

# You Know that it's Got to be Dedication that I am Still Here.

The Experiences of Direct Support Professionals during  
Hurricanes Katrina and Rita, and Aftermath

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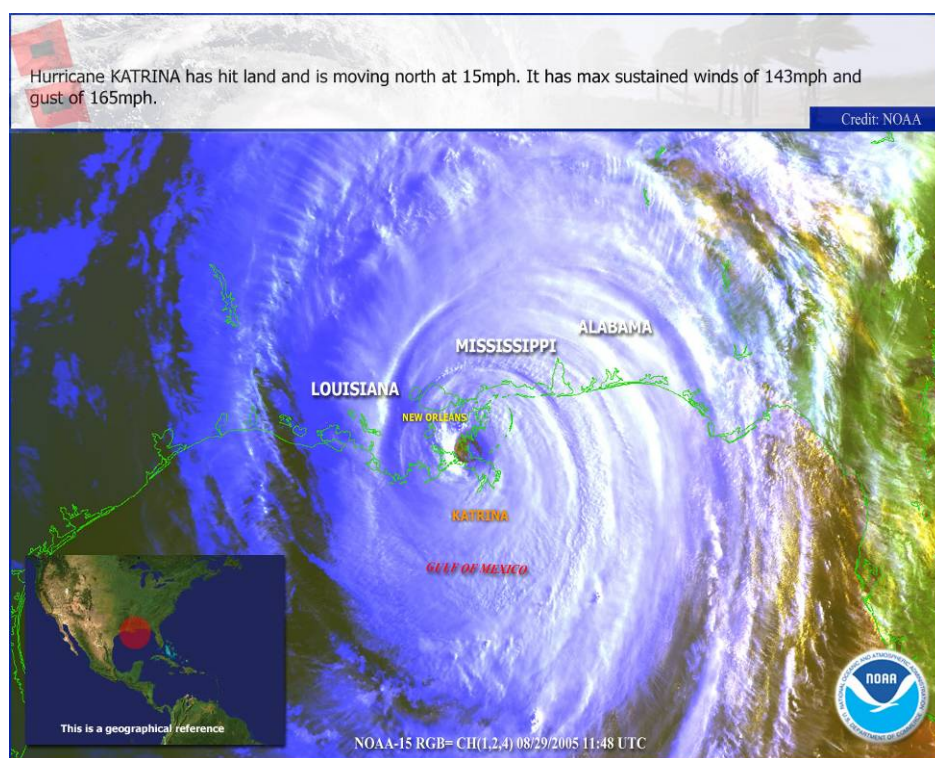
## Table of Contents

Table of Contents .....	3
Overview .....	5
Background .....	5
The Project .....	8
Participants .....	9
Katrina Experiences .....	10
Reasons for Staying.....	12
Dedicated Direct Support Professionals.....	13
Dedication .....	13
Commitment to the Individuals Served.....	14
Added Responsibilities.....	16
Work Life During and After the Hurricanes .....	17
Working Conditions .....	17
Extreme Hours .....	17
Added Responsibilities, Burdens, and Use of Personal Finances .....	18
Lack of Staff.....	19
Lack of Time Off, Personal Freedom and Privacy.....	19
Family and Work Dual-Loyalties.....	21
Management and Practices.....	21
Work Relationships .....	22
Relationships With Other DSPs .....	22
Relationships With VOA Affiliate Staff .....	23
Relationships With Management .....	23
Personal Experiences .....	24
Before the Hurricanes .....	25
During the Hurricanes .....	25
After the Hurricanes.....	26
Health Issues .....	28
Government Response .....	29
Kinship.....	30
Family Left Behind .....	30
Family Conflict .....	31
Family Members Becoming DSPs .....	31
Sharing Family Resources.....	31
Children.....	32
Trauma .....	33
Inability to Grieve .....	33
Other Trauma .....	34
Communication.....	35
Communication with VOA .....	36
Communication with Family.....	36
Faith .....	36
Religion.....	37
Prayer .....	38
Miracles.....	38
The Big Picture .....	38
Poverty Influences Experiences .....	38

Kindness and Generosity of Others.....	39
Crime.....	39
Management Experiences .....	40
Arranging Temporary Housing .....	41
Management Personal Lives .....	41
Staffing Bonuses .....	41
Making Changes/Improvements .....	42
Consumer Experiences.....	43
Health and Safety Issues .....	44
Evacuation Experiences .....	46
Concern for Belongings and Pets .....	46
Living Conditions After Returning to New Orleans .....	47
DSP Recommendations to VOA.....	49
References .....	50
Resources .....	50

## Overview

On August 29, 2005 at 7:30 a.m., Hurricane Katrina struck the City of New Orleans. Katrina directly impacted every staff member and person supported by Volunteers of America (VOA) of Greater New Orleans. In 2006, the University of Minnesota was asked to conduct a series of interviews and focus groups with staff from two of VOA's programs: Supported Living Services (offering individualized family supports day and night, and semi-independent living supports to adults and children with disabilities) and Community Living Services (offering group homes for adults and children with developmental disabilities). This report describes the experiences of the direct support professionals working for VOA between August 2005 and May 2006.



## Background

In August 2005, VOA New Orleans employed 180 Personal Care Attendants in the Supported Living Services division who supported 122 people living in their own homes or with their families. They employed 100 direct support professionals in Community Living Services who supported 75 people living in 12 group homes. They also ran a substance abuse program, a correctional center, an auto donation program, a single room occupancy housing program, family and youth programs and elderly services.

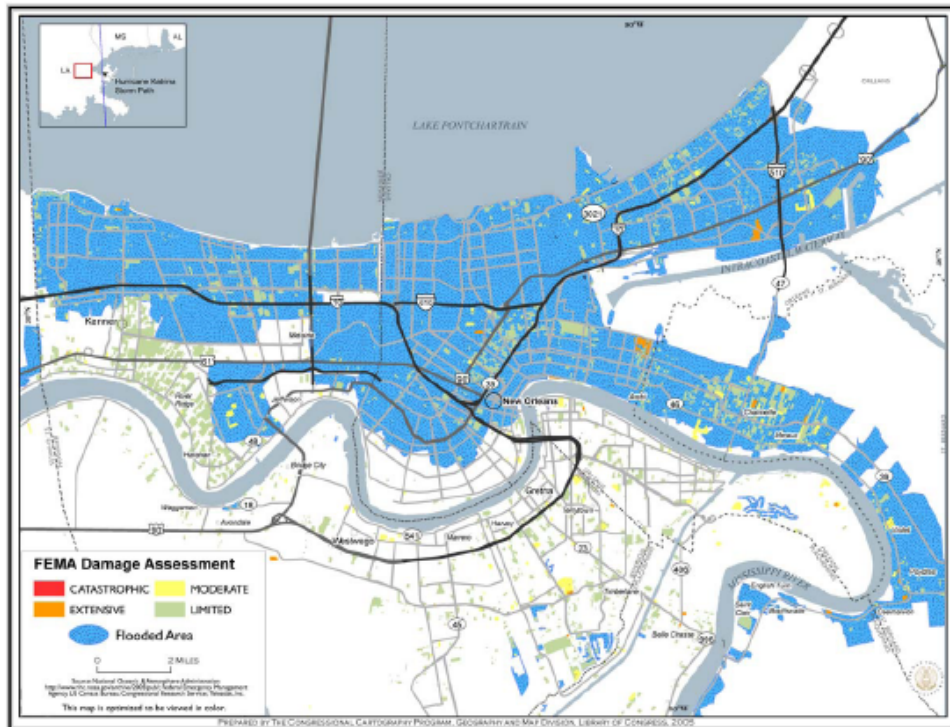
On August 26, 2005 when VOA administrators realized that Hurricane Katrina was going to hit New Orleans with life threatening intensity, an evacuation plan

was put into motion and the organization began moving staff and consumers to safety. Evacuation plans for the Community Living Services division called for a group evacuation which began on Saturday August 27<sup>th</sup>. That morning, 50 direct support professionals, 75 consumers, plus administrators and bus drivers evacuated in 3 busses and 3 vans. By the time they arrived in Palestine Texas, there were only 22 staff and their immediate families. Evacuation plans for the Supported Living Services division were individualized. Some people evacuated with family members, many more evaluated with VOA staff members and a few evacuated to shelters on their own.

At its peak on August 28, Katrina was a category 5 hurricane with sustained winds of 150 knots. Katrina made landfall on August 29<sup>th</sup> in Grand Isle Louisiana as a strong category 4 hurricane with sustained winds of 140 miles per hour. Katrina made a second landfall near the Louisiana/Mississippi border as a category 3 hurricane with sustained winds of 125 miles per hour. The damage and destruction from flooding continued into September. At the peak of the flooding, 80% of New Orleans was underwater with some locations under 20 feet of water (Townsend, 2006). On September 24, 2005 Hurricane Rita, a category 3 storm at landfall struck southwestern Louisiana and caused further damage and dislocations. By October 4, 2005, 1.5 million people had been evacuated from Louisiana (Wikipedia, June 9, 2006). As of May 19, 2006, Hurricane Katrina had cost the lives of 1,836 people including 1,577 from Louisiana, and had caused an estimated \$81.2 billion in damage making it the costliest natural disaster in U.S. history (Wikipedia, February 1, 2007).

*At the peak of the flooding, 80% of New Orleans was underwater with some locations under 20 feet of water (Townsend, 2006)*

Figure 3. Hurricane Katrina: FEMA Damage Assessment — - New Orleans and Vicinity



The communities served by VOA in New Orleans and surrounding communities were hard hit by the hurricane. Most of the people receiving supports from the



SLS division had lived in Orleans, Jefferson, St. Bernard, or St. Tammany Parish. Most of the SLS staff lived in Gentilly, the Ninth Ward or New Orleans East. Most of their homes were badly damaged or totally destroyed by the winds or flooding that accompanied Hurricane Katrina.

Much of VOA's property in the region was damaged or destroyed. FEMA estimates of the proportion of homes that were damaged or destroyed ranged from 39% for homes in Vermillion Parish to 90% for homes in Cameron Parish (see Table 1). The Congressional Research Service (2006) reported that the flooding affected 77% of the population of Orleans Parish and nearly all of the residents of St. Bernard Parish. An estimated 645,000 residents of Louisiana were acutely affected by flooding or structural damage to their homes (Congressional Research Service, 2006). Those who were affected were more likely than Americans overall to be poor (21%), black (44%), and without a high school education (23%; CRS, 2006). An estimated 352,930 dwellings were destroyed and 139,646 sustained major damage. Approximately 200,000 people in Louisiana were left homeless by Katrina and the associated floods, and 75,000 were left homeless by Rita (Louisiana Geographic Information Center, 2006). The evacuation that was expected to last just three days, instead stretched for months as large parts of New Orleans and surrounding communities were uninhabitable due to wind and water damage. By January 2006, more than four months after the Hurricanes only 35% of the pre-Katrina population was living in New Orleans (City of New Orleans, 2006).

*Most of the staff lived in Gentilly, the Ninth Ward or New Orleans East. Most of their homes were badly damaged or totally destroyed by the winds or flooding that accompanied Hurricane Katrina.*

**Table 1 FEMA April 2006 Reimbursable Damage Estimates from Hurricanes Katrina, Rita and Wilma**

New Orleans Parish	% of homes damaged or destroyed		
	Own	Rent	Total
Orleans	76%	67%	71%
Jefferson	50%	58%	53%
St. Bernard	75%	97%	81%
St. Tammany	71%	68%	70%
Calcasieu	61%	73%	64%
Cameron	84%	127%	90%
Plaquemines	72%	111%	80%
Vermillion	38%	41%	39%

US Department of Housing and Urban Development, Office of Policy Development and Research, April 7, 2006

During the evacuation, staff and individuals in the Supported Living Service division were scattered throughout the southeast United States. They evacuated to Houston, Conroe, and Dallas Fort Worth Texas; Shreveport, Baton Rouge, Monroe, and other areas in Louisiana; Gadsden and Birmingham, Alabama; Jackson, Picayune, and Hattiesburg, Mississippi; and parts of Arkansas and Tennessee. They stayed in cars, shelters, hotels, trailers, with family members, or in VOA affiliate program sites. Many had to move again when Hurricanes Rita



hit. Staff and consumers in the Community Living Division stayed in a hotel in Houston for a week, then evacuated to the Houston Astrodome for one day, finally ending up at the Lakeview Methodist Conference Center in Palestine, Texas for 64 days.

When the flood waters receded and rebuilding efforts began, VOA was a much smaller organization. At the end of the evacuation, 12 New Orleans direct support professionals and 69 people with disabilities remained at the Palestine Lakeview Conference Center in Conroe Texas. By May 2006, 72 consumers had returned to the New Orleans area and were living in 6 group homes supported by 50 direct support professionals. Of those supported by the Supported Living Services division, 78 people were receiving services in their own homes, temporary shelters, or the homes of VOA staff members from 76 Personal Care Attendants. A couple of VOA consumers died in the months following the evacuation and a few others were moved to nursing homes or state institutions. No other services were operating out of the New Orleans office of VOA in May 2006.

The region served by VOA was also vastly different after the storm. After the storm, FEMA provided housing assistance to more than 700,000 families and individuals (Wikipedia, 2007). As of July 2007, 71,134 people were living in FEMA provided trailers in Louisiana and an enormous housing shortage existed in the City of New Orleans (FEMA, 2006). Before the hurricane, New Orleans had a population of 484,674 served by 4,486 doctors and 117 schools. In early 2006, the population of New Orleans was 181,400 and was served by 1,200 doctors and 25 schools (L9 Common Ground, 2007). Even in May 2006, some parts of New Orleans were still without electricity and running water (particularly in the 9<sup>th</sup> ward). At least 1,042 displaced people with intellectual or developmental disabilities were admitted to nursing homes in Louisiana by October 2005 (Advocacy Center et al, 2006).

This report tells the story of direct support professionals from New Orleans and surrounding communities who supported people with disabilities during and after Hurricanes Katrina and Rita.

