

Children with Special Needs during Disasters



Chapter 5

Children with Special Needs during Disasters

On successful completion of this chapter you should be able to:

- 1) Apply the concept of special needs populations to children and adolescents
- 2) Identify stressors that affect children with special needs during disasters
- 3) Identify strategies to support children with special needs during disasters

Key Concepts

- Children with special needs include the psychiatrically and medically ill, those who have suffered from multiple episodes of child maltreatment from parents and caretakers, the developmentally disabled, children in foster care and children who are disadvantaged by poverty.
- During disasters and extreme events, children with special needs may have diminished resiliency and fewer resources to manage disaster adversities, leading to heightened risk for psychological disorders.
- Special needs children should be prioritized in disaster planning.
- Children with special needs require customized interventions to optimize their safety and protection during disasters.

Source: FEMA photolibrary

Introduction

Special populations are defined as “groups of people whose needs may require additional, customized, or specialized approaches in preparedness for, response to, and recovery from extreme events” (Flynn, 2006). Children with special needs include those who have been exposed to multiple and repetitive psychosocial adversities before, during, and after disaster impact.

When children encounter interpersonal violence; live in poverty; or experience severe medical illness, developmental disabilities or psychiatric disorders; their psychological vulnerability to future traumatic events is increased (Balaban, 2006). In consequence, special needs children include: children who have suffered maltreatment, children with developmental disabilities, children with special psychiatric needs, children with special medical needs, children living in foster care, children living in poverty and children with limited language proficiency (Table 5.1).

Table 5.1
Children with Special Needs

Children who have been exposed to maltreatment

- Physical abuse
- Emotional abuse
- Neglect
- Sexual abuse

Children with developmental disabilities

- Blind and visually impaired
- Deaf and hard of hearing
- Mobility impaired
- Mentally ill
- Brain disorders and injuries
- Chronically ill
- Drug and/or alcohol dependent
- Dually-diagnosed with mental illness and substance abuse

Children with special psychiatric needs

- Children who were previously defined as psychiatrically disturbed, and/or who were receiving psychotropic medication, and/or whose condition worsened due to the lack of access to medications
- Children with preexisting psychosocial and psychiatric problems which are exacerbated by the stress of disaster

Source: American Psychiatric Association, 2007

Children who experience cultural/ethnic health disparities or live in geographic isolation

- Cultural/ethnic groups
- Rural residents

Children with limited language proficiency

- Limited-English or non-English speaking
- Refugees
- Legal immigrants
- Illegal/undocumented immigrants
- Sign language

Children who live in economic disadvantage

- Population-wide poverty
- Living at or below the poverty line
- Working poor

Children with special medical needs

- Children with medical trauma
- Children with medical needs
- Families with children with medical needs

Others

- Juvenile offenders
- Dependent on public transportation
- Families underserved by public health
- Sheltered juveniles: runaways, battered youth
- Homeless youth

Children Exposed To Maltreatment

Complex Trauma

Complex trauma derives from repetitive and cumulative exposure to traumatic episodes. Applied to children, complex trauma refers to exposure to violence which begins in childhood and is repeated throughout the developmental years. The consequences of complex trauma exposure--emotional crisis, loss of a safe base, loss of direction, and inability to detect or respond to danger cues--increase the child's vulnerability to future trauma. In complex trauma, the child is exposed to dangers that are unpredictable and uncontrollable; the child's resources are redirected toward survival rather than growth and development. Children who experience complex trauma are particularly susceptible to the "add on" of traumatic experience associated with disaster.

Source: NCTSN, 2003

Child maltreatment is a complex trauma experienced within a family or care-giving environment in which a child is exposed to multiple episodes of physical, emotional, and verbal abuse, and possibly sexual abuse. Extending into adulthood, abused individuals suffer from the enduring effects of childhood traumatic experiences. Child maltreatment is a risk factor for disruptive behaviors, mood and anxiety disorders, and posttraumatic stress disorder (McLeer et al., 1994). Annually in the United States, three million reports of child maltreatment are processed by child protective services and one million are definitively documented and confirmed (1.3 percent of the pediatric population) (Kaufman, 2007). A global estimate indicates that 133-275 million children worldwide are exposed to domestic violence (UNICEF, 2006). For the United States, estimates range from 339,000 to 2.7 million.

