Special Issue: Parting the Waters, Disaster and Disability
Guest edited by Alex Lubet and Christopher Johnstone, University of Minnesota

Table of Contents

Forum: Disaster and Disability

Book Reviews

RDS Information

FORUM: PARTING THE WATERS, DISASTER AND DISABILITY

In the Beginning

Alex Lubet, Ph.D.
University of Minnesota

Welcome! Christopher Johnstone and I are proud that *RDS* has selected us to guest-edit this timely forum, "Parting the Waters: Disaster and Disability." The forum includes contributions from a diverse group of scholars and professionals. We thank the authors for the privilege of facilitating the dissemination of their vital work. Thanks also, of course, to our third partner, *RDS* Co-Editor, Megan Conway.

Beyond our obvious interest in disability, many of us also love this field for its interdisciplinarity. As our editorial team's "arts and humanities guy" I cherish what social scientists and clinical professionals teach me. Especially admirable in these fields is the near-mandatory appraisal within a study of its limitations. The arts and humanities could surely benefit from more such introspection and humility.

We can certainly rejoice in offering many fine essays on recent events. As the obvious inspiration for this forum, they should dominate its pages as they do. But we had also hoped for a broader historical perspective. My essay must suffice – for now – with the encouragement to Disability Studies (DS) scholars of the more distant past to share stories and thicken this plot.

I am not alone in valuing highly not only what DS (obviously) has to say about disability, but also disability's value as a standpoint. Disaster, disability's partner theme in this forum, shares that attribute, as a view that yields broad enlightenment about both life and ways of knowing. Disaster, like disability, is not only something that happens and is experienced; it is also an assessment, a valuation, an attitude, a perspective.

Standpoints such as these may become even more unique when several are juxtaposed. Disability and disaster thus become a set of lenses which together offer much broad sociocultural understanding; both about the way things work and, apparently and unfortunately, how they mostly don't (at least for now).

If two lenses are good, how much better might three, four, or more be? Every essay in this collection brings at least one additional perspective, that of methodology, to the questions of disability and disaster. I suspect I share with many DS folk that I am often asked to lend opinion – sometimes editorial opinion – to matters far from those intuitively associated with my professional expertise. When this occurs during an editing project, I "test the waters" to see if my methodological skill set offers something that warrants an essay of my own.

It seems that disability studies sheds insight upon everything. I believe historian Douglas Baynton who said that, "Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write" (2001, p 52). It took no time to find a place in our forum for both music, my discipline, and my secondary affiliation, Jewish Studies. Disaster and disability are focal themes in Jewish history, religion, and culture. Music has always figured prominently in Jewry's self-identity. In particular, attitudes toward music have served as a barometer of Jewry's appraisal of its own well-being. It is exciting for me to have my essay paired with Marcy Epstein's "update" of events in Israel and Palestine, in which she critically examines the discursive politics of disability and disaster as the concepts are strategically deployed by both Israelis and Palestinians in their seemingly, sadly irreconcilable confrontation. The more things change…

It was essential that some of the *Waters* be the deluges left behind by Hurricane Katrina

and the great Southeast/South Asian tsunami. Both are regarded from afar by Laura Hemingway and Mark Priestley, from the distinguished DS program at Britain's University of Leeds. They offer lessons of both theory and praxis. A very different and far more experiential kind of lesson of Katrina comes from Professor Barbara White, a deaf/Deaf social worker from Gallaudet University, who offers a firsthand account of "deaf helping deaf" that is at once riveting and rigorous. When Barile et al part very different and much colder *waters* in their account of the Montreal ice storm, their use of survey methodology combines the best of Hemingway/Priestley and White's scholarly worlds; a large *n* that includes some very moving prose responses to open-ending questions.

One theme that runs continuously if not always explicitly through *Parting the Waters* is that, like disability, disaster is a social construct. In Thomas and Grace Christ's study of protocols for dealing with the grief and recovery of children with learning disabilities who lost parents in the 9/11 tragedy, we are painfully reminded that disasters are sometimes also social destruction. Cataclysms are not always simply the consequence of the collusion of powerful environmental factors and immense human failings, but sometimes sheer, unambiguously calculated and cruel violence visited upon the innocent. Although the HIV/ AIDS crisis in Africa that is the subject of Laura Behling's discourse analysis originated in a virus writ pandemic, like 9/11 and the Middle Eastern events chronicled by Marcy Epstein and myself, there is an element of social agency different from the more overtly ecological disasters that rightly dominate this forum, one Behling interrogates thoroughly.

Finally, two of the essays, Christensen et al, and Ballan and Sormanti, transcend individual events in the interest of developing larger theories of crisis management. They do this in very different ways from one another that obliquely and interestingly parallel the past/present dialogue over Israel between myself and Marcy

Epstein. Through the window of built environments, Christensen and his colleagues review the literature to critique, from a social model perspective, what has been done thus far to accommodate people with disabilities in disaster situations. In an entirely different and equally compelling manner, Ballan and Sormanti assemble a comprehensive set of best practices for meeting the needs of adults with intellectual disabilities. While their work is of the present, it offers the additional gift of directing us to a more humane future. That brighter, more empathetic time is, of course, the pragmatic intent of the entirety of *Parting the Waters*.

Shalom/Salaam/Peace,

Alex Lubet
St. Paul
June 20, 2006

References

Baynton, D. (2001). Disability and the justification of inequality in American history. In P. Longmore & L. Umanski (Eds.), *The new disability history: American perspectives*. New York: New York University Press.

How Can We Sing a Song of the LORD on Alien Soil?: Disability, Disaster, and the Idea of Music in Judaism

Alex Lubet, Ph.D.
University of Minnesota

Abstract: An analysis of Psalm 137, a poetic chronicle of the Babylonian captivity following the destruction of the First Temple, Judaism's paradigm of disaster, is poetically represented through images of music and disability. This Psalm's influence on Jewish attitudes regarding music, which have served as a barometer of the Jewish people's sense of their collective social welfare, is discussed. Of special importance is Abrams' idea, derived from the Deutero-Isaiah, of the Jews, living in exile after the destruction of the Temple, as Israel disabled; an entire people's calamity understood metaphorically as a single individual's impairment. Particular attention is given to the discourse surrounding Late Renaissance Italian Jewish composer Salamone Rossi, who challenged the idea that the "disability" of exile required Jewish musical expression only to mourn the state of post-Temple Diaspora.

Key Words: disaster, music, Judaism

By the Rivers of Babylon

That *Parting the Waters* refers to the divine intervention of disaster rescue in the book of *Exodus* is hardly subtle. (Of course, the divine intervention of the Ten Plagues is, from the Egyptian perspective, an unambiguous narrative of disaster *as* disability). The Israelites' plight of long wandering in *Exodus* presages a recurrent theme of exile and Diaspora in Jewish history that has served as a paradigm for many people's struggles. For Jews, physical and spiritual exile, the exemplar of disaster, is powerfully associated with disability and poetically expressed in musical terms.

Nowhere is Jewry's understanding of the binding of disability and disaster with historical and musical themes more clear than in Psalm 137:1-6:

> By the rivers of Babylon, there we sat,sat and wept,as we thought of Zion. There on the poplars we hung up our lyres, [3]for our tormentors asked us there for songs, our tormentors, for amusement, "Sing us one of the songs of Zion." How can we sing a song of the LORD On alien soil? If I forget you, O Jerusalem, let my right hand wither; let my tongue stick to my palate if I cease to think of you. if I do not keep Jerusalem in memory even at my happiest hour.

This translation is from the Jewish Publication Society (JPS) (Berlin and Brettler, 2004, p. 1435). The familiar "forget its cunning," ("her cunning" in the King James version) which JPS attributes to (earlier) "Others," has been replaced with "wither." "Forget its cunning," exquisitely expresses rabbinic Judaism's attitude toward disability and ability; that cognition, including memory, is primary. Thus even physical skill is characterized as cognitive. Although this image is rich and poetic, JPS no longer considers the translation accurate.

The historical moment chronicled in Psalm 137 is obvious and hugely formative in the Jewish ethos. The Babylonian exile (597-538 BCE)[1] was the first, albeit temporary, involuntary Diaspora, an important psychological foundation for the subsequent transformation of Judaism from its *Torah*/Temple/Priestly to its *Talmud*/Synagogue/rabbinic praxes, in the early Common Era. Notably, the more authoritative of Judaism's two *Talmud* (Oral Law) compilations, from the 5th-7th centuries CE, is the *Bavli*, or "Babylonian."

That exile is regarded as a disaster in Psalm 137 is immediately and utterly apparent. The Judaism of the time – and thus the ethos of the Jewish people – was entirely rooted in Jerusalem's Temple cult and in the landed nation of Israel. Thus the psalmist weeps at the thought of Zion lost. That Zion is "thought of" is a more than casual word choice, as becomes evident later in the text. In exile, cognitive ability is privileged, along with the ability to communicate ones thoughts, as the Jewish asset par excellence. Not so within the ancient land of Israel, where the idealized human type was the physically blemishless "perfect priest" (Abrams, 1998, p. 69), able to withstand the rigors of Temple worship.

The dilemma and danger of the liminality of Judaism in exile per these conflicting systems of idealized human valuation – physical perfection versus cognitive acumen – is posited eloquently in terms of disability in verses 5-6. If the psalmist loses his cognizance -- forgetting Jerusalem -- he invites punishment in the form of physical disability, the loss of right hand skill. Even this corporeal trauma is expressed in cognitive terms; as forgetting the hand's "cunning."

Cognition, though, is only half the story. Deeply communal, Judaism requires not only understanding, but also powers of articulation with which to share it. Failure to recall Jerusalem -- a lapse in cognition -- must also be punished by speech dysfluency, the tongue adhering to the palate – a communication impairment.

There is more here than the psalmist's partnering of physical disability imposed upon the human body with exilic disaster inflicted upon the body politic. The 137 is the only Psalm that chronicles explicitly the Babylonian exile, which sowed the first seeds of the transformation from Temple Judaism, which celebrates place (Israel and the Temple) and idealizes the perfect priestly body, to rabbinic Judaism –which idealizes *Torah* study. Scholarship it seems, then as now, was anything but the province of athletes such as Temple priests.

In *Judaism and Disability: Portrayals in Ancient Texts from the Tanach through the Bavli* (1998, p. 76-78), Rabbi Judith Z. Abrams observes that God's "suffering servant" of Deutero-Isaiah (Isaiah, chapters 40-55) was the creation of an author living in exile in Babylonia. According to Isaiah 52 (Berlin and Brettler, 2004, p. 889-891):

> My servant shall prosper, Be exalted and raised to great heights. He is nonetheless, as Abrams observes (1998, p. 76), "clearly disabled and wounded": Just as the many were appalled at him— So marred was his appearance, unlike that of man, His form beyond human semblance—It gets worse. In verse 53:3 (Berlin and Brettler, 2004, p.891): He was despised, shunned by men, A man of suffering, familiar with disease. As one who hid his face from us,
>
> He was despised, we held him of no account. Isaiah 53:4-5 (Berlin and Brettler, 2004, p.891) explains, though, that the servant suffers on behalf of all Israel: Yet it was our sickness that he was bearing, Our suffering that he endured. We accounted him plagued,
>
> Smitten and afflicted by God; But he was wounded because of our sins, Crushed because of our iniquities He bore the chastisement that made us whole, And by his bruises we were healed. The significance of this prophecy can hardly be underestimated, for either Judaism or disability studies.

According to Abrams (2004, p. 77), the suffering servant might represent either the entire Jewish people or its religiously faithful core-in-exile, but not Israel the state. Rather, "Israel is idealized, either in whole or in part, as a person with disabilities."

This is heady stuff for disability studies and disability pride, though not quite so heady or inclusive as one might wish. Abrams is always clear that in ancient Israel (as everywhere) that until very recent times no single category of "disability" existed. The impaired hero whose praises are sung in Isaiah is auspiciously proposed as a replacement, during Israel's first exile, for the idealized perfect physical specimen, the Temple Priest. But this suffering servant can be accepted as a role model only with certain impairments and not others, those that would not impede his functioning as the new type of ideal:

> "The servant's strengths come from his intellectual and spiritual qualities, not from his physical, ascribed attainments. He is the literary creation of a stateless teacher, trying to define Judaism in exile" (Abrams, 1998, p. 77-78).

> But: "We should also note that the suffering servant is not described as blind, deaf, or mentally disabled. In other words, his ability to learn and teach [the idealized skills of a Diaspora Jew] is unimpaired by his disabilities; he is not debilitated intellectually or spiritually, only physically. These disabilities, and indeed this image as a whole, could naturally be seen as political metaphors, not only moral

ones, for Jewry as a whole, by Jewish readers of later eras. The servant suffers as the faithful of Israel suffer. He is downcast as the exiles are downcast. To be stripped of one's country and one's [Temple] cult is to be disabled" (Abrams, 1998, p. 77).

In modern Israel, only the country and not the cult is restored. The Temple is yet un-re-built. Most who believe in the restoration of the priestly rite believe the Temple may only be resurrected pending a sign from God. Judaism in Israel as elsewhere remains in its rabbinic form; religiously uncompleted, it adherents unhealed. The attributes of the "suffering servant" would become the paradigm for the new, intellectual, Jewish ideal-in-exile, the sage whose status would later be formalized in the rabbinate:

> "He has no role in politics, war, or the cult (McKenzie [1968, p.] lii). Rather it is through his devotion in the face of suffering that he attains his purpose. This description could also fit the situation of the sages after 70 C.E. [following the destruction of the Second Temple], and significantly, they are the ones who will later emphasize the concept he so vividly illustrates – that suffering may replace the atonement previously found in the cult" (Abrams, 1998, p. 78).

We Hung Up Our Lyres

The Psalms are strongly associated with music. '"Psalms" derives from the Greek *psalmos*, a translation of the Hebrew *mizmor*, "A song with the accompaniment of a stringed instrument" (Berlin and Brettler, 2004, p. 1282). Psalm

137 is particularly musical, especially its second verse:

> for our captors asked us there
> for songs, our tormentors, for
> amusement…

The Israelites' storing away their stringed instruments should be taken principally at face value (Berlin and Brettler, 2004, p. 1282). They refused to perform for their captors, particularly their own repertoire: sacred, patriotic, and/or nostalgic. That they not only refuse to sing but also to play is prophetic, applying not only to the destruction of the First Temple, but the Second as well (Shiloah, 1992, p.73). Following the destruction of the Second Temple in 70 CE, in a gesture of mourning, instruments were banned from use in Jewish worship.[2]

Circumspection regarding instruments, particularly though not exclusively in worship, occurs in much of Islam and some Christian denominations. However, the association of instrumental music with well-being, mirrored by extensive restrictions on its use as a gesture of loss is particularly Jewish.

Three of six verses of (the final) Psalm 150 enumerate the instruments of Temple worship:

> Praise Him with blasts of the
> horn; Praise Him with harp
> and lyre. Praise Him with
> timbrel and dance; Praise Him
> with lute and pipe. Praise Him
> with resounding cymbals;
> Praise Him with loud-crashing
> cymbals (Berlin and Brettler,
> 2004, p. 1445-46).

Temple music (of whose actual sound we know little more than scripture provides) and other Temple attributes such as architecture have long served as ideals in Judaism   In the Renaissance, not only the Temple orchestra's impressive instrumentarium and "joyful noise," but also its apparent rhythmic vitality (its per-cussion section of timbrel and cymbals) and possibly its polyphony (five different types of melody instrument) were admired. In Jewish Renaissance Mantua, Italy, where circa 1600 life was somewhat better and less-restricted for Jews than elsewhere in Europe, Biblical Israel and the Temple cult were icons of Humanism for Jews, much as Gentiles cleaved to the glories of Classical Greece and Rome (Harrán, 1999, p. 204).

A controversy ensued among Mantuan Jews regarding the right and duty to emulate the Humanistic musical qualities of exuberance, instrumental color, meter, and counterpoint, aesthetic foundations of secular and sacred Gentile Renaissance art music. The debate focused on the innovative sacred music of Mantuan Jewish composer Salamone Rossi (ca. 1570-ca. 1630). This question engaged many Jewish intellectuals, including six rabbis who contributed to the prefaces to the premiere publication of Rossi's *Songs of Solomon* (1622-23), the first publication of Hebrew texts set to polyphonic music (Harrán, 1999, p 201). The rabbinical apologetics were largely a response to critics (Harrán, 1999, p. 201-218). Difference of opinion and praxis remains ongoing, largely regarding instruments, among and within the various movements in Judaism.

Whether Jews must still musically mourn ancient disasters (arguably at least partially mended by Israeli independence in 1948) remains divisive. And, recalling Abrams, despite restoration of the Jewish state, the sense of incompletion accompanying the unrebuilt Temple is still regarded as a collective disability.

From a disability perspective, rabbinic Judaism's idealization of cognitive and expressive gifts seems progressive, at least in its considerable acceptance of physical disability. Although the "suffering servant" of Isaiah, as Abrams notes, could not have fulfilled his role had he sensory or cognitive impairments, Judaism has always been relatively empathetic to blindness as well. For example, the Talmudic sage Rav Yosef was

blind (Abrams, 1998, p. 193-96). And Judaism, unlike ancient Greek and Roman culture, always forbade infanticide (Abrams, 1998, p. 119-122). Where ancient Judaism seems least enlightened by contemporary standards is, not surprisingly, in regards to cognitive and communication impairments, a category in which Jewry included deafness (Abrams, 1998, p. 168-190).

Let My Tongue Stick to My Palate

If Psalm 137:2 lays precedent for Judaism's proscriptions upon instrumental music, is captive Israel's refusal also to sing for its oppressors similarly prophetic? Jewish sacred music, especially of the synagogue and the Sabbath, is mostly, in most congregations exclusively, what Western typology calls "singing." But Western definitions of music and singing are currently so prevalent even beyond the West that it may be difficult even to imagine alternative taxonomies.

Many cultures have traditionally lacked an overarching category of "music." Others have distinguished music from "singing." Clearly, Judaism treats instrumental music as a highly distinct category, for handling or eschewing with care. The often simple cantillation of sacred text prevalent in worship in Rossi's Italy and, it would seem, dominant throughout most of the rabbinic period, has at times been regarded as distinct from music (Harrán, 1999, p. 204) or at least exempt from the condemnation of all other musics by some ultra-Orthodox commentators, who argue that perpetual mourning is mandated by the Second Temple's destruction (Shiloah, 1992, p. 73-80).

Rossi's sacred choral works were highly innovative, the first clear, extant exceptions among a repertoire otherwise comprised (almost?) exclusively of cantillation, the latter arguably a liminal category between music and declamation. In Rossi's time, the answer to the psalmist's, "How can we sing a song of the LORD on alien soil?" was, "We couldn't, we can only chant," but for Rossi. Notably, though his *Songs of Solomon*

embodied of Jewish Renaissance musical Humanism -- rhythmic, polyphonic, and joyous -- they were nonetheless a cappella, still honoring Jewry's strictest exilic musical prohibition.

Strikingly, one of the two laments among the 33 *Songs of Solomon* is Psalm 137. Ironically, given Rossi's Humanism, the Mantua ghetto, less oppressive than most of its time, was sacked, its residents expelled in 1630, likely around the time of Rossi's death (Harrán, 1999, p. 12). By virtue of his musicianship privileged for a Jew, exempt from wearing the yellow badge (Harrán, 1999, p. 25-26), and an optimistic musical advocate for the potentials of Diaspora life, Rossi appears likely nonetheless to have perished in a pogrom, one of many reprises of the Babylonian captivity, Jewry's paradigm of disaster.

Returning to Psalm 137 and to disability, the psalmist's refusal to sing is not a choice, but something that *can't* be done, lest "my tongue stick to my palate." Neither is playing the lyre possible, lest "my right hand lose its cunning." Verse 2's musical "work stoppages" are paired respectively with impairments that impede instrumental and vocal performance in verse 3, a subtle poetic expression of Israel's self-perceived disability.

Rendsberg and Rendsberg (1993, p. 399) (who attribute the above poetic analysis to medieval rabbi David Qimhi), diagnose both these hand and speech impairments as symptoms of "a stroke, localized in the left side of the brain" (1993, 386). They prefer the translation "become paralyzed" to "forget its cunning" or "wither" (1993, 386).[3] The Rendsbergs (1993, p. 388-390) show that strokes were both known and survived in the Ancient Near East, observing that: "Quite clearly, the ancient Jewish poet utilized the stroke victim to evoke the emotional ties of exilic Israel to its capital city."

Quoting R. Westbrook (1990, p. 577), they observe that if a point "is to be explained by a metaphor drawing upon the everyday life of the audience, then that metaphor, to be effective,

must reflect accurately the reality known to the audience."

Stroke, as now, appears to have worried the psalmist's audience. Baynton's observation that "disability is everywhere in history…" also applies to Judaism.

I would propose that – metaphorically, at least – the history of the place of music in Judaism carries an implicit endorsement of the social model of disability. Among the musical qualities defended in the rabbinic apologetics prefacing the debut publication of Rossi's *Songs of Solomon* was their joyousness (Harrán, 1999), an emotion some among Jewry disdain. Psalm 137 is the most ancient source cited by scholars for the need to mourn without music (Shiloah: 73). The anonymous ultra-Orthodox Israeli author of *El gil ka'ammin* ("Rejoice not, O Israel… as other people," Hosea 9:1) (1999) declares that:

> "When the Temple was destroyed it was decreed not to play any instrument of music or sing any songs and all who sing songs are forbidden to be joyful and it is forbidden to let them be heard because of the destruction…" (1969, quoted in Shiloah,1992, p. 74). [Cantillation is exempt from this decree, even among adherents of this view].

Implicit in this plaint is that perpetual despair is the only appropriate, dignified response to exilic disaster – Jewry's collective disability – until the "cure" of the World to Come; the Messianic Age, when the Temple and its cult are resurrected. Rossi and his defenders proposed instead that a joyous life – despite the disability of exile and with no reasonable expectation of its "cure" at hand -- is nonetheless attainable through such acts as music making. In the prefaces to the *Songs of Solomon*, Rossi's leading advocate, cantor Leon Modena, charged those who would sing these works to:

> "… Give honour to the Lord and glorify the place of His Lesser Sanctuary [the synagogue] and the festivities of His commandments by singing them [the 'Songs'] each in its proper time [many being occasional works]" (Harrán, 1999, p. 213).

Thus life's purposes are to be fulfilled in "His Lesser Sanctuary," despite lacking the Greater Sanctuary of the Temple. Rossi et al. were declaring symbolically and sonically not just the possibility of having a full and joyous life in a disabled, exilic body, but the supremely ordained Jewish duty – the Commandment – to do so.

Music has long loomed large in Judaism's ongoing "culture war" over the appropriate countenance for Temple-less times. At a unique moment in Jewish music history, Rossi and his allies made extensive, eloquent pleas for a "social model of Diaspora," rejecting stateless exile – Jewry's paradigmatic disaster -- as a pathology requiring a Messianic "cure." But they were neither unique in this stance, nor in stressing music's vital spiritual role. For Hasidic Jews, the Lubavitcher sect in particular:

> "[Music is] one of the most powerful forms of human expression, it is a part of prayer, celebration, and teaching. Music and its performance have the potential to elevate the soul, inspire a student, open up the gates of joy" (Koskoff, 2001, p. 72).

Rossi and the Lubavitchers, though united in their esteem for music, differ markedly with regard to musical style. Rossi answered the question of how to sing the Lord's song in a strange land in the style of the art music of the late Italian Renaissance, by absorbing local culture and eschewing Jewish cantillation altogether. In contrast, the nigunim, the archetypal and dis-

tinctive Lubavitcher musical genre (while hardly devoid of non-Jewish influence) is certainly stylistically Jewish (Koskoff, 2001). Lubavitchers, unlike Rossi, are circumspect about what they see as the seductive power of classical music (Koskoff 2001, p. 156-159).

Thus, post-Temple exile – which has disabled Israel as a people – is accommodated through rabbinic Judaism and its Lesser Sanctuary the synagogue. Both Rossi and his allies and those influenced by Hasidism have regarded music as among Diaspora's most potent accommodations.

And It Was So

If this essay seems a strange greeting for this forum, its aims ultimately transcend its esoteric subject. My first goal has been to provide a case study that shows that the disability and disaster motifs of Psalm 137 are as timeless as any themes we have available.

My second purpose has been to exemplify how disaster, like disability, is socially constructed. As a nation and a people, Israel has endured much that is universally understood as tragic, much of it as manifestations of exile. But Jewry's collective and long-standing – if much renegotiated – reactive grief has been a social response, sometimes blessedly aestheticized in musical and literary imagination.

Finally, I note how our forum's seemingly dual themes of disability and disaster might be read as one. Much of Jewry's self-perception is as a nation and people whose archetypal, ethos-forming disasters of Temples destroyed and subsequent exile rendered its body politic disabled. While massive devastation and individual impairment are events experienced, disaster and disability are their respective social constructions; related to each other as culturally significant articulations of loss, though vastly different in scale. If this is convincing and helpful, then we have begun this auspicious forum well. In the word of the psalmist, "Hallelujah!"

Alex Lubet, Ph.D., is Morse Alumni and Graduate & Professional Distinguished Teaching Professor of Music, a member of the Center for Jewish Studies, and Adjunct Professor of American Studies at the University of Minnesota. He teaches music composition and popular culture. A composer and performer, his research in disability studies focuses on musicians as cultural workers, as students, and as media images, especially in film.

Endnotes

[1] Editor's Note: "BCE" stands for "Before the Common Era (CE)" which is the equivalent of "BC." "CE," or "Common Era," is the equivalent of "AD."

[2] The ban on the use of instruments applies primarily to the Sabbath and its devotions, although much of Jewry excludes them from worship more extensively. This restriction ended in Reform Judaism in the early 19th century and later in some Conservative congregation, but remains prevalent. Amnon Shiloah (74) reports that some ultra-Orthodox Israeli Jews eschew instruments entirely, including radios, phonographs and tape machines.

[3] Berlin and Brettler's *The Jewish Study Bible*, based on the JPS translation used here, also accepts "become paralyzed" as an alternative.

References

Abrams, J. (1998). *Judaism and disability: Portrayals in ancient texts from the Tanach through the Bavli*. Washington: Gallaudet University Press.

Berlin, A., & Brettler, Z. (Eds.). (2004). *The Jewish Study Bible*. New York: Oxford University Press.

El Gil Ka'ammim. (1969). Jerusalem.

Harrán, D. (1999). *Salamone Rossi: Jewish musician in late renaissance Mantua*. Oxford: Oxford University Press.

Koskoff, E. (2001). *Music in Lubavitcher life*. Urbana: University of Illinois Press.

McKenzie, J. (1968). Second Isaiah. *The Anchor Bible*. New York: Doubleday.

Rendsburg, G., & Rendsburg, S. (1993). Physiological and philological notes to Psalm 137. *The Jewish Quarterly Review, LXXXIII*, (3-4), 385-399.

Shiloah, A. (1992). *Jewish musical traditions*. Detroit: Wayne State University Press.

Westbrook, R. (1990). Adultery in ancient Near Eastern law. *Revue Biblique*, *97*, 542-580.

Esau's Mission, or Trauma as Propaganda: Disability after the Intifada

Marcy Epstein
University of Michigan

Abstract: Israelis and Palestinians, while sharing an I/Abrahamic root, many chapters of Semitic history, and common values of resourcefulness and valor, both have defended their cultural boundaries through the exchange of mutilating, annihilative blows upon the other. The *intifada* (an Arabic word meaning to shake off or shiver because of illness, fear, or weakness) of the millennium signify a trope of body and status among the fragmented population in the region; specifically, the propagandizing of traumatic events that suggest victimization and invalidation. The discursive nature of "unnatural" catastrophe— devastation of Palestinian communities by Israeli Defense Forces, blitzing of Israeli civilians in planned attacks— substitutes the propaganda of trauma for the reality of disability experienced in both cultures. Reflecting the duality of rhetorical positions seen in I/Abraham's disposition of both Isaac and Esau, this essay links the root of trauma propaganda to the ideology of religious fitness and righteousness.

Key Words: trauma, Intifada, Biblical sources

> "Is it really necessary that the lives of two nations living together in one place depend on the solely political concepts of majority and minority? Has not the time come to try to put the concept in different terms? And isn't it possible that this particular location and our particular situation may be just the circumstances in which to begin trying? True, it is very difficult, very, very difficult; it demands tremendous daring, and in order to accomplish it

courageous and independent thinking is required, capable of formulating a new means to achieve new goals. But whoever knows our situation thoroughly, knows that we have no other choice; only here, if anywhere lies the true path--all other paths are deceptive."

Martin Buber, "We Must Grant Arabs Truly Equal Rights" (1962)

"Group feeling results only from blood relationship or something corresponding to it. . . One feels shame when one's relatives are treated unjustly or attacked."

Ibn Khaldun, Chapter 8 of the Muqaddimah (1377)

Islamists use a curious word, *missions*, to divide our pasts into eras, of which Muhammad is the ultimate messenger. This essay begins by describing closely part of one particular mission corresponding to the second half of the Hebraic *Bereshit* (Genesis), although it is not intended to transmit the Holy Qu'ran nor provide an authoritative *midrash* (exposition) of chapter and verse. Rather, I intend to examine a third, hard-wound thread—an early representation of what it means to be *disabled*—that is woven more and more visibly into two mutually referential "missions" colliding now between Israel and Palestine. The missionary elements comprising A/Ibraham's[1] time to Joseph's—where the religious clans of Isaac and Ishmael were sent to settle, how they became two peoples in relation to one land, the nature of the rupture-- provides a remarkable view into subconscious messages brought forward to modern times in the Middle East. The mission of sacred text and modern geo-politics combine vis a vis the traditional disability social construct of advantage and disadvantage. This social construct may be first seen in the relationship of Esau and Jacob, next in

the ensuing construction of related people with varying religious ideologies, and more recently in the destruction of modern "religious" states.

Even more, ingrained in both versions of the mission are the precursors of *intifada* well before the term energized us on the evening news. The Intifada (of recent history, based on an Arabic word meaning to shake off or shiver because of illness, fear, or weakness) spur an important trope of body and status that both major populations in the region (for there other populations in addition to Jews and Arabs) communicate to each other and to an international audience. This *intifada*[2] is seen most in the aural and visual images projected by Western and Eastern media in order to raise awareness, and perhaps outrage, over the subjection of the weak. Most often, these are traumatic images of people's bodies in various states of physical harm. Although the media does not call this the creation of disability among Israelis or Palestinians, disabled people are created from within the promise of nationalist gain; thus physical and emotional disabilities are expressed in the language of politics and religion.

Metaphorically and socio-politically, people with disabilities are rising up with their depiction, their identities as "disadvantaged" in an "advantaged" society shaken off as the destruction of people on both sides of the conflict grows more disastrous. Within this traumatic conflict this "third" people is born of the children of Ishmael and Isaac, born from the same post-Biblical mission. Their identities are forcibly created and shifted by the undercurrent discourses of righteousness and catastrophe both Israeli and Palestinian governments transmit to the public. Created and empowered in this process, people with disabilities from both Islamic and Jewish states have arrived transfiguratively in the Promised Land, even while they may have lived there their whole lives. This *intifada* is separated but intrinsically related to the more famous one. Additionally, a wide range of Jewish-Arab conflict propagandists, independent and bureau-

cratic, sanctioned and unsanctioned, guide the representation of disability in order to advance an entirely different dimension of civil rights. The experiences of people disabled in holy war may thus be distorted into the master construct of the political Intifada, their words and bodies used as propaganda. However, their presence on both sides of the conflict speaks to the establishment of new "peoples with disabilities" worthy of examination.

The Canaanite Equation: Disability and Displacement

> "Stranger on the bank, like the river . . . tied up to your name by water. Nothing will bring me back from my free distance to my palm tree: not peace nor war. Nothing will inscribe me in the Book of Testaments. . . And what are we to do, then? What are we to do without exile?" (Mahmoud Darwish, "The Bed of the Stranger," 1999).

In lore, A/Ibraham blesses and charges his daughter-in-law Rebecca to deliver the peoples of the ancient Middle East. In the holy Torah, she is told by her god, "Two nations are in your womb, two separate peoples shall issue from your body. One people will be mightier than the other, And the older shall serve the younger" (Gen. 25:23).[3] Like his uncle Ishmael, a latter patriarch of Muslims whom Isaac replaces in the birthright of the Judeans, Esau is born first to Rebecca but loses his position in the familial order.[4] Esau is described as more aggressive, like his mother, Jacob more passive, like his father. Esau is born freakishly mature and strong, with hair all over his body; Rebecca overprotects his underdeveloped twin, nicknaming Jacob "Tam," for "simple." In a community where strength means survival and weakness means non-viability and mortality, the contrast between infants is apparent. Their physical difference—strong

and weak, hairy and slippery, punching out of the womb or clinging on to the stronger's heel—connects their relative abilities and disabilities—Esau mightier, Jacob meeker—to their places in the social order.

That the meek inherit the earth proves to be both true and an overstatement. Certainly Jacob's mild disabilities and disposition shield and define him. Esau grows into a man who conquers the outdoors; Jacob stays close to his own clan of matriarchs, eats carefully, and limits his activity. Perhaps most obvious in their mutual dislike, the sons together form one truly viable entity. They resent the other as their own lack. American rabbi Moshe Reiss (1961) wonders at the crossroads of generation and geography, if Isaac (the father and brother to Ishmael) hoped that giving his birthright to Esau would be a *tikkun*, a "corrective experience to rewrite his own history," Isaac's own passivity when he lay beneath A/Ibrahim's sacrificial knife. But events conspire against Issac's *intifadic* intent to correct both his passivity and his father's expulsion of Ishmael. One evening Jacob manipulates a famished Esau into trading his legal standing for a bowl of cooked lentils. Next he positions himself as Esau before the decrepit Isaac. Finally Jacob extracts the covenant father gives to son: "Be master of your brothers," and be protected from those who would attack him. When all seems lost for the son whom Isaac truly admires, he manages to bless Esau inversely with words binding Esau to Ishmael, "Serve your brother, but when you gain your freedom, break his yoke from your neck" (Gen. 27:40). Jacob herds sheep, gathers wives, makes more Jews. Esau's end is *untold*. We return to his "mission," his *intifadah*, later.

While Reiss views this consecration as the pre-figuration of the Jews and Rome, the tighter explication may be that Esau's path in life, beginning with a plot to kill his brother, intertwines with the unfinished business of disinherited and privileged sons in Canaan. And rather than prefigure the religious conflict of unrelated clans,

this pre-Koranic picture is arguably linked to the split generations of Ishmael and Esau, Isaac and Jacob. Not just child birthright seals this ancient dispute, but also marriage. Esau returns to Ishmael to marry his first cousin, granddaughter of A/Ibraham. Without birthright, Esau still exerts his domination among the laws of nature and heredity, for Esau most intensively carries the Canaanic line. Palestinians and Israelis are kin. The inversion remains, too: Those who lost their rights are the ones with natural law behind them, strength and birth order. Despite their abilities, Esau's descendants are disadvantaged. And despite his disability and disadvantage, Jacob's descendants are given advantage, an advantage borne from subversion of natural law in favor of religious certainties like blessings, legal birthrights, and subversive "chosenness."

In the Hebrew Bible, the two brothers forgive each other and share the riches of the region, both blessed by the divine in their own ways. This ideal assumes the true reckoning of advantages by both natural and religious affirmation. In the Qu'ran, Esau and Rebecca, including the description of his natural domination, are absorbed into Ibrahim (A/Ibraham), Ishmael, and Elisha's establishment of a second people, to whom the last Prophet Muhammed and other believers trace themselves. Around Esau in the Qu'ran there is exegetical *silence*, certainly no reconciliation scenario. The *tikkun* of Hebraic lore is replaced by a purposeful, abstractly faithful mediation that Allah strands his people so that they must assert their beliefs through corrective action (Qu'ran, trans. 1997): "We never sent a messenger, save with the language of his folk, that he might (make the message) clear for them. Then Allah sendeth whom He will astray, and guideth whom He will."[5] This teaching of Islam (surrender to belief and struggle with those who impose stories of disbelief) reformulates the entire thread of Genesis and Israel, so that the outsider becomes the correction to the correction. To the point, those who are in the fertile lands with their "disbeliefs" and their "advantages" should be put out, while the Islamists

who endure banishment are those who will ultimately inherit the earth. This becomes the greater mission of Muhammed. Now A/Ibraham thanks Allah for both sons (Sûr. XIV, v. 39) but foresees—as does the patriarch of each following generation—that familial, geo-political, and religious order will clash.

That the religious and geo-political bodies of modern Israel and Palestine are in a similar mortal combat few people would disagree. Dual narratives fuel dueling states. The religious discourse contained and passionately construed as "birthright" trumps all other methods of delineation between the descendant clans of A/Ibraham. Semites or disabled, birthright translates into civil freedom and belonging, the ability to determine ones destiny despite another's advantage. When birthrights clash—and this is basically the case in the region and in the cultural logic about people with disabilities who live there—the effects are profound, indeed bloody, rhetorical, and enduring. Complicated further by the relatively recent near-extermination of the Jews in the first half of the twentieth century, the warrior and the spiritualist clans are now figured in *jihad* (holy war) and *eretz yisrael* (the instating of the children of Israel) for what is possibly the longest disaster (and possibly the longest genocides) in history.

Contest of the Fittest

Israelis and Palestinians, while sharing an A/Ibrahamic root, many chapters of Semitic history, and common resourcefulness and dedication, clash over cultural and geo-political boundaries through the exchange of mutilating, annihilative blows upon the other. Including executions and bombers, over three thousand Palestinians have been killed in the latest phase of conflict (Palestinianmonitor.org, n.d). Since September 2000, Israel has suffered as the result of more than 40 suicide bombings, 500 mortalities, and 4,000 casualties, including army infiltrators (Meforum.org, n.d.). What goes less noticed in such warfare of ideology and difference is the

reading of disability in the "contest of the fittest" between natural and religious right. Most readers of this journal are familiar with the physical events occurring in both civilian communities, although we are coming to associate these disabling characteristics with conflicts in Baghdad or Darfur. People are being maimed, disfigured, dismembered, and broken down quickly and slowly, from live ammunition, shelling, explosions, and reactive conditions like heart attack or stroke.