## The Project

In May 2006, a series of focus groups were used to glean information from direct support professionals, and frontline supervisors about their experiences throughout the 2005 Katrina storm, flood and evacuation. We also gathered information about their return from the evacuation back to the New Orleans area and to their jobs at VOA. The purpose was to learn why staff members stayed with VOA throughout the hurricane and evacuation and why they remained with VOA upon their return to New Orleans.

A brief survey was used to gather demographic information about focus group participants and to get answers to a core set of questions about their experiences. The surveys were done anonymously and were not linked to any other data elements.



*This report tells the story of direct support professionals from New Orleans and surrounding communities who supported people with disabilities during and after Hurricanes Katrina and Rita.*



A total of five focus groups were conducted each lasting approximately 100 to 130 minutes. Participants talked about four general topics: What happened at the time of the hurricane, what made them decide to return to Louisiana, what worked and what did not work about the evacuation process, what are their concerns and suggestions for the future.

Participants in the focus groups who registered their attendance were given a \$50 stipend for participating paid for from Centers on Medicaid and Medicare Services Direct Service Worker Demonstration grant funds.

In addition to the focus groups, a series of interviews were conducted with key administrators and managers from the New Orleans and regional offices of VOA to gather information about the events surrounding Hurricane Katrina, the evacuation, and the return to New Orleans. This included a tour of some of VOA’s properties that were damaged by the storm. Notes from those interviews were kept individually by project staff members.

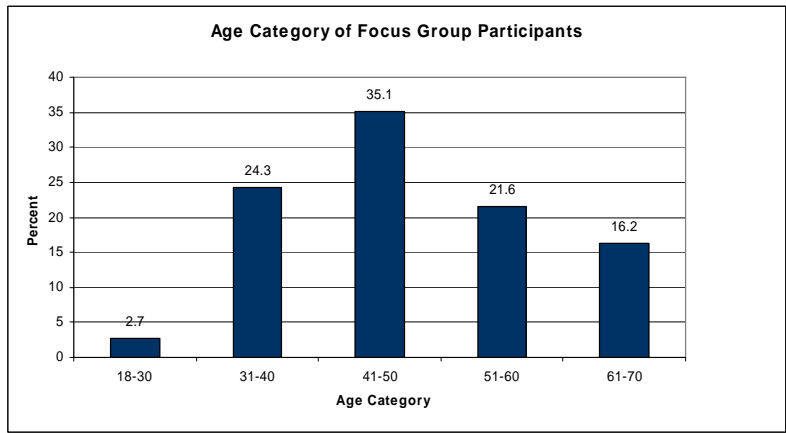
Focus group meetings were taped and the proceedings were transcribed in their entirety. The transcriptions were reviewed by the project team and codes were developed to describe the major themes that emerged. Three team members (including one who had not participated in the focus groups) then used the InVivo software to code the transcribed notes from the focus group meetings using the themes identified by the teams. Reliability was assessed across the three coders. The surveys were analyzed using descriptive statistics from the SPSS software.

Participants

Altogether, the focus groups included 41 participants. In addition, interviews were conducted with 6 administrative and other support staff members. Surveys were returned by 37 focus group participants.

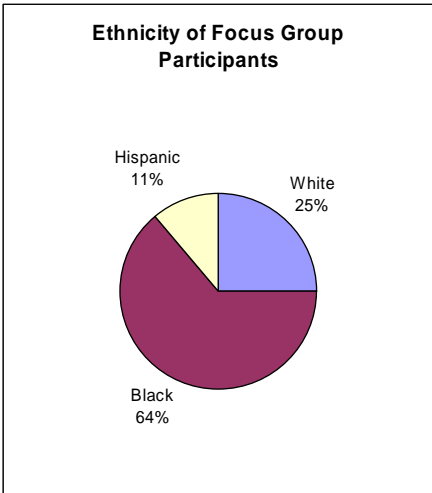
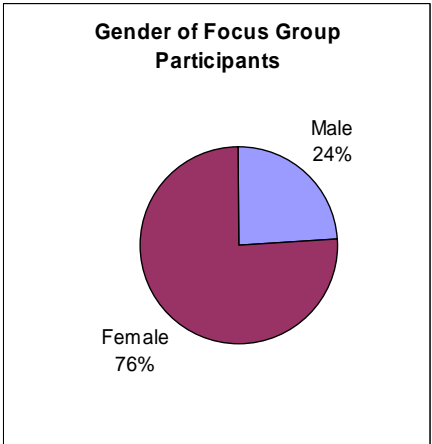
The focus group participants were primarily female (76%) and the majority were Black (64%).

Participants were diverse in age with a somewhat higher representation of older participants than younger. Overall 35% of the participants were between 41 and 50 years old, 22% were between 51 and 60 years old and 16% were between 61 and 70 years old.



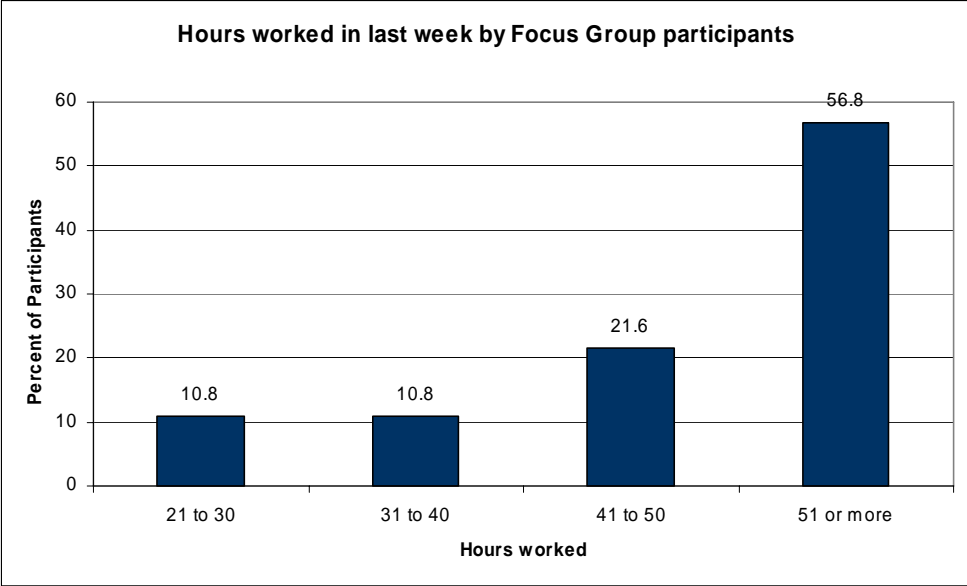
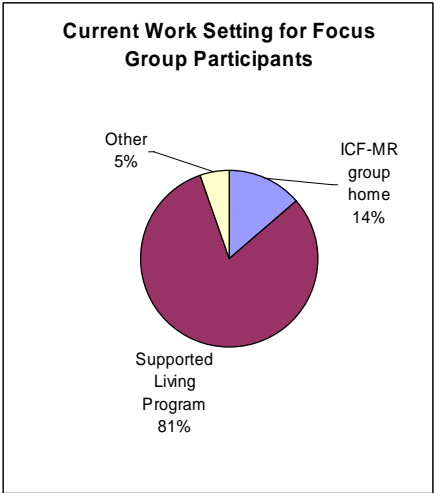
The majority of focus group participants worked more than 10 hours of overtime in the week prior to the focus group

Five focus groups were conducted with 41 participants. In addition, interviews were conducted with 6 administrators and other support staff members.



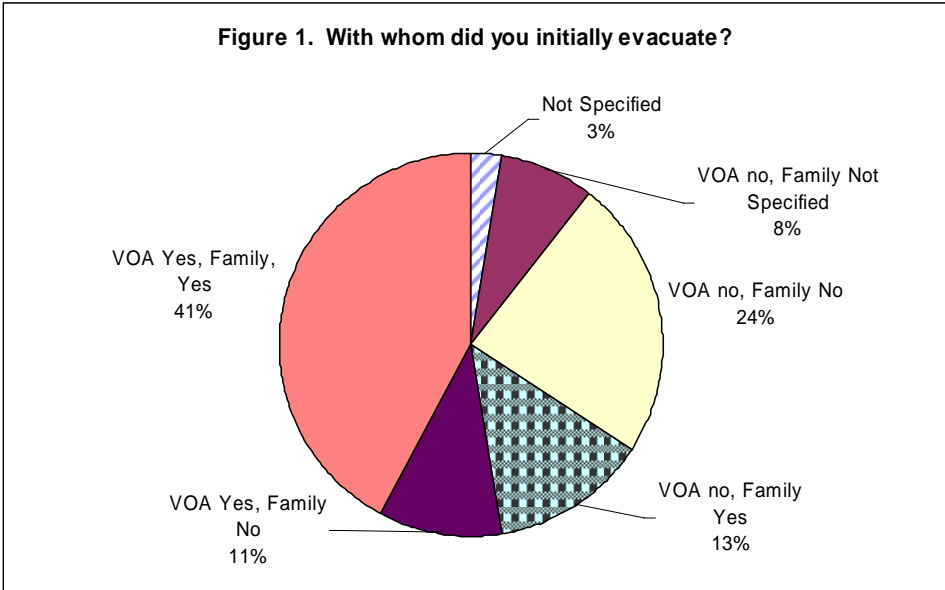
meeting (57%). In fact, some participants reported working 168 hours during the week prior to the focus group. Only 22% of focus group participants reported working less than 40 hours in the week prior to the focus group.

Most of the focus group participants were direct support professionals (76%) while 19% reported working in a Facilitator role, and 5% reported working in a House Manager role. The majority of participants worked in Supported Living Services (81%), while 14% worked in a Community Living Services group home and 5% reported working in another type of setting.



### Katrina Experiences

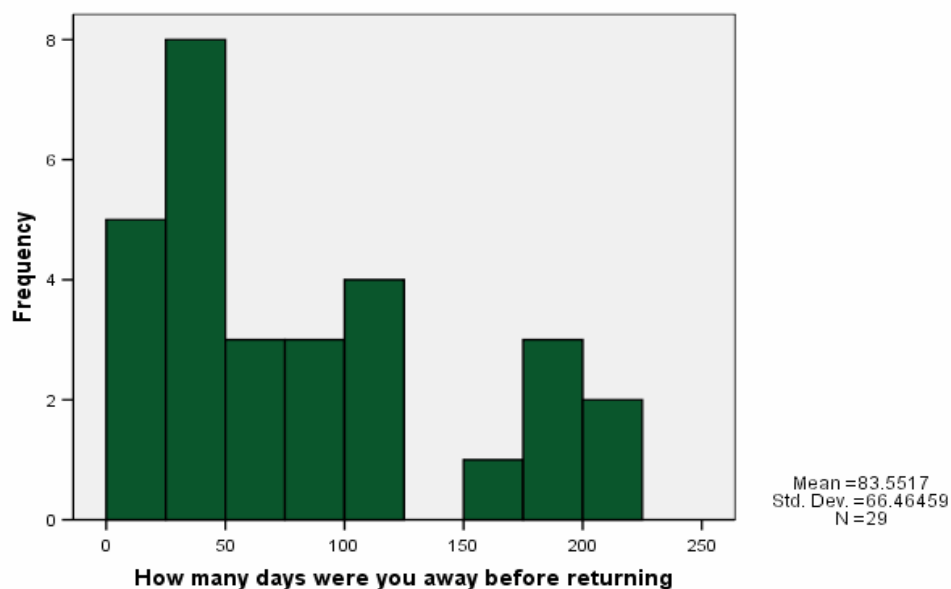
Focus group participants had different evacuation experiences depending on whether they were on duty at the time of the evacuation and whether they



*Of those who evacuated, 52% left the New Orleans area with one or more consumers from VOA including 41% who evacuated with both VOA consumers and with family members and 11% who evacuated with consumers but not with family members.*

evacuated alone, with family members, with VOA consumers or with both family members and VOA consumers. The vast majority of participants were VOA employees at the time of Katrina (95%) and all but one of the participants evacuated from their home (97%). Of those who evacuated, 52% left the New Orleans area with one or more consumers from VOA including 41% who evacuated with both VOA consumers and with family members and 11% who evacuated with consumers but not with family members. Overall 24% of staff focus group participants evacuated alone and 13% evacuated with family members but no consumers. Some participants evacuated from the New Orleans on their own or with family members but after checking in with VOA they learned that they were needed and joined up with an evacuated person in another city at some point after the initial evacuation. Others who initially evacuated with VOA left to be with their families after a period of time only to return to VOA once the programs reopened in New Orleans. A few focus group participants were hired to work at VOA after returning to the New Orleans area.

*The average staff reported being away from the New Orleans or Slidell areas for 83 days.*



Each bar on this chart represents 25 days away from the New Orleans area. The average staff reported being away for 83 days. Eight staff reported returning after one to two months away. Five staff reported returning to the area within 4 weeks of the hurricane, while six reported being away for four to six months before returning.

## Reasons for Staying

Focus group participants provided rich descriptions of why they continued to work at VOA throughout the Katrina experience. The bulk of this report is devoted to describing those experiences. At the end of the focus groups, participants also answered a survey question about why they stayed. A total of 22 reasons for staying or leaving organizations were listed. Participants marked all the choices they felt applied to them. Table 1 shows the percent of respondents that selected each option. By far, the most common reasons staff reported staying with VOA was because of they liked the people they supported (92% selected this option), and they felt that the people they supported liked, appreciated and needed them. Fewer than half of the participants selected the other choices.

