

Trauma, Grief and the Social Model: Practice Guidelines for Working with Adults with Intellectual Disabilities in the Wake of Disasters

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Abstract: Formulating personal needs assessments and plans for self-protection have been the recent focus of disaster preparedness manuals for individuals with intellectual disabilities and their caregivers. Interventions to address the minimization of psychological ill effects of trauma and grief in the aftermath of disasters for this population, however, remain largely unexplored. In the wake of such events, persons with intellectual disabilities require trained mental health professionals to assist them in identifying and coping with trauma exposure and its associated, often sudden losses. Intervention should be based on the unique needs of this population within the context of disaster and each individual's cognitive strengths and capacities. Coupled with reviews of research and practice in the area of disaster mental health, the social model of disability served as a foundation for the formulation of best practice guidelines for tertiary interventions with adults with intellectual disabilities. The guidelines suggest approaches that will enable professionals to identify and minimize acute and chronic responses to disasters as well as foster resilience and enhance the valuable contributions of adults with intellectual disabilities in disaster-affected communities.

Key Words: intellectual disabilities, social model, trauma

Disasters are natural or human-made catastrophes that result in widespread destruction, distress and sudden loss. Damage from severe weather calamities and other natural phenomena during the past decade resulted in 460 Presidential declarations of major disasters, nearly double the number issued for the previous ten-year period in the United States and more than any other decade on record (Federal Emergency Management Agency, 2000). Studies of these natural disasters and the September 11th attacks have led to a considerable body of literature on the psychosocial sequelae of disasters in general and recommended psychosocial interventions to address related trauma and grief for individuals in disaster-affected communities (Danieli & Dingman, 2005; Roberts, 2005a; Voelker, 2006). More recently, studies denoting recommended practices for symptom alleviation in vulnerable populations affected by disasters (e.g., residents in low-income housing, children, older adults) have proliferated (Munson, 2002; Sanders, Bowie, & Bowie, 2003; Zakour & Harrell, 2003). Although adults with intellectual disabilities are likely to be among those regarded as vulnerable, this community has been largely ignored in the current dialogue on disaster studies. Researchers have not identified individuals with intellectual disabilities as a separate group with distinct needs. Consequently, disaster mental health professionals are neither specially trained to identify the potentially unique manifestations of trauma and grief in this population nor to tailor interventions to minimize acute and chronic sequelae. This article will a) present a review of the trauma and grief literatures as they relate to disasters, b) briefly examine the social model as a foundation for best practice guidelines, and c) delineate approaches for tertiary interventions with individuals with intellectual disabilities in the wake of disasters.

Disaster and Trauma

Trauma occurs when an experience is perceived as threatening and overwhelms typical coping skills (Behrman & Reid, 2002). Based on a nationally representative sample of adults, it is anticipated that more than 60% of men and 50% of women will experience at least one traumatic event during their lives (Kessler, Sonuga, Bromet, Hughes, & Nelson, 1995). U.S.-based data indicate that sexual abuse is the most common form of trauma experienced by women, whereas men are more likely to experience combat-related trauma and non-combat violence such as witnessing homicide or severe injury (McFarlane & de Girolamo, 1996). Trauma resulting from disasters - whether natural, human-made, or some combination of the two - accounts for additional cases among both men and women (Razza & Tomasulo, 2005).

Theory and research have long considered both the psychological and physiological dimensions of trauma and its aftermath. Multiple studies have documented biological abnormalities such as ongoing autonomic hyperarousal and disturbed sleep physiology in some trauma survivors (Friedman & Schnurr, 1996; Regehr & Sussman, 2004). Studies also reveal higher than normal scores on measures of somatic complaints and medical conditions (Norris et al., 2002), suggesting that exposure to disasters may increase the likelihood of relapse and perceived burden of pre-existing conditions (Norris et al., 2002) or contribute to the development of serious health problems such as heart disease and gastrointestinal disorders (Friedman & Schnurr, 1996).