As Arabs and Jews struggle to resolve the trope of disability that resonates in geo-political advantages and disadvantages over the land, the more they contest, the more people with disabilities are created and the more intertwined their warfare and welfare become. The Israeli army positions itself as the arbiter of Palestinian sovereignty, perceiving themselves defensive victims of past incursions into their country. Frequent bombings in Israeli cities and towns generate powerful sympathy for this position, including the citizens of all nationalities who are being hurt. Palestinians who live within Israeli territories, injured or not, are particularly vulnerable in the staging of this conflict, since their state disability benefits are limited and based on the determination that they cannot be linked, at any level writes *The Arabic News* (1997), to "combatant activity."[6] In Palestinian society, which had long cast disability as a type of shame, the retaliation of the Israeli army against men and boys throwing stones added the consequence of disability to a long list of civil rights infractions. Negative perceptions of physical disability began to change with the Intifadas, starting with a mass uprising in 1987 and reoccurring every few years, continuing to change with new waves of resistance. Kozue Nagata, an Economic Affairs Officer for the United Nations Economic and Social Commission, explains: "The issue of disability became an important political agenda all of a sudden" (2003).

Specifically the propagandizing of traumatic events suggests vulnerability and invalidation.

Palestinians have been expelled from their homes and farms by imminent domain practices of the Jewish State, sometimes violently so by bulldozing, military evacuation, and refugee internment in several camps along the territorial border. Israeli civilians have been attacked regularly both within occupied territories and the areas given to them by the British Mandate. The resistance efforts on both sides make for excellent journalistic fodder. Internet, television, radio, and print media of all party persuasions spare us nothing: People's bodies splayed on bloodied gurneys say enough for most spectators. The body disabled through war trauma appears more final, more mortal, than any political organization could provide an answer for. Therefore, this image of disability is a genius stroke for social manipulators, since it resonates to any number of issues related to human vulnerability.[7] Because they can be judged by readers both East and West, each state's public relations bureau may spin at least two contesting messages from the relentless "traumatization" of the clash. First, how unfair it is to harm and disable people who are trying to live in their homeland, and second, how the disability, harm, and death of civilians make right additional action. Like all wars, the destruction of people's bodies is "unnatural," human-made, not a "natural" disaster like tsunamis, droughts, or hurricanes. The recursive nature of "unnatural" catastrophe—devastation of Palestinian communities by Israeli Defense Forces, blitzing of Israeli civilians in planned attacks— roils propaganda of trauma for the reality of disability experienced in both cultures.

'In the Steel Trap': Trauma Propaganda

"Alas, alas! If only you could remain the child, the human being! But I shudder, and live in dread That you may grow up inside the trap, In this time with amputated legs, clad in khaki, In cruel death, in smoke and sorrow. I fear, my child,

that the human in you may
be smothered" (Fadwa Tuqan,
"Eytan in the Steel Trap").

"Trauma" (wounding) itself provokes two natural responses, defense and offense. The declaration of trauma tells us that people are wounded and thus are more vulnerable, perhaps why Israeli agencies document each bombing incident with sober, non-incendiary fashion. To declare trauma and to document each incident with zeal, piety, injustice, and righteousness serves the second response to wounding. The more people are shown decrying the invalid, the more people with disabilities may be linked with the invalidation of the greater State. Demonstrated there is the rhetoric of trauma and disability that interweaves itself in the region's contemporary conflict. Such is the case with many Palestinian reports and websites, as will be shown later.

In the sense that media coverage migrates toward public interest in the physical and emotional aftermath of regional conflict, the propagandizing of trauma in images of disability may be used for political ends. It may even fuel the war between peoples as long as people are outraged over messages in disability about vulnerability and invalidation without evaluating the rhetoric behind them. Another curious use of this current "mission" rides on the energy being put into the new visibility and accommodation of disabled people in both Israel and Palestine. In Israel, the ethos of disability discrimination and institutionalization of people with disabilities is being edged out by this visibility. Shekel, Alut, Enoch, Shalva, TASH, and other disability organizations are networked more closely with Bizchut, Israel's Human Rights Center for People with Disabilities (2002). Within two years of the establishment of Palestine in its latest form of statehood under Yasser Arafat and his proponents, reports the Hasbra Commission, the "Israeli ADA" that Bizchut advocated had its first chapter passed: "The Equal Rights for People with Disabilities Law of 1998 **.**" Oren Ganor,

a spokesperson for Bizchut, the region's center for human rights for people with disabilities, intended for the law to enforce the modification of all public buildings with full accessibility and to open up public transportation by March, 2005.

Trauma propaganda about disabled people is trading in more diverse cultural currencies than it first intended. Bizchut now maintains a civil rights hotline and a legal department to address the rights of people with disabilities, regardless of ethnicity or nationality. They serve in both Arabic and Hebrew. Their one limitation is that they specify "Israeli veterans." But the factual increase of people with disabilities (600,000, of whom 142,000 qualify for state assistance, according to an Australian on-line access clearinghouse in 1992) on both sides of the Canaanic equation transmogrifies into an increase in call for accommodations by people disabled through *jihad* or defense of *eretz yisrael*, i.e., in the "heroization" of the weak. While just six percent of this figure suffered serious wounds[8] as a result of serving in security forces, these disabled men and women are featured prominently as Israel's pride in its service-people, and receive cars, education subsidy, and medical treatments that support independent living. In its article, "Disability Inequality in Israel," the Access Foundation interviewed Sammy Smooha, a sociologist in Haifa: "Being 'war-wounded' is the best deal for a disabled person." Yoav Kraiem, a young disability activist, rejoins that veterans should be supported by a culture that so desperately needs their warriors, but his point is disputed within the disability community.

Ilan Ghilon, who is a lawmaker, is left wing, and also has a disability, underscores the link between Israel's propagandizing of disabled veterans and its relative cruelty to civilian people with disabilities: "[No matter which disability and how it is sustained] it's time we stop making this distinction between the 'hero' and the 'weak'." Once soldiers with disabilities leave the Arab-Jewish limelight, their disabilities assume a dif-

ferent somatic hue. Recalling Esau, one soldier paralyzed in 1973 explained that his visibility as "rugged" and "pioneering" for Israeli autonomy evaporated once time passed and he no longer bore immediate association with traumatic conflict. He reported to the Access Foundation that his injury had later "depersonalized him in the eyes of his countrymen." Here is the crux of the Esau-Jacob polarity, the valorization of disabled warriors or wounded civilians and the simultaneous invalidation of those thought meek.

'In a Steel Trap': Warring and Disability

Public visibility of people with disabilities is growing amidst a market for such imagery, a market now wearied with the propagandistic echoes of war trauma. Disability policy and education in both territories now must take advantage of the caché of disadvantage when "disadvantage" musters such deep awe in the region. Some pick up on this "mission." Kraiem and two dozen other activists with disabilities camped out at the Labor and Welfare ministry in 2002, with Reuters reporting that the group ventured into busy traffic and grappled with police in front of the Knesset, Israel's Parliament (Access Foundation, 2002). Protesters are demanding minimum wage for government stipends for people with disability (currently the stipend is a little more than half that), as well as transportation and nursing subsidies. Representatives of Parliament responded that the Palestinian uprising was so costly that such terms could not be met. The discourse around trauma is being taken up appropriately by disability activists. "More than political display," Kraiem argued that the "dignity of all of Israel's 'weak'" lay in advocacy by people with disabilities.

Jewish and Islamic traditions of caring for people with wounds, mutilations, paralysis, and other physical disabilities vary slightly; the propaganda of each nation thus varies in the formulation of trauma as the war's "terror scale" or the "wounds of innocents." Since disability has

become a litmus test for the humanity of their cultures, both Israel and Palestine are forwarding civil rights and services for people with disabilities as their economies allow. Meira Weiss (2002), in her book, *The Chosen Body: The Politics of the Body in Israeli Society*, suggests that gender and disability together describe the sociology of Israeli perspective, a "hybrid society" that must deal with a range of contradictory and distorted body images. Childhood disability, army injury, and soldier death figure into an iconography of Zionist "restoration" of a culture unified, secular and religious, by its army.

Sander Gilman (2004), in his review of Weiss, provided the crucial context for reading propagandized bodies in Israel specifically He reflected that people who get their disabilities from war have more visible bodies, presumably for the international media to reflect, yet face the same cultural obstacles as their counterparts born with disabilities: "The warrior's body is sacrosanct. Disability trumps the warrior's body in contemporary Israeli society." The Qu'ran advises Palestinian Muslims to forbid the "feeble-minded" and other disabled people direct use of their own wealth Ethically and legally they are expected to absorb this wealth and clothe and feed people with disabilities (Sûr. IV, v. 5). Very similar attitudes may be found in Jewish Scripture (Abrams, 1998).[9] Sadly, neither Israel nor Palestine treats people with congenital disabilities much beyond patronage or medical rehabilitation, still regularly abandoning disabled children and institutionalizing adults. In Israel, the image of disability and the treatment of people with disabilities are just coming into any alignment. The natural state of people with disabilities is beginning to modify the propagandized message about a society wounding itself by perpetual conflict.

Nonetheless, mutual characterization of Israel and Palestine exposes the enemy as a wholly dehumanizing and disabling force, the face of which is shifting too rapidly for this writer to depict in relation to disability development or

history. As I began to write this essay in December, 2005, the group Hamas called for all factions to renew the attacks against Israel that had begun in 1987 and again in 1997 for the reason that the "Zionist occupier" had continued to destroy Palestine (Palestine Information Center, 2005). National Public Radio reported that Hamas and Fatah, Palestine's *in situ* and *ex officio* parties, are bombing each other (June 1, 2006). In Palestine, millions of dollars were funneled into rehabilitation centers for Palestinians, but these were designed as triage for Intifada-injured, permanent disabilities coming from stone and gun fire, like spinal cord injuries, amputations, and loss of eyes. According to Palestinian Ph.D. student George Malki, the majority of disabled Palestinians were "eclipsed" in treatment by this minority of disabled martyrs, in part, he claims, because non-government organizations (NGOs) control them. Thus, the NGOs, explains Malki (1997), serve some of the "unreachable" but mainly attend to the martyrs whose images reflect political ends. Little cooperation exists between the NGOs about disability and the Palestinian National Authority, but community-based rehabilitation was introduced by local health workers, and in 1990, a central National Committee of Rehabilitation was formed. The political dynamic within each culture may vary slightly, but the connections and disconnections among ideological governments, holy values, and actual populations of people with disabilities reveal nearly identical problems. Trauma elicits more politics than accommodations. It is left to disability communities to assert their own "mission" within a highly complicated poli-speak. People within these disability communities must identify their own beliefs both in contrast and in relation to their greater geo-political situations.

Disability in the Aftermath of Catastrophe

Left in the background of media representation, traumatized Israelis and Palestinians with disabilities struggle for civil rights, basic services,

and reparations. Their disabilities are physical, psychiatric, and emotional. And because of the visibility of disability civil rights now, links between propaganda and trauma are also growing more apparent. According to the National Committee of Rehabilitation's (NCR) guidelines, for example, 3-4% of Palestinians have disabilities, approximately 60,000-80,000 persons, of these, a majority need rehabilitation. The international webzine *Disability World* extended this coverage with Nawaf Kabbara's 2003 report on the Beirut disability and violence conference, which stated that over 4000 Palestinians had been injured since the 2000 Intifada.[10] When NCR sources emphatically blame the Israeli Army violence for disability, it declares that its response will not be retaliation but the healing of itself. In a promising action that demonstrates sovereignty, Palestine will accommodate its disabled population by shifting their rehabilitative emphasis to the social integration of people with disabilities through community-based interventions (Abdeen et al., 1994). In the last fifteen years, the NCR has funded many studies that report about the concerns of people with disabilities within the eight districts of the West Bank and Gaza Strip.

The reports appear consistent in their claims that intellectual disability highly correlates with poverty, that more men than women are disabled, that a great majority report serious rather than mild disabilities, and that most report Israeli army violence alongside their general disability demographic. An author known as "K.V." (1992) directly assesses the effect of Palestinian rehabilitation for the Intifada. He or she finds that despite rehabilitation programs, the 131 people with disabilities interviewed had not successfully achieved social integration, a finding that parallels the experience of Israeli soldiers with disabilities once the political gaze of the world has moved on. The actual number of Intifada injuries does not surface in these reports.

Figuratively speaking, the Qu'ran's silence on Esau's response to Jacob allows the bifurcation of mission, since his outcome has in part to do with how he lives in relation to his privileged brother, and in part with how he comes to resolution in his own lifetime. Both trajectories offer an understanding of disability via advantage and disadvantage useful to the conflict between Israel and Palestine and for its combined, sizable, and growing population of people with disabilities. This understanding of disability may be instantly folded back into rhetoric, for the numbers of the hurt and disabled do surface with alacrity on websites serving the political arm of Palestine and critics of Israeli policy in the region. The Palestinian National Information Centre of the Palestinian National Authority claims that the number of disabled in both the West Bank and Gaza Strip reached 29,849 and 16,214 respectively. On the Israeli far left, too, the criticism takes on an aggressive tone of resistance. The website Refusingtokill.net features Ethan Rabin's depiction, via passionate account, of "severe mental crises" like "real time bombs." One hundred discharged soldiers report this pseudo-psychiatric condition which sound more like attacks of conscientious objection. Using the propaganda style of infomantics, Rabin links their guilt and self-disgust over killing and mutilating with being drug addicts, depressives, and mental patients, one of whom breaks down shouting "Muhammed, Muhammed, Muhammed." The author expounds, "The Intifada had finished him."

Yet as we come away from the propaganda-for-war tactics in Palestine and the traumatic aftermath of each bombing in Israel dissipates for the outsider, it is important to note that each nation, by taking advantage of their disabled minorities, are also for the first time really giving people with disabilities a place and a voice. The Palestinian Red Crescent Society has begun to amass statistics of Intifada-injured families and is now providing psycho-social support, physical therapy, and learning therapies within poorer refugee areas. Of particular interest is M.O. Salem's, *Stigma and the Origin of Disability: The Case of the Palestinians*, a Master's thesis that advances disability as a social construct. Salem (1990) observes that the "Intifada-disabled" have "honorific disabilities" because of their steadfastness and symbolism for collective resistance. Salem contextualizes the ancient struggles between Jews and Arabs in the Middle East in terms of the honorific-disabled from cultures such as those of Eritrea, South Africa, or Nicaragua. As though shifting the axis of analysis from A/Ibrahim's familial metaphor, Salem attempts the longitudinal analysis of disability over a period of time in relation to political wars on the global stage. For example, Salem points our understanding of Intifada disabilities toward the "different adoptive measures used by the individual and society in accommodating a new physical state." He views disabilities as the function of "momentary political violence." This analysis is similar to Thomas Couser's (2005) third paradigm of disability in *Paradigm's Cost: Representing Vulnerable Subjects*, in which the author attributes a positive shift in definition to disability activists and scholars in the United States and United Kingdom since 1990. Couser's basic idea grows more ample when applied to the understanding of disability after Intifada. Disability is constructed synchronically, from culture to culture, and diachronically, over time. We are watching a fascinating "mission" unfold, of how disability identity and justice emerge with Israel and Palestine's respective acknowledgments of disability in traumatic times, not only in traumatic acts or representations.

To a small degree, what is happening for people with disabilities in the Middle East reflects a transformation into Western and liberal sociopolitical models as much as an equally small tug in the opposite direction of Eastern values. Studying disability and domestic citizenship in Delhi, Veena Das and Renu Addlakha (2001) emphasize that in Eastern contexts, notions of domestic citizenship may be elicited from "the *performance* of kinship." Kinship itself is "enacted in relation to disability and impairment,"

a psychiatric and social adjustment. Drawing on both Weiss and Deutsch & Nussbaum's 2000 scholarship on defect, Das and Addlakha study this adjustment as a way to engage cross-cultural and multigenerational attitudes toward visible difference and (referring to Weiss's depiction of Middle Eastern children) the "appearance-impaired." If we were to shift this representation of the "appearance-impaired" from treating disability as object to making disability the subject of the Palestinian-Israeli Conflict, this perspective echoes both the Israeli iconography of dying and disabled commuters as a vision of restoration of Zion, as well as the Palestinian representation of mothers wailing over injured or dying children. Both cultures are "appearance-impaired." Both Palestine and Israel may use the appearance of disability and injury from the conflict to represent other interests, but they may miss the message that disability justice and disability experience could bring to the socio-political table. Like Esau and Jacob, their collective future is both entwined and separate, together in sameness and difference. Such is the human experience of all people with disabilities.

Reuniting Jacob and Esau: Peace in Disability?

> "Now. See your events as my events. Everything will be as before: Abraham will again be Abram. Sarah will be Sarai" (Yehuda Amichai, "Do Not Accept").

Perhaps it is naïve to suggest that natural and religious rights cannot exist without the other. Religious politics of East and West, Judeo-Christianity and Islam enrobe this region with various influences and agendas. Similarly, the identities of people with disabilities in Israel and Palestine will reflect this context, even consciously so. Perhaps part of the difficulty in the composition of disability rights and dignity, even as they are created through this long-lived disaster, is that Esau's thread has not been con-textualized beyond two improbable, divergent endings. Among Jews, he surrenders to Jacob and forgives him for taking advantage when Jacob has been enabled to do so. Among Muslims, he dissipates into his uncle's vision of a separate people. Among people with disabilities, the resultant squabble over sovereignty and justice is absorbing, since the "hero-weakling" dyad has long worked against people with disabilities, and it is, on *only rare, deserving* occasion, refreshing to be honored as heroes. Furthermore, people with disabilities should be the heroes of their own narratives rather than those of territory wars or other phenomena of disaster that hurt, stigmatize, objectify, abandon, or exclude people. Disability represents human evolution and wholeness, and thus the experience of disability is desecrated when attached to forces of destruction and fragmentation, like war.

Are there words for the original wounds in sacred traditions that have spurred such trauma, such profound hatred between related peoples? How must Esau have felt toward his family and their abandonment? How would Jacob feel about his enablement? What lacunae are there in the Torah's rendering of social disadvantage from which Israelis (and we) might learn, and what voices for missing sons and daughters might the believers of Islam abide in an embrace of difference? For the majority of people with disabilities in Israel and Palestine, the Intifada and the Defense are opportunities to connect in the language of disability the long thread of dispute over the human condition which they share but require accommodation to enjoy, Esau's naturalness and Jacob's spiritedness, one whole child of A/Ibraham, without lack and at peace. Disability may become this catastrophe's antidote. Disability consciousness may offer a lasting settlement. In the case of A/Ibraham's descendents, *culture to culture* and *time to time* demand of people with disabilities the ability to see their time and place as concurrent and self-same, even as extremely powerful forces work in and around them. Esau and Jacob, Muslim and

Jewish, Arab and Jew, Palestinian and Israeli, in disability they are both common and sovereign.

Marcy Epstein is currently an advanced research Fellow at the University of Michigan for the U.S. Department of Education/OSERS National Institute for Disability Research and Rehabilitation, and Assistant Professor of Education, Language Arts, and Disability at the University of Windsor. She writes about her spinal cord injury during the onset of *intifada* in her recent collection, *Deep: Real Life with SCI*. She has been developing new methodologies for narrative research for the medical and health sciences, facilitating the translation of disability experience into research and clinical practice. She plans to return to teaching disability studies next year.

Endnotes

[1] The name A/Ibraham represents the linguistic split between Muslim and Judaic translations of the father of faith. There are several variations on this name, but I choose this one so as to simplify the use of the name while preserving the separation of peoples in relating to their respective and still identical patriarchal root. I use standard English transliterations for all other names of people and places so not to distract the reader. Note here, too, that this essay will not be treating Christian sources on the patriarchs and matriarchs. Nor do I focus later on Christian Israelis and Palestinians, even though they may be equally passionate about the regional conflict and particularly since Christian notions of disability may dominate Western consciousness about the sick and the weak.

[2] Here I distinguish between the Intifada, the historical events of the last fifteen years marked by Israeli and Palestinian violence, and *intifada* (uncapitalized) as concept of resistance or shaking off of weakness as a way toward justice, a "lifting of the yoke" seen later in the Sûrah of I/Abraham in the next section.

[3] In the holy Qu'ran, this is not originally a disputed point, but "serving" the Jews is understood as correcting their spiritual ways.

[4] Significantly, this marks the beginning of the geo-political dispute between Israeli Jews and Palestinian Muslims. A/Ibraham and Ishmael's first attempt to establish a holy temple starts in Jerusalem, but according to Muhammed, Jews in Al-Medinah wanted to switch the center for religious enlightenment to their city.

[5] Sûrah XIV, "Ibrahim: Revealed at Mecca." Note that A/Ibraham becomes changed to the more Islamic *Ibrâhîm*, when he settles Ishmael, patriarch of Moslem Arabs, into the infertile valley of Mecca. For a fascinating discussion of the *hunafa*, decidedly unclannish agnostics who yearned for the religion of A/Ibraham (by extension, the laws of the Jews and not their perceived idolatry) and what Mohammed himself became, see citation below. Although the pattern of the outcast son protected by male clansmen continues into the earliest history of the prophet Mohammed, since, parallel to Esau, he loses his father at birth in Mecca and is protected first by his grandfather, then by his uncle.

[6] The tone of the remainder of this article is highly inflammatory and exemplifies the manner in which people with disabilities are positioned within a larger rhetoric on Palestinian civil rights and resistance against Israeli Occupation.

[7] Here is an opportunity to show the reader an onslaught of graphic and disturbing images associated with this bloody and highly personal war, an opportunity I consciously pass on I am less interested in extending trauma images, propaganda or not, for any number of reasons. Here, too, is the opportunity to "report" the extent of physical, psychological, and cultural trauma that lines the contemporary conflict; but again, the power to describe what is seen in each place can also traumatize, and even more likely the unpacking of each image I have myself witnessed or seen from photography (from artists and colleagues who have documented the Intifada in various peace efforts) will transmit some level of propaganda. Frankly it is difficult to see truths about people with disabilities in these war photographs or narratives. Each image of wounded and disabled people, whether seen in the destruction of body or of mind, detours the reality of life with disabilities in Israel and Palestine in favor of the "heroic weakness" inherent in the lore of warring antipodes.

[8] People with milder physical and psychological wounds may or may not be included in the first statistic.

[9] I thank Alex Lubet for this point.

[10] Kabbara has co-founded the Arab Organization of Disabled People to monitor the civil rights of Arabs with disabilities in all countries.

References

Abdeen, Z., Habash, A., & Harami, G. (1994). *Development of a systematic tool for the collection of occupational data on disabled persons*. Gaza: Central Committee for Rehabilitation.

Abrams, J. K. (1998). *Judaism and disability: Portrayals in ancient texts from the Tanach through the Bavli*. Washington, DC: Gallaudet University Press.

Accessibility Foundation (2002). *Disability inequality in Israel*. http://www. accessibility.com.au

Bizchut.org.il, n.d.

Couser, G. T. (2005). Paradigms' cost: Representing vulnerable subjects. *Literature and Medicine*, *24*(1), 28-29.

Das, V., & Addlakha, R. (2001). Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture*, *13*(3).

Gilman, S. (2004). Review: Meira Weiss, *The chosen body. Modern Judaism, 24*(1), 91-93.

Introduction and Sûrah XIV, Ibrahim: Revealed at Mecca. *The Meaning of the Glorious Koran* (1997) (Mohammed Marmaduke Pickthall, trans.), xi, 186-190. New York: Meridian.

Kabbara, N. (2003). *Arab conference on disability held October 2002 in Beirut identifies violence as a major cause of disability*. Beirut: Arab Organization of Disabled People. http://www. disabilityworld.org

K. V. (1992). The effect of Palestinian rehabilitation organizations for Intifada Disabled. *Bethlehem University Journal*, *11*(12), 97-98. Bethlehem: Bethlehem University.

Malki, G. (1997). Reaching the unreached: The Palestinian experience during the intifada. *Enabling Education Network Newsletter, I* (December). Manchester: Centre for Educational Needs, University of Manchester. http://www. eenet.org.uk

Meforum.org, n.d.

Nagata, K. K. (2003). Gender and disability in the Arab region: The challenges in the new millennium. *Asia Pacific Disability Rehabilitation Journal*, *14*(1),14.

New law would bar Palestinians from claiming compensation from Israel. *Arabic News*. (n.d.) http://www.arabicnews.com

Palestinian Information Center. (2005). *Hamas tad'u li-al-tasadi li-al-'udwan al-sahyuni wa-tudin qiyam al-sulta bi-l'tiqal al-Mujahideen*. http://www.palestine-info. net

Palestinianmonitor.org, n.d.

Reiss, R. M. (1961). Esau, son of Isaac and grandson of Abraham. In J. Abramowitz, trans., *Bible Commentator*; *"Deuteronomy": Midrash Rabbah*, *I*(15), 16-18. London: Soncino.

Salem, M. O. (1990). *Stigma and the origin of disability: The case of the Palestinians*. (excerpt, electronic version) Manchester: unpublished Master's thesis.

Weiss, M. (2002). *The chosen body: The politics of the body in Israeli society*. Stanford: Stanford University Press.

The Relationship Between the Design of the Built Environment and the Ability to Egress of Individuals with Disabilities

Keith M Christensen, Shawnee D. Collins, Judith M. Holt, & Curtis N. Phillips
Utah State University

Abstract: Recent catastrophic events have brought into focus the importance of planning for the evacuation needs of all persons, regardless of their diverse physical and mental abilities. While these efforts are primarily concerned with the activities before and after a crisis, there is also a renewed interest in evaluating how effectively the built environment accommodates the needs of all individuals during a crisis. This discussion focuses on the current body of knowledge concerning the relationship between the design of the built environment, the collective egress behavior of complex decentralized groups of individuals, and the ability of individuals with disabilities to effectively egress from the built environment during emergency events.

Key Words: emergency, built environment, egress

Introduction

Recent catastrophic events demonstrated an unacceptable, disproportionate effect of emergency evacuations on individuals with disabilities. These events highlight policies and practices that are less than effective and possibly counterproductive. Research, policy, and practice regarding critical aspects of emergency evacuations focus primarily on the individual with a disability, followed by the evacuation process, and then the built environment (Christensen, Blair, & Holt, under review). This focus results in policy and planning that emphasizes "helping the disabled individual to adjust and accept the existing environment rather than upon altering the environment to accommodate the needs of disabled persons" (Hahn, 1985).

Purpose and Method

Emergency evacuation research, policy, and practice will continue to be ineffective until premised on the understanding that disability is a product of the environment rather than inherent in the individual. Emergency evacuation research, policy, and practice must recognize and respond to the environment first. Christensen, Blair, and Holt (under review) describe four distinct forms of emergency evacuations as they relate to individuals with disabilities: protective, preventive, rescue, and reconstructive. These emergency evacuation forms are defined by classifying the timing (long-term, short-term) and period of evacuation (pre-impact, post-impact). While the built environment is an essential component of each form of emergency evacuation, the emphasis on mitigating the immediate effects of health and safety threats in a rescue evacuation (short-term, post-impact) accentuates the role of the built environment. Under these conditions, when one exits a burning building, for example, there may be insufficient time to adapt to barriers in the environment, requiring that the environment accommodate the behavior of the individual without extraneous supports.

In an effort to facilitate this shift in emphasis to the role of the built environment, an exhaustive review of emergency evacuation research concerning individuals with disabilities was conducted. Initially, a number of databases, such as EBSCOhost and Google Scholar, were searched for publications focused on individuals with disabilities and evacuations, the built environment, emergencies, and other related terms. Roughly one third of the reviewed literature was identified in this way. The remainder was identified by reviewing the citations of previously identified literature, a process which continued until unidentified citations no longer appeared in the literature. During this process, literature was selected for inclusion in this review when there was both a clear focus on an individual(s) with a disability and a focus on the role of the

character and design of the built environment. A third criterion was included to identify studies which also focused on evacuations or a closely related aspect of an evacuation. Four studies, concerning navigating the built environment with a visual impairment, dementia, or a cognitive disability, were included as navigating the environment is an important aspect of an evacuation. One study, which may meet the inclusion criteria, was not included in this review as it is only available in Swedish (Hallberg and Nyberg, 1987). Of the three criteria, the role of the character and design of the built environment was the limiting criteria. The identified literature focused on the design of the built environment as it relates to the ability of individuals with disabilities to egress in emergency evacuations is described in this manuscript. From this body of knowledge, future research priorities and general implications are drawn.

Review of the Built Environment Evacuation Literature

The following summary of the literature, focused on the design of the built environment as it relates to the ability of individuals with disabilities to egress in emergency evacuations, is presented by emphasis. The majority of the available literature is a description of the behavior of the individual with a disability in response to the built environment, described almost solely by speed of egress (i.e. how quickly an individual is able to travel along an evacuation route). The majority of the remaining literature is either a description of individuals with disabilities as a constraining factor in the built environment or a description of individuals with disabilities interpreting the built environment.

Individuals with Disabilities' Speed of Egress in the Built Environment

After reviewing the literature, 44% of the articles included in this review addressed individual with disabilities' speed of egress. In general, the authors measured speed of egress in terms of rate (e.g., meters per second or 70%

the rate of an individual without a disability). Moreover, at least one study measured speed of egress in terms of duration (i.e., the duration between the sound of the alarm and the individual exiting the building). Many of the articles identified factors of the built environment possibly influencing an individuals' speed of egress (e.g., stairs); however, with one possible exception, the authors did not experimentally evaluate the effects of the built environment on an individual's speed of egress. The following 11 studies targeted an individual with disabilities' speed of egress.

Sime and Gartshore (1986) investigated the assisted egress speed of an individual in a wheelchair from a six story building. The authors collected data during an unannounced evacuation drill where two men in their 20s, who had no knowledge of the research or special training in assisting in the evacuation of a person in a wheelchair, carried an individual in a wheelchair down the evacuation stairway. The authors determined the average descent speed of the three individuals was .41 meters per second; only slightly slower than the typical .5 meters per second descent speed for a non-wheelchair user. The individual in the wheelchair instructed the men providing assistance as to the proper manner for safe assistance. The authors concluded that the three individuals did not pose a serious obstacle to other evacuees, but note that stairways should be closer to the maximum width of 62 inches instead of the minimum of 47 inches to allow overtaking evacuees to pass. Furthermore, they recommended future research to evaluate different stair widths for evacuation. The authors also suggested that the inclusion of "passing bays," similar to passing lanes on a highway, might be useful in allowing those with faster egress speeds to pass others.

Similarly, while developing a procedure for including mobility-impaired individuals in evacuation models, Rubadiri, Ndumu, and Roberts (1997) measured the speed of six individuals with wheelchairs along a defined evacua-

tion route. The findings were used to develop an evacuation performance index described as the ease of evacuating an individual with a disability relative to the ease of evacuating an individual without a disability. The index is determined by the unassisted speed of the individual through built environments of various types: straight and obstacle-free route, an identified section of an escape route, and the escape route that the individual will use in an emergency. In this way, the effect of the built environment on the egress of the individual with a disability is addressed, but only for the specific route. The factors in the built environment which affect the speed of the individual are not addressed, although various built environments could be compared based on the related evacuation performance index for a specific individual.

Moreover, Pearson and Joost (1983) conducted a series of evacuation studies in a residential setting according to various disabilities including blind occupants, wheelchair users, and the elderly. The authors discussed the mean speed of evacuation for the various groups and concluded that individuals with disabilities had longer, but sufficient, evacuation times. However, the authors did not address the condition of the built environment through which the participants egressed.

In addition to the studies discussed above, three studies evaluated speed of egress for individuals with visual impairments in various built environment. The first study, conducted by Wright, Cook, and Webber (1999), evaluated the effects of different emergency lighting conditions and wayfinding provisions on the mean walking speed of 30 individuals with visual impairments walking through an egress route. Mean walking speeds were also compared with those of individuals without disabilities completing the egress route under the same lighting and wayfinding conditions. The authors found that "visually impaired subjects walk at 43 to 69 percent the rate of a normally sighted person on level parts of the route, and at 70 to 87

percent on the stairs" (p. 39). Individuals with visual impairments achieved the highest walking speeds under both normal lighting conditions and powered emergency lighting systems, such as light emitting floor strips and overhead emergency lighting. Non-powered lighting systems had a negative effect on walking speeds.

The second study, by Soong, Lovie-Kitchin, and Brown (2000), evaluated the differences in preferred walking speed for individuals with visual impairments using a sight guided technique and individuals using a non-sighted guide technique (i.e., walking unassisted along a straight, unobstructed path). The authors found no significant differences in preferred walking speed between the two experimental conditions.

In the third study, Clark-Carter, Heyes, and Howarth (1986) measured the walking speed of people with visual impairments in environments of various complexity. The authors found that the walking speed of individuals with visual impairments is negatively affected by the increasing complexity of the travel environment. In addition, individuals with visual impairments who use guide dogs are not as affected by complex built environments as those who use long canes.

Dunlop, Shields, and Silcock (1996) conducted a series of experimental programs to determine the "numbers of disabled people using different types of buildings, the nature of their disabilities and their corresponding capabilities… effecting their escape in the event of an emergency" (p. 154). These studies were commissioned by the Department of the Environment in London and are described in detail in the final report, *Escape of disabled people from fire: a measurement and classification of capability for assessing escape risk* (Shields, Dunlop, & Silcock, 1996). It is important to note that their study methodology is based on disability defined as "the restriction or lack of ability to perform activities in a manner which may be considered normal for a human being" and "could be mea-

sured in terms of capability" (p. 3-4), a premise that may have led to the intense scrutiny of individual functional competency rather than the built environment. The authors conclude that "all other things being equal, the presence of a seeing or hearing disability may not be as critical as conventional wisdom suggests in emergency situations" (p. 124). However, the conclusions of this report should be interpreted as referring to comparisons between classifications of individuals with disabilities according to functional competency and not the built environment. The authors describe the findings of these experimental programs in a series of four publications described hereafter.

Boyce, Shields, and Silcock (1999a) determined movement capabilities of 155 individuals living in large day centers on level surfaces, movement on ramps, and movement on stairs. Results are reported in four disability categories: unassisted ambulant, unassisted wheelchair users, assisted ambulant and assisted wheelchair users. One hundred seven of the participants moved through the horizontal route without assistance at a mean speed of 1.0 m/s. Moreover, 14 wheelchair users moved through the horizontal section at mean speeds of .89 m/s and .69 m/s for electric wheelchair users and manual wheelchair users, respectively. Ambulatory individuals requiring assistance walked the horizontal section at various speed (range = .21-1.40 m/s, M = .78 m/s). Assisted wheelchair users went through the horizontal section fastest (M = 1.30 m/s). On ramps, only 54 participants moved upward and downward on ramps without assistance; the mean speeds were .62 m/s (upward) and .60 m/s (downward). Only one individual with a wheelchair used the ramp unassisted at a mean speeds of .7 m/s (upward speed) and 1.05 m/s (downward speed). Eight ambulatory individuals used the ramps with assistance at mean speeds of .53 m/s (upward) and .69 (downward). Seven individuals using manual wheelchairs moved on the ramps with assistance with a mean upward speed of .89 and downward speed of .96 m/s.

A second experiment within the same study evaluated individuals' (N = 136) speed of moving through a 90 degree bend. The authors reported results for all four groups: 95 ambulatory individuals traversed without assistance (M = 3.6 sec.), 11 wheelchair users moved through without assistance (M = 3.5 sec. for electric wheelchair users and 4.2 sec. for manual wheelchair users), 16 ambulatory individuals moved through bend with assistance (M = 4.6 sec.), and 14 wheelchair users moved through with assistance in two to four seconds. Finally, the researchers studied individuals (N = 34) movement on stairs: 30 participants moved on the stairs without assistance (M = .38 m/s), four participants required assistance (M = .29 m/s).

The second study by Boyce, Shields, and Silcock (1999b) evaluated egress capabilities of individuals with disabilities in public-assembly buildings. The authors used 1989 census data from Great Britain and Northern Ireland to report descriptive statistics (e.g., percentages of children and adults with disabilities able to evacuate without assistance).

Boyce, Shields, and Silcock (1999c) evaluated the abilities of 113 individuals with disabilities to negotiate doors with closing forces ranging from 20 N to 70 N. Between 1.5% and 6.9% (1.5% at lowest closing force and 6.9% at highest closing force) of ambulatory individuals failed to negotiate the doors. For those ambulatory individuals who negotiated the doors, mean times increased as a function of closing force (push range = .32 sec. – 4.2 sec. and pull range = 3.5 sec. – 4.6 sec.). Percentage of failures increased for individuals using wheelchairs (N = 7) (push range = 14.3% - 28.6% and pull range = 28.6% - 71.4%).

The final study by Boyce, Shields, and Silcock (1999d) evaluated the effects of exit signs (i.e., non-illuminated, internally illuminated, and light emitting diode (LED) signs) on the locating and reading behavior of individuals with disabilities. One hundred eighteen individuals

participated in the study (25 with visual impairments). Overall, participants located and read the LED sign before the illuminated and non-illuminated signs.

Individuals with Disabilities as Constraints in the Built Environment

The second most common dependent variable targeted in this literature is the impact of an individual with a disability as a constraint in the built environment. This topic accounted for 24% of the articles included in this review. In general, constraint is defined in terms of how the individual with a disability affects the ability of others to egress during an evacuation. The following six studies targeted individuals with disabilities as constraints in the built environment.