Table 5.2 Child Maltreatment

Physical abuse: Non-accidental physical harm or injury to a child resulting in physical injuries (ranging from minimal to fatal) inflicted by persons caring for them. Acts of violence include, but are not limited to: slapping, shaking, punching, hitting, kicking, and burning the child.

Emotional abuse: Habitual patterns of verbal abuse and related behaviors characterized by the caretaker demeaning, belittling, tormenting, and denigrating the child's feelings of self-worth and confidence.

Psychological abuse: Actions causing psychological distress including social isolation, intimidation, degradation, humiliation, false accusations, ignoring and dismissing the child's needs.

Neglect: Willful failure to provide adequate care and protection for children. Neglect may take many forms such as physical, emotional and educational neglect manifested by failure to arrange for appropriate care, custody and supervision. Neglect may involve such deprivations as not providing food, clothing, or appropriate medical treatments; exposing children to dangerous environments; or keeping children from school.

Sexual abuse: Sexual exploitation of children and/or the erotization of children. Sexual abuse refers to any sexual behaviors which occur without consent, without equality or as a result of coercion. Sexual aggression invariably involves the use of threat, intimidation, exploitation of authority, or force with the aim of imposing one's sexual will on a non-consenting person for the purpose of sexual gratification.

Exposure to violence in the home is frequently multi-generational. Predictors of maltreatment include weak family bonding, ineffective parenting, inadequate parental supervision and monitoring, exposure to violence and reinforcement of coercive behaviors in the home.

Although high-profile school shootings are rare and extreme events, youth-on-youth violence is prevalent among school-age youth, with physical fighting and bullying behavior reported by 30-40 percent of students (Olweus, 1997; Nansel et al., 2001). Bullying is defined as the intentional, repeated production of physical and/or psychological injury or discomfort upon another person who is unable to defend him/herself. Boys are more likely to self-report engaging in physical bullying activities and to be the victims of physical violence. Girls are more likely to report being victimized by social exclusion, gossip and

sexual comments. The most common type of bullying involves verbal bullying such as name-calling, taunting, teasing or rumor-mongering.

A survey of 1,100 school students demonstrated that those exposed to violence are at increased risk for psychiatric disorders (Schwab-Stone et al., 1995). Child victims of complex trauma may exhibit impairment in one or multiple domains (Table 5.3). Children who experience maltreatment at home, in school or in their neighborhoods are more vulnerable to the psychosocial consequences of subsequent trauma exposure, including disaster, due to the cumulative effects of trauma exposure, loss of resiliency, diminished self-efficacy and lack of psychological support from caregivers.

Table 5.3
Domains of Impairment in Children Exposed to Complex Trauma

I. Attachment

- Uncertainty about the reliability and predictability of the world
- Problems with boundaries
- Distrust and suspiciousness
- Social isolation
- Interpersonal difficulties

II. Biology

- Increased medical problems
- Problems with coordination, balance, muscle tone
- Hypersensitivity to physical contact
- Somatization—bodily symptoms

III. Emotional Regulation

- Difficulty with emotional self-regulation
- Difficulty describing feelings
- Difficulty communicating wishes and desires

IV. Dissociation

- Distinct alterations in states of consciousness
- Amnesia—loss of memory for selective events
- Depersonalization and derealization

V. Behavioral Control

- Difficulty understanding and complying with rules
- Poor modulation of impulses
- Self-destructive behavior
- Aggression against others
- Sleep disturbances
- Eating disorders
- Substance abuse
- Communication of traumatic past by reenactment in day-to-day behavior or play

VI. Cognition

- Learning difficulties
- Problems with language development
- Difficulties in attention regulation and executive functioning
- Difficulty planning and anticipating

VII. Self-Concept

- Lack of a continuous, predictable sense of self
- Low self-esteem
- Shame and guilt

Source: NCTSN, 2003

Children in Foster Care

The United State welfare system subsumes a complex matrix of services and programs which vary by state and across communities (Grigsby, 2002). Children who are placed in foster care have usually experienced neglect and physical, emotional and/or sexual abuse. These children have frequently experienced a myriad of stressors within the family including mental disorders, substance abuse, domestic violence, financial hardships, chronic medical illness, and death of loved ones. Environmental stressors may include racial and ethnic discrimination, unemployment and poverty.