Exposure to potentially traumatic events also has been shown to lead to a broad range of mental health problems in the general populace, including dissociative disorders, somatization disorder, self-mutilation, eating disorders, panic and anxiety disorders, phobias, protracted states of depression, and the characteristics of relational instability, impulsivity, and emotional lability that are commonly associated with borderline personality disorder (Courtois, 2004; Herman, 1992; Mayou, 2001; Rundell, Ursano, Holloway, & Silberman, 1989; van der Kolk, 1996). Specific investigations of people who have survived disasters show that many of these psychological problems are also manifest in this group (Norris et al., 2002).

Despite the obvious challenges to physical and mental health, the majority of men and women exposed to potentially traumatic events successfully manage the associated distress and disruption and do not experience psychopathology (Gray & Litz, 2005; Norris et al., 2002; Regehr & Sussman, 2004). Indeed, individual and community-level resilience are commonly noted in the aftermath of even the most catastrophic events and post-traumatic growth is now recognized as an important potential outcome for survivors (Ai & Park, 2005; Davis & McKearney, 2003; Powell, Rosner, Butollo, Tedeschi, & Calhoun, 2003).

Extant research has demonstrated that one's ability to adapt to a disaster is associated with a continuum of variables including mastery, control, flexibility and optimism (Regehr & Sussman, 2004), causal attributions of the event (e.g. to human intention or nature) (Briere & Elliott, 2000), secondary losses or stresses associated with the event (Brewin, Andrews, & Valentine, 2000; Hobfoll, 2001), prior history of trauma or psychiatric issues (Norris et al., 2002), strength of personal networks and social supports (Norris et al., 2002), and the community response to the event (Paton & Johnston, 2001; Regehr & Sussman, 2004). Each of these factors must be considered closely for individuals with intellectual disabilities if we are to better understand the risks and resilience of this population.

Disability and Trauma

Individuals with intellectual disabilities, who often are reliant upon others to provide care (Developmental Disabilities Act Amendment, 1990), are believed to be at greater risk for victimization and its psychological sequelae (Garbarino & Brookhouse, 1987; Sobsey, 2005; Sullivan, Brookhouser, Knutson, Scanlon, & Schulte, 1991). Numerous studies indicate that persons with intellectual disabilities have high rates of traumatic exposure (Allen & Borgen, 1994; McCabe, Cummins, & Reid, 1994; Sobsey, 2005; Sobsey & Varnhagen, 1989; Wilson & Brewer, 1992). For example, Valenti-Hein and Schwartz (1995) found that almost 50% of persons with intellectual disabilities in their sample experienced 10 or more abusive incidents within their lifetime. Despite these data, few researchers have explored the effects of trauma on this population and even fewer have examined traumatic exposure and mental health needs of individuals with intellectual disabilities following disasters. Accepting that people with intellectual disabilities can and do suffer from the ill effects of trauma may be difficult for some professionals to comprehend (Newman, Christopher, & Berry, 2000). It is only within the last two decades that there has been a full acknowledgement that individuals with intellectual disabilities could have a dual diagnosis of serious mental illness.

Disaster and Grief

Profound loss is at the center of every potentially traumatic event and must be negotiated by survivors. Although death is frequently viewed as the most challenging loss, many other individual and community-level losses arise in the aftermath of disaster. These losses include health, functional ability, meaningful possessions and places, jobs, economic stability, sense of safety and security. An underlying thread tying these losses together is the attachment that one has to what is lost. Any attachment - whether, for example, to a person, place, object, belief, expectation, or dream - that is severed can be experienced as a loss, which causes the pain we call grief. Grief is commonly recognized to be a complex psychological state that affects people emotionally, cognitively, spiritually, socially and physically. Although grief and bereavement are sometimes used interchangeably, bereavement typically refers to the specific condition or state of having experienced the death of a significant other. The active process of adaptation that people who have experienced the death of a significant other undertake is often referred to as mourning.