In an early research program, also commissioned by the Department of the Environment, Shields (1993) performed a series of case studies on the evacuation of individuals with disabilities involving a museum, residential home, leisure center, sub-surface station, hospital, and a department store. The author concluded that communication was the critical factor which hindered the evacuation of individuals with disabilities. Additionally, Shields conducted two experiments involving a hotel and a theater to evaluate interactions between individuals with disabilities and those without. Shields found that in the hotel evacuation, individuals who used wheelchairs required 1.9 times longer to evacuate hotel bedrooms than the able-bodied evacuees; were not affected by standard doorway widths (762 mm); did not impede able-bodied evacuees, but did impede other individuals who used wheelchairs. In the theater evacuations, the author concluded that "the orientation of motorized wheelchairs can be just as important in some situations as their location" (p. 63) and that its owner may dominate the evacuation process due to its size and weight.

Moreover, Shields, Smyth, Boyce, and Silcock (1999a, 1999b) conducted a second study

evaluating the effects of unannounced fire drills on evacuation of individuals in two residential homes. Only 13 of 22 residents evacuated. The authors discuss the need for evacuation skills during day-time and night-time evacuation, training programs, accommodation strategies, and pre-determined evacuation plans.

In a third study, Boyce, Shields, Silcock, and Dunne (2002) evaluated the effect of an individual using a wheelchair entering the flow of evacuees during an unannounced evacuation. Following the evacuation, researchers viewed video footage of the evacuation and noted that when the wheelchair user entered the stairway, it caused "considerable congestion" and also noted that "at no stage during the evacuation did any evacuee attempt to overtake and pass the wheelchair party, although there was sufficient free width of stair to do so" (p. 144).

Furthermore, Miyazakie, et al. (2004) evaluated the behavior of 30 pedestrians and a wheelchair user. The authors found that the behavior of the pedestrians and wheelchair user influenced the behavior of the other. Moreover, depending on the psychological condition (e.g., competitive, noncompetitive) pedestrian speed changed. The researchers developed a model demonstrating psychological phenomena (e.g., "group psychology") and pedestrian behavior (e.g., speed) in relation to the distance from an individual using a wheelchair.

Additionally, Averill, et al. (2005) described the egress system and evacuation of individuals in the World Trade Center on September 11, 2001. Regarding individuals with disabilities affecting mobility (e.g., physical impairment, wheelchair user, visual impairment), the authors discussed the influence of total distance to an exit on ones ability to exit independently (i.e., as the distance to an exit increases, individuals with disabilities require more assistance). Following their interviews, the authors report that, "51% percent of the occupants in WTC 1 and 33% of the occupants in WTC 2 in 2001, noted

that injured and disabled persons in the stairwell were a constraint to evacuation" (p. 159). Following numerous interviews and focus groups, analysts built causal models of the WTC to explore the sources of evacuation initiation delay (i.e., the latency between emergency communication and individuals moving out of the building) and stairwell evacuation time.

Individuals with Disabilities Interpreting the Built Environment

An individual with a disability's ability to interpret the built environment comprised an additional 20% of the articles included in this review. Interpreting the built environment was generally defined as an individual's ability to identify and effectively use certain safety features (e.g., maps, alarms). The following five studies targeted individuals with disabilities interpreting the built environment.

Salmi, Ginthner, and Guerin (2004) compared the effects of environmental features on wayfinding behavior of individuals with mild intellectual disabilities (n = 13) and individuals in the general population (n = 10). The authors found participants with disabilities took longer to exit then individuals in the general population. Information accessible in maps to the general population was inaccessible to individuals with intellectual disabilities.

Moreover, Edelman, Herz and Bickman (1990) explored the behaviors of residents in a nursing home during a fire emergency. The authors determined that the major determinant of the resident's actions was familiarity with the egress routes (85/91 residents used only one of four available stairways due to the familiarity of the used route).

Furthermore, Vanderkooy (2002) investigated the effect of the acoustic characteristics of residential built environments on the ability of individuals with moderate hearing impairments to hear audible alarms. The study concluded that audible alarm signals are altered by intervening walls or doors causing the signal to fall in the range of sounds associated with hearing loss. The author recommended that either the frequency of audible alarms be changed to make the alarm more detectable by individuals with moderate hearing impairments regardless of obstructions in the built environment or that the alarm is located where the built environment would not obstruct the signal.

Similarly, Robertson and Dunne (1998) discussed wayfinding design and suggest including "elements of buildings or aids that maximize the utility of residual vision" (p. 2) and audible cues. The authors then discussed their findings regarding the accessibility of four buildings to individuals with visual impairments. The authors concluded that purpose-built buildings are most accommodating. Furthermore, the authors made recommendations to improve the environments in each of the buildings (e.g., apply tinted film to lights to reduce glare, replace dado rails with handrails, use non-uniform carpet to increase tactile or sound orientation). The authors also surveyed local authorities (e.g., hospital staff, public transportation buildings) and noted that special provisions for individuals with visual impairment were rarely reported. Generally, provisions were the minimum required for building codes and regulations.

In addition, Passini, et al. (1998) performed an experiment with 14 patients diagnosed with dementia of Alzheimer's type (DAT) and 28 healthy elderly people. They were to find the way from a bus stop to a dental clinic inside a hospital. The authors concluded that organizing space in the simplest manner increases the ability of patients with DAT to find their way. Further, they conclude that graphics identifying locations of interest or characteristics of the building must be done in a consistent and simple manner to maximize functional use by patients with DAT.

Select Related Studies of Individuals with Disabilities in the Built Environment

The final 12% of articles discussed in this literature review were included because they addressed issues of an individual with a disability's ability to egress during an evacuation. However, they do not specifically target speed of egress, constraint, or interpretability in or of the built environment.

Yoshimura (1998) conducted a survey of 220 individuals near Kobe, Japan with lower-extremity disabilities to assess their escape behavior with the intent of using the data to suggest safer fire escape design. Coincidentally, the conclusion of the original survey coincided with the Kobe Earthquake of 1995, after which Yoshimura used the same survey instrument to assess the escape behavior of the participants for comparison pre- and post-earthquake data. The author suggests that the participants confidence in their ability to escape from the built environment during a disaster decreased post-earthquake, and that a barrier-free exit was the most trusted means of egress (although the author did not specify the characteristics of a barrier-free exit) followed by a fireproof elevator, area of rescue assistance, stairwell, exit sign (interpreted as directional assistance), and a rooftop heliport.

Moreover, Proulx (2002) reviewed the literature addressing fire safety planning, building characteristics, procedures to assist those with disabilities, and specific techniques to assess the needs of persons with different types of disabilities in Canada. The author primarily describes various methods to assist individuals with disabilities respond to the emergency and the environment during an evacuation. Consideration of the built environment includes the concept of areas of refuge, safe elevators, sprinkler systems, and ways to effectively communicate the emergency with occupants.

Proulx and Yung (1996) define egressibility and briefly describe two egress strategies: protect-in-place and *everybody-out*. The protect-in-place strategy requires fire and smoke safe compartments for individuals with disabilities to wait for rescue crews. The *everybody-out* strategy requires all individuals evacuate. Both methods have limitations. The authors further discuss protocols to improve both strategies: evacuation procedures and occupant training. Moreover, the authors identify several building characteristics that impact safe evacuation of individuals with disabilities: areas of refuge (particularly if the protect-in-place strategy is used), safe elevators, fire protection systems, communications (e.g., PA system), wayfinding signage (e.g., safe elevator sign), fire wardens (i.e., an on sight employee trained in evacuation procedures), list of occupants requiring assistance, and a buddy system.

Limitations of the Current Body of Knowledge

The preceding review of the literature represents the current body of knowledge focused on the design of the built environment as it relates to the ability of individuals with disabilities to egress in emergency evacuations. Three conclusions can be drawn from this review. First, it is unfortunate that while individuals with disabilities are a significant portion of evacuating populations (Gershon, 2005) they have received very little scholarly attention. The review of the literature focused on individuals with a disability and emergency evacuations identified only 25 published studies indicating a focus on the design of the built environment. There is a significant lack of scholarly study focused on the design of the built environment as it relates to the ability of individuals with disabilities to egress in emergency evacuations.

Second, not only is there a lack of experimental studies in general, there is a significant lack of investigation focused on the design of the built environment. Primarily, the disseminated studies are descriptions of functional competency, predominantly described by travel speed, for individuals with a specific type of disability in a

specific environment. Very little investigation is focused on the effect of different environments on the functional competency of an individual with a disability to evacuate. As a result, the majority of empirical data regarding emergency evacuations in the built environment and individuals with disabilities is focused on the ability of the individual with a disability rather than on the design of the built environment.

The effectiveness of using travel speed, or time-to-egress, as a measure of an individual's ability to evacuate in an emergency is secondary to whether or not it is the ability of the individual to negotiate the environment or the ability of the environment to accommodate the function of the individual which affects travel speed, and ultimately successful evacuation. For example, Wright, Cook, and Webber's study (1999) measured the mean walking speed of individuals with visual impairments for various emergency lighting conditions. Interestingly, in preparation for the study a tap board was added along the left-hand side of the stairwell part of the route to facilitate the use of long and short canes by the participants. The authors did not consider this modification to the built environment as part of the study, but assumed it was a necessary accommodation. Future research should evaluate the effect of the tap board in the egress route on the mean walking speed of individuals with visual impairments.

Similarly, while an individual with a disability has been found to be a constraint to evacuation (Averill, et al. 2005; Shields, et al. 2002; Shields, 1993), the question remains as to whether the individual with a disability is a constraint in the built environment or the built environment is a constraint on the individual with a disability? The distinction is critical if the underlying premise of emergency evacuation is that an individual should be able to physically reach safety unassisted.

Third, the majority of the research regarding emergency evacuations in the built environment and individuals with disabilities has been conducted in the United Kingdom (14 of 25) followed by Canada (4), Japan (2), and New Zealand (1). Where the current body of knowledge describes the functional competency of the individual according to a specific environment, generalizing the findings to the United States or other nations may be problematic given the different built environment standards and practices for each. Surprisingly, given the development of the Americans with Disabilities Act Design Requirements for Accessible Egress (DOJ, 2002), there has been no concerted investigation to determine built environment design requirements for accessible egress in the United States.

Future Direction and Priorities

Currently, digital evacuation models are one of the most widely used tools to investigate emergency evacuations in the built environment with upwards of 40 evacuation models currently in use worldwide and many more in development (Galea, 2003). These evacuation models must replicate observable pedestrian phenomena to be considered reliable predictors (Helbing, 2005). As a result, it is problematic to conduct simulations involving individuals with disabilities without an adequate body of empirical data regarding the effect of the built environment on individuals with disabilities. Previously, Shields and Dunlop (1993) note that the common evacuation models did not adequately address the attributes of individuals with disabilities in their simulated occupant populations. The same observation is valid more than a decade later. Indeed, as a result of the emphasis of scholarly study on the functional competency of the individual with a disability, when individuals with disabilities are incorporated into the simulation population, there is the tendency to "standardize" to a singular form of mobility impairment defined by narrow functional characteristics. For example, one model defines individuals with disabilities as those who require assistance and "appliances" in order to move (Kakegawa, et al., 1994). The extent of progress

during the past decades is that current models simulate individuals with disabilities by limiting their speed of movement, a narrow approach in keeping with the available empirical data.

Future emergency evacuation research must address the significant lack of scholarly study on the design of the built environment as it relates to the ability of individuals with disabilities to egress. Additionally, future research regarding the built environment must be premised on a model of disability which recognizes that disability is largely a product of environment rather than inherent in the individual (Christensen, Blair, & Holt, under review). This premise is critical if research is to focus on designing the built environment to accommodate the individual, rather than adapting the individual with a disability to the environment.

Keith M. Christensen, MLA, is a Landscape Architect with the Center for Persons with Disabilities at Utah State University. Christensen's research emphasizes the planning and design of socially inclusive environments, including current research activities focused on the built environment and the egress behaviors of individuals with disabilities.

Shawnee D. Collins, is a doctoral candidate in the Department of Special Education at Utah State University.

Judith M. Holt, Ph.D., is the Director of the Interdisciplinary Training Division of the Center for Persons with Disabilities at Utah State University. Dr. Holt's research and exemplary service emphasizes the social system issues of disability, and includes numerous multi-site interdisciplinary research, education, and technical assistance programs.

Curtis N. Phillips is a doctoral candidate in the Department of Special Education at Utah State University.

References

Averill, J. D., et al. (2005). Occupant behavior, egress, and emergency communications (Draft). *National Institute of Standards and Technology, World Trade Center Investigation*: U.S. Department of Commerce.

Boyce, K. E., Shields, T. J., & Silcock, G. W. H. (1999a). Toward the characterization of building occupancies for fire safety engineering: Prevalence, type, and mobility of disabled people. *Fire Technology, 35*(1), 35-50.

Boyce, K. E., Shields, T. J., & Silcock, G. W. H. (1999b). Toward the characterization of building occupancies for fire safety engineering: Capabilities of disabled people moving horizontally and on an incline. *Fire Technology, 35*(1), 51-67.

Boyce, K. E., Shields, T. J., & Silcock, G. W. H. (1999c). Toward the characterization of building occupancies for fire safety engineering: Capability of disabled people to negotiate doors. *Fire Technology, 35*(1), 68-78.

Boyce, K. E., Shields, T. J., & Silcock, G. W. H. (1999d). Toward the characterization of building occupancies for fire safety engineering: Capability of people with disabilities to read and locate exit signs. *Fire Technology, 35*(1), 79-86.

Christensen, K. M., Blair, M. E, & Holt, J. M. (submitted). *The built environment, evacuations, and individuals with disabilities: A guiding framework for disaster preparation and emergency response*. Manuscript submitted for publication.

Clark-Carter, D. D., Heyes, A. D., & Howarth, C. I. (1986). The efficiency and walking speed of visually impaired people. *Ergonomics, 29*(6), 779-789.

Department of Justice-DOJ (2002). *ADA accessibility guidelines for buildings and facilities (ADAAG).* Washington, DC: U.S. Government Printing Office.

Dunlop, K. E., Shields, T. J., & Silcock, G. W. H. (1996). Towards the quantification of emergency egress capabilities for disabled people. *Fire Engineering and Emergency Planning,* 154-161.

Edelman, P., Herz, E., & Bickman, L. (1990). A model of behaviour in fires applied to a nursing home fire. In E. Canter (Ed.), *Fires and Human Behavior* (pp. 181-203). London: David Fulton Publishers.

Galea, E. R. (Ed.). (2003). *Proceedings of the 2nd International Conference on Pedestrian and Evacuation Dynamics.* Greenwich, UK. 20-22 August 2003.

Gershon, R. (2005, January 26). Personal Communication / Center for Disease Control moderated conference call.

Hahn, H. (1985). Disability policy and the problem of discrimination. *American Behavioral Scientist, 28*(3): 293-318.

Hallberg, G., & Nyberg, M. (1987). *Utrymningssakerheten i servicehus.* Byggnadsfunktionslara KTH (Rapport R3: 1987). Stockholm, Sweden.

Helbing, D., Buzna, L., Johansson, A., & Werner, T. (2005). Self-organized pedestrian crowd dynamics: Experiments, simulations, and design solutions. *Transportation Science, 39*(1), 1-24.

Kakegawa, S., Yashiro, Y., Ebihara, M., & Ohtsuki, A. (1994). Evaluation of fire safety measures in care facilities for the elderly by simulating evacuation behavior. In L. Rubadiri (Ed.), *Fire Safety Science—Proceedings of the Fourth International Symposium* (pp. 645-656).

Miyazaki, K., Matsukura, H., Katuhara, M., Yoshida, K., Ota, S., Kiriya, N., & Miyata, O. (2004). Behaviors of pedestrian group overtaking wheelchair user. *National Maritime Research Institute (NMRI)* (Report 181-0004). Shinkawa Mitakashi, Tokyo, Japan.

Passini, R., Rainville, C., Marchand, N., & Joanette, Y. (1998). Wayfinding and dementia: some research findings and a new look at design. *Journal of Architectural and Planning Research 15*(2), 133-151.

Pearson, R. G., & Joost, M. G. (1983). *Egress behavior response times of handicapped and elderly subjects to simulated residential fire situations.* National Bureau of Standards, Department of Commerce (Report No. PB83-222695). Washington, DC,

Proulx, G. (2002). *Evacuation planning for occupants with disability.* Internal Report No. 843, Fire Risk Management Program, Institute for Research in Construction, National Research Council Canada.

Proulx, G., & Yung, D. (1996). Evacuation procedures for occupants with disabilities in high-rise buildings. *3rd International Symposium, Applications of Performance Concept in Building.* Symposium held at Tel-Aviv, Israel.

Robertson, B .S., & Dunne, C. H. (1998). Wayfinding for visually impaired users of public buildings. *Journal of Visual Impairment & Blindness, 92*(5), 349-355.

Rubadiri, L., Ndumu, D. T., & Roberts, J. P. (1997). Predicting the evacuation capability of mobility-impaired occupants. *Fire Technology First Quarter,* 32-53.

Salmi, P., Ginthner, D., & Guerin, D. (2004). Critical factors for accessibility and wayfinding for adults with intellectual disabilities. *Designing for the 21st Century.* Symposium held at Rio de Janeiro, Brazil.

Shields, T. J. (1993). Fire and disabled people in buildings. *Building Research Establishment* (Report No. BR 231). Borehamwood, England.

Shields, T. J., Boyce, K. E., Silcock, G. W. H., & Dunne, B. (2002). The impact of a wheelchair bound evacuee on the speed and flow of evacuees in a stairway during an uncontrolled unannounced evacuation. *Evacuation from fires. Volume II.* (139-149). Amityville, NY.

Alternate Source – Boyce, K. E., Shields, T. J., Silcock, G. W. H., & Dunne, B. (1998). The impact of a wheelchair bound evacuee on the speed and flow of evacuees in a stairway during an uncontrolled unannounced evacuation. *Journal of Applied Fire Science, 7*(1), 277-289.

Shields, T. J., Dunlop, K. E., & Silcock, G. W. H. (1996). Escape of disabled people from fire: A measurement and classification of capability for assessing escape risk. *Building Research Establishment Laboratory Report*, Watford, England.

Shields, T. J., Smyth, B., Boyce, K. E., & Silcock, G. W. H. (1999a). Evacuation behaviors of occupants with learning difficulties in residential homes. *Disability and Rehabilitation, 21*(1), 39-48.

Shields, T. J., Smyth, B., Boyce, K. E., & Silcock, G. W. H. (1999b). Towards the prediction of evacuation behaviors for people with learning difficulties. *Facilities, 17*(9/10), 336-344.

Sime, J. D., & Gartshore, P. J. (1987). Evacuating a wheelchair user down a stairway: A case study of an 'assisted escape'. In J. Harvey and D. Henning (Eds.), *Environmental design research association conference* (pp. 128-133). Symposium held in Ottawa, Canada.

Soong, G. P., Lovie-Kitchin, J. E., & Brown, B. (2000). Preferred walking speed for assessment of mobility performance: sighted guide versus non-sighted guide techniques. *Clinical and Experimental Optometry, 83.5,* 279-282.

Vanderkooy, J. (2002). Audible alarms for the hearing impaired. *Journal of Audio Engineering Society, 50*(1/2), 73-79.

Wright, M. S., Cook, G. K., & Webber, G. M. B. (1999). Emergency lighting and wayfinding provision systems for visually impaired people: Phase I of a study. *Lighting Research Technology, 31*(2), 35-42.

Yoshimura, H. (1998). Sounding out the disabled in the lower-extremities on their escape behavior in building fire for safer fire escape design. *Human Behavior in Fire-Proceedings of the First International Symposium*. Belfast, UK: 353-359.

Ice Storm Experiences of Persons with Disabilities: Knowledge is Safety

Maria Barile
Adaptech Research Network

Catherine Fichten
Dawson College, Adaptech Research Network,
McGill University, Jewish General Hospital

Vittoria Ferraro
Adaptech Research Network,
McGill University

Darlene Judd
Adaptech Research Network, Montreal
Association for the Blind
Montreal, Quebec, Canada

Abstract: Questionnaire responses of ice storm victims with and without disabilities were compared and 15 women with disabilities were interviewed about their experiences. Results are examined from the Social Model of Disability perspective in terms of dealing with unexpected environmental barriers to inclusion.

Key Words: ice storm, disaster, social model

January is one of the coldest months of the year in Eastern Canada. In January, 1998, however, Montreal had an unusual weather event. In less than 24 hours the city was covered with freezing rain. Its accumulation during this brief period caused a crisis. A considerable part of the population of Montreal and the southern portion of the province of Quebec was without electricity and heating for homes and offices. For some, this lasted up to three weeks. This incident became widely known as "the ice storm" and it differed from other natural disasters in that it did not cause massive death or famine. Canadians who lived through the ice storm went back to their regular routines relatively quickly once weather conditions returned to normal. But the ice storm had dramatic effects on the everyday lives of those who experienced it.

To examine these effects, in Study 1 we administered a battery of questionnaires to individuals with and without disabilities immediately after the ice storm. In Study 2, we examined unstructured interview responses of women with various disabilities. Some of these interviews involved retrospective recollections of the incident while others were obtained through informal conversations with women recorded during the 1998 ice storm.

Theoretical Assumptions: Social Model of Disability

The Union of the Physically Impaired Against Segregation (1976) defines impairment as "lacking part or all of a limb, or having a defective organ or mechanism of the body," and disability as "a disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and, thus, excludes them from the mainstream of social activities" (cited in Oliver, 1990, p. 11). This definition of disability is commonly associated with the social model of disability, which states that the problems of people with disabilities are primarily socially constructed. A lack of access to resources for persons with disabilities, which are otherwise available to nondisabled persons, creates unequal distribution of opportunities in society. The term disabling environments (Oliver, 1993) refers to physical, social, and cultural environments that impose barriers to participation by people with disabilities.

This definition of disabling environments is assumed to apply under "non-crisis" conditions. It is expected that unexplained crises exacerbate these situations. Based on data from the 1998 ice storm (Office des personnes handicapées du Québec,[1] 1998a; 1998b; Kailes, 1996) and on findings of studies dealing with persons with disabilities and other types of disasters (e.g., Takahashi, Watanabe, Oshima, Shimada, & Ozawa,

1997), several recurring factors emerge as important for disaster preparedness: (1) awareness of where persons with disabilities are during the time of the crisis (for example, home or work); (2) a well-planned early rescue, and (3) accessible resources that allow disaster workers to act in a safe and speedy manner.

Background

Most of the literature regarding emergency preparedness and emergency evacuation and disabilities refers to the acquisition of disabilities as the result of disasters such as hurricanes, earthquakes, and wars (e.g., Center for Disability Issues in the Health Professions (CDIHP), 2004). Very little research has been devoted to such incidents as the ice storm or to situations where people with disabilities are forced to live in environments associated with unaccustomed stressors and in environments which do not facilitate their getting around.

Discussion of the specific situation of the 1998 ice storm was found in three documents of Canadian origin, only one of which reported empirical findings (Gignac, Cott, & Badley, 2003). The other two documents are official reports by the Office des personnes handicapées du Québec presented to the Commission scientifique et technique[2] (1998b) and to the Commission sur la crise du verglas[3] (1998a).

Gignac, Cott, and Badley (2003) examined individual perceptions of pain levels and outcome measures of pain management and impairment from a medical model perspective. Their paper describes the impact of the 1998 Canadian ice storm on the physical and psychological health of older adults (age 55+) living with osteoarthritis and/or osteoporosis. Responses of 59 ice storm victims were compared to those of 55 matched controls living outside the ice storm area. Assessments of disability, pain, self-reported health, helplessness, depression, and independence were performed prior to the ice storm and approximately 17 months later. This study showed that 60% of ice storm victims lived with

others, 33% were divorced, 10% were widows and 2% were never married. From a health perspective, it was found that those who reported better health before the ice storm were less likely to report that the ice storm had an adverse impact on their chronic condition, whereas those who reported greater helplessness reported having been adversely affected by the ice storm.

The study's authors refer to external environmental barriers that had an impact on the outcomes of ice storm victims as *objective impact*. These include loss of heat, electricity, and phone service, damage to property, and whether people had to leave their homes. Half of the sample of ice storm victims reported receiving no support during the storm, while the other half reported that they did receive support.

In its report the Office des personnes handicapées du Québec (1998a) told the commission that, generally, service provision to persons with disabilities during the 1998 ice storm had gone relatively well, with the exception of several issues. First, although the major Montreal social service agencies, the "Centre local de services communautaire[4]" (CLSCs), and rehabilitation centres, were ready with emergency plans, some had not updated these in a long time. Except for those cases where individuals were not registered with these social service organizations, persons with disabilities were reached the first day of the ice storm. Second, services to Deaf and hard-of-hearing persons were inadequate due to a lack of captioning and sign language interpretation on television programs that informed the rest of the population about disaster updates. Third, also problematic was the lack of adequate means of transport to serve those who needed it. Police and fire departments had difficulty helping people with mobility disabilities who were also overweight. Fourth, problems were identified with respect to the ability of shelters to adequately provide services to persons with disabilities.

Manuals and guides exist to assist in the case of future disasters (e.g., LeBlanc, 1996; Mas-

son, 2001; Laroche, 2005). Most of these are meant to educate workers about impairments. For example, the Montreal Urban Community's (Masson, 2001) manual devotes some 30 pages to the description of impairments and another 20 to explaining how to evacuate people from long-term care facilities, their own homes, and other locations. These manuals assume that rescue workers and volunteers most likely do not have much experience with different types of impairments.

An important component that is often missing from the literature is self-assistance skill-building. Incidents such as the terrorist attacks on the United States on September 11, 2001 (CDIHP, 2004) and hurricanes (Takahashi, et al., 1997), among others, have shown that in the initial moments of a disaster and afterward persons with and without disabilities must often fend for themselves. Self-assistance skill-building and pre-planned evaluation of needs, such as described by the American Red Cross Disaster Services in their publication, *Disaster Preparedness for People with Disabilities* (n.d.), are likely to be useful tools in the face of disaster.

Present Investigation

The present investigation explored the experiences of Montreal residents with disabilities who endured the 1998 ice storm. In a quantitative investigation, Study 1 examined the experiences of 10 ice storm victims with disabilities via a structured questionnaire. Their responses were compared to those of 93 individuals without disabilities. Study 2 presented qualitative data gathered through semi-structured interviews about the experiences of women with disabilities during the ice storm.

Study 1

Method

Participants

Participants consisted of a convenience sample of 10 individuals, 5 men and 5 women, who self-reported at least one impairment and 93 nondisabled individuals, 42 men and 51 women. All participants were recruited from the greater Montreal community by students enrolled in "Introduction to Psychology" courses at Dawson College, a large English-speaking junior/community college, and by one of the authors (D.J.). The students recruited individuals in their neighborhoods. Students did not receive any monetary compensation or marks for helping to recruit participants.

Participants with disabilities were those 10 individuals who answered "Yes" to the question, "Do you have a disability?" Participants indicated the nature of their disability or disabilities on a self-report checklist. The mean age of participants with disabilities was 40 years (range 20-48). Mean age of participants without a disability was 37 (range 16-63). Six persons had a visual impairment, two had a mobility impairment, one had a hearing impairment, and one had both a mobility and a hearing impairment.

Materials

Demographic items. Ten items evaluated demographics and socio-economic status such as sex, age, education, marital status, income, disability status, rural/urban location, and pre-ice storm living arrangements (for example, alone or with spouse/partner).

Ice Storm Diary. A daily diary was used to record responses to questions inquiring about whether participants had electricity (yes/no/partial), whether they went to work (yes/no), where they slept that night (own home/public shelter/friend or family home/hotel/other location), whether they sheltered others in their home (if yes, how many), and whether they had telephone service (yes/no) and tap water (yes/no).

Ice Storm Experiences. A questionnaire, developed specifically for this investigation, focused on the nature and quality of participants' overall

Table 1

Comparison of Scores of Participants With and Without Disabilities				
Question	Participant Group	N	Mean	Meaning of Scores
In general, how many good/positive experiences did you have during the ice storm period?	With a disability	10	3.5	1= very few, 6=very many
	No disability	92	3.9	
In general, how many bad/negative experiences did you have during the ice storm period?	With a disability	10	3.6	1= very few, 6=very many
	No disability	93	3.2	
Compared to most others, how do you feel you coped psychologically during the ice storm period?	With a disability	8	2.3	1= much better, 6=much worse
	No disability	93	2.5	
Compared to most others, how do you feel you coped physically during the ice storm period	With a disability	10	2.8	1= much better, 6=much worse
	No disability	93	2.5	
Overall, how were you affected by the ice storm and its aftermath?	With a disability	10	3.8	1=very negatively, 6=very positively
	No disability	92	4.4	
Compared to how you usually feel, generally how anxious did you feel during the ice storm period?	With a disability	10	3.6	1= more anxious, 6=less anxious
	No disability	93	3.7	
Compared to how you usually feel. generally, how depressed did you feel during the ice storm period?	With a disability	10	3.8	1= more depressed, 6=less depressed
	No disability	93	3.7	
Compared to how you usually. sleep, generally, how well did you sleep during the ice storm period?	With a disability	10	3.2	1= much worse, 6=much better
	No disability	93	3.9	

experiences during the ice storm period. Items used 6-point Likert-type scales or an open-ended format and inquired about the nature and frequency of good/positive and bad/negative experiences, perceived physical and psychological coping during the ice storm period, number of moves, volunteer experiences, physical injuries and property damage, responsibility for the welfare of others, and consultations with health care and mental health professionals.

Good Things and Bad Things Checklists. Two checklists each included 35 items. Participants indicated as many items as applied. The "Good Things Checklist" included events that could have made people feel good during the ice

storm period (e.g., reading or hearing of people helping others, finding a warm place, knowing there were shelters to which one could go). The "Bad Things Checklist" included events that could have made people feel bad (e.g., feeling alone or uncared for, not having a hot shower or bath, reading or hearing about people taking advantage of the situation). Items were generated based on unstructured interviews and group discussions with approximately 100 individuals, including college students, middle-aged and older adults, and people with visual impairments. Several items appear on both the "Good" and "Bad Things Checklists" (including going to a shelter and going to work).

Procedure

Data were collected during late January and early February, 1998, within 1-2 weeks of most Montreal area residents regaining electricity. Participants were asked to use the period of January 5 to 17 as a frame of reference.

Results

The educational background of the 10 participants with disabilities varied from less than high school to a Master's degree. All ten participants were employed at the time of the ice storm; five full-time and five part-time. Four were married or lived with a partner. The other six were either divorced or separated. Five participants reported living alone, four lived with a spouse, partner or child, and one did not respond to this question.

Similarly, the educational background of the 93 nondisabled participants varied from less than high school to a doctorate. Sixty-seven participants (i.e., 72%) were employed at the time of testing and 54 (i.e., 58%) were married or lived with a partner.

Nine of the ten participants with disabilities lost power in their homes for some portion of the two-week ice storm period, seven for more than two days. Four of these participants went to work for at least a portion of the two-week

period. Similarly, 80 of the 93 participants (i.e., 86%) lost power at some time during the ice storm period, 76 (i.e., 82%) for two or more days.

Ice Storm Experiences

On a series of questions using 6-point Likert-type scales, participants reported on their experiences. Table 1 shows the mean scores of participants with and without disabilities. Because of the small size of participants with disabilities (n=10), it was not appropriate to carry out t-tests to compare their scores with those of the 93 nondisabled participants. We provide means in Table 1 only to show the direction of the results.

On the question dealing with how many good/positive experiences participants had, the results for those with disabilities showed a mean score of 3.5, on a scale where 1 equals very few and 6 equals very many. Similarly, the mean was 3.6 for the item that dealt with bad/negative experiences, indicating that, on average, participants with disabilities had scores in the middle of the scale for both positive and negative experiences. It is noteworthy that the scores of the 93 nondisabled participants were 3.9 and 3.2, respectively, suggesting that participants with disabilities had relatively fewer positive and more negative experiences than their nondisabled counterparts. Nevertheless, it should be noted that these differences are minimal, and that individuals with and without disabilities had, overall, similar experiences.

The mean score of participants with disabilities on the item dealing with how they were affected by the ice storm and its aftermath overall was 3.8, where 1 equals very negatively and 6 equals very positively, indicating that participants felt that, overall, they were affected slightly positively. The mean for the 93 nondisabled participants was 4.41, suggesting that participants without disabilities felt that their overall experience was slightly better than those of participants with disabilities.

Table 2

Rank	Item	Number of Participants	Percent of Participants
Highest Ranked Items from Good and Bad Things Checklists for Participants with Disabilities			

Rank	Item	Number of Participants	Percent of Participants
	Good Things		
1	Reading or hearing of people helping others	9	90%
2	Having a hot shower or bath	8	80%
3	Appreciating things we usually take for granted	8	80%
4	Hydro company doing all they could	8	80%
5	Finding a warm place	7	70%
6	Spending time with family members	6	60%
7	Having electric power	5	50%
	Bad Things		
1	Feeling worried or anxious about the situation	7	70%
2	Reading or hearing about people taking advantage of the situation	6	60%
3	Seeing the state of the streets and trees	6	60%
4	Hearing or reading about people dying	6	60%
5	Not knowing whether the electrical power would go out	5	50%
6	Not having a hot shower or bath	5	50%
7	Finding the situation going on for too long	5	50%

Note. Responses provided by all 10 participants with disabilities.

We also asked participants, "Compared to most others, how do you feel you coped *psychologically* during the ice storm period?" and, "Compared to most others, how do you feel you coped *physically* during the ice storm period?" The response scale ranged from 1 equals much better to 6 equals much worse. The mean score of participants for psychological coping was 2.3. It was 2.8 for physical coping, suggesting that participants felt they coped slightly better than average. The corresponding scores of the 93 nondisabled participants were 2.5 on both scales, suggesting that participants with disabilities felt they coped psychologically somewhat better and physically somewhat worse than their nondisabled counterparts.

It can be seen in Table 1 that the mean score of participants with disabilities on the item that asked about anxiety experienced during the ice storm period compared to other times was 3.6, indicating that there was no change in participants' anxiety level during the ice storm. The same was true of nondisabled participants, whose mean score was 3.7. The mean score of participants with disabilities on the item that asked about how depressed they were was 3.8, again indicating that there was no difference in their depression level during the ice storm and at

Table 3

Rank	Item	Number of Participants	Percent of Participants
Highest Ranked Items from Good and Bad Things Checklists for Participants Without Disabilities			
Good Things			
1	Having a hot shower or bath	72	77%
2	Having hot food	61	66%
3	Appreciating things we usually take for granted	67	72%
4	Spending time with family members	59	63%
5	Feeling of being able to cope	58	62%
6	Finding a warm place	58	62%
7	Seeing the ice on the trees as beautiful	56	60%
Bad Things			
1	Reading or hearing about people taking advantage of the situation	68	73%
2	Seeing the state of the streets and trees	58	62%
3	Hearing or reading about people dying	53	57%
4	Not knowing whether the electrical power would go out	46	49%
5	Finding the situation going on for too long	46	49%
6	Not having a hot shower or bath	43	46%
7	Feeling worried or anxious about the situation	37	40%

Note. Responses provided by all 93 participants without disabilities.

other times. The mean score of nondisabled participants was 3.7. Thus, there is virtually no difference among participants with and without disabilities or between anxiety and depression levels before and during the ice storm.

Table 1 also shows that participants with disabilities had a mean score of 3.2 on the item which inquired about how well they slept during the ice storm period. This indicates that their sleep was slightly worse than usual. In contrast, the sleep of participants with no disabilities, with a mean score of 3.9, was slightly better than usual.

Participants were asked, "Where did you spend your time during the daytime during the ice storm period?" and told to check all options that applied. Results indicate that approximately half of both groups of participants stayed home, went to work, and visited friends or relatives at some time during the ice storm period. A substantially larger proportion of participants with (60%) than without disabilities (27%) looked after others in their home and went to a shopping mall (40% vs. 12%, respectively). None of the participants went to a public shelter.

Seventy percent of those with and 82% of those without disabilities reported having lost

power for at least two days (i.e., enough time for one's home to cool down significantly and for items in the refrigerator to spoil). Responses of participants with and without disabilities about how they coped with the lack of electricity indicate that approximately 2/3 of participants in both groups used candles and/or an oil lamp for light. Large numbers in both groups (approximately 40%) used candles as well as a fireplace for heat. Approximately 1/3 of participants in each group had to heat water for washing and/or washed in cold water. About 10% of each group used a wood stove and/or a generator to heat and cooked on a fondue burner. Nondisabled participants also reported that they cooked on a wood fire and/or an outdoor barbecue.

Seventy percent of participants with and 58% of participants without disabilities stated that they had a shortage of, and had difficulty obtaining, some essential supplies. Results indicate that the largest numbers of individuals in both groups experienced a shortage of batteries. Shortages also occurred for both groups in wood, water, and food. Substantial numbers in one group or the other also had a shortage of candles, fondue burner fuel, and money. None of the participants experienced a shortage of medication.

One of the 10 participants with a disability responded to the question on sustained injuries and stated that he or she had "stiff muscles" and five experienced some form of property damage. Similarly, 10 of the 93 nondisabled participants (i.e., 11%) indicated an injury and 52 (i.e., 56%) noted some form of property damage.

Examination of the open-ended question on best moments during the ice storm revealed two types of responses. Some participants with disabilities were delighted when the ice storm was finally over and mentioned that the moment their power was restored was the best moment. Others, who made the best of the experience, expressed that "being safe and comfortable," "keeping the house habitable," "keeping pipes

from freezing," "being with friends and family," and "not having school" were their best moments.

With regard to their worst moments, several participants made reference to not being able to meet their basic needs. For example, "not being able to find wood," "not having food," "not being able to sleep or take a shower," were common responses. Others referred to the danger of injury or damage to their property, such as the "potential for falling when outside," "flooded basement," and "leaking roof."