**Table 1 What made you decide to keep working for VOA during and after Katrina?**

I like the people I support	92%
The people I support appreciate me	81%
The people I support like me	81%
The people I support need me	81%
VOA's mission and service goals	41%
Flexible hours/schedule	38%
Work atmosphere	35%
Work is rewarding	35%
This is a good company to work for	27%
Tasks and activities I do for my job	27%
Staff members are team players	27%
Co-workers	24%
Training and development opportunities	22%
Supervisors and managers	19%
Location	19%
I need the people I support	16%
Opportunities for personal or professional growth	14%
Availability of overtime hours	14%
Recognition for a job well done	11%
Pay rate/salary	8%
Job variety	8%
Benefits	5%
Other	5%

*By far, the most common reasons staff reported staying with VOA was because of they liked the people they supported.*

## Dedicated Direct Support Professionals

Throughout the focus group discussions the dedication of VOA's Direct Support Professionals (DSPs) was evident. Worker characteristics emerged from actual workers' self-described statements, descriptions of co-workers, descriptions of DSPs by managers and researchers' observations. Characteristics included but are not limited to: thoughtful, conscientious, dedicated, hard-working, responsible, trustworthy, (remained) calm, focused, able to work under pressure, able to think creatively/resourceful, and stable.

Managers were very forthcoming with stories and examples of dedication embodied by VOA DSPs. In fact, there were times when managers were brought to tears while describing the heroic efforts of DSPs on behalf of individuals with disabilities. Although some DSPs describe feeling unappreciated by VOA, the managers repeatedly stated their appreciation for the DSPs that worked during the hurricane and those that supported consumers in the long aftermath and resettlement periods. While this schism about appreciation exists there is no questioning the unanimous sentiment that VOA DSPs demonstrated extreme dedication throughout the hurricanes and subsequent recovery.

### Dedication

The dedication demonstrated by DSPs can be seen through actions and attitudes; both of which enhanced the lives of the people they supported during and after the disaster. As discussed elsewhere in this report, DSPs generously gave of their personal time to fill the numerous uncovered work shifts resulting in time away from their own families, time away from the rebuilding efforts in their own homes, and time away from their own health maintenance and emotional recovery needs. DSPs frequently worked around the clock in the early days after Hurricane Katrina and continued a grueling work pace up until the time of the focus groups.



*"I am very grateful and the Volunteers of America is very grateful that these staff have actually sacrificed not only their personal lives and time, but also many other sacrifices to benefit the people we serve. It has been a challenge." VOA Manager*

*"You also have to take care of your problems you had at home ... and the same time you have to, no you wanted to come and help your consumer because you know that, that person was also going through what you were going through and it's a lot difficult for them so you did a little bit at home and you spend 24 hours doing theirs ..."*

*"You have to be strong for your children, your consumers, because you're helping them put their lives back together. They look at you and say, 'Cheryl (synonym) I lost my furniture.' And I get to say, 'Well, you get to buy new furniture.' You have to be upbeat about it and then you go about getting them FEMA money and you start buying them new furniture and help them put their lives back together."*



In addition to their time, DSPs dedicated a great deal of their own resources to VOA and the people they supported. It was uncanny. DSPs told the same story over and over of how they packed three days of clothes and personal supplies for themselves, family members and their consumers. When it was clear that the evacuation would be in effect for a much longer period of time while the city and VOA rebuilt, DSPs who provided independent living services, found themselves having to purchase food, clothes and supplies for consumers on an ongoing basis. Some of the DSPs kept receipts and were able to get reimbursed by VOA, others just absorbed the expenses. For many, cash was not available so interest on credit cards was also incurred.

DSPs relied heavily upon their families to support individuals with disabilities throughout the disaster. This often took the form of sharing living space and on occasion included soliciting family members to perform DSP duties such as bathing, feeding, and providing community support. DSPs showed extreme dedication and commitment to those they served by offering their own families as resource.

## Commitment to the Individuals Served

The DSPs that participated in the focus groups were exceedingly clear in their position that it was their commitment to the individuals that they served that kept them working throughout the disaster and return to the Greater New Orleans area. DSPs routinely stated that the people they supported were like their own family. Many of the DSPs in the focus groups talked about having provided support to “their” individuals for very long periods of time; sometimes over a decade of service. DSPs told stories of consumers living with them, staying with them on holidays, being in their weddings, and evolving friendships over time. The people that continue to stay with VOA in New Orleans and support individuals with disabilities do it because of their deep and profound commitment to those individuals.



*“She (consumer) needs more clothes, ‘cause the clothes everybody meddled with her outfits so what she had was what I purchased out of my own money that I’m working for. So ok what do we do here ‘cause you know at this point I am starting to get aggravated ‘cause winter is in full bloom, here in Shreveport its not New Orleans so it is a different winter so I am buying jackets I am buying for my kids, but at this point I am feeling like she (consumer) is one of my kids ‘cause I am providing.”*

*“I left [the New Orleans area] with the job because I have been with them for 15 years and I am dedicated to my clients, like became my family.”*

*“Oh, now that was the hardest part because I had six individuals that I didn’t know anything about, didn’t have most of their information due to it was lost. Now getting back to the group home where I work, come back staff quick ‘cause I’ll be short handed. I had 12 individuals, I worked by myself to take care of all their needs and I did that for a week after I started, ‘cause there was no help. That was the hardest part and the hardest part still.”*





Throughout the focus groups DSPs told stories about their relationships with the people that they served. While each relationship was a testimony to the amazing qualities of these DSPs, one story in particular conveys the emotion, love and dedication common among this group of professionals. A DSP told of his relationship with the man he supported for twenty years. They were roommates in college together, the man with the disability was the best man in the DSP's wedding, and they loved each other deeply as best friends. As a secondary result of the hurricane the man with the disability died due to complications of pneumonia. The DSP never left his side and although he was in the hospital at the time of his death with hospital staff to perform the personal care duties, the DSP insisted that he give his friend his last bath. It was the act of a family member. Theirs was a deep friendship, the kind that can not be described in words and one that was born out of direct support.



*"The other consumer that I took with me, I wasn't working with at all. He just popped up at my house and said can I go with you, with two dollars in his pocket and that was it, his clothes on his back. That was.....probably could have taken him to a shelter and he didn't want a shelter so I took him also, knowing that I wasn't going to get paid for him what-so-ever from VOA".*

*"It is not so much VOA that you are dedicated to, it is the people. I have children that were saying, 'Mama come live in OH. Mama come live in MS. Mama come live in GA.' You can't give up part of your family (consumers) and they depend on me. You have to help them get through this."*

*"We stayed because, I stayed and I could probably speak for everybody here, because of the consumers, I mean we had 72 consumers. If everybody had left I don't know who would have helped them."*

*"I have been working with that man since 1986, he was like a family member to me and it is difficult to lose him."*



*“When they were able to go back to look at their homes, came back because of not of the money, because the money is not even worth it. It’s because of the dedication to the consumers and half of us been here, we’ve been here for years, over ten years, most of the staff that’s here.”*

## Added Responsibilities

VOA DSPs demonstrated an unprecedented willingness to take on added responsibility and burden during the evacuation process as well as during the nine months following the hurricanes. At times, several DSPs put themselves in harms way in order to provide support to people with disabilities. In many cases the added responsibility included providing support to individuals that they didn’t know as other DSPs dropped consumers off at safe locations. Other situations called upon (and continue to call upon) DSPs to provide support for more individuals than seemed humanly possible. Group homes were doubled in size and yet the staffing shortage forced staffing patterns to remain at or lower than pre-hurricane levels. In all cases DSPs were called upon to help individuals with disabilities to salvage their belongings (if possible), re-establish housing, gut houses and apartments, clean mold, hire contractors, apply for FEMA benefits etc... Each of these duties went above and beyond their normal direct support duties.

*“There was one consumer that refused to go because he said his family was going to take him and they didn’t. That consumer was left, who was physically challenged, left in his own secretions for three days, until finally I was able to sneak into the area, past the National Guard to get to him and get him rescued.”*



# Work Life During and After the Hurricanes

## Working Conditions

A typical work day for Direct Support Professionals can be stressful, chaotic, unpredictable, and down right hard work. Add Katrina, Rita and Wilma to the mix and the typical work day for DSPs supporting people with intellectual and developmental disabilities becomes unimaginably difficult. Direct Support Professionals shared stories and issues regarding their working conditions both during and after the hurricanes hit and evacuations occurred. Challenges related to working extremely long hours, taking on added responsibilities and burdens, using their own resources and money to support the people they cared so deeply about, not having adequate resources to do their jobs, working months at a time with little personal privacy or freedom, working with strangers, and cohabitating with multiple families and the people with disabilities they supported. They also experienced challenges related to the response and support of management staff and the organization in which they were employed.

## Extreme Hours

DSPs often work multiple jobs and it is typical for their work week to exceed 40 hours. For the DSPs who evacuated with individuals with intellectual and developmental disabilities, the hours became unending. Most who evacuated with people they supported worked 24 hour shifts seven days a week for weeks or, for some, months at a time. DSPs in the ICF/MR programs eventually got some respite from workers who came from throughout the United States to assist at the Lakeview Methodist Conference Center. Yet this relief was not immediate and some DSPs continued to work long shifts because the support needs of the people served, such as suctioning and G-tube feeding, demanded skills or a familiarity with the individuals that the relief workers did not have. By contrast, DSPs who worked in HCBS waiver supported living services often had no help and no breaks, other than that provided by their immediate family members who often became working DSPs.

DSPs worked under these conditions for many, many months. Working extremely long hours distracted them and kept them focused on providing services and working. Yet, the wonder, the fear and the unknown about their family members, homes and futures loomed in their minds and souls and penetrated their well-being. Over time they simply could not do it any longer and any and all relief was welcomed. Depending upon strangers and family members to help out with new roles and duties became an essential and everyday occurrence.

When they were able to return to New Orleans the working hours did not subside either. Housing was in very short supply. Some DSPs lived in the group homes, others in trailers in the yards of group homes and others had consumer living with them in their own homes. Many DSPs found it difficult or impossible to meet the demands of work and find time to secure new housing or benefits for themselves. Others have homes that need gutting and repair but have not had the time to begin, let alone finish, such daunting tasks because they are working so many hours. But, as many said, "If we don't work the hours, who will?"

*"I was working 24 hours along with everybody else...when we got back I told my husband – that's it I cannot do it 24 hours...no longer. It was always me, my family and my consumers 7 days a week 24 hours a day...I couldn't do it no more, I couldn't sleep. I needed some time for myself."*

*"All the time I was working 24 hours and working and being with my husband and kids... we were all helping one another out."*

*"Some of us are just really, really tired. We really are. We are trying to hang in there."*

*"We're trying to find people who will come back to work, because... we were like one person taking care of five consumers or more."*

*"I was working 24 hours until I stopped. I stopped because no one was going to tell me not to...I rented a house two months ago and I've never slept in that house, I had to...give it up. I don't want to do 24 hours no more, now I am down to 57 hours a week...I think I was doing 168 hours a week."*

*"I worked 24 hours a day from the time of the storm on the 28<sup>th</sup> of August until January and then another person came and we worked together."*



## Added Responsibilities, Burdens, and Use of Personal Finances

Added responsibilities and burdens were the norm for Direct Support Professionals working for VOA of New Orleans after Katrina. Personal lives were in disarray. Some DSPs supported individuals with personal finances until benefits and resources could be found and accessed (e.g., food stamps, FEMA, social security). Some DSPs ran out of money a few days into the evacuation, others used up personal savings. Most DSPs who spent their personal money on the people they support were eventually reimbursed; some shortly after the hurricane, others 5 months later. However, some were never reimbursed because they were unable to produce receipts documenting their expenditures.

As some DSPs left VOA to attend to their families, those who remained took on additional clients and responsibilities. Many supervisors provided direct support during the evacuation. The people supported during the evacuation had the same needs as they had before the evacuation (some people developed new and even more intense needs). For DSPs this meant finding new medical doctors, making new appointments, trying to get new services started, securing housing, and finding clothing. Many DSPs, especially those in the Supported Living Services group, took on tasks for which DSPs would not normally have responsibility. They often did these things without access to the resources and information they needed. Many people were evacuated from accessible homes, but while evacuated lived in places that were not accessible, and “made do” without the adaptive equipment they needed. DSPs took on these roles and did the extra work because it was the right thing to do.



The return to the New Orleans area did not relieve the added burdens and responsibilities. Many DSPs became “general contractors” of sorts trying to coordinate housing re-development and helping the people with IDD they supported to fix up their homes. Working with FEMA was a new burden for DSPs. As advocates, they had to work with the federal government to assist people with disabilities in getting their entitlements; often with the government representatives not believing that they worked as a DSP and/or not understanding what a DSP was. Some DSPs reported that FEMA representatives accused them of trying to commit fraud.

*“When we left Houston we had six consumers with me. I had six of them in my Suburban and she [my wife] had everyone else [family] in the truck and I stuck my two little boys in the back cargo area. When we was heading back there was no bathroom and no gas....”*

*“...this one guy, his worker said she can’t work with him anymore. She has to take care of her house. In my mind I said, “Well the guy can’t stay there in the hotel by himself.” I said “I will go to Baton Rouge on my way back from Slidell and Shreveport and pick him up....” We had about 7 people then, our family and the guys we were working with.”*

*“her mother and I began to gut the house ourselves and to console her we tried to tell her we’re putting all of your stuff in boxes and we tried to save the most we can.....Day after day, cleaning and putting things in boxes so she could take it home.....it was so bad not even with a mask we could breath.”*

*“After a week there I was footing the bill for everybody.... I had two guys with me who had zero money you know and I am feeding everybody and everybody’s hotel is rented. My bill is getting up to a thousand bucks on my credit card. Credit cards is nice but you got to pay them you know.”*

## Lack of Staff

Turnover of staff during and after Katrina had a serious effect on the DSPs. During and after the evacuation as well as upon return to the city, DSPs carried extra responsibility and burden brought on by turnover of not only DSP but also management staff. Not all of the DSPs who evacuated with people with IDD remained with them. Many DSPs ended up supporting additional people with IDD because their original staff members were unable to continue providing support.

