

Medicaid Regulations for Maintaining Back-up of Medications and Supplies: Tips from Family Leaders

Many Children/Youth with Special Health Care Needs (CYSHCN) need daily medications or other supplies to maintain their health. In a natural disaster, such as a hurricane, access to needed medications and supplies is often compromised. However, FEMA and Red Cross recommend that people maintain a 30-day back-up supply of all of their medications and supplies. For the many families of CYSHCN that depend on Medicaid, regulations under that program (do not permit this. What can families of CYSHCN do?

From Kelly Morris (FV of Ohio):

1. Pre-Storm: Identify other ways of maintaining a backup supply of medications/medical supplies:
 - A family may be able to clean certain supplies that may be stored and reused in an emergency situation. Depending on the specific medical supply, some may be used more than once, for example, feeding bags.
 - Sometimes other families will donate unused formula/supplies. A family could connect with their County Board and ask to be put on a list to receive any donated supplies that would help them in an emergency.
 - Food pantries and the state/local health department may also receive donated supplies.
 - Family-to-Family Health Information Centers may be able to help families connect with these agencies or organizations that have donated supplies.

From Karen Scallan (BLFHF – Louisiana):

2. Pre-Storm: Issue Emergency Orders:
 - In anticipation of a disaster, the Medicaid state office can issue an emergency order authorizing a 2 month supply of medication renewals. *(Also true for Alaska per Amy Westfall)*
 - This has now become the standard practice when hurricanes are expected in the Gulf, and private insurance companies also typically allow for a 2 month supply due to anticipated disasters.
3. Post-Storm: Filling scripts
 - Local mental health departments operate mobile units that stock non-controlled substances allowing them to fill scripts at shelters for both residents and anyone else needing refills
 - Faith-based groups also provide mobile medical units to refill scripts
 - Private insurance companies were sensitive to the needs of families in flooded areas and would usually refill a script that someone lost
 - These practices are not followed for controlled substances
 - If people received their scripts from the public hospitals, those hospitals who were open and running 24 hours after the storm, could fill those scripts. If transportation was an issue, our organization called the state offices for Public Health, Mental/Behavioral Health to work out individual issues that couldn't be worked out through faith-based or local means.

Karen Scallan (Louisiana): You may want to contact Governor Christi's office and find out who the FEMA liaisons are for

- Equipment for individuals with disabilities
- Housing
- Rental assistance
- Disability general liaison

There should be one or probably more for each in your area. For Hurricane Isaac, they were helping people access replacement equipment, working with the FEMA inspectors doing assessments of damage to help them understand the more urgent needs for housing among people with disabilities or special needs, they were trying to expedite housing issues, particularly for people in need of ramps. FEMA is no longer using the small FEMA trailers like they did for Katrina because of the formaldehyde issues, but they did bring in full size single wide mobile homes once sites were established and utilities established. Individuals with disabilities, especially those needing wheelchair ramps, etc. should be first on the list.

Additionally, it might be useful to start gathering resources if you don't already have them for groups, volunteers, and others who are willing to build ramps once the trailers are placed or for those that had ramps destroyed by the flooding.

I recommend getting a conference call systems set up with other groups to partner and share information and resources on individuals in need as well as resources to help them. This worked well here.

One thing that I was concerned about during the response to Isaac, was that there was not enough emphasis placed on needs of individuals with mental health issues or those with disabilities like Autism who have severe issues with change or behavioral issues.

I will say that FEMA came in and provided excellent support in the shelters with equipment though including communication devices people could use in the shelters, etc. Disability.gov put out a video of the equipment supports that were available there.

Hope this helps. Call us if you need us or have any questions Diana. We're here for you guys.

My personal cell is 504-430-3604.

Amy Westfall (Alaska): For our state, when we had our floods and stuff, as soon a state of emergency was declared, Medicaid allowed for those emergency supplies to be sent out. We were involved with helping how sometimes, because regular means weren't possible. Diana and other folks over there, if you need anything more throughout all this, just ask, we are all here. In Alaska, we don't have many natural disasters but flooding and winds are our thing, so we have lots of experience. And there will be issues and questions after it seems to die down from the news, I'm glad we have this network.

Julie Finholm (Washington): I feel this would be news worthy - I would contact National Morning Shows as well as local news cast stations - Pres. Obama might like 2 highlight this as well - go big or go home :) - I wish u all peace.

Karen Scallan (Louisiana): I wouldn't rely on donated supplies first. I would seek donations for purchases and have people contact their insurance companies and Medicaid for replacement items or supplies first. They know there's a disaster so I'm sure many will be authorizing new supplies. Donated supplies can tend to be expired or not in good condition if they are equipment donations. I had this experience during Katrina. Some things were great. Others not so much.

The Developmental disabilities councils may receive money from the federal level for F2FHICs or others to go into shelters and seek individuals with disabilities who need assistance. Check with them.

WIC may also authorize extended benefits.

They may also have already started to take Disaster food stamp applications. Those sites will be swamped! ! Believe me, I worked them for GUSTAV!! And saw them for Katrina and Isaac.

THIS IS A GOOD PLACE TO GO TO WORK....

I went there on the F2FHIC and did outreach and found that the site I was assigned to during GUSTAV had no triage for individuals with disabilities so I wound up doing their triage and dealing with lack of accessibility issues there.