Good Things and Bad Things Checklists

Examination of participants' responses showed that the most frequently identified items were the same for both Checklists (see Tables 2 and 3). For example, "not having a hot shower or bath" was a popular negative item while, "having a hot shower or bath" was a popular positive item. Although participants with and without disabilities identified some of the same items, the ranking of the items was slightly different for the two groups. Participants in general were more likely to check off an item that was phrased in the positive (e.g., "reading or hearing of people helping others") than the corresponding item phrased in the negative (e.g., "hearing or reading about people dying").

Results in Tables 2 and 3 show that participants with and without disabilities indicated identical 7 worst experiences on the 35 item Checklist (i.e., top 20%). In alphabetical order these are: feeling worried or anxious about the situation, finding the situation going on for too long, hearing or reading about people dying, not having a hot shower or bath, not knowing whether the electrical power would go out, reading or hearing about people taking advantage of the situation, and seeing the state of the streets and trees. There was somewhat greater variability between groups on the "Good Things Checklist," although here, too, most (4/7) of the top ranked items were common to both groups. In alphabetical order these are: appreciating things

we usually take for granted, finding a warm place, having a hot shower or bath, and spending time with family members.

Discussion

As suggested by the Social Model of Disability, persons with disabilities are accustomed to living in disabling environments under noncrisis conditions. We hypothesized that the additional disabling circumstances created by an unexpected crisis would create greater social barriers for persons with disabilities.

For the purposes of the present study, we operationally defined "disabling situation" as having been without power in the home for more than two days. A lack of electricity for two or more days typically meant that people were deprived of basic needs such as food and warmth because appliances, such as refrigerators, freezers, and heaters had not have been functioning for an extended period. Although such adverse circumstances affect everyone, for some persons with disabilities, a lack of electricity as a result of the ice storm could have been responsible for the inability to recharge motorised wheelchair batteries or, in some cases, to operate respirators.

In our samples, approximately 90% of individuals lost power at some time during the ice storm period. Approximately 75% of both samples were without power in their homes for more than two days. According to the definition of objective impact given by Gignac, et al. (2003), as they were affected by external environmental barriers that had an effect on their outcomes, these participants can be classified as having experienced "high objective impact."

It was interesting to find that our two samples experienced very similar problems and outcomes during the ice storm period. For example, approximately half of both groups of participants stayed home, went to work, and visited friends or relatives at some time during the ice storm period. Approximately 75% of partici-

pants in both groups remained at home in spite of lengthy periods without electricity and none went to a public shelter.

To cope with the lack of electricity, almost two-thirds of participants in both groups used candles and/or an oil lamp light. Candles and a fireplace were frequently mentioned as means of providing heat. Less common options for providing heat mentioned by approximately 10% of each group include using a wood stove and a generator. Many individuals reported that they had to heat water for washing and that they washed in cold water. Some participants cooked on a fondue burner.

About two-thirds of participants in both groups had a shortage and experienced difficulty obtaining some essential supplies. The worst shortage was in the case of batteries. Shortages also occurred in wood, potable water, candles, fondue burner fuel, and money. None of the participants experienced a shortage of medication.

The two groups of participants were in good agreement about the most important good and bad experiences during the ice storm period. Negatives include: feeling worried or anxious about the situation, finding the situation going on for too long, hearing or reading about people dying, not having a hot shower or bath, not knowing whether the electrical power would go out, reading or hearing about people taking advantage of the situation, and seeing the state of the streets and trees. Positives were: appreciating things we usually take for granted, finding a warm place, having a hot shower or bath, and spending time with family members.

Perhaps the most important aspect of the findings relates to understanding what happens to people during a sustained power outage in the winter and appreciating the types of resources needed to cope. For example, most people stayed home in very cold dwellings instead of staying with others or going to a public shelter. In doing so they experienced a variety of

shortages, most notably in batteries and wood for heating and fondue burner fuel for cooking. Water and insufficient food also posed problems. Although many people experienced some type of property damage, the worst thing for most were the intangibles, such as hearing negative news and uncertainty about the duration of the emergency situation. Positive experiences largely consisted of the absence of negatives with one notable exception: people reported that the crisis allowed them to spend more time with family and friends.

Study 2

The second study investigated the experiences of female members of a non-profit advocacy organization for women with disabilities. During and after the ice storm, members of the board of directors of "Action des Femmes Handicapées de Montreal"[5] (AFHM) made efforts to be in touch with each other as well as with most of the membership.

Method

Participants

Fifteen female members of the group "Action des Femmes Handicapées de Montréal" (AFHM) were interviewed by one of the authors, 6 of them in-depth. The women were between the ages of 20 and 55.

Materials

The initial interviews consisted of informal conversations with the participants to verify how they had been coping during the ice storm. After the ice storm, more structured follow-up interviews took place, consisting of the following questions: Where did you stay? What do you remember most about this experience in relation to your disability? What obstacles did you encounter?

Procedure

On Saturday, January 10, 1998 the monthly meeting which had been planned for the organi-

zation was cancelled as a consequence of the ice storm. A few days before the planned meeting, one of the authors attempted to contact the 15 participants by telephone. Nine of the women could not be reached due to ice storm-related problems with telephone lines and power failures or because the women were not staying at home. The other six women were reached at their homes. One week after the ice storm, the participants were contacted a second time and the more structured interviews took place.

Results

The information gathered via the two interviews revealed how the ice storm affected the daily activities of the women. Three reported staying with friends during the ice storm while three others reported staying in shelters set up by the city.

One woman with a visual impairment recounted her living situation during the storm. After having lost power, she spent one night in her apartment. The following day she got in touch with a community organization, the "Regroupement des Aveugles et Amblyopes du Montréal Métropolitain (RAAMM),"[6] which helped her move into a nearby shelter. The shelter was a large gymnasium. As she was not familiar with this location, she chose not to walk around by herself, thereby limiting her autonomy. She also described the lack of privacy she encountered, specifically in the bathing area where many women shared a tiny shower and hot water was limited. "People were nice, but I felt ill at ease," she said. She spent only three days at the shelter before asking her brother to pick her up.

A second woman, who had fibromyalgia and arthritis, also stayed in a shelter. She found the large gymnasium difficult to move around in and noticed that she was often last in line when provisions such as cots and food were being distributed. She spent four days at the shelter. On the fifth day she went home to see if power had been restored and decided to stay in her apartment. For two days and nights she experienced

frequent and unpredictable power outages. Electricity was fully restored on the third day. Of her experience at the shelter she said, "Because people could not see my disability, they assumed I was OK. So, no one offered to help. I paid the consequences of this later as the pain was so bad for weeks after the storm." The chairperson of the group did not lose power at her home. She, therefore, played host to several friends as well as her daughter. She reported that, for her, it seemed like, "a big party for three days." Another participant, who was diabetic, did not view the experience as favourably. As she put it, "The worst part, for me, was having to get used to eating cold, uncooked food for days because I used the available power to do other things. I wonder how our great-grandparents lived."

Another woman, who used a cane to walk, reported having fallen when she tried to get to a shelter on her second day without power. Consequently, she decided to go back home and tough it out under a pile of blankets. On the fourth day she was assisted in getting to a shelter, but stayed only two nights before the power was restored. Another woman, who had polio, had spent four days alone at home, in bed and without electricity before being taken to a rehabilitation center. Members of AFHM discovered that she had died a few days later at the rehabilitation centre. The remaining nine women either stayed home, where they endured frequent power outages, or stayed with family members.

Discussion

The experiences of the AFHM group help to illustrate two points. First, women with disabilities, who were offered help, accepted it for the most part, even though the services they received were not always adequate to meet their needs. Second, as others have noted, being aware of the location of persons with disabilities is central to emergency preparedness programs (Office des Personnes Handicapées du Québec, 1998a; Takahashi, et al., 1997).

The Social Model of Disability makes reference to the lack of access for persons with disabilities to everyday tools that allow nondisabled persons to move around in the environment and perform social activities (Oliver, 1993). This lack of access creates *disabling conditions* for persons with impairments. The data presented in Study 2 illustrate, that disabling conditions can also take the form of assistance that is put into place in times of unexpected crisis (e.g., lack of access to shelters, lack of knowledge about invisible disabilities, etc.). Such disabling conditions are due to lack of preparedness and lack of attention paid to the needs and concerns of individuals with disabilities. As seen in Studies 1 and 2, the presence of an impairment did not produce differential results in the way ice storm victims experienced this crisis. Rather, it was the environmental obstacles within the resources provided that created different, but not necessarily greater, disabling conditions than the women in Study 2 would have experienced in their everyday environments.

As reported by Enarson (2002) and Castaneda (2005), disaster preparedness is designed for the general population, without taking into account subgroups with specific needs, for example groups who are typically associated with high poverty rates, such as the elderly, persons with disabilities, members of visible minorities, the homeless, and single mothers. These people experience disabling conditions in one form or another even under non-crisis circumstances. Thus, if the tools put into place to help in times of crisis are not designed with their specific needs in mind, the end result is greater disabling conditions for members of these groups relative to the rest of the population.

General Discussion

Our original expectation was that the additional disabling circumstances created by an unexpected crisis would create greater social barriers for persons with disabilities. In fact, our results suggest that participants in Study 1, who

remained in their regular environments, faced a different set of social barriers in comparison with participants in Study 2, who left their homes to seek out shelter and assistance. Participants with and without disabilities in Study 1 were equally likely to report experiencing new barriers created by the ice storm, such as not being able to cook, not being able to go out to work, and having property damage. Participants in Study 2 experienced different barriers as a result of being in a different environment.

Several differences between the methodologies and participant characteristics in Studies 1 and 2 may have led to the dissimilarities between the findings of the two studies. In Study 1, participants were recruited from a primarily English-speaking Montreal community and did not know each other. These respondents completed a questionnaire. In contrast, the participants in Study 2 were mostly French-speaking members of an advocacy group, which met regularly. These respondents were interviewed by one of the authors, who herself was a member of the group at the time of the interviews. As women with disabilities who were part of an organized advocacy group, these individuals were likely well informed with respect to self-help and well practiced at identifying problems and finding solutions. As well, as group members, these women had formed an alliance which may have enhanced their ability to help themselves (Carpinello, Knight, & Jatulis, 1992). These qualities may have made the women in Study 2 more likely to seek out assistance and to cope with the obstacles they encountered in unfamiliar surroundings.

The gender of the respondents in the two studies may have also contributed to the differences in results. In Study 1, participants were divided almost equally between the two genders, while Study 2 participants were only women. According to the Pan-American Health Organization (2006), there are some gender based differences in response to natural disasters:

"Women are most effective at mobilizing the community to respond to disasters. They form groups and networks of social actors who work to meet the most pressing needs of the community. This kind of community organizing has proven essential in disaster preparedness and mitigation" (p. 1).

As Enarson (2002) explains, "Gender inequalities embodied in everyday life put girls and women at special risk" (p. 2). She further describes that relevant differences and inequalities among women and men throughout the disaster process are increasingly being documented:

"But living life as a woman also empowers women at critical junctures, from risk assessment and hazard mitigation to emergency preparedness, disaster response, and post-disaster reconstruction. Accounts were shared of women's efforts to reduce social vulnerabilities and identify and mitigate environmental hazards in the communities they know best. Again and again, we learned that women build communities, promote safety, and reweave the fabric of everyday life after disasters" (p. 3).

The findings of our two studies are consistent with the literature in terms of disaster preparedness. In particular, it is necessary for the locations of persons with disabilities to be known so that assistance may be provided. Furthermore, persons with disabilities must be equipped with self-assistance skills to survive in times of crisis. The dearth of literature concerning persons with disabilities in times of disaster reflects the fact

that those who have disabilities have been integrated in the general community only relatively recently (Longmore & Umansky, 2001). Therefore, it is not surprising that sophisticated and regularly updated crisis intervention plans are not readily available for them.

Participants with disabilities in our investigation implied that they had to care for themselves much of the time during the ice storm. When disaster strikes, neither individuals with nor without disabilities can be guaranteed that assistance will be readily available. Thus, manuals that detail how persons with disabilities and their caregivers can prepare themselves for disasters are crucial. *Disaster Preparedness for People with Disability,* by the American Red Cross Disaster Services (n.d.), contains a personal assessment sheet which can be used to identify what individuals with disabilities can do in the event of disaster and what kinds of help they may need. In addition, safe and speedy rescues can be facilitated if emergency response teams have access to resources which help to ensure safe outcomes for persons with disabilities.

One limitation of the studies presented here is the small number of individuals with disabilities in our samples. This restricts the generalizability of our findings. Nevertheless, the small number of participants with disabilities in Study 1 reflects the incidence of impairment in the population studied. Also, these individuals were sampled in the same way and from the same population as the nondisabled participants. This resulted in a sample of participants with disabilities which was very similar to the nondisabled sample on a number of demographic parameters. Yet, their small number made inferential statistical tests inappropriate, leaving us with descriptive findings only. Also, the initial interviews of Study 2 emerged as a result of the ice storm and were not pre-planned. Although efforts were made in designing the post-storm interviews to compensate for this, the amount of information yielded by these interviews was limited in type and quantity.

"Disasters unfold in worlds shaped by culture and class, race and ethnicity, age, physical abilities and other power relations—including those based on gender" (Enarson, 2002, p. 2). Different individuals in different environments will not face the same barriers in times of crisis. Disaster preparedness must take into account not only the nature of the disaster but also both the characteristics of individuals as well as of their environments.

Catherine Fichten holds a Ph.D. in Psychology. She is a Professor in the Department of Psychology at Dawson College and is an Associate Professor in the Department of Psychiatry at McGill University. She co-directs the Adaptech Research Network.

Maria Barile holds a Master's in Social Work and has been a community-based activist in disability and women's issues for many years. She co-directs the Adaptech Research Network.

Vittoria Ferraro is a Master's student in Educational Psychology at McGill University. She is a research assistant at the Adaptech Research Network.

Endnotes

[1] Offices des personnes Handicapées du Québec (Offices for persons with disabilities)
[2] Commission scientifique et technique (Scientific and Technical Commission - a parliamentary commission)
[3] Commission sur la crise du verglas (Commission on the ice storm crisis - a parliamentary commission)
[4] Centre local de services communautaire (Local Community and Social Services Centre)
[5] Action des femmes handicapées de Montréal (a Montreal based disabled women's organization)
[6] Regroupement des aveugles et amblyopes du Montréal métropolitain (an organisation of blind and partially sighted persons in Montreal)

References

American Red Cross Disaster Services. (n.d.). *Disaster preparedness for people with disabilities*. Retrieved March 7, 2006, from http://www.redcross.org/services/disaster/beprepared/disability.html

Center for Disability Issues in the Health Professions. (2004). *Disaster preparedness for people with disabilities*. Pomona, CA: Western University of Health Sciences. Retrieved March 7, 2006, from http://www.cdihp.org/links.html

Carpinello, S. E., Knight, E. L., & Jatulis, L. L. (1992). A study of the meaning of self-help, self-help group processes, and outcomes. *Proceeding of the Third Annual Conference on State Mental Health Agency Services Research and Program Evaluation*. Alexandria, VA: NASMHPD, Inc.

Castaneda, D. (2005, November 9). Emergency preparedness heeding Katrina's lessons. *The San Francisco Chronicle*, p. B13.

Enarson, E. (2002, March). *Building disaster resilient communities: Learning from community women*. Paper presented at the meeting of the United Nations Commission on the Status of Women Forty-Sixth Session, New York, NY. Retrieved June 28, 2006, from http://www.un.org/womenwatch/daw/csw/csw46/panel-Enarson.pdf

Gignac, M. A. M., Cott, C. A., & Badley, E. M. (2003). Living with a chronic disabling illness and then some: Data from the 1998 ice storm. *Canadian Journal on Aging*, *22*, 249-259.

Kailes, J. (1996). *Living and lasting on shaky ground: An earthquake preparedness guide for people with disabilities*. Los Angeles, CA: Governor's Office of Emergency Services. Retrieved March 7, 2006, from http://www.oes.ca.gov

Laroche, R. (2005). La prévention des incendies et l'évacuation des résidences hébergeants des personnes âgées. Québec, Québec: Ministère de sécurité publique.

LeBlanc, A. (1996). *Évacuaction d'urgence des personnes atteintes de diverses déficiences -- Petit guide pour les cégeps*. St-Lambert, Québec: Champlain College.

Longmore, P. K., & Umansky, L. (2001). *New disability history: American perspectives*. New York: New York University Press.

Masson, F. (2001). *Guide d'intervention adaptée en mesures d'uregence auprès des personnes handicapées et des personnes a mobilité réduite*. Montréal, Québec: Centre de sécurité civile de la Communauté urbaine de Montréal.

Oliver, M. (1990). *The politics of disablement*. London: Macmillan Education.

Oliver, M. (1993). *Social work: Disabled people and disabling environments*. London: Jessica Kingsley.

Office des personnes handicapées du Québec. (1998a). *Mémoire de l'OPHQ à la crise du verglas*. (DEIP-1034). Drummondville, Québec: Government of Québec.

Office des personnes handicapées du Québec. (1998b). *Mémoire présenté à la Commission scientifique et technique chargée d'analyser les événements relatifs à la tempête de verglas*. (DEIP-1032). Drummondville, Québec: Government of Québec.

Pan-American Health Organization. (2001). *Fact sheet program on women, health and development: Gender and natural disasters.* Retrieved June 28, 2006 from http://www.gdnonline.org/resources/paho-gender&disasters.doc

Takahashi, A., Watanabe, K., Oshima, M., Shimada, H., & Ozawa, A. (1997). The effect of the disaster caused by the great Hanshin earthquake on people with intellectual disability. *Journal of Intellectual Disability Research, 41,* 193-196.

Disaster Relief for Deaf Persons: Lessons from Hurricanes Katrina and Rita

Barbara White, Ph.D.
Gallaudet University

Abstract: Victims of disasters who are deaf face unique and insurmountable obstacles in accessing disaster relief. The response to deaf disaster victims of Hurricane Katrina is an example of how the Federal government failed this population, particularly the community of Deaf African Americans who lived in New Orleans' Lower Ninth Ward. In the aftermath of this disaster, the natural helping networks of the deaf community and its organizations proved to be more effective than the organized relief agencies. The author, a deaf social worker, spent two weeks in the Gulf region assisting deaf evacuees who fled both Hurricane Katrina and Hurricane Rita during the now infamous hurricanes of 2005.

Key Words: disaster preparedness, Hurricane Katrina, deaf organizations

When disaster strikes an entire geographic area with a sizeable deaf population, such as New Orleans, the Deaf community, its organizations and churches, are better positioned to provide help than the major government-sponsored relief organizations. As a deaf professional social worker with disaster mental health training, I spent two weeks in Houston in September, 2005 working with deaf evacuees. This paper is the story of my experience.

When the weather forecasts began to predict a devastating hurricane hitting landfall in the Gulf region of the United States, the deaf[1] community began to prepare for the worst. We are all too familiar with lack of health, education, social and mental health services, and political representation on a daily basis. We knew there were many deaf people in the Gulf Region, and many of them were poor without access to the technology that more affluent deaf people have

such as computers with Internet access, mobile pagers, captioned television and video phones. Were they receiving the warnings about Hurricane Katrina? Did they have access to captioned television broadcasts, text pagers, or even concerned neighbors to convey the warnings to them? The Federal government failed dismally in its response to one of the worst natural disasters in the United States (Hseu, 2006). The response to persons who are deaf and hard of hearing was also dismal, and exposed the widespread neglect of this community, particularly the community of Deaf African Americans who lived in New Orleans' Lower Ninth Ward. The only people who truly recognized the needs of this group were people already connected with the deaf community: deaf professionals, deaf organizations, sign language interpreters, and "deaf churches"—churches with the expressed mission of serving a deaf congregation.

Calls for Help Meet with Resistance

In the days following Katrina's destruction, the Gallaudet University Mental Health Center received requests for help from the deaf communities of Baton Rouge and Houston, two cities that were sheltering the majority of the evacuees from New Orleans. I volunteered for deployment since I had been certified as a Red Cross Disaster Mental Health Service (DMHS) volunteer. While hearing professionals with the same education and training were being sent daily, I would not be sent for another week. The delay in sending me and other colleagues from Gallaudet, the only liberal arts university for deaf and hard of hearing students in Washington, D.C., was because the major relief agencies would not acknowledge the need to deploy trained mental health professionals with fluency in American Sign Language to work in the Gulf region. They did not acknowledge that there was a "significant" need.

Whatever the reasons for this resistance, whether it was financial, or because the deaf population comprised a miniscule percentage of

the total number of evacuees, or because relief agencies were not trained to communicate or work with deaf people, it was clear that an entire group of people who needed disaster relief was being summarily dismissed by the major relief organizations.

After many phone calls and emails among Gallaudet University representatives, the American Red Cross agreed to deploy two mental health professionals with disaster training and fluency in American Sign Language to Louisiana. A "deaf shelter" was set up at the Louisiana School for the Deaf. The other four disaster mental health providers were sent with the financial backing of Gallaudet University. Two professionals, including myself, were sent to Houston, without the auspices of any major relief organization. We were on our own.

Needs of Deaf Persons in Evacuation Centers

The evening of my arrival in Houston on September 18, 2005, there was a community wide meeting at Woodhaven Baptist Deaf Church, located in the northwest quadrant of the city. At this meeting reports were given about the services provided the previous week to deaf evacuees at the Houston Astrodome and the nearby George R. Brown (GRB) Convention Center. Both of these large facilities served as evacuation centers and mass shelters for thousands who fled New Orleans and the surrounding towns. Frustration with the major relief organizations and fragmented services to deaf people were quite obvious from the speakers at this community meeting. A sign language interpreter told the group about going to the GRB shelter with other volunteers and using a large sign to identify the deaf evacuees there so they could be together and provide services. Because the majority of the deaf evacuees used American Sign Language, few of the shelter volunteers could communicate with them, and in some cases, evacuees tried to send these volunteers away. The deaf evacuees missed out on im-

portant announcements that streamed from the public address systems of the large shelters. The announcements instructed evacuees which line to stand in to get federal financial assistance, which line to go to for medical appointments, and how to register to locate missing relatives. Deaf evacuees never got this information and thus were passed over for services the first week at the shelter (Parks & Warren, 2005).

My colleague and I arrived in Houston 19 days after Hurricane Katrina, and three days before Hurricane Rita. We prioritized needs day to day. We were sent to provide "psychological first aid," a term the Red Cross uses to provide emotional support following a disaster. In reality, we did everything from case management to driving evacuees to get food and supplies, helped with applications for Social Security Disability Income, FEMA money, and school registrations for the evacuees' children. At times the adults found catharsis in retelling their rescue stories, vividly describing their ordeals in ASL. One deaf man told me he was airlifted by helicopter from his roof to a shelter in rural Louisiana. He had no one to communicate with for two weeks because no one at the shelter knew ASL. He was trying to explain to the shelter volunteers that he was separated from his family and wanted to find them. He miraculously saw them on television when Oprah Winfrey was interviewing evacuees in the Houston Astrodome. He finally made the volunteers understand by pointing to the television that his family was in Houston and he was eventually sent there to be with them.

We spent a lot of time on the computer trying to locate missing relatives and getting FEMA checks sent to their new address. My colleague, Alexis Greeves, a certified play therapist, worked with the children with play activities to help them express their grief and loss. The residents used the church's new videophone—a new technology that allows video conversations in sign language using a television monitor and computer. In this way the evacuees could connect with missing relatives and know they were safe.

One deaf woman cried with joy at the sight of her deaf daughter on the videophone. She was evacuated to another state and had been missing for several weeks. When we drove her to the airport to fly to meet her daughter, she said she had never been on a plane before. It was a new experience for her being inside an airport. Although she had no identification, the airlines allowed her to board after going through security.

A Deaf Church's Response

Faith-based organizations all over the city reached out to evacuees with donations and meals. The Woodhaven Baptist Deaf Church was the only church in Houston that reached out to the deaf evacuees. Food, clothing, children's toys and equipment, household items, supplies, hearing aids, TTYs (telecommunication devices to make phone calls), were donated by church and community members. The church was used for community meetings to plan strategies to provide relief, as well as special prayer services for missing relatives and community members. The church also provided critically important relief services in a "deaf friendly" environment where everyone there used American Sign Language (ASL). The deaf church has a critical role in times of disaster, and this church rose to the occasion. The church essentially became a social agency and a center for social support for the evacuees.

Volunteers from the deaf community offered tangible assistance and support to the evacuees in the days following Hurricane Katrina, but after several weeks they experienced "helping fatigue" and their numbers waned. The church pastor, Arthur Craig, and his staff provided the bulk of the needed services in the aftermath of both Hurricane Katrina and Rita, even hiring a person to serve as case manager for several months after the storms.

Some of the deaf evacuees found family members and friends to live with, but four families were immediately relocated to apartments in close proximity to the church. Making home

visits to the apartments was the first step in identifying needs of the residents and also building trust. Since they had just moved in, basic items were needed such as cooking utensils and shower curtains, and things needed fixing such as sink drains and air conditioning, which we reported to the apartment manager. We spent the first few days taking the residents in small groups to shop for needed items and these outings provided an opportunity to engage them in a helping relationship.

Evacuating the Evacuees

Three days after arriving in Houston, there were new warnings about another hurricane named Rita. The warnings grew more intense and the adults in our group pointed to the captioned television forecasts with concern and fear. They had just evacuated New Orleans, and now we were being told to evacuate Houston. They had signed a six months' lease on their new apartments, and now they had to evacuate. The church's pastor, Arthur Craig, rented a van and helped prepare for a 165-mile trip to Austin, where volunteers were waiting for us in a shelter supposedly being set up as "deaf friendly" with interpreters ready to assist us with registration when we arrived. They waited all night because it took us 15 hours to get to Austin. Normally this is a three-hour drive. The evacuation route was clogged and poorly planned with millions of other people evacuating at the same time. The most harrowing part of this trip for me was having a pregnant deaf mother and her three children in my car and not being able to hear the radio for updates on the hurricane warnings. Before we started out, the captions on the television read "Rita now a Category 5 monster." Driving was the easy part; the hard part was not knowing if we were still in danger. I subscribed to emergency alerts on my Sidekick pager, but I did not have reception in some of the towns we passed. During the night my husband back in Maryland emailed to my pager alternate routes to try that he found on Mapquest. One could

say that text pagers are a deaf person's best friend; in this case I felt it was a life saving device.

In the late morning of August 22, our caravan of eleven evacuees and two volunteers arrived at the first shelter supposedly set up for deaf evacuees. We were told it was closed and given instructions to go to a nearby high school that was also sheltering evacuees. We got to the high school and everyone got out of the van to unload their belongings, which they had packed in large green trash bags. Then we were told this shelter was also full and we had to go to another one. Finally, exhausted and irritated that space was not held for the deaf or other disabled evacuees, we were escorted to the next shelter by two deaf community members who worked for a nonprofit organization, Community Services for the Deaf (CSD). Soon after our arrival, we put up signs on the front of the school which read, "Deaf evacuees welcome here."

To our disappointment, there were no cots set up at this shelter. I felt guilty because my colleague and I had been offered beds at the nearby Texas School for the Deaf. Leaving our group there with no beds was out of the question. By this time I felt totally responsible for this group of deaf evacuees, and after driving them away from another hurricane for 15 hours, I felt like they were family. This is a feeling that Shein (1989) calls "at home among strangers," in his book by that name, and proposed a theory of the deaf community that includes both a strong sense of affiliation no matter where deaf people live in the world, as well as a sense of alienation from the hearing society that does not understand them. This strong sense of affiliation among deaf people provides a natural helping network. This was demonstrated in Austin when we realized there were no beds at the shelter. We sent the word out to the deaf community that cots and mattresses were needed by the deaf evacuees. Within hours they began arriving, along with a captioned television and TTY devices for deaf evacuees to make phone calls. It was rather amusing that we had to sneak the items

in while all the evacuees were in the cafeteria, as there was a policy in the shelter that donations cannot be targeted to any one person or group. Yet, this was a clear demonstration that the deaf community network was more efficient that any major relief organization! The Texas School for the Deaf gave us dorm rooms when the shelter closed after the second day—another example of "deaf helping deaf."

We spent three days in Austin. We connected with the local deaf church in Austin, whose pastor came to visit the evacuees. We found deaf community volunteers to take some of the evacuees to the deaf club. Although the communication with some evacuees was difficult, due to their educational backgrounds and distinct New Orleans sign language, there were obvious feelings of connection among the evacuees and deaf community volunteers. After the Mayor of Houston announced it was okay to return to Houston, we headed back, and this time the trip only took four hours.

We kept a blog of our experience on the laptop we brought, which turned out to be therapeutic on a personal level as we could share our experience on a daily basis with people back home. One of the evacuees wanted to type an entry into the blog to express his feelings about the evacuation:

> "Hello. i m happy that Dr. Barbara White and Ms. Alexis Greeves good active going to keep business help people help for deaf that wonderful more for safety hurricane katrina. pastor chruch friend going to help them becxz of reason come again hurricane in houston tx what have plan get van and car make sure plan night pickup everybody went to travel wow traffic full i make sick of this traffic very slow in hrs 21 arrive there in austin tx.

> we went at in shelter for while time 3 days. but dr .barbara and ms.alexis still see check there in shelter becxz make sure everbody okay" (White and Greeves, 2005).

Helping the Helpers

First responders and volunteers often need emotional help in times of disaster as well as the victims. We found this to be especially true when we listened to the stories of the "first responders" to the deaf Katrina evacuees—the interpreters and community volunteers who reached out to the deaf evacuees when they first arrived at the Houston Astrodome. We held a community meeting specifically for the helpers to discuss and understand symptoms of post traumatic stress disorder. It was apparent that many of the helpers were experiencing some signs of PTSD as they expressed angry feelings about the way the deaf evacuees were treated.

Evidence of Need to Deaf Disaster Victims

A report by the National Organization on Disability highlights the neglect of deaf and hard of hearing people during Hurricane Katrina:

> "The most underserved group were those who are deaf or hard of hearing. Less than 30% of shelters had access to American Sign Language interpreters, 80% did not have TTYs, and 60% did not have TVs with caption capability. Only 56% of shelters had areas where oral announcements were posted so people who are deaf, hard of hearing or out of hearing range could go to a specified area to get or read the content of announcements. This meant that the deaf or hard of hearing had no access to the vital flow

of information" (National Organization on Disability, 2005).

A month after Hurricanes Katrina and Rita, I participated in an online discussion sponsored by The American Deafness and Rehabilitation Association (ADARA) on disaster planning and the deaf community. The quotes below highlight the frustration felt by concerned professionals who work with deaf people all over the country (American Deafness and Rehabilitation Association, 2005):

> "We were told "insufficient evidence of need" [by FEMA].
>
> "If FEMA had told us last year that the problem was insufficient money, I could have dealt with that more than 'deaf people don't need it'."
>
> "We have had no success in getting in touch and volunteering [as interpreters] to help."

There are no studies focusing on a specific group of people with disabilities in disaster planning, so not much is known about the deaf community, blind community, or other disability groups in terms of disaster planning and preparation. There is an ongoing study at the University of Kansas, "Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments." This is a three year project funded by the Center for Disease Control (http://www.nobodyleftbehind2.org/). Yet, even this federally funded study may overlook investigating the unique communication needs of particular groups such as deaf people. A deaf colleague, in advocating for inclusion of deaf people in disability studies research and disaster preparation planning, shares her biggest fears in being caught in a disaster, which highlights some of these unique communication needs of deaf people:

> "One of my biggest fears, if I should ever be caught in a disaster, is that I could become injured, or maybe miss out on opportunities to pick up food, water, and other supplies, due to missing full access to information disseminated in an auditory format, or maybe have rescuers overlook me because I don't hear and respond to their calls. I can picture myself in a group of frightened hearing people who are clearly listening closely to some announcement I cannot hear, feeling even more frightened than anyone else because I have even less information about what's going on. And I wonder, 'Who will make sure I'm not left out.' If I ask someone to repeat important information to me will they help or will they be impatient because they are under such extreme stress themselves? Will they remember me the next time important information is disseminated or will I have to ask again, or ask someone else?" (Shettle, 2005).

Ongoing Challenges for Deaf Organizations in Disaster Preparedness

Deaf organizations around the country rallied to set up special funds and services for deaf evacuees. Gallaudet University provided financial support for four employees to deploy to the Gulf region in the aftermath of Hurricane Katrina. The University Mental Health center set up a free counseling service to provide psychological first aid to any deaf evacuee via videophone with mental health professionals who are fluent in American Sign Language. The

University also sponsored a major conference on Telecommunication and Disaster Response in November, 2005. Student organizations went to the Gulf region and assisted in relief efforts during Thanksgiving and Spring Breaks.

The National Association of the Deaf (NAD) supports ongoing relief efforts to deaf people in the Gulf region through its Hurricane Katrina Relief Fund. These funds have been dispersed to agencies in Louisiana, Texas and Mississippi to be used to provide case management, interpreting services, TTYs, videophones, hearing aids and other assistive technologies. The NAD is working with emergency management agencies to enhance and modify their emergency broadcasts and procedures so that the deaf community can be better prepared to respond to disasters. NAD's web site includes a wealth of information on their work with industry to improve paging systems, civil defense strobe lights, emergency captioning, weather warning systems, and radio receivers using text technology (National Association of the Deaf, 2006).

Telecommunications for the Deaf, Inc. (TDI) advocates for equal access by deaf and hard of hearing people to telecommunications and media. TDI is the recipient of a Department of Homeland Security grant to provide training to the deaf community and first responders on the needs of deaf and hard of hearing people in disasters, the Community Emergency Preparedness Information Network (CEPIN) Project. TDI's web site provides fact sheets on various forms of emergencies and how to prepare for them (Telecommunications for the Deaf, Inc., 2006).

The Deaf and Hard of Hearing Consumer Action Network (DHHCAN) is an advocacy coalition made up of 16 member organizations represent deaf, hard of hearing, late-deafened, and deaf-blind people. The member organizations include the American Association of the Deaf-Blind, the American Society for Deaf Children, the American Deafness and Rehabilitation Association, the Association of Late-Deafened Adults, the Conference of Educational Administrators of Schools and Programs for the Deaf, Deaf Seniors of America, Gallaudet University Alumni Association, Jewish Deaf Congress, the National Association of the Deaf, National Black Deaf Advocates, National Catholic Office of the Deaf, Registry of Interpreters for the Deaf, Telecommunications for the Deaf, Inc., United States Deaf Sports Federation, and WGBH in Boston, Massachusetts.

In a major report, DHHCAN found major weaknesses in the nation's emergency preparedness and planning for deaf and hard of hearing populations (Deaf and Hard of Hearing Consumer Action Network, 2004). In addition, DHHCAN sent a representative to a conference sponsored by the Federal Communication Commission in March, 2006 to make recommendations for emergency response to the deaf community. One tragic story told in this report was of a deaf man at a shelter who did not know the food was free so he did not eat for three days. He later went into diabetic shock (Heppner, 2006).

Conclusion

Out of tragedy, we learn lessons. The lessons from the Gulf hurricanes revealed fragmentations and gaps at all levels of government. The crisis has generated meetings, conferences and calls for journal articles to address emergency preparedness and response with the deaf and hard of hearing population. The goal of a master plan to assist deaf people who are victims of disasters is a vision, one which can be accomplished with the persistent efforts of government, community agencies, and the deaf community working together.

Barbara White, Ph.D., is a Professor in the Department of Social Work at Gallaudet University. She holds a doctorate in social work from the Catholic University of America, an MSW from the University of Maryland, and

Bachelor's degree in social work from Gallaudet University. She teaches graduate courses in the MSW program at Gallaudet, which focuses on social work practice with deaf and hard of hearing populations.

Endnotes

[1] The word *deaf* in this article refers to all people with hearing loss who were victims of these Gulf disasters. In most writings about Deaf people, the word is capitalized to honor the cultural existence of a Deaf community and the people who identity with the linguistic minority of Deaf people and use American Sign Language. By not capitalizing deaf, I am mindful of the large numbers of deaf and hard of hearing people who lost out on the assistance provided by the major relief agencies because they could not hear, and perhaps even lost their lives.

References

American Deafness and Rehabilitation Association (2005). *Archived chats. Crisis response and the Deaf Community*. Retrieved October 17, 2005, from http://www.adara.org/cgi-bin/datacgi/database.cgi?file=ChatArchive&report=SingleTranscript&TranscriptsID=0005

Heppner, C. (2006). *Report to the Federal Communications Commission.* Jackson, Mississippi. (unpublished).

Hsu, S. (2006, February 12). Katrina report spreads blame. *The Washington Post*. Sunday, February 12, 2006.

The Deaf and Hard of Hearing Consumer Action Network (2004). *Emergency preparedness and emergency communication access: Lessons learned since 9/11 and recommendations*. Retrieved August 15, 2006, from, http://www.nad.org/atf/cf/%7BA2A94BC9-2744-4E84-852F-D8C3380D0B12%7D/DHHCANEmergencyReport.pdf

National Association of the Deaf (2006). Retrieved August 15, 2006, from http://www.nad.org/site/pp.asp?c=foINKQMBF&b=91587

National Organization on Disability. (2005, October). *Report on special needs assessment for Katrina evacuees (SNAKE) Project*, pp.8-9. Retrieved August 15, 2006, from http://www.nod.org/Resources/PDF/katrina_snake_report.pdf

Parks, L. & Warren, K. (2005). Deaf evacuees: Unable to hear, many were left lost. *Houston Chronicle*. Retrieved September 11, 2005, from http://www.chron.com/disp/story.mpl/front/3348415.html

Shettle, A. (2005). Personal communication, used with permission.

Telecommunications for the Deaf. (2006). Retrieved August 15, 2006, from http://www.tdi-online.org/tdi/resources.asp

White, B., & Greeves, A. (2005). *Hurricane Katrina relief update*. Retrieved August 15, 2006, from http://clercblog.gallaudet.edu/hurricane/index.html

Natural Hazards, Human Vulnerability and Disabling Societies: A Disaster for Disabled People?