The foster care population is estimated to number about 500,000, with children residing in a variety of settings such as youth shelters, group homes, domestic violence shelters, residential treatment centers and foster homes. Children in foster care have higher rates of child maltreatment and psychiatric disorders. The high prevalence of previous trauma increases the vulnerability and diminishes the resilience of foster children when they are subsequently exposed to disasters and extreme events.

Hurricane Katrina brought the vulnerabilities of foster care children into sharp focus. Many of the 13,000 children who were in foster care in Louisiana, Alabama and Mississippi prior to storm impact were displaced after the storm. The foster children of Katrina frequently experienced separations from adult caretakers and the other foster care children with whom they were living at the time of storm impact. Displacement and relocation of foster children disrupted their schooling and friendship networks. Those who were resettled to other states often lost their eligibility to receive the welfare and Medicaid benefits from their state of origin (Gelles, 2006).

Children with Developmental Disabilities

Developmental disability is defined as physical or mental disability, or a combination of both, that is continuous and manifest during childhood. Developmental disability is frequently evidenced by limitations in expressive and receptive language, self-care, learning, mobility, and capacity for independent living. The population prevalence of developmental disability is 2-3 percent. Developmental disabilities may derive from a diversity of origins: congenital malformations; birth injuries; brain injuries; and chronic medical illnesses such as cystic fibrosis, HIV infection, diabetes, and neurological disabilities.

Developmentally-disabled children are at elevated risk for child maltreatment, physical abuse and sexual abuse. Children with disabilities are two to ten times more likely to be sexually abused and twice as likely to be physically abused compared with children who have no disabilities (Westat Inc., 1993).

Disability and abuse interrelate in a vicious cycle. Children with developmental disabilities are more likely to be abused. Abuse, in turn, precipitates further developmental delays across social, psychological, physical and cognitive domains. Worsening developmental problems exacerbate the risk for further abuse. Ongoing and repetitive episodes of trauma sustained by children with developmental disabilities significantly increase their vulnerability when they confront a natural or human-generated disaster.

Children with Special Medical Needs

Medical illness and medical procedures are associated with emotional distress, anxiety, feelings of helplessness, physical pain and fears of threat to life--powerful traumatic stressors for children. Moreover, these stressors reverberate throughout the child's family, straining coping capacities and draining financial resources.

Approximately 5 percent of children are hospitalized for an acute or chronic illness, injury or disability. One thousand children receive organ transplants each year. One-in-five children admitted to a pediatric intensive care unit will develop PTSD within six months following discharge.

Annually, in the United States, between 9,000 and 12,000 children are newly diagnosed with cancer (Zebrack, 2007). Cancer is the second leading cause of death for children, ages 1-14 years. There are more than 250,000 child cancer survivors in the United States. Parents of adolescents with cancer have a 35-45 percent chance of developing PTSD, a higher rate than that experienced by the child cancer victims (Kazak et al., 2004).

The care of children with acute and chronic medical conditions represents a serious challenge for those planning and preparing for disaster. Children with special medical needs are often biologically stressed, less resilient and more vulnerable to the added impact of disaster stressors. In the aftermath of Hurricane Katrina there was a catastrophic loss of hospitals, community and private medical offices, pharmacies, patient information systems, and health insurance coverage. Children with acute and chronic medical conditions were precipitously deprived of medical support services. Many families sought emergency care to obtain life-sustaining medications for their children with medical conditions such as asthma, diabetes, and renal disease requiring regular dialysis. The St. Jude Children's Research Hospital website documented the disruption of live-sustaining cancer treatments for 170 pediatric patients due to the closure and evacuation of Gulf Coast hospitals. A significant portion of the pediatric inpatient population in New Orleans experienced the rigors of evacuation to specialized pediatric health care facilities outside the storm-damaged area.

Recommendations for disaster preparedness for parents with medically ill children are presented in the Table 5.4.