Grief and bereavement can be associated with significant physical and psychological morbidity (Elklit & O'Connor, 2005; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Latham & Prigerson, 2004; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Summers, Zisook, Sciolla, Patterson, & Atkinson, 2004). Most who are affected are able to adapt (i.e. mourn) successfully, albeit in different ways and in different time frames depending upon a wide range of individual and loss-specific factors (e.g., type or emotional intensity of the original attachment, meaning ascribed to the loss), and do not experience psychopathology (Bonanno & Kaltman, 2001; Jordan & Neimeyer, 2003; Matthews & Marwit, 2004). This normative adaptation to bereavement, which has been referred to variously as "normal," "simple," and "uncomplicated," has been described extensively in the literature. This sizeable literature, however, has been largely conceptual and more recent research suggests that many of the long-held assumptions about the bereaved, and the grief they experience, do not have empirical support (Bonanno & Kaltman, 2001; Stroebe, 1992; Stroebe & Schut, 1999; Wortman & Silver, 1989). Some of these theories, such as the assertion that successful adaptation to bereavement requires repeated confrontation of the events related to the death, have been challenged. In their

place, newer models (e.g. the Dual Process Model developed by Stroebe & Schut, 1999) have begun to further specify the multiple processes that are involved in mourning and have stimulated exciting new research that extends our conceptualizations of these important phenomena (Stroebe, 2001).

Although current research suggests that most bereaved people experience uncomplicated grief, a clinically significant subset of bereaved individuals do experience difficulties that extend beyond those which are viewed as normal (Neimeyer, 2002; Shear, Frank, Houck, & Reynolds, 2005). Within the context of disasters and other potentially traumatic experiences, grief or mourning may be especially prolonged and distressing (Nader, 2001; Regehr & Sussman, 2004). When losses are sudden, violent, or perceived as unjust, some survivors may experience an overlap of trauma and grief reactions that can lead to complications (Eth & Pynoos, 1985; Nader, 1997). Rubin, Malkinson and Witztum (2003) propose that “personal experience of traumatizing proportion can occur in the case of bereavements that give no hint that external circumstances are particularly ‘traumatic’” (p. 678). This response process, which has been referred to most recently as “traumatic grief” or “complicated grief”¹(Burnett, Middleton, Raphael, Dunne, Moylan, & Marinek, 1994; Jacobs, 1999; Prigerson et al., 1999; Shear et al., 2005), is thought by some to be manifested in a set of core symptoms that may resemble those associated with both Major Depressive Disorder and Post-Traumatic Stress Disorder (PTSD), but reflects a distinct disorder/syndrome (Prigerson & Jacobs, 2001; Shear et al., 2005). However, serious concerns about the clinical validity of complicated grief as a distinct disorder applicable to all groups of bereaved individuals have been raised (Hogan, Worden, & Schmidt, 2003). For example, there has been scant research in the area of grief for persons with intellectual disabilities.

Disability and Grief

Losses faced by disaster victims with intellectual disabilities are often compounded by the cumulative losses incurred throughout their lives, which may complicate mourning (Clegg & Lansdall-Welfare, 2003). Among these many losses are privacy due to communal living arrangements, relationships resulting from family members who have withdrawn or interpersonal problems with peers, and health due to secondary impairments. Despite such losses, it is only within the past two decades that grief and bereavement have been recognized and studied in those with intellectual disabilities (Hollins & Esterhuyzen, 1997). This significant knowledge gap may be related to erroneous assumptions that people with intellectual disabilities do not possess either the ability to form the relational bonds that ultimately could lead to feelings of personal loss and grief (Dodd, Dowling, & Hollins, 2005) or to “really” understand the concept of death or its impact (MacHale, 2002; Moddia & Chung, 1995; Read, 2001; Speece & Brent, 1984).