Laura Hemingway & Mark Priestley
Centre for Disability Studies
University of Leeds (UK)

Abstract: The policy and research literature on disaster management constructs disabled people as a particularly "vulnerable group." In this paper, we combine concepts from disaster theory and disability theory to examine this assumption critically. Drawing on primary, secondary and tertiary sources, we assess the vulnerability of disabled people in two globally significant disasters: Hurricane Katrina in August 2005 and the Asian tsunami of December 2004. In both cases, disabled people were adversely affected in terms of their physical safety and access to immediate aid, shelter, evacuation and relief. Using a social model analysis we contest the view that this vulnerability arises from the physical, sensory or cognitive limitations of the individual and show how it may be attributed to forms of disadvantage and exclusion that are socially created. The paper concludes that "natural hazards" are realised disproportionately as "human disasters" for disabled people, and most notably for disabled people in poor communities. Social model approaches and strong disabled people's organisations are key to building greater resilience to disaster amongst "vulnerable" communities in both high-income and low-income countries.

Key Words: natural hazard, vulnerable groups, social model

The unprecedented human disaster that followed the Asian tsunami drew global attention to environmental vulnerability in poor coastal communities throughout the world. In the aftermath of Hurricane Katrina we have begun to understand more clearly the global dimensions of this vulnerability and its relationship to patterns of social inequality. Disabled people are defined as a particularly "vulnerable group" in this context, yet this vulnerability is rarely theorised or explained.

Debates about the disabled people's presumed vulnerability must be framed within the historic shift from individualised interpretations of disability to those focusing on social barriers and human rights. Traditional perspectives, based on assumptions of individual limitation, have shaped the construction of disabled people's vulnerability to natural hazards as tragic yet unavoidable. However, individual model approaches have been challenged in other fields by the activism of the disabled people's movement and the development of a social model approach (Charlton, 1998; Fleischer & Zames, 2001; Oliver, 1990; Priestley, 1998). The application of this approach to disabled people's vulnerability in disaster situations is therefore central to the analysis we present in this paper.

Human Vulnerability and Environmental Risk

In order to understand vulnerability in disasters, it is important to understand the reciprocal relationship between human populations and environments. Thus, the environment itself needs to be understood as "a combination and interaction of natural and human systems, which both produce and are affected by global change" (Klein, 2006). Within this context, the increasing vulnerability of human habitats and livelihoods to climatic hazards must also be seen as socially produced. The idea that vulnerability to natural hazard is socially created is by no means new, and is particularly evident in human geography and political economy analyses (Blaikie, Cannon, Davis, & Wisner, 1994; Cutter, Boruff, & Shirley, 2003; Cutter, 1996, 2006; Dow, 1992; Liverman, 1990; Timmermann, 1981). Such approaches have generated increasing interest in non-climatic social factors and policies, rather than purely science-driven ap-

proaches to vulnerability (Füssel & Klein, 2002, 2006 in press).

In a similar way, the International Disaster Reduction Strategy defines vulnerability as, "The conditions determined by physical, social, economic, and environmental factors or processes, which increase the susceptibility of a community to the impact of hazards" (United Nations & International Strategy for Disaster Reduction, 2004). This is the definition incorporated in the Hyogo Framework 2005-2015. From this perspective, human vulnerability to natural hazard is framed by social organisation and "by everyday patterns of social interaction and organisation" (Morrow, 1999: 2). Thus:

> "Some patterns of consumption, production and development have the potential for increasing the vulnerability to natural disasters, particularly of the poor and socially disadvantaged groups. However, sustainable development can contribute to reduction of this vulnerability, if planned and managed in a way to ameliorate the social and economic conditions of the affected groups and communities" (International Strategy for Disaster Reduction, 1994).

Looking at the problem in this way, it is easy to see the connection with a social model analysis of disability. Just as disability is no longer perceived as a natural consequence of impairment, within the social model approach, so human disaster is no longer seen as a natural consequence of environmental risk. In contemporary social theory, the causes of both disability and disaster are increasingly viewed as socially produced. By synthesising these approaches it is then possible to deconstruct and reconstruct the specific vulnerability of disabled people in disaster situations.

If human vulnerability to natural hazard can be socially produced, then socially disadvantaged groups are likely to be disproportionately affected. Recent climate change agreements (such as Hyogo, Kyoto, and Gleneagles) highlight the specific vulnerability of poor communities and the Millennium Development Goals suggest a clear link between global poverty reduction and reduction of climate change vulnerabilities (see Yamin, Rahman, & Huq, 2005).

Disabled people constitute a significant proportion of the poorest communities in both low and high income countries, and up to 80% live in low-income countries, often in disaster or conflict-prone areas of the world (Asian Development Bank, 2000; Department for International Development, 2000; Elwan, 1999). Yet the concept of vulnerability is a complex one and cannot be considered simply as a proxy for poverty. It is also a function of coping, resilience and adaptability within communities:

> "Communities are not homogenous. Sharing climate impacts or threats does not imply that each member of the community is affected in the same way as all others. Whether small or large, communities are highly differentiated in terms of access to resources and factors such as age, gender, class and ethnicity and these differences are highly significant to the vulnerability and adaptive capacity of particular individuals" (Yamin et al., 2005: 2).

In summary, just as disability is not the inevitable outcome of functional impairment, human "disaster" is not the inevitable outcome of natural "hazard." Rather, disabled people's vulnerability to human disasters is embedded with-

in social structures, institutional discrimination and the presence of environmental barriers. The combination of these factors leads us to hypothesise that the presumed vulnerability of disabled people to natural hazards can be usefully explained from a social model perspective. Our analysis uses evidence of risk and vulnerability in relation to two recent case studies. Elsewhere we explore the implications of this analysis for longer-term recovery, disaster preparedness, and the rebuilding of inclusive communities (Priestley & Hemingway, 2006). Here, we focus on explaining the situation of disabled people during the acute phase of immediate impact and disaster response.

Case Studies and Methods

One of the significant paradoxes of global climate change is that environmental hazards, particularly hydrometereological hazards, are becoming both more likely and less predictable (McCarthy, Canziani, Leary, Dokken, & White, 2001). At the same time, the proportion of people living in coastal areas has risen dramatically (around 23% of the world's population lives within 100 kilometres of the coast, predicted to rise to around 50% in the next 25 years). In the tsunami-affected countries, coastal vulnerability was increased by many factors - including population growth, economic dependency on Western coastal tourism, low-cost building design, over-fishing, coral erosion, mangrove deforestation, and the absence of an Indian Ocean tsunami warning system. Similarly, the vulnerability of New Orleans to Katrina's impact had been exacerbated by economic development in high risk areas, by draining coastal swamplands, and by under-investment in ageing flood defences (Bohannon & Enserink, 2005; Travis, 2005). These social and economic developments increased vulnerability to hazard particularly for poorer communities with less resilient social infrastructures (Adger, Hughes, Folke, Carpenter, & Rockstrom, 2005).

Between August 25 and 29, 2005 Hurricane Katrina struck Florida and the Gulf States of Louisiana, Mississippi and Alabama. Whilst the strength of the storm did not exceed that of Hurricanes Wilma and Rita, the scale of damage was immensely greater, as the accompanying storm surge flooded low lying areas of the city of New Orleans. Official figures suggest that around 1,300 people lost their lives and that more than a million were displaced from their neighbourhoods. As a natural hazard Katrina was by no means unique; as a human disaster it was unprecedented for a high income country like the United States.

On December 26, 2004, the Sumatra-Andaman Islands earthquake created tsunamis in the Indian Ocean that wreaked devastation around the South Asian coastline. Although registering 9.0 on the Richter scale, this was only the fourth largest earthquake since 1900 yet it resulted in unprecedented loss to human lives, livelihoods and communities in eleven countries. Estimates suggest that up to 275,000 people may have been killed and that more than a million people remained displaced a year after the event (US Geological Survey, 2005).

In both Katrina and the tsunami, disabled people appeared to be over-represented in local populations. For example, the prevalence of congenital impairment in the Nicobar Islands had been high amongst indigenous people, compounded by recent polio outbreaks (Chari & Padmanabhan, 2005) whilst US Census data reveals that the communities affected by Katrina had significantly higher numbers of disabled people than the national average (e.g. in 2000 more than 20% were recorded as disabled in New Orleans, St Bernard, Jefferson, Hancock and Jackson). In order to investigate disabled people's vulnerability in these two disaster scenarios we draw on a wide range of data sources.

In a systematic review of research abstract databases we identified 180 articles addressing disability and disaster. These were dominated by

research that focused on the psycho-emotional dimensions of post-traumatic stress disorder or on the epidemiology of acquired physical impairment, whereas studies of disabled people's vulnerability, or the social impact of disasters upon them, were very few. By contrast, there was evidence of an emerging "grey" literature that recognises the value of social model approaches, or the role of disabled people's organisations as agents of resilience and change within disaster zones (Blanck, 1995; Center for International Rehabilitation, 2005; Kett, Stubbs, & Yeo, 2005; Wisner, 2002).

In addition to policy documents produced by government agencies and international donor organisations, we were able to review evaluation reports, policy documents and websites from a wide range of practice-based and advocacy organisations (it is relevant to note that these reviews were conducted between September and December 2005 and that new documents emerged throughout the period). Numerous media reports, press releases and online discussion contributions were also used to identify how disabled people were affected or responded. Primary data was generated through direct contact with key informants in 18 organisations involved in the Katrina or tsunami recovery effort. These included international co-ordinating organisations, international donor organisations, disabled people's organisations, US government and state agencies, and local service providers or community-based projects. The following analysis draws on these diverse sources of evidence first to illustrate the immediate impact and second the initial response.

Immediate Impact

Evidence from previous disasters suggested that disabled people are at greater risk of injury, mortality, disease, destitution and displacement when compared with the general population, while new injuries also swell the disabled population (California Department of Rehabilitation, 1997; Lathrop, 1994; Smith, 2001; World Health Organisation, 2005a). From an individual model perspective, this "vulnerability" is generally taken to imply limited physical or cognitive ability to escape from hazard. However, as recent studies have begun to show, disabling barriers to survival and relief have a significant impact - mirroring those encountered by disabled people in everyday life. For example, experiences from the 9-11 attacks in New York showed how inaccessible warning signs and blocked escape routes impacted directly on those with sensory and physical impairments (Byzek & Gilmer, 2001; Nobody Left Behind, 2004). More generally, Chou et al. (2004: 694) conclude that the "the impacts of a disaster are not random" and can "disproportionately affected sick, moderately disabled, and poorer people."

Reporting on the tsunami, the WHO (2005b) note large numbers of permanent injuries resulting from building collapse and flood debris (e.g. spinal cord injury). However, the worst affected areas saw more fatalities amongst disabled people and fewer new impairments (e.g. Kett et al., 2005). Thus, the mortality rate amongst disabled people in Aceh (Indonesia) and the Andaman and Nicobar Islands (India) appears to have been greater than in Thailand or the Indian mainland, where newly-acquired impairments appear to have been more common (Center for International Rehabilitation, 2005: 5). Disabled people seem to have been particularly vulnerable, and graphic eye-witness accounts were widely reported in the media (e.g. at the Sambodhi home for disabled people in Galle, Sri Lanka, where most of the residents died).

All but two respondents to our own consultation considered disabled people more badly affected than the general population. In both the tsunami and Katrina, disabled people left behind had died waiting for help, but there were also differences. For example, in the USA greater reliance on electrical technologies raised new risks that were not reported in tsunami-affected communities. Cuts in electrical power

were known to have disabling, sometimes life threatening, implications for people using electric wheelchairs or respirators following the 1994 Northridge earthquake (Lathrop, 1994) and similar consequences were evident during Katrina. Browne (2005) highlights the risk to those using dialysis, while respondents to our consultation reported that, "Many people died in hospitals and nursing homes because they were dependent on power supplies that gave out during the storm" (questionnaire response, Advocacy Center, Louisiana).

Whilst examples are easy to obtain, systematic data remain at best patchy and at worst non-existent. Some agencies specifically sought to identify disabled survivors. For example, following the tsunami in Sri Lanka, Child Vision identified more than five thousand disabled people in the Eastern province (TamilNet, 2005) while the Department of Census and Statistics surveyed those newly disabled in Grama Niladhari divisions (2005: 5). However, few relief organisations included disability in their evaluation methodologies. For example, the Tsunami Evaluation Coalition (TEC) was established to provide a generic approach and to optimise shared learning. At the time of writing (December 2005), eleven evaluation reports were available yet no reference to disability was made in nine of these (other than passing references to "vulnerable groups"). Specific reference in the other two focused only on inaccessible latrine design in shelters and only one consortium highlighted disability issues more generally – concluding simply that, "All agencies have not sufficiently taken this on board" (Rawal et al., 2005: 44).

Where data have been collected there is evidence that disabled people's lives were put adversely at risk, not simply by individual limitations but by social and environmental factors. These included the vulnerability of buildings and facilities used by disabled people, an absence of specific evacuation plans, inaccessible warning information, lack of accessible evacu-

ation transport, failure of backup systems, and sometimes, the actions of neighbours, staff and rescue workers. This evidence suggests that even at the most basic level of survival it is important always to view "vulnerability" in social model terms and to consider what might be done to balance the risks for disabled and non-disabled people more evenly.

Barriers to Shelter and Relief

Social and environmental barriers also disadvantage disabled people in accessing shelter and basic relief during the acute phase (McClain-Nhlapo, 2005) and evidence from the two case studies illustrate how disabled people were often excluded from full participation and equality in these areas. Where there are barriers to accessing formal information or shelter, disabled people may also be overlooked in the distribution of essentials such as food, water, medical care and other basic relief (Wisner, 2002), especially if they have been omitted from emergency registration systems (Oosters, 2005). Information can save lives, conserve resources and reduce anxiety in disaster situations but top-down approaches can be problematic (Wisner, 2002). Communication in accessible formats is therefore important (a U.S. Federal Communications Commission (FCC) requirement), yet barriers to information were widely reported with deaf people amongst the most excluded (National Organization on Disability, 2005). Despite available guidance on shelter accessibility (e.g. SEEDS, 2001) frequent difficulties were encountered by wheelchair-users and people with visual, hearing or cognitive impairments (HIC, 2005; Kett et al., 2005). Where disabled people were able to access shelters or temporary living centres, latrines were often inaccessible to those with mobility impairments (Center for International Rehabilitation, 2005; Mashni, Reed, Sasmitawidjaja, Sundhagul, & Wright, 2005; Rawal et al., 2005). Inaccessibility combined with lack of knowledge meant that, in some areas, "…Disabled people were being turned away from relief camps despite the

high levels of resources and numerous references to the need for disability access in humanitarian relief documents" (questionnaire response, DfID). Since shelters and temporary living centres are key providers of other relief this raises considerable concerns for the basic safety and welfare of disabled survivors:

> "The lack of accessibility created not only problems for the immediate need of shelter, but also other problems of access. To the extent that additional relief services, such as food distribution or medical services, were concentrated through the shelters, these services also became inaccessible" (Center for International Rehabilitation, 2005: 6).

Distribution services may also be biased in unexpected ways. For example, HelpAge expressed concern when emergency food packages did not cater for the dietary requirements of tsunami survivors with diabetes or high blood pressure (Mudur, 2005).

In the U.S., the immediate needs of disabled people were known from earlier emergencies. For example, in the wake of the 1989 Loma Prieta earthquake, the San Francisco Disability Program drew attention to issues of communication, mobility, and shelter accessibility (Imperiale, 1991). After Hurricane Katrina, there was less direct criticism of physical accessibility in shelter design. However, there were access difficulties with temporary accommodation and trailers provided by FEMA (questionnaire response, unnamed state agency, Louisiana). Disabled people were also discouraged from reporting to shelters and urged to call "triage" telephone lines with requests for accessible accommodation (access to federal relief assistance was also contingent on prior registration of disability status).

To summarise, there was considerable evidence from evaluation reports, relief agency sources and key informants that disabled people were disadvantaged in the delivery and design of immediate relief due to physical and social barriers. This evidence, and the illustrative examples, suggests that disability issues remain inadequately integrated in relief and planning. Relief agencies and managers therefore require mechanisms for mobilising the rapid involvement of disability expertise to ensure equity of provision to disabled people.

The Role of Disabled People's Organisations

Shaw and Goda (2004: 21) highlight the importance of local communities in relief and recovery. Using examples from the Kobe earthquake, they point to the effectiveness of information, knowledge, leadership and technologies within community-based organisations. More specifically:

> "Organizations with a history of specialized service delivery to the disability and aging populations have built their reputations on unique and credible connections trusted by the people they support. Their refined skill-sets and expertise represent a unique know-how and understanding that is a valuable, but often overlooked, source of knowledge. These organizations must be included as partners during emergency planning, preparedness, response, recovery and mitigation activities" (National Organization on Disability, 2005: 3).

In the context of this paper, the significance of this expertise extends beyond the local to the wider international disabled people's movement. Indeed, a distinctive feature of the two case stud-

ies, when compared to previous disasters, was the rapid response capacity of disabled people's organisations and their support networks.

Although there was little evidence of early targeted assistance to disabled people from mainstream relief organisations in either case, disability organisations moved quickly to fill gaps. However, they did not share in the "over-funding" reported by other international NGOs and, with limited resources, exploited peer-to-peer requests for support. For example, within days of the tsunami Disabled People's International (DPI) had established a relief fund, via its Asia-Pacific Regional Office in Thailand, while DPI assemblies in Japan and Indonesia were already assisting disabled people in affected areas (DPI Indonesia also opened two "Awareness Aceh" crisis centres in Jakarta). Relief funds were also established locally (e.g. by the Spinal Injuries Association of Sri Lanka) while offers of prosthetic or mobility devices were also common (e.g. donations from the California-based Free Wheelchair Mission or the Society for the Disabled of Phuket).

Internet contacts within the disability movement were significant and rapidly exploited, with disability activists and their allies utilising existing websites and global email networks within the first 24 hours. Using Internet searches, websites and mailing lists we were able to locate numerous examples of self-initiated offers and requests from disabled people's organisations in affected and non-affected countries. The rapidity of these peer-to-peer interventions (the majority logged within one week of the event) and their international reach (e.g. email lists reaching 50-100 countries) indicates both the readiness and extent of global disability action networks that can be exploited in emergency situations.

In response to Katrina, disability organisations were also quick to establish specific relief funds, from Paralyzed Veterans of America and the National Alliance for the Mentally Ill to the International Association of Assistance Dog

Partners. Email discussion groups and informal websites, like http://katrinadisability.info, were launched to locate and support disabled people displaced in the disaster, and to match offers of expertise with requests for assistance. These community-led initiatives were often distinctive from mainstream relief efforts in adopting a social model, legal rights or independent living approach (e.g. in facilitating access to disability advocates, legal rights attorneys, disability access consultants, assistive technology specialists, personal assistance services, etc.). Within two weeks, rapid response teams from the National Organization on Disability's Emergency Preparedness Initiative had assessed response and recovery issues for disabled people and other "special needs populations" (NOD 2005). The initial report, noted "systemic failures" at all levels of government and concluded that disabled populations were "woefully under-prepared" for the emergency.

By contrast, community-led organisations at the local level were targeting disabled people's needs. For example, the Louisiana Association of the Deaf collected funds and supplied video phones while Centres for independent living in Shreveport, Baton Rouge, and Lake Charles were assisting evacuees and calling for supplies (those in Biloxi, Mississippi and New Orleans were damaged or destroyed). This active engagement led at least one organisation to conclude that the "best shelters were run by the community not FEMA or the Red Cross" (questionnaire response, Families Helping Families, Louisiana).

To summarise, there was considerable evidence in both case studies of the readiness and capacity for disaster response among disabled people's organisations and community-led advocacy organisations. This readiness was reflected in informal networks of support and communication and in specific forms of disability expertise that were not readily available within the mainstream disaster response systems.

Conclusion

Disabled people have been made more vulnerable to natural hazards through historical processes of exclusion and impoverishment. As a consequence, their experience of disaster may be more acute and long-standing than non-disabled populations. These effects are accentuated in poor communities throughout the world where disabled people remain amongst the poorest of the poor. Moreover, when disaster strikes, disabled people encounter inequities in access to shelter or relief and are often excluded from full participation in response and recovery.

The analysis in this paper suggests that there is considerable mileage in applying a social model of disability perspective to the assessment and evaluation of disabled people's vulnerability in disaster situations. In particular, important distinctions between "impairment" and "disability" mirror the established distinction between "natural hazards" and "human disaster." The synthesis of concepts from disability and disaster theory is productive in exposing a critique of medically-driven assumptions about disabled people's "natural" vulnerability. Examining vulnerability from a structural, socio-economic, perspective reveals how inequalities within societies can be as significant as those between them. Whether in Aceh or Louisiana, there must be concern that disabled people remain amongst the poorest of the poor, and that specific vulnerabilities arise at the intersections of disability, class, gender, and ethnicity. Drawing on a wide variety of evidence from the two case studies, and from previous disasters, we conclude that disabled people are disproportionately vulnerable to natural hazards primarily as a consequence of social disadvantage, poverty and structural exclusion.

On a practical level, the research illustrates the very real and heightened risks that disabled people face in disaster zones, including greater risk of death, injury and displacement. As survivors, disabled people may be further disadvantaged by the ways in which immediate information, shelter, evacuation and relief systems are designed and managed. It is also clear that such risks are compounded where there are pre-existing barriers to disabled people's full participation in local communities and their equitable access to appropriate housing, transport, education or service provision. Significantly, the case studies suggest that similar kinds of vulnerability may be experienced in both low-income and high-income societies. We conclude that the structural vulnerability of disabled people to disaster must not be considered only as a problem for developing countries.

One of our key findings was the increasing readiness of the disabled people's movement to respond in disaster relief. Examples from Katrina and the Asian tsunami suggest that centres for independent living, disabled people's organisations and informal networks throughout the world now hold great capacity to respond in disaster situations. Internet communications and the growth of strong community-based organisations have increased this capacity and fostered a new resilience against vulnerability. However, it was also clear that such organisations lacked adequate resources to sustain their contribution and that their expertise was underutilised within the disaster relief effort. We conclude therefore that improvements in resilience to disaster must include investments in the full participation and equality of disabled people within "vulnerable" communities.

Laura Hemingway is a doctoral research student and Mark Priestley is Reader in Disability Studies and at the Centre for Disability Studies, University of Leeds, UK.

References

Adger, W., Hughes, T., Folke, C., Carpenter, S., & Rockstrom, J. (2005). Social-ecological resilience to coastal disasters. *Science, 309*(5737), 1036-1039.

Asian Development Bank. (2000). *Technical assistance for identifying disability issues related to poverty reduction*. Manila: Author.

Blaikie, P., Cannon, T., Davis, I., & Wisner, B. (1994). *At risk: Natural hazards, people's vulnerability and disasters*. London: Routledge.

Blanck, P. (1995). *Disaster mitigation for persons with disabilities: Fostering a new dialogue*. Washington, D.C.: Annenberg Washington Program in Communications Policy Studies of Northwestern University.

Bohannon, J., & Enserink, M. (2005). Hurricane Katrina - Scientists weigh options for rebuilding New Orleans. *Science, 309*(5742), 1808-1809.

Browne, T. (2005). Hurricane Katrina: The psychosocial aftermath for ESRD patients and caregivers. *Dialysis & Transplantation, 34*(11), 832-+.

Byzek, J., & Gilmer, T. (2001). *September 11, 2001: A day to remember*. New Mobility. Retrieved October 18, 2005, from http://www.newmobility.com/review_article.cfm?id=461

California Department of Rehabilitation. (1997). *Disaster preparedness for persons with disabilities: Improving California's response*. Retrieved October 18, 2005, from http://www.atnet.org/education/prepare.pdf

Center for International Rehabilitation. (2005). *Disability and early Tsunami relief efforts in India, Indonesia and Thailand*. Chicago: Center for International Rehabilitation.

Chari, R., & Padmanabhan, R. (2005). *Report on the visit to the Andaman & Nicobar islands to study the impact of the Tsunami tragedy vis-a-vis disability*. National Centre for Promotion of Employment for Disabled People/DPI India. Retrieved November 15, 2005, from http://ncpedp.org/policy/pol-res01.htm

Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.

Chou, Y. J., Huang, N., Lee, C. H., Tsai, S. L., Chen, L. S., & Chang, H. J. (2004). Who is at risk of death in an earthquake? *American Journal of Epidemiology, 160*(7), 688-695.

Cutter, S., Boruff, B., & Shirley, W. (2003). Social vulnerability to environmental hazards. *Social Science Quarterly, 84*(1), 242-261.

Cutter, S. L. (1996). Vulnerability to environmental hazards. *Progress in Human Geography, 20*, 529-539.

Cutter, S. L. (2006). *Hazards, vulnerability and environmental justice*.

Department for International Development. (2000). *Disability, poverty and development*. London: Author.

Dow, K. (1992). Exploring differences in our common future(s): The meaning of vulnerability to global environmental change. *Geoforum, 23*, 417-436.

Elwan, A. (1999). *Poverty and disability: A survey of the literature*. Geneva: World Bank.

Fleischer, D. Z., & Zames, F. (2001). *The Disability Rights Movement: From charity to confrontation*. Philadelphia, PA.: Temple University Press.

Füssel, H., & Klein, R. (2002). *Assessing vulnerability and adaptation to climate change: An evolution of conceptual thinking*. Paper presented at the UNDP Expert Group Meeting on Integrating Disaster Reduction and Adaptation to Climate Change, Havana, Cuba, 17–19 June. Retrieved January, 2006, from http://www.pik-potsdam.de/~fuessel/download/undp02_final.pdf

Füssel, H., & Klein, R. (2006). Climate change vulnerability assessments: An evolution of conceptual thinking. *Climatic Change*, *75*(3), 301-329

Humanitarian Information Center. (2005). *Weekly Humanitarian Overview - Batticaloa District, 5 - 10 April 2005*. HIC for Sri Lanka.

Imperiale, P. (1991). Special needs in emergency planning and preparedness. *Earthquake Preparedness News, 6*(2).

International Strategy for Disaster Reduction. (1994). *Yokohama strategy and plan of action for a safer world*. Retrieved November, 2005, from http://www.unisdr.org/eng/about_isdr/bd-yokohama-strat-eng.htm

Kett, M., Stubbs, S., & Yeo, R. (2005). *Disability in conflict and emergency situations: Focus on Tsunami-affected areas*. Norwich: International Disability and Development Consortium, University of East Anglia.

Klein, R. (2006). *Environmental vulnerability assessment*. Retrieved January, 2006, from http://www.pik-potsdam.de/~richardk/eva/

Lathrop, D. (1994). DISASTER! If you have a disability, the forces of nature can be meaner to you than anyone else. *Mainstream, November 1994*.

Liverman, D. (1990). Vulnerability to global environmental change. In R. Kasperson, D. Dow, D. Golding, & J. Kasperson (Eds.), *Understanding global environmental change: The contributions of risk analysis and management*. Worcester, MA: Clark University.

Mashni, A., Reed, S., Sasmitawidjaja, V., Sundhagul, D., & Wright, T. (2005). *Multi-agency evaluation of Tsunami response: Thailand and Indonesia*. CARE International & World Vision International. Retrieved December, 2005, from http://www.alnap.org/tec/pdf/IWG_TH_ID_Evaluation_20050901.pdf

McCarthy, J., Canziani, O., Leary, N., Dokken, D., & White, K. (Eds.). (2001). *Climate change 2001: Impacts, adaptation and vulnerability*. Cambridge: Cambridge University Press.

McClain-Nhlapo, C. (2005). *Terror wave: Tsunami and disability*. Disability World. Retrieved October 10, 2005, from http://www.disabilityworld.org/12-02_05/news/wavesofterror.shtml

Morrow, B. (1999). Identifying and mapping community vulnerability. *Disasters, 23*(1), 1-18.

Mudur, G. (2005). Aid agencies ignored special needs of elderly people after tsunami. *British Medical Journal, 331*(7514), 422-422.

National Organization on Disability. (2005). *Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project*. Washington DC: Author.

Nobody Left Behind. (2004). *Lessons learned from the World Trade Center disaster: emergency preparedness for people with disabilities in New York*. Author. Retrieved October 8, 2005, from http://rtcil.org/lesson.htm

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oosters, B. (2005). *Looking with a disability lens at the disaster caused by the Tsunami in South-East Asia*. Brussels: CBM International.

Priestley, M. (1998). Constructions and creations: Idealism, materialism and disability theory. *Disability & Society, 13*(1), 75-94.

Priestley, M., & Hemingway, L. (2006). Disability and disaster recovery: A tale of two cities? *Journal of Social Work in Disability and Rehabilitation*.

Rawal, V., Fautin, C., Moore, J.-L., Kalonge, S., Walden, V. M., & Bhattacharjee, A. (2005). *Multi-agency evaluation of Tsunami response: India and Sri Lanka*. CARE International, Oxfam GB & World Vision International. Retrieved December, 2005, from http://www.alnap.org/tec/pdf/IWG_IN_LK_Evaluation_20050901.pdf

SEEDS. (2001). *High powered committee on disaster management: Report on women, children, aged and challenged in disasters*. Government of India. Retrieved October 10, 2005, from http://www.benfieldhrc.org/disaster_studies/disability&disasters/hpc_seed.pdf

Shaw, R., & Goda, K. (2004). From disaster to sustainable community planning and development: The Kobe Experiences. *Disaster Prevention and Management, 28*(1), 16-40.

Smith, K. (2001). *Environmental hazards: Assessing risk and reducing disaster* (3rd ed.). London: Routledge.

Sri Lanka Department of Census and Statistics. (2005). *Preliminary report 2: Census of buildings and persons affected by the Tsunami 2004*. Hambantota District: Thissamaharama DS Division.

TamilNet. (2005). *Child vision survey identifies five thousand disabled in East*. Retrieved September, 2005, from http://www.tamilnet.com/art.html?catid=13&artid=15690

Timmermann, P. (1981). *Vulnerability, resilience and the collapse of society*. Toronto: Institute for Environmental Studies, University of Toronto.

Travis, J. (2005). Hurricane Katrina - Scientists' fears come true as hurricane floods New Orleans. *Science, 309*(5741), 1656-+.

United Nations, & International Strategy for Disaster Reduction. (2004). *Living with Risk: A global review of disaster reduction initiatives*. Geneva: Author.

US Geological Survey. (2005). *Sumatra-Andaman Islands earthquake*. Retrieved November, 2005, from http://earthquake.usgs.gov/eqinthenews/2004/usslav/

Wisner, B. (2002). Disability and disaster: Victimhood and agency in earthquake risk reduction. In C. Rodrigue & E. Rovai (Eds.), *Earthquakes*. London: Routledge.

World Health Organisation. (2005a). *Disasters, disability and rehabilitation*. Retrieved October 8, 2005, from http://www.who.int/entity/violence_injury_prevention/other_injury/disaster_disability2.pdf

World Health Organisation. (2005b). *Injuries and disability: priorities and management for populations affected by the earthquake and tsunami in Asia.* Retrieved October 10, 2005, from http://www.who.int/violence_injury_prevention/other_injury/tsunami/en/print.html

Yamin, F., Rahman, A., & Huq, S. (2005). Vulnerability, adaptation and climate disasters: A conceptual overview. *Ids Bulletin-Institute of Development Studies, 36*(4), 1-14.

Academic and Behavioral Reactions of Children with Disabilities to the Loss of a Firefighter Father: The New York City World Trade Center Attack 9/11/01

Grace H. Christ, MSW, DSW
Columbia University

Thomas W. Christ, Ed.S, Ph.D.
University of Hawaii at Manoa

Abstract: This five year comparative case study explores how children with disabilities responded to the loss of their firefighter father in the World Trade Center attack. Preliminary findings presented will be useful for teachers and researchers interested in designing appropriate interventions for children traumatized by the death of a parent.

Key Words: learning disability, grief, 9/11

Introduction

On September 11, 2001, the Counseling Service Unit of the Fire Department of New York began the difficult task of providing immediate support for active-duty firefighters and their families. For those affected by the World Trade Center attacks, supports included bereavement groups for parents and wives of the 343 firefighters who died in the attacks and a broad range of mental health services for surviving firefighters and their families (Green, Kane, Christ, Lynch, & Corrigan, 2006).

While still immersed in their own intense reactions, mothers became increasingly concerned about finding ways to help their grieving children cope with the loss. Grief reactions and stress-related behaviors displayed by many children during the first years included sleep problems, difficulty concentrating in school, fluctuating grades, social withdrawal, separation anxiety and a variety of phobias and anger man-

agement problems. For some of the children these symptoms were severe and prolonged and caused major disruptions in school and at home. For many, symptoms were intermittent. It was not surprising that mothers requested assistance in understanding and managing children's behaviors.

The Counseling Services Unit of the New York City Fire Department was responsible for providing mental health services for the families of the firefighters killed on 9/11/01. One response to families' requests for assistance was the creation of the Family Guidance Program (Christ, 2006). This program provided in-home therapeutic and evaluative services from a team of two or more clinicians for each family. The clinicians offered assistance to the families including ongoing feedback about how the children were functioning. The guidance program began to provide services on March 1, 2002, less than six months after the World Trade Center attack.

Most of the firefighter fathers had been instrumental in providing some level of school-related assistance to their children. For many of the children with disabilities, this assistance helped support their academic progress. The unique schedule of the firefighters, two 24-hour shifts each week, allowed fathers to actively participate in their children's lives. Their deaths had a profound effect on all children, but sometimes there were unique and unanticipated outcomes for the children with disabilities. This longitudinal study focused upon the course of recovery of four children diagnosed with a learning disability prior to 9/11/2001.

Background

Research on child bereavement due to a parent's death has focused upon mediators and moderators that can mitigate the impact of loss (Dowdney, 2000; Haine, Wolchick, Sandler, Millsap, Roger, & Tim, 2006; Lin, Sandler, Ayers, Wolchik, & Luecken, 2004; Lutzke, Ayers, Sandler, & Barr, 1997; Raveis, Siegel, & Karus, 1999; Tremblay & Israel, 1998). Risk factors in children and adolescents include, among others, pre-existing mental health problems; protective factors include intellectual and social competence (Christ, Siegel, & Christ, 2002; Lin et al., 2004).

Children's reactions to the loss of a parent include depression, yearning for the lost parent, somatic reactions and cognitive distortions (Christ, 2000; Lutzke et al., 1997; Weller, Weller, Fristad, & Bowes, 1991; Worden, 1996). Other reactions include tension, restlessness, guilt, aggression, and impatience (Malkinson, Rubin, & Witztum, 2000). Research suggests that declining academic performance, inappropriate behaviors, and harmful physiological reactions to traumatic loss can be reduced if the home environment remains relatively stable. Unfortunately, changes in living arrangements and economic factors are common in families after the death of a parent. Research also suggests that changes in routines such as childcare, school, and the home environment can have a significant effect upon the long-term mental health of children. Accumulation of stressful events including changes and reminders has been shown to have negative impact on children (Elizur & Kaffman, 1983; Silverman & Worden, 1992; Thompson, Kaslow, Price, Williams, & Kingree, 1998; West, 1997).

The quality of the relationship between children and the surviving caregiver is related to how children adjust. Parenting skills including appropriate discipline and communication have been found to reduce negative behaviors and psychological symptoms in children (Haine et al., 2006; Kwok, Haine, Sandler, Ayers, Wolchik, & Tein, 2005; Raveis et al., 1999; Sanders, 1989). Individual strengths in children including personal efficacy in coping skills have been associated with fewer mental health problems and negative behaviors (Sandler, Ayers, Wolchik, Tein, Kwok & Haine, (2003). Other factors related to the grieving process include the level of exposure to a traumatic event and the

strength of the relationship to the person who died. Pfefferbaum, Nixon, Tucker, Tivis, Moore and Gurwitch (1999) found that children who lost a sibling in the Oklahoma City bombing exhibited extreme distress.

Dyregrov (2004) reviewed the literature on the educational consequences due to loss and trauma and urged researchers to perform long-term studies that can present evidence of the impact of loss on academic functioning. Christ and Stodden (2005) found in their two-year study of academic supports that students with learning disabilities are more likely to see educational success if they receive appropriate supports and accommodations. Further, supports for students with learning disabilities are more likely to be embraced if they are provided by mentors or peers (Whelley, Radtke, Burgstahler & Christ, 2003).

A thorough review of the literature revealed that no studies address the response of children with learning disabilities to the traumatic death of a caregiver or how the academic environment and peer support has an impact on stresses such as the loss of a parent. Lin et al. (2004) and Siegel (1992) found that research does not differentiate reactions in particular sub-groups of children. This research study will begin to explore the effects of supports, the learning environment, and stressors on how children with learning disabilities respond over time. Information gained can help inform practitioners and family about particular challenges and coping strategies that emerged over several years.

The Guidance Program

The FDNY-CSU/ Columbia University Guidance Program was implemented by an interdisciplinary team of Columbia University School of Social Work faculty and doctoral students, all with five or more years of individual, group, or child therapeutic experiences. Members also included a psychiatric nurse, a child psychiatrist, a school psychologist, a research methodology specialist, and a special educator. A

close working relationship with the Fire Department New York Counseling Service Unit was maintained throughout as they provided services to meet additional needs identified by the guidance program interviews (Christ, 2006). The guidance program is a family-focused strengths-based therapeutic intervention that aims to help families master the challenges of adaptation to the sudden highly stressful traumatic loss of a parent. Unique features of this program include a five-year commitment to the families, an offer to provide individual therapeutic interviews in the family's homes, and ongoing evaluative feedback for the children and their parents. Families are encouraged to use other available services they find helpful.

After consent, each family member was seen twice a month for four sessions. Interviews were recorded and transcribed. A battery of child, parent, and teacher measures were also completed. Monthly interviews of the mothers and children completed the first half-year interval. Most of the interview time during this half-year was spent dealing with severe grief, and providing mothers guidance in understanding their children's reactions and how best to provide optimal support. The interviews and the measures provided the team with material necessary to begin the process of identifying critical issues and provide feedback on the current status of each child. Monthly meetings with all family members were scheduled during the first three years. Interviews were more variable in the fourth and fifth years and depended on each family's needs and preferences. The battery of mother, teacher and child measures were performed twice during the first year and yearly thereafter.