When group home staff returned to the New Orleans area, their burdens increased as they supported twice as many people in the homes that had been repaired because other homes were not inhabitable. The housing shortage meant that many people were living in different and more crowded homes than before Katrina. People were living with others whose characteristics and needs were quite diverse. For example, before Katrina seniors with mobility limitations lived in one home but after Katrina several young people with severe challenging behavior also moved into the home. Several people with intense behavioral or mobility support needs who had previously lived separately were combined into one larger home. DSPs in the Supported Living Services group supported more clients, drove greater distances and were responsible for helping people to put their lives in order regarding housing, benefits and jobs.

While most DSPs had worked with VOA prior to or during the evacuation, new DSPs were hired to replace those who had not returned to New Orleans. Unfortunately, many of the new staff left their positions shortly after being hired. This caused long-term staff to report that new staff members were not reliable. Staffing shortages meant that DSPs had to become more involved in helping to find new staff. If they want time off, they have to figure out who will replace them while they are gone. DSPs reported that the quality of care has suffered because they are working such long hours, short staffed and under such stress both at work and at home due to the Katrina aftermath.

## Lack of Time Off, Personal Freedom and Privacy

Throughout Hurricanes Katrina, Rita and Wilma, DSPs worked under very difficult circumstances. Many had expected that the evacuation would be routine. They approached it with past experiences in mind, thinking they would be on the road for three days and then come home. However, it became clear early on that this would not be the case. Some DSPs described seeing the “big ball of fire” headed toward New Orleans on the news, others report watching it unfold on CNN. When they realized this would not be a typical evacuation, they were concerned. Most only had clothes and supplies for three days, many had little money and no one had plans for hotel or other accommodations past the initial three days. Days in cars, hotels with cockroaches, apartment complexes with maggots are just a few of their experiences. They had little water, hot water, lack of gasoline, no adult diapers, no additional medication and for some no program or medication files about the people with IDD with whom they evacuated. They took the situation as it came to them and independently problem-solved as best they could. Sometimes the options were good; other times they were barely survivable.

DSPs who had worked in the group homes landed in a far off Texas camp where they lived in large buildings with little privacy and few opportunities to

*“I think my situation was different. When I was in Houston we were running out of money. We didn’t get any money back. We didn’t get any kind of financial help. Everything was on me.”*

*“We have new people [supervisors] now. They’re not all understanding the impact of what went on and what is going on. Their demands are the same as, “okay Katrina did happen, but we need to move on.” I really believe they are going to lose some more good people.”*

*“There is double work because we have double consumers...”*

*“Believe it or not I am calling around trying to find staff during my vacation. That is what they [supervisor] told me – “Find your staff, find your staff...”*

*“To me it took your rights away. It took your transportation away.”*

*“It was creepy and scary and some nights I slept [with other people] because it was just me.”*

*“The picture is that we need to heal...You still have people who are giving you service that are still in need themselves.”*

get away from their work environment. They described a lack of personal freedom brought on by co-habitation and not having individual transportation or access to working telephones. The lack of normalcy and the unknown about what their personal situations were at home in New Orleans added to their stress and burden. This was difficult for DSPs and for family members (both children and adults) that were with them. DSPs who had worked in supported living services found themselves in various situations. Some were supported by other service providing organizations in local communities. Many lived in cramped quarters, with a lot of people and described their situations as being difficult at best.



DSPs essentially worked 24 hours a day 7 days a week. Few had any time off. For some this was a God-send in that it distracted them from the realities they were facing in their personal lives. For others it was what they felt they had to do for the people with IDD they supported, and for their families. For all it was exhausting, unhealthy and took a severe emotional toll on their personal well-being. Working day in and day out with little break from it all was grueling, challenging and none of the DSPs would ever want to experience it again. Some family members who evacuated with the DSP were hired to work as DSPs, others worked for free supporting the individual with a disability so that the DSP could simply get a break.

DSPs reported having little opportunity to reflect on what was happening, talk about it and grieve the multitude of losses they were experiencing. Their losses were many: homes, work sites, family members, routine, community, church, friends, photos, pets, supervisors, etc... Their focus was on doing the work that had to be done and helping their children and family members get through the day. At the end of the day there was little time to reflect and think about their situation let alone to grieve and begin a healing process. In fact many DSPs at the time of the focus groups indicated they still were only beginning their grief and loss process.

*“You have to take care of your problems you had at home, ...and at the same time you have to, no you want to, come and help your consumer because you know that, that person was also going through what you were going through and it’s a lot difficult for them so you did a little bit at home and spend 24 hours doing theirs....”*

*“...sometimes I was eating one meal a day. You have too much on your mind what you’re going to do.”*

*“I love her to death....but at what point am I not doing justice to my own family? It is not fair to them. You know they are raising my grandchildren who I am supposed to be raising. My husband who is sick....I say take care of these kids.....so I said, I just got to stop I was getting sick myself. I love my consumer to death....but I have to stop breaking myself down and letting myself go.”*

*“You had to work your way and fight your way in to get your own personal life separate from your work life. It was mostly work all of the time....”*



## Family and Work Dual-Loyalties

DSPs who supported people with IDD before, during and after hurricane Katrina struggled immensely with dual loyalties. On the one hand they were and remain deeply committed to the people with IDD they support. On the other hand they have families and are deeply committed to them as well. DSPs had to care for themselves too in order to survive. Facing this reality was difficult for many. It took the reality of mental and/or physical health issues to make them realize they could no longer work so many hours under such incredible pressure. Other DSPs faced this reality early on and opted to not remain with consumers post evacuation.

## Management and Practices

The circumstance and working relationship between DSPs and management staff is often difficult. DSPs often report feelings of being misunderstood, under-appreciated and disregarded by management. The DSPs who were interviewed reported both positive and negative feelings toward management and the decisions they made before, during and after hurricanes Katrina, Rita and Wilma.

The decision to evacuate was made early and all group home and individuals had evacuation plans in place. This enabled DSPs to gather items and family members and get out of the New Orleans area. Management was involved and supportive of DSPs when communication was available and restored. The decision was made early to ensure that DSPs still had paychecks and to pay them for all hours worked. The organization quickly engaged national affiliates to assist with the long term evacuation efforts and these organizations were highly supportive of the DSPs and the clients with whom they evacuated. Most managers and administrators were supportive and helpful to DSPs throughout the process.



*"I said at one of our staff meetings, I requested something to compensate the people [DSPs who evacuated and returned with people with IDD] even if it was a gift card, to say thank you for what you have done. Well they have yet to receive it. Not even a thank you letter or anything of that nature. The thing is that these people gave up being with their families and loved ones and still have yet to receive a thank you."*

*"It is just fateful. You have dedicated employees that ... if there is anything difficult you work it out. We might get on each other's nerves every once in a while but we stayed together and worked together."*

*"I think Mandy, wasn't Mandy there? And the president Jim, he came out. They came out, him and his wife. They kept coming; actually he was like giving bonuses like cash, money or whatever, whatever he could do ... for the new staff that they had left to make them feel appreciated."*

Since the return to the New Orleans area there have been inconsistencies in management style and decision making that led to some DSPs reporting negative feelings and attitudes toward the organization and its management. Inconsistencies exist in how DSPs who evacuated with clients are rewarded and appreciated. For example, group home staff had a recognition luncheon where they received a small gift but the supported living staff did not. Group home staff are supporting more clients (twice as many in some circumstances) but are not compensated in any way for their extra effort and in most cases are supporting these extra clients but working with fewer staff. DSPs had varied experiences in when and how they were reimbursed for their expenses and the money they spent on clients while evacuated. DSPs also reported inconsistencies in the attitude they hear expressed from management. While some managers are described as supportive and helpful, others were described as unsupportive and having a lack of understanding about the experiences of the DSPs. For example, several DSPs reported that they recently had been told by management, “OK Katrina did happen, but we need to move on.” This statement was painful to DSPs whose lives remain unraveled by the hurricane situation. People who are working 60 – 80 hours per week, supporting twice as many clients as they used to with fewer staff, living apart from their children or in homes of friends and family members, struggling harder to make ends meet because of price gouging and other harsh realities, awaiting decisions about their own homes from insurance companies and government...for these DSPs moving on is hard and will not happen at the word of a manager.

## Work Relationships

Throughout the hurricane and the aftermath, VOA staff had to rely on their working relationships in order to continue to provide critical services. Tensions arose in the relationships with management staff, other DSP staff, and with VOA affiliate staff who rotated in to help in various locations.

### Relationships With Other DSPs

Despite intense and confined working conditions DSP relationships didn’t appear to suffer or become comprised throughout the evacuation and recovery process. DSPs reported that as frontline staff they came together to get the job done and often formed stronger friendships than they once had and/or developed new friendships. That said there were instances where DSPs who are no longer with the company didn’t perform their duties as expected. This behavior resulted in frustration on the part of DSPs who stayed with their consumers and continued to provide support.

*“Several administrators lost nothing or if they lost everything they have their house paid off with insurance and everything is back to normal. Isn’t that wonderful. It is not balanced.....We can’t forget. We can’t just expect everybody to be moving on just because we are.”*

*“No one asked “how are you going to find shoes,” or “where are you going to sleep?””*

*“Where we were, we were in Palestine, we worked together as a team and we were like a family.”*

*“We all helped each other ... when we hear they were coming in we helped them unpack, we helped them set up mattresses and everything. It was a good thing to have company.”*

*“You definitely find out what people are all about in situations ... There was one facilitator that was in Baton Rouge and she was real good; she was a team player.”*

## Relationships With VOA Affiliate Staff

While the recovery process began most DSPs and the individuals they supported lived scattered across the Texas, Louisiana and Mississippi area. They worked with fellow VOA staff from those areas as well as staff that came from all over the country. ‘Respite’ VOA staff helped to provide housing for the DSPs, their families and individuals with disabilities. They also provided resources, supplies and added manpower. While much help was provided and appreciated by the New Orleans VOA DSPs, challenges also presented themselves with the added help. In most cases the ‘respite’ VOA staff didn’t know the individuals being supported and therefore found it difficult to offer person centered supports. In some cases local staff had not brought along records so effective ways of managing challenging behaviors couldn’t be accessed. In some situations New Orleans DSPs also reported feeling judged and criticized by respite staff that came in without having experienced the trauma of the hurricane, the evacuation, sleep deprivation and the excessive workload. There were also challenges associated with cultural differences between the New Orleans staff and those from other parts of the country who only stayed for a week or two and didn’t have a time to learn “how we do things around here.”



## Relationships With Management

Throughout the focus groups DSPs talked about both positive and challenging aspects of their relationships with VOA management. There was a great deal of discussion by those working in the Group Home settings of the appreciation shown by Chief Executive Officer Jim LaBlanc, his wife and the VOA management staff. Numerous challenges also existed however, and centered

*“I looked in the phone book and I’m remembering that VOA is a chain, they had different offices... I called the business district and they gave me the number to the local VOA there and I talked to them. I just told them ‘look I’m from Slidell and we evacuated and we are trying to get in touch with someone that can help us out here... The next day we got a call and it was Mr. LaBlanc, and ... he had said that he got word from Shreveport VOA and that they are going to try and find something for us to move into and he said that it was a great idea to call.”*

*“They are going to feel it because they are going to lose some good people. And it is really going to be a shame; it really is because of it. Some of us are just really, really tired. We really are. We are trying to hang in there.”*

*She was told, ‘Well that is your choice to live in Baton Rouge.’ [Being told you have a choice] “is kind of like someone robbing you and putting a gun to your head and saying, ‘give me everything you’ve got or your life’ but you [already] gave them your wallet. You have no choice right now.”*

around three areas: 1) management was expecting the same work (regulatory and policy expectations) from DSPs despite the conditions; 2) management provided physical support to DSPs in terms of resources for the individuals served but there hadn't been ongoing emotional support for the staff; and 3) management wasn't listening to DSPs in terms of what is and is not possible related to working conditions.

While DSPs acknowledged that the organization needed to move forward and begin to restore a sense of normalcy to the day to day operations there was also a strong sentiment that things just aren't normal and it is somewhat ridiculous to act as though they are. DSPs reported that rather than consistently looking at the big picture, there were instances where management focused on mundane details of organizational policy that were inconsequential considering the circumstances in which services were being provided. The focus on returning to normalcy under conditions which continued to be adverse (at the time of the focus groups) placed a strain on the DSP/management relationships.

DSPs reported an ongoing need for emotional support while they attempted to function in their personal lives and their work lives during the disaster recovery. Although VOA did provide some support by way of resources for rebuilding/recovery, there was a lack of emotional consideration. Many DSPs reported unbelievable circumstances in which they continued to live such as extended travel to work from the only places they could find to live, trying to maintain relationships with their children who were living out of state with other relatives, homelessness and living with friends, neighbors and co-workers just so they could continue to work and provide services to individuals with disabilities. DSPs remarked that there was a sentiment expressed from management that they had a choice whether to live under those severe circumstances such as traveling far distances. This created resentment within the frontline staff which is in continued need of attention and repair. DSPs reported that speaking at the focus groups was the most therapeutic situation that they had encountered within VOA and that by just having an opportunity to talk with each other about their experiences, they felt better.

Finally, staff discussed damage caused to their relationship with management stemming from dissatisfaction with decisions that were made by management without any input by direct support staff. These decisions centered on service provision and the daily work carried out by DSPs. They felt that under the conditions they should be included in discussion regarding certain decisions or have some type of avenue for input since they were the ones that knew how the daily work had changed and was currently being managed. DSPs felt disenfranchised as their input was neither sought nor rebutted when it was offered.

## Personal Experiences

Focus group participants talked a lot about their personal experiences during and after the Hurricane and how those experiences affected their capacity to do their jobs. While it is difficult to separate personal experiences from work and consumer experiences, particular attention in this section is paid to DSPs' experiences with their own disaster outcomes including their homes and their

*"But you (manager) have to look down at her slippers and say, 'You have slippers on.' I am not worried about my feet, I need somewhere to sleep. It is silly because you [manager] are trying to worry about a policy that is irrelevant right now. You have staff that work for you that don't have anywhere to stay ... Whether she comes barefooted in her birthday suit, she is here trying to help the consumers."*

*"I told a supervisor, 'Well you know we just can't do four wheelchairs. I don't care how you do it, but four you can't do four wheelchairs [in one group home].' 'Oh yes you can.' Take in mind this is a person that have never ever done direct service. There are transportation problems. They worked in mental health services but never worked in a group home setting."*



health and to their attempts to recover in the face of government response and the response of others.