Current knowledge about bereavement in adults with intellectual disabilities is largely based upon observation of behavior change or the development of mental health problems (Dodd, Dowling, & Hollins, 2005). Case reports and a few systematic studies have identified the myriad responses of individuals with intellectual disabilities to bereavement. In their examination of bereavement in adults with mild intellectual disabilities, Mitchell and Clegg (2005) documented breathing difficulties, disorientation, hyperactivity, increased sexual behavior, suicidal statements, loss of body function and pretending to be dead. Harper and Wadsworth (1993) reported that bereaved individuals with moderate to severe intellectual disabilities experienced disruption to their lives, symptoms of anger, anxiety, confusion and discomfort as well as loneliness. Cases of mania, schizophrenia, affective and adjustment

disorders have also been reported in bereaved individuals with intellectual disabilities (Hollins & Esterhuyzen, 1997; Singh, Jawed, & Wilson, 1988; Yapa & Clarke, 1989), as have increases in aberrant behaviors (Bonell-Pascual et al., 1999).

Although individuals with intellectual disabilities are very likely to experience a range of grief reactions that are similar to their nondisabled counterparts, some manifestations of their grief may not be identified by mental health professionals. For example behaviors such as increased compulsivity, intensified frustration, self-injurious actions, relationship difficulties, somatic complaints and social withdrawal may be viewed as problematic but either not recognized as expressions of grief (Kauffman, 2005), or misinterpreted as signs of mental illness, particularly when they are intense or very disruptive to others (Carder, 1987; Lipe-Goodson & Goebel, 1983). Failure to identify grief may lead to additional developmental and emotional disruption (Clements, 2004) and may prolong the grieving process (MacHale, 2002). Accordingly, some have questioned whether the behavior changes and other reactions that have been observed represent normative or traumatic grief in this population (Dodd, Dowling, & Hollins, 2005). Further research is necessary to more fully understand grief in adults with intellectual disabilities in the wake of disaster.

Social Model of Disability

A review of the social model of disability aims to elucidate the attitudinal underpinnings guiding individual and societal responses to trauma and grief experienced by individuals with intellectual disabilities. Social model theorists posit that the “locus” of disability lies not in individual impairment, but rather in physical, social, economic, political and cultural barriers erected by society. Impairment is a condition of the body or mind, an attribute of an individual (Burchardt, 2004). According to the social model, it is not bodily, sensory or intellectual impairment, but rather social discrimination and biases that in fact produce “disability” and exclude or disadvantage individuals (Barnes, Mercer, & Shakespeare, 1999).

The implications of the social model of disability for counseling are quite profound. The social world in which counseling has developed has been overtly ablist and characterized by the exclusion and marginalization of people with disabilities from mainstream society (Barnes, 1991 as cited in Reeve, 2000). The “distress and psychological problems” experienced by people with disabilities is most often caused by the disabling environment rather than the impairments (Oliver, 1995). Based on general reviews of the social model of disability and counseling (Reeve, 2000; Swain, Griffiths, & Heyman, 2003), disaster mental health practice guided by the social model would encourage professionals to challenge their beliefs and limited knowledge of disability cultivated in a predominantly ablist society, encourage clients to discuss their experiences of barriers that deny them full participation to cope with the disaster and its effects, and address individual and social change by highlighting capacities and personal resources to challenge disabling barriers.

Tertiary Interventions

The stated aim of numerous humanitarian organizations (e.g. American Red Cross) is to impart emergency relief to individuals and families in a crisis, oftentimes employing special efforts to target the most vulnerable members of a disaster-affected community. Individuals with intellectual disabilities tend to be viewed as a vulnerable group who may be less able to cope

following disaster (DeWolfe, 2000). This vulnerability warrants specialized attention from disaster mental health professionals. Currently, the absence of disaster mental health training specific to the unique issues faced by individuals with intellectual disabilities can detract from the quality of services they receive or impede their access to existing services. In the wake of the Hanshin earthquake in Japan, dehumanization, segregation, exclusion and powerlessness emerged as common experiences for individuals with intellectual disabilities (Takahashi, Watanabe, Oshima, Shimada, & Ozawa, 1997). Accordingly, the following practice guidelines are based upon the social model of disability and focus on consultation, inclusion and empowerment. Although primary and secondary interventions are critical in the aftermath of disasters, a discussion of these types of mental health responses is beyond the scope of this paper. Rather, we delineate a series of tertiary interventions to facilitate adaptation and coping in the face of grief and trauma.