The guidance program utilizes a normalizing approach in therapy, which includes reducing general distress and grief, improving family communication and relationships, and developing skills to deal with ongoing stressors such as the repeated reminders of the traumatic death. This approach emphasizes parent-guidance to understand and deal with their children's reac-

tions and responses to the death and its aftermaths as well as supportive-therapeutic work directly with the mother and the children. Its development is guided by experience and research that suggests that the widow and her children's behaviors in the first years may be adaptive to the situation (Christ, 2006; Siegel, Mesagno, & Christ, 1990).

Participants in the guidance program included the families of firefighters who actively served on 9/11/01 and were killed in the terrorist attack. One criterion for participation required that the families have at least one child age 3 to 18 living at home. All families reside in the five boroughs of New York City, in Nassau, Suffolk, and Westchester Counties of New York State or in New Jersey. Four children were purposefully selected for this study from the 48 families and 121 children, because they had been diagnosed with a learning disability before 9/11/01 and were eligible for special education services.

Method

This exploratory qualitative research study of four children with learning disabilities was conducted through successive analyses of transcript and measures. Transcribed therapeutic interviews, observations, and the measures were analyzed following the suggestions of Maxwell (2005), Creswell (2003), Tashakkori and Teddie (1998), and Yin (2004), which allowed for case summaries that were compared to determine emerging themes. This method provided the opportunity to describe the children and their families' reactions to grief and trauma over time. Each child represented an individual case that provided an opportunity to perform a cross-case analysis (Miles & Huberman, 1994), allowing for the exploration of behavioral and academic reactions.

Findings

Children and wives of the firefighters who perished in the World Trade Center were traumatized in ways unseen before (Christ, 2006).

Unique was the prolonged exposure to the powerful reminders of the traumatic death. Some mothers described disconnecting the television, canceling newspaper and magazine subscriptions, and refusing to listen to news on radio because of the continuous and frequent allusions to the 9/11 terror experience that precipitated waves of grief. Less preventable were the many funerals or memorials for firefighters whose bodies were never recovered. Other painful reminders were the street-naming dedications, the national 9/11/02 memorial, and the ongoing trauma associated with finding bodies and eventually body parts. Over time, many of the mothers learned to shield their children from participation in order to reduce stressors as much as possible in these events. Much of the therapeutic work done by the guidance program team with the children and the mothers during the first 18 months was related to teaching them how to contain and control their reactions and responses to these reminders.

The children with disabilities exhibited a somewhat different reaction from other children. Several of the mothers wondered if they were grieving. After the initial outbursts of emotion, many of the children in the study appeared to tune out the painful reminders and focus on less painful topics more rapidly than their siblings or other children whose father was killed. For many of the children, being in school with their friends was an important escape. Although the students with learning disabilities continued to have academic problems, teachers in the first year after 9/11 focused on being supportive. This support included access to guidance counselors and, for the younger children, bereavement art therapy. This level of support for students with disabilities was especially helpful during traumatic reminder periods such as the six-month and year anniversaries and the closing of the World Trade Center site. Despite these supports, most of the school personnel, parents, and children indicated that the first year was a loss both socially and academically. This finding was consistent for the children classified as having a learning disability

prior to 9/11 as well as for their non-disabled peers. The children with disabilities, after 9/11 felt less ostracized by their peers due to their disability as they received positive attention from peers and teachers as children of heroes.

Specific reactions exhibited by all children in the first year included sleep problems and difficulty concentrating in school. This did not necessarily result in a drop in grades, as most teachers did not hold the students who had a parent die to the same standards as their peers. Behavioral reactions for all of the children in the first year varied. Some children became withdrawn, others exhibited emotional outbursts, anger, and behavioral regression, and some maintained previous functional levels. Several of the children had unusual fluctuations in weight and many exhibited separation anxiety, fear, and phobias.

One of the challenges faced by the parents and therapists working with younger children in the first year was their difficulty in accepting that their father had died. Several 9 year-olds in this study continued to hold out hope that their father had survived, months after 9/11. One child was convinced Spiderman had plucked his father out as the tower was falling. He explained that his father had been hit in the head by a rock and had amnesia, but that he would soon return. Another child knew her father had participated in extensive survival exercises and might survive by eating bugs and catching dew on his handkerchief. She was convinced her father was still alive and became very upset when the site was closed nine months after 9/11. She did not believe her mother, but finally accepted her teacher's statement that no one could survive that devastation.

Students receiving services for a disability were at some advantage over their non-disabled peers as the educational specialists had a better picture of pre-existing academic progress, overall temperament, and behaviors prior to 9/11. This allowed the specialists to better gauge changes

in mood and affect most likely attributed to the death of the father in the World Trade Center. The specialists' knowledge of the students was helpful, as they could monitor their behaviors and provide input to those designing appropriate educational, behavioral and emotional supports.

Four Case Studies

The four children with learning disabilities chosen for this study included Andrew, a six year-old and in first grade, Barbara, an eight year-old in second grade, Connie an eleven year-old in fifth grade and Doug, also eleven and in fifth grade. The names used in this study have been changed, and other identifying characteristics deleted in an effort to preserve confidentiality.

Andrew

When first interviewed, Andrew was quiet and soft-spoken. He let his younger brother choose all games, and seemed depressed, withdrawn, and numb. He was distraught by the death of his father who had been very supportive, teaching him games, sports, and helping him with learning material presented in kindergarten. His mother and the team shared their concerns. Andrew's mother contacted his first grade teacher and worked out a mutual plan to promote interests and assertiveness. By the end of the first year, Andrew dramatically changed. He now seemed angry, defiant, provocative, and bossy. Andrew would threaten to hit his brother if he did not play the games he wanted and he adamantly refused to do any of the measures for the guidance team. His mother was pleased with Andrew's assertiveness, but she was somewhat dismayed by the extent of his defiance.

Andrew's mother requested a male teacher at the start of second grade. Although Andrew continued to be quite negative at home, he was starting to have more fun at school. Andrew still resisted his mother's help with homework and had difficulty concentrating, but could be

coaxed to attend. Andrew was placed into a mainstream classroom in second grade that had a special education assistant. By the middle of the year his teacher rated his academic performance as far below grade level in reading and writing, below grade level in social studies, handwriting and science, and at grade level in math. Andrew's teacher noted that he did not work as hard and learned slightly less than his peers. His teacher also noted that Andrew did not present any challenging behaviors in the classroom setting but he was less happy, and talked sadly about his father. According to his teacher, Andrew avoided certain academic tasks but was very creative, artistic, funny, and had a strong vocabulary. Andrew's special education teacher rated his academic performance as improved by the end of second grade. He was at grade level in three subjects and slightly below in one. At home, Andrew's mother was successful at setting limits which reduced his rebellious behaviors and her help with homework appeared to contribute to his academic successes.

By the start of the third grade, Andrew's academic performance had dramatically improved. His teacher rated him at grade level in all subjects. His special education teacher maintained concern as Andrew continued to be easily frustrated and at times became emotional when confronted with difficult tasks. According to Andrew's special education teacher, he appeared to be more impulsive, overly eager to answer questions and had difficulty waiting his turn. His special education teacher also described Andrew's strengths and noted that he was a very kind child who was pleasant to have in class. According to both his teachers, Andrew was very conscientious about doing his school work and put a great deal of effort into everything he did.

Andrew's initial reactions were similar to many of his peers who lost a parent in 9/11. Initially depressed, withdrawn, angry, and defiant, Andrew showed few signs of pleasure in the first year. Support offered by his mother and the understanding but firm responses by his second

grade teachers helped Andrew to gradually regain some control over his emotions and grief.

Barbara

Although Barbara exhibited academic difficulties since first grade, she compensated by being socially adept. According to Barbara's mother, the effects of her prescribed medication tended to wear off by the time she came home and she would become irritable and difficult with some "downright nasty flare-ups." Barbara's mother felt that it was best that Barbara's anger occur at home rather than in school. She also expressed that she understood the academic challenges Barbara faced as both she and her husband had disliked school and had struggled academically.

Barbara's father had always helped her with her homework and her mother did not feel she could help as that had always been her husband's task. Her solution was to hire tutors. When Barbara was asked what she thought about having a tutor, she replied "No one else has tutors. They are all going to think I am dumb." Barbara resented her tutors, never finding one who she liked until three years after 9/11.

During the first year after her father died, Barbara quickly embraced the identity of being a member of a special group of "9/11" children. Her family participated in the many events developed for the children including trips to Disneyland, a boat excursion, and events for the families at her father's firehouse. As the events decreased, Barbara continued to compensate for her learning problems by being socially competent, with many friends. In school Barbara was a leader among her large group of friends and in her neighborhood she was a magnet for the younger children who enjoyed her athletic skills and humor. Barbara was always well-behaved and liked in school by her teachers, and her beauty and poise added to her acceptance by peers. Barbara was particularly pleased when assigned to a mainstream classroom with a few other students with learning disabilities who received help from a specialist as necessary. The

mainstream setting allowed Barbara to maintain acceptance by her peers.

Problems for Barbara appeared in the fifth year after her father's death. She was now a young adolescent and the family moved to a different state in preparation for her mother's remarriage. This removed Barbara from her social circle where she had felt accepted and popular. Barbara became withdrawn and morose, expressing her sadness more often than in the first years after her father's death. For the first time in her life, Barbara felt she had no peer support and she was apprehensive about making new friends. This was the first time Barbara began to confront the reality of her learning disability, which had previously been nothing more than an isolated irritant in the past. Barbara's mother stated that her daughter feared that her learning disability might lead to her being ostracized from classmates and neighborhood children. In her new environment, Barbara was fearful of taking the steps needed to make friends and was struggling with academic demands. She was no longer seen as special and no one seemed to know or care that her father died a hero.

Connie

Connie's learning disability was handled very differently by her family. The family refused special education services. Connie was an only child and her parents worked "endless hours" with her on her school work. Connie was a superb athlete, very articulate, well-spoken, and liked by her teachers and peers. The death of her father was devastating to Connie. Her grades immediately dropped despite her mother's effort. When Connie began to fail some subjects, she complained that her mother was not helping her as her father had in the past. Connie adamantly refused help offered through the school and instead received private tutoring. Gradually, Connie's academic performance began to improve. She worked hard at sports and over time her grades and self-esteem increased. Connie's school may have contributed to her recovery by creatively encouraging several students who

had a parent die in 9/11 to spend time together. Connie valued these relationships enormously as they seemed to help her maximize her considerable strengths while coping with academic challenges.

Doug

Doug was always the youngest in his class due to his birthdate. His teacher quickly referred him for special education services when he was unable to keep up with his peers. Over the years he was assigned to a variety of special education and mainstream settings. Doug was devastated when he heard of his father's death and mourned him deeply. Within a few months his mourning dissipated and according to his mother, Doug became his old happy-go-lucky self. He had a few friends in the neighborhood and he would "hang out" with them. Although barely passing, Doug was always overjoyed when his report card showed no failed classes. He always liked mathematics in which he often excelled, but found reading and writing difficult.

Doug gradually developed a parent-like relationship with his brothers occasionally using his size to stop his brothers from fighting with each other. When Doug was unsuccessful at helping his siblings join a neighborhood group, the brothers formed a band playing popular songs. Although his mother tried to dissuade his paternal role, Doug subtly maintained this position.

Toward the end of the third year after his father's death, Doug had three consecutive stressors that seriously affected his self-esteem. First, he was turned down by a girl he asked to the school dance. He was devastated despite the fact that very few of the boys in his school had asked a girl to the prom. Second, his report card revealed that he was not doing well, shattering his hopes to be mainstreamed when entering high school. Doug's teacher indicated that his poor grades were reflective of the minimal effort he exerted at school and he was working much below his capacity. The third stressor was that his mother started to date a man who spent part

of the weekend helping around the house as his father had done. The next day Doug was very quiet, kept to himself, and became profoundly depressed. He broke down sobbing when his mother came into his room and shared his distress with her.

Conclusions

Several themes are beginning to emerge in the early stages of this longitudinal study. A number of children with learning disabilities had less noticeable traumatic responses during the first two years than their non-learning-disabled siblings and peers. Some even looked forward to the memorials rather than avoiding them. The four students in this study were sad and grieved, but they did not experience the intrusive thoughts and recollections that plagued many of the other children who lost a father in 9/11.

Several factors seem to contribute to the different ways children react to trauma. One factor that appeared to have an effect upon the four students in this study was the way the schools responded to 9/11. For the students in special education, the staff immediately mobilized to provide a supportive environment. For example, the teachers helped classmates send sympathy cards and they worked with the students to help them understand how their classmates would be grieving. The special education teachers were also helpful in monitoring the student's academic, behavioral, and emotional responses post 09/11/01. This information was provided to the school counselors who needed this input and was offered to the mothers who often maintained close contact. For children without special education supports, needs were not identified as quickly or as accurately and the supports were delayed or ambiguous.

Another factor that appears to have contributed to the way the four children in this study reacted was their status. Some experienced a new identity, as children of fallen heroes rather than a child with a disability. Gradually this special status began to change as educational demands increased and their identity as children of heroes faded. Some of the children moved to new locations, others transitioned into new schools, and some of the families emphasized moving on. These and other factors coupled with maturation appear to have awakened a new confrontation with their loss.

Each of the four children in this study reacted differently to the death of their father. One child, sheltered from confronting her disability by the effort of both parents, no longer had this support available. She was forced to confront the reality of having a disability without extraordinary parental support. One of the adolescents showed serious reactions in year three and another in year five. This finding indicates that reactions do appear later than most would expect. One case showed how the combined efforts of excellent special education personnel working closely with a motivated parent contributed to the reduction of trauma from the loss of a very important father.

Future Directions

The World trade Center Disaster on 9/11 brought with it a very unusual set of circumstances (as is the case with any large scale disaster). Much has been learned from examining four children with a pre-existing learning disability as well as their non-disabled cohorts. Unusual in this case, and unlike most disasters, was the outpouring of financial and emotional support from a grateful nation. Regardless of the circumstances accounting for a large scale disaster, interventions are necessary. In the case of the four children in this study, supports were provided by specialists, including excellent special education teachers coupled with other school related interventions. These supports provided a safe and consistent environment for the children as they recovered from the trauma and loss associated with 9/11. School supports combined with the services provided from the Family Assistance and Guidance Program helped the four

children in this study to minimize adverse reactions. Disaster studies can seldom be duplicated, but an effort to learn from them can. Over time, the comparison of reactions of children with learning disabilities to diverse disasters may clarify best approaches to support. This study has shown that a longitudinal approach when examining interventions brings about many surprises and provides insight for future research. Due to the preliminary nature of the analysis in this five year study, much more will be learned from the extensive data as it is carefully examined for themes and findings related to the responses and coping strategies of children and adolescents, including those with disabilities.

Grace H. Christ, MSW, DSW., Associate Professor, Columbia University School of Social Work. She is director of the FDNY-CSU/Columbia University Family Guidance Program and a specialist in child bereavement research.

Thomas W. Christ, Ed.S, Ph.D., is a School Psychologist and Learning Disability specialist who teaches graduate research methods and educational psychology courses at the University of Hawaii. His research interests include international education, post secondary student services, evaluation, and qualitative research methods.

The authors may be reached at:

Child Bereavement; Grace H. Christ, Associate Professor, Columbia University School of Social Work. 1255 Amsterdam Ave, New York, NY 10027

Learning Disabilities; Thomas Christ, University of Hawaii Curriculum Studies. 1776 University Avenue, Wist Annex #224. Honolulu Hawaii 96822

References

Christ, G. (2000). Impact of development on children's mourning. *Cancer Practice, 8*(2), 72-81.

Christ, G. (2006). Providing a home-based therapeutic program for widows and children. In P. Greene, D. Kane, G. Christ, S. Lynch, & M. Corrigan (Eds.), *FDNY crisis counseling: Innovative responses to 9/11 fire fighters, families and communities.* New York: Wiley.

Christ, G., Siegel, K., & Christ, A. (2002). Adolescent Grief "It Never Really Hit Me...Until it Actually Happened." *JAMA, 288*(10), 1269-1279.

Christ, T., & Stodden, R. (2005). Advantages of developing survey constructs when comparing educational supports offered to students with disabilities in postsecondary education. *Journal of Vocational Rehabilitation*, *22* (1), 23-31.

Creswell, J. W. (2003). *Qualitative, quantitative & mixed methods design*. London: Sage.

Dowdney, L. (2000). Annotation: Childhood bereavement following parental death. *J. Child Psychol. Psychiat., 41*(7), 819-920.

Dyregrov, A. (2004). Educational consequences of loss and trauma. *Education and Child Psychology, 21*(3), 77-84.

Elizur, E., & Kaffman, M. (1983). Factors influencing the severity of childhood bereavement reactions. *American Journal of Orthopsychiatry, 53*(4), 668-676.

Green, P., Kane, D., Christ, G., Lynch, S., & Corrigan, M. (2006). *FDNY crisis counseling: Innovative responses to 9/11 firefighters, families, and communities.* New York: Wiley.

Haine, R., Wolchick, S., Sandler, I., Millsap, I., Roger, E., & Tim, S. (2006). Positive parenting as a protective resource for parentally bereaved children. *Death Studies, 30*(1), 1-28.

Kwok, O., Haine, R., Sandler, I., Ayers, T., Wolchik, S., & Tein, J. (2005). Positive parenting as a mediator of the relations between parental psychological distress and mental health problems of parentally bereaved children. *Journal of Clinical Child and Adolescent Psychology, 34*(2), 260-271.

Lin, A., Sandler, I., Ayers, T., Wolchik, S., & Luecken, L. (2004). Resilience in parentally bereaved children and adolescents seeking preventive services. *Journal of Clinical child and Adolescent Psychology, 33*(4), 673-683.

Lutzke, J., Ayers, T., Sandler, I., & Barr, A. (1997). Risks and interventions for the parentally bereaved child. In S. Wolchik & I. Sandler (Eds.), *Handbook of children's coping: Linking theory and intervention* (pp. 215-243). New York: Plenum Press.

Malkinson, R., Rubin, S. S., & Witztum, E. (Eds.). (2000). *Traumatic and nontraumatic loss and bereavement: Clinical theory and practice*: (2000). xvii, 346pp.

Miles, M., & Huberman, A. (1994). *Qualitative data analysis* (2nd ed.). Thousand Oaks: Sage.

Maxwell, J. (2005). *Qualitative research design: An interactive approach* (3rd ed.). London: Sage.

Pfefferbaum, B., Nixon, S. J., Tucker, P. M., Tivis, R. D., Moore, V. L., Gurwitch, R. H., et al. (1999). Posttraumatic stress responses in bereaved children after the Oklahoma City bombing. *Journal of the American Academy of Child & Adolescent Psychiatry, 38*(11), 1372-1379.

Raveis, V., Siegel, K., & Karus, D. (1999). Children's psychological distress following the death of a parent. *Journal of Youth and Adolescence, 28*(2), 165-180.

Sanders, C. (1989). *Grief: The mourning after*. New York: John Wiley & Sons.

Sandler, I. N., Ayers, T. S., Wolchik, S. A., Tein, J.-Y., Kwok, O., & Haine, R. (2003). The family bereavement program: Efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. *Journal of Consulting and Clinical Psychology, 71*(3), 587-600.

Siegel, K., Mesagno, F., Karus, D., Christ, G., Banks, G., & Moynihan, R. (1992). Psychosocial adjustment of children with a terminally ill parent. *Journal of the American Academy of Child/ Adolescent Psychiatry, 31*, 327-333.

Siegel, K., Mesagno, R., & Christ, G. (1990). A preventive program for bereaved children. *American Journal of Orthopsychiatry, 60*, 168-175.

Silverman, P., & Worden, W. (1992). Children's reactions in the early months after the death of a parent. *American Journal of Orthopsychiatry, 62*, 93-104.

Tashakkori, T., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Thompson, M., Kaslow, N., Price, A., Williams, K., & Kingree, J. (1998). Role of secondary stressors in the parental death-child distress relation. *Journal of Abnormal Child Psychology, 26*, 357-366.

Tremblay, G. C., & Israel, A. C. (1998). Children's adjustment to parental death. *Clinical Psychology: Science and Practice, 5*(4), 424-438.

Weller, R., Weller, E., Fristad, M., & Bowes, J. (1991). Depression in recently bereaved prepubertal children. *American Journal of Psychiatry, 148*, 1536-1540.

West, D. L. (1997). *Perceived effects of media attention of child trauma victims and their families.* California School of Professional Psychology - Berkeley/Alameda, US,1.

Whelley, T., Radtke, R., Burgstahler, S., & Christ, T. (2003). Mentors, advisers, role models and peer supporters: Career development relationships and individuals with disabilities. *American Rehabilitation*, *27*(1) 42-49.

Worden, J. (1996). *Children and grief: When a parent dies.* New York: Guilford Press.

Yin, R. (2003). *Case study research: Design and methods* (3rd ed.). London: Sage.

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

Michelle S. Ballan & Mary Sormanti
Columbia University

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, Sonega, 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 mor-

bidity (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 be-

havior) (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, & Arean, 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 non-disabled 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 (Kloeppel & 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.

Dr. Ballan is an Assistant Professor at the Columbia University School of Social Work. For over a decade, her research, teaching and clinical practice has focused on empirically-based interventions for the sexual and mental health needs of individuals with disabilities and their families.

Dr. Sormanti is Associate Professor of Professional Practice at the Columbia University School of Social Work. Her

clinical practice experience includes extensive work with pediatric cancer patients and their families. In 2002-03 she served as the Clinical Director for a federally-funded program addressing the mental health needs of individuals and families affected by the terrorist attacks of September 11, 2001.

Endnotes

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

References

Ai, A. L., & Park, C. L. (2005). Possibilities of the positive following violence and trauma: Informing the coming decade of research. *Journal of Interpersonal Violence, 20*(2), 242-250.

Allen, B., & Borgen, K. (1994). Multimodal therapy for survivors of sexual abuse with developmental disabilities: An evaluation of treatment effectiveness. *Sexuality and Disability*, 12(3), 201-206.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction.* Cambridge: Polity Press.

Behrman, G., & Reid, W. J. (2002). Post-trauma intervention: Basic tasks. *Brief Treatment and Crisis Intervention, 2*(1), 39-47.

Benson, B. (2005). Mental health. In W. M. Nehring (Ed.), *Health promotion for persons with intellectual and developmental disabilities* (pp. 73-86). Washington, DC: American Association on Mental Retardation.

Benson, B. A., & Valenti-Hein, D. (2001). Cognitive and social learning treatments. In A. Dosen & K. Day (Eds.), *Treating mental illness and behavior disorders in children and adults with mental retardation* (pp. 101-118). Washington, DC: American Psychiatric Publishing, Inc.

Bonanno, G., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review, 21*(5), 705-734.

Bonell-Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedgwick, P., Abdelnoor, A., & Hubert, J. (1999). Bereavement and grief in adults with learning disabilities. A follow-up study. *British Journal of Psychiatry, 175*, 348-350.

Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17-27.

Brewin, C. R., Andrews, B., & Valentine, J. D. (2000). Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology, 68*(5), 748-766.

Briere, J., & Elliott, D. (2000). Prevalence, characteristics and long-term sequelae of natural disaster exposure in the general population. *Journal of Traumatic Stress, 13*(4), 661-679.

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social model of disability. *Disability and Society, 19*(7), 735-751.

Burnett, P., Middleton, W., Raphael, B., Dunne, M., Moylan, A., & Marinek, N. (1994). Concepts of normal bereavement. *Journal of Traumatic Stress, 7*, 123-134.

Caplan, G. (1961). *An approach to community mental health*. New York: Grune & Stratton.

Caplan, G. (1964). *Principles of preventative psychiatry*. New York: Basic Books.

Carder, M. M. (1987). Journey into understanding: Mentally retarded people's experience around death. *Journal of Pastoral Care, 4*, 18-31.

Clegg, J. A., & Lansdall-Welfare, R. (2003). Death, disability and dogma. *Philosophy, Psychiatry, and Psychology, 10*, 67–79.

Clements, P. T. (2004). Making sense of the senseless. *The Journal of Psychosocial Nursing, 42*(1), 6-7.

Courtois, C. A. (2004). Complex trauma, complex reactions: Assessment and treatment. *Psychotherapy: Theory, Research, Practice, Training, 41*(4), 412-425.

Danieli, Y., & Dingman, R. (Eds.). (2005). O*n the ground after September 11: Mental health responses and practical knowledge gained*. New York: Haworth Maltreatment and Trauma Press.

Davis, C. G., & McKearney, J. M. (2003). How do people grow from their experience with trauma or loss? *Journal of Social and Clinical Psychology, 22*(5), 477-492.

Day, K. (1985). Psychiatric disorder in middle aged and the elderly mentally handicapped. *British Journal of Psychiatry, 147*, 665–668.

Deb, S., Matthews, T., Holt, G., & Bouras, N. (Eds.). (2001). *Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability*. Brighton, Great Britain: Pavilion.

Developmental Disabilities Assistance and Bill of Rights Act of 1990, Pub. L. No. 101-496, 104 Stat. 1191 (1990).

DeWolfe, D. J. (2000). *Training manual for mental health and human service workers in major disasters* (2nd ed., DHHS Publication No. ADM90-538). Washington, DC: U.S. Department of Health and Human Services.

Dodd, P., Dowling, S., & Hollins, S. (2005). A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(7), 537-543.

Doka, K. J. (Ed.). (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.

Elklit, A., & O'Connor, M. (2005). Post-traumatic stress disorder in a Danish population of elderly bereaved. *Scandinavian Journal of Psychology, 46*(5), 439-445.

Eth, S., & Pynoos, R. (1985). Interaction of trauma and grief in childhood. In S. Eth & R. Pynoos (Eds.), *Post-traumatic stress disorder in children* (pp. 171-186). Washington, D.C.: American Psychiatric Press.

Everly, Jr., G. S., & Mitchell, J. T. (1999). *Critical incident stress management (CISM): A new era and standard of care in crisis intervention*. Ellicott City, MD: Chevron.

Federal Emergency Management Agency. (2000, April). *FEMA and NOAA join forces to warn of the impact of climate change*. Retrieved December 27, 2005, from http://www.fema.gov/news/newsrelease.fema?id=7436

Feuerstein, P. B. (2005). 911 and people with disabilities. In Y. Danieli & R. Dingman (Eds.), *On the ground after September 11: Mental health responses and practical knowledge gained* (pp. 89-95). New York: Haworth Maltreatment and Trauma Press.

Friedman, M. J., & Schnurr, P. (1996). Trauma, PTSD and health. *NC-PTSD Clinical Quarterly, 6*(4), 75-76.

Fullerton, C. S., Ursano, R. J., Kao, T., & Bharitiya, V. (1992). The chemical and biological warfare environment: Psychological responses and social support in a high stress environment. *Journal of Applied Social Psychology, 22*, 1608-1623.

Garbarino, J., & Brookhouse, P. (Eds.). (1987). *Special children, special risks: The maltreatment of children with disabilities*. New York: Aldine de Gruyter.

Ghaziuddin, M. (1988). Behavioural disorders in the mentally handicapped. The role of life events. *British Journal of Psychiatry, 152*, 683-686.

Gray, M. J., & Litz, B. T. (2005). Behavioral interventions for recent trauma: Empirically informed practice guidelines. *Behavior Modification, 29*(1), 189-215.

Harper, D. C., & Wadsworth, J. S. (1993). Grief in adults with mental retardation: Preliminary findings. *Research in Developmental Disabilities, 14*, 313-330.

Herman, J. (1992). Complex PTSD: A syndrome in survivors of prolonged and repeated trauma. *Journal of Traumatic Stress, 5*, 377-391.

Hobfoll, S. E. (2001). The influence of culture, community, and the nested-self in the stress process: Advancing conservation of resources theory. *Applied Psychology: An International Review, 50*(3), 337-370.

Hogan, N. S., Worden, J. W., & Schmidt, L. A. (2003). An empirical study of the proposed complicated grief disorder criteria. *Omega: Journal of Death and Dying, 48*(3), 263-277.

Hollins, S., & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry, 170,* 497-501.

Jacobs, D., Mazure, C., & Prigerson, H. G. (2000). Diagnostic criteria for traumatic grief. *Death Studies, 24*, 185-199.

Jacobs, S. (1999). *Traumatic grief: Diagnosis, treatment, and prevention*. Philadelphia: Brunner/Mazel.

Jordan, J. R., & Neimeyer, R. A. (2003). Does grief counseling work? *Death Studies, 27*(9), 765-786.

Kanel, K. (2007). *A guide to crisis intervention* (3rd ed.). Pacific Grove, CA: Wadsworth.

Katz, C. L., Pellegrino, L., Pandya, A., Ng, A., & DeLisi, L. E. (2002). Research on psychiatric outcomes and interventions subsequent to disasters: A review of the literature. *Psychiatry Research, 110*(3), 201-217.

Kauffman, J. (2005). *Guidebook on helping persons with mental retardation mourn*. Amityville, NY: Baywood Publishing Co.

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Posttraumatic stress disorder in the National Comorbidity Survey. *Archives of General Psychiatry, 52*(12), 1048-1060.

Kirchner, L., & Mueth, M. (1999). Suicide in individuals with developmental disabilities. In R. Fletcher (Ed.), *Therapy approaches for persons with mental retardation* (pp. 127-150). Kingston, NY: The NADD Press.

Kloeppel, D. A., & Hollins, S. (1989). Double handicap: Mental retardation and death in the family. *Death Studies, 13*, 31-38.

Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J., & Steineck, G. (2004). Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: A population-based follow-up. *Psychological Medicine, 34*(8), 1431-1441.

Latham, A. E., & Prigerson, H. G. (2004). Suicidality and bereavement: Complicated grief as psychiatric disorder presenting greatest risk for suicidality. *Suicide and Life Threatening Behavior, 34*(4), 350-362.

Lavin, C. (1989). Disenfranchised grief and the developmentally disabled. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow.* (pp. 229-237). Lexington, MA: Lexington Books/D. C. Heath and Com.

Levitas, A. S., & Gilson, S. F. (2001). Predictable crises in the lives of people with mental retardation. *Mental Health Aspects of Developmental Disabilities, 4*(3), 89-100.

Li, J., Laursen, T. M., Precht, D. H., Olsen, J., & Mortensen, P. B. (2005). Hospitalization for mental illness among parents after the death of a child. *New England Journal of Medicine, 352*(12), 1190-1196.

Lindsay, W. R., Richardson, I., & Michie, A. M. (1989). Short-term generalised effects of relaxation training on adults with moderate and severe mental handicaps. *Mental Handicap Research, 2*(2), 197-206.

Lipe-Goodson, P. S., & Goebel, B. L. (1983). Perception of age and death in mentally retarded adults. *Mental Retardation, 21*(2), 68-75.

Luchterhand, C., & Murphy, N. (1998). *Helping adults with mental retardation grieve a death loss*. Philadelphia: Taylor & Francis.

Lundin, T. (1994). The treatment of acute trauma. *Psychiatric Clinics of North America, 17*, 385–391.

MacHale, R. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities, 30*, 113-117.

Masi, G., Brovedani, P., Mucci, M., & Favilla, L. (2002). Assessment of anxiety and depression in adolescents with mental retardation. *Child Psychiatry and Human Development, 32*(3), 227-237.

Matthews, L. T., & Marwit, S. J. (2004). Complicated grief and the trend toward cognitive-behavioral therapy. *Death Studies, 28*(9), 849-863.

Mayou, R. (2001). Prediction of psychological outcomes one year after a motor vehicle accident. *American Journal of Psychiatry, 158*, 1231-1238.

McCabe, M. P, Cummins, R., & Reid, S. B. (1994). An empirical study of the sexual abuse of people with intellectual disability. *Sexuality and Disability, 12*(4), 297-306.

McCarthy, J. (2001). Post-traumatic stress disorder in people with learning disability. *Advances in Psychiatric Treatment, 7*, 163-169.

McFarlane, A. C., & de Girolamo, G. (1996). The nature of traumatic stressors and the epidemiology of posttraumatic reactions. In B. A. van der Kolk, A. C. McFarlane, & L. Weisaeth (Eds.), *Traumatic stress: The effects of overwhelming experience on mind, body, and society* (pp. 129-154). New York: Guilford Press.

Mitchell, A., & Clegg, J. (2005). Is post-traumatic stress disorder a helpful concept for adults with intellectual disability? *Journal of Intellectual Disability Research, 49*(7), 552-559.

Moddia, B., & Chung, M. C. (1995). Grief reactions and learning disabilities. *Nursing Standard, 9*(33), 38-39.

Munson, C. E. (2002). Child and adolescent needs in a time of national disaster: Perspectives for mental health professionals and parents. *Brief Treatment and Crisis Intervention, 2*(2), 135-151.

Nader, K. (1997). Childhood traumatic loss: The interaction of trauma and grief. In C. R. Figley, B. E. Bride, & N. Mazza, (Eds.), *Death and trauma: The traumatology of grieving* (pp. 17-41). London: Taylor and Francis.

Nader, K. (2001). *Terrorism: September 11, 2001 trauma, grief, and recovery.* Retrieved March 10, 2006, from http://www.giftfromwithin.org/pdf/firstaid.pdf.

Neimeyer, R. A. (2002). Traumatic loss and the reconstruction of meaning. *Journal of Palliative Medicine, 5*(6), 935-942.

Newman, E., Christopher, S. R., & Berry, J. O. (2000). Developmental disabilities, trauma exposure, and post-traumatic stress disorder. *Trauma, Violence and Abuse, 1*(2), 154-170.

Nezu, C. M., Nezu, A. M., & Arean, P. (1991). Assertiveness and problem-solving training for mildly mentally retarded persons with dual diagnoses. *Research in Developmental Disabilities, 12*, 371-386.

Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I, an empirical review of the literature, 1981-2001. *Psychiatry, 65*(3), 207-239.

Nugent, J. (1997). *Handbook on dual diagnosis: Supporting people with a developmental disability and a mental health problem.* Evergreen, CO: Mariah Management.

Oliver, M. (1995). Counseling disabled people: A counselor's perspective. *Disability and Society, 10*, 261-279.

Oswin, M. (1985). Bereavement. In M. Kraft, J. Bicknell, & S. Hollins (Eds.), *Mental handicap: A multidisciplinary approach* (pp. 197-205). Ballierre, England: Tindall.

Paton, D., & Johnston, D. (2001). Disasters and communities: Vulnerability, resilience and preparedness. *Disaster Prevention and Management, 10*(4), 270-277.

Powell, S., Rosner, R., Butollo, W., Tedeschi, R. G., & Calhoun, L. G. (2003). Posttraumatic growth after war: A study with former refugees and displaced people in Sarajevo. *Journal of Clinical Psychology, 59*(1), 71-83.

Prigerson, H., & Jacobs, S. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut. (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 613-645). Washington, DC: American Psychological Association.

Prigerson, H., Bierhals, A., Kasl, S., Reynolds, C., Shear, M., Newsom, J., & Jacobs, S. (1996). Complicated grief as a disorder distinct from bereavement-related depression and anxiety: A replication study. *American Journal of Psychiatry, 153*, 1484-1486.

Prigerson, H., Shear, M., Jacobs, S., Reynolds, C., Maciejewski, P., Davidson, J., et al (1999). Consensus criteria for traumatic grief: A preliminary empirical test. *British Journal of Psychiatry, 174*, 67-73.

Prout, H. T., & Cale, R. L. (1994). Individual counseling approaches. In D. C. Strohmer & H. T. Prout (Eds.), *Counseling & psychotherapy with persons with mental retardation and borderline intelligence* (pp. 103-141). Hoboken, NJ: John Wiley & Sons, Inc.

Razza, N. J., & Tomasulo, D. J. (2005). *Healing trauma: The power of group treatment for people with intellectual disabilities*. Washington, DC: American Psychological Association.

Read, S. (2001). A year in the life of a bereavement counseling and support service for people with learning disabilities. *Journal of Learning Disabilities, 5*(1), 19-33.

Reeve, D. (2000). Oppression within the counseling room. *Disability and Society, 15*(4), 669-682.

Regehr, C., & Sussman, T. (2004). Intersections between grief and trauma: Toward an empirically based model for treating traumatic grief. *Brief Treatment and Crisis Intervention, 4*(3), 289-309.

Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency, 86*(6), 567-574.

Roberts, A. R. (2005). Bridging the past and present to the future of crisis intervention and crisis management. In A. R. Roberts (Ed.), *Crisis intervention handbook: Assessment, treatment, and research* (3rd ed.)(pp. 3–34). New York: Oxford University Press.

Roberts, A. R. (Ed.). (2005a). *Crisis intervention handbook: Assessment, treatment, and research* (3rd ed.). New York: Oxford University Press.

Rubin, S. S., Malkinson, R., & Witztum, E. (2003). Trauma and bereavement: Conceptual and clinical issues revolving around relationships. *Death Studies, 27*(8), 667-690.

Rundell, J. R., Ursano, R. J., Holloway, H. C., & Silberman, E. K. (1989). Psychiatric responses to trauma. *Hospital and Community Psychiatry, 40*(10), 68-74.

Rush, A. J., & Frances, A. (2000). Expert consensus guideline series: Treatment of psychiatric and behavioral problems in mental retardation. *American Journal on Mental Retardation, 105*(3), 159-226.

Sanders, S., Bowie, S. L., & Bowie, Y. D. (2003). Lessons learned on forced relocation of older adults: The impact of hurricane Andrew on health, mental health, and social support of public housing recipients. *Journal of Gerontological Social Work, 40*(4), 23-35.

Servaty-Seib, H. L. (2004). Connections between counseling theories and current theories of grief and mourning. *Journal of Mental Health Counseling, 26*(2), 125-145.