## Before the Hurricanes

One significant stressor for DSPs was the reluctance of family members to evacuate. Although many of those families routinely decide not to evacuate, this storm was different. DSPs experienced increase stress and anxiety as a result. DSPs were not in conflict because of their decision to evacuate with consumers (they described a sense of dedication and duty to their consumers). Rather, they struggled with the decisions of their family members. As the DSPs evacuated they continued however to believe that they were going to be gone for three days and they would return to clean up minor debris as they had in the past. For some DSPs, the hurricane season had been taken more seriously and they reported having purchased their homes in areas [Slidell] where they thought they would be on higher ground and at less risk for loss and devastation from a hurricane.

## During the Hurricanes

During the evacuation, DSPs sought safety across the Southern United States. DSPs reported evacuating to Mississippi, Florida, Texas, Tennessee, Arkansas and other parts of Louisiana. As described earlier, the DSPs' work experiences and personal experiences were intertwined. It was difficult for DSPs to focus on their personal situations during hurricane Katrina because of the demands on their time to address the needs of the individuals with disabilities that they were supporting. In their personal lives, DSPs experienced stress, trauma, anxiety, and confusion. In many cases they didn't know where family members and loved ones were, if they had evacuated or even if they had survived. They were hearing unsubstantiated stories of what was happening within the Greater New Orleans area including dead bodies hanging from trees in their neighborhoods, the devastation of their homes, loss of all their personal belongings, shootings, lootings etc. DSPs were unable to connect with friends, family and neighbors to confirm these reports due to the break down in the communication infrastructure in much of Louisiana, Mississippi and other areas hit by the hurricanes.

During the evacuation DSPs experienced both the kindness and rudeness of strangers. They spoke of the incredible generosity of people in their willingness to help them find safe places to go, donations of food, clothing and supplies. Other DSPs experienced hostility and rudeness from people in the local communities in which they sought shelter. The increased stress of having to move because of potential civil disobedience in addition to the danger of the hurricane was more than some could bear.

Several DSPs were not part of the VOA evacuation as the people they supported left with family members or had other evacuation plans. Some of these DSPs evacuated to other states while others attempted to remain in the area. Those that stayed experienced the devastation of the storm first hand. They described the snapping of tall pine trees and the destruction of buildings all around them. Due to their location they didn't rely upon unconfirmed reports of the situation; rather

*"I went home and packed my clothes, still thinking it wasn't that big of a deal and it wasn't until Sunday morning when they said it was a category 5. I thought I was going to pass out and so we just packed up as much as we could in our car. I'm thinking I didn't think the house was going to be there when I can back so I packed everything I thought was important in the car."*  
*"The people weren't friendly, they were very standoffish; this particular area of Texas. I can't speak for other areas, but this area really didn't welcome people from New Orleans."*

*"I lost my home. I lost everything that I have. I came back to my home that I had worked all my life to put together. I am one of these people who has all their soldiers in a row. I had a few more years 'til I could retire... The last 10-15 years I fixed one room at a time, perfect. My house was perfect...I came back to a three story home that all of my money had gone into for all of my work life. All of my belongings [are gone]... The windows were blown out, the doors were blown off, the frames were ripped off. Everything I owned was either washed out into the swamp or completely destroyed..."*

they experienced the damage, looting, and the National Guard presence immediately following the passing of Hurricane Katrina.

## After the Hurricanes

Focus group participants estimated that 90% of the VOA direct support staff lost everything in the hurricane and subsequent floods. Just as many consumers lived in affected areas due to their low incomes, DSPs resided heavily in the impoverished and hardest hit areas of New Orleans such as the Lower Ninth Ward and Gentilly. It is difficult to comprehend losing everything for those that haven't seen the devastation or experienced it. The loss is overwhelming. Most DSPs lost everything they owned including electronics, family photographs and memorabilia, cars, homes, important documents (birth certificates, insurance papers, death certificates, passports, mortgage and other loan documents, credit card information etc.), children's toys, academic materials, trinkets and special mementos, etc... Some staff who evacuated with VOA who had left their cars at the group homes in order to be on the VOA busses and vans found that those cars had also been destroyed. For many, all they had after the storm was what little they had taken with them, or had acquired during the evacuation. The losses experienced by DSPs and their families were the result of one or a combination of the following: Hurricane Katrina, the levy breach/flooding, looting, Hurricane Rita.



DSPs returned to their homes at various times throughout the recovery and aftermath of Hurricanes Katrina and Rita. Those that returned in the first days of the aftermath described a sense of disbelief, numbness and feeling of being overwhelmed. There was no electricity, no clean water, and depending upon where their homes were located; very little to salvage. Regardless of whether or not they were able to return to view the damage, all evacuated DSPs [and the people they supported] had to plan for alternate living arrangements. Some DSPs

*"They weren't living in temporary housing. I actually have staff that are (still) living with clients"*

*"I didn't have anything. I didn't have clothes, nothing. I saved nothing. I didn't have nothing but the three outfits I brought to Texas besides what I picked up while in Texas."*

*"I go back and forth from here to Houston every week, because my children are in Houston. Whatever I have I just bring with me. I mean you can't bring a bunch of stuff with me on the plane."*

*"At night it is just the creepiest thing when you go to some parts of the neighborhoods. It is just creepy. It is dark. There is nobody around there."*

*"You know how much a one bedroom house is now with the price gouging because they know people don't have anywhere to stay? A one bedroom is starting at \$600 and a two bedroom ... is \$1100. We have been checking around. You tell me where am I going to go for \$7.00 an hour?"*



and their families were in transient housing situations for months and were just returning to their homes at the time of the focus groups, many others were still living in temporary housing and had no firm timeline for obtaining permanent housing (nine months after Hurricane Katrina).

Alternative living arrangements for DSPs who worked in VOA group homes included the accommodations provided in Palestine, Texas. Upon return to the New Orleans area many of these DSPs lived in the repaired group homes with consumers since they had no where else to live and there were no other staff living in the area that could provide services. As group homes were renovated the number of bedrooms was increased. This helped to temporarily accommodate staff (and their families) living in the group homes, although they were eventually made to leave under what they referred to as an “eviction notice” issued by VOA.

Post hurricane accommodations were also difficult to secure for DSPs who provided support services to individual in independent or semi independent living situations. Some of these DSPs were connected with VOA affiliates and were assisted in securing temporary living arrangements in unused transition homes or group homes. Eventually some of the DSPs and consumers began to transition back into the New Orleans area. For many that meant living together; DSP, family and consumer(s). For others it meant finding a place to stay with friends, families or in the hard to secure FEMA trailers. Many DSPs reported living in very crowded conditions with multiple families sharing small spaces. DSPs shared their *ongoing* hardships such as sleeping on the floor, sleeping in a bathroom or under a sink, sharing FEMA trailers and living apart from their children and/or families in order to continue working and living in the New Orleans area. Many were sharing accommodations because they could no longer afford the rents being charged for apartments in New Orleans. One DSP spoke of how she secured temporary housing on one of the riverboats, however she had to say that her consumer was her brother or they wouldn’t allow him to share the living space.

Throughout the focus groups DSPs also detailed frustrating experiences related to their attempts to rebuild or restart their lives. DSPs returned to a city where price gouging was common place and where goods and resources were hard to come by. Mortgage companies did not provide most people with forgiveness programs or even breaks on the late fees associated with their missed mortgage payments. Significant frustration was reported regarding their dealings with insurance companies. DSPs spoke of the incredible amount of time that it took to obtain information as to how they should proceed with claims, the actual processing of claims, and the struggles to find and secure contractors/workers to do the jobs of rebuilding. Several reported not getting settlements because they were unable to provide proof of ownership (for cars) or other documents that had been destroyed in the flood. Because of the growing mold and risk for serious health problems, most people were unable to repair their homes themselves. In addition, DSPs described the set insurance payments as ridiculous and offensive.

*“You come back to these tremendous bills. I had a ... water bill of \$400 some dollar, a mortgage that was \$3000. The mortgage company that I was dealing with wasn’t doing what they called a deferred payment. They were saying that because you were a Katrina victim the amount you are late with would be divided up into payments. Meaning if my mortgage was \$500 it goes up to \$900 to catch up to what I was behind. There were charging a late fee on top.”*

*“They tell me it is a process ... running around ... the adjuster they had and he quit or something, then they give you another adjuster. They tell you your paperwork is lost so you are just constantly spinning on the phone trying to get your money for your house to get it back right.”*



*“If you had a one-bedroom house or something they give you \$10,000 and if you have two bedrooms you would be lucky to get \$14,000. These people who have these great big beautiful homes and worked 3-4 jobs they have to be big. You accumulate stuff over years. The max they are giving you is \$26,000.”*

## Health Issues

As people struggled to secure safe housing, they also struggled with coordinating health services and staying healthy. For many, personal medications were lost or destroyed during the hurricane. DSPs that evacuated took a three to four day supply of their medication with them as that was the normal evacuation procedure. DSPs were fortunate if they filled their prescriptions at networked pharmacies. If prescriptions were filled in neighborhood pharmacies however, records were lost or destroyed and in most cases doctors could not be reached to reissue new medication orders. DSPs reported that they were able to obtain medications from the American Red Cross as long as they knew the name and dosage of each prescription.

During the evacuation, pregnancies were impacted within the DSPs’ families. A DSP’s daughter had to stop enroute to Texas to give birth. The DSP continued to provide direct support rather than attending the birth. Later she was to meet her grandchild in the hospital. DSPs struggled with their young children’s reactions to the disaster and their subsequent mental health complications. Their efforts to support their children in the aftermath continue. DSPs also continue to monitor and manage their own emotional trauma and mental well-being. Although access to formal mental health support or counseling was limited, some DSPs sought help on their own in the few personal hours that they had outside of work. Several DSPs spoke about their need to begin taking medication in an effort to manage anxiety and depression as a result of the disaster and evacuation experience.

*“It was a hard experience. My little boy, he had a nervous break down and he’s only 10 at the time. My six year old, I don’t know, it just destroyed him. Every time he go to the city he wants to know if there’s water ‘cause he’s trapped in it.”*

*“I use to suffer from anxiety, it had gone away, but now I feel that sometimes it’s back to the fact that I had to go to my doctor and re-get my Xanax.”*

## Government Response

All of the DSPs that spoke of government response or assistance reported frustration and dissatisfaction. DSPs described a government system that was overwhelmed and difficult to navigate. Government requirements to receive aid were at times impossible to meet due to the devastation of the hurricane. For example, DSPs were asked to produce documents (identification papers, proof of ownership or mortgage documents, etc.) that were lost to the flood waters or the hurricane damage. They reported that without some of these documents they were unable to obtain emergency compensation. Finding time to apply for assistance was a problem because they were working so many hours.



For those that were able to obtain financial compensation or assistance, it simply hasn't been enough. DSPs who have chosen to return to the New Orleans area, reported having to use their FEMA money for daily living (due to the price gouging), to replace destroyed vehicles or in some cases to commute across state lines to visit their children. With this in mind they aren't able to use the money to rebuild their homes or reinvest the money in a new residence.

DSPs also had difficulties obtaining emergency government housing. While some DSPs have been able to secure FEMA trailers, many have not. The majority of those in FEMA trailers received assistance through VOA to obtain them. Reportedly the receipt of trailers through employers is a process riddled with problems. The exact process and details of the problems remain confusing to the researchers and clearly were so for the DSPs. Some reported that the trailers were in VOA's name but under the employees' number. Significant and understandable concern centered on an employee's separation from the company; was the trailer theirs (under their own FEMA number) or was it VOA's (they obtained the trailer and it is located on VOA property). The problem that seemed to be emerging as this was discussed was that nine months after Hurricane Katrina DSPs still didn't know the status of their FEMA trailer situations. To compound the problem, VOA hadn't made the process clear to those DSPs who used FEMA trailers obtained by VOA or what would happen should the DSP terminate employment services.

*"I have to go somewhere to try and get the title and registration papers before I can get anything. They said they won't pay me for that [vehicle] because they need the title [which was in my house]."*

*"If you did come back to work and you were able to do that; fine, but the government gave everyone unemployment. That is what happened to a lot of our direct care staff. Why work when you can get a check for a little less than you are making and not work."*

*"I am still waiting on insurance money to fix my house. They never sent the check for the roof or nothing. My roof caved in. FEMA gave more than enough to fix up the roof and I had to live everyday ... I had to buy another car and all of that because they hadn't paid me for my van."*



## Kinship

The experiences of Direct Support Professionals (DSPs) with their families evoked considerable emotion and stress during the focus group sessions. While many DSPs were able to reflect on their families' experiences with some distance and perspective, others continued to be immersed in the emotion of trauma and family loss. Seven sub-themes emerged from the kinship theme including: family left behind, family conflict, family members becoming DSPs, sharing family resources, and children.

### Family Left Behind

Several DSPs indicated that the single biggest stressor to them in the early stages of the hurricane disaster was that they did not know where family members were or if they were safe. In some families there were members who refused to evacuate and then when forced to evacuate communication systems, such as landline telephones and cell phones, had broken down and families did not know where their members scattered to. In other families, members who did not evacuate were trapped when the levies broke. Health problems compromised numerous individual family members (e.g. unmediated diabetes, high blood pressure and heart conditions). For example, one family member was stranded on a highway overpass without medication for a long period of time despite having used a cell phone to call for help.