IF YOU DO THIS, bring lists of phone numbers at the state level. I must have called a half a dozen times about problems with accessibility issues to get them fixed.

START AN EMERGENCY DIRECTORY OF ASSISTANCE....

The resources will start rolling in and you'll find them on line, etc. I think I have a copy of the one I did for Katrina as an example. Easier to set it up now than later, believe me....

Separate resources by Food, Housing, Home demolition and gutting assistance, medical care, medications, clothing, etc.

You're going to see lots of free help coming in as the days go on. Mostly from churches. Contact the churches in the area in a few days and see what they have coming in or expected.

Donna DeStefano (Tennessee): Our Metro Nashville government was instrumental in coordinating everything during the flood and recovery periods, which was helpful to all of us in the disability community here. The folks from the various disabilities agencies that were able to be involved with this initially did so, others joining as they (and/or their staff) who were affected themselves were able to do so. I've attached a handout from FEMA that helped to outline the overall process from emergency to relief to long-term recovery, including information on Small Business Association assistance. Hope this is helpful to you.

Attachment: FEMA Handout *Sequence of Delivery*

Josie Thomas (Maryland): For those of you who are responding to the requests for information regarding Sandy and emergency resources, we thank you. You are providing such important information for all of us as we work our way through the mess that Sandy left behind. While we in Maryland did not receive the hit that NJ and NY did, we have many families on our Eastern Shore without power, phones, drinkable water, and their homes and area are flooded. Schools are closed because they are being used

as shelters. We are working with our Title V program to contact the local health departments in those areas hardest hit to identify needs right now.

Brooke Lehmann (DC): Here in DC we have mostly recovered from the storm and would like to turn our attention to those states still in the process. I have one very specific question- is children's clothing something that would be helpful? I can begin collecting that immediately and drive it up or ship it up myself.

As for the other suggestions, they are all wonderful and I'm sure FV can collect them all in a useful form.

To those in the states effected here in the east, I'm more than willing to drive up with my children this weekend and lend a hand in any way that would be helpful. Just please let me know if/where/when.

Donene Feist (North Dakota): To all of you dealing with the many issues that are happening, know our thoughts are there with you

And that if there is anything that we can help with we are happy to do it.

The FEMA disability liaison was very helpful here in ND to bring all of the advocacy groups together to work united.

Although I realize we have far less people to deal with. Heck you have more in one city than we have in the entire state.

Anyway you all are in my thoughts

Jill McCormick (Washington): Piggybacking on what Julie said. Twitter may be the way to start the conversation. Both the White House and President Obama have twitter accounts. Just an idea for immediate contact. I know a lot of you have been doing this a long time and are masters of telling the story but documenting how the Network provides direct resources to areas and families most impacted is a way to show that Family Voices and F2F's serve an important function for families especially in times like this.

Brooke Lehmann (DC): We are initiating a children's clothing drive here in DC and will be using our schools, soccer clubs, etc. to collect warm clothes for children/youth who are in need due to the storm. If you are an F2F that is hearing from families that they need clothing, please let me know. We will be collecting things over the next week and will then ship the boxes directly to your offices or wherever you suggest. If any special requests come in (winter boots, etc.) please let me know and we'll do our best target those items.

Kay Johnson: Could someone set up a way for contributions to go through PayPal or some other automated system? I think this is simple for those who are familiar with the technology. That would avoid having to send checks or whatever to NJ and others. Kay

Diana Autin (New Jersey): SPAN has paypal on our website at <http://www.spanadvocacy.org/content/donate-span> (you can access it from our home page, www.spanadvocacy.org, at the top on the Donate Now button)

Karen Scallan (Louisiana): To Brooke and anyone sending clothing... just a suggestion ...

I did this after Katrina, taking in clothing, medical supplies and equipment.

It will be helpful if people who are donating are asked to sort the clothing before sending by size and boy/girl or ladies/men's.

They can place the clothing in plastic bags with a note taped to the top. ;
This will help the people working the clothing drive and reduce time in sorting or digging for sizes.
You're going to get way more donations than you ever imagined.

For those organizing the clothing drive, you may wish to partner with an area Arc or other such facility. We did in Baton Rouge and individuals with disabilities who worked at the Arc helped unload the items from trucks coming in, helped sort items and assisted us. The Arc in Baton Rouge had a large enough space to store the items.

We also found that when people lost things they lost EVERYTHING. We collected boxes from grocery stores, sorted clothing by size and boy/girl as noted above and marked boxes very visibly and then when someone needed Boy's Size7 clothing, we just pulled the box and gave it to them or taped it up and shipped it directly to the person.

A lot easier that way and not as time consuming to continually go through items piled up.

We also put the word out about the clothing drive to all Families Helping Families Resource agencies who had funding to go to shelters throughout the state and assess need for individuals with disabilities. When they found someone in need, they just contacted me and we coordinated to get the items to the individuals either by mail or by posting info on anyone going to various cities on our newsgroup, etc.

Hope this helps.

Karen Scallan: Does anyone else besides Diana need a copy of the Post-Katrina Resource Guide I did for the PTI in LA?

Let me know and I will send it... located an electronic copy.