Shear, K., Frank, E., Houck, P. R., & Reynolds, C. F. (2005). Treatment of complicated grief: A randomized controlled trial. *Journal of the American Medical Association, 293*(21), 2601-2608.

Singh, I., Jawed, S. H., & Wilson, S. (1988). Mania following bereavement in a mentally handicapped man. *British Journal of Psychiatry, 152*, 866–867.

Sobsey, R. (2005). Violence. In W. M. Nehring (Ed.), *Health promotion for persons with intellectual and developmental disabilities* (pp. 205-234). Washington, DC: American Association on Mental Retardation.

Sobsey, R., & Varnhagen, C. (1989). Sexual abuse and exploitation of people with disabilities: Toward prevention and treatment. In M. Csapo & L. Gougen (Eds.), *Special education across Canada* (pp. 199-218). Vancouver: Vancouver Center for Human Development and Research.

Speece, M. W., & Brent, S. B. (1984). Children's understanding of death: A review of three components of the death concept. *Child Development, 55*, 1671-1686.

Stavrakaki, C. (1997). Anxiety disorders in persons with mental retardation: Diagnostic, clinical and treatment issues. *Psychiatric Annals, 27*, 182–189.

Stavrakaki, C., & Antochi, R. M. (2004). Trauma may spark OCD in patients with Down syndrome. *Psychiatric Annals, 34*(3), 196-201.

Stroebe, M. (1992). Coping with bereavement: A review of the grief work hypothesis. *Omega: Journal of Death and Dying, 26*(1), 19-42.

Stroebe, M. S. (2001). Bereavement research and theory: Retrospective and prospective. *The American Behavioral Scientist, 44*(5), 854-865.

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224.

Sullivan, P. M., Brookhouser, P. E., Knutson, J. F., Scanlon, J. M., & Schulte, L. E. (1991). Patterns of physical and sexual abuse of communicatively handicapped children. *Annals of Ontology, Rhinology, and Laryngology, 100*, 188-194.

Summers, J., Zisook, S., Sciolla, A. D., Patterson. T., & Atkinson, J. H. (2004). Gender, AIDS, and bereavement: A comparison of women and men living with HIV. *Death Studies, 28*(3), 225-241.

Swain, J., Griffiths, C., & Heyman, B. (2002). Towards a social model approach to counseling disabled clients. *British Journal of Guidance and Counselling, 31*(1), 137-152.

Takahashi, A., Watanabe, K., Oshima, M., Shimada, H., & Ozawa, A. (1997). *Journal of Intellectual Disability Research, 41*(2), 193-196.

Tedeschi, R. G., & Kilmer, R. P. (2005). Assessing strengths, resilience, and growth to guide clinical interventions. *Professional Psychology: Research and Practice*, *36*(3), 230-237.

Valenti-Hein, D., & Schwartz, L. (1995). *The sexual abuse interview for the developmentally disabled*. Los Angeles: James Stanfield and Co.

van der Kolk, B. A. (1996). The complexity of adaptation to trauma: Self-regulation, stimulus discrimination, and characterological development. In B. A. van der Kolk, A. C. McFarlane, & Weisaeth (Eds.), *Traumatic stress: The effects of overwhelming experience on mind, body and society* (pp. 417-440). New York: Guilford Press.

Voelker, R. (2006). Post-Katrina mental health needs prompt group to compile disaster medicine guide. *Journal of the American Medical Association, 295*(3), 259-260.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, *42*(1), 1-18.

Wilson, C., & Brewer, N. (1992). The incidence of criminal victimization of individuals with an intellectual disability. *Australian Psychologist, 27*(2), 114-117.

Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, *57*, 349-357.

Yapa, P., & Clarke, D. (1989). Schizophreniform psychosis associated with delayed grief in a man with moderate mental handicap. *Mental Handicap Research, 2*, 211–212.

Zakour, M. J., & Harrell, E. B. (2003). Access to disaster services: Social work interventions for vulnerable populations. *Journal of Social Service Research, 30*(2), 27-54.

Politics and the Pandemic: HIV/AIDS, Africa, and the Discourse of Disability

Laura L. Behling
Gustavus Adolphus College
St. Peter, Minnesota

In 2004, *Africa News* filed a report on then 12-year old William Msechu, a young African who lost both of his parents to AIDS in 1999. He, too, was HIV positive. Msechu is characterized as a "very bright boy," although, the article reports, he is "yet to come to terms with his HIV status." "'I was told that I have tuberculosis and I am getting better,'" the article quotes William as saying to journalists ("HIV-AIDS and STDs," 2004). William Msechu's disbelief at having contracted HIV is unremarkable; persons diagnosed with severe diseases, including HIV/AIDS, often work through denial and incredulity.[1] Just as unremarkable, however, is Msechu's contention that he had not tested positive for HIV, but rather, had contracted tuberculosis, another widespread disease but not nearly as stigmatizing as HIV/AIDS. Substituting "tuberculosis" for "HIV" may be an affirming measure for Msechu, but it also provides one more example of the rhetorical slipperiness that historically, and still continues to accompany, the HIV/AIDS pandemic.

In the late 1980's and early 1990's, HIV/AIDS was beginning to consistently "break" as a news and human interest story, in part because the cause of HIV/AIDS at the time was still widely misunderstood. Yet almost from the start, an understanding of HIV/AIDS has been intimately linked to linguistic constructions. In 1988, Paula Treichler argued that "AIDS is not merely an invented label, provided to us by science and scientific naming practices, for a clear-cut disease entity caused by a virus. Rather, the very nature of AIDS is constructed through language" (1988, 31). Like Susan Sontag, who posits illness as a metaphor, Treichler claims that "AIDS is a story, or multiple stories . . . a nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another" (1988, 42). In the more than 20 years that HIV/AIDS has been identified, the language used to define it has suggested several realities: that belonging to a particular cultural or ethnic group was a greater risk factor than behavior; that women are only passive receptacles for the virus; that AIDS is an "exotic" disease because it originated "elsewhere" (outside the geographic boundaries of the United States), and that, in the early 1980s, those who presented with the ubiquitous markers of infection, were informally categorized as suffering from "WOGS: the Wrath of God Syndrome," as David Black recounts in his early history of the disease (1985).

Despite the relative "youth" of HIV/AIDS as a disease, it created, in Treichler's phrase, a "dense discursive jungle" (1988, 48). The complexity of the rhetoric has only grown as the disease has come to be recognized as a global pandemic that can all too quickly refute the previous realities that were constructed about it. "WOGS" and "G.R.I.D." (Gay Related Immune Disease) (Black 1985) are now only historical linguistic markers, race and ethnicity are not causes of infection, and rates of infection among women are increasing. Yet the reality of the disease continues to be created by language, particularly in this post-September 11 world. The rhetoric that has accompanied and constructed HIV/AIDS now relies on the linguistic framework that the current wars in Afghanistan and Iraq, and the "war on terrorism" provide.

This essay first examines how the current U.S. political discourse about war and terrorism is mirrored in its rhetoric about HIV/AIDS, particularly in the Bush administration's initiative for Africa, the "Emergency Plan for AIDS Relief." In 2003, President George W. Bush stated the worldwide AIDS epidemic has become a "U.S. foreign-policy priority," and he

placed this historic "mission of rescue" of Africa within the long line U.S. global, altruistic know-how. "The United States of America has a long tradition of sacrifice in the cause of freedom," he explained, "and we've got a long tradition of being generous in the service of humanity. We are the nation of the Marshall Plan, the Berlin Airlift and the Peace Corps. And now we are the nation of the Emergency Plan for AIDS Relief." Allan Brandt avers that AIDS "makes explicit, as few diseases could, the complex interaction of social, cultural and biological forces" and "demonstrates how economics and politics cannot be separated from disease" (1988, 163).

In this paper, I argue that this rhetorical strand introduces crippling metaphors of the disease that simultaneously mask and demarcate a disability composed of certain moral behaviors, race, and sex/gender. The Emergency Plan for AIDS Relief advocates an "ABC" approach toward HIV/AIDS prevention, comprised of "abstinence," "be faithful," and "condom use." The shift in discourse that supports the funding is clear; attacking the pandemic of HIV/AIDS is no longer simply about fighting the disease, but also about addressing the types of behavior that allow the transmission of the disease. That the "Emergency Plan" is directed to Africa (sub-Saharan countries, in particular) yet ignores the real discrimination faced by African women, crafts a discourse of disability that is reconstituting the global body politic as one composed of healthy--defined according to sex/gender, morality (both personal and political), and race--and disease-free citizens.

The Politics of the Pandemic: The Emergency Plan for AIDS Relief

At the 1992 Republican National Convention that nominated George W. Bush for President of the United States, HIV-positive and reluctant AIDS activist Mary Fisher addressed the delegates on the convention floor:

"I would never have asked to be HIV positive, but I believe that in all things there is a purpose… The reality of AIDS is brutally clear. Two-hundred-thousand Americans are dead or dying. A million more are infected. Worldwide, forty-million, sixty-million, or one-hundred-million infections will be counted in the coming few years. But despite science and research, White House meetings, and congressional hearings; despite good intention and bold initiatives, campaign slogans, and hopeful promises, it is--despite it all--the epidemic which is winning tonight" ("Official Report," 1992).

Although Fisher assures the delegates that the AIDS virus is "not a political creature," the history of the rhetoric of HIV/AIDS has proven this view to be naïve.[2] At the very heart of HIV/AIDS, even the very name of the disease, is a story fraught with battles over language, misunderstandings (deliberate and inadvertent) about risk groups and means of transmission, and a medically-defined disease that became associated with the popular currents of the late-twentieth, and now early twenty-first centuries.

Almost from the start, the discourse on AIDS quickly was couched in the rhetoric of war. As Michael S. Sherry explains, such appropriation of war rhetoric was not surprising; "There was," he notes, "a long tradition before AIDS of militarizing disease" (1993, 45). Donna Haraway concurs. "Modern immunology," as Treichler explains Haraway, "moved into the realm of high science when it reworked the military combat metaphors of World War II (battles, struggle, territory, enemy, truces) into the language of postmodern warfare: communication command control—coding, transmission, messages—interceptions, spies, lies" (1988, 59). Even more specifically, the 1980s

had seen a "war on terrorism," a "trade war" with the Japanese that was linked to the U.S.-Japan military battles of World War II, and of course, the "Cold War" stand-off between the United States and the Soviet Union. Moreover, as Sherry observes, the late 1980s also brought a "war on drugs, "complete with incessant talk of 'battle plans,' 'fronts,' enemies,' 'victory,' and 'prisoner-of-war camps'" (1993, 46). Such discourse mobilized not only the government to take action according to a plan with which they were familiar--military engagement--but also activated community groups. In the early 1990's, the first Iraq War both flamed the militaristic discourse and allowed activists to draw a clear contrast between the war abroad and "the neglected war against AIDS" at home (Sherry, 1993, 50). "It prompted," as Sherry explains, "a far more pointed and conscious deployment of the war metaphor, whose earlier use had been reflexive and diffuse" (1993, 50). Treichler (1988) wryly observes, "The epidemic of signification that surrounds AIDS is neither simple nor under control" (p. 63).

Perhaps not surprisingly, in the post-September 11 world, the rhetoric that has accompanied and constructed HIV/AIDS has infiltrated national security discussions. Sandra Wallman suggests that "metaphors used to explain or blame disease are neither random nor idiosyncratic" but instead "reflect the anxieties of the cultures that give them currency" (1998, 175). Indeed, HIV/AIDS is "inextricably connected with war and civil unrest," Dennis Altman explains, referencing the use of rape as a weapon in multiple civil conflicts and the conditions in camps to which war refugees are subject (2003, 421). Even more specifically, the discourse of HIV/AIDS has relied on the linguistic framework that the current wars in Afghanistan and Iraq provide. Former U.S. Secretary of State Colin Powell termed HIV/AIDS "the greatest weapon of mass destruction in the world today, killing 8,000 people every single day and infecting so many more every single day" ("Secretary of State," 2005). More recently, current Secre-

tary of State Condoleeza Rice suggests that the President's Emergency Plan for AIDS Relief "is a key example of effective foreign assistance and transformational diplomacy in action" ("Remarks," 2006).[3] The non-partisan Council on Foreign Relations, in a special report released January 2006, argues that responding to Africa is about "more than humanitarianism." Focusing on the rise of terrorism on the continent, conflicts within failing states, an increasing Western interest in oil and gas reserves, and the HIV/AIDS pandemic, Africa has increasing strategic significance and threatens economic and political stability around the globe ("More than Humanitarianism," 2006).

Indeed, HIV/AIDS plays a role in the national security strategy issued by the Bush administration in March 2006, a reaffirmation of the Doctrine of Preemptive War. According to the *Washington Post*, the Doctrine outlines action against terrorists and hostile states with chemical, biological or nuclear weapons. The document "lays out a robust view of America's power and an assertive view of its responsibility to bring change around the world," Peter Baker writes, and includes topics such as genocide, human trafficking, and AIDS ("Bush to Restate," 2006). This shift in conceiving of HIV/AIDS as a national security issue does initially seem to offer the pandemic political clout it had heretofore not enjoyed, although it does so by changing the nature of the pandemic from disease to weapon. Such increased discursive importance veils significant political and humanitarian trade-offs.

Specifically, the political rhetoric of HIV/AIDS in the United States can be understood to have two interrelated parts. First, the pandemic is viewed to be a threat to national (U.S.) security. Second, the U.S. understands itself to have a moral duty to combat the spread of HIV/AIDS that is clearly linked to controlling certain behaviors. Stefan Elbe contends the "prospect of normalizing the sexual behavior of people around the world has been one of the principal attractions driving more conservative

and religious political groups to join the global struggle against AIDS" (2005, 414). In the last two years, these components to the U.S. government's rhetoric of HIV/AIDS have escalated and become more firmly entrenched.

In a 2003 address, President George W. Bush stated that AIDS "is a tragedy for millions of men, women and children, and a threat to stability of entire countries and of regions of our world" ("President Urges," 2003). Fighting the worldwide AIDS epidemic has become a "U.S. foreign-policy priority," he continued, with a focus on, "Compassionate pricing policies and aid from developed nations." The initiative, called the "U.S. Leadership against HIV/AIDS, Tuberculosis and Malaria Act," seeks to integrate prevention, treatment, and care ("United States," 2005). In a speech to commemorate the 2005 World AIDS Day, Bush painted this vision of America: "I believe America has a unique ability, and a special calling," he said, "to fight this disease. We are blessed with great scientific knowledge. We're a generous country that has always reached out to feed the hungry, and rescue captives, and care for the sick. We are guided by the conviction of our founding--that the Author of Life has endowed every life with matchless value" ("President and Mrs. Bush," 2005). Even Irish rock star Bono, long a critic of Western governments' responses to global political, health, and economic crises, couches the fight against HIV/AIDS within the terrorist milieu of post-September 11 and the belief that the United States holds hope and promise. September 11 "was not just an attack on physical America," Bono argues. "It was an attack on the idea of America, too" ("U2's Bono," 2005).

The Emergency Plan for AIDS Relief relies on a litany of three behaviors: "abstinence, be faithful, use condoms." In testimony before the Committee on Senate Health, Education, Labor and Pensions, Claude A. Allen, former Deputy Secretary, Department of Health and Human Services, elaborated upon the Bush administration's "ABC" policy toward HIV/AIDS trans-

mission prevention. "For too long," he begins, "people in the developing world have seen a diagnosis of HIV infection as a death sentence. And it has been. But with the promise of care and treatment, for the first time, learning your HIV status can be seen as a stepping-stone to needed care. An HIV test will be the gateway to services. For those who are infected, they will be able to receive treatment--and essential prevention and support services to keep from transmitting the virus to others. For those who are not infected, they can receive vital prevention services to learn how to remain HIV-free, emphasizing the ABCs of HIV prevention. 'A' is for abstinence in young people, 'B' is for being faithful within a relationship, and 'C' for condom use in high risk populations with the knowledge that condoms are not as effective in preventing all sexually transmitted diseases as they are with HIV." Then, Allen adds his own testimonial for this method: "I have traveled to Uganda, and I have seen that ABC is working. Uganda is the only country in Africa with an increasing life expectancy. The ABC prevention concept is something that we should seriously examine in our own country" ("Congressional Testimony," 2003).

The shift in rhetoric that supports the funding is clear; attacking the pandemic of HIV/AIDS is no longer simply about fighting the disease, but also about addressing the types of behavior that allows the transmission of the disease. Antonio Maria Costa, director of the United Nations Office on Drugs and Crime, announced that "the HIV/AIDS epidemic among injecting drug users can be stopped--and even reversed--if drug users are provided with... outreach, provision of clean injecting equipment and... substitution treatment." A few months later, an assistant secretary of state forced Costa to publicly affirm that the UN Office would "neither endorse needle exchange as a solution for drug abuse nor support public statements advocating such practices" (Hunter, 2005). Several Congressional representatives have even begun suggesting U.S. funds should be withdrawn from relief agen-

cies that operate or promote needle exchange programs. Mark Souder (R-Indiana) explains: "These lifestyles are the result of addiction, mental illness or other conditions that should and can be treated rather than accepted as normal, healthy behaviors" (Hunter, 2005). The people suffering from HIV/AIDS, these comments infer, are considered to be socially deviant and as a result, their infected bodies have become disabled, incapable of performing the normality of disease-free ablebodiedness.

This sense of HIV/AIDS as a threat to national security in the United States goes hand-in-hand with the moral imperative behind the U.S. action, a similar rhetoric apparent in the administration's desire to bring democracy to the Middle East. The government's rhetoric often invokes its "passion about doing our duty" ("President Urges, 2003), and touts the important work of faith-based and community organizations, often affiliated with churches and religious orders.[4] To assist in such a message, political speeches and announcements are often wound through with Biblical narratives and allusions, which, given the Bush administration's public professions of faith, lend a Judeo-Christian undertone to official national positions. "We know that AIDS can be treated," Bush begins in touting the Global HIV/AIDS Initiative. "Anti-retroviral drugs have become much more affordable in many nations, and they are extending many lives. In Africa, as more AIDS patients take these drugs, doctors are witnessing what they call the Lazarus effect, when one patient is rescued by medicine, as if back from the dead." The cause of fighting AIDS on the global scale is "rooted in the simplest of moral duties. When we see this kind of preventable suffering, when we see a plague leaving graves and orphans across a continent, we must act. When we see the wounded traveler on the road to Jericho, we will not, America will not pass to the other side of the road" ("President Urges," 2003). In the same announcement, Bush declared, "Confronting this tragedy is the responsibility of every nation. For

the United States, it is a part of the special calling that began with our founding. We believe in the dignity of life, and this conviction determines our conduct around the world. We believe that everyone has a right to liberty, including the people of Afghanistan and Iraq. We believe that everyone has a right to life, including children in the cities and villages of Africa and the Caribbean" ("President Urges," 2003).

The special nature of the United States' founding carries significant weight in this call to action, yet it is a calling whose motivations are not clearly delineated and, in fact, become blurred by the rhetoric that invokes a "right to life" or the "Author of Life," the term the Administration uses to signal a divine origin to all life. Even more so, linking those countries suffering under the assault of HIV/AIDS to the warfare in Afghanistan and Iraq further emphasizes the war-like nature required to battle the epidemic. Democracy, a state in which the body politic exists, now goes hand-in-hand with disease-free bodies. To eradicate a lethal virus is the same as eradicating a (lethal) dictator--the body and body politic have become one, the individual is erased in favor of the state, and fighting a disease is both a political and moral imperative.[5]

This linking of the political to the moral in the fight against AIDS in Africa is not surprising given the historical conceptions of the "dark continent." Lucy Jarosz traces the imagery back to British colonial commercial, religious, and exploratory initiatives in East Africa, and Simon Watney points to "the long discursive tradition" made most completely available, perhaps, in Joseph Conrad's *Heart of Darkness* (1989, 46). Africa has long been viewed in Western perspective as a place mired in depravity and licentiousness, and that is dirty even unclean, rampant with promiscuous sexuality, and primitive, as critics such as Joane Nagel have claimed (2003). In Watney's study of images of AIDS in Africa appearing in the popular press in the 1980s, Africa "becomes a deviant continent," (1989, 50) in-

fected by a terrible disease and the rhetoric used to describe such a place is "far more interested in stopping 'promiscuity' than it is in stopping the transmission of HIV" (1989, 46).

So it is now more than 20 years later. with current United States political rhetoric, except with one important addition. Africa still teems with a disastrous disease capable of infecting the global population. But the threat is no longer simply biological or viral. Rather, the disease has been mutated into a terrorist weapon, capable of not only infecting the human body, but most importantly, of destroying the United States body politic. Epidemic disease, as Wallman posits, "is seen as a threat to the purity and the survival of 'us' as moral beings" (1998, 176), thus explaining and reinforcing the patriotic rhetoric of America's identity and destiny as articulated by Bush. And like the vague use of the term "terrorist" or "war on terror" employed so readily in characterizing the motivation for the battles in Iraq and Afghanistan, so too is the far from specific term of "Africa" used to locate the pandemic. As Watney notes, "Every country affected by HIV has its own epidemic, shaped by a multitude of variable local factors" (1989, 51). Referencing the scores of countries, tribes, regions, and cultures of all the people on the continent as solely "Africa" denies their individual identities, and, as Treichler notes, "Once again reinvents 'Africa' as an undifferentiated mass of disease" (1991, 88).

The Discourse of Disability: African Women with HIV/AIDS

Disability studies scholars have been productive not only in interrogating cultural understandings of physical difference in human bodies, but also in suggesting that social constructions of ableness inform categories such as "normal" and "disabled," and in identifying the ways in which the "disabled" have been ignored. Douglas Baynton, writing about the ways "disabled" status has been applied in American history, suggests, "Disability has functioned his-

torically to justify inequality for disabled people themselves, but it has also done so for women and minority groups. That is, not only has it been considered justifiable to treat disabled people unequally, but the *concept* of disability has been used to justify discrimination against other groups by attributing disability to them" (2001, 33).

Critiques of the HIV/AIDS pandemic have identified the transformation of several minority populations. In the early social history of the disease they were the four H's: homosexuals; hemophiliacs; Haitians; and heroin users (Black, 1985). These were termed "risk groups," emphasizing and projecting, as Meira Weiss contends, the disabling "politics of stigma and marginality" (1997, 458). People were segregated by their normal or deviant behaviors, by their races or ethnicity, or by their already-compromised physical status.[6] In current political discourse, such is the case with Africans whose very behavior interferes with or prevents their "normal" achievement, and even more terrifying, who threaten the security health of the entire world.

Today, women make up the majority of bodies already infected with HIV or already suffering from AIDS. In sub-Saharan Africa, women and girls make up 60 percent of those infected by HIV and in most of these countries, the rate of new infections is highest among women in their twenties and thirties; in southern Africa, young women aged between 15 and 24 are at least three times more likely to be HIV positive than men of their same age. According to the 2005 report on the Emergency Plan for AIDS Relief, approximately 60 percent of those receiving antiretroviral treatment are women; about 69 percent of those who receive counseling and testing are women; and among orphans and vulnerable children, about 52 percent are girls. According to Helen Jackson, HIV/AIDS advisor for southern Africa with the UN Population Fund, "The physiological data seem to indicate

it's something like twice as easy for women to become infected as for men" (Vespirini, 2005).

The reasons for this discrepancy in infection rates are both biological and sociocultural. Infection often occurs between older men and younger women, and women are often economically dependent on a male partner. Domestic violence also plays a role, as do ignorance of or lack of women's legal rights. As a result of their economically and culturally disenfranchised status, it is difficult for women to insist that their male partner use a condom or to refuse unprotected sex, even if they suspect the man is infected or sick. Additionally, once women become infected, their access to HIV testing, counseling, and care is often dictated by their male partner, or their compromised economic state. To make matters worse, women account for the majority of the world's hungry or malnourished, and often must assume the burden of breadwinner and primary caregiver, should their male partner develop AIDS and become unable to work. In Nigeria, the Women's Leadership Centre (WLC) has urged the government to implement fully the National Gender Policy in order to ensure that Nigerian women "enjoy full human rights that would enable them to survive the HIV/AIDS pandemic," and to make women's employment a priority. As Nadia Ihuhua, one of the WLC's workshop participants explained: "Women who are dependent on boyfriends and husbands will not have the courage to demand the use of condoms. You cannot say no to unprotected sex at night and ask your boyfriend in the morning to give you taxi money" ("HIV-Aids and STDs," 2005).[7]

Some activist-critics have argued that the "ABC" campaign of the Emergency Plan for AIDS Relief, that relies on the easily-remembered refrain of abstinence, be faithful, and condom use, needs to be expanded to include "DEF" since "ABC" does not allow for culture- and sex/gender-specific behaviors. "D," these activists argue, should be for disclosure because "women living with HIV-AIDS risk violence or abandonment in disclosing their status and are often blamed for bringing the virus into the household." Disclosure, then, must necessarily occur in a safe environment. "E" should stand for education because women's lack of educational access worsens their economic exploitation. "F" posits that women need female-controlled prevention methods, such as microbicides and female condoms, so that they can be in control of their sexual health (Fleischman, 2004, A23). The pandemic is at a critical juncture, and the global response to it must include programs targeted specifically toward women, journalists Janet Fleischman and Kathleen Cravero suggest. "Expand prevention messages beyond 'abstinence, be faithful, use condoms,' which are often not in a woman's power to decide, especially for married women" (Fleischman and Cravero, 2004, A15).

African women suffer from a variety of contradictory stigmas that disenfranchise them and disable their political power in their societies. Patricia Stamp asks, "What is thought about African women today?" In answer, she notes the stereotypical, "facile but compelling Western popular imagery," which reduces the African woman "to the anguished, helpless mother holding a famished child" (1995, 71). Sexually, African women occupy the binary of prostitute or wife and mother (Austin 1989-1990). Yet, as Patton argues, the concerns of women "have been erased from AIDS policy and media accounts because women are not considered to be persons. Women, and especially women's bodies," she continues, "are decontextualized from women's concrete social existence, and treated as of concern only insofar as they affect men or children" (1994, 107). HIV/AIDS still, as was the case in the early years of the disease, is considered to be a disease of the behaviorally-deviant. Those who contract the disease, given the current political discourse, are encouraged to modify their deviant behavior in order to reenter the mainstream society. The stakes are high, for both the state that has made HIV/AIDS a security issue and for the person who contracts

HIV/AIDS. Stefan Elbe cautions against potential outcomes of what Michel Foucault called "biopolitical strategies," a growing concern of political powers with shaping biological characteristics of populations (Elbe, 2005).[8] On one hand, biopolitics have created hospitals and universal healthcare systems, Elbe contends, but on the other, "They have also led to justification of eugenics and mass death" (2005, 408). Should Africans succeed in such modification and adoption of normalizing practices as the U.S. discourse of "A, B, C" would have them do, they assist in stabilizing the state but do so at the expense of their autonomy and perhaps, personal cultural beliefs.

Shifting the rhetoric of HIV/AIDS into conversations of national security and war and away from the view of the pandemic as a humanitarian crisis reinforces existing power and the powerful, and tamps down the threat to those who have the most to lose. "At some level," Altman contends, "politicians understand that to speak of empowering women, of abolishing stigmas based on unpopular behaviour and status, threatens the status quo from which they benefit" (2003, 423).   But until these views are publicly articulated, the current discourse will continue to disenfranchise and disable the individuals who most greatly suffer.

Laura L. Behling teaches American literature and culture, with a particular interest in medicine and literature, at Gustavus Adolphus College (Minnesota). Her publications include, *The Masculine Woman in America, 1890-1935* (2001), and *Hospital Transports: An Embarkation of the Sick and Wounded from the Peninsula of Virginia in 1863* (2005), as well as articles in the *Journal of Medical Humanities*, *Women's Studies*, *College English*, and the *Journal of Modern Literature*.

Endnotes

[1]   Health care workers also have been reported as not disclosing a diagnosis of AIDS to patients in several African countries because of the stigma the diagnosis carries, as Kwesi Yankah explains. "Narrative in Times of Crisis: AIDS Stories in Ghana," Journal of Folklore Research 41. 2/3 (2004): 181-198.

[2] There are activists who deny the pandemic proportions of HIV/AIDS and instead suggest that the staggering figures of people with the disease are simply computer-generated statistics that are grotesquely exaggerated when set against population statistics. According to Rian Malan, in an editorial published in The Spectator, "We all know thanks to Mark Twain that statistics are often the lowest form of life, but when it comes to HIV/AIDS, we suspend all skepticism. Why? Aids is the most political disease ever." Later, Malan acknowledges that although "people are dying,… this doesn't spare us from the fact that Aids in Africa is indeed something of a computer game. Africa Isn't Dying of Aids," The Spectator, December 13, 2003.

[3] "Remarks on the Release of the Second Annual Report to Congress on the President's Emergency Plan for AIDS Relief." Condoleeza Rice, February 8, 2006, Washington, D.C., State Department Documents and Publications. Even the rhetoric used to categorize compliant pharmaceutical companies--those who commit to produce less expensive drugs for use in Africa--has started to resemble the rhetoric of the "coalition of the willing" of the Iraq War. In response to a question on whether the U.S. has given up on resistant pharmaceutical companies, Dr. Mark Dybul, Deputy U.S. Global AIDS Coordinator, claims, "We haven't given up on anyone. We need all companies who are willing to engage in this battle." "On-the-Record-Briefing on the President's Emergency Plan for AIDS Relief." State Department Documents and Publications, February 8, 2006.

[4] Given the strength of such conviction regarding the behaviors that increase risk of contracting HIV/AIDS, it is not unanticipated that religious beliefs and institutions play a pivotal role in moderating the rhetoric of the disease. In late 2004, the Vatican attributed the HIV/AIDS pandemic to an "immunodeficiency" of moral and spiritual values, while at the same time calling for increased education and access to medications. Pope John Paul II referred to HIV/AIDS as a "pathology of the spirit" that should be fought with "correct sexual practice"

and "education of sacred values." Echoing U.S. foreign policy toward HIV/AIDS, the Vatican reiterated its view that "chastity" and "responsible sexual behavior" are the best ways to prevent HIV transmission," while maintaining its controversial position that condoms do not protect against HIV. Education, lower-cost antiretroviral drugs, and eliminating the stigma and discrimination associated with people with HIV/AIDS should be the focus of the fight against the disease" ("PanAfrica, 2004).

[5] In contrast to the political uses of morality, African American church leaders in California have become heavily involved in education efforts and are disseminating HIV/AIDS Church Information Kits in an effort to convince their Black parishioners to be tested. The Kits contain potentially life-saving information and resources on HIV testing and support services available in local communities. "'It would be a sin and a crime not to do this work" of raising awareness about HIV/AIDS, the Rev. Dr. Clyde W. Oden, Jr., said, "'because so many of our communities are affected by this disease due to a lack of understanding and education'" ("African American Churches, 2004).

[6] In a different perspective, several recent news reports document the affect of the pandemic on the disabled. In Namibia, hearing-impaired people often lack access to HIV prevention campaigns because the messages are deployed on the radio and television and sign language interpretation is limited. Zimbabwe reports that sexual violence, which fuels the spread of HIV, is increasing against women and girls with disabilities, and testing and counseling facilities are limited by both biased attitudes of staff toward people with disabilities, and by a lack of resources, such as Braille literature. In Uganda, people with disabilities have launched an association whose major aim is to fight the spread of HIV among disabled people.

[7] "HIV-Aids and STDs; Gender Policy Key in Fighting HIV/AIDS." Africa News, October 19, 2005. United States First Lady Laura Bush provides a counter to Ihuhua's comments: "'I think it's very important to talk about abstinence, especially in countries where girls think they have to comply with the wishes of men, in countries where girls are not educated, where they are oppressed, in many instances.'" (italics added) "U.S. First Lady Defends Abstinence Approach to AIDS in Africa."

Agence France Presse--English, January 21, 2006.

[8] Foucault traced biopolitical strategies back to eighteenth-century Europe, as Elbe articulates, "around the government of 'life'" (404). "If one of the goals of biopolitics is to maximize the health of populations, then disease could no longer be left to random the random fluctuations of nature," Elbe explains, "but would have to be brought under continuous political and social control" (406). "AIDS, Security, and Biopolitics." Stefan Elbe. International Relations 2005 v. 19.1: 403-419.

References

Business Wire. (2004). *African American churches continue efforts to increase HIV testing: HIV/AIDS church test kits support efforts to increase HIV testing in the black community*. Author.

Altman, D. (2003). AIDS and security. *International Relations*, *17*(4), 417-427.

Austin, S. B. (1989-1990). AIDS and Africa: United States media and racist fantasy. *Cultural Critique*, *14*, 129-152.

Baker, P. (2006, March 16). Bush to restate terror strategy: 2002 doctrine of preemptive war to be reaffirmed. *The Washington Post*.

Baynton, D. (2001). Disability and the justification of inequality in American history. In P. K. Longmore & L. Umansky (Eds.), *The New Disability History: American Perspectives* (pp. 33-57). Albany: New York University Press.

Black, D. (1985). *The plague years: A chronicle of AIDS, the epidemic of our times*. New York: Simon & Schuster.

Brandt, A. (1988). AIDS: From social history to social policy. In E. Fee and D.M. Fox (Eds.), *AIDS: The burden of history* (pp. 147-171). Berkeley: University of California Press.

(2003). "Congressional Testimony," Senate Health, Education, Labor and Pensions, March 27.

Elbe, S. (2005). AIDS, security, and biopolitics. *International Relations*, *19(*1), 403-419.

Fleischman, J. (2004, June 29). Beyond 'ABC': Helping women fight AIDS. *The Washington Post*, A23.

Fleischman, J., & Cravero, K. (2004, March 8). A focus on women and AIDS. *Boston Globe*, A15.

(2003). "George W. Bush Delivers Remarks at Signing of U.S. Leadership Against HIV/AIDS, Tuberculosis and Malaria Act." FDCH Political Transcripts, May 27.

Haraway, D. J. (1979, Spring-Summer). The biological enterprise: Sex, mind, and profit from human engineering to sociobiology. *Radical History Review*, *20*, 206-237.

HIV-AIDS and STDs; heavy toll on Africa's economy. (2004, November 21). *Africa News*.

HIV-AIDS and STDs; gender policy key in fighting HIV/AIDS. (2005, October 19). *Africa News*.

Hunter, R. (2005, March 10). Moralizing doesn't fight AIDS. *Badger Herald*.

Jarosz, L. (1992). Constructing the dark continent: Metaphor as geographic representation of Africa. *Geografiska Annaler. Series B, Human Geography*, *74(*2), 105-115.

Lugar statement on HIV/AIDS Bill. (2003, May 15). Congressional press releases.

Malan, R. (2003, December 13). Africa isn't dying of AIDS. *The Spectator*.

More than humanitarianism: A strategic U.S. approach toward Africa. (2006). Council on Foreign Relations.

Nagel, J. (2003). *Race, ethnicity, and sexuality: Intimate intersections, forbidden frontiers*. Oxford: Oxford University Press.

Official report of the proceedings of the thirty-fifth Republican National Convention. (1992). Houston, Texas.

On-the-record-briefing on the president's emergency plan for AIDS relief. (2006, February 8). State Department Documents and Publications.

PanAfrica: daily HIV/AIDS report. (2004). *Africa News*.

Patton, C. (1994). *Last served?: Gendering the HIV pandemic*. London: Taylor & Francis.

President and Mrs. Bush discuss HIV/AIDS initiatives on World AIDS Day. (2005, December 1). FDCH Federal Department and Agency Documents.

President urges Congress to act quickly on global HIV/AIDS initiative. (2003, April 29). Regulatory Intelligence Data.

Rice, C. (2006, February 8). Remarks on the release of the second annual report to Congress on the President's emergency plan for AIDS relief. Washington, D.C.: State Department Documents and Publications.

Secretary of State speaks to Kenyan students on HIV/AIDS. (2005, January 8). U.S. Federal News.

Selvin, J. (2005, November 11). U2's Bono makes fiery case for rocking the world with ambitious mission to eradicate global misery. *San Francisco Chronicle*.

Sherry, M. S. (1993). The language of war in AIDS discourse. In T. F. Murphy & S. Poirier (Eds.), *Writing AIDS: gay literature, language, and analysis* (pp. 39-53). New York: Columbia University Press.

Stamp, P. (1995). Mothers of invention: Women's agency in the Kenyan state. In J. Kegan Gardiner (Ed.), *Provoking agents: Gender and agency in theory and practice* (pp. 69-92). Urbana: University of Illinois Press.

Treichler, P. (1988). AIDS, homophobia, and biomedical discourse: An epidemic of signification. In D. Crimp (Ed.), *AIDS: Cultural Analysis/Cultural Activism* (pp. 31-70). Cambridge, MA: MIT Press.

Treichler, P. (1991). AIDS, Africa, and Cultural Theory. *Transition*, *51*, 86-103.

United States, Canada and Africa: fighting global AIDS epidemic a U.S. foreign-policy priority. (2005, February 17). U.S. Department of State Press Release.

U.S. First Lady defends abstinence approach to AIDS in Africa. (2006, January 21). Agence France Presse--English.

Vesperini, H. (2005, December 7). Women more vulnerable to HIV/AIDS infection than men, less apt to cope. Agence France Presse--English.

Wallman, S. (1998). Ordinary women and shapes of knowledge: Perspectives on the context of STD and AIDS. *Public Understanding of Science, 7*, 169-185.

Watney, S. (1989). Missionary positions: AIDS, Africa, and Race. *Critical Quarterly*, *31*(3), 45-62.

Weiss, M. (1997). Signifying the pandemics: Metaphors of AIDS, cancer, and heart disease. *Medical Anthropology Quarterly*, *11*(4), 456-476.

Wilson, T. (1997). Engendering *AIDS: Deconstructing sex, text and epidemic*. London: SAGE Publications.

Yankah, K. (2004). Narrative in times of crisis: AIDS stories in Ghana. *Journal of Folklore Research*, *41*(2/3), 181-198.