Crisis Intervention

A crisis is personal and is dependent on an individual's perception of the crisis-inducing event, his or her personality and temperament, life experiences, and varying degrees of coping skills (Roberts, 2005). A crisis may be thought of as a response condition wherein: 1) psychological homeostasis has been disrupted; 2) one's usual coping mechanisms have failed to reestablish homeostasis, and 3) the distress engendered by the crisis has yielded some evidence of functional impairment (Caplan, 1961, 1964; Everly & Mitchell, 1999). Many individuals with intellectual disabilities are products of structured lives and for some, only minor changes in that structure can precipitate a crisis (Prout & Cale, 1994). Because the magnitude of a disaster will likely alter multiple aspects of an individual's life, crisis intervention is likely to be required.

Crisis intervention is the provision of emergency psychological care to facilitate the victim's return to an adaptive level of functioning and to prevent or mitigate the potential negative impact of psychological trauma (Kanel, 2007). Crisis intervention should be received voluntarily, delivered up to four weeks after a disaster and provided on an "as-needed" basis. Crisis intervention will be most effective for individuals with intellectual disabilities when both individual and systemic issues are addressed (Prout & Cale, 1994).

Suggested practice guidelines include:

- Differentiate pre-crisis characteristics and behaviors from those that have emerged post-crisis. In general, people in crisis often experience disorganized thinking which may make conversations with others, including mental health professionals, confusing and hard to follow (Kanel, 2007). Individuals with intellectual disabilities often have difficulty with abstract concepts such as time and recollection of details. Some may demonstrate perseveration of words, ideas, or behaviors. Careful evaluation will allow the disaster mental health professional to distinguish between baseline capacities (e.g. recall ability) and post-disaster disruptions in these capacities that are likely to dissipate with time.
- Recognize that some persons with intellectual disabilities have experienced a lifetime of learned helplessness and are thus, unnecessarily dependent on authority figures. Accordingly, maintain a balance between assisting the person and supporting capacities and efforts to act on her/his own behalf. While time-limited dependence on a mental health professional after a disaster is a natural response and may be a necessary precursor to an individual's resumption of independent activities, the

perceived need to have someone else in charge makes individuals with intellectual disabilities particularly susceptible to influence from others, rendering them vulnerable. Help individuals to develop the skills to discriminate between what is beneficial for them and what could be harmful and, in the absence of a competent mental health professional, the skills to determine to whom they should listen.

- Use simply worded, open-ended questions about cognitive, affective and behavioral states to elucidate the severity of the crisis on the individual with an intellectual disability. Instruments used to assess the impact of crises have not been normed on this population. When formulating a biopsychosocial assessment, do not forego questions typically asked of the nondisabled (e.g., trauma history, psychopathology, substance use).
- Be mindful of the potential for suicide and tailor assessments to the unique needs of adults with intellectual disabilities. Suicide assessment should parallel that with the nondisabled; however attention to psychosocial development and functioning is crucial (Kirchner & Mueth, 1999). Important questions to consider include: Is the threat expressed in concrete or abstract terms? Does the person understand the permanence of death? Is the person physically able to act upon suicidal wishes? Is the person able to communicate his/her anguish in suicidal terms? Is the exhibited behavior truly suicidal or is it self-injurious? (Kirchner & Mueth, 1999, p.132).
- Collaborate with disability agencies and other advocacy groups to gather information on available resources to support this population within the disaster-affected community. Residential and vocational agencies serving individuals with intellectual disabilities offer the potential for an umbrella of support in times of crisis (Prout & Cale, 1994).

