I just want to end this call by saying we will talk with South Carolina, with Roy and his colleagues there about setting up a call on the Care Call system. We will send you materials that have been promised from the speakers and get them posted on the website as well as a recording of this and the transcript once it has been summarized and approved for dissemination.

I also wanted to say in our assessment calls with the Independence Plus grantees, we have looked at all the emerging or most emergent issues to discuss and the second one aside from this one was Support Brokerage. How is that working? What are some good state examples? Similar to what you heard today, the challenges, the costs, all of those kinds of issues. So that will be the next call that we arrange and we hope to do that within the next couple of weeks.

So again I want to thank, and I also want to thank two people in particular. Suzanne Crisp, who has been very quiet on the phone, who is a consultant with Medstat and works with us on the technical assistance exchange, has been very helpful in organizing this call. Also Nirvana Huhtala, who works with me at Rutgers who as someone has noted, Beth noted, has been doing all the emailing back and forth so thank you for your support in organizing the call, Nirvana. Thanks to all of you and we will talk to you very soon.

Female: Thanks Susan.