Children with Special Psychiatric Needs

Disasters have greater impact on families where a family member has a psychiatric or substance abuse diagnoses. One out of every five adults will have a diagnosable mental disorder or substance abuse problem. There are approximately 11 million children with a parent who is alcohol dependent. Children who suffer the consequences of parental psychopathology often have significant emotional and behavioral problems.

As a further complication, there is evidence of increasing fragmentation of the American family. The birth rate among unmarried women has increased by fifty percent between 1980 and 1990 (Gilliam et al., 2007). One out of every four children lives in a single parent family (and among African American families, the rate is one-in-two). Half of all marriages result in divorce.

According to the 1999 Surgeon General's Report, 21 percent of United States children, ages 9-17 years, have a diagnosable mental or addictive disorder. Furthermore, 5-6 percent of youth have a mental disorder that significantly impairs school performance, social functioning and abilities to meet the demands of everyday life (DHHS, 1999). There is evidence of an increase in pervasive developmental disorders characterized by developmental delays coupled with impairments in language, communication and social skills. Severe mental disorders, such as autism, childhood-onset schizophrenia, mood and anxiety disorders, obsessive compulsive disorders, Tourette's, attention deficit disorders and severe behavior control problems often require ongoing psychopharmacological interventions. The encounter with disaster may disrupt the family system which is already challenged to maintain effective support and essential therapy for children with psychiatric needs.

Table 5.4
Recommendations for Caregivers of Children with Special Health Needs

- Have a clearly defined disaster care plan for child.
- Develop strong alliances with health care providers.
- Maintain phone numbers of health providers.
- Know the location of emergency health centers.
- Have a medical supplies kit tailored to the needs of the child.
- Obtain medical identification tags for your child.
- Train family members to assume the role of in-home health care providers.
- Identify a common point of contact (neighbor, friend, or relative) in the event that family members are separated.
- Identify an out-of-state contact person in the event that local communications are disrupted.
- Stockpile foods that are essential for special dietary needs or restrictions.
- Learn the disaster plan at the child's school, including how the school plans to reunite children and families if a disaster strikes during school hours.
- Know where evacuation shelters are located.
- Learn the community's evacuation routes.
- For children with medical conditions requiring electrical power, notify utility companies to provide emergency support during a disaster.
- Identify shelters in the area that provide continuous power during disasters.
- Create contingency plans should the utility company not be able to provide alternative sources of power in the event of power loss.
- Evacuate when told to do so.

Source: Adapted from Markenson and Reynolds, 2006

Poverty, Ethnicity and Culture

Poverty:

Children living in poverty represent a special population with elevated risks for psychological consequences following trauma exposure due to limited resources compounded with ongoing financial and household stressors. Poverty, with its associated child-specific stressors, poor prenatal care, low birth weight, malnutrition, environmental stressors, and feelings of powerlessness, is a risk factor for mental disorders. Poor families lack transportation, adequate housing, access to health care, and money to spend on health-promoting activities.

The National Center for Children in Poverty reports that 13 million children live in poverty (less than \$20,000 for a family of four). This translates to approximately 19 percent of all children under 18 years of age (Gilliam et al., 2007). Several race/ethnic minorities are over-represented among the impoverished with poverty rates estimated at 35 percent for African-Americans, 28 percent for Latinos, and 29 percent for American Indians (National Center for Children in Poverty, 2006). In contrast, the poverty rate is lowest for Asian Americans at 11 percent.

Children living in poverty frequently live in housing that offers minimal protection in times of disaster. For example, at the time of Hurricane Katrina, 13 percent of children in Louisiana lived in “extreme poverty” (defined as household income that is below half of the federal poverty level, or \$9,675 for a family of four). These families lived in decrepit housing in flood zones with no dependable transportation and thus no way to evacuate.

Culture/Ethnicity:

The United States is a multicultural society with a race/ethnic composition of 68.4 percent White/non-Hispanic, 14.2 percent Hispanic/Latino, 12.2 percent Black/non-Hispanic, 4.2 percent Asian/Pacific Islanders, and 1.0 percent American Indian/Alaskan Native citizens (U.S. Census Bureau, 2004). There is evidence that children from minority backgrounds are at increased risk for trauma exposure and posttraumatic stress disorder during disasters (Norris et al., 2002a,b).