Trauma

Trauma recovery is a dynamic adaptive process by which survivors attempt to integrate a traumatic event into their self-structure. The process should not be labeled pathological unless it is prolonged, blocked, excessive, or interferes significantly with functioning. Trauma treatment is aimed primarily at symptom management and elimination of intrusive images of the traumatic event (Regehr & Sussman, 2004). Research on the efficacy of psychotherapeutic interventions to treat trauma and use of acute medication management for nondisabled disaster victims is scarce (Katz, Pellegrino, Pandya, Ng, & DeLisi, 2002). Even less is known about the utility of trauma interventions for individuals with intellectual disabilities; however, the high prevalence of concomitant mental illness in this population suggests that considerable attention be paid to identification and assessment of trauma-related symptomatology in the wake of disasters.

Suggested practice guidelines include:

- Recognize that trauma symptoms may resemble those exhibited by the nondisabled (e.g., somatic complaints, sleep disturbances, anger) or may take atypical forms (e.g. increases in impulsive behavior) (Levitas & Gilson, 2001).

- Assess for lifetime exposure to traumatic events (e.g., abuse, deinstitutionalization), determine exposure to the current traumatic event, and separate new from pre-existing symptoms. Regardless of the assessment instrument selected, the demands on receptive and expressive language can present impediments to accurate completion (Benson, 2005).
- Conduct a detailed screening for PTSD. Agitation, disorganized behavior, self-injurious behavior, increased psychological sensitivity and arousal, outbursts of anger, physical aggression, irritability, depressed mood and sleep problems are among the many symptoms of PTSD in adults with intellectual disabilities (McCarthy, 2001; Nugent, 1997).
- Utilize relaxation training, problem-solving, and modeling to minimize symptoms associated with trauma. These interventions have decreased aggressive behavior, anxiety, depressive symptoms and anger in individuals with intellectual disabilities (Benson & Valenti-Hein, 2001; Lindsay, Richardson, & Michie, 1989; Nezu, Nezu, & Areat, 1991).
- Provide information about trauma symptoms and risk factors associated with more serious problems such as PTSD, which may require the help of a specialist. Discuss the timing and processes of self-referral for specialized treatment. Identify strategies for self care including the importance of limiting further exposure to traumatic material via the media.
- Lessen the impact of trauma and the likelihood of psychopathology by developing and utilizing naturally occurring social supports (Fullerton, Ursano, Kao, & Bhartiya, 1992). Individuals with intellectual disabilities are often devoid of these opportunities and networks.
- Exercise caution when considering the use of psychotropic medications for acute trauma. Medications not specifically tested for this population in randomized controlled trials are widely prescribed. There is also the potential for overmedication (Benson, 2005).
- Avoid diagnostic overshadowing, the phenomenon in which the presence of intellectual disabilities takes diagnostic precedence over coexisting psychological difficulties (Reiss, Levitan, & Szyszko, 1982), which may be more germane to the current stressor (e.g. disaster).
- Recognize that short and long-term stressors such as repeated failure experiences, unstable living environments, and stigmatization are associated with mental illness in this group (Deb, Matthews, Holt, & Bouras, 2001; Rush & Frances, 2000). Such stressors are likely to reoccur in the wake of disasters and should be minimized whenever possible.

- Acknowledge that individuals with intellectual disabilities may develop anxiety disorders such as obsessive-compulsive disorder following a traumatic event (Stavrakaki & Antochi, 2004). Prevailing symptoms of anxiety disorders have included aggression, agitation, self-injurious behavior, obsessive fears, insomnia, and specific symptoms of panic attacks, agoraphobia, sexual dysfunction, mood changes, and depersonalization (Stavrakaki, 1997).

