



The Northern California Wildfires: Perspectives from Families of Children with Disabilities

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Background

- Research on disasters suggests that adults with disabilities are disproportionately vulnerable and encounter barriers during emergency evacuation, sheltering, and recovery (Boon, 2015; Good et al., 2016; Stough & Kellman, 2017; Van Willigen et al., 2002).
- Children with disabilities are considered particularly vulnerable to the adverse effects of disaster due to social, physical, educational and psychological factors (Ronoh, 2015; Stough, Ducey & Kang, 2017). For example, children with intellectual disabilities may need additional explanations during evacuation or children with autism may have difficulty when encountering unexpected stimuli. However, children with disabilities are often neglected from school disaster planning (Boon, 2011) and families of children with disabilities are often underprepared for emergencies (Wolf-Fordam et al., 2015).
- Families of children with disabilities may require tailored disaster information to best meet their needs (Hipper et al., 2018). Additionally, community response to children with disabilities and their families may influence resiliency in disasters (Peek & Stough, 2010). However, studies focus on adults with disabilities or children without disabilities leaving little known about children with disabilities and their families.

Study Design

- **This study aims to understand the experience of children with disabilities and their families impacted by the 2017 Sonoma County Fires. There is a particular focus on any challenges encountered and factors perceived as helpful across all phases of disaster. Parental reports of the health, emotional and behavioral reactions of their children are also explored.**
- Ten parents of children and youth with disabilities have completed in-depth interviews. Recruitment efforts are ongoing and will continue until Summer 2019.
- Constructivist grounded theory coding methods (Charmaz, 2014) are being used to analyze the data. There are two coding phases: 1) Initial coding involves assigning provisional codes to units of data. 2) Focused coding consists of synthesizing initial codes and making analytic decisions about categories.
- Example of coding: The initial codes of “nightmares”, “missing friends”, “increased anxiety” were collapsed into the focused code of “child impact.”
- The final analysis will include rich descriptions of categories that emerge from the data. For purposes of this presentation, participant quotes are used to support initial category descriptions.

Participants

- **9 mothers and 1 father interviewed**
- **Ages of children ranged from 3-20**
- **Disabilities included Autism, Intellectual disability, ADHD, Down syndrome, paraplegia, dyslexia, visual and hearing impairments, asthma and other health impairments**
- **All families were evacuated and displaced (1 week to over a year) as a result of the Tubbs (n-9) and Nuns (n-1) fires**
- **All children missed preschool or school (1 week to 3 months)**
- **All children experienced a disruption in disability-related supports**
- **One child’s school was destroyed**
- **Three families lost their homes**
- **Four families relocated to new towns as a result of the fire**

Preliminary Results

1. UNPREPARED: Parents discussed not being prepared for a disaster of this scale. Disability and health related needs were on their mind during evacuation although there was inconsistency evacuating with disability related supplies and equipment.

“The girls have asthma so I didn’t grab their inhalers, because they have celiac, the one thing I did grab was a bag of gluten free crackers because if we go somewhere they were not going to have anything for them to eat.” (P07)

“It is like you have to run and get out fast. How do you do that with a wheelchair? And she is so heavy. I thought about piggy back.” (P04)

“Unfortunately you are in such a panic that I didn’t always grab the right things. The biggest things that we left back with regard to my daughter was her communication systems, she lost her wheelchair, an adaptive bike, she lost those things.” (P09)

2. NAVIGATING DISABILITY NEEDS WHILE DISPLACED: Parents attended to the disability and health related needs of their children while simultaneously navigating their evacuation and recovery. This was complicated due to the loss and disruption of typical supports.

“...Especially with all of his stuff, he only eats pureed foods, being away that long, I had to make his food at other people’s houses and that is not an easy task, pureeing foods and then storing them, it was really difficult.” (P02)

“...the next morning I had called all around. I called the Red Cross. I was trying to find an accessible hotel, anything. And everything was booked and taken.” (P04)

“I feel that I don’t have the same structure and supports that I knew about in Santa Rosa, the kind of places to take my son, the ‘Ian friendly’ ones.” (P03)

3. CONNECTING WITH OTHERS: Parents believed connecting with social supports, teachers, and recreational contacts were beneficial. For example, parents were grateful to stay with family and friends because they thought a public shelter would not appropriately address disability-related needs. Connections were not always possible because of the impact of the fire on the family and the broader community.

“..the Special Olympics coaches decided not to cancel practice because they knew people needed to come together. There was a lot of hugging and crying and just letting the young people be together. I remember feeling like I could breathe and be okay for a minute.” (P03)

“I am not inviting her group of friends over anymore. I know she misses that, she shows me pictures of what she would like to do. That is a huge change that has to do with the fire because I am working now.” (P09)

4. IMPACT OF FIRES ON CHILDREN: Parents reported a range of health, emotional and behavioral reactions including breathing difficulties, increased anxiety, bedwetting, regression of skills, grieving and sleep changes. Parents believed the disruption or loss of disability related supports had a negative impact on their children.

“We lost all the sensory stuff that was in our house, and it was a safe haven for them, it would help to avoid meltdowns, not having that has made their behavior worse.” (P07)

“It has been really hard for him. He told me was really depressed. He had a nightmare that the fires had started again, nightmares about red flag warnings.” (P03)

5. DISABILITY SPECIFIC SUPPORT: Parents did not receive preparedness information or evacuation support specific to disability. Parents indicated mixed views on the response of schools and the community. The child’s typical needs such as concrete explanations or maintaining routines influenced how parents supported their child.

“I think having some type of medical outreach for those of us who went through what we went through. I did not lose my home but it was traumatic for me in a different way.” (P02)

“I think that is what the school does well. They provided therapy dogs. They tried to keep things as predictable as possible. At the temporary site, desks had organizers on it, visuals, their schedule.” (P08)

Discussion

- Parents identified a need for increased attention to the specific needs of children with disabilities and their families impacted by disasters.
- Parents are most familiar with their child’s needs and should be involved in equitable emergency planning efforts for children with disabilities.