Disability Studies and Disaster Services: Putting the "DS" in "DS"

Christopher Johnstone, Co-Guest Editor
University of Minnesota

Abstract: This article is a synopsis of articles found in this special issue of the *Review of Disability Studies* that focused on disability and disaster. In this article, information is gleaned and summarized from all the historical, research, and current events discussed in this issue. As part of the synopsis, the question is posed, "How can Disability Studies, as an academic and social endeavor, inform disaster services?" Examples from various articles are provided to inform readers how "DS" (disability studies) might influence "DS" (disaster services).

Key Words: disability, disaster, current events

Introduction

Recent events in the U.S., Canada, Southeast Asia, the Middle East, and Sub-Saharan Africa have raised global awareness about human responses to natural disasters, terrorist attacks, and health crises'. Media images of the political turmoil in the Middle East, the tsunami in southeast Asia, the Al Qaeda attacks on New York City, the ice storm in Quebec, Hurricane Katrina in the U.S. South, and the African AIDS crisis have reinforced notions that humans are still at the mercy of nature and other humans, even when their lives appear tranquil.

To this end, this edition of the *Review of Disability Studies* highlights the efforts of disaster response teams to curb the deleterious effects of unplanned incidents. As we learn from all of our authors, the effects of natural disasters, human tragedy, and health crises' are exacerbated by impairment and by inappropriate responses to persons with special health, mobility, and communication needs. The authors of this special issue of *RDS* provide readers with both historical context and first-hand, research-based, and media-inspired accounts of the tragedies and hopeful successes related to the immediate needs of persons with disabilities when unexpected disasters occur.

The issue spans millennia in terms of coverage. Lubet's and Epstein's reviews of ancient texts provide valuable insights into the cultural and religious interpretations of disability that have permeated modern Judeo-Christian and Islamic culture. Lubet's investigation into music, disability, and deliverance in Jewish tradition provides context and a long view of disability in society, demonstrating that disability has been a socially-constructed concept for time immemorial.

The modern critiques found in the pages of this journal are sound, based on evidence gathered using a variety of methods (literature review, first-person narrative, media analysis, surveys, and interviews). Authors, however, move beyond the act of simply critiquing practice to make concrete suggestions for policy makers and disaster response teams regarding future approaches to disaster relief for persons with disabilities.

For example, Epstein takes a cultural-studies approach to contemplating interpretations of disability on both sides of the Israeli-Palestinian conflict. Images of war and heroism are present throughout Epstein's discussion. She demonstrates that both cultures valorize persons who fought in the interests of their homeland and, as a result, became injured and disabled. Epstein quickly points out, however, that the "ordinary" disabled – civilians harmed by attacks from either side, persons who suffered from lack of adequate health care, or persons for whom disability issues were exacerbated by conflict and poverty, are often overlooked in national discourse. Thankfully, Epstein notes policy approaches in Israel and community-based interventions in Palestine that hold promise for reversing ableist and veteran-centric cultural practices.

Across the Atlantic, Barile, Fichten, Ferraro, and Judd use survey methods to better understand the effects of an ice storm in Canada. The authors found that 70% of their sample had no electricity for two or more days following the 1998 Montreal ice storm. Lack of electricity is an inconvenience (and could possibly be a safety issue) for non-disabled populations. For persons who depend on electricity to power electric wheelchairs or respirators, however, electricity becomes a necessity for movement and the ability to breathe. Barile et al. also discovered through qualitative methods that most of their 15 research participants with disabilities were stuck in their houses throughout the entire ice storm (a notable exception to this was a woman who was dropped at a closed rehabilitation center and subsequently died from neglect). Others endured the discomfort of having to negotiate shelter environments that were inaccessible and over-crowded.

Shelters set up after disasters are not meant to be comfortable, luxurious, or spacious. By nature, they are temporary environments to meet people's most basic needs in the face of disaster. The accounts recalled in this special issue, however, demonstrate that there was little in the design and culture of shelters that indicates that shelters were disability-friendly. Barile et al.'s subjects reported orientation and movement issues within shelters. Barbara White also provides first-hand accounts of the social and informational exclusion experienced by D/deaf Louisianans in the face of Hurricane Katrina. White's on-the-ground report of the failure of shelter personnel to adequately meet the informational needs of D/deaf evacuees is riveting. It appears as if the only people who had any idea how to meet the most basic of needs for D/deaf consumers were deaf professionals, deaf church representatives, and sign language interpreters. Without the presence of these professionals and community representatives, otherwise capable evacuees would have been left uninformed about the storm's progress and unaware of how to obtain food and services at disaster-relief shelters.

White's frustration and exasperation with the bureaucracy of disaster relief were evident in her article. Her inability to travel quickly to the disaster region and her insistence that people with low-incidence disabilities are an important piece of the evacuation equation are noteworthy. For those who were not a part of the evacuation of Hurricane Katrina, it is easy to imagine the triage approach to evacuation and temporary shelter. Relief workers were forced to make difficult decisions and provide whatever they could to the people they could reach. The communication needs of D/deaf Louisianans may not have been the top priority of relief workers in the hurricane-affected area. To those affected by the disaster, however, communication is vital. The response of the Louisiana School for the Deaf, Gallaudet University, and the Woodhaven Baptist Deaf Church (in Texas) provided examples of how simply having ASL interpreters and captioned television available to evacuees is vital to their emotional and physical well-being.

The countless examples of "deaf helping deaf" found in White's articles provides readers with an epistemological reminder of the essence of Disability Studies (DS) as an academic endeavor. Disability Studies scholars frequently take the approach that learning about disability comes from the experts – persons with disabilities themselves (Epp, 2001). Indeed, when White exclaims that the most effective relief organizations for D/deaf Louisianans were Deaf Churches, Deaf Schools, and Deaf Universities, we are reminded of models of empowerment within other disability communities (Fleisher & Zames, 2001). In these models, persons with disabilities take charge of needed services to produce needed outcomes. Indeed, the emic perspective of disability is one that appears to be missing from large disaster relief endeavors, but one that could improve outcomes.

Disaster and Social Model of Disability

Viewing disaster relief from the lens of a social and empowerment model of disability pro-

vides important steps forward in our knowledge about disasters and related services. Lubet and Epstein both demonstrate that disability as a socially-constructed concept is not a contemporary invention. The seeds of modern civilization were sewn in the plains of Eastern Africa, the Indus Valley, the Americas, and the Middle East. From the Middle East came two historically-similar but contemporarily-contested cultures: Judaism and Islam. Lubet describes the heroes of war, the impaired musicians, and the tension between impairment and ability found in the Psalms and prayers of the Torah. The exodus of the Jews across the deserts of the Middle East was punctuated by stories of persons with a variety of impairments who were central characters in the development of a culture. Lubet's inspection of ancient texts helps us to better understand the meanings of disability across millennia in order to better understand meanings today.

Such meanings are further pondered by Epstein. The author's investigation into modern and historical interpretations of the Torah and Koran provided readers with perspective on a group often forgotten in modern cultural disputes – persons with disabilities. Epstein aptly points out that persons with disabilities have been viewed as heroes or helpless, have been exalted or ignored by both cultures historically – and continue to be today. It is only in recent years, according to Epstein, that Israel and Palestine – as societies – have broadened their views of social inclusion and empowerment to include people with disabilities who are not war or Intifada veterans.

Similar to those recently ignored in Israel and Palestile, Barile et al. note, that persons with disabilities were largely ignored in the Montreal Ice Storm. Likewise, White notes that when D/deaf populations were evacuated in the U.S. Gulf Region following Hurricane Katrina, the responses to the communication needs of D/deaf populations were largely inadequate. Responses from Montreal and New Orleans did not fall into the medical model vs. social model tension typically found in Disability Studies literature (see Ballan and Sormanti in this issue). Rather, in Barile et al. and White's accounts, there appears to be *no* model or awareness of disability. The needs of persons with a variety of impairments appear to be ignored in the face of a large-scale humanitarian crisis.

A social model of disability, then, may provide important information for model-building for disaster relief. Four articles in this issue describe, in detail, how a social model of disability may inform disaster relief services in the future. In the first article, Christensen, Collins, Holt, and Phillips provide an important discussion of the built environment and the ability of individuals with disabilities to exit in the case of disaster. Much of the research cited by Christensen et al. was "medical model" research (i.e., measuring the physical capabilities of persons with disabilities and, at times, pointing out deficiencies). The authors, however, take an interesting stand in their conclusion and find problems in environments – not people – as limitations for egress.

The authors never use the term "universal design," but carefully lay out an argument for more universally-designed environments (Mace, 1998) that consider both the physical accessibility of persons entering and the ability of a person to exit, if needed, from that environment. The authors' approach of taking environments to task is refreshing, and their review of the literature provides architects and building code policymakers ways of promoting maximal egress for persons with a wide variety of impairments. The authors focus on removing barriers illustrates an important point – that fires, tornadoes, hurricanes, and other disasters do happen. Environments set up so that egress is differential between persons with and without impairments are as egregious as those that set up differential access to those attempting to enter a structure.

Christensen et al.'s literature review provides important points about disasters – that proac-

tive steps need to be taken before disasters occur and that such steps need to provide persons with disabilities the same opportunities as their non-disabled peers. The authors frame issues of egress as a policy concern, but note that important legislation such as the Americans with Disabilities Act has done little to push the egress research agenda forward.

Egress is one piece of a larger focus that human service agencies must consider when planning for disaster relief. In this issue, Hemingway and Priestley use the tsunami in Southeast Asia and Hurricane Katrina to provide readers with broad-based suggestions on how to implement disaster relief from the perspective of a social model of disability. In their article, the authors challenge notions that persons with disabilities are vulnerable because of physical limitations. Rather, the authors note that "vulnerability" may be as much a social construction as disability itself.

To support this thesis, Hemmingway and Priestly cite social organization theory, which is grounded in the assumption that vulnerability is evident as a result of interactions between humans and their environments. According to the authors, vulnerability to natural disasters has as much to do with the environments humans live in, and present economic conditions, as the natural forces that bring about disasters. Specifically, Hemmingway and Priestly note that persons with disabilities are among the poorest people on earth. Eighty percent of people with disabilities live in low-income countries (Asian Development Bank, 2000), making disabled populations among the most affected by poverty in the world. Because of these and other factors, Hemmingway and Priestly aptly note that major climatic events are to disaster as impairment is to disability, i.e., according to social theories of disability, impairment only becomes disability when coupled with environmental barriers. Likewise, major climatic events such as hurricanes or tsunamis only become disasters when they interact with human settlement. Vulner-

ability to disaster is increased when one has little access to pre-disaster environments. In times of major natural disasters, the everyday environment is minimized, thus increasing barriers for persons with disabilities.

According to Hemmingway and Priestly, barriers to evacuation and shelter for persons with disabilities exist in a number of areas. One primary area of concern is in the immediate evacuation of persons with disabilities from disaster areas. In Southeast Asia, the accessibility of escape routes and evacuation planning for persons with disabilities were problematic. Eyewitness accounts reported by the authors alluded to people waiting in vain for help, some suffering tragic deaths by drowning. In New Orleans, access to electricity was a major barrier, causing people in electric wheelchairs and who use other electricity-powered devices to become immobile or even die (as was the case for people who needed dialysis machines).

Those who did find shelter faced a new set of barriers, from inaccessible information to inaccessible physical environments. By contrast, relief efforts led by persons with disabilities themselves (or allies in advocacy organizations) in both the United States and Southeast Asia appeared to be successful in assessing and providing evacuation and shelter efforts for persons with disabilities. This finding echoes White's first-hand account of deaf organizations' successes in the aftermath of Hurricane Katrina. In summary, Hemmingway and Priestly find that "for the people, by the people" (Werner, 1994) approaches may have relevance beyond matters of social justice and extend to practical endeavors such as disaster relief. The accounts of Disabled People's Organizations' ability to use formal and informal networks to meet the disaster relief needs of persons with a variety of impairments demonstrates that one plan does not fit all in times of crisis. Rather, as noted in Barile et al. and White's essays, the experts on disability and evacuation are those who are disabled and in need of evacuation. This socially-grounded

approach appears to have been missing from the ethos of relief organizations worldwide.

The Time Continuum of Disaster

For the purposes of this issue, many authors discuss disasters as *events* in time. Such perspectives are necessary from the practical position of planning and responding to climatic or human-caused disasters. Lubet, Epstein, and Behling, however, discuss disaster polytemporally, i.e. as ongoing events that encompass ancient, modern, and future times. From an ancient perspective, Lubet notes that Jewry has a long history of imposed and natural disasters for which music has been, alternately, an icon of memory or a means of catharsis. Such methodology has been largely more inclusive than other social institutions such as politics and leadership in temples.

Epstein as well points to the long history of violence in the Middle East that, sadly, appears to have no end in sight. This human disaster is an ongoing reminder that "disaster relief" as a field may be as much about mitigating human conflict as it is about levees and temporary shelters. Behling concurs, describing the tragic HIV/AIDS crisis in Africa, which is as much an indicator of social oppression in Southern Africa as it is a medical emergency.

Contributors to this special issue who focus on disaster as an event capture an important facet of disaster relief – the continuum of time from preparation to long-term grief recovery is also longer than the unitary event of disaster. Christensen et al. carefully lay out arguments for why preparation for disasters is essential, and why such preparation needs an explicit disability focus – not in the isolation of characteristics of impairments but in the close examination of built environments. Barile et al. and White use a snapshot approach to describe events immediately following major natural disasters. Their timely feedback on important issues such as shelter and communication provide food for thought for readers on important disaster relief issues. Hemmingway and Priestly expand upon

these thoughts, contributing theoretical substance to the need for social model of disability perspectives in disaster relief efforts and a re-examination of the meaning of "vulnerability."

Long after the shelters have emptied and the media has gone home, however, the issues associated with the loss of home or loved ones endure. Authors Christ and Christ examine the grief patterns found in young children with learning disabilities who lost a father in the 9/11 attacks on the World Trade Center of New York City. Christ and Christ's theoretical positioning is sound. According to the authors, there is little understanding of how children with disabilities cope with the loss of a loved one. While there is ample literature on children's grief, the authors are concerned that children with disabilities may have unique needs and coping strategies. In their article, Christ and Christ examine how children with learning disabilities cope with the loss of their firefighter fathers. The selection of children with learning disabilities as a subject matter was an interesting one for this journal. For scholars interested in K-12 education, the study of learning disabilities is particularly germane. This label, more than any other, is often seen as justification for special education services in K-12 schools (Education Week, 2004).

Christ and Christ are interested in the grief and mourning patterns of four children with learning disabilities in a post-9/11 counseling program. Their findings indicate that "helping professionals" were very helpful to the children. Despite Disability Studies and sociological critiques of the helping professions and their ineffectiveness, stigma-producing behavior, and sometimes egregious motivations (Goffman, 1963), Christ and Christ find that special education teachers were very helpful in catalyzing productive grief responses for the research subjects. Furthermore, the careful documentation of students' academic progress and emotional well-being that was associated with the children's special education services helped children to progress through stages of grief better than

their non-disabled peers (whose manifestations of grief may have gone quietly unnoticed).

Christ and Christ's final arguments are compelling. Their first argument is that schools as communities can be important in aiding the grief processes for survivors of disasters. The authors argue that schools can provide essential social and academic supports to students who are affected by disaster. It is important that this line of research continue in the current era, where students are expected to participate in high stakes assessments. The social supports provided by school personnel allowed students to carry forward with their academic and social lives.

In conclusion, Christ and Christ point out that their research only scratches the surface in understanding how children with disabilities move through the grief process. As noted by the authors, further research is needed in this area, and the long term healing processes of children with disabilities in areas such as Pakistan, Indonesia, New Orleans, and the Middle East are important places to start such research. Children with disabilities may be affected differentially than their non-disabled peers by natural disasters, war, and terrorism. An important factor to consider is how such children grieve in the long term, and how societal response either helps or exacerbates the grieving process.

Grief and psychological resilience are also the subject of Ballan and Sormanti's article. In this article, the authors set forth a series of "best practices" based on research from a variety of fields designed to help persons with intellectual disabilities cope with loss. One of the most poignant recommendations that Ballan and Sormanti make is to avoid "diagnostic overshadowing." This term refers to the practice of overlooking potentially significant mental health challenges in people with intellectual disabilities because it is assumed that behaviors are a result of a disability rather than emotional reactions to external events.

The authors relate their suggestions to the social model of disability. In this case, the social model is based on the process of dismantling barriers to valuable mental health services after disasters. The authors suggest several approaches to making services more inclusive, including accessible information. For persons with intellectual disabilities, accessibility includes simple language and pictorial representations of information. In addition, political organizing by people with intellectual disabilities may be important for making access to services more readily available to consumers. Finally, Ballan and Sormanti challenge mental health professionals to reassess their own attitudes about disability. According to the authors, two major barriers must be dismantled in order to provide persons with intellectual disabilities with appropriate post-disaster services. First, professionals must examine their own perceptions about the assumed limited range of emotions that persons with intellectual disabilities may have. Second, traditional approaches to therapy must be examined for how worthwhile they are for persons with intellectual disabilities. The authors' points are relevant in a society that is heavily populated with service professionals. Ballan and Sormanti's call to service professionals to provide service for consumers' sake (rather than for the profession's sake) is grounded in disability theory and has implications beyond disaster relief.

Societal Reactions to Disaster and Disaster Victims

The social model approaches that Epstein, White, Hemmingway and Priestly, and Ballan and Sormanti propose in this issue are direct responses to societal views of disability. Interpretations of disabled populations as vulnerable or helpless are the direct result of environments that are inaccessible (see Barile et al. and Christensen), communication practices that are not inclusive (see White) or societal misconceptions that place the "blame" of disability on the person with disability rather than society's inability to remove physical, communicative, or attitudi-

nal barriers (see Ballan and Sormanti, Epstein, Hemmingway and Priestly, and Lubet).

Society's understanding of disability comes from a variety of sources, two of which are cultural texts and mass media. Lubet and Epstein demonstrate that disability (although not always with modern labeling) has been a perennial fixture in the ancient spiritual texts that guide two world religions. Our modern sensibilities of disability, consciously or unconsciously, have been borne in the texts that many hold sacred. Understandings of cure, helplessness, heroism, and inclusiveness are, for many, learned in the subtexts of Temple and Mosque.

In secular society, Behling critically examines how media images of the HIV/AIDS crisis in sub-Saharan Africa mirror images proffered by the current Bush administration in Washington. In an attempt to dismantle the "crippling metaphors" of the current administration's media briefings and policies, Behling challenges the idea that AIDS can be stopped via grand behavior modification plans for the people of Africa. Rather, the author notes that policies and programs that encourage abstinence over finding a cure are short-sighted and culturally irrelevant. Behling later explains that viewing the HIV/AIDS crisis as a "war" is equally troubling and is likely to be equally ineffectual. According to media sources that Behling cites, the Bush administration's hard-line "war on AIDS" is misguided and does not reflect the needs of persons living with HIV and AIDS in Africa. Rather, Behling suggests that the HIV/AIDS crisis is far more complicated than that which behavior modification and war metaphors can solve. Rather than simple, prescriptive approaches, Behling encourages readers to consider health care access, the status of women in HIV/AIDS-affected countries, the availability of treatment programs, the stigma attached to persons disclosing their HIV status, access to education (especially for women), and the availability of female-controlled prevention methods (microbicides and female condoms). In essence,

Behling recommends a culturally-relevant social model approach to understanding and acting upon the HIV/AIDS crisis in Africa.

Conclusions

Both readers new to the area of disaster relief and readers who are familiar with the literature in this area have something to gain from the diversity of articles found in this special issue of the *Review of Disability Studies*. This issue provides readers with important considerations to help understand the nature of disasters as they relate to humans with disabilities. Although the articles address a variety of issues, the lessons learned from this issue are broad-based, comprehensive, and enlightening. Three major themes emerge which may be useful for scholars, activists, professionals, and victims of disaster in the near future. We learn that, a) disasters are not fixed events in time (there is much activity that has been and can be taking place before disasters and both short- and long-term effects of disasters on victims, b) social models of disability that examine disability from a systems perspective are useful when thinking about disaster and vulnerability, and c) disaster response involves careful thinking about the needs of victims as well as the deployment of persons with disabilities as ambassadors, translators, and effective support personnel. Such a response is most helpful when it takes a polytemporal view of disaster.

Disasters Are Not Unitary Events in Time

From the small sampling of articles found in this issue, we find that "disasters" are not events that we can speak of in isolation. Disaster is defined in various ways by our authors: Christ and Christ, Epstein, and Lubet describe the long and culturally-mediated disasters that human conflicts have caused; Barile et al., White, and Hemmingway and Priestly refer to climatic events that were relatively unexpected; Christensen et al. refer to disasters as any event that requires sudden and immediate egress from a built structure, and Behling examines media at-

tention to a slow and consuming health crisis that spans an entire subcontinent.

From these different definitions of disaster comes a better understanding of disaster from a temporal framework. Lubet and Epstein describe disasters as, at times, ongoing. Hemmingway and Priestly describe "disaster" as an interaction between humans and a climatic event. According to Christensen et al., traumatic interactions may be greatly minimized if architects and city planners are dedicated to building for universal egress. In such a case, disaster thinking takes place long before an event typically categorized as a disaster takes place.

Barile et al., White, and Hemmingway and Priestly frame their articles in the time immediately following a major climatic event. In times such as these, human response is critical to the survival of those affected by climatic events. The authors point out that simply finding shelter for people with disabilities is not enough. Housing someone in a shelter that is physically inaccessible, without multiple modes of communication, and without emergency power supplies for wheelchairs or other medical devices is ineffective. The first few hours after a major climatic event are critical to people for addressing the external shock caused by the event. Disaster effects can be minimized when disability perspectives are considered.

Three articles focus on the immediate aftermath of disasters, and two focus on the long-term effects of disasters and associated grief. Christ and Christ and Ballan and Sormanti describe the grief process and how that process must be monitored for persons with disabilities. Christ and Christ describe the successful supports provided by schools for children with learning disabilities and Ballan and Sormanti propose ideas about how to support persons with cognitive disabilities in grief processes. Both articles remind readers that as long as a disaster is a part of a person's memory and emotions, the effects of the disaster are still felt and the disaster is still

a reality. Examining grief is an important lesson in understanding that disasters are not isolated events, but linger in the psyches of victims for years to come.

Finally, Behling and Epstein provide evidence of how disasters remain in the collective psyche of societies through media attention. Behling examines how disasters (such as the HIV/AIDS pandemic in sub-Saharan Africa) are framed by government officials and reported in the media. Social model theorists spurn the idea of blaming an impairment on the impaired, and would prefer to focus on the interaction between a person with an impairment and the barriers they face in society. To this end, Behling points out the shortsightedness of policy statements and media reports about HIV/AIDS stemming from the Bush administration. Behling's critical, systems-oriented discourse reminds readers that disasters are complicated affairs, and have as much to do with the options available to affected persons as affected peoples' behavior choices.

Epstein describes how the sorting of persons with impairments into two categories – heroic war veterans and helpless others – is problematic for those who live with impairments that are likely related to long-standing conflict but not directly acquired in combat. The dismantling of disability hierarchies appears to be an important step in relief of centuries-old "disasters."

Social Model of Disability

Each of our authors addresses the social model of disability either directly or indirectly. In sum, this special issue leaves readers with a better understanding of the social model of disability within the context of disaster relief. From this issue we gain a better understanding of cultural understandings of disability (Epstein and Lubet), the disabling effects of environments (Christensen et al.), "one size fits all" disaster relief plans (Barile et al. and White), grief models (Ballan and Sormanti), and media portrayal of disasters (Behling). Our authors all carefully examine disability from a framework of inter-

action with built and social environments. Our authors each address disaster from the sophisticated worldview of understanding the challenges of having an impairment but deconstructing the myth that vulnerability falls squarely on the shoulders of a person with a disability. Rather, the thoughtful scholarship in each of the articles carefully documents the interaction of persons with impairments in (many cases) disabling environments, and our cultural understanding of disability. From there, White, Hemmingway and Priestly, Ballan and Sormanti, and Christ and Christ recommend further study and action related to framing short and long-term disaster relief in ways that are empowering and relevant to persons with disabilities.

Disabled Populations in Disaster Relief Roles

Finally, Barile et al., Epstein, Hemmingway and Priestly, and White all discuss the importance of having people with disabilities on the front lines of disaster relief. Such activity is also happening in Africa related to the HIV/AIDS crisis (Kalinaki, 2002), but, as Behling notes, such information is not typically reported in the mainstream media. In planning for and thinking about future climatic and human disaster response, it appears evident that the participation of persons with disabilities is essential. Participation could include (but is not limited to): 1) participating in a critical cultural examination of longstanding beliefs about impairment (see Epstein); 2) advising on egress for built environments (see Christensen et al.); 3) advising and serving as front-line workers in temporary shelters (see Barile et al., Hemmingway and Priestly, and White); 4) participating in group grief counseling approaches and advising social service agencies on the interplay between grief, loss, and impairment (see Ballan and Sormanti and Christ and Christ); and 5) serving as media representatives (see Behling). Ballan and Sormanti, Barile et al., Epstein, and White demonstrate how disaster relief services are less effective when such perspectives are ignored. White and Hemmingway and Priestly, however, provide

evidence of successful relief approaches that involved persons with disabilities. It is evident that services organized by persons with disabilities themselves show great promise.

Future Directions

We conclude this special issue by calling upon those in the disaster relief fields to assess their thinking about disability as a construct. Disability Studies, as a field, promotes the understanding of disability from a social perspective. Scholars in this field are concerned with empowerment, removing barriers, and the micro, mezzo, and macro-societal implications of impairment and ableism. Scholars contributing to this special issue present both encouraging and frightening evidence of when disability perspectives are (or are not) considered in disaster relief efforts. Based on the evidence in this special issue, we can clearly determine that Disability Studies perspectives (those of social critique, empowerment, accessible communication and environments, and expertise in the lived experience of disability) are not only relevant, but essential in the planning for disasters, the immediate relief thereafter, and long-term coping programs for people affected by disasters. The next disaster to occur in the world is unknown, but it is evident, based on the research in this issue, that putting DS (Disability Studies) perspectives into DS (disaster services) appears to be a promising approach and future direction.

Christopher Johnstone is an Assistant Professor of Special Education at Augsburg College in Minneapolis, MN. He is also Research Associate at the University of Minnesota's Institute on Community Integration, serving as Associate Director for its Global Resource Center on Inclusive Education. He has published widely on issues related to disability and international development and is a regular reviewer for this journal, the *Review of Disability Studies: An International Journal*.

References

Asian Development Bank. (2000). *Technical assistance for identifying disability issues related to poverty reduction*. Manila: Author.

Education Week. (2004). *Quality counts 2004, count me in: Special education in an era of standards*. Retrieved April, 2006, from http://counts.edweek.org/sreports/qc04/

Epp, T. (2001). Disability: Discourse, experience and identity. *Disability Studies Quarterly*, 134-144.

Fleisher, D. Z., & Zames, F. (2001). *The disability rights movement: From charity to confrontation*. Philadelphia, PA: Temple University Press.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

Kalinaki, D. (2002, June). How to crush AIDS: End the stigma. *New Internationalist*. Retrieved April, 2006, from http://www.newint.org/issue346/sick.htm

Mace, R. (1998). *A perspective on universal design*. An edited excerpt of a presentation at Designing for the 21st Century: An International Conference on Universal Design. Retrieved January, 2002, from www.adaptenv.org/examples/ronmaceplenary98.asp?f=4

Werner, D. (1994). *Nada para nosotros sin nosotros*. Palo Alto, CA: Hesparian Foundation.

BOOK REVIEWS

Book Review

Title: *The Down Syndrome Nutrition Handbook, A Guide to Promoting Healthy Lifestyles*

Author: Joan E. Guthrie Medlen, R.D., L.D.

Publisher: Baltimore: Woodbine House, 2002

Paper, ISBN: 1-890627-23-2, 352 pages

Cost: $19.95

Reviewer: Martha Guinan, MPH, Center on Disability Studies, University of Hawai`i

The Down Syndrome Nutrition Handbook is written by the ultimate authority - a practicing dietician and mother of a young man with Down syndrome. The Handbook is based on years of personal and professional experience and supported by the latest medical research and insights from other parents and adults with Down syndrome. This well written, person-centered, and health-centered book is intended for the parent, with practical advice and tips that could only come from another experienced parent. The result is an outstanding resource for people with Down syndrome throughout their life span and for the people that help them. A wide variety of topics are addressed from bottle versus breast feeding, general nutrition to nutritional intervention for diabetes mellitus, alternative therapies, celiac disease and other health issues. Ms. Medlen discusses selecting shoes, promoting active lifestyles, and teaching your child to be responsible for their own good health. The book also includes growth charts, suggested documents to include in your child's 504 plan and recipe templates for understanding how your child grows. It truly is an invaluable resource to have all in one place.

This Handbook helps parents, dietitians, and therapists understand the connection between Down syndrome, lifestyle, and nutrition. It is beneficial when read cover-to-cover

or when used as a reference book. The writing style is clear and the pictures make it a valuable education tool for people with a wide variety of reading abilities. It is the assistant every parent needs to guide their children toward a healthier future.

Book Review

Title: *Helping Your Teenager Beat Depression: A Problem–Solving Approach for Families*

Authors: Katharina Manassis and Anne Marie Levac

Publisher: Bethesda, MD: Woodbine House, 2004

Paper, ISBN: 1-890627-49-6, 201 pages

Cost: $19.95

Reviewer: Shirley Gerum, Center on Disability Studies, University of Hawaii at Manoa

Why do depressed teens get angry? "Probably because anger doesn't feel so bad," explain Katharina Manassis, MD, FRCPC and Anne Marie Levac, RN, MN, in Chapter 10 (p.95) of *Helping Your Teenager Beat Depression*.

Manassis and Levac explain how anger and other negative emotions make one feel "strong—not vulnerable, like fear or sadness—" (p.95) and address how teens get to this point and how parents can help them out.

The advice and problem-solving strategies in this paperback are based on a form of cognitive-behavioral therapy the authors call L.E.A.P.: (1) LABELing their own thoughts and emotions regarding their teen's behavior; (2) EMPATHIZING with their teen's perspective and exploring options for response; **(3)** APPLYing an alternative way to respond, and (4) PICKing a follow-up time to think through the process and PLAN the next steps.

The workbook-style format is user-friendly and invites parents to respond to situational

roadblocks with this clearly-outlined process. Clearly-defined, eye-catching boxes highlight key points; checklists help readers identify and write their own responses to behaviors. Situational problem-solving tips are included as are exercises for changing unhealthy patterns: dealing with anxious situations; improving habits, causes and treatments of depression; seeking professional help for your teen; discussing what is "normal" for adolescents; dealing with school and peers, and the importance of activity/getting teens moving.

There is empathy and encouragement for parents as well as teens throughout the pages. The authors provide parents with a checklist of what to expect at each step when seeking professional counseling and mental health assessments—including, what conditions need to be ruled out, what happens after assessments, worst-case scenarios, deciding if medications are right for your teen, side effects, school avoidance, bullies, and peer pressure. Chapter 13 anticipates and addresses the ripple effect in families of depressed teens: "Talking About Depression" (pp.128-129), "What Should a Parent Who is Depressed Do?"(pp. 129-130), and "Parenting Despite Depression (p. 132).

The combined author education and experience bring a wide range of depth to this publication. Anyone who parents, works with, or teaches teens may find the insights, suggestions in this book helpful.

The publisher's use of extra-large print for paragraph topics and key points are helpful. However, the two-tone fractured shading for the page numbers creates reading challenges. The publisher's choice of various shades of pinks, with a photo of a lone young girl for the book cover will catch the eye of parents of teen girls. The chance taken here is that this insightful book may go unnoticed—or dismissed by parents of young males.

Book Review

Title: *A History of AIDS Social Work in Hospitals: A Daring Response to an Epidemic*

Editors: Barbara I. Willinger and Alan Rice

Publisher: Binghamton, NY: Haworth, 2003

Paper, ISBN: 0 7890-1587-0, 360 pages

Cost: $39.95

Reviewer: J. Gary Linn, Ph.D., Professor, School of Nursing and Center for Health Research Tennessee State University

A History of AIDS Social Work in Hospitals primarily targets Master's level social work students. It provides many varied first hand accounts of social workers' early and more recent responses to the HIV/AIDS epidemic in the United States. However, it should also be of interest to scholars in public health, health policy, medical sociology, and nursing because it touches on clinical, organizational, policy, and community issues related to AIDS social work. This comprehensive collection of case histories is a unique contribution to our knowledge about the personal and organizational strategies developed by social workers in different parts of the country, e.g., New York, San Francisco, and South Carolina, to address the early epidemic. We learn about the Harper Model for social work with hospitalized AIDS patients from the inner city New York, the Social Work AIDS Network (SWAN) in San Francisco, and daily life in a southern AIDS service organization (ASO) during the 1980s. In response to confidentiality and safety concerns regarding clients of the Palmetto AIDS Life Support Services (PALSS) in South Carolina, the agency's location was not published during its first ten years of existence. Individuals who called for support services or to volunteer were verbally directed to the facility. HIV stigma was assumed to be rampant in the local community, and PALSS staff believed that it was not safe to inform the community of their address.

Each chapter of Willinger and Rice's book makes an interesting statement. The experience and frustrations of the frontline AIDS social workers during the past 25 years are described in exquisite detail. Early encounters of an adult infectious disease doctor and a pediatrician with AIDS patients in New York are told in poignant and sometimes humorous narratives. Moving stories of courageous struggles with HIV/AIDS stigma and discrimination in the rural south are eloquently related. Added together, the 33 chapters document many facets of the early epidemic. The reader begins to get a sense of the enormous scope of HIV/AIDS issues and responses during that era.

Perhaps the most important contribution of Willinger and Rice's book is that it preserves in an organized framework the first experiences of AIDS social workers. Without this special history, much of this experience would be unrecorded and lost. Fortunately, we now have a wide range of case histories included in a single volume from which we can all learn.

No apparent effort has been made to make this book accessible to people with disabilities. Nevertheless, it is worth its $40 price. I would recommend *A History of AIDS Social Work in Hospitals* to graduate social work students and to scholars in social work, public health, health policy, medical sociology, and nursing. In fact, any reader wanting to become more informed about the most important health issues of our time would find this book interesting.

RDS Information

Information for Advertisers

The Review of Disability Studies, published by the Center on Disability Studies at the University of Hawaii at Manoa, invites advertisements from (a) publishers of books, films, videos, and music, (b) employers with position announcements, and (c) producers and distributors of products and services. For questions or to advertise with RDS, please email rds@cds.hawaii.edu or call 808-956-5688.

Why Advertise With RDS?

The Review of Disability Studies is the ideal vehicle for reaching an international audience in the field of disability studies. We have and are pursuing affiliations with other major organizations in the field.

Subscribers are academics, advocates, and libraries. It is a highly receptive audience for appropriately targeted advertising. Research shows that specialty journals such as the Review of Disability Studies are cited by professionals as the most useful source of information for the purchase of products and services, more so than conferences, direct mail, and direct sales.

Copy Requirements and Cost

Advertisements must be submitted in an electronic format - preferably a PDF file with fonts embedded or as a Microsoft Word file - in an email attachment sent to rds@cds.hawaii.edu.

Dimensions for a half page are 7 x 4 inches at a cost of $300. Dimensions for a full page are 7 x 8 inches at a cost of $500.

Discounts:

10% discount for 3, 4 or 5 insertions

20% discount for 6 or more insertions

10% publishers discount

10% discount for first time advertisers

Please note: Only one type of discount will be applied to each booking. Combinations of discounts are not accepted.

Frequency and Length

RDS is published four times a year and runs approximately 100 pages.

Terms and Conditions

1. All advertisements submitted are subject to editorial approval. We reserve the right to refuse or to remove advertisements at our discretion.

2. A confirmation of your order will be supplied upon acceptance.

3. We cannot make any guarantees as to publication dates. While we will make every effort to ensure that your advertisement will be published, the Review of Disability Studies may run ahead or behind schedule.

4. All advertisements are accepted on a space available basis. On rare occasions it may not be possible to accommodate a particular advertisement. Should this be the case, a refund or substitute issue will be offered.

5. No liability is accepted by the Center on Disability Studies or the University of Hawaii for the content of any advertisements or quality of any products, materials, or services advertised.

6. The Center on Disability Studies and the University of Hawaii do not accept any liability for loss or damage arising from the use of any products or materials purchased as a result of advertisement publication.

7. Invoices for all advertisements must be

settled within 30 days of receipt from the date as postmarked.

8. All advertisement prices are subject to sales tax, general equity tax, value added tax, or any similar tax if chargeable and at the current rate.

9. Prices are correct at the time of publication. The Center on Disability Studies, at the University of Hawaii at Manoa, reserves the right to increase advertisement rates at any time.

About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawaii at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai`i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawaii University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawaii, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawaii, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

Review of Disability Studies Subscription Form

Please complete this form and mail with payment to the address below.

Please enter a one-year subscription of the Review of Disability Studies for:

Name: _____

Address: _____

_____

_____

Email: _____   Phone: _____

Please Select:

__Personal $50.00 (personal check only)

__Libraries and Institutions $100.00 (check or purchase order)

__Student $25.00 (please provide a photocopy of a photo ID or other proof of status)

__Additional $15.00 for first class mail outside the U.S. and Canada

Amount enclosed by check or purchase order $_____

Please make payable to RCUH 2144

Credit Card #_____ Exp. Date_____

VO#_____

Please select if you would like an alternative format to the print version:

__Braille   __Diskette   __Audio Cassette

__CD-ROM   __Large Print

Mail Form and payment to:

RCUH 2144

University of Hawaii at Manoa/CDS

1776 University Avenue, UA 4-6

Honolulu HI, 96822

Attention Subscriptions: Velina Sugiyama

For questions please email rds@cds.hawaii.edu or phone 808-956-5688