Grief

Fundamental aims of disaster mental health professionals include enhancing survivors' sense of support and control (Neimeyer, 2002), which are so often disrupted in the aftermath of traumatic loss, and respecting and normalizing survivors' early experiences or expressions of their grief. As the fuller implications of losses become evident to disaster survivors, grief reactions may intensify, especially for those faced with the death of a loved one. In the later phases of disaster-relief, facilitating the bereaved individual's expression of both positive and negative emotions directed towards oneself, the deceased, and others may become important intervention components. Failure to express these highly charged emotions may place individuals at risk of complicated grief (Regehr & Sussman, 2004). In the general population, grief is not considered pathological unless it includes marked and persistent symptoms (i.e., present at least six months after the death), such as avoidance of reminders of the deceased, numbness and detachment, difficulty acknowledging the death, and excessive irritability, bitterness and anger, in addition to significant functional impairment (Jacobs, Mazure, & Prigerson, 2000). Individuals with intellectual disabilities may be at risk for complicated reactions, especially if their grief is "disenfranchised," that is not publicly acknowledged, socially supported or openly mourned (Doka, 2002).

Suggested practice guidelines include:

- Recognize that individuals with intellectual disabilities experience grief even though its expression (i.e. mourning) may appear distinct from those of nondisabled survivors (Kauffman, 2005).
- Identify aggressive and self-harming behaviors, increased frustration and compulsivity, relationship difficulties, somatic complaints, social withdrawal, and regression in maintenance of personal hygiene as possible behavioral expressions of grief rather than characteristics of the disability (Bonell-Pascual et al., 1999; Kauffman, 2005; Lavin, 1989).
- Explore the individual's understanding of death and provide cognitively appropriate materials to supplement the learning process. Explain the facts of death as clearly and simply as possible, avoiding euphemisms like, "He is with God."
- Provide information about common manifestations of grief and the mourning process. Affirm a range of emotions, cognitions, behaviors, and physical reactions (e.g., anger, crying, fatigue) as understandable responses to a profound loss. Use visual materials such as a "feelings chart" to assist with the identification and description of responses.

- Discuss the purpose of rituals such as wakes, funerals and burials and be very explicit and specific regarding what the person should expect (e.g., if the casket will be open, what the deceased will look like, potential reactions of other mourners).
- Curtail the desire to shield individuals from the reality of death and mourning rituals. Such well-intentioned “protective” interventions may stifle an individual’s natural coping efforts and may delay grief reactions, leaving individuals with intellectual disabilities at higher risk for development of psychiatric problems (Day, 1985; Kauffman, 2005).
- Utilize techniques of guided and supported grieving (e.g., expressing feelings, verbal rehearsal, interpretation of loss events) for individuals with reduced verbal expressive skills and limited intellectual abilities (Kloepfel & Hollins, 1989; Oswin, 1985). Consider the use of activities that allow non-verbal expressions of grief (e.g. art, dance, music).
- Encourage caregivers and family members to allow individuals with intellectual disabilities to participate in the creation or implementation of activities and rituals related to their loved one’s death. Such opportunities can mitigate helplessness and hopelessness that often accompany sudden or traumatic losses (Neimeyer, 2000). Specific examples include participation in post-death arrangements (e.g., caregiver or family member can lay out several outfits and permit the individual to choose), ceremonial events (e.g., handing out song sheets, serving as a pallbearer, delivering a reading), and acknowledgements of support from family and friends (e.g., addressing or stamping envelopes for cards expressing appreciation for sympathy) (Luchterhand & Murphy, 1998).
- Consult with the individual to determine if he/she wants to maintain routines to the extent possible. Maintenance of routines serves to minimize the number of losses experienced following the death of a loved one and may facilitate a sense of safety and control.
- Support the individual’s participation in a bereavement support group with individuals who are nondisabled. The candor of some individuals with intellectual disabilities may benefit group participants by enabling them to speak more freely. Simultaneously, individuals with intellectual disabilities may learn new expressions of grief and find comfort from others who have experienced a similar loss.
- Assess for complicated grief six months after a disaster-related death. Additionally, provide educational materials that describe the symptoms of complicated grief to individuals with intellectual disabilities and their caregivers so that they can be alerted to the need for additional services if the symptoms are present.