Special Categories of Children with Special Needs

Consideration must be given to other subsets of children who are at increased risk for exposure to disaster stressors. These include youth who are confined to juvenile detention centers, substance abuse treatment centers and halfway houses; children who are placed in shelters for domestic violence; and children in youth hostels and centers for homeless and runaway youth, as well as those who remain on the streets. As described above, many children chronically experience the stressors associated with poverty and economic disadvantage, ethnic and racial discrimination, and illegal immigration. Many of these youth are outside of the reach of systems that provide safety, shelter, services and support during disasters.

Interventions

Pre-impact Phase:

Children with special needs require medical and community interventions that are mobilized to ensure the safety and protection of the child. This includes child protective services, medical care venues, foster care placement, and residential care when indicated. Children with identified special needs are usually in an ongoing intervention program prior to the occurrence of a disaster in their community. Since programs for special needs children are multifaceted and time-phased, continuity of care is essential for optimal outcomes. This requires a sustained investment of resources and planning for continuity of operations during extreme events. Pre-disaster planning must prioritize support for the entire family with special needs children since optimal therapeutic outcome is closely tied to parental and family influences.

In the pre-impact phase, efforts should be made by both municipal and mental health professionals to promote community contingency plans for children who have been exposed to cumulative traumatic experiences and who will need to have special consideration at the time of disaster. Parents need to prepare for the eventuality of emergency situations such as disasters that may interfere with the

continuity of healthcare, family stability and social supports. It is important for families to be informed about the potential hazards that are likely to occur in the local area. It is prudent to anticipate and prepare for such emergencies by becoming informed about community disaster and evacuation plans, school plans for reuniting children and families at the time of disaster, and the locations of special needs shelters. Parents are encouraged to develop alliances with healthcare providers, to prepare emergency supply kits with the child's critical medical supplies and necessary medications, and to have contingency plans to request and receive assistance from other family members in time of need.

Impact Phase:

During disaster impact, children in harm's way are exposed to a range of disaster stressors. This is the time to put into operation the family's emergency plans for ensuring continuing health care and family stability. Knowing that previous exposure to psychosocial adversities increases the vulnerability to additional traumatic exposure, special needs children should be prioritized for evacuation to safe environments with ongoing provision of services in order to minimize the intensity of exposure and the disruption of care.

Post-Impact Phase:

Post-impact, the focus for special needs children should be on maintaining or rapidly restoring supportive services and care environments. Accurate assessment of the child's symptoms facilitates tailored and customized intervention as needed in the aftermath of the disaster experience. Every effort should be made to enhance the child's coping capacities and resiliency, and to mitigate the child's uncertainty, physical discomfort and perception of social isolation or separation from loved ones.

Particular attention should be given to providing disaster recovery and behavioral health support for the parents and caregivers of special needs children. The parent's management of essential care is critical for mitigating the traumatic events for the child.

Assessment and intervention at the time of disaster impact and its aftermath must be sensitized to culturally-

competent practices. A traumatic event is interpreted and given meaning within the context of ethnic and cultural values and beliefs. During disasters, care and support must be provided to disaster-affected populations that reflect a mix of cultures, value systems, health beliefs and primary languages.

It is necessary to assess the level of acculturation and corresponding level of "acculturative stress." For example, a child may feel comfortable speaking English and be more acculturated than the parents who may prefer to speak their native language. When possible, use an interpreter or find a provider who is fluent in the family's native language. A culturally-competent assessment will address issues of cultural identity, values and health beliefs, treatment expectations, family supports, cross-generational differences in acculturation and trauma associated with migration and relocation. It is important to perceive the child as part of the family unit and to engage the family as a whole. For example, the cultural value of "familismo" in the Hispanic community requires that helpers recognize the importance of engaging the entire family in any assessment or integration process.

Summary

Children with special needs include the psychiatrically and medically ill, those who have suffered from multiple episodes of child maltreatment from parents and caretakers, the developmentally disabled, children in foster care and children who are disadvantaged by poverty. During disasters and extreme events, the child with special needs may have reduced resiliency and fewer resources to manage the repeated exposures to stressors, leading to heightened risk for psychological disorders, including disaster-associated posttraumatic stress symptoms. Special needs children must receive priority consideration in disaster planning to maintain continuity of care and to minimize traumatic exposure.