The mental and emotional state of DSPs who were unsure about the safety of their family members was obviously impacted. [*“They had family members missing and they couldn’t function.”*] As a result most were understandably *“... not themselves”* and had difficulty focusing on providing support to individuals with disabilities. Yet their dedication to the individuals kept them engaged in their employment throughout the evacuation. On several occasions DSPs were

*“A lot of people were just afraid. They didn’t know where their families were, they didn’t know where their kids were. Those who did not bring their kids with them, minus their husbands so they’re like panicked. It’s not that I don’t think that they didn’t want to come, it’s just that they need to get to their family members.”*

*“We found out that my nephew, whose wife was pregnant, didn’t evacuate and they had to scramble to get over the bridge. They had an incident where a man got shot that was right next to where they were so that was a horrible experience for them.”*

*“... trying to evacuate all your own family and then try to convince your family ‘Hey I have a couple consumers here, would you mind them staying with you?’ [People] who they don’t know, don’t know how to handle and don’t want you in their house because you have other folks with you.”*

asked by VOA administrators if they were missing family members because they did not offer or talk about that information while remaining dedicated and performing their support duties. When the DSP was clearly compromised in their ability to work, VOA management encouraged them to go and find out about the status of their families and return to help support consumers if they could.

## Family Conflict

Family conflicts developed for some DSPs that continued to work throughout the evacuation or returned to work shortly after the hurricane. Often conflicts were natural occurring and would have happened regardless of if they were a DSP or not. These conflicts included trying to get family members to evacuate when they refused, turmoil resulting from experiencing violence in the hurricane aftermath such as shootings and looting, and parent-child conflicts around the general instability of New Orleans as people returned to the area.

Some family conflicts occurred when extended family members were asked to provide housing or shelter for their DSP family member along with one or more individuals with disabilities whom they did not know. These extended family and friend arrangements at times resulted in strained exchanges as not everyone knew what to expect in providing shelter and support for a person with a disability who may or may not have displayed challenging behaviors. Other family conflicts were more internal. DSPs spoke of having to divide their time between taking care of and spending time with their spouses and/or children while also providing support to one or more individuals with disabilities.

## Family Members Becoming DSPs

Due to the needs of individual consumers and the lack of staffing during the long-term evacuation, some family members of DSPs who evacuated with VOA began to provide direct support to individuals with disabilities and took on the role of DSP. In some situations they knew the person needing support because their spouse had provided supports to that person for a long time. In other situations both the DSP and the spouse or family member were providing supports to individuals they didn't even know. In either case, the dedication of the DSP was paralleled by the dedication of their family members.

## Sharing Family Resources

DSPs talked openly about the need for their families to share (often times scarce) resources during and after the disaster. DSPs and their families shared a variety of resources with the individuals with disabilities they supported as well as their DSPs and *their* family members. Tangible resources that were shared included: homes, hotel rooms, cash and credit, food, clothes, personal care supplies and utilities. At times the resources that the DSPs were sharing weren't even their own but rather were already being shared with them by their extended family members.

Less tangible resources were shared as well, perhaps with even more significant impact on the DSPs and their immediate families. These resources included DSP's *time* which would have otherwise been spent with their family or spent taking care of the complex activities involved in rebuilding their lives in the New Orleans area. Many DSPs spent their time providing extended hours of

*"Brothers, sisters, husbands and wives that we had to employ at one point to help because we were just so short."*

*"They received a check, like us, like we did because of the loss of other staff and they stuck it out. I think a lot of the wives and husbands and other family members stuck it out because we stuck it out. They wanted to support their husband or their wives and like some of the staff said there was just actually no where to go at that point and people who, when able to go back to look at their homes, came back because of – not the money because the money is not even work it – it's because of the dedication to the consumers."*

*"I called my husband and said we can't take anything. I said, 'I'll pack 3 outfits of clothes, you pack 3. I have the trunk filled with Jimmy's stuff and over half of the back seat.' I evacuated to Hattiesburg Mississippi to my son's house with Jimmy [consumer], my husband, three outfits of clothes for me, three outfits of clothes for my husband and everything I needed for Jimmy."*

support to the individuals they served and assisted those individuals in completing the activities for rebuilding in New Orleans. DSPs also gave freely of their *personal space*. During the evacuation, space in automobiles was scarce. Not only did DSPs and their families sacrifice space to assist individuals with disabilities evacuate, DSPs also chose to take fewer personal items of their own so that there was more room for the personal belongings and adaptive equipment of the people they supported.

## Children

As one would expect in any emergency situation, DSPs who were parents, foster parents and grandparents, expressed numerous concerns about their children. Throughout this section the term “children” is used broadly to reflect the experiences of biological children, foster children and grandchildren who were in the care of a DSP. As they recounted their stories of evacuation, time away from home and their return to their New Orleans area, DSPs clearly continued to be emotionally affected by the hurricane experiences associated with their children regardless of their ages.

DSPs’ concerns about their children centered on issues of separation, exposure to large numbers of people they didn’t know (some who had challenging behaviors), school issues, and a lack of social networks. During the evacuation DSPs had to either arrange alternative evacuation plans for their children or bring their children with them as the evacuated with VOA. In cases where children evacuated with someone other than their parent, the DSPs were stricken with worry and concern as their ability to remain in contact with their children was compromised by interrupted telephone service and lack of cell phone service. In numerous situations DSPs didn’t even know where their children had evacuated to since hurricane Rita presented all evacuees with additional challenges. Children experienced the same horrors that adults did throughout the disaster such as being separated from family in the Superdome, seeing people die in front of them, and experiencing the looting and general hostility within their immediate area.

Some DSPs kept their children with them during the evacuation. While these parents didn’t worry about their children’s whereabouts they did worry about other issues. The children who remained with their parents were exposed in many situations to congested living conditions be it in large shelters, shared apartments or at the camp in Palestine. Children expressed fear of sleeping in big open spaces with strangers surrounding them. In many cases DSPs eventually sent their children away to live with relatives in other parts of the United States so they could establish some sense of stability and normalcy. These were not easy decisions for the DSPs and they did not always work out as planned. One DSP sent her children to live with her sister out of state. One month later her sister died of a heart attack. The DSP was not only grieving the loss of her sister but was also consumed by grief related to the instability and continued losses her children were experiencing.

At the time of the focus groups many of the DSPs’ children continued to live away from their parents. As DSPs and other citizens returned to the New Orleans area much of the infrastructure was still in disarray. In situations where DSPs did return to the area with their children, they described concerns such as inadequate schools, unaccredited schools, lack of normalcy, lack of consistency, few friends

*My son went to Tennessee, my sister went to Mississippi, then they ended up leaving from Mississippi ... so we were all separated. Now that was the hardest part because when we found how Katrina hit them too, yeah that was the hardest part ‘cause we didn’t know where each other was and the cell phone wasn’t working. That was the hardest part right there.”*

*“Everybody’s away and she’s the only one here. So she comes, she’s got nobody to talk to and she’s like, she’s in her own little world, like she’s by herself.”*

*“Because you know you have small kids and you have children and sleeping in this big open place with everybody laying all over the floor. It was just hard to accept you know you’re not use to living like that but you have to do it because of the situation that came about ‘cause I had my son with me, he cried. He didn’t want to stay – you know it just was.”*

*“I have family but everybody was in Houston. I wanted to be here with my job. My children don’t like it. They didn’t want to come back. There is nothing to come back to.”*



in the area, and a lack of extracurricular activities all resulting in a sense of isolation and depression. DSPs described wanting to bring their children in for counseling and yet they face a lack of health services too.

## Trauma

Due to the nature of the disaster, VOA staff experienced considerable trauma as did all citizens of New Orleans. Because of the need for DSPs to work 24 hours a day, 7 days a week their ability to grieve was diminished. DSPs experienced trauma through their fear for their personal safety, trouble experienced on the road after hurricane Rita and through either having to leave family behind or losing them in the process of the evacuation.

## Inability to Grieve

The inability to grieve for the many losses DSPs faced was a raw and somewhat volatile emotional factor that was revealed during the focus groups. Many of the DSPs described their inability to grieve as a result of their day-to-day work of supporting individuals with disabilities. Those not working 24 hours a day, 7 days a week kept busy with concrete personal tasks such as visiting children sent to live in other places, rebuilding their homes, or looking for new residences. Regardless of whether or not a DSP was working constantly or able to focus on their own life's details they appeared (and reported) to have not yet gone through the grieving process. Whether through choice or obligation DSPs have occupied their time since the disaster with tasks and duties rather than the emotional side of the grieving process.

DSPs reported a desire to grieve and process their experiences; however they indicated that they haven't had an outlet or opportunity to do so. They spoke of the organization (VOA) and their experience in receiving concrete support around the work that they do or concrete resources however they felt that the emotional piece of grieving remained unaddressed. Administrators reported that at Palestine, opportunities to process the trauma were offered but not taken. For DSPs in other locations, those opportunities did not occur. Managers were not unaware of the lack of discussion around loss; however they may have mistaken DSPs' lack of discussion around their personal situations as "pride". The DSPs however related it as a lack of interest by the organization in the DSPs' emotional state post-disaster.

When staff did try to talk about their feelings, frustration and struggles, they were told by at least one manager, "I am so sick of everyone using Katrina as an excuse, just move on." That particular statement [an exchange with a manager] was repeated in several of the focus groups revealing a consistent message that staff received from at least one person that it was time to move on and work (VOA) was not the place to bring your troubles. This has appeared to have devastating effects on the DSPs' ability to move through their grieving process as their work is completely intertwined in their disaster experience. Some staff members reported going on medication such as antidepressants to be able to deal

[A significant challenge was] "trying to find people who will come back and work because for a while we were like one person taking care of 5 consumers or more. It's still happening now. You also have to take care of your problems you had at home and at the same time you have to, no you wanted to, come and help your consumer because you know that that person was also going through what you were going through and it's a lot more difficult for them so you did a little bit at home and you spend 24 hours doing theirs... it's still there's no one coming back to work ..."

Person 1 "We had meeting sometimes with Jim and voiced our opinions."

Person 2 "It wasn't about that."

Person 1 "It wasn't about how we felt. It wasn't about how scared we were. It wasn't about did you find your mother? Do you know where your sister is?"

Person 3 "Nobody really sat down and said well, your house is under water when you go back what plans do you have? What can we do? ..."

Person 4 "Doing this group here was probably really good for some of us to get some of it out, because we are trying to heal. I don't think people know that. I'm not going to say they [management] don't care, but I am going to say they don't know it."

with the situation. People also chose to deal with their grief and trauma through their individual fortitude or their faith in a higher power.



## Other Trauma

DSPs who evacuated to the Houston area faced a second disaster in Hurricane Rita. The raw trauma and emotion detailed by the DSPs who endured a second evacuation was striking. The evacuation process itself was described as chaotic. Essential services such as gasoline stations and food stores didn't remain open during the early portions of the evacuation causing people to run out of gas, stirring anxiety and fear amongst those leaving the city and creating panic. People wouldn't pull off the road to stop for the bathroom for fear of being cut off and not allowed back onto the road. Supplies ran out and people were surviving for days at a time in the car without food, water or bathrooms. The experience left consumers, DSPs and their families devastated.

In addition to the trauma caused by the Rita evacuation from Houston, other trouble on the road during Hurricane Katrina created challenging and sometimes traumatic circumstances for consumers, DSPs and family members. Traffic was heavy and there were shortages of supplies along the evacuation routes. Many people delayed their evacuation which created intense traffic jams late in the storm surge. Some DSPs evacuated with consumers to town which welcomed them however this was not always the case. In some situations DSPs felt threatened by certain townspeople where they were "talked to us like dogs." Some of the shelters ended up being more unsafe than safe, such as in Bakers where "They had, all they had people in there doing drugs and everything and we just had to leave..."

*"You got bonuses and Jim said thank you a million times. They wrote a chart out of everything they did while we were out there (Palestine). They are still missing the whole picture."*

Researcher-"What is the whole picture?"

*"The picture is that we need to heal. You are overlooking the big picture."*

*"The worst part of evacuating is getting on the road and that's why a lot of people don't evacuate."*

*"It was just really hard because the clients didn't understand that we could not, would not let them go to the bathroom. There was no where to go, there was no where to go and it was really hard. It was hard on my kids, it was hard"*

*"We had taken a couple vehicles, we headed out on the road, course like everyone else we discovered the traffic which was tremendous so one of the situations that we were facing is, one of the guys that we support, my wife was working with him and he has really high needs. This particular person has a feeding tube and frequent bowel movements so we knew we weren't going to be going very fast or very far. We would have to make frequent stops, but in the traffic it was very difficult. There were times where we would have to stop on the side of the road and try and get him cleaned up and all that."*





## Communication

Communication issues emerged as a major concern for Direct Support Professionals doing their job during Hurricanes Katrina and Rita. DSPs reported a lack of communication with VOA, and no communication with their family especially in the early days of the evacuation. At the camp in Palestine, most cell phones did not work and public phone access was severely limited.



*“The hardest thing was I really couldn’t reach my mother or my brother. It was terrible not to know where people are at, especially family members with a storm like that.”*

*I had text messaging with them [family]. We couldn’t get through the telephone lines so I did text messages, every day”*

*“Where we were, you couldn’t use the phone. If you could get a line, it was all tied up, that was the hardest thing is trying to make sure the baby is all right.”*

*“The first week that while we were away I didn’t know where 5 of my family members were. We were all living in a hotel room when we first came down. I was calling around, we had gotten on the internet and had other people on the internet trying to find our family members. We didn’t know where my niece and nephew were for a week so I had to deal with that. No knowing where they were.”*

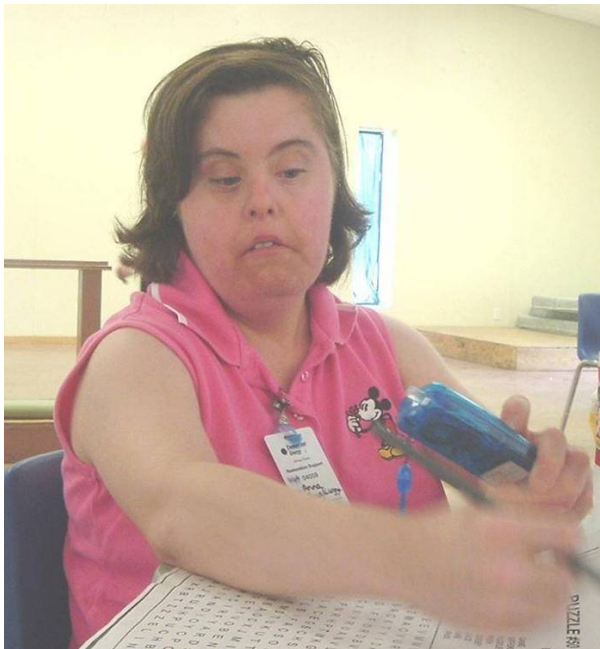
## Communication with VOA

Lack of communication with VOA resulted in stressful situations and uncertainties about how to handle things. Many DSPs reported that they felt as if they were in limbo, and needed guidance from supervisors on how to proceed. It was unclear whether there was a central location to check in, approve expenses, find lodging, etc. Phone communications were unreliable, and neither cell nor land lines were consistently working. Additionally, many DSPs reported not having access to advanced technological equipment such as laptop computers, Blackberries, internet, or the technical knowledge that people in managerial positions had. The DSPs eventually figured out that while cell phone calls were not going through, text messages were. This became a very beneficial form of communication.