Fostering Resilience and Enhancing Contributions

A full discussion about adaptation to disaster must include the concept of resilience. Many mental health professionals consider resilience to be a dynamic process of positive adjustment to difficult circumstances that includes an interplay of forces across different system levels (e.g., individual, family, community, societal). In broad terms, resilience has been described as “effective coping and adaptation in the face of major life stress” (Tedeschi & Kilmer, 2005, p. 231) and “the ability to withstand and rebound from disruptive life challenges” (Walsh, 2003, p. 1). Although research on resilience has focused primarily on children, the construct is now being used with other populations (see Walsh, 2003 for discussion of resilience in families) and has applicability to persons with intellectual disabilities in general and in the context of disasters.

One significant way to promote resilience in the context of disasters is by validating, facilitating, and enhancing the contributions of individuals with intellectual disabilities both during and after these stressful events. Interventions that require – or at least are enhanced by – relationships with competent caring adults in the community, have also been reported to foster resilience (Tedeschi & Kilmer, 2005; Walsh, 2003). By recognizing both the needs and contributions of individuals with intellectual disabilities, mental health professionals may be able to collaborate effectively with this group on efforts to provide disaster-relief for all members of affected communities.

Suggested practice guidelines include:

- Focus on the development and refinement of problem-solving skills (e.g., identification of barriers that deny full participation in disaster recovery efforts, consideration of strategies and solutions for minimizing obstacles) as a means of addressing immediate and longer-term individual needs. Provide constructive feedback that acknowledges self efficacy and enhances motivation for ongoing problem-solving efforts.
- Create opportunities for active participation on community planning boards and emergency preparedness committees and meaningful collaboration in the tasks of relief provision and rehabilitation.
- Encourage the development of support groups created by and for individuals with intellectual disabilities. Such groups can address a range of important coping strategies including hiring and managing personal care assistants, accessing health care, preparing for future emergencies and protection from abuse. The power of self-help groups is central to the healing process, particularly when individuals are able to move from the position of being the recipients of care to being the givers of care (Feuerstein, 2005). Group meetings can be organized using participatory rapid appraisal (PRA) techniques such as mapping and modeling to allow this population to identify, prioritize and begin to address their problems and explore their capacities.
- Engage adults with intellectual disabilities in the conduct of research that promotes empowerment and autonomy for this population. Research can incorporate the politics of disability and recognize that disability is a social construct. Research that does not perpetuate oppression enables individuals with intellectual disabilities to

contribute to an understanding of effective interventions, treatment protocols and service provider training.

- Validate participation in disaster-relief efforts through a variety of publications including professional newsletters and journals. Co-authorship with individuals with intellectual disabilities who were collaborators on the relief efforts described in the publication may further model the concept of meaningful partnerships.

Conclusion

Disasters of all types are likely to affect individuals and communities across the world for the foreseeable future. Individuals with intellectual disabilities represent a sizeable and important segment of these communities and warrant the same professional attention regarding assessment and treatment of related psychosocial sequelae as do their nondisabled counterparts. Unfortunately, as has been the situation with numerous other health and mental health issues, individuals with intellectual disabilities have not received the same attention as other vulnerable groups. In this article we have attempted to address this serious gap by examining several of the major psychological issues associated with disasters (i.e., trauma and grief) with persons with intellectual disabilities as the focus. Although numerous interventions for both trauma and grief have been examined extensively in the literature, the guidelines suggested here represent an initial attempt to prioritize both the needs and capabilities of this group. Given the multiple systemic barriers and challenges to daily functioning that individuals with intellectual disabilities still endure - and indeed transcend - it is incumbent upon disaster mental health professionals to take every opportunity to facilitate their successful coping in all aspects of life. Because all future disasters are unlikely to be prevented, this article is intended to serve as a useful guide to examine tertiary practices with individuals with intellectual disabilities in their aftermath.

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¹ Traumatic grief and complicated grief will be used interchangeably throughout the text.