## Communication with Family

Lack of communication with family made it difficult for DSPs focus on job tasks and influenced psychological health and emotional well-being. DSPs relied on news and word of mouth to receive information. This elevated stress levels and created increased anxiety. DSPs reported that management did not respond sympathetically to their challenges and concerns about not being able to communicate with family.

Some DSPs were able to communicate with family members through text messaging, but others were not able to communicate with their family at all. Concerns about family made it difficult to effectively do their job and focus on responsibilities. As a result, many DSPs chose or were asked to leave. Others found it very difficult to balance work and personal life.



## Faith

Faith emerged as an important and common theme in the focus group interviews. Focus group participants were clear in reporting their dedication and commitment

*The only milestone with problems we did have was communication. We could not contact the facilitator. She was nowhere to be found, and we did have a valid number but then I also heard that from experiences that a lot of phone circuits, excuse me, were not working so that was a problem with communication.*

*They said that the Blackberries, computers, and internet worked. Which none of us had. All we had was our cell phones.*

*We had lost all communication. We didn't pick up anything on the radio and then all you heard for a week were rumors. I mean the rumors were just awful.*

*People don't believe in our Creator, they get lost. I think first of all you have to have God with you. You have to be strong.*



to their faith. The commitment to their faith both nurtured and sustained through difficult times, and gave many Direct Support Professionals (DSPs) the strength to continue supporting individuals with disabilities as well as the ability to persist under the tragedy and uncertainty of Hurricane Katrina.

## Religion

Many DSPs spoke of religion as a source of strength, support, and direction in their lives. Several DSPs indicated the strong role that their faith played in supporting their psychological well-being during difficult times. Reliance on a higher power was a guiding force in their daily lives. Other DSPs spoke of God as providing them information and direction when they were unsure of what path to take.

DSPs also focused on how blessed they felt and grateful they were to God for their homes, family members, and jobs. DSPs reported a strong sense that God was looking after them and their families. Because many of them felt blessed and grateful to God, they felt a moral and spiritual calling to continue working with their consumers.



DSPs reported that putting God first helped them to focus on consumer needs. This helped them to attend to the task at hand and provide good care to the

*Put God first and you know your individuals can't take care of themselves so you keep yourself focused to take care of them because the ones I work with they worry about me if they think I am sick or worried so you can't show this here so number one is putting God first.*

*You put God first and stay focused, trying not to lose grip because if you sit there and you begin to meditate on what's going on around you, that would make you feel, mind and focus on the task at hand.*

*The morals that we have, each and everyone one of us here, won't allow us to do that to our clients you know because they are family. They are God's creation, but they're riding on your back now. In other words, you take care of two or three they said you know basically for the price of one, then that opens the door for us to be overworked, overlabored, everything and by allowing it, it is very, very frustrating.*

*I did this for my creator 'cause he was helping me. I am a very Christian person, but they didn't say thank you*

*I said of God, now what are we going to do?*

individuals they support. Many DSPs expressed that if you lose sight of God, you risk losing your mental and spiritual focus.

Many DSPs shared that their values systems were shaped by a Christian moral ethic. Their Christianity drew them to the occupation, and sustained them when other aspects of the job were challenging and overwhelming. However, many DSPs expressed frustration, disappointment, and resentment around VOA's management. Many DSPs reported feeling taken advantage of, unappreciated or treated poorly. This was especially painful as VOA is a Christian based organization. Some of VOA's actions contradicted what DSPs expected from an organization with Christian values.

## Prayer

Prayer was both a source of strength and comfort for DSPs. DSPs used prayer to find reassurance and answers in difficult times. Prayer was especially comforting when there were uncertainties, and when the location of friends and family was unknown. Further, without prayer and communication with God, DSPs said they would not have been able to function effectively in their jobs.

## Miracles

Miracles were yet another prominent theme. Comments were made about faith and miracles and God's role in reuniting them with family members and friends. One woman whose husband was stranded on a bridge for three days reported, "We stayed in contact with each other, his phone for some reason, his phone stayed charged." Others reported that God miraculously provided food or shelter for them, their families and the people they were supporting. The belief in miracles provided both strength and hope to DSPs and their families.

## The Big Picture

### Poverty Influences Experiences

One cannot look at the circumstances of Hurricanes Katrina, Rita and Wilma and the lives of people with intellectual and developmental disabilities and their support workers without acknowledging the role of poverty in their experiences. Nearly all of the people with IDD who owned or rented their own homes and most of their Direct Support Workers lived in the most impoverished neighborhoods decimated by hurricane Katrina. Most of these neighborhoods remained boarded up and there was literally no human activity when as researchers we walked the streets of their neighborhoods. Few if any FEMA trailers, no construction workers, no garbage men. The only other human we saw was a single artist who was painting a picture of a pile of garbage. Yet when this is compared to the image of the neighborhoods where middle class people lived the images are completely different. In these neighborhoods there were many FEMA trailers, contractors working overtime and the largest piles of rubbish were no longer there.

VOA went to great lengths to ensure that DSPs were paid for the hours they worked during and after the evacuation. Yet DSP wages in Louisiana are

*I was blessed so I came back to my consumers. Fortunately, God was on my side. I'm like thank you God I've got a home.*

*I knew we were blessed definitely. God looking after us.*

*...I prayed. I asked God for some direction and basically it was given to me.*

*I kept thinking this is not the same city it was, I had to go back and ask God what it was that you want me to do. I knew I had to come back to start the process of getting it back together.*

*We all came together as one and eventually God just revealed to me where my family members were.*

*...One day, one night, about 10 o'clock the phone rings-- one room for you! I was praying a ton believe me. I feel miracles. My God is still truly with me.*

*Where am I going to get the strength to come back and start all over again? Where's my house? ... The questions everyday which I am faced ... is when we are going to get our home back? They didn't lose it in the storm. The other ones lost theirs, but they don't have a home.*

appallingly low. DSPs reported earning as little as \$7.00 per hour. One DSP, who had been in the field for 15 years, earned \$9.65 per hour. Meanwhile Wendy's fast food restaurant was offering a \$250.00 monthly bonus and an \$11.00 an hour starting wage. This made finding new workers to relieve existing workers very difficult. In response, VOA raised the starting salary of DSPs to get new applicants. But this reduced the gap between new and existing workers and caused alarm and discontent from the DSPs interviewed. One DSP was making \$7.62 per hour after 8 years; while a new worker with less experience was hired at \$7.25 per hour. DSPs reported that with the escalating rents, sky high utilities costs, and mortgages on houses have been destroyed, it is impossible for them to support themselves and their families working as DSPs. VOA was able to increase wages for DSPs in 2006 after the focus groups were completed but wages remain very low compared to other locations in the country.

The DSPs, by the very nature of their wages and their need to work more than one job to pay their bills, live at or very close the poverty level. DSPs who were separated from their spouses or children they did not have the resources to go and visit them routinely. DSPs who had to pay a mortgage on their house that was destroyed did not have the resource to also pay rent. DSPs who had to pay utilities on their destroyed property had no money to pay for utilities on a rented property. These people who sacrificed so much to ensure that the most vulnerable citizens who experienced the hurricanes were safe are overworked, overburdened and in need of time, resources and support to grieve and move on with their lives.

## Kindness and Generosity of Others

DSPs were resourceful and utilized help from fellow citizens. Many went to churches and local shelters for food, clothing and shelter. They spoke of kindness, generosity and people willing to go out of their way to help. DSPs found clothes in piles that were left by strangers in the street and food in food shelves and pantries. The fellow DSPs in other states provided support and kindness as well.

## Crime

DSPs witnessed crime and feared for their lives. Whether it was en route during the evacuations or following the hurricane DSPs experienced many types of crime, including people waving guns to get gasoline first, fist fights, gangs or looters. Many told stories of the National Guard and how afraid they were to be experiencing a police state with curfews. The lack of electricity added to their challenges and their fear. Just about everyone experienced or witnessed some type of crime. Even for the DSPs (and the clients they supported) who had homes that were not destroyed by the hurricane most have lost all of their belongings because of looters.

DSPs experienced looting of their personal property and crimes against them during the evacuation process. One DSP spoke of knowing that strangers sought shelter in her home during the hurricane and although they didn't appear to steal anything it still seemed like a violation. Other accounts of the crime trauma included accounts of fighting at gasoline stations, lack of electricity and the

*"My client is going to start a new job Monday at Burger King and he's going to be making 10 cents an hour less than what I am making now and I have worked here [as a DSP] for 11 years next month."*

*"There was a nice church family that adopted the whole group of us and they met a lot of our needs, they were really, really nice."*

*"She lost everything, what she didn't lose the looters took the rest."*

*"Six weeks after if you had electricity in your area you were lucky. At six o'clock they had a curfew. You couldn't be on the street."*

*"Now we are back and I still think about my home, because I didn't have any water damage because I live upstairs, but I still had a lot of stuff stolen."*

imposition of a city wide curfew due to the crime that was occurring all around them.

## Management Experiences

Discussions with management revealed themes of responsibility, hard work, and frustration. Like the DSPs, managers also experienced challenges balancing the needs of personal, family, home and work. This was particularly difficult because management had so many other people depending on them for support and guidance. Managers spoke of the stress and discomfort of not being able to communicate with DSPs and consumers. They shared how much front end planning and time they put into trying to get rooms and transportation arranged for consumers and DSPs. This was especially challenging to do considering the large number of people evacuating, as well as the scattered and uncertain nature of the emergency evacuation progress.



Once on the road, managers reported the challenge of dealing with people in the time of crisis. They had to focus on the safe evacuation, but many of the staff and consumers were desperately concerned about friends and relatives back home. Managers talked about the compounded stress of dealing with the crisis as well as both consumer and staff needs.

*I stayed up the whole night reserving hotel rooms, talking to staff... We had lots of hotel rooms reserved all over the state and one of my facilitators took the initiative to reserve a block of hotel rooms, something was telling her this was bad. We pretty much knew generally where people were going to be, we were scattered, we had people going to Houston, Georgia, Memphis, Alabama, and dealing with hotels.com that night they were like what is going on, none of these hotel rooms are available. They themselves were like we can't find anything. I stayed on the phone the entire night and we kept going more north, more north, more north.*

*It was really hard at that point to function and talk to people knowing the people you have known for years could just be gone.... It was really hard to try to keep functioning and think okay this is what we need to do. It was so chaotic. You kept getting different in information from different news channels and it wasn't accurate, that was very difficult. At that point I started getting on the email to see if I could reach some people by email... We were able to start emailing through the hotmail account and I did a list of everybody that I knew where they were and we were in contact with.*



Managers also spoke to the need for putting consumer safety and concern first. They had to make decisions concerning staff employment that were in the best interest of the consumers. Although they expressed some understanding of the unique and challenging personal circumstances that many of the DSPs were facing, the safety and well-being of the consumers was the primary goal. As a result, some DSPs were asked to take a leave from employment. The DSPs who were asked to leave were given appropriate accommodations.



## Arranging Temporary Housing

Managers described the significant damage to the group homes, as well the challenge of finding and arranging temporary housing for consumers. A large percentage of the group homes were damaged and needed significant repairs. Although there were many consumers who were ready to come home, there simply was not enough housing for them. Management arranged for some trailers for DSPs to live in so that they could help support and work with consumers.

## Management Personal Lives

Managers acknowledged the personal sacrifice they and the staff had made in trying to get the consumers lives back on track. They discussed the difficult balance of personal life and professional life in a time of crisis. They acknowledged a wealth of challenges in their own lives. Although some managers sustained very little damage, others homes needed significant repairs. Their families often lived in other areas or even in other states such as Texas while the managers commuted in every week to work at VOA.

## Staffing Bonuses

Managers recognized the importance of acknowledging staff contributions and providing bonuses and incentives for hard work and dedication. They raised the salary of direct care staff by a dollar an hour, and would like to increase salaries for DSPs across the board. Although the organizational funds are somewhat

*Even early on arriving to Palestine there were people we asked to leave. We didn't just put them out and let them exit without finding support .... You could tell that they were just ineffective, they couldn't focus. Rightly so, they lost everything and their life was in turmoil and they were no use to the consumers, to the people we were serving or to the management staff. There were a few of the managers that we asked to leave as well as DSPs who were not following through on anything. We gave them funds and put them up in a hotel for a couple of days. We put them on a train.*

*It has been a challenge. I myself sacrificed a lot because my family was in Houston, TX. I would go to Houston two times a week to visit with my husband and two daughters. Throughout the process I actually lived in Palestine and I'm still commuting...*

limited, they recognize the significant and vital contributions DSPs make to the organization. In December, 2006 DSPs were given bonuses of \$1,500 in recognition of their service during Katrina.



... We have been looking at that and we have done cost analysis of things of that nature to see how we can address all of that with the limited funds we have available. For the folks who were with the group homes in order to continue to keep them incentivized, when they were in Palestine, TX we would just give them money separate and apart from their checks, they would get the overtime. They deserved it, they worked for it, they earned it. We would give \$500 here, \$250 there, to the managers. One time we gave \$1500 checks. We couldn't do a whole lot, but we tried to do what we could to show our level of appreciation. One day the president came out, Jim, and he just gave them \$100, that is all we had at the time.

## Making Changes/Improvements

Managers felt that they had handled the situation the best that they could have under the circumstances. They identified lessons they had learned and ideas for how to handle future emergencies more effectively. Their ideas included providing better staff training, arranging more housing availability, better communication, and more back up staff. The evacuation plan is currently being re-evaluated and potentially re-developed. This process is expected to take some time. Managers suggested that more open dialogue between staff and management would be beneficial in trying to improve the quality of care for consumers. One of the issues is that if you have a 1-800 that serves the LA area, that system may go down. It has in the past. So we now plan to have a number that will be established outside of the area as a 1-800 number where people can contact that number and get information.

We have also talked about the volunteer base, we have a group of people that we have made contact with and they will set up a phone bank. Calls will come in and we will have people answering those calls and being able to assist them...One of the things that we really wanted to get settled on as which affiliate. We were really leaning toward Shreveport.

To be honest with you I would handle it the same way that I did in the past...Hindsight is 20/20. You say if I would have known this I would have done this. Now is the opportunity for us to change and improve the things that require improvement. For our frontline employees I think the good thing is just keeping that dialogue and open communication going. We still hear our staff saying, "we have these issues and we don't want this to occur." My question always goes back to them, "Give me a solution to the problem and let's see if it works."





*Not only do they have the office space to house us, they also have room to accommodate employees.*

*Key administrative staff that we have identified will evacuate and that is something we have not done in the past.... If that means you bring your immediate family with you to operate that office that is what you need to do...The other thing is that we have looked at the fact that we have lost so many records in this process. What we have elected to do is identify folks that will take the network drives and backups with them. That way we can still process payroll and backup our files to our ultra bridge system and things of that nature. There are some things we are doing to get that taken care of.*

## Consumer Experiences

Hurricanes Katrina and Rita presented many unique and difficult challenges for consumers. The tragedy of the situation was often magnified by feelings of powerless, a sense of uncertainty, dependency on others, a lack of resources, as well as concern for family members, belongings, and pets. DSPs reported that individuals with disabilities had difficulty when they returned to see the destruction of their homes and possessions. The instability and uncertainty were particularly difficult. Many consumers could not understand what was happening or why they could not go back to their homes. They faced challenges living in temporary housing with persons that were not necessarily compatible with them (e.g., behavioral issues, age mismatches, and personality conflicts). DSPs tried their best to make the transition as smooth as possible, but the lack of resources and unique conditions of the situation made it difficult to adequately meet the needs of the consumers.

*There is one set fighting here and one fighting there, but you are supposed to be able to stop all the fights at one time.*

*I felt real bad because I felt like I was doing what I should have done to help the clients I'm not trying to say you were all, we got off the road after three years, I mean three days, we were dirty, we were wet, some of the clients had defecated on themselves, we couldn't help them.*



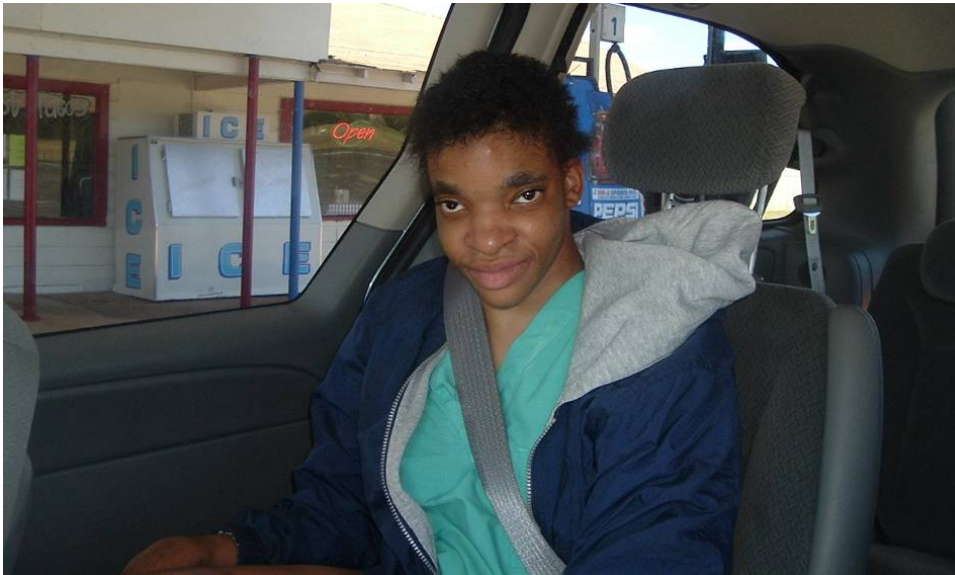
## Health and Safety Issues

During the storm and its aftermath the safety of both consumers and staff were at risk. Most of the threats to personal safety were not due to willful malice on the part of DSPs or families. More frequently the circumstances, lack of resources, and the overall crisis of Hurricane Katrina and Hurricane Rita challenged everyone. Managers identified several instances where consumer safety had been jeopardized, and DSPs noted that conditions while traveling to safety were extremely stressful and that resources were extremely scarce. Food, water, and bathroom facilities were very difficult to find.

Even after settling into temporary housing, managers expressed frustration with the quality of care, professional focus, and decision making skills of some DSPs. Many of these challenges could be attributed to the turmoil and uncertainty in DSPs personal and family lives. Concerns were expressed over decisions made by staff about consumer's evacuation plans. There were also times when decisions by consumers to stay in their homes led to some risky situations. Consumers were often reluctant to leave their homes, belongings, and pets. In some cases, DSPs took extreme measures to help ensure the health and safety of consumers.

*I evacuated with my client and early that Sunday morning and you know I called him that night and said pack up. It was right in the evening and I picked him up and told him we'd get back and everything we got... It's usually about a 2 and a ½ hour ride so we took back roads and we got up there pretty good. Some parts got slow, and we got there in about 7 hours and when I left there were two cars because I had my daughter, she had her cat, we left with cats, and my grandson and his two cats, and my two cats and my client and we got up there and we were in a roach motel for about a week, but we were glad we had a place to stay.*





The stress of the evacuation, lack of appropriate resources, changes in routine and medical misunderstandings all contributed to health concerns. DSPs made great efforts packing medication and personal care items for consumers. However, many issues arose around medication administration. Due to a lack of necessary delegation forms and medication documentation books, many DSPs were not able to obtain or document medications appropriately. Additionally, circumstances and conditions during evacuation made it a challenge to administer medications in a timely and appropriate manner. Some DSPs felt that their professional opinions concerning the health of their consumers were devalued, and that their expertise on their consumer's care was disregarded--even in cases in which the DSPs had worked with a consumer for years. In a few extreme cases, consumers became seriously ill and died.

*Katrina played a part, but it wasn't direct.... We always knew this consumer would die from the common cold, because that was just his disability... When he caught the cold there were things we could have done to fight it off, but ... he was at a hospital that didn't know anything about his disease. The records were at Tulane hospital, which was under water. Therefore, the doctors didn't know what to do. Of course, they didn't want to listen to an LPN. I am at the bottom of the totem pole even though I know everything that was going on with the consumer and as a result he passed. Forgive me, but I am still bitter about it.*

*She had to be rescued from the building.... She is a diabetic and didn't have her insulin for 3 days. She couldn't go to the hospital in New Orleans, and she had to be flown from there to Atlanta. She almost lost her foot, which they saved.*



## Evacuation Experiences

DSPs did the best they could under the circumstances during the evacuation. Limited resources, lack of a comprehensive plan, and difficult conditions on the road led to a difficult evacuation experience for both DSPs and consumers. It was particularly challenging to meet the needs of consumers with high personal care needs on the road as accommodations such as accessible bathrooms and showers were extremely difficult to find or were nonexistent. Behavioral issues and crowded living conditions were often challenging.



## Concern for Belongings and Pets

During the evacuation, many consumers expressed concern over belongings and pets. This made it very difficult for some consumers to agree to evacuate, and some refused to evacuate at all. Upon returning, many consumers lost not only their homes and other possessions, but treasured collections and photo albums that were sources of enjoyment, pride, and self esteem. The situation was further complicated as it was hard for many consumers to comprehend why and how the destruction had happened as well as how to solve the problem. DSPs recognized the feelings of loss and helped consumers salvage and replace many of their personal belongings. DSPs went to great lengths to help consumers regain a sense of safety and normalcy.

*She was crying. I had to console her because she had no house anymore...My client because she was devastated, it was kind of a shock to find out there was no house anymore and she had gotten flooded several times, but this time it was the worst and there was no help and when you turn around, look around all the houses were in the same shape that her house was. She didn't know how to cope with that, and she was real emotionally and upset. So her mother and I began to gut that house ourselves and to console her...we tried to save the most we can.*

*He had about five feet of water in his house so he lost everything so he was moaning all the, he had a nice collection of records and tapes and CDs and we whatever was in the top of the closet was the only thing that we could get and I did go through the house and the only thing that I could really recover out of there was one of his roommates, we used to try to teach him how to hang pictures correctly, but he always hung the pictures up to the ceiling. Those were the only pictures we could save...That was all we recovered from his house, and he was really sad about that. I spent most of my time trying to encourage him to talk, we can build your collection again 'cause our thing was going to thrift stores and garage sales and collect all of these things. I said we are going to go we're going to do that.*

*It wasn't only the storm it was the returning. We lost three pets. He wasn't home a week and he was in a mental ward for about 3 or 4 days. When you have to go home and take the dead pets out and he was very attached to them you know.*





## Living Conditions After Returning to New Orleans

Many of the consumer's homes and group homes sustained considerable damage. Although some consumers were able to return to their previous homes, others were displaced and had to find new places to live. The sudden rent inflation and price gouging made new housing and renting difficult to access. Because of the extreme housing shortage, many consumers who were ready to come home could not. Some lived in crowded group homes. Some consumers were placed in inappropriate settings (e.g., persons who were violent placed with persons who were fragile). In some settings staff members were unsure of how to care for and communicate with the consumers. Consumers experienced increased emotional issues, behavior problems, fighting, self abusive behaviors, and health concerns. Uncertainty about future contributed to these challenges.

*When we were going back, he was worrying about his TV and I was explaining to him that was no longer and when we got back it would have to be replaced. For awhile, he was okay, but then we moved somewhere else he still wanted to know when we were going back home.*

*...they lost all of their furniture, all of their clothes, all of their belongings, their pictures, things that are very important to them.*







## DSP Recommendations to VOA

The DSPs in the focus groups made a series of recommendations about how to improve disaster response in the future. These recommendations included:

- Create more open dialogue with DSPs, listen to their concerns and then act upon their concerns.
- Provide staff in supported living with credit cards or pre-paid cards that they can activate and use if evacuations last over three days.
- Have a planned long term accommodation plan in place so that in the event of longer evacuations, staff have a place to go to with clients.
- Give us identification cards so we can “prove” that we have an official role in the lives of the clients we support.
- Have a national toll free number that is staffed 24 hours a day so we can call for assistance during evacuations. This number needs to be housed outside of the LA area.
- Obtain non-Louisiana emergency contact names and phone numbers for all staff. Then in an emergency these individuals can be contacted for information about the whereabouts and well-being of the DSPs and the clients they support.
- Develop an emergency per diem for staff and clients. Direct deposit this per diem into their accounts so that staff do not have to worry about receipts when they are in the midst of such trauma.
- Provide personal, individual thank you’s to each staff member.
- Provide some type of “disaster pay” where you get additional money for each hour worked, above and beyond your regular pay.
- Create a national pool of relief staff.
- Figure out a way to ensure that critical information about clients (e.g., medications, treatment plans, health) are available in an electronic format accessed over the internet or at a central location so that no matter where a person is this information is available.
- Provide VOA vans to evacuate supported living staff and consumers.
- Use consistent approaches across all services within the organization to recognize and appreciate staff.
- Plan for and make available staff housing during major disasters. You cannot get services back up and running without staff and if staff have no place to live you will likely lose many. Work with FEMA and other federal agencies to assist with this.
- Provide technology for DSPs to use to be able to communicate with management during a crisis. Perhaps pre-paid cell phones for emergencies at the houses.

*They need to set up a 1-800 number at the corporate office in Baton Rouge.... I don't know, maybe they could network with someone where we have the walkie-talkie 'cause whether you believe it or not, it was my only means of communication, that walkie talkie. I was able to call anybody, and it wasn't through Sprint. It was through somebody else.... I think that is something they need to invest in and that evacuation plan needs to be revamped specifically and especially with the communication and financial.*

*“...Yeah we did receive paychecks, they did give us some incentives but I don't think they really know or I don't think the staff feel...they just don't know how lucky they are to have the staff they have right now and the dedication...the ones that stayed and stuck it out.”*

*“Everybody lost. If you lived in this area, anywhere near this area you lost.... With so many things going on I can see if they (management) would have just said \$250 for consumers and \$250 for staff. I mean and not by chance I am being selfish but I just think we had, we had a loss like everybody else and I know we are all trying to get back up and running... Now that's just like at Christmas time, if you [VOA] give a turkey. You know I just feel right now it's time for the turkey because we all need to feel appreciated.... At this point I know, you know [about] the pay checks, trust me I loved it, but I just think at some point [they should] show some kind of gratitude to the employees, the ones that stuck in for the long haul, because it was a long haul you know and some people are still doing it.”*

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## Resources

The Times-Picayune website includes an interactive graphic depiction of the flooding in New Orleans at the following address:

<http://www.nola.com/katrina/graphics/flashflood.swf>

This archive contains links to 61 million Katrina related documents and websites that had been developed by November, 2005.

<http://websearch.archive.org/